

Critical Care Nurses' Perceptions about Palliative Care and Moral Distress:

Implications for Practice

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Abstract

Background: As the need for palliative care in the intensive care unit becomes increasingly recognized, it is unknown how gaps and variations in palliative care education and utilization are associated with the moral distress of critical care nurses.

Purpose: To examine critical care nurses' perceived knowledge of palliative care, examine their recent experiences of moral distress, and explore how these variables may be related.

Design: Quantitative, descriptive study design.

Methods: Survey questionnaires were distributed to 517 critical care nurses across seven intensive care units at an academic medical center in central Virginia. Validated instruments were used to measure participants' perceptions, beliefs, and experiences with palliative care in their practice setting and their recent experiences of moral distress.

Results: A total of 168 surveys were returned (response rate = 32.5%), of which 167 were analyzed. Each palliative care domain was rated highly important by a majority of respondents, but fewer than 40% of respondents reported being highly competent in any domain, with the lowest proportions rating themselves highly competent in knowledge of advance directives, assessing patient-family support and resources, and self-care. Most respondents reported little to no recent preparation in palliative care, with 38% reporting no palliative care education in the past two years. Most respondents reported some degree of moral distress during the study period, and there were significant differences in moral distress level based on perceived utilization of palliative care services ($F = 3.02, p = .03$). Respondents who reported palliative care services being more frequently utilized appropriately tended to experience lower levels of moral distress during the study period. A small, significant inverse correlation was found between moral distress levels and self-care, resilience, recognizing/managing stress, grief, and

moral distress, indicating that respondents who felt less competent in this domain experienced greater moral distress during the study period.

Conclusion: Palliative care knowledge gaps and moral distress remain highly prevalent in critical care nurses. Health system leaders and educators must improve and expand opportunities for nurses to become more competent in palliative care and how to cope with situations that may lead to moral distress, and empower nurses as leaders and advocates to reduce barriers to palliative care.

Keywords: palliative care, end-of-life care, moral distress, ethics, critical care nursing

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Critical Care Nurses' Perceptions about Palliative Care and Moral Distress:
Implications for Practice

Introduction and Background

Critical care has primarily focused on curative treatment (Ferrell, Virani, Paice, Malloy, & Dahlin, 2010). However, one in five Americans dies in the intensive care unit (ICU) (Angus et al., 2004), and an increasing number of survivors experience chronic critical illness that increases their risk of mortality and reduces their quality of life (Wiencek & Winkelman, 2010). Mounting evidence demonstrates the debilitating symptom burden (Choi et al., 2014; Jubran et al., 2010; Nelson, Meier, Litke, Natale, Siegel, & Morrison, 2004) and high risk of mortality (Cox et al., 2007; Wunsch, Guerra, Barnato, Angus, Li, & Linde-Zwirble, 2010) among numerous critically ill patients. The suffering experienced by critically ill patients underscores the need for high-quality palliative care in the ICU. Palliative care is focused on enhancing the quality of life of seriously ill patients and their families (Aslakson, Curtis, & Nelson, 2014; Center to Advance Palliative Care [CAPC], 2012) during life-sustaining treatment and at the end of life, when such treatment is no longer warranted (Isaac & Curtis, 2015). Although it is the fastest-growing medical subspecialty (CAPC, 2011), palliative care is also recognized as an important competency for all clinicians who care for persons with serious illnesses (Institute of Medicine, 2014). Early initiation of palliative care for critically ill adults has been recommended by numerous critical care professional societies (Carlet et al., 2004; Lanken et al., 2008; Selecky et al., 2005; Truog et al., 2008). Despite these evidence-based recommendations, there are significant barriers to access to palliative care in the ICU (Aslakson, Curtis, & Nelson, 2014), including unrealistic patient, family and clinician expectations of ICU treatment (Nelson, 2006), inability of patients to participate in treatment discussions (Nelson, 2006), and insufficient

education and training for physicians (Nelson et al., 2006) and nurses (White, Roczen, Coyne, & Wiencek, 2014).

Among critical care nurses, the failure to address patients' palliative care needs and the compulsion to provide unwarranted aggressive treatment are sources of moral distress, a phenomenon that occurs when an individual knows the morally correct action to take but is prevented from taking it due to internal or external constraints (Jameton, 1984). Moral distress is particularly common in critical care nurses (Elpern, Covert, & Kleinpell, 2005; Hamric & Blackhall, 2007), and its consequences impact patients, nurses, and healthcare organizations (Corley, 2002). Up to 46% of surveyed nurses have reported leaving or considering leaving a position due to moral distress (Oh & Gastmans, 2015). In a time of nationwide nursing shortage (Juraschek, Zhang, Ranganathan, & Lin, 2012) and an increasing population of chronically and critically ill persons (Marini, Vincent, & Annane, 2015), it is imperative to examine factors that may influence the moral distress experienced by critical care nurses.

The purpose of this study is to answer the following question: What is the relationship between critical care nurses' perceived knowledge of palliative care in their practice setting and their levels of moral distress? This research question will be answered by fulfilling three main objectives: (a) Assess critical care nurses' perceptions, beliefs, and experiences with palliative care in their practice setting; (b) Assess critical care nurses' recent levels of moral distress; and (c) Explore the relationship that may exist between critical care nurses' perceptions of palliative care and their recent level of moral distress. Fulfilling these objectives may reveal existing palliative care knowledge gaps for critical care nurses, and may demonstrate how variations in palliative care access and training relate to nurse moral distress, providing valuable information to health system leaders about how future interventions may affect nurses and other clinicians.

Review of Literature

A literature review was performed in order to examine moral distress among critical care nurses, and how previous studies have connected moral distress and palliative care in the ICU. CINAHL, Ovid MEDLINE, PsycINFO, Web of Science, Joanna Briggs Institute (JBI), Cochrane Library, and Google Scholar were used to perform the literature search. Ancestry searches of the reference lists of relevant articles were also performed, and local experts on palliative care and moral distress were consulted for additional relevant literature. The following keywords were used in the database search: “*moral distress*”, “*palliative care*”, “*supportive care*”, “*end-of-life care*”, “*end of life*”, *end-of-life, ICU*, “*critical care*”, “*intensive care*”, “*intensive care unit*”, “*critical illness*” and a combination of these terms. Suggested major headings and subheadings were also added. All theoretical and empirical research articles, reviews, guidelines, case studies, case series, and expert opinions published between 1984 and 2016 examining moral distress in critical care nurses were eligible for review. Articles were excluded if they were published in a non-English language, conducted outside the ICU setting, or if full text was not available.

Moral Distress among Critical Care Nurses

The definition of moral distress. In his 1984 book *Nursing Practice: The Ethical Issues*, philosopher Andrew Jameton distinguished moral distress from several other moral phenomena observed in nursing practice. Unlike moral dilemmas or moral uncertainty, moral distress occurred when a nurse knew the morally correct action to take, but institutional or interprofessional constraints prevented the nurse from initiating the action, resulting in painful feelings as the nurse was forced to act against their moral decision. Building upon the original definition, Wilkinson (1987) further elucidated moral distress as the result of not following

through on a moral decision. The experience of moral distress implies the presence of a moral situation, a moral decision, a perceived inability to act on that decision, and the painful feelings and psychological disequilibrium that result. External constraints inhibiting a nurse's moral action may include inadequate team collaboration, arbitrary legal statutes, and lack of administrative support. Internal constraints are inherent variables that affect moral decision-making, such as an individual's fear of losing their position, a lack of courage, or inclinations to follow orders without question. The amount of experience and knowledge of available options affects the degree to which a nurse can overcome restraints.

In her Moral Distress Model, Wilkinson (1987) postulated that nurses frequently encounter moral issues in practice, and they make autonomous moral decisions based on a cognitive moral framework, feelings of empathy, and a desire to help the patient. When constraints, real or perceived, prevent the nurse from implementing a moral decision, negative feelings and psychological disequilibrium result. Nurses may feel powerless and overwhelmed when they cannot successfully cope with their moral distress. With repeated exposure to moral distress, the nurse begins to experience damage to their wholeness and self-esteem that may culminate in the nurse changing jobs or even leaving the nursing profession altogether. Some nurses may stay in their position, but with potential damage to their self-esteem, wholeness, and ability to provide patient care (Wilkinson, 1987, p. 27).

In his later work, Jameton (1993) recognized that nurses in moral distress often do face dilemmas – not about the right action to take – but about how to respond when one is prevented from taking the morally right action. These “‘second-order’ moral dilemmas” (p. 544) faced by nurses can cause two types of distress: initial and reactive. Initial distress describes the feelings of anger, frustration, and anxiety when first faced with institutional or interprofessional

constraints to moral action. When nurses do not act upon their initial distress, reactive distress remains, manifesting in a number of potential ways, such as crying, depression, nightmares, and feelings of worthlessness.

The lingering effects of reactive distress were characterized by Webster and Baylis (2000) as moral residue, noting that “people who have lived through serious moral compromise carry the remnants of the experience for many years, if not a lifetime” (p. 223). According to Webster and Baylis, moral residue may have positive and negative effects on a nurse’s moral integrity. These authors’ conception of moral distress included situations where the nurse failed to pursue the right action because of an error in judgment or a personal failure, rather than merely constraints beyond the nurse’s control.

Although moral residue has not been robustly studied, previous studies of the consequences of repeated experiences of moral distress support the existence of moral residue (Epstein & Hamric, 2009). Epstein and Hamric clarified moral residue as the “lingering feelings after a morally problematic situation has passed” (p. 332). When a morally distressing crisis ends, the nurse’s acute moral distress may decrease, but some moral residue remains and serves as the new baseline for moral distress. Over time, moral residue continues to increase with repeated crescendos of moral distress, evoking stronger reactions as a nurse is reminded of earlier situations. The interaction between the moral distress and moral residue crescendos is known as the Crescendo Effect.

Although moral distress is considered a concrete phenomenon (Epstein & Hamric, 2009), its subjective nature has opened it to multiple interpretations and definitions. McCarthy and Dedy (2008) expressed concern that existing research on moral distress lacked conceptual clarity and unintentionally broadened the definition of moral distress. The authors proposed a

definition of moral distress as an umbrella term rather than as a single concept, characterizing the range of experiences of morally constrained individuals – those who are unable to do the right thing or who do what they believe is the wrong thing. Epstein and Hamric (2009) warned against conflating moral distress and psychological distress, emphasizing that moral distress implies a violation of one's core values and duties, concurrent with a feeling of being constrained from taking ethically appropriate action. Varcoe, Pauly, Webster, and Storch (2012) proposed that moral distress should be defined in relation to both institutional influences and a broader sociopolitical context. Moreover, because nurses often act in the face of moral distress, the authors proposed a refined definition of moral distress as “the experience of being compromised as a moral agent in practicing in accordance with accepted professional values and standards. It is a relational experience shaped by multiple contexts, including the socio-political and cultural context of the workplace environment” (p. 59).

Thomas and McCullough (2015) proposed a taxonomy to provide further conceptual clarity to moral distress, specifically related to moral knowledge and the impediments to acting on moral knowledge. Moral knowledge, according to the authors, originates in one's professional and individual integrity and the durable values and judgments that underpin them. Professional integrity requires the sustained commitment to intellectual and moral excellence related to one's profession, such as prioritizing the interests of the patient. Individual integrity requires the sustained commitment to intellectual and moral excellence outside of one's profession, such as looking after one's family members. Thomas and McCullough's taxonomy describes six categories of ethically significant moral distress: challenges to, threats to, and violations of professional integrity; and challenges to, threats to, and violations of individual integrity. Challenges describe situations when it becomes somewhat difficult to do the right

thing because incentives activate self-interest. Threats occur when powerful and not-easily-removable impediments undermine one's ability to act on or maintain one's professional or individual integrity. Violations are impediments that are not removable and are so powerful that one is completely unable to do the right thing. When professional and individual integrity are violated and one is unable to do the right thing, professionally or individually, one becomes "morally undone" (p. 112). A nurse's awareness of acting against their moral judgment results in moral distress, manifested by anxiety, frustration, anger, and poor patient care. Awareness or perception of being morally undone may have even worse effects - burnout, depression, and dangerous patient care. If the challenges and threats to one's professional and individual integrity occur repeatedly, they may accelerate, potentially weakening one's moral resolve and integrity. The Crescendo Effect occurs when weakened professional or individual integrity results in routine violations that result in the individual acting against their moral judgment.

Since it was first described by Jameton in 1984, moral distress has been interpreted and defined in a number of different ways. Moral distress describes the scope of experiences of nurses who know the morally right action to take but experience constraints that prevent them taking it. More recent clarification describes nurses' claim to know as originating from the durable values and judgments that are formed from their professional and individual integrity. When a nurse's professional or individual integrity is violated, they are unable to act morally and thus experience moral distress. Repeated exposure to challenges and threats to professional and individual integrity result in the accumulation of moral residue, precipitating the Crescendo Effect and weakening the nurse's resolve to take the morally right action in future situations.

The prevalence and frequency of moral distress. Moral distress has been described as an unavoidable reality (Rushton, Kaszniak, & Halifax, 2013) as well as a part of the historical

fabric of nursing (Hamric, 2000), perhaps in part due to nurses' historical pressure not to question authority or participate in patient care decision-making (Gutierrez, 2005). According to Corley (2002), moral standards infuse nursing practice, and the stated goals of nursing are ethical: to protect patients from harm, provide care that prevents complications, and maintain a healing psychological environment for patients and families. It is therefore understandable that moral distress has been extensively studied among nurses in the ICU, an environment where the expectations of patients, families, healthcare providers, and the institution are frequently in conflict (Maiden, Georges, & Connelly, 2011).

The seminal work of Wilkinson (1987) aimed to explore the newly characterized phenomenon of moral distress in hospital nurses. Her qualitative interviews of 24 nurses included 12 subjects who had ICU nursing experience, 6 of whom were currently working in the ICU. Several subjects were no longer working as staff nurses because of an apparent inability to cope with moral distress. Overall, subjects perceived moral distress occurring frequently, with only three subjects reporting moral distress frequency less often than once per week. Despite this frequency, Wilkinson cautions against generalizing about the frequency of moral distress experienced by other nurses, since the nurses who responded to the interview request may have suffered particularly frequent moral distress.

Elpern, Covert, and Kleinpell (2005) used a descriptive questionnaire to assess moral distress in 28 medical ICU nurses at a single institution. Using a valid and reliable instrument to evaluate frequency and intensity of moral distress, situations associated with moral distress did not occur frequently in this sample. However, the mean moral distress intensity rating among the sample was moderate, indicating that most nurses experience some degree of moral distress.

In a cross-sectional survey of 44 nurses in a single medical-surgical critical care unit, Mobley, Rady, Verheijde, Patel, and Larson (2007) reported ten situations in which over 50% of subjects reported moral distress. The authors found that the frequency of moral distress was highest in older nurses with more experience and more time employed on the unit. Similar results were reported by Mason et al. (2014) in a convenience sample of 26 surgical trauma ICU nurses, with over 65% of subjects reporting experiences of moral distress. The presence of moral distress among critical care nurses in a burn ICU was confirmed by Leggett, Wasson, Sinacore, and Gamelli (2013). However, further research is needed in a larger sample to determine the frequency and intensity of moral distress among burn ICU nurses.

In a descriptive pilot study of 14 ICUs in two institutions in Virginia, Hamric and Blackhall (2007) examined moral distress among critical care nurses and physicians caring for dying patients. In general, critical care nurses reported more frequent moral distress than physicians. Similarly, Whitehead, Herbertson, Hamric, Epstein, and Fisher (2015) detected moral distress among all groups of healthcare professionals in their descriptive study of 592 clinicians at a single healthcare system in Virginia. However, moral distress was significantly higher in nurses and other professionals ($p < .001$) than in physicians.

The mixed methods study by Maiden, Georges, and Connelly (2011) examined 205 critical care nurses who were members of the American Association of Critical-Care Nurses (AACN). Overall, respondents reported an elevated level of moral distress. However, the types of ICUs where respondents practiced were not reported in this study, making it difficult to generalize these results.

In a descriptive, qualitative study, Wiegand and Funk (2012) used open-ended surveys to identify clinical situations that caused nurses to experience moral distress in the ICU. In a

convenience sample of 47 critical care nurses at a university medical center, 79% of survey respondents reported that they had experienced moral distress.

In a recent quantitative literature review, Oh and Gastmans (2015) found that older, more experienced nurses tend to suffer more frequent moral distress of variable intensity, but there is no clear congruence regarding the relationship between sociodemographics and moral distress. However, O'Connell (2015) reported that female critical care nurses ($n = 24$) had significantly higher moral distress scores ($p < .05$) compared to males ($n = 7$) in a descriptive online survey of critical care nurses. However, the small sample size and convenience sampling method of this study prevents generalizability.

Evidence to date demonstrates that most critical care nurses experience moral distress in their practice, albeit infrequently, occurring with moderate intensity that may worsen in situations in which patients do not receive safe or proper care (Oh and Gastmans, 2015).

Sources of moral distress in the ICU. As they attempt to provide morally and clinically competent care, critical care nurses encounter a multitude of potential situations and conflicts that may ultimately serve as sources of moral distress. Wilkinson (1987) reported that the moral distress among the nurses in her qualitative study most often concerned the prolonging of life of patients who were dying; performing unnecessary tests and treatments (especially on the terminally ill); situations involving lying to patients; and incompetent or inadequate treatment by a physician. Building upon Wilkinson's work, Corley (1995) designed an instrument to capture the level of moral distress experienced by critical care nurses and identify the issues associated with moral distress that occur most frequently. Aggressive care was the source of greatest distress for critical care nurses in this study, with the most frequent situations involving actions that prolonged a patient's death, following a family's wishes to continue life support when it was

not in the patient's best interest, caring for hopelessly injured patients because no one would "pull the plug" (p. 283), and carrying out physicians' orders for unnecessary tests and treatments. Gutierrez (2005) also implicated aggressive care as a source of moral distress in a purposive sample of 12 critical care nurses in a single surgical ICU. The moral conflicts described by nurses in this study most often involved overly aggressive treatment (92%), inappropriate resource use (75%), physicians providing incomplete or inaccurate information to patients and families (67%), patient wishes being disregarded (67%), and disparate treatment goals between family members (33%) or between the physician and family (25%). The descriptive study by Elpern, Covert, and Kleinpell (2005) found similar results in a sample of medical ICU nurses. Using Corley's Moral Distress Scale (MDS), Elpern and colleagues found that the sources of greatest moral distress among the sample ($n = 28$) were items related to aggressive care that was not in the patient's best interest.

McClendon and Buckner (2007) also used the MDS to measure levels of moral distress among nurses in the intensive and coronary care units at a hospital in the southeastern U.S. Similar to previous studies, the most frequently experienced sources of moral distress included following the family's wishes to continue life support even though it was not in the patient's best interest, following the family's request not to discuss death with a dying patient who asks about dying, following a physician's order not to tell the patient the truth when he or she asks for it, and initiating extensive life-saving actions when the nurse thinks it is only prolonging death.

Mobley, Rady, Verheijde, Patel, and Larson (2007) examined the relationship between moral distress and futility among critical care nurses in a single critical care unit. Using the MDS, the authors found that futile care was the most frequently encountered source of moral distress that nurses faced in the critical care unit. However, aggressive treatments that offer a

slim chance of benefit may be conflated with care that is physiologically futile. Mobley and colleagues did not account for the potential differences in nurses' perceptions of futility, limiting the validity and generalizability of this study.

In the qualitative, descriptive study of 47 critical care nurses by Wiegand and Funk (2012), 73% of reported situations that resulted in moral distress were related to the end of life, such as medical futility, organ donation, inadequate or excessive administration of analgesic medications, and other end-of-life issues.

Congruent findings have been reported with regard to intensity of moral distress. De Villers and DeVon (2012) used the MDS in a survey of 68 critical care nurses and 28 non-critical care nurses recruited from several organizations. The MDS item with the highest score for moral distress intensity was initiating life-saving actions when the nurse thinks it only prolongs death. In a convenience sample of 33 critical care nurses in an Internet nursing community, O'Connell (2015) also found that the most distressing item was following the family's wishes to continue life support when the nurse believes it is not in the patient's best interest.

According to the literature to date, end-of-life issues such as perceived medical futility, poor communication, disparate goals of treatment, and inappropriate care at the end of life are sources of frequent and intense moral distress among critical care nurses. The provision of quality care at the end of life is an integral component of comprehensive palliative care in the ICU. Critical care nurses who are unable to provide comfort and maintain the dignity of dying patients and their families in the ICU may consequently suffer alongside them.

Consequences of moral distress. In her theory of moral distress, Corley (2002) illustrated the impact of nurse moral distress, moral suffering, and moral residue on individual nurses, the patients whom they care for, and the organizations in which they practice. According

to Corley, nurses experience moral distress when they do not take moral action when they know a moral problem is involved. Their moral distress may take the form of anger, frustration, or guilt that may eventually lead to outcomes such as resignation, burnout, or departure from the profession of nursing altogether. Morally distressed nurses may avoid patients or provide inappropriate patient care, potentially increasing their burden of suffering. The compromised quality of patient care, concomitant with high nursing turnover and low patient satisfaction, signifies the devastating fallout of nurse moral distress for healthcare organizations.

Rushton, Kaszniak, and Halifax (2013) proposed a neuroscientific, social, and psychological framework to further explain clinicians' responses to morally distressing situations. Responses to distressing events, according to this framework, involve four dimensions: empathy, perspective taking, memory, and moral sensitivity. When these dimensions are highly aligned, clinicians can effectively identify and respond to ethically challenging situations with "principled compassionate action" (p. 1077), which ultimately preserves their integrity and builds resilience. However, when these dimensions are not highly aligned in clinicians, they may be less morally sensitive and more emotionally dysregulated, which undermines their ability to effectively identify or respond to ethically challenging situations. The resulting personal or moral distress that may occur can eventually lead to unregulated moral outrage, acute secondary stress, or burnout. Rather than acting out of empathy for the patient, these clinicians may instead act to relieve their own distress by physically avoiding the patient or family, reacting out of anger or contempt (such as abruptly resigning from a position), or becoming emotionally numb in ethically challenging situations.

Empirical research has supported theoretical conceptions of the consequences of moral distress. Meltzer and Huckabay (2004) used the MDS and a validated instrument to measure

burnout, the Maslach Burnout Inventory, to study the relationship between perceptions of futile care and burnout in a convenience sample of 60 full-time critical care nurses with at least one year of practice experience. The frequency of moral distress related to futile care was significantly correlated to the experience of emotional exhaustion ($p = .05$), and linear regression revealed that frequency of moral distress related to futile care was predictive of emotional exhaustion ($p = .01$). In a survey of 114 nurses from neonatal, pediatric, acute care, and critical care settings at one institution, Rushton, Batcheller, Schroeder, and Donohue (2015) found that moral distress was a significant predictor of all three aspects of burnout, as measured by the Maslach Burnout Inventory. On the other hand, nurses with greater self-reported measures of well-being tended to experience less burnout, and nurses with greater perceived resilience and hope tended to experience less emotional exhaustion and depersonalization and more personal accomplishment. These results suggest that strategies to increase nurse resilience and coping might help to reduce burnout in environments that are particularly prone to ethically challenging situations.

Elpern, Covert, and Kleinpell (2005) identified a number of worrisome themes in the free-text responses of medical ICU nurses in their study. Participants were asked to describe the impact of morally distressing situations, and their responses were analyzed independently by three evaluators to detect common themes. The main themes identified in the free text responses included negative impacts in the following areas: job satisfaction/retention, actions/attitudes toward patients, psychological responses, physical responses, interactions with coworkers, self-image, spirituality, and health-related actions/decisions. Feelings of powerlessness, hopelessness, and a lack of support were also reported. The qualitative, descriptive study of surgical ICU nurses by Gutierrez (2005) further corroborated the effects of moral distress on

nurses and the care that they provide. Half of the nurses in the study ($n = 6$) revealed that they requested not to be designated as the primary nurse for the patient involved in the conflict, and one-third described decreasing interactions with the patient's family as a result of the morally distressing situation. Three nurses reported physical symptoms such as pain or dysfunctional sleep.

In the pilot study by Hamric and Blackhall (2007), nurses with high moral distress scores reported a more negative ethical climate in their ICU, lower satisfaction with quality of care, and less collaboration with physicians than those with low moral distress scores. Forty-five percent of nurses at one study site reported having left or considered leaving a position because of moral distress, and nurses with high moral distress were more likely to have left or considered leaving than those with lower scores. Cummings (2011) used several instruments, including the MDS, to examine the relationships between moral distress, professional stress, and nursing retention among a sample of 234 acute care nurses, including ICU nurses (29.9%), in Florida. None of the individual factors of moral distress or professional stress were significantly related to intent to stay, but when all factor groups were combined, they were predictive of intent to stay ($p = .001$). In the qualitative study of burn ICU nurses by Leggett, Wasson, Sinacore, and Gamelli (2013), none had left a position due to moral distress. However, two nurses reported having considered leaving a prior position due to moral distress.

Moral distress has been implicated as a factor in job dissatisfaction, compassion fatigue, and burnout. Maiden, Georges, and Connelly (2011) employed mixed methods to examine the relationships between moral distress, compassion fatigue, perceptions about medication errors, and nurse characteristics in a purposive sample of 205 certified critical care nurses. Overall, respondents had an elevated level of moral distress and a low level of compassion fatigue. There

was a weak, significant positive correlation between the level of compassion fatigue and level of moral distress. Contrarily, Mason et al. (2014) did not find significant correlations between moral distress and work engagement in a small sample of surgical trauma ICU nurses.

In their descriptive, cross-sectional study, De Villers and DeVon (2012) found a small positive correlation between moral distress and avoidance behavior in critical care and non-critical care nurses. There was no significant difference in moral distress scores between critical care and non-critical care nurses.

Measures of moral distress. The subjective nature of moral distress has made direct observation of the phenomenon difficult. Corley (1995) developed the MDS to measure critical care nurses' moral distress, quantify their level of moral distress, and identify the issues associated with moral distress occurring most frequently. The 32-item MDS was based on Jameton's concept of moral distress and the results of the qualitative study by Wilkinson (1987). Items included prolonging life, performing unnecessary tests and treatments, lying to patients, and incompetent/inadequate treatment by a physician (Corley, 1995, p. 281). Each item was scored on a 7-point Likert scale, with 1 indicating low and 7 indicating high moral distress. The MDS demonstrated adequate content validity (100% agreement on content validity index), test-retest reliability ($r = .86, p < .01$), and internal reliability (Cronbach's $\alpha = .93, p < .01$). Further testing and validation of the MDS was performed by Corley, Elswick, Gorman, and Clor (2001) and subsequently modified by Corley, Minick, Elswick, and Jacobs (2005) to include items on pain management, managed care or incompetent health care personnel, which they identified as additional important nursing ethical concerns in the literature.

The MDS has demonstrated validity and reliability in measuring the intensity and frequency of moral distress for critical care nurses. However, it was not tested outside the ICU,

and its validity and reliability in measuring moral distress in other health professionals is limited. Hamric, Borchers, and Epstein (2012) developed the Moral Distress Scale-Revised (MDS-R) to be used in a variety of healthcare settings and across health professions. Unlike the MDS, the MDS-R is a 21-item scale that comes in six different versions to measure moral distress in adult and pediatric nurses, physicians, and other health professionals. Each item on the MDS-R is scored on a Likert scale from 0 to 4 for both frequency and intensity of moral distress. Higher scores indicate higher levels of moral distress. The MDS-R has demonstrated validity in measuring moral distress across professions, and a recent institution-wide survey by Whitehead, Herbertson, Hamric, Epstein, and Fisher (2015) reported satisfactory reliability in nurses ($\alpha = 0.90$), physicians ($\alpha = 0.88$), and other healthcare providers ($\alpha = 0.90$).

The development of the MDS and MDS-R provided tangible measurements of the intensity and frequency moral distress in certain situations, but neither measurement was designed to assess moral distress at a given point in time. The Moral Distress Thermometer (MDT) was developed by Wocial and Weaver (2013) to quickly identify “real time” (p. 168) presence of moral distress and more effectively measure the effectiveness of interventions. The MDT is an 11-point, single-item scale with numbers ranging from 0 to 10, measuring the degree of moral distress. Respondents are provided with a definition of moral distress and then asked to reflect on their clinical practice in the last two weeks and identify on the thermometer their level of moral distress. In its initial psychometric testing, the MDT demonstrated significant low to moderate correlation with the MDS ($r = .404, p < .001$), indicating adequate convergent validity. Nurses who had never considered leaving their position had lower mean MDT scores than those who had considered leaving ($p < .001$) or had left a position ($p = .004$) due to moral distress.

Reliability testing was not considered feasible by the authors, as moral distress is considered dynamic and not suitable to a test-retest approach (p. 170).

Managing moral distress in the ICU. Corley (2002) called for researchers to identify effective interventions to decrease and prevent moral distress. However, moral distress cannot be extinguished (Rushton, 2006), perhaps partially explaining why existing intervention studies have had varying results. However, numerous strategies exist to effectively respond to moral distress. Epstein and Delgado (2010) summarize and synthesize a number of strategies and suggestions from the literature for addressing moral distress in any practice setting.

In 2004, the AACN released a position statement recognizing the deleterious impact of moral distress in the ICU, calling for nurses and their employers to take action to address and mitigate the effects of moral distress in the work environment. The AACN's *4 A's Model to Rise Above Moral Distress* is a framework for support and action for critical care nurses who may experience moral distress. This framework consists of four main concepts: Ask, Affirm, Assess, and Act. "Ask" represents the first action - asking whether one is experiencing moral distress. Suffering may manifest in physical, behavioral, emotional, and spiritual responses. When distress is evident, the nurse should appraise the situation to determine whether it is a threat to their integrity or individual ethics (Rushton, 2006). According to the *4 A's* model, nurses should ask themselves (AACN, n.d., p. 3): "Am I, or members of my team, feeling symptoms or showing signs of suffering? Have coworkers, friends, or family members noticed these signs and behaviors in me?" "Affirm", the next action, refers to nurses affirming their distress and their commitment to address it. Nurses should validate their feelings and perceptions with others, including colleagues, friends, family, and professional resources, and affirm their responsibility to preserve their own personal integrity. The third action, "Assess", is the stage in which the

nurse identifies the source of their moral distress and assesses their readiness to act by determining how important and feasible it is to change the situation and weighing the risks and benefits. The final action, “Act”, describes the nurse’s preparation and action taken to address the source of moral distress in their work environment.

Few studies have examined the effects of specific interventions on reducing moral distress. Beumer (2008) utilized the *4 A’s* framework in designing a two-hour workshop intervention aimed at presenting ways to identify, cope with, and diminish moral distress for nurses. In general, more critical care nurses in this study ($n = 25$) strongly agreed with being able to advocate for their patients’ wishes after the workshop (29%) than before the workshop (8%), and less respondents reported distancing themselves from patients after the workshop (29%) than before the workshops (54%). However, a lack of inferential statistics and lack of a validated or reliable survey tool clouds the significance of these results.

In a pilot study, Leggett, Wasson, Sinacore, and Gamelli (2013) designed an intervention to decrease moral distress in burn ICU nurses. The intervention consisted of one 60-minute educational session per week for 4 weeks. Participants received information on moral distress, signs and symptoms of moral distress, barriers to addressing moral distress, and strategies to deal with moral distress. Participant moral distress levels were measured using the MDS-R. Surprisingly, nurses in the post-intervention group had significantly higher median MDS-R scores than nurses in the pre-intervention group (92.0 vs. 40.5, $p = .03$), indicating that moral distress was higher among nurses who had received the education intervention. The authors cited similar findings that were observed in an interventional study on moral distress in the neonatal ICU. The use of a separate sample pretest posttest design, along with heterogeneity and small size of the samples, may have contributed to the results.

Identifying ethical issues early could help nurses become more proactive in addressing conflicts that may lead to moral distress. In a recent pilot study, Pavlish, Hellyer, Brown-Saltzman, Miers, and Squire (2015) tested the feasibility of an early ethics screening and intervention tool for critical care nurses. Twenty-eight oncology and ICU nurses participated at two study sites. Participants attended a 4-hour ethics workshop and received orientation to the ethics tool. After the workshop, participants were requested to apply the screening tool in clinical practice for 3 months, after which they evaluated the tool's usefulness and acceptability. The tool was initiated most often on older patients with multiple comorbidities and currently hospitalized for life-threatening sepsis or organ dysfunction. Nurses who witnessed patients' suffering and deterioration were more likely to initiate use of the tool. The most prominent early indicators of ethical conflicts were signs of patients' suffering, unrealistic expectations, and indications of provider moral distress. Although the tool's direct effects on provider moral distress are unclear, focus groups revealed that the screening tool's primary benefit for nurses was its capacity to clarify issues in complicated clinical situations, empower nurses to advocate for an ethical plan of care, and promote teamwork, which relieved their moral distress (p. 252). The authors suggest further testing of the tool to determine its effectiveness in relieving providers' moral distress.

Relationships between Palliative Care and Moral Distress in the ICU

Few studies have directly examined how moral distress relates to palliative care in the ICU. In the qualitative, descriptive study of 12 surgical ICU nurses by Gutierrez (2005), participants were asked to identify the moral action they identified as the correct one to take in the conflict they described. Two-thirds of participants identified providing supportive care only or refraining from resuscitative therapies as the appropriate action that should have been taken.

Ferrell (2006) similarly found that instances of moral distress related to futile care most predominantly involved conflicts of “aggressive care denying palliative care” (p. 926), as nurses described how patients who died in the ICU often did so painfully, in the absence of family, and with inadequate attention to their physical and spiritual needs. In a sample of 49 critical care nurses, Wiegand and Funk (2013) also noted that although most of the morally distressing situations were related to the end of life, none of the nurses in their study suggested consulting the palliative care team, a finding that the authors attributed to the palliative care service’s lack of presence in the ICU.

In a quantitative, descriptive study, Browning (2013) used the MDS and the Psychological Empowerment Instrument to examine the relationships between moral distress, psychological empowerment, and demographic characteristics of nurses providing end-of-life care in the ICU. The sample was comprised of 277 critical care nurses recruited from an AACN email newsletter list. A weak but significant negative correlation between nurse collaboration in end-of-life patient care conferences and frequency of moral distress related to deception ($p = .007$), meaning that as collaboration in end-of-life care conferences increased, frequency of moral distress tended to decrease among the nurses. Additionally, there were weak but significant positive correlations between nurse End-of-Life Nursing Education Consortium (ELNEC) training and total moral distress frequency score ($p = .02$) and moral distress frequency item “not in patient’s best interest” ($p < .01$). In fact, completion of ELNEC training was a significant predictor of nurse moral distress frequency ($p < .01$), with ELNEC-trained nurses having, on average, 21.5% higher moral distress frequency. In the institutional survey of healthcare providers by Whitehead, Herbertson, Hamric, Epstein, and Fisher (2015), nurses and other providers who had received training in end-of-life care had higher mean levels of moral

distress than those without end-of-life care training ($p < .01$). A similar but non-significant trend was found among staff members with advanced pain management training.

Critical care nurses frequently encounter ethically challenging situations in practice that may lead to moral distress. When nurses are unable to effectively respond to their moral distress, they experience the lingering effects of moral residue that serves as their new baseline of moral distress. Repeated experiences of moral distress evoke stronger reactions and create a crescendo of moral distress and moral residue that can culminate in compassion fatigue, burnout, job dissatisfaction, and intent to leave a position or the profession of nursing altogether. For critical care nurses, conflicts that give rise to moral distress often involve the prolonging of life and death, provision of inappropriate or futile treatment, and following the wishes of a family member to continue life support when it is not in the best interest of the patient. Limited evidence also connects palliative care with critical care nurses' moral distress in several important areas, including end-of-life care education, collaboration and participation in end-of-life care, perceptions of aggressive care or inadequate palliative care, and the effects of moral distress on care provided by nurses. However, no known study has formally examined how critical care nurses' perceptions, beliefs, and experience with palliative care may relate to their moral distress. This descriptive study aims to fill this important evidence gap by using validated instruments to assess the relationship that may exist between critical care nurses' perceived knowledge of palliative care in their practice setting and their experiences of moral distress.

Conceptual Framework

Moral residue and the Crescendo Effect serve as a conceptual framework for this study. When a morally distressing situation ends, nurses may be left with moral residue that serves as their new baseline for moral distress. With repeated exposures to morally distressing situations,

nurses continue to accumulate moral residue, leading to higher and higher crescendos of moral distress as they are reminded of earlier distressing situations. As moral distress recurs and moral residue continues to rise, nurses may eventually reach a breaking point (Epstein & Delgado, 2010) that results in burnout, departure from their position, or even departure from the nursing profession altogether.

Methods

Brief Introduction

Critical care nurses may experience moral distress when they feel forced to provide aggressive, life-prolonging interventions and unable to provide palliative care. Several small descriptive studies have demonstrated an alarming pattern of moral distress that is particularly significant among nurses who have received training in palliative or end-of-life care, warranting further investigation about relationships that may exist between palliative care knowledge and moral distress among critical care nurses.

Definition of Terms

For the purpose of this project, the following terms are defined:

- A “critical care nurse” is a licensed registered nurse, with or without specialty certification, actively employed in an ICU setting and responsible for managing or providing care to acutely and critically ill patients.
- “Perceived knowledge of palliative care” refers to an individual’s self-assessment of their level of competence in each of the ten realms of palliative care, as measured by the Palliative Care Competencies of Registered Nurses Survey.

- “Practice setting” (or “unit”) refers to the type of intensive care unit environment in which an individual is currently employed and practicing (e.g., surgical ICU, medical ICU, coronary ICU, etc.).
- “Moral distress” is state of negative feelings or psychological disequilibrium that occurs when a nurse recognizes the morally correct action to take but is prevented from taking it due to institutional or interprofessional constraints, whether real or perceived. This variable was measured using the Moral Distress Thermometer.

Research Design

A descriptive design was used to assess critical care nurses’ perceptions, beliefs, and experience with palliative care in their practice setting, assess critical care nurses’ recent experiences of moral distress, and measure associations between these variables.

Sample

A convenience sampling method was used in this study. The sample of critical care nurses was comprised of bedside nurses, advanced practice nurses (namely clinical nurse specialists and nurse practitioners), charge nurses, nurse managers, and nurse educators who are currently employed in one of the seven ICUs described below. Participants had to hold current licensure as a registered nurse and practice in one of the seven study ICUs. Nurses in non-permanent positions, such as travel, agency, or float staff, were excluded from analysis.

Setting

The study took place across seven ICUs at one institution, a 600-bed, level I trauma, tertiary, academic medical center in central Virginia, U.S.A. The institution employs over 500 critical care nurses and currently operates seven ICUs, consisting of a 28-bed medical ICU, a 15-bed surgical-trauma-burn ICU, a 10-bed coronary ICU, a 24-bed thoracic-cardiovascular ICU, a

12-bed neuroscience ICU, a 45-bed neonatal ICU, and a 14-bed pediatric ICU. At this institution, the palliative care service does not have inpatient admitting privileges, and operates as a consult-only service. Bedside nurses generally do not have the authority to formally initiate a referral for a palliative care consult.

Procedures

The study protocol was submitted and subsequently exempted by the Institutional Review Board for Health Sciences Research. Prior to beginning data collection, the investigator contacted the nurse managers of each of the seven ICUs to explain the purpose of the study, answer questions, address any outstanding concerns, and obtain permission to proceed in their unit. An email announcing the study was drafted by the investigator and sent to each ICU nurse manager for distribution to nursing staff. Informational flyers were posted explaining the study in each of the seven ICUs.

Paper surveys and unsealed, privacy-tinted envelopes were distributed to the mailboxes of 517 critical care nurses across the seven ICUs. The first page of the questionnaire informed participants that there were no foreseeable risks, discomforts, or costs for participation, nor a penalty for not participating. Although there was a small risk that an information breach could occur, participants' names were not collected for study, and the risk of violation of privacy or confidentiality was minimal. Participants' consent was implied when surveys were completed and returned. The survey questionnaire designed for this study can be found in Appendix B.

To avoid duplicate entry of data, each survey was distinctly marked with a mutually exclusive participant number. Participants were instructed to place their completed survey inside the attached envelope, seal it, and place it in a secure, clearly marked box in a designated location on their unit. During the two-week study period, the investigator regularly visited each

of the units to remind staff about the survey, encourage participation, and answer questions. Once collected by the investigator, completed surveys were stored in a secure office until data could be entered electronically. No further information was collected from participants after surveys were collected.

Measures

Two validated instruments were used to measure the variables of interest: the Palliative Care Competencies of Registered Nurses survey and the Moral Distress Thermometer. A third survey component was used to collect demographic information from participants. All data was electronically entered into Microsoft Excel 2011 and analyzed using IBM SPSS Statistics version 22.0.

The Palliative Care Competencies of Registered Nurses. The Palliative Care Competencies of Registered Nurses (PCCRN) survey was developed by White and Coyne in 1999 “to determine the scope, substance, and volume of continuing education about palliative and end-of-life care among practicing nurses, identify their perceived level of aptitude, and provide content-related recommendations for improvement for nursing school curricula and continuing education programs” (White, Roczen, Coyne, & Wiencek, 2014, p. 267). The most up-to-date instrument consists of 33 questions divided into four sections: basic information, palliative care core competencies, individual palliative care preparation, and organizational palliative care commitment. In the first section, respondents provide basic information, including their work experience. In the second section, respondents are asked to rank the importance of each of the palliative care core competencies, which represent the domains of palliative care outlined by the National Consensus Project for Quality Palliative Care and the preferred practices of the National Quality Forum (White & Coyne, 2011). In the third section,

respondents report on their individual palliative care preparation, including the quantity and perceived quality of palliative care continuing education. A 4-item scale allows respondents to report on the usefulness, currency, applicability, and overall rating of palliative care continuing education they have received. In the fourth section, respondents answer questions related to whether and how the respondent's organization of practice provides formalized palliative care services and how the respondent perceives the quality of these services (p. 267).

The PCCRN survey was initially validated by White, Coyne, and Patel (2001) in a descriptive survey of 750 members of the Oncology Nursing Society. In a later study, White and Coyne (2011) modified the survey by adding the questions about the organization of practice and the organization's involvement in palliative care services. The modified tool was successfully used in a study of hospice and palliative nurses (White, Coyne, & White, 2012) and later in a pilot study to identify acute and critical care nurses' beliefs, perceptions, and experiences with patients' palliative care needs (White, Roczen, Coyne, & Wiencek, 2014). In the most recent study by White and colleagues, the four-item measure of perceived quality of palliative care education demonstrated acceptable internal consistency and reliability (Cronbach's $\alpha = .79$). Based on the results of the pilot study, the PCCRN survey was further modified for the acute and critical care nurse population (K.R. White, personal communication, July 6, 2015). The PCCRN survey is a valid and reliable tool to measure nurses' perceptions of their own palliative care practices. The language in the survey reflects the critical care nursing practice environment and has been tested in critical care nurses, and the relative brevity of the survey further reinforced the instrument as an ideal choice for this study. Permission to use the tool was obtained from the copyright holder, Dr. Kenneth R. White.

Participants were asked to rate the importance of ten domains of palliative care, on a scale from 0 (not important) to 3 (highly important). The next question on the survey asks participants to rate their perceived competence in each of the ten domains on a scale from 0 (not competent) to 3 (highly competent). Participants were then asked questions related to their preparation and practice in palliative care, including the degree to which they perceive palliative care services being utilized in their practice setting. Responses to these questions on the PCCRN survey were used to assess critical care nurses' perceptions of their own knowledge related to palliative care practices and the degree to which those practices are present on their unit.

The Moral Distress Thermometer. The Moral Distress Thermometer was first developed and psychometrically tested by Wocial and Weaver (2013) to measure moral distress in hospital nurses. The MDT is a single-item visual analog scale with an 11-point verbal numeric rating scale from 0 to 10, with 0 representing the absence of moral distress and 10 representing the worst possible moral distress, and thus the highest point on the thermometer. Verbal descriptors on the scale serve to clarify the degree of distress represented by each number. The MDT provides a definition of moral distress and asks respondents to reflect on their clinical practice in the last two weeks and identify on the thermometer their level of moral distress. In its initial testing in a sample of pediatric and adult nurses (49.9% of whom were critical care nurses), the MDT demonstrated low to moderate correlation with adult ($r = .404, p < .001$) and pediatric ($r = .368, p < .001$) Moral Distress Survey scores, providing evidence of convergent validity with the Moral Distress Survey. Nurses who had never considered leaving their position had lower mean MDT scores than either those who had considered leaving ($p < .001$) or those who had left ($p = .004$), consistent with levels of moral distress measured on the Moral Distress Survey and evidence of concurrent validity. Reliability testing, however, was not

considered feasible by the authors, as moral distress is considered dynamic and not suitable to a test-retest approach (Wocial & Weaver, 2013, p. 170).

The MDT was an ideal instrument to measure critical care nurses' moral distress in this study because it is the first and only known validated tool that measures real-time levels of moral distress. Previously developed instruments have helped researchers to identify situations that cause frequent or intense moral distress, but the MDT answered a documented need for a tool to identify moral distress as it is occurring in real time (Morris & Dracup, 2008) to allow for prompt identification of factors contributing to moral distress and the ability to measure the effectiveness of interventions aimed at alleviating moral distress. Moreover, the MDT is simple to understand and could be completed rapidly. Permission to use the MDT in this study was granted by the author, Dr. Lucia Wocial. Figure 1 illustrates the version of the MDT that was used in this study.

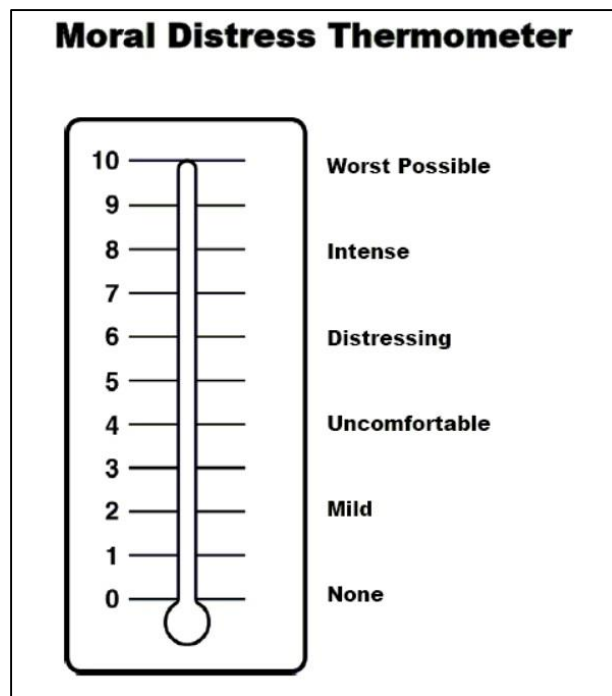


Figure 1. The Moral Distress Thermometer. Adapted from <http://www.fairbankscenter.org>. Reprinted with permission.

While the MDT scale was not modified, checkbox items were added to the questionnaire to capture the clinical, interprofessional, communication, institutional, and regulatory issues that were contributing to critical care nurses' recent experiences of moral distress. Additional space was provided for participants to describe other issues contributing to their moral distress. These items reflected morally distressing situations reported by nurses in previous studies.

Additionally, since moral distress previously demonstrated direct effects on nurses' intent to leave their position, three additional questions were added to the moral distress portion of the questionnaire. These questions asked nurses to indicate whether or not they had left a critical care nursing position due to moral distress, whether they had considered leaving a position due to moral distress, and whether they were currently considering leaving their position due to moral distress.

Demographics. Demographic data was collected from respondents, including the following: age, race, gender, years in practice, years in position, current practice setting, level of nursing education, and presence of specialty certification. Respondents were also asked to report whether their current position was a float, agency, or travel assignment.

Data Analysis

Descriptive statistics were computed on all survey data. Frequencies and valid percentages were computed for all nominal and ordinal-level data. Medians and quartiles were also calculated for ordinal-level variables. Means and standard deviations were computed for normally distributed continuous variables, and medians and quartiles were computed for continuous variables with nonparametric distribution.

Independent *t* tests and one-way analyses of variance (ANOVA) were used to detect significant differences in normally distributed continuous variables between groups. Dunnett's

2-sided *t* test was used for post-hoc analysis of significant differences detected by ANOVA, after confirming homogeneity of variances. The Mann-Whitney *U* test and Kruskal-Wallis *H* test were used to detect differences in continuous variables with nonparametric distributions. Pearson's correlation coefficient was used to evaluate linear associations between normally distributed continuous variables. For associations involving ordinal level variables or continuous variables with nonparametric distributions, Spearman's rho was used.

Results

There were 168 surveys completed and returned, for an overall response rate of 32.5%. One respondent was a travel, agency, or float nurse, and was thus excluded from analysis, leaving 167 surveys for final analysis. Demographic data for the entire sample is illustrated in Table 1.

Demographics

Age, gender, and race. Among the entire sample, participants' ages ranged from 22 to 65 years, with a mean age of 34.8 ± 10.8 years. There were no significant differences in mean age based on practice setting. Most respondents in the sample were between the ages of 22 to 35 years (61.0%), female (87.1%) and white (91.5%). Black and Hispanic respondents accounted for a combined 3.6% of the sample.

Highest degree of nursing education. Most respondents (62.7%) held a Bachelor of Science in Nursing (BSN) as their highest degree of nursing education, and 24.8% of respondents held a Master of Science in Nursing (MSN) degree. A combined 12.4% of the sample held either a diploma or an Associate's degree in Nursing. None of the respondents reported holding a doctoral degree in nursing.

Years in nursing practice. Respondents had been in nursing practice for an average of 9.4 years \pm 9.7 (range = .08 to 41 years). There were no significant differences in years of nursing practice experience based on practice setting. Over half of respondents (51.5%) had been in practice for five years or less.

Years in current position. The median number of years in current position among the entire sample was 2.0 years (IQR 1.0-7.0). There were no significant differences in years in current position based on practice setting. The majority of respondents (54.4%) had been in their position for two years or less, with nearly one-third of all respondents (33.1%) reporting one year or less in their current position.

Current practice setting. Among the survey responses analyzed, 34 respondents (20.6%) practiced in the neonatal ICU, 30 respondents (18.2%) in the pediatric ICU, and 26 (15.8%) practiced in the thoracic-cardiovascular ICU. Another 26 respondents (15.8%) practiced in the medical ICU. Eighteen respondents (10.9%) practiced in the neuroscience ICU, 17 respondents (10.3%) practiced in the surgical-trauma-burn ICU, and 14 (8.5%) in the coronary ICU.

Specialty nursing certification. Seventy-nine respondents (47.9%) reported at least one specialized nursing certification. Among the 79 certified nurses, 50 reported CCRN® certification, 9 reported board certification as an acute care nurse practitioner, and 9 reported specialized neonatal ICU certification. Eight respondents reported certification as a clinical nurse leader (CNL).

Respondents' Perceptions of Palliative Care in their Practice Setting

Perceived importance of palliative care domains. Table 2 lists the palliative care competency domains by the percentage of respondents rating each domain as highly important.

Domain C (pain management practices) was the most highly valued palliative care competency domain, with 92.7% of all respondents rating this domain as highly important. Domain A (interdisciplinary team collaboration, care coordination, and team education in palliative care) and Domain H (communicating with patients and families, talking with patients and families about death and dying, dealing with angry patients and families) were also highly valued, with 90.9% of all respondents rating each of these domains as highly important. On the other hand, Domain D (management of other symptoms) and Domain F (assessing and supporting patient and family spiritual needs) had the lowest proportions of respondents rating the domain as highly important (62.8% and 57.9%, respectively). Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy) and Domain F had the highest proportions of respondents rating these domains as not important or only somewhat important (7.4% and 7.9%, respectively). Only two respondents (1.2%) rated any of the ten domains as not at all important.

Table 3 shows the proportions of respondents from each practice setting rating each of the palliative care domains as highly important. For Domain A (interdisciplinary team collaboration, care coordination, and team education in palliative care), over 90% of respondents from the neonatal ICU, coronary ICU, neuroscience ICU, and surgical-trauma-burn ICU rated this domain as highly important. The lowest proportion of respondents rating this domain as highly important came from the pediatric ICU (86.7%).

Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy) was rated as highly important by a larger proportion of nurses in the medical ICU (79.2%) and coronary ICU (78.6%), compared to the pediatric ICU (53.3%), neuroscience ICU (64.7%), or neonatal ICU (67.7%). Additionally, this domain was rated as not important or only

somewhat important by 13.3% and 11.7% of the respondents in the pediatric and neonatal ICUs, respectively.

For Domain C (pain management), over 90% of respondents from the pediatric ICU, neonatal ICU, thoracic-cardiovascular ICU, coronary ICU, and medical ICU rated this domain as highly important. The lowest proportion rating this domain as highly important came from the surgical-trauma-burn ICU (75.0%).

Domain D (management of other symptoms) was ranked as highly important by 85.7% of respondents from the coronary ICU and 76.7% of respondents from the pediatric ICU, while less than 70% of respondents from other practice settings rated this domain as highly important. Only 47.1% of respondents from the neuroscience ICU rated Domain D as highly important.

Domain E (assessing patient-family support and resources) was ranked as highly important by 85.7% of respondents from the coronary ICU, 80.0% from the pediatric ICU, and 73.5% from the neonatal ICU, while only 46.2% from the thoracic-cardiovascular ICU ranked this domain as highly important.

Fewer than 75% of respondents from each of the seven ICUs ranked Domain F (assessing and supporting patient and family spiritual needs) as highly important. The highest proportions were in the coronary ICU (71.4%) and neonatal ICU (70.6%), while the lowest were in the surgical-trauma-burn ICU (37.5%) and thoracic-cardiovascular ICU (46.2%). Additionally, 23.1% of respondents from the thoracic-cardiovascular ICU rated this domain as not important or only somewhat important.

Domain G (providing culturally sensitive care) was highly ranked by 80% and 79.4% of respondents from the pediatric and neonatal ICUs, respectively. On the other hand, 58.8% of respondents in the neuroscience ICU ranked this domain as highly important.

Domain H (communicating with patients and families about death and dying) was rated as highly important by 100% of respondents from the surgical-trauma-burn ICU, and greater than 90% of respondents from the pediatric ICU, neonatal ICU, and coronary ICU. The lowest proportion rating this domain as highly important came from the medical ICU (84.0%).

Domain I (communicating with team, intraprofessional communication) was rated as highly important by greater than 85% of respondents in all of the study ICUs, with the exception of the neuroscience ICU (70.6%) and medical ICU (72.0%).

Fewer than 75% of respondents on each unit rated Domain J (self-care, resilience, recognizing and managing stress, grief, and moral distress) as highly important, with the exception of the pediatric ICU (76.7%).

Table 4 illustrates the percentages of respondents rating each domain as highly important, organized by highest level of nursing education. One hundred percent of diploma-prepared respondents rated Domain C (pain management), Domain E (assessing patient-family support and resources), Domain G (providing culturally sensitive care), and Domain H (communicating with patients and families about death and dying) as highly important. Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), Domain F (assessing and supporting patient and family spiritual needs), Domain I (communicating with team, intraprofessional communication), and Domain J (self-care, resilience, recognizing and managing stress, grief, and moral distress) were rated as highly important by 75% of diploma-prepared respondents. Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy) and Domain D (management of other symptoms) had the lowest proportions, with 50% of diploma-prepared respondents rating these domains as highly important.

Associate's-prepared respondents also highly rated Domain H (communicating with patients and families about death and dying), with 100% rating this domain as highly important. Most Associate's-prepared respondents (93.8%) rated Domain A (interdisciplinary collaboration, care coordination, team education in palliative care) as highly important, and 87.5% rated Domain G (providing culturally sensitive care) as highly important. Only 62.5% of respondents rated Domain E (assessing patient-family support and resources) as highly important.

Among respondents with a Bachelor's degree, Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), Domain C (pain management), Domain H (communicating with patients and families about death and dying), and Domain I (communicating with team, intraprofessional communication) had the highest proportions of respondents rating these domains as highly important. The lowest proportion was for Domain F (assessing and supporting patient and family spiritual needs), in which only 54.1% rated as highly important.

Among Master's-prepared respondents, 87.5% rated Domain A (interdisciplinary collaboration, care coordination, team education in palliative care) and Domain I (communicating with team, intraprofessional communication) as highly important, and 97.5% rated Domain C (pain management) as highly important. Additionally, 95% of Master's prepared respondents rated Domain H (communicating with patients and families about death and dying) as highly important. The lowest proportions were for Domain F (assessing and supporting patient/family spiritual needs), in which only 57.5% rated this domain as highly important.

Among the entire sample, the most important domains of palliative care were Domain A (interdisciplinary team collaboration, care coordination, and team education in palliative care),

Domain C (pain management practices), Domain H (communicating with patients and families about death and dying), and Domain I (communicating with team, intraprofessional communication), with 97% or more respondents rating each of these domains as fairly or highly important. The domains of less importance among this sample were Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy), Domain D (management of other symptoms), Domain F (assessing and supporting patient and family spiritual needs), Domain G (providing culturally sensitive care), and Domain J (self-care, resilience, recognizing and managing stress, grief, and moral distress), with 6-8% of respondents rating each of these domains as not important or only somewhat important.

Perceived competence in palliative care domains. Table 5 illustrates the frequencies and percentages of respondents who rated themselves as highly competent in any of the domains of palliative care. Overall, relatively few nurses reported being highly competent in any of the domains of palliative care. Domain I (communicating with team, intraprofessional communication) had the highest proportion of respondents rating themselves as highly competent (38.3%), followed by Domain C (pain management) with 34.7% and Domain A (interdisciplinary collaboration, care coordination, team education in palliative care) with 28.3%. The domains with the smallest proportions of respondents rating themselves as highly competent were Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy) with 11.4%, Domain E (assessing patient-family support and resources) with 20.6%, and Domain J (self-care, resilience, recognizing and managing stress, grief, and moral distress) with 23.4%.

Among all respondents, 45.8% reported that they were not competent or only somewhat competent in Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy). Additionally, greater than 25% of respondents reported that they were not competent or

only somewhat competent in Domain E (assessing patient-family support and resources), Domain F (assessing and supporting patient and family spiritual needs), Domain G (providing culturally sensitive care, meeting patient and family cultural needs, accessing language and cultural services), and Domain H (communicating with patients and families about death and dying).

Table 6 illustrates the percentages of respondents rating themselves as highly competent in any palliative care domain, organized by practice setting. For Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), the highest proportions of respondents rating themselves as highly competent were in the neuroscience ICU (50.0%) and the neonatal ICU (47.1%), whereas the lowest proportions were in the surgical-trauma-burn ICU (11.8%) and pediatric ICU (13.8%).

Relatively few respondents from any practice setting rated themselves as highly competent in Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy). The practice setting with the highest proportion of respondents rating themselves highly competent in this domain was the coronary ICU (21.4%). Less than 20% of respondents from each of the other six practice settings rated themselves as highly competent in this domain. None of the respondents from the medical ICU rated themselves highly competent in Domain B.

For Domain C (pain management practices), the highest proportions of respondents rating themselves as highly competent were in the thoracic-cardiovascular ICU (57.7%) and pediatric ICU (36.7%), while the lowest came from the surgical-trauma-burn ICU (11.8%) and medical ICU (15.4%).

For Domain D (management of other symptoms), the thoracic-cardiovascular ICU (34.6%), pediatric ICU (33.3%), and neuroscience ICU (33.3%) had the highest proportions of

respondents rating themselves highly competent in this domain, while the lowest proportions were in the surgical-trauma-burn ICU (11.8%) and coronary ICU (14.3%).

For Domain E (assessing patient-family support and resources), the highest proportions of respondents rating themselves as highly competent were in the pediatric ICU (30.0%) and the coronary ICU (28.6%). The lowest proportions of highly competent respondents for this domain were in the medical ICU (8.0%) and surgical-trauma-burn ICU (11.8%).

For Domain F (assessing and supporting patient and family spiritual needs), the coronary ICU had the highest proportion of respondents rating themselves highly competent (35.7%), followed by the neonatal ICU (30.3%). The lowest proportions were in surgical-trauma-burn ICU (5.9%), thoracic-cardiovascular ICU (19.2%), and medical ICU (19.2%).

For Domain G (providing culturally sensitive care), the highest proportions of highly competent respondents were in the neonatal ICU (44.1%) and neuroscience ICU (38.9%), while the lowest proportions of highly competent respondents were from the surgical-trauma-burn ICU (5.9%), thoracic-cardiovascular ICU (11.5%), and medical ICU (11.5%).

For Domain H (communicating with patients and families about death and dying), the highest proportions of highly competent respondents were from the neuroscience ICU (38.9%) and neonatal ICU (38.2%). The lowest proportions of highly competent respondents were from the surgical-trauma-burn ICU (11.8%) and medical ICU (15.4%).

For Domain I (communicating with team; intraprofessional communication), the highest proportions of highly competent respondents were from the neonatal ICU (50.0%) and coronary ICU (50.0%), while the lowest proportions came from the surgical-trauma-burn ICU (17.6%) and medical ICU (23.1%).

For Domain J (self-care; recognizing and managing stress, grief, and moral distress), the highest proportions of highly competent respondents were from the neonatal ICU (41.2%) followed by the coronary ICU (28.6%). The lowest proportions came from the medical ICU (7.7%) and neuroscience ICU (16.7%).

Table 7 shows the percentages of respondents rating themselves as highly competent in any palliative care domain, organized by highest level of nursing education. Among the four diploma-prepared respondents, most (75.0%) felt highly competent in Domain C (pain management), Domain D (management of other symptoms), and Domain I (communicating with team, intraprofessional communication). Only one (25.0%) felt highly competent in the Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy), Domain E (assessing patient-family support and resources), or Domain F (assessing and supporting patient and family spiritual needs).

Among those with an Associate's degree, the domains with the largest proportion of respondents rating themselves as highly competent were Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), Domain C (pain management), and Domain H (communicating with patients and families about death and dying). Domain J (self-care, resilience, recognizing and managing stress, grief, and moral distress) had the lowest proportion of respondents rating themselves as highly competent, with only one Associate's-prepared respondent (6.3%) reporting being highly competent in this domain. Additionally, only 12.5% of respondents rated themselves as highly competent in Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy), Domain D

(management of other symptoms), or Domain I (communicating with team, intraprofessional communication).

Among Bachelor's-prepared respondents, 42.6% reported being highly competent in Domain I (communicating with team, intraprofessional communication), 34.7% rated themselves as highly competent in Domain C (pain management), and 28.7% rated themselves highly competent in Domain D (management of other symptoms). On the other hand, only 8.9% of Bachelor's-prepared respondents rated themselves as highly competent in Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy).

Among Master's-prepared respondents, the highest proportion of nurses rating themselves as highly competent was in Domain I (communicating with team, intraprofessional communication), with 37.5% rating themselves as highly competent. A similar proportion (37.0%) rated themselves as highly competent in Domain A (interdisciplinary collaboration, care coordination, team education in palliative care), and 35.0% rated themselves highly competent in Domain H (communicating with patients and families about death and dying). In this group, the smallest proportion of respondents rating themselves as highly competent were in Domain B (knowledge of advance directives, living wills, powers of attorney, DNR policy) and Domain G (providing culturally sensitive care), with only 15.0% and 17.5%, respectively.

Aggregate competence scores. The sum of each participant's competence rating for each of the ten domains of palliative care was combined into an aggregate score. Only those who rated their competency for each of the ten domains had an aggregate score calculated. The maximum possible aggregate score was 30, indicating the highest possible perceived competence in the domains of palliative care. Among those with calculable scores ($n = 162$), aggregate scores for competence in the domains of palliative care ranged from 0 to 30, with a mean

aggregate score of 20.0 ± 5.1 . Descriptive statistics for aggregate palliative care competency scores by demographic variable are listed in Table 8.

There was a significant difference in mean aggregate competence scores based on age group ($F = 3.11, p < .05$). In post-hoc analysis using Dunnett's 2-sided t test, respondents aged 22-35 years had significantly lower aggregate competency scores than respondents aged 50 years and older (19.3 vs. $22.2, p = .03$), with a mean difference of -2.95 points (95% CI = $-5.67, -0.22$). Respondents aged 36-49 years had a lower mean aggregate score than those aged 50 years and older, but the difference was not statistically significant. A small significant positive correlation was detected between aggregate competency scores and age ($r = .201, p = .01$), indicating increased overall perceived competency among older nurses.

Respondents with 5 years or less nursing practice experience had significantly lower overall palliative care competence scores than those practicing for greater than 5 years (19.0 vs. $20.9, p = .01$). The less experienced nurses reported aggregate scores that were, on average, 1.97 points lower (95% CI $-3.53, -0.41$) than those with more experience. A very small, significant positive correlation was detected between aggregate competency scores and years in nursing practice ($r = .171, p = .03$), indicating a pattern of increased overall perceived competency among nurses with more years of experience.

There were no significant differences in mean aggregate scores based on amount of palliative care education, unit's use of palliative care services, attendance of ELNEC, years in position, educational level, or presence of specialty certification.

When analyzing scores by unit, the lowest mean aggregate competence scores were in the surgical-trauma-burn ICU (17.5 ± 4.0) and medical ICU (18.6 ± 3.9), and the highest were in the

neonatal ICU (21.5 ± 5.5) and coronary ICU (20.7 ± 4.7). However, there were no statistically significant differences in aggregate competence scores detected across the seven ICUs.

Hours of palliative care education in past two years. Respondents were also asked to provide information about their palliative care preparation. Table 9 illustrates the frequencies and percentages for the amount of palliative care education reported among the entire sample, organized by unit.

Sixty-three respondents (38.0%) reported having no palliative care education in the last two years. Among those who had not received any palliative care education in the past two years, approximately one-third was from the neonatal ICU. Forty-eight respondents (28.9%) reported 1-2 hours spent on palliative care education in the last two years, 25 respondents (15.0%) reported between 3-6 hours of palliative care education. Twenty respondents (12.0%) reported having seven or more hours of palliative care education in the last two years.

Reported formats of palliative care education. Among those who reported receiving palliative care education in the last two years, the most frequently reported type of education was written materials (36.2%), followed by inservice education (35.2%). Eighteen participants (17.1%) reported engaging in active learning, such as simulation or computer-based training. Various other formats were reported by 38.1% of those who received palliative care education. Examples of other educational formats reported by respondents included conferences, new graduate nurse residency content, lectures attended in nursing school, online courses, direct patient care, and consultation with palliative care experts.

Perceived usefulness of palliative care education. Most respondents (55.6%) found their palliative care education to be somewhat useful, and 39.4% found it very useful. Only five respondents (5.1%) did not find their palliative care education useful. Among those who found

their palliative care education very useful, the largest proportions were those aged 22-35 years (50.0%), BSN-prepared (48.6%), and practicing for greater than 5 years (51.3%) but fewer than two years in their current position (56.4%).

Importance of palliative care education for critical care nurses. Most respondents regarded the importance of palliative care education for ICU nurses as “extremely important” or “very important” (58.8% and 36.4%, respectively). Only 4.8% chose “somewhat important”, and none of the respondents rated palliative care education for critical care nurses as “not important”. Among the eight respondents who viewed palliative care education as only somewhat important, seven (87.5%) reported no palliative care education in the past two years, and six (75.0%) did not hold a specialty nursing certification.

ELNEC training. Among the entire sample, 22 respondents (13.2%) reported having received ELNEC training. Thirteen of these respondents (59.1%) had attended ELNEC-Core, three (13.6%) had attended ELNEC-Critical Care, three had attended ELNEC-Pediatric, two (9.1%) attended ELNEC-Geriatric, and three respondents did not remember which session they attended. Over half of the ELNEC-trained respondents came from either the neonatal ICU or neuroscience ICUs.

Perceptions of utilization of palliative care services. Overall, 14.1% of respondents reported that palliative care services were “never or rarely” utilized when appropriate on their unit. The largest proportion of respondents (41.1%) reported that palliative care services were “sometimes” utilized when appropriate on their unit. Another 38.7% of respondents reported that palliative care services were “frequently” utilized when appropriate, and 6.1% of respondents reported that palliative care services were “always” utilized when appropriate.

In the pediatric ICU, 10.3% of respondents reported that palliative care services were never or rarely utilized when appropriate. Most respondents (62.1%) reported that palliative care services were sometimes utilized appropriately. Eight respondents (27.6%) reported that palliative care services were frequently utilized appropriately, and zero respondents reported that palliative care services were always utilized when appropriate.

In the neonatal ICU, 12.1% of respondents reported that palliative care services were never or rarely utilized when appropriate on their unit. Most respondents (66.7%) reported that palliative care services were sometimes utilized appropriately on their unit. Another 15.2% of respondents reported that palliative care was frequently utilized appropriately, and two respondents (6.1%) reported that palliative care was always utilized appropriately.

Nearly all respondents from the thoracic-cardiovascular ICU reported that palliative care services were never or rarely (53.8%) or sometimes (42.3%) utilized appropriately on their unit. One respondent (3.8%) reported that these services were frequently utilized appropriately, and zero respondents reported that these services were always utilized appropriately.

In the coronary ICU, 21.4% reported that palliative care services were sometimes utilized appropriately, and 71.4% reported these services as frequently utilized appropriately. One participant (7.1%) reported these services as always utilized appropriately. None of the respondents reported that palliative care services were never or rarely utilized appropriately on their unit

In the neuroscience ICU, 50.0% of respondents reported that palliative care services were frequently utilized when appropriate, and 27.8% reported that palliative care services were always utilized appropriately on their unit. Another 22.2% reported that palliative care services

were sometimes utilized when indicated. None of the respondents reported that palliative care services were rarely or never utilized appropriately on their unit.

In the medical ICU, most respondents (84.0%) reported that palliative care services were frequently utilized appropriately on their unit. The remaining 16.0% reported that these services were sometimes utilized when appropriate, and none of the respondents reported that these services were always or never utilized when appropriate.

In the surgical-trauma-burn ICU, 11.8% of respondents reported that palliative care services were rarely or never utilized appropriately on their unit. Another 29.4% reported that these services were sometimes utilized appropriately. The largest proportion (52.9%) reported that palliative care services were frequently utilized appropriately. One respondent (5.9%) reported that these services were always utilized appropriately.

Overall, the unit with the greatest perceived utilization of palliative care services – in other words, the unit with the highest proportions of respondents reporting palliative care services as frequently or always utilized appropriately – was the medical ICU (84.0%), followed by the coronary ICU (78.5%), neuroscience ICU (77.8%), surgical-trauma-burn ICU (58.6%), pediatric ICU (27.6%), and neonatal ICU (21.3%). The thoracic-cardiovascular ICU had the lowest perceived utilization of palliative care services (3.8%).

Free text responses. Survey participants were asked to provide a free text response to describe the barriers to effective palliative care access on their unit. Responses to this question are provided in Appendix C. Additionally, participants were asked to provide a free text response to describe what they would change in their practice setting to improve the care that critically ill patients receive. Responses to this question are provided in Appendix C.

Moral Distress

During the study period, respondents reported Moral Distress Thermometer scores ranging from 0 to 10, with an overall mean moral distress level of 4.2 ± 2.6 . Seventeen respondents (10.8%) reported zero moral distress during the study period. One-fifth (20.4%) of respondents rated their moral distress levels between 0.01 and 2 out of 10 on the Moral Distress Thermometer. The largest proportion of respondents (26.8%) rated their moral distress levels between 2.01 and 4. Another 21.0% of respondents rated their moral distress level between 4.01 and 6, and 19.1% of respondents rated their moral distress level between 6.01 and 8. Three respondents (1.9%) reported moral distress levels greater than 8 out of 10.

Table 10 shows descriptive statistics for moral distress level by demographic variable. There were significant differences in moral distress levels based on age group ($F = 3.1, p < .05$). Post-hoc analysis using Dunnett's 2-sided t test revealed that respondents aged 22-35 years had significantly higher levels of moral distress than respondents aged 50 years and older (4.5 vs. 2.9, $p = .03$). Respondents aged 22-35 years scored, on average, 1.60 points higher on the Moral Distress Thermometer than respondents aged 50 years and older (95% CI = 0.18, 3.02). Respondents aged 36-49 also had a higher mean score than respondents aged 50 years and older, but this difference was not found to be significant.

Respondents who had been in their position for two years or less had significantly greater moral distress scores than those in their position for over two years (4.7 vs. 3.8, $p = .03$). In fact, there was a weak but significant negative correlation between years in current position and moral distress level ($r = -0.20, p = .02$), indicating that nurses with less time in their current position tended to experience more moral distress during the study period.

There were no significant differences in mean moral distress level based on gender, race, highest level of nursing education, years in practice, or presence of specialty certification. Table 11 illustrates descriptive statistics for moral distress scores based on other categorical variables. During the study period, the highest mean levels of moral distress were reported in the surgical-trauma-burn ICU (5.9 ± 2.7), followed by the thoracic-cardiovascular ICU (5.0 ± 2.4), medical ICU (4.6 ± 2.5), neonatal ICU (4.0 ± 2.3), coronary ICU (3.9 ± 2.9), pediatric ICU (3.8 ± 2.6), and neuroscience ICU (3.1 ± 2.3). Significant between-group differences in moral distress levels were detected based on practice setting ($F = 2.52, p = .02$). In post-hoc analysis using Dunnett's 2-sided t test, the surgical-trauma-burn ICU had a significantly higher mean moral distress level than the neuroscience and pediatric ICUs.

Significant differences in mean moral distress levels were found based on respondents' perceptions about palliative care utilization in their practice setting ($F = 3.02, p = .03$). Mean moral distress levels were highest among respondents who reported that palliative care services were "never" utilized when indicated (5.1 ± 2.3), followed by those reporting these services as sometimes utilized (4.3 ± 2.4) or frequently utilized when indicated (4.3 ± 2.8). Mean moral distress scores were lowest in those who reported that palliative care services were always utilized when indicated in their practice setting (2.1 ± 1.8). In post-hoc analysis using Dunnett's 2-sided t test, respondents who perceived palliative care services as never or rarely, sometimes, or frequently utilized as indicated reported significantly higher moral distress scores than those who perceived these services as always utilized as indicated.

There were no significant differences in moral distress levels based on the amount or type of reported palliative care education in the past two years. Nurses who reported that their palliative care education was "not useful" did not have significantly different levels of moral

distress than those who reported their palliative care education as “somewhat useful” or “very useful”. There were also no significant differences in mean levels of moral distress between respondents who had attended ELNEC and those who had not.

There were significant differences in mean moral distress based on respondents’ perceived importance of ICU nurse education in palliative care ($F = 3.94, p = .02$). In post-hoc analysis using a Dunnett’s 2-sided t test, respondents who viewed palliative care education as “very important” were found to have significantly lower mean moral distress than those who viewed palliative care education as “extremely important” (3.5 vs. 4.7, $p = .012$) and scored, on average, 1.21 points lower on the Moral Distress Thermometer (95% CI = -2.18, -0.23). There were no other detectable differences in moral distress based on perceived importance of palliative care education.

Sources of moral distress. Table 12 lists the frequencies and percentages for reported sources of moral distress among the entire sample. The most frequently reported issues contributing to moral distress among this sample were unclear goals of care (66.9%), prolonging dying (59.6%), lack of consensus regarding treatment plan (54.2%), inadequate staffing/experience (51.8%), and proving false hope (49.4%).

Table 13 shows the frequencies and percentages of reported sources of moral distress by practice setting. Unclear goals of care was the most frequently cited source of moral distress for respondents in the pediatric ICU (83.3%), medical ICU (65.4%), and surgical-trauma-burn ICU (82.4%). Lack of consensus regarding the treatment plan was the most frequently cited source of moral distress for respondents in the neonatal (61.8%) and thoracic-cardiovascular (80.8%) ICUs. Prolonging dying was the most frequently cited source of moral distress for respondents in the coronary ICU (78.6%) and surgical-trauma-burn ICU (82.4%). Inadequate

staffing/experience was the most frequently reported source of moral distress in the neuroscience ICU (47.1%) and thoracic-cardiovascular ICU (80.8%).

In addition to the aforementioned issues, participants were also given the opportunity to write in other issues contributing to their moral distress that were not otherwise listed in the survey. Six respondents – 3 from the coronary ICU, 2 from the medical ICU, and 1 from the surgical-trauma-burn ICU – provided responses to this question. These free text responses are presented in Appendix C.

Participants who did not report a score on the Moral Distress Thermometer but did report sources of moral distress during the study period were defined as having “unspecified moral distress”. Among the 8 participants (4.8% of the sample) that were found to have unspecified moral distress, 3 came from the neonatal ICU, 2 from the pediatric ICU, 2 from the medical ICU, and 1 from thoracic-cardiovascular ICU. The most common issues reported by those with unspecified moral distress were unclear goals of care (87.5%), prolonging dying (75.0%), lack of consensus regarding treatment plan (62.5%), and providing false hope (62.5%).

How many nurses have left a position due to moral distress? Among the entire sample of critical care nurses, 12 respondents (7.3%) reported that they had previously left a critical care nursing position due to their moral distress. The largest number came from the pediatric ($n = 4$), neonatal ($n = 3$), and thoracic-cardiovascular ($n = 3$) ICUs. Among the entire sample, there was not a significant difference in mean moral distress scores based on whether or not respondents had left a previous position due to moral distress.

How many nurses have considered leaving a position due to moral distress? Sixty-four respondents (38.8%) reported that they previously considered leaving a critical care nursing position because of moral distress. The largest number came from the thoracic-cardiovascular

ICU ($n = 14$), followed by the neonatal ICU ($n = 11$), the surgical-trauma-burn ICU ($n = 10$), and the pediatric ICU ($n = 10$). Among the entire sample of critical care nurses, respondents who previously considered leaving a position due to moral distress had significantly higher mean moral distress scores compared to those who had not considered it (5.4 vs. 3.5, $p < .001$). On average, those who had considered leaving a position due to moral distress scored 1.87 points higher (95% CI = 1.09, 2.66) on the Moral Distress Thermometer during the study period, compared to those who had not. A moderate, significant inverse correlation between the variables was found ($r = -.353$, $p < .001$).

How many nurses are currently considering leaving their position due to moral distress? Twenty-nine respondents (17.7%) reported that they are currently considering leaving their position due to their moral distress. In the surgical-trauma-burn ICU, 35.3% of respondents reported that they are currently considering leaving their position due to moral distress, as did 30.8% of respondents from the thoracic-cardiovascular ICU. Among the entire sample, respondents who were currently considering leaving their position due to moral distress reported significantly higher mean moral distress scores compared to those who were not (6.5 vs. 3.8, $p < .001$). Those currently considering leaving their position due to moral distress reported scores on the Moral Distress Thermometer that were, on average, 2.7 points higher (95% CI = 1.74, 3.67) than those who were not. A moderate, significant inverse correlation was detected between the variables ($r = -.402$, $p < .001$).

Relationships between Palliative Care Perceptions and Moral Distress

Overall perceived palliative care competency and moral distress. Among the entire sample of critical care nurses, there was no detectable correlation between respondents' perceived overall competency in the domains of palliative care and their levels of moral distress.

However, when analyzing correlations between respondents' perceived competency in individual domains of palliative care and their levels of moral distress, a small, significant inverse correlation ($r = -.206, p = .01$) was found between moral distress levels and Domain J (self-care, resilience, recognizing/managing stress, grief, and moral distress), indicating that respondents who felt less competent in self-care, resilience, and recognizing/managing stress, grief, and moral distress experienced greater moral distress during the study period. There were no other significant correlations between moral distress and perceived competency in other individual domains of palliative care.

Perceptions of palliative care service utilization and moral distress. Significant differences in mean moral distress levels were found based on respondents' perceptions about palliative care utilization in their practice setting ($F = 3.02, p = .03$). Mean moral distress levels were highest among respondents who reported that palliative care services were "never" utilized when indicated (5.1 ± 2.3), followed by those reporting these services as sometimes utilized (4.3 ± 2.4) or frequently utilized when indicated (4.3 ± 2.8). Mean moral distress scores were lowest in those who reported that palliative care services were always utilized when indicated in their practice setting (2.1 ± 1.8). In post-hoc analysis using Dunnett's 2-sided t test, respondents who perceived palliative care services as never/rarely, sometimes, or frequently utilized as indicated reported significantly higher moral distress scores than those who perceived these services as always utilized as indicated.

Discussion

This quantitative, descriptive study examined critical care nurses' perceptions, beliefs, and experiences of palliative care in their practice setting; investigated critical care nurses' recent experiences of moral distress; and examined how critical care nurses' perceived knowledge of

palliative care in their practice setting may relate to their recent moral distress. The results of this study illuminate numerous key knowledge gaps and ongoing deficiencies in palliative care education and training among critical care nurses, and necessitate further inquiry about how palliative care services can be best utilized within the health system. This study also illustrates the high prevalence of moral distress among critical care nurses during the study period, particularly in situations in which they felt they were prolonging the dying process or that the goals of treatment were unclear, and reveals an alarming number of nurses who have pondered leaving their position due to moral distress.

Palliative Care Knowledge Gaps

Important knowledge gaps persist in each of the palliative care competency domains among critical care nurses in this study. Most respondents found each of the palliative care domains to be highly important in their practice. Despite the widespread agreement, most nurses did not feel highly competent in any of the domains of palliative care. For instance, more than 90% of the respondents perceived pain management, interdisciplinary collaboration, and communicating with patients and families about death and dying to be highly important, but fewer than 35% felt highly competent in any of the three domains. Furthermore, fewer than one-quarter of nurses perceived themselves to be highly competent in their knowledge of advance directives; assessing patient-family support and resources; and self-care, resilience, recognizing and managing stress, grief, and moral distress. The fact that critical care nurses did not feel highly competent in domains that they highly value as a part of their practice represents necessary knowledge gaps that are concerning. The identification of these crucial knowledge gaps denotes a need to examine and adjust nursing education curricula, continuing education programs, and resources in practice (White, Roczen, Coyne, & Wiencek, 2014), but it is

important to first consider how variations in the perceptions of palliative care knowledge across generations, educational levels, and practice settings may have contributed to the results of this study.

Most respondents in this study were between the ages of 22 to 35 years, with fewer than five years nursing practice experience. The youth and relative inexperience of a large proportion of this sample is an important consideration in examining perceived importance and competence in palliative care domains, as previous studies of acute and critical care nurses (White, Roczen, Coyne, & Wiencek, 2014) have demonstrated differences across generations. The greatest proportions of respondents ranked pain management, interdisciplinary collaboration, communicating with patient and family about death and dying, and intraprofessional communication as highly important. Using a previous iteration of the PCCRN instrument in a small sample of acute and critical care nurses, White, Roczen, Coyne, and Wiencek (2014) found that critical care nurses placed highest importance on overall knowledge of palliative care practice, followed by symptom management and communicating with patients and families about death and dying. Control of pain or other symptoms and communicating with patients about death and dying were the highest-rated domains in previous surveys of perceived competency in end-of-life care in oncology nurses (White, Coyne, & Patel, 2001; White & Coyne, 2011). Consequently, there is a growing body of evidence suggesting that the ability to communicate with patients and families about death and dying and to adequately relieve patients' pain and other symptoms are decidedly important competencies across generations of nurses who care for patients with life-threatening illnesses. It is alarming, therefore, that comparatively few respondents in this study felt highly competent in these domains.

Another key finding in this study is the high importance that critical care nurses placed on the domains of interdisciplinary collaboration as well as intraprofessional and team communication. Although earlier studies of nurses' perceptions of palliative care competencies did not specifically examine these domains, the fact that these domains were among the highest in terms of perceived importance in this study may reflect the increasing emphasis of these domains within nursing education in the past decade, with the American Association of the Colleges of Nursing integrating interprofessionalism into its "Essentials" for nursing education at all levels (Interprofessional Education Collaborative Panel, 2011), and how these changes may have affected the values of newer generations of nurses who have learned the importance of these tenets in the care they provide. However, most nurses in this study, regardless of their level of nursing education, did not feel highly competent in the domains of interdisciplinary collaboration and communication, highlighting a continuing need to provide practicing nurses (and other members of the healthcare team) at all practice levels with training and skills to function and communicate effectively as team members.

In this sample, younger nurses (aged 22-35 years) had lower aggregate perceived competency scores than older nurses (aged 50+ years), and nurses with less practice experience tended to have lower perceived competency than more experienced nurses. While the overall clinical significance of these quantitative findings is unclear, the measurable differences in overall perceived competency based on age and practice experience warrants further assessment. The increasing number of elderly Americans with chronic illnesses (Institute of Medicine, 2008), concomitant with an aging nursing workforce (U.S. Department of Health and Human Services, 2013) will ultimately produce increased demand and job growth for critical care nurses over the next decade (U.S. Department of Labor, 2015). However, the increasing turnover of older nurses

means that critical care nurses with more training, experience, and actual or perceived competency in palliative care could become far scarcer in the years to come, further underscoring the need for universities and healthcare institutions to evaluate the current state of palliative care education, training, and competency among newer generations of nurses in acute and critical care.

There were noticeable variations in how nurses in different practice settings perceived certain palliative care competency domains. Although pain management was perceived as highly important by most critical care nurses in each practice setting, the management of other symptoms (such as fatigue and nausea) was not as unanimously important in each practice setting. Less than half of nurses in the neuroscience ICU rated this domain as highly important, and only one-third felt highly competent. This finding may reflect different perceptions of symptom burden for the neuroscience ICU patient population, which may be influenced by variables such as the number of patients with an altered level of consciousness, or the number of patients who require sedatives to prevent intracranial hypertension. In the coronary ICU, where over 85% of nurses perceived management of other symptoms as highly important but less than 15% perceived themselves as highly competent, nurses may be more attuned to the symptom burden of advanced cardiac disease, such as dyspnea and fatigue. However, the fact that few nurses felt highly competent in managing other symptoms, even in practice settings where it was perceived to be highly important, exposes another important knowledge gap for many critical care nurses.

Although a majority of respondents in this sample did not feel highly competent in any of the individual palliative care domains, very few respondents – regardless of educational level or practice setting – rated themselves as highly competent in their knowledge of advance directives,

living wills, powers of attorney, and DNR policy. In fact, this domain had the highest proportion of respondents who rated themselves as not competent or only somewhat competent. Previous studies have illuminated widespread knowledge gaps among acute and critical care nurses in this domain (Bellini & Damato, 2009; Putman-Casdorph et al., 2009), and there is growing evidence suggesting that nurses, physicians, and other healthcare providers often confuse advance directives and do-not-resuscitate orders (Mirarchi, Costello, Puller, Cooney, & Kottkamp, 2012; Mirarchi, Hite, Cooney, Kisiel, & Henry, 2008; Mirarchi, Kalantzis, Hunter, McCracken, & Kisiel, 2009; Mirarchi, Ray, & Cooney, 2014). Given the legal and ethical implications of this domain, this study illustrates another key area for improvement in palliative care education and training for critical care nurses.

Deficiencies in Palliative Care Education and Training

Evidence of numerous palliative care knowledge gaps among critical care nurses is further reinforced by the paltry amount of palliative care education and training reported by the nurses in this study. Over two-thirds of respondents reported two hours or less devoted to palliative care education and training over the past two years. In fact, forty percent of all respondents reported no palliative care education at all during that time period. The lack of palliative care education and training among critical care nurses in this sample is consistent with previous studies surveying palliative and end-of-life care education and training in acute and critical care nurses (White, Roczen, Coyne, & Wiencek, 2014) and oncology nurses (White & Coyne, 2011).

In addition to the importance that respondents placed on each of the domains of palliative care, nearly every respondent in this survey reported that palliative care education for critical care nurses was very important or extremely important, and nearly all participants found their

education somewhat useful or very useful. The widespread lack of palliative care education among a sample of critical care nurses that largely values palliative care as a part of their practice denotes a need for further local assessment by health system leaders and educators into the state of palliative care education and training for pre-licensure nursing students and new graduate nurses entering practice in critical care, as well as the requirements for continuing education in palliative care for critical care nurses. The Palliative Care Competencies and Recommendations for Educating Undergraduate Nursing Students (Palliative CARES) may serve as a useful tool for nursing educators, as it describes the important roles nurses play and outlines the necessary competencies that nurses must possess when caring for seriously ill patients (American Association of Colleges of Nursing, 2016). The American Association of Colleges of Nursing endorsed the Palliative CARES document in February 2016.

The End-of-Life Nursing Education Consortium (ELNEC) is another national initiative that was launched by the American Association of the Colleges of Nursing in 2000 to improve palliative care education for nurses (American Association of the Colleges of Nursing, 2015). ELNEC courses provide nurses, nursing educators and leaders, and other healthcare professionals with essential training in the domains of palliative care that can subsequently be shared and taught by participants to students and healthcare professionals in their own communities. Through November 2015, over 20,500 nurses and other healthcare professionals have received training at a national ELNEC course and have returned to their institutions and communities to provide training to an estimated 615,000 additional nurses (American Association of the Colleges of Nursing, 2015). Despite the remarkable growth of ELNEC since its inception, most respondents in this study had never attended an ELNEC course, though at least one respondent from each ICU reports receiving ELNEC training. The prevalence of

formal training in palliative care among critical care nurses is an important consideration in assessing the current state of human resources to hold future unit-wide, institution-wide, or community-wide educational events, including ELNEC. Although very few respondents in this sample had received ELNEC training, the presence of at least one ELNEC-trained nurse on each unit presents a crucial opportunity for health system leaders to empower these valuable stakeholders to spearhead efforts to improve the amount and quality of palliative care education for all critical care nurses in their practice setting – including, but not limited to, coordinating and teaching local ELNEC courses.

Utilization of Palliative Care Services

Overall, a majority of respondents in this study reported that palliative care services were infrequently utilized when indicated in their practice setting, with over 55 percent of respondents reporting that palliative care services were either never/rarely or only sometimes utilized appropriately. However, there was variability in how critical care nurses in different practice settings perceived the utilization of palliative care services. Critical care nurses' perceptions of when palliative care services are indicated may vary based on their experience and educational background, the amount of training they have received in palliative care, and the unit in which they practice. The perceived lack of access to palliative care services was particularly evident among respondents in the thoracic-cardiovascular ICU, where over half of respondents reported that palliative care services were never or rarely utilized when appropriate. In fact, all but one respondent from the thoracic-cardiovascular ICU reported that palliative care services were either never or rarely, or only sometimes utilized. The particular lack of perceived utilization of palliative care services in the thoracic-cardiovascular ICU is unsurprising, given the unique challenges that have been previously observed and reported in surgical ICU settings – including

surgeons' strong sense of personal responsibility to optimize patient outcomes, as well as disparate opinions about communicating prognosis to the patient and family, leading to frequent disagreements between surgeons and ICU team members regarding appropriate goals of care (Aslakson, Curtis, & Nelson, 2014).

Outside of the thoracic-cardiovascular ICU, relatively fewer respondents from the other units reported palliative care services were never utilized, with less than 15 percent of nurses from any unit reporting so. Not a single respondent from the coronary ICU, neuroscience ICU, and medical ICU reported that palliative care services were never utilized. Most respondents from these three units reported that palliative care services were frequently utilized as indicated. Similarly, most respondents in the surgical-trauma-burn ICU reported palliative care services were frequently utilized as indicated in their practice setting. Although few respondents from any unit reported palliative care services were always utilized appropriately, the most came from the neuroscience ICU. The pediatric and neonatal ICUs had the highest proportions of respondents who felt that palliative care services were only sometimes utilized as indicated, with approximately two-thirds from each unit reporting so.

Survey respondents were asked to provide a free text response about what they perceive to be the most challenging barriers to effective palliative care in their practice setting. Although qualitative responses are not robustly analyzed in this study, there are observable and sometimes identical similarities in how respondents answered this question. Respondents across each practice setting cited insufficient education for healthcare providers, misconceptions about the role and meaning of palliative care in critical illness, unrealistic or disparate expectations on the part of licensed independent providers and/or family members, and patients being managed by multiple teams as significant factors in their practice setting that ultimately prevent patients from

receiving palliative care. Previous studies have illustrated each of these as significant barriers preventing the integration of palliative care in the ICU (Aslakson, Curtis, & Nelson, 2014).

There are numerous evidence-based interventions to overcome barriers to palliative care access, including structured communication techniques, interventions to increase support for family members and surrogate decision makers, screening tools and decision supports, order sets, and interventions to support ICU clinicians (Aslakson, Curtis, & Nelson, 2014). It is important to note, however, that interventions to improve palliative care access should not simply aim to increase the number of palliative care consultations and referrals. Continued workforce shortages in palliative care will limit reliance on a consultative model (Lupu, 2010). Therefore, it remains crucial for team members in the ICU – particularly nurses – to achieve a basic competency in the domains of palliative care. Health system leaders must work together with front-line healthcare providers to identify barriers to both consultative and integrative palliative care unique to each practice setting.

Moral Distress

Moral distress was a common experience among respondents across all practice settings, with most respondents reporting some degree of moral distress during the study period. Few respondents reported no moral distress, though even fewer experienced severely intense moral distress (scores of 8 or higher on the Moral Distress Thermometer). Although the frequency of feelings of moral distress was not measured in this study, the overall intensity of moral distress, as measured by the descriptors on the Moral Distress Thermometer, was typically characterized as mild to distressing. The high prevalence of moral distress reported in this quantitative study reinforces moral distress as a common emotional experience among critical care nurses, as illustrated nearly three decades ago by Wilkinson (1987) and in subsequent studies in critical

care nurses (Elpern, Covert, & Kleinpell, 2005; Hamric & Blackhall, 2007; Maiden, Georges, & Connelly, 2011; Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2015), with variable frequency and intensity depending upon the situation (Oh & Gastmans, 2015). The consistently high prevalence of moral distress among all respondents in this study could have been triggered by ongoing situations occurring during the study period, lingering feelings (exemplifying moral residue) from previously distressing situations, or a combination of both.

Variations in levels of moral distress. There were noteworthy variations in the levels of moral distress experienced by certain groups of respondents in this study. Respondents in the surgical-trauma-burn ICU reported the highest levels of moral distress during the study period – significantly higher than respondents in the pediatric and neuroscience ICUs – the units with the lowest moral distress levels during the study period. In order to account for other variables that could have influenced respondents' experiences of moral distress during the study period, nurse managers from each of the seven study ICUs were interviewed following the study period, and additional information was gathered from the moral distress and ethics consultation services. There were no moral distress consultation referrals in any of the ICUs during the study period. Only one ethics consult occurred during the study period, in the medical ICU. There were expected numbers of deaths occurring on each unit during the study period, with the exception of the pediatric ICU, which experienced an unusually high number of deaths during the study period, according to the nurse manager. All seven ICUs were at or near their patient capacity throughout the study period. Staffing may have been an influential factor in the thoracic-cardiovascular ICU, with shortages reported on both day and night shifts during the study period. In addition, there was a thoracic-cardiovascular ICU morbidity and mortality conference held during the study period in which an attending surgeon had allegedly accused nursing staff of

manipulating a patient's family to withdraw life-sustaining treatment. Several other factors were disclosed by the manager that may have influenced respondents' moral distress in the thoracic-cardiovascular ICU: poor working relationships between surgeons and intensivists resulting in poor team communication and care coordination; recurring hostility between physicians and staff nurses during complicated cases; and recent staff turnover. Other units have implemented interventions that may have indirectly prevented morally distressing events from occurring. For instance, in the neonatal ICU, staff members meet regularly with an ethicist every two weeks to discuss an ethically challenging case. In the medical and surgical-trauma-burn ICUs, a protocol had been implemented to identify medically complex patients and more effectively coordinate their care across the continuum. In the neuroscience ICU, a clinical nurse specialist collaborated with members of the interdisciplinary team to identify and refer patients who may have complex care needs, including the need for specialty palliative care.

In this study, younger nurses (respondents aged 22-35 years) reported significantly higher levels of moral distress than older nurses (respondents aged 50 years and older) during the study period. Although the relationship between moral distress and age remains unclear, the findings of several previous studies also suggest that older, more experienced nurses may experience less intense moral distress, though with more frequency in some cases, than their younger colleagues (Oh & Gastmans, 2015). The variations in frequency and intensity of moral distress according to age may be attributed to the coping strategies that nurses may acquire with more age, experience, and education. Moreover, it is plausible that older and more experienced nurses in this study have felt moral distress numerous times before, and could have been describing their baseline moral residue if they were not currently experiencing a morally distressing situation in their practice setting. Some older respondents may have become morally numbed from repeated

exposure to morally distressing situations (Epstein & Delgado, 2010), altering their perception of the severity of their moral distress during the study period.

Respondents with less time in their current position (2 years or less) reported significantly higher moral distress during the study period than those with more time in their position (greater than 2 years), but there were no detectable differences in moral distress scores based on years of nursing experience. Several previous studies reported that nurses with more experience and more years in their current position were more frequently confronted with moral distress than those with less nursing experience and time in their position (Oh & Gastmans, 2015), and that the intensity of moral distress may increase with more nursing experience and time employed in a position (Oh & Gastmans, 2015). However, previous studies have largely used instruments that measure moral distress experienced by nurses in past situations, or hypothetical scenarios. In this study, the Moral Distress Thermometer was used to measure critical care nurses' recent and ongoing experiences of moral distress, which may have illuminated key differences in how nurses of varying ages, years in practice, and years in their position report their ongoing moral distress versus past or hypothetical situations causing moral distress. Older, more experienced nurses may have been more likely to recall prior situations causing moral distress than younger nurses with less experience. Using a valid instrument that measured real-time moral distress, this study finds that critical care nurses across all demographics experienced moral distress, and younger nurses with less experience and time in their position experienced moral distress of equal or greater intensity than their older, more experienced colleagues. Thus, it is imperative that educators and leaders not underestimate the potential for damaging moral distress among these vital members of the healthcare workforce.

Sources of moral distress. Among the entire sample of critical care nurses in this study, the most frequently cited situations causing moral distress were unclear goals of care, prolonging dying, lack of consensus regarding the treatment plan, inadequate staffing and/or experience of staff, and providing false hope to patients and family members. Over two-thirds of respondents reported unclear goals of care were contributing to their moral distress, and well over half of critical care nurses had evidently cared for a patient in which they felt that they were simply prolonging their dying. Unclear goals of care were frequently cited sources of moral distress for most respondents in the pediatric ICU, medical ICU, and surgical-trauma burn ICU. In the coronary ICU and surgical-trauma-burn ICU, greater than 75% of respondents reported prolonging dying as contributing to their moral distress. Providing interventions perceived as inappropriate, overly aggressive, or even futile – especially near the end of a patient’s life – has been a universally common source of intense and frequent moral distress in prior studies of critical care nurses (Corley, 1995; De Villers and DeVon, 2012; Gutierrez, 2005; Hamric & Blackhall, 2007; McClendon & Buckner, 2007; Mobley, Rady, Verheijde, Patel, & Larson, 2007; O’Connell, 2015; Oh & Gastmans, 2015; Wiegand & Funk, 2012; Wilkinson, 1987). Lack of consensus regarding the treatment plan and inadequate staffing and/or experience were the most frequently cited sources of moral distress for over 80% respondents in the thoracic-cardiovascular ICU, a unit which reportedly struggled with staffing during the study period and had longstanding issues with staff turnover and poor team communication, per the nurse manager. Other previous studies indicate that nurses experience more intense moral distress when they perceived a negative ethical climate, had inadequate staff to provide safe patient care, and when patients or family members were inappropriate or uncooperative (Oh & Gastmans, 2015). The results of this study support previous evidence that critical care nurses experience

moral distress when they feel unable to provide ethically or medically appropriate care to patients, especially those whom they believe to be nearing the end of life. Unit- and institution-wide initiatives to enhance communication between team members and with the patient and family may help alleviate these significant sources of staff moral distress. These interventions may reduce confusion and discord regarding goals of care, avoid treatments that may be inappropriate, and improve patient, family, and staff satisfaction.

Survey respondents were also given the opportunity to provide a free text response to describe other sources of moral distress not otherwise described in the survey. Only six respondents provided free text responses in this section. Although these free text responses are not robustly analyzed in this study, one specific response merits specific mention. One respondent described an incident that had occurred prior to the study period in which referrals to both the ethics and moral distress consult services were needed, and that both the issues and intensity of feelings were still lingering a month later. Although the respondent did not describe other details of this incident, the “lingering” of moral distress experienced by this respondent presents further evidence that moral distress is cumulative and may yield harmful psychological residue for some critical care nurses, as previously postulated (Epstein & Hamric, 2009; Webster & Baylis, 2000).

Consequences of moral distress. Few respondents in this study reported having left a prior critical care nursing position due to moral distress. However, a considerably larger proportion – nearly 40% of the entire sample – had previously considered leaving a position due to moral distress. Nearly 20% of critical care nurses surveyed were currently considering leaving their position due to moral distress, with the largest numbers coming from the thoracic-cardiovascular and surgical-trauma-burn ICUs. As previously mentioned, respondents from the

surgical-trauma-burn ICU had the highest mean levels of moral distress from any practice setting, and respondents from the thoracic-cardiovascular ICU had the second highest scores. Among the entire sample, respondents who had previously considered leaving or who were currently considering leaving a position due to moral distress had higher moral distress scores than those who had never considered leaving. Similar findings have been reported in previous studies (Hamric & Blackhall, 2007; Wocial & Weaver, 2013). Although other consequences of moral distress were not measured in this survey, previous studies have linked moral distress with elements of burnout (Oh & Gastmans, 2015; Rushton, Batcheller, Schroeder, & Donohue, 2015), decreased job satisfaction (Elpern, Covert, & Kleinpell, 2005), and avoidance behavior (De Villers & DeVon, 2012). These alarming outcomes support the relationships theorized by Rushton, Kaszniak, and Halifax (2013), that nurses who cannot modulate their moral distress may thus act to reduce their own suffering, by avoiding ethically challenging situations, becoming emotionally numb, or departing from their position. Without appropriate intervention to prevent scenarios that lead to moral distress and improve critical care nurses' resilience, the consequences of moral distress may have far-reaching effects on nurse well-being as well as turnover and staffing, which may threaten patient safety and cause needless waste of important human and financial resources.

Relationships between Perceptions of Palliative Care and Moral Distress

Using two separate, validated instruments, this study elicits crucial information about existing palliative care knowledge gaps and deficits in education and training for critical care nurses and provides a unique snapshot into recent encounters of moral distress experienced by these nurses during a short period. Measures of correlation were used to determine whether nurses' recent experiences of moral distress could have related to variations in their perceptions

of palliative care competence, education, and utilization in their practice setting. Given the purpose of each of these instruments, statistical associations between variables should be interpreted cautiously.

Competence and Education. There was no statistical association between critical care nurses' moral distress and their overall perceived competence in the domains of palliative care, and there were no significant differences in moral distress scores based on reported amount of palliative care education or attendance of ELNEC training. An earlier study by Browning (2013) found modest positive correlations between ELNEC-Critical Care training and moral distress related to care not in the patient's best interest and between ELNEC-Critical Care training and total score for moral distress frequency. Although only 16 nurses in that study reported attending ELNEC, the presence of ELNEC training was also a significant predictor of moral distress frequency in that study. In a survey of nurses, physicians, and allied healthcare providers by Whitehead, Herbertson, Hamric, Epstein, and Fisher (2015), healthcare providers who reported receiving specialized training in palliative care had significantly higher moral distress scores than those without training. Respondents with more palliative care education may be more likely to recognize situations in which patients are not receiving adequate palliative care, and thus might be more prone experience moral distress. However, most respondents in this study had little palliative care education and training in the past two years, and few had attended an ELNEC program, which may help to explain the lack of detectable differences based on education and preparation in this study. Moreover, the instrument used to measure moral distress in this study did not assess the frequency with which moral distress occurred, as was measured in the previous study by Browning. While the relationship between overall palliative care competence and experiences of moral distress remains unclear, there is no evidence that nurses who are better

prepared to provide palliative care experience less moral distress. Therefore, efforts to improve palliative care in the ICU must extend beyond merely education interventions for healthcare providers and must involve identifying and reducing other barriers to these services.

When analyzing associations between moral distress and competency in each of the individual domains of palliative care, there was a weak inverse correlation between moral distress scores and competency in self-care, resilience, recognizing and managing stress, grief, and moral distress, indicating that those who feel less competent in this domain tended to experience greater moral distress during the study period. Nurses who feel less able to cope effectively with morally distressing situations they may encounter might thus experience more intense moral distress. Although most respondents did not rate themselves as highly competent in any domain of palliative care, the self-care domain was among the areas of lowest competency. Given the aforementioned potential consequences of moral distress without proper intervention, the emotional well-being of healthcare providers – including the recognition and management of moral distress – should be a priority for healthcare institutions. The *4 A's Model* serves as a useful framework to guide interventions aiming to reduce or manage moral distress for critical care nurses. One such intervention at the University of Virginia is the moral distress consultation service, a unique interdisciplinary team of professionals that can be consulted by any team member when a morally distressing situation arises. Members of the moral distress consultation service meet with healthcare providers to discuss the morally distressing issue and help staff strategize and coordinate management of the current situation, and help to prevent future situations from occurring (Epstein & Delgado, 2010). Although evidence demonstrating the success of this service is still forthcoming, this novel approach to managing moral distress

could be utilized institution-wide to help critical care nurses and other healthcare professionals to become more adept at effectively recognizing and managing morally distressing situations.

Utilization. Respondents who perceived palliative care services as being never or rarely utilized when indicated in their practice setting reported higher levels of moral distress during the study period, compared to respondents who perceived palliative care services as being sometimes, frequently, or always utilized when indicated. Those who perceived palliative care services as always utilized when indicated had the lowest levels of moral distress during the study period, among the four groups. Although a cause-and-effect relationship cannot be determined from this data, the high importance that respondents almost unanimously placed on palliative care, concomitant with the sources of moral distress frequently cited by the respondents, indicates that critical care nurses who perceive deficiencies in palliative care access may be more likely to experience moral distress – especially when these deficiencies precipitate harm to patients, such as prolonging the dying process.

Evidence-based interventions exist that aim to improve access to palliative care for patients in the ICU (Aslakson et al., 2014). Many of these interventions have resulted in improved patient outcomes such as decreased ICU and hospital length-of-stay and increased patient satisfaction, while having no discernible impact on patient mortality. Few studies have examined how improving access to consultative and integrative palliative care for ICU patients might impact critical care nurses and other clinicians. Based on the results of this study, however, identifying and addressing major barriers to integrative and consultative palliative care services in each ICU may help ameliorate major sources of moral distress for nurses in these practice settings.

Limitations

There are a number of important limitations to this study. This was a survey of critical care nurses' perceptions – rather than researcher observations – of moral distress and palliative care in their practice setting. Although valid instruments were used to measure the variables of interest, and definitions provided to participants, it is still conceivable that some respondents may have conflated moral distress with other phenomena they were experiencing, such as psychological stress. Respondents' perceptions of palliative care utilization could have underestimated or overestimated the actual utilization of palliative care services during the study period. Respondents may have also underestimated or overestimated their competency to provide palliative care. Additionally, critical care nurses who participated in this survey could have been more likely to suffer from moral distress than the general population of critical care nurses, making this study particularly susceptible to response bias. Moreover, the relatively small sample size and research setting limit the generalizability of the results of this study. Lastly, this study used a newer survey instrument to measure critical care nurses' moral distress at a single point in time, and it is unknown whether participants' scores might have varied with repeated measures over a period of hours, days, or weeks.

Implications for Nursing Practice, Education, and Research

This quantitative, descriptive study surveyed critical care nurses about their perceptions of palliative care in their practice setting; investigated their recent experiences of moral distress; and examined how their perceptions of palliative care may relate to their recent experiences of moral distress. Overall, most respondents perceived the domains of palliative care to be highly important, but most did not perceive themselves to be highly competent to provide palliative care. The youngest respondents in the sample (nurses aged 22-35 years) reported significantly

lower overall palliative care competency than the oldest respondents (nurses aged 50 years and older). Most respondents in this sample had received very little palliative care education and training, with most reporting two hours or less in the past two years. A majority of respondents reported that palliative care services were never/rarely or only sometimes utilized in their practice setting. Most respondents reported some level of moral distress, and up to 40% of respondents reported previously or currently considering leaving a position due to moral distress. Moral distress was significantly higher among the youngest respondents, those with less than two years' experience, those who practiced in the surgical-trauma-burn ICU, and those who perceived palliative care services to be never or rarely utilized when indicated. Although there was not a statistical correlation between overall palliative care competency and moral distress, there was a weak inverse correlation between moral distress and competency in the self-care domain of palliative care, indicating that respondents who felt less competent in this domain tended to experience worse moral distress during the study period. Respondents who perceived palliative care as being utilized more frequently when indicated in their practice setting tended to experience less moral distress during the study period. The results of this study generate numerous implications for nursing practice, education, and research.

Practice. Palliative care is now considered an integral component of quality critical care for patients in the ICU, but the results of this survey highlight persistent knowledge gaps across all of the palliative care competency domains, as well as inadequate education and training for critical care nurses. Moreover, there appears to be inconsistent utilization of palliative care services perceived by nurses in some practice settings. Together, these findings signify inadequate access to consultative and integrative palliative care services for critically ill patients. Executive and unit-based leadership at each healthcare institution must empower and partner

with front-line team members to identify and remove barriers to consultative and integrative palliative care in each practice setting and across the institution.

Secondly, the results of this survey indicate that moral distress remains a highly prevalent occurrence for critical care nurses, particularly in situations in which they feel the goals of care are unclear, they are prolonging the dying process, there is a lack of consensus regarding the treatment plan, or there is inadequate staffing or experience in their practice setting. During the study period, nurses who felt less competent in the domain of self-care, resilience, and the recognition and management of grief, stress, and moral distress tended to experience higher levels of moral distress during the study period. Although resources are available for staff members who are experiencing moral distress, the resources may not be well known to all team members. Ethics and moral distress consultation services should be established and made familiar and accessible to all team members who care for seriously ill patients, and efforts should be made to promote self-care and resilience in practice for critical care nurses and their colleagues.

Education. The results of this study convey widespread agreement among critical care nurses regarding the importance of palliative care in their practice settings, and further expose knowledge gaps in each of the palliative care competency domains. Palliative care knowledge gaps may differ based on generation, level of nursing education, and practice setting. The results of this survey indicate the need for nursing educators and health system leaders to appraise the current requirements and opportunities for palliative care education for all nurses, paying particular attention to ensure that nurses are adept in the domain of self-care, resilience, and the recognition and management of grief, stress, and moral distress.

Secondly, the results of this survey indicate that despite the national growth of palliative care education programs like ELNEC, many nurses continue to report a lack of formal education and training in palliative care. However, in this study, at least one respondent from each practice setting had received ELNEC training. Each of these ELNEC-trained respondents represents a potential “champion” of palliative care initiatives within their practice setting and across their institution. These important stakeholders should be empowered as palliative care educators and resources for their colleagues, and efforts should be made by health system leaders to empower these stakeholders to organize educational events for critical care nurses, including ELNEC, on a regular basis.

Research. Previous studies have illustrated that critical care nurses experience particularly intense and frequent moral distress when they feel they are providing interventions that they perceive are unwanted, overly aggressive, inappropriate, or futile, especially as patients near the end of life. This study adds important local knowledge about how critical care nurses perceive palliative care in their practice setting and how these perceptions may relate to their experiences of moral distress. Future studies should continue to refine real-time measurement of moral distress and should use these measurements to evaluate the success of interventions aimed at reducing it. Intervention studies aimed at improving palliative care access and training should remain focused on improving patient and family-level outcomes, but would be prudent to consider measuring improvements in staff outcomes, including the frequency and intensity of real-time moral distress among all healthcare team members.

Conclusion

As the role of palliative care continues to grow, critical care nurses play an increasingly pivotal role in providing critically ill patients with high-quality palliative care during life-

sustaining treatment and at the end of life. The persistent knowledge gaps and deficiencies in palliative care preparation that were reported by the nurses in this study indicate that there are numerous opportunities for improvement to better prepare nurses as skilled, compassionate, and resilient providers of palliative care in the ICU. Empowering critical care nurses as leaders and advocates to eliminate barriers to palliative care access may help to prevent scenarios that frequently cause moral distress. By better preparing nurses to effectively integrate palliative care competencies into their practice and simultaneously improving patients' access to expert palliative care services, health system leaders and educators can reduce the burden of suffering for critically ill patients in the ICU, and the nurses who are trusted to care for them.

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Appendix A

Tables

Table 1

Description of Study Sample

Demographic Variable	Response
Gender	<i>n</i> (%)
Female	142 (87.1)
Male	21 (12.9)
Age in years	
22-35 years	94 (61.0)
36-49 years	39 (25.3)
50+ years	21 (13.6)
Race	
White	150 (91.5)
Black	3 (1.8)
Hispanic	3 (1.8)
American Indian/Alaska Native	1 (0.6)
Asian	1 (0.6)
Prefer not to answer	6 (3.7)
Degree of Nursing Education	
Master's	40 (24.8)
Bachelor's	101 (62.7)
Associate's	16 (9.9)
Diploma	4 (2.5)
Years in Nursing Practice	
5 years or less	84 (51.5)
Greater than 5 years	79 (48.5)
Years in Current Position	
2 years or less	87 (54.4)
Greater than 2 years	73 (45.6)
Current Practice Setting	
Pediatric ICU	30 (18.2)
Neonatal ICU	34 (20.6)
Thoracic-Cardiovascular ICU	26 (15.8)
Coronary ICU	14 (8.5)
Neuroscience ICU	18 (10.9)
Medical ICU	26 (15.8)
Surgical-Trauma-Burn ICU	17 (10.3)

Specialty RN Certification

Yes	79 (47.9)
No	86 (52.1)

Note. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ICU = Intensive Care Unit; IQR = interquartile range; RN = registered nurse; SD = standard deviation

Table 2

Palliative Care Competency Domains, Listed by Highest Perceived Importance Among All Respondents

Palliative Care Domain	Respondents Rating Domain as Highly Important	
	<i>n</i>	%
Pain management practices	152	92.7
Interdisciplinary collaboration	149	90.9
Communicating with patient and family about death and dying	149	90.9
Communicating with team, intraprofessional communication	142	86.6
Providing culturally sensitive care, meeting patient and family cultural needs	120	73.2
Self-care, resilience, recognizing and managing stress, grief, and moral distress	113	68.9
Knowledge of advance directives, living wills, powers of attorney, DNR policy	111	68.1
Assessing patient-family support and resources	108	66.3
Management of other symptoms (fatigue, nausea, etc.)	103	62.8
Assessing and supporting patient and family spiritual needs	95	57.9

Note. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. DNR = do-not-resuscitate

Table 3

Perceived High Importance of Domains of Palliative Care, Distribution by Practice Setting

Domain	Respondents Rating Domain as Highly Important						
	PICU n (%)	NICU n (%)	TCVICU n (%)	CCU n (%)	NNICU n (%)	MICU n (%)	STBICU n (%)
(A) Interdisciplinary Collaboration	26 (86.7)	31 (91.2)	23 (88.5)	14 (100)	16 (94.1)	22 (88.0)	15 (93.8)
(B) Knowledge of advance directives, living wills, powers of attorney, DNR policy	16 (53.3)	23 (67.6)	18 (69.2)	11 (78.6)	11 (64.7)	19 (79.2)	11 (68.8)
(C) Pain Management	29 (96.7)	31 (91.2)	25 (96.2)	14 (100)	14 (82.4)	25 (100)	12 (75.0)
(D) Management of other symptoms	23 (76.7)	18 (52.9)	14 (53.8)	12 (85.7)	8 (47.1)	17 (68.0)	9 (56.3)
(E) Assessing patient-family support and resources	24 (80.0)	25 (73.5)	12 (46.2)	12 (85.7)	9 (56.3)	13 (52.0)	11 (68.8)
(F) Assessing and supporting patient/family spiritual needs	17 (56.7)	24 (70.6)	12 (46.2)	10 (71.4)	9 (52.9)	15 (60.0)	6 (37.5)
(G) Providing culturally sensitive care	24 (80.0)	27 (79.4)	18 (69.2)	11 (78.6)	10 (58.8)	19 (76.0)	9 (56.3)
(H) Communicating with patient and family about death and dying	28 (93.3)	32 (94.1)	22 (84.6)	13 (92.9)	15 (88.2)	21 (84.0)	16 (100)
(I) Communicating with team, intraprofessional communication	27 (90.0)	31 (91.2)	24 (92.3)	14 (100)	12 (70.6)	18 (72.0)	14 (87.5)
(J) Self-care, resilience, recognizing and managing stress, grief, and moral distress	23 (76.7)	25 (73.5)	15 (57.7)	10 (71.4)	11 (64.7)	17 (68.0)	10 (62.5)

Note. Bold font denotes highest rated domain in each practice setting. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ICU = Intensive Care Unit; PICU = Pediatric ICU; NICU = Neonatal ICU; TCVICU = Thoracic-Cardiovascular ICU; CCU = Coronary ICU; NNICU = Neuroscience ICU; MICU = Medical ICU; STBICU = Surgical-Trauma-Burn ICU; DNR = do-not-resuscitate

Table 4

*Perceived High Importance of Domains of Palliative Care,
Distribution by Educational Level*

Domain	Respondents Rating Domain as Highly Important			
	Diploma n (%)	ADN n (%)	BSN n (%)	MSN n (%)
(A) Interdisciplinary Collaboration	3 (75.0)	15 (93.8)	90 (91.8)	35 (87.5)
(B) Knowledge of advance directives, living wills, powers of attorney, DNR policy	2 (50.0)	11 (68.8)	68 (70.1)	24 (60.0)
(C) Pain Management	4 (100)	13 (81.3)	90 (91.8)	39 (97.5)
(D) Management of other symptoms	2 (50.0)	11 (68.8)	60 (61.2)	25 (62.5)
(E) Assessing patient-family support and resources	4 (100)	10 (62.5)	61 (62.2)	27 (69.2)
(F) Assessing and supporting patient/family spiritual needs	3 (75.0)	11 (68.8)	53 (54.1)	23 (57.5)
(G) Providing culturally sensitive care	4 (100)	14 (87.5)	64 (65.3)	33 (82.5)
(H) Communicating with patient and family about death and dying	4 (100)	16 (100)	85 (86.7)	38 (95.0)
(I) Communicating with team, intraprofessional communication	3 (75.0)	13 (81.3)	85 (86.7)	35 (87.5)
(J) Self-care, resilience, recognizing and managing stress, grief, and moral distress	3 (75.0)	13 (81.3)	61 (62.2)	30 (75.0)

Note. Bold font denotes highest rated domain at each educational level. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ADN = Associate's Degree in Nursing; BSN = Bachelor's of Science in Nursing; MSN = Master's of Science in Nursing; DNR = do-not-resuscitate

Table 5

Palliative Care Competency Domains, Listed by Highest Perceived Competence Among All Respondents

Palliative Care Domain	Respondents Self-Rating as Highly Competent in Domain	
	<i>n</i>	%
Communicating with team, intraprofessional communication	64	38.3
Pain management	58	34.7
Communicating with patient and family about death and dying	50	29.9
Interdisciplinary collaboration	47	28.3
Management of other symptoms (fatigue, nausea)	45	26.9
Providing culturally sensitive care	41	24.7
Assessing and supporting patient/family spiritual needs	39	23.5
Self-care, resilience, recognizing and managing stress, grief, and moral distress	39	23.4
Assessing patient-family support and resources.	34	20.6
Knowledge of advance directives, living wills, powers of attorney, DNR policy	19	11.4
<i>Note.</i> All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. DNR = do-not-resuscitate.		

Table 6

Perceived High Competence of Domains of Palliative Care, Distribution by Practice Setting

Domain	Respondents Self-Rating as Highly Competent in Domain						
	PICU <i>n</i> (%)	NICU <i>n</i> (%)	TCVICU <i>n</i> (%)	CCU <i>n</i> (%)	NNICU <i>n</i> (%)	MICU <i>n</i> (%)	STBICU <i>n</i> (%)
(A) Interdisciplinary Collaboration	4 (13.8)	16 (47.1)	7 (26.9)	4 (28.6)	9 (50.0)	5 (19.2)	2 (11.8)
(B) Knowledge of advance directives, living wills, powers of attorney, DNR policy	3 (10.0)	6 (17.6)	2 (7.7)	3 (21.4)	3 (16.7)	0	2 (11.8)
(C) Pain Management	11 (36.7)	15 (44.1)	15 (57.7)	3 (21.4)	6 (33.3)	4 (15.4)	2 (11.8)
(D) Management of other symptoms	10 (33.3)	10 (29.4)	9 (34.6)	2 (14.3)	6 (33.3)	4 (15.4)	2 (11.8)
(E) Assessing patient-family support and resources	9 (30.0)	7 (21.2)	4 (15.4)	4 (28.6)	4 (22.2)	2 (8.0)	2 (11.8)
(F) Assessing and supporting patient/family spiritual needs	7 (23.3)	10 (30.3)	5 (19.2)	5 (35.7)	5 (27.8)	5 (19.2)	1 (5.9)
(G) Providing culturally sensitive care	8 (27.6)	15 (44.1)	3 (11.5)	3 (21.4)	7 (38.9)	3 (11.5)	1 (5.9)
(H) Communicating with patient and family about death and dying	9 (30.0)	13 (38.2)	9 (34.6)	5 (35.7)	7 (38.9)	4 (15.4)	2 (11.8)
(I) Communicating with team, intraprofessional communication	9 (30.0)	17 (50.0)	10 (38.5)	7 (50.0)	11 (61.1)	6 (23.1)	3 (17.6)
(J) Self-care, resilience, recognizing and managing stress, grief, and moral distress	8 (26.7)	14 (41.2)	5 (19.2)	4 (28.6)	3 (16.7)	2 (7.7)	3 (17.6)

Note. Bold font denotes domain with greatest perceived competency in each practice setting. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. DNR = do-not-resuscitate

Table 7

*Perceived High Competence in Palliative Care Domains,
Distribution by Educational Level*

Domain	Respondents Self-Rating as Highly Competent in Domain			
	Diploma	ADN	BSN	MSN
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
(A) Interdisciplinary Collaboration	1 (25.0)	6 (37.5)	27 (27.0)	12 (30.0)
(B) Knowledge of advance directives, living wills, powers of attorney, DNR policy	1 (25.0)	2 (12.5)	9 (8.9)	6 (15.0)
(C) Pain Management	3 (75.0)	5 (31.3)	35 (34.7)	13 (32.5)
(D) Management of other symptoms	3 (75.0)	2 (12.5)	29 (28.7)	9 (22.5)
(E) Assessing patient-family support and resources	1 (25.0)	3 (18.8)	18 (18.2)	10 (25.0)
(F) Assessing and supporting patient/family spiritual needs	1 (25.0)	4 (25.0)	25 (25.0)	8 (20.0)
(G) Providing culturally sensitive care	2 (50.0)	2 (13.3)	28 (27.7)	7 (17.5)
(H) Communicating with patient and family about death and dying	2 (50.0)	5 (31.3)	27 (26.7)	14 (35.0)
(I) Communicating with team, intraprofessional communication	3 (75.0)	2 (12.5)	43 (42.6)	15 (37.5)
(J) Self-care, resilience, recognizing and managing stress, grief, and moral distress	2 (50.0)	1 (6.3)	26 (25.7)	10 (25.0)

Note. Bold font denotes domain of greatest perceived competency at each educational level. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ADN = Associate's Degree in Nursing; BSN = Bachelor's of Science in Nursing; MSN = Master's of Science in Nursing; DNR = do-not-resuscitate

Table 8

Aggregate Palliative Care Competency Scores, Descriptive Statistics by Demographic Variable

Demographic Variable		Aggregate Palliative Care Competency Score	
Unit	<i>n</i>	<i>Mean (SD)</i>	<i>Range</i>
PICU	28	19.9 (4.7)	11.0-30.0
NICU	33	21.5 (5.5)	11.0-30.0
TCV-ICU	26	19.7 (5.9)	0-29.0
CCU	14	20.7 (4.7)	11.0-27.0
NNICU	18	21.1 (5.8)	5.0-29.0
MICU	24	18.6 (3.9)	10.0-29.0
STBICU	17	17.5 (4.0)	11.0-26.0
Age Group			
22-35 years	91	19.3 (4.6)*	0-30.0
36-49 years	39	20.5 (5.8)	5.0-30.0
50+ years ^a	20	22.2 (5.2)*	11.0-30.0
Years in Practice			
5 years or less	81	19.0 (5.2)	0-30.0
Greater than 5 years	77	20.9 (4.7)*	11.0-30.0
Years in Position			
2 years or less	84	19.3 (5.1)	0-30.0
Greater than 2 years	72	20.7 (5.0)	11.0-30.0
Highest Degree of Nursing Education			
Diploma	4	24.0 (4.2)	20.0-30.0
Associate's	15	18.3 (5.4)	5.0-26.0
Bachelor's	98	20.1 (4.9)	0-30.0
Master's	40	19.6 (5.7)	10.0-30.0
Hours of Palliative Care Education in Past 2 Years			
None or Don't Remember	71	19.9 (4.8)	11.0-29.0
1 hour or more	90	20.0 (5.3)	0-30.0
Attendance of ELNEC Training			
Yes	22	20.6 (5.4)	11.0-30.0
No	138	19.8 (5.1)	0-30.0
Use of Palliative Care Services			
Never or Rarely	22	18.5 (5.8)	0-27.0
Sometimes	66	19.6 (5.2)	5.0-30.0
Frequently	60	20.4 (4.8)	10.0-30.0
Always	10	22.3 (4.8)	17.0-30.0
Specialty Nursing Certification			

Yes	78	20.1 (5.1)	10.0-30.0
No	82	19.8 (5.2)	0-30.0

Note. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ICU = Intensive Care Unit; PICU = Pediatric ICU; NICU = Neonatal ICU; TCVICU = Thoracic-Cardiovascular ICU; CCU = Coronary ICU; NNICU = Neuroscience ICU; MICU = Medical ICU; STBICU = Surgical-Trauma-Burn ICU; ELNEC = End-of-Life Nursing Education Consortium

^aRespondents aged 50 years and older were used as the control group to compare aggregate competency scores across age groups using post-hoc Dunnett's 2-sided *t* test.

**p* < .05

Table 9

Hours of Palliative Care Education in Last Two Years, Distribution by Unit

Unit	Hours of palliative care education in last two years					
	None	1-2 hours	3-4 hours	5-6 hours	7+ hours	Don't remember
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
PICU	9 (30.0)	9 (30.0)	5 (16.7)	2 (6.7)	1 (3.3)	4 (13.3)
NICU	21 (61.8)	5 (14.7)	3 (8.8)	1 (2.9)	4 (11.8)	0
TCVICU	12 (46.2)	11 (42.3)	2 (7.7)	0	0	1 (3.8)
CCU	1 (7.1)	8 (57.1)	0	2 (14.3)	3 (21.4)	0
NNICU	5 (27.8)	2 (11.1)	3 (16.7)	1 (5.6)	6 (33.3)	1 (5.6)
MICU	5 (19.2)	9 (34.6)	4 (15.4)	1 (3.8)	5 (19.2)	2 (7.7)
STBICU	9 (52.9)	4 (23.5)	0	1 (5.9)	1 (5.9)	2 (11.8)

Note. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ICU = Intensive Care Unit; PICU = Pediatric ICU; NICU = Neonatal ICU; TCVICU = Thoracic-Cardiovascular ICU; CCU = Coronary ICU; NNICU = Neuroscience ICU; MICU = Medical ICU; STBICU = Surgical-Trauma-Burn ICU

Table 10

Moral Distress Thermometer, Descriptive Statistics By Demographic Variable

Demographic Variable		Moral Distress Score	
Gender	<i>n</i>	Mean (SD)	Range
Female	133	4.4 (2.6)	0-10
Male	20	3.9 (2.6)	0-8.0
Race			
American Indian or Alaska Native	1	8.0 (--)	8.0-8.0
Asian	1	6.0 (--)	6.0-6.0
Black	3	6.7 (1.2)	6.0-8.0
White	141	4.2 (2.6)	0-10
Hispanic	3	3.7 (2.1)	2.0-6.0
Prefer not to answer	5	5.4 (2.5)	3.0-9.0
Age Group			
22-35 years	88	4.5 (2.4)*	0-10
36-49 years	38	4.4 (2.7)	0-9.0
50+ years ^a	19	2.9 (2.8)*	0-8.0
Years in Practice			
5 years or less	80	4.6 (2.4)	0-9.0
Greater than 5 years	73	4.1 (2.7)	0-10.0
Years in Position			
2 years or less	82	4.7 (2.4)*	0-10
Greater than 2 years	68	3.8 (2.7)*	0-9.0
Highest Degree of Nursing Education			
Diploma	4	3.5 (2.5)	0-6.0
Associate's	16	4.1 (3.2)	0-9.0
Bachelor's	92	4.5 (2.4)	0-10
Master's	39	4.0 (2.7)	0-9.0
Presence of Specialized Nursing Certification			
Yes	74	4.0 (2.5)	0-9.0
No	81	4.6 (2.6)	0-10

Note. Dashes (--) indicate data that could not be calculated due to small sample size. SD = Standard Deviation.

^aRespondents aged 50 years and older were used as the control group when comparing moral distress levels using post-hoc Dunnett's 2-sided *t* test.

**p* < .05

Table 11

Moral Distress Thermometer, Descriptive Statistics By Categorical Variable

Categorical Variable		Moral Distress Score	
Practice Setting	<i>n</i>	Mean (SD)	Range
STBICU ^a	17	5.9 (2.7)*	0-10
TCVICU	25	5.0 (2.4)	0-8.0
MICU	23	4.6 (2.5)	0-8.0
NICU	31	4.0 (2.3)	0-8.0
PICU	28	3.8 (2.6)*	0-8.0
CCU	14	3.9 (2.9)	0-9.0
NNICU	17	3.1 (2.3)*	0-9.0
Perceived Utilization of Palliative Care Services on Unit			
Never or Rarely	22	5.1 (2.3)*	2.0-8.0
Sometimes	63	4.3 (2.4)*	0-10
Frequently	59	4.3 (2.8)*	0-9.0
Always ^b	9	2.1 (1.8)*	0-4.0
# Hours of Palliative Care Education in Last 2 Years			
None	59	4.4 (2.8)	0-10
1-2	45	4.1 (2.5)	0-8.0
3-4	15	3.4 (2.3)	0-8.0
5-6	8	4.6 (2.1)	2.0-8.0
7 or more	19	4.3 (2.8)	0-9.0
Don't remember	10	5.3 (2.0)	0-10
Attendance at ELNEC			
Yes	21	4.0 (2.6)	0-9.0
No	134	4.3 (2.6)	0-10

Note. SD = Standard Deviation; ICU = Intensive Care Unit; PICU = Pediatric ICU; NICU = Neonatal ICU; TCVICU = Thoracic-Cardiovascular ICU; CCU = Coronary ICU; NNICU = Neuroscience ICU; MICU = Medical ICU; STBICU = Surgical-Trauma-Burn ICU; ELNEC = End-of-Life Nursing Education Consortium.

^aRespondents from the STBICU were used as the control group when comparing moral distress levels across practice settings using post-hoc Dunnett's 2-sided *t* test.

^bRespondents who reported palliative care services as "always" utilized as indicated in their unit were used as the control group to compare moral distress levels based on perceived palliative care utilization using post-hoc Dunnett's 2-sided *t* test.

**p* < .05

Table 12

Frequency of Reported Sources of Moral Distress Among Entire Sample

Source of Moral Distress	Respondents Reporting Source of Moral Distress		Moral Distress Level Mean (SD)
	<i>n</i>	%	
Unclear goals of care	111	66.9	5.1 (2.3)
Prolonging dying	99	59.6	5.3 (2.3)
Lack of consensus regarding treatment plan	90	53.9	5.2 (2.3)
Inadequate staffing, inadequate experience	86	51.8	5.4 (2.3)
Providing false hope to patients or families	82	49.4	5.4 (2.3)
Inadequate communication among team members	74	44.6	5.1 (2.6)
Lack of continuity regarding treatment plan	58	34.9	5.4 (2.3)
Inadequate symptom relief	54	32.5	5.0 (2.4)
Inappropriate treatment	53	31.9	5.7 (2.3)
Lack of continuity of providers	50	30.1	5.2 (2.5)
Lack of nursing involvement in decision-making	38	22.9	5.7 (2.5)
Tolerance of disruptive behavior from families/patients	38	22.9	4.9 (2.5)
Work with clinically incompetent providers	32	19.3	5.2 (2.7)
Hierarchies within the health system	31	18.7	5.7 (2.6)
Inappropriate use of resources	31	18.7	5.1 (2.9)
Disregard of patient preferences	29	17.5	5.7 (2.6)
Interprofessional conflict	28	16.9	5.6 (2.5)
Lack of administrative support	26	15.7	6.3 (2.6)
Treatment based on fear of litigation	25	15.1	5.5 (2.4)
Poor collegial relationships	22	13.3	5.1 (2.7)
Safety concerns	20	12.0	5.6 (1.9)
Compromised care to reduce costs	17	10.2	5.1 (2.7)
Policies that conflict with care needs	15	9.0	6.0 (2.6)
Tolerance of disruptive behavior from staff	14	8.4	5.8 (2.7)
Inadequate informed consent	13	7.8	6.2 (2.6)
Hastening dying	8	4.8	6.5 (1.8)
Other issues (free text)	6	3.6	5.2 (2.8)

Note. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. SD = Standard Deviation.

Table 13

Frequency of Reported Sources of Moral Distress, by Practice Setting

Source of Moral Distress	Practice Setting						
	PICU <i>n</i> (%)	NICU <i>n</i> (%)	TCVICU <i>n</i> (%)	CCU <i>n</i> (%)	NNICU <i>n</i> (%)	MICU <i>n</i> (%)	STBICU <i>n</i> (%)
Inappropriate treatment	3 (10.0)	12 (35.3)	12 (46.2)	3 (21.4)	5 (29.4)	9 (34.6)	9 (52.9)
Prolonging dying	17 (56.7)	20 (58.8)	17 (65.4)	11 (78.6)	5 (29.4)	15 (57.7)	14 (82.4)
Hastening dying	1 (3.3)	1 (2.9)	3 (11.5)	0	2 (11.8)	1 (3.8)	0
Disregard of patient preferences	1 (3.3)	0	10 (38.5)	0	5 (29.4)	3 (11.5)	10 (58.8)
Inadequate symptom relief	6 (20.0)	12 (35.3)	7 (26.9)	4 (28.6)	4 (23.5)	12 (46.2)	9 (52.9)
Unclear goals of care	25 (83.3)	20 (58.8)	20 (76.9)	10 (71.4)	5 (29.4)	17 (65.4)	14 (82.4)
Lack of consensus regarding treatment plan	18 (60.0)	21 (61.8)	21 (80.8)	6 (42.9)	3 (17.6)	9 (34.6)	12 (70.6)
Lack of continuity regarding treatment plan	13 (43.3)	14 (41.2)	11 (42.3)	4 (28.6)	1 (5.9)	6 (23.1)	9 (52.9)
Interprofessional conflict	3 (10.0)	6 (17.6)	11 (42.3)	0	1 (5.9)	3 (11.5)	4 (23.5)
Poor collegial relationships	1 (3.3)	5 (14.7)	7 (26.9)	0	4 (23.5)	3 (11.5)	2 (11.8)
Work with clinically incompetent providers	5 (16.7)	1 (2.9)	12 (46.2)	2 (14.3)	3 (17.6)	4 (15.4)	5 (29.4)
Inadequate informed consent	0	2 (5.9)	3 (11.5)	1 (7.1)	1 (5.9)	4 (15.4)	2 (11.8)
Providing false hope	11 (36.7)	18 (52.9)	18 (69.2)	7 (50.0)	5 (29.4)	10 (38.5)	13 (76.5)
Inadequate communication among team members	13 (43.3)	13 (38.2)	17 (65.4)	3 (21.4)	6 (35.3)	12 (46.2)	10 (58.8)
Lack of continuity of providers	7 (23.3)	11 (32.4)	8 (30.8)	5 (35.7)	4 (23.5)	8 (30.8)	7 (41.2)
Lack of nursing involvement in decision-making	4 (13.3)	11 (32.4)	8 (30.8)	4 (28.6)	2 (11.8)	2 (7.7)	7 (41.2)
Inadequate staffing, inadequate experience	14 (46.7)	11 (32.4)	21 (80.8)	5 (35.7)	8 (47.1)	16 (61.5)	11 (64.7)
Lack of administrative support	1 (3.3)	5 (14.7)	11 (42.3)	0	3 (17.6)	0	6 (35.3)

Policies that conflict with care needs	1 (3.3)	3 (8.8)	5 (19.2)	0	0	2 (7.7)	4 (23.5)
Tolerance of disruptive behavior from staff	0	1 (2.9)	5 (19.2)	1 (7.1)	2 (11.8)	3 (11.5)	2 (11.8)
Tolerance of disruptive behavior from families/patients	3 (10.0)	4 (11.8)	6 (23.1)	5 (35.7)	6 (35.3)	6 (23.1)	8 (47.1)
Compromised care to reduce costs	5 (16.7)	3 (8.8)	5 (19.2)	0	0	3 (11.5)	1 (5.9)
Hierarchies within the health system	5 (16.7)	2 (5.9)	10 (38.5)	0	4 (23.5)	5 (19.2)	5 (29.4)
Inappropriate use of resources	7 (23.3)	5 (14.7)	3 (11.5)	5 (35.7)	3 (17.6)	3 (11.5)	5 (29.4)
Safety concerns	1 (3.3)	5 (14.7)	5 (19.2)	1 (7.1)	1 (5.9)	4 (15.4)	3 (17.6)
Treatment based on fear of litigation	1 (3.3)	0	8 (30.8)	1 (7.1)	3 (17.6)	8 (30.8)	4 (23.5)

Note. Bold font denotes single most frequent source of moral distress reported in each practice setting. All percentages are valid percentages, reflecting proportions of respondents that provided answers to the individual question. ICU = Intensive Care Unit; PICU = Pediatric ICU; NICU = Neonatal ICU; TCVICU = Thoracic-Cardiovascular ICU; CCU = Coronary ICU; NNICU = Neuroscience ICU; MICU = Medical ICU; STBICU = Surgical-Trauma-Burn ICU

Appendix B

Study Questionnaire



**Palliative Care Practices and Moral Distress
among Acute and Critical Care Nurses**

This study seeks to bring together two topics of great concern to clinicians and researchers today—palliative care practices in the ICU setting and moral distress among clinicians—to determine the extent of the problem of moral distress in ICUs, the degree of understanding of palliative care practices in ICUs, and the degree to which these two phenomena are related. Information from this study will be used to develop new strategies for education and practice.

This survey will require approximately 20 minutes of your time. The survey is anonymous in that we are not collecting names or other identifying information. We are, however, collecting information about your role, your years of clinical experience, and the unit on which you work. Completion of the survey is voluntary and will be taken as your agreement to participate.

There are no foreseeable risks, discomforts, nor cost to you for your participation. There is no penalty for not participating. The information obtained from this survey will be aggregated and no individual data will be reported.

Even though you are in no way obligated to participate in this project, its success depends on your involvement. Thank you in advance for your participation and contribution to discovering new knowledge. If you have questions, suggestions, or complaints, please contact Alex Wolf (atw3dy@virginia.edu), Dr. Kyle Enfield (ke4z@hscmail.mcc.virginia.edu), Dr. Ken White (krw6cc@virginia.edu), Dr. Beth Epstein (meg4u@virginia.edu).

Palliative Care Practices

This section addresses your perspectives about the domains of palliative care. It is ok if you are not familiar with these domains specifically. We are interested in knowing how important certain aspects of patient care are and how comfortable you feel with them.

1. How important are the following issues in caring for critically ill patients?

Nursing Palliative Care Domains		Not Important (0)	Somewhat Important (1)	Fairly Important (2)	Highly Important (3)
A	Interdisciplinary team collaboration, care coordination, team education on palliative care				
B	Knowledge of advance directives, living wills, powers of attorney, DNR policy				
C	Pain management practices				
D	Management of other symptoms (fatigue, nausea)				
E	Assessing patient-family support and resources				
F	Assessing patient and family spiritual needs, accessing resources for spiritual support				
G	Providing culturally sensitive care, meeting patient and family cultural needs, accessing language and cultural resources				
H	Communicating with patient and family: how to talk to patients and families about death and dying, dealing with angry patients and families				
I	Communicating with team: intraprofessional team communication, managing differences of opinion				
J	Self-care: resilience, recognizing and managing stress and grief, moral distress				

2. How would you rate your OWN level of competence on the following items?

Nursing Palliative Care Domains		Not Competent (0)	Somewhat Competent (1)	Fairly Competent (2)	Highly Competent (3)
A	Interdisciplinary team collaboration, care coordination, team education on palliative care				
B	Knowledge of advance directives, living wills, powers of attorney, DNR policy				
C	Pain management practices				
D	Management of other symptoms (fatigue, nausea)				
E	Assessing patient-family support and resources				
F	Assessing patient and family spiritual needs, accessing resources for spiritual support				
G	Providing culturally sensitive care, meeting patient and family cultural needs, accessing language and cultural resources				
H	Communicating with patient and family: how to talk to patients and families about death and dying, dealing with angry patients and families				
I	Communicating with team: intraprofessional team communication, managing differences of opinion				
J	Self-care: resilience, recognizing and managing stress and grief, moral distress				

Palliative Care Preparation and Practice

3. Approximately how many hours of palliative care education did you receive in the last 2 years?
- ☐ None
 - ☐ 1-2 hours
 - ☐ 3-4 hours
 - ☐ 5-6 hours
 - ☐ 7 or more hours
 - ☐ Don't remember
4. If you received palliative care education, what format was used?
- ☐ Inservice
 - ☐ Written materials
 - ☐ Active learning (role play, interactive discussion)
 - ☐ Other _____
 - ☐ Don't remember
5. If you received palliative care education, how useful was this education in your daily practice?
- ☐ Not useful
 - ☐ Somewhat useful
 - ☐ Very useful
6. How important is it that ICU nurses have education in palliative care?
- ☐ Not at all important
 - ☐ Somewhat important
 - ☐ Very important
 - ☐ Extremely important
7. Does your unit utilize palliative care services?
- ☐ Never/rarely
 - ☐ Sometimes
 - ☐ Frequently
 - ☐ Always

8. If you believe palliative care services are not utilized enough on your unit, what do you see as the barriers?
9. If you could change one thing in your practice setting that would improve the care that critically ill patients receive, what would you change?
10. Have you attended an End-of-Life Nursing Education Consortium (ELNEC) training session?
- ☐ Yes
 - ☐ No
11. If yes, which program(s) have you attended?
- ☐ Core
 - ☐ Critical care
 - ☐ Gerontology
 - ☐ Pediatric
 - ☐ Don't remember

Demographic Information

12. What is your birth year? 19_____
13. What is your gender?
- ☐ Female
 - ☐ Male
14. What is your race?
- ☐ American Indian/Alaska Native
 - ☐ Native Hawaiian/other Pacific Islander
 - ☐ Asian
 - ☐ Black/African American
 - ☐ White/Caucasian
 - ☐ Other: _____
 - ☐ I prefer not to answer
15. What is your highest level of nursing education?
- ☐ Diploma
 - ☐ Associate's degree
 - ☐ Bachelor's degree
 - ☐ Master's degree
 - ☐ Doctoral degree (PhD, DNP)
16. How many years have you been in practice? _____
17. How many years have you been in your current position?
18. What is your current practice setting?
- _____
19. Do you have specialized certification(s)?
- ☐ Yes: _____
 - ☐ No

Moral Distress

Moral distress occurs when you believe you know the morally right thing to do, but something or someone keeps you from pursuing the right course of action, resulting in negative feelings such as anger, frustration, or powerlessness.

Please circle the number (0-10) on the thermometer that best describes your level of moral distress in the past 2 weeks.

10 ————— Worst
9 —————
8 ————— Intense
7 —————
6 ————— Distressing
5 —————
4 ————— Uncomfortable
3 —————
2 ————— Mild
1 —————
0 ————— None

Please checkmark the issues that have contributed to your feelings of moral distress in the past 2 weeks.

Clinical issues:

- ☐ Inappropriate treatment
- ☐ Prolonging dying
- ☐ Hastening dying
- ☐ Disregard of patient preferences
- ☐ Inadequate symptom relief
- ☐ Unclear goals of care
- ☐ Lack of consensus regarding treatment plan
- ☐ Lack of continuity regarding treatment plan

Interprofessional issues:

- ☐ Interprofessional conflict
- ☐ Poor collegial relationships
- ☐ Work with clinically incompetent providers

Communication issues:

- ☐ Inadequate informed consent
- ☐ Providers giving false hope
- ☐ Inadequate communication among team members

Institutional issues:

- ☐ Lack of continuity of providers
- ☐ Lack of nursing involvement in decision making
- ☐ Inadequate staffing, inadequate experience
- ☐ Lack of administrative support
- ☐ Policies that conflict with care needs
- ☐ Tolerance of disruptive behavior from staff
- ☐ Tolerance of disruptive behavior from families/patients
- ☐ Compromised care to reduce costs
- ☐ Hierarchies within the health system
- ☐ Inappropriate use of resources
- ☐ Safety concerns

Legal/regulatory issues:

- ☐ Treatment based on fear of litigation

☐ **Other issues (please describe):**

Please circle “yes” or “no” for the following questions:

I have left a critical care nursing position because of moral distress.	Yes	No
I have considered leaving a critical care nursing position because of my moral distress.	Yes	No
I am currently considering leaving my critical care nursing position because of moral distress.	Yes	No

Appendix C

Survey Free Text Responses

Table 14

*Perceived Barriers to Palliative Care, Free Text Responses by Unit***Pediatric ICU***Attitudes/beliefs about when to initiate services**cohesive plans amongst different teams**Doctors talking w/ families about switching a pt to palliative care**Dr only seeing it as end-of-life need; staff**Failure to withdraw, parents keeping on when child may be suffering, interdisciplinary team trying all measures first**families aren't ready to broach the discussion**Frequently the different services get upset if palliative care is brought up. Lack of education - we are not saying the pt needs to die - we are saying they need palliative care!**I don't think that people think about using them. It would be nice if they were more of a presence in the unit.**It seems that we are our own palliative care team. There is usually urgency in considering withdrawal (sic) of care and our attendings/staff usually treat it as another part of our practice.**Maybe the fact that most of our patients are managed by multiple different teams, sometimes with competing priorities? (ie. Followed by Heme/Onc service + by cardiology)**MD readiness dependent upon MD on service & consult MD**Misconceptions about palliative/hospice. Not enough education on when/how to use palliative care and when to call for consults.**Misinformation regarding appropriate use of palliative care (ie, it is not only for death)**Pediatric ICU- multiple teams of doctors that are not on the same page.**staff education on when to involve them**Staffing; often pt's die quickly (illegible) code event...not a lot of time for palliative care**We work with children. Sometimes I feel that we see palliative care as giving up. Children are very resilient and I don't think anyone wants to be the one to redirect care.***Neonatal ICU***busy teams, limited staffing resources, rapidly changing pt needs at times**consulting early**Education**Failure to identify appropriate patients for service. Fear that family will think palliative care is the same as Hospice care.**In the ICU already a ton of teams + hard to somehow integrate another team that typically is not on the unit*

Lack of information on resources

lack of knowledge

Lack of resources and understanding need for palliative care in a unit caring for newborns.

LIP impression of need

LIP team often declines to consult, barrier in belief of need d/t age of population (NICU)

n/a

not enough information on who it would benefit most and how to contact them.

Not ready to give up on patients, some providers feel palliative care is giving up

Pain management

Parents wishes that everything be done to prolong pt's life.

prolonging the inevitable because everybody hopes for a miracle

See "palliative" care as for a pt who is dying

Some attending physicians feel there are other life prolonging treatments to try. Sometimes "palliative" is interpreted as "hospice" or giving up to let someone die.

sudden deaths

The physicians want to save every baby and have a hard time letting other disciplines do their job.

the role palliative care has for a patient, even if end-of-life is not imminent

too many other issues/mtgs/initiatives take precedence

TCV ICU

#1 SURGEONS

A "flog-'em til they're done" mentality/culture exists.

lack of education and agreement with physicians

Lack of education; surgeons, physicians, working in a surgical ICU where the culture is to save everyone at all cost; inability to request palliative (sic) care anonymously therefore the surgeon of physician (sic) against supporting palliative (sic) + end of life knows who requested it

lack of knowledge on what palliative can/will help with

lack of knowledge/education

Perceived stigma by the physicians

Physician objection

Physicians unwilling to address

Post-operative state makes physician less willing to "give up" and consult palli services.

Recognition of criteria for palliative service; when withdrawing support in our unit pts usually pass quickly.

RN knowledge, Intensivists

See Above Rant. The barriers are Attendings. As often as I can, I'll advocate for a consult as appropriate, early in a complicated course. I'll typically get shot down by Fellows via Attendings, In spite of families/pts expressing interest.

Surgeons not wanting to stop treatments + talking pt families out of it

Surgeons view death as failure,

Surgerical (sic) Patients, MD's not willing to use them.

The thought that "palliative care" = withdrawal of care/giving up on the patient.

the transition to palliative care is often drawn out before a decision is made (mostly our team vs. family)

The word palliative to surgeons means "we are giving up"; they see it along the equivalence of hospice & withdrawal of support

Unreasonable goals of care.

We do not want to let them go. They usually Die while trying other medical interventions

when to initiate palliative care

Yes our surgeons are a barrier

Coronary ICU

ATTENDING PREFERENCE (sic)

Barrier to MD education about how palliative care isn't always end of life. I also think it's utilized too late in a lot of cases.

end of life care not addressed early enough! We wait too long to discuss.

I wish it could be a "nursing screening referral", feel as though I have to "convince" MD team in rounds.

It depends on the attending. If the attending is not an early advocate/acceptor of palliative care assistance then we tend to have more issues when it is necessary down the road.

LIP reluctance to give realistic outcomes to patients. RN reluctance to request palliative care. LIP resistance to RN suggestion of palliative

MDs' pride, not wanting to give up, afraid of talking about death & dying and symptom mgmt

Physician staff sometimes delay consultation

Physicians often think consulting palliative is not necessary

Physicians waiting too long in a patient's hospitalization to consult palliative care

Primary team, not ready to consult (particularly HF attendings)

What palli care means/benefits to pt

Neuroscience ICU

(Zero)

Education of when, how, + why we to use the them (sic)

Family readiness

Multiple teams not having same opinion

n/a

N/A

Not consulted in timely fashion. I think we should consult them right away on pts who are admitted with grave prognosis.

primary team difference of opinoin. Ignorance as difference b/t palliative care + hospice

W

Medical ICU

Attending preferences. Also, the name "palliative" frightens people. Why not "quality of life team?"

Family "do everything" approach, practicing medicine when care is futile

focus on resolving medical complications and treatment vs. making experience most comfortable for pt.

I believe we use palliative care services appropraitley (sic) and often in the MICU

Interns/residents do not want to consult often, feel like it would upset patient

Lack of decision making regarding goals of care

Lack of education - palliative (not equal to) hospice

Lack of education of services

Mainly team hesitancy to seek consultant input.

MD consults, they often want to manage themselves but don't have time + those pts are forgotten

MDs don't always want to relinquish control

*MDS STILL RELUCTANT TO GET PALLIATIVE INVOLVED. AND LACK OF RN NEDUCATION - THE ROLE TRANSITION IS VERY DIFFICULT. YOU GO FROM AGGRESSIVELY CARING FOR EXTREMELY ILL PATIENTS TO UNDOING ALL YOUR WORK, THEN CARING FOR EOL SYMPTOMS. WITHOUT EDUCATION, THIS IS DISTRESSING & CHALLENGING
MICU DOCTORS - WHEN WE SUGGEST A PALLIATIVE CONSULT THEY USUALLY CRINGE OR SAY "NOT YET" I THINK IT'S BECAUSE PALLATIVE IS OFTEN MISUNDERSTOOD AS HOSPICE OR THAT WE ARE GIVING UP - IT'S NOT DEFINED WELL TO THE MD'S*

Misconceptions about palliative care services - patients/family/healthcare members thinking it means end of life care necessarily

N/A

No Barriers, just need to call them.

Palliative care being too closely connected with end-of-life

Recognition + Acknowledgment by medical team.

Some teams don't feel the need with certain patients

The Medical Team.

We need family meetings initiated sooner & palliative introduced/educated before it's a last option.

STBICU

Absolutely. Most surgical services underutilize palliative medicine b/c they seem to think palliative means ONLY end of life care which it certainly does not.

Certain services look @ palliative care as giving up rather than a comfort (?issue) - bring them in way too late in the game

Doctors are reluctant to consult palliative care, view it as last resort or giving up

Doctors not being upfront with a real prognosis and outcomes

Doctors refusing to allow consults

I think some of the providers stand as barriers

I think the turnover of residents hinders discussion of palliative care and often it's not discussed soon enough.

LIP perceptions

MDs unwilling to consult, options not given to family to talk to them.

Miscommunication between services; LIPs not consulting palliative / holding family meetings sooner

Most often, I feel the medical team does not think palliative is appropriate so it's never really brought to the table.

physician attitude regarding "giving up," abruptly changing pt. status

Sometimes physicians feel like consulting palliative services is admitting (sic) defeat.

Surgeons belief that to do so would mean that they failed. Also family members that do not understand.

team communication, length of stay (i.e. long term transplant)

Triggers for consulting palliative care are not well established. This leads to delay in involving these experts

We use them very frequently!

Table 15

*Desired Changes about Care in Practice Setting, Free Text Responses by Unit***Unit not reported**

Greater presence of pastoral support for pts & family who desire it. Often times when crisis occurs and pastoral support is needed, there is a delay in getting chaplains to the bedside because they are with other pts. As a caregiver, when dealing with stressful situations, I could also use pastoral support. As a caregiver, I grieve and feel a sense of loss also, but I'm expected to deal with those feelings on my own.

Pediatric ICU

better weaning off sedation

Collaboration/Communication between teams/families regarding complex patients/plan of care/end of life discussions --> real life outcomes

Getting PT/OT involved sooner on pts that are intubated/sedated. Many of these kids would benefit from more passive ROM than what nurses are usually able to do in a shift.

Having clear end goals that don't change just because attendings do

Having open and honest conversations with all of our long term patients families. I feel like we wait too long to have difficult conversations and then it becomes too late to do anything differently.

How our doctors approach families when the outcomes look poor.

I wish we could utilize palliative care more on the unit. I feel like most of our long term/ (illegible) cardiac patients need a palliative care consult or "check in".

I would like a team of professionally (sic) trained MD's, NP's and RN's to be consulted/available for consult when we are considering the possibility of palliative care. Too often we have a try-everything approach. If families were better educated/knew their options we could potentially prevent a lot of prolonged suffering on both the patient's and the families' behalfs

Improving narcotic gtt weaning to prevent withdrawal

Including family in rounds.

information sharing btwn (sic) teams and parents

Involving palliative care service earlier, instead of at the last minute

More routine family meetings; Routine rounding techniques - bedside for all teams

more routine family mtgs

Our teams ability to keep plans consistent when changing care providers (ie - attendings each do their own practice differently & is frustrating when kids wax and wane); Letting families oversee MD orders

Recognizing sooner that patients are at the end of life

Standardization of care amongst physicians!

The conversation to switching to palliative care sooner in the care of the pt

the decision making timeframe for when a patient should become palliative

when care is redirected toward palliative care, sometimes it should be sooner.

Neonatal ICU

(increase) communication between LIP and family. Daily updates.

Active education opportunities provided to all ICU providers. Key identifiers/guidelines on when palliative care is indicated

Attending to Attending inconsistency

Being straightforward w/ parents, we often fluff the situation and paint a brighter situation than it is

Care provider variability - often plan of care changes or parents are given varying information

Communication

consistency

education regarding analgesics + sedatives (FEAR OF ADDICTION)

Helping providers feel better about palliative care, especially at a quicker pace instead of weeks to months down the road.
Hope is important, but physicians need to be brutally honest with patients - even if they don't like the news they are giving. Honesty leads to better outcomes for all, even if that outcome is death. Leave your ego at the door. I would change how the plan of care changes when a new attending comes on service.
I would want the entire medical/nursing/ancillary care staff to have a uniform approach to individual patients. Often, the care plan changes depending on which attending physician or NNP is the primary care provider on any given day.
Improved honesty/transparency on prognosis (clearly stating potential outcomes, not just painting a rosy picture) or giving false hope
LIP continuity
more counseling when palliative care seems inevitable
More direct & honest communication with families that give them realistic outcomes & goals
n/a
Not dragging out death, sometimes you just have to say enough is enough & not allow them to continue to suffer
Openness to embrace what palliative care service offers and follow suggestions they make
private rooms - need to be able to better manage environmental stimuli and create a better environment for parents/family too
Smaller patient ratio to nurse. There is so much to be done + done safely in an ICU + it would be safer w/ smaller ratios.
staffing/(increase) support for bedside RN to actually complete what the management/MD staff/unit and institution expects of them. Very stressful environment for both younger and older nurses. Seems to be getting worse.
Suffering of patients!
The Ability to help parents redirect care more easily
The medical team needs to recognize that there are some patients for whom death is a better option than continued medical care. When that is the case we shouldn't make that the family's decision/choice - we should direct the care and relieve them of the choice/burden
To provide comfort

Thoracic-Cardiovascular ICU

a palliative consult for all chronic pt's
At some point (LOS) there should be an automatic ethics and/or palliative consult.
Better communication + more open communication about goals of care. More meetings between providers + family to establish goals
Better communication/coordination between the ICU team + the surgeons.
better pain/symptom management
Encourage them before surgery to have a living will, not just an advanced (sic) Directive
Have palli consulted on all pt (with) length of stay greater than 3-4 weeks.
Include palliative in rounds on our patients that are here longer (or even daily rounds.) To help our families as well. Or make weekly rounds. Educate surgeons what is involved.
involving palliative care earlier, instead of last minute
Lack of communication between the surgical physicians & ICU physicians.
More frequent palliative care consults, earlier consults for palliative care
More resources, staff
pain management
Palliative fellow rotation in ICU settings. Having the palliative voice ever-present would decrease the stigma and help move patients in the appropriate path sooner.
Physician communication with family r/g grave conditions/poor outcome

Possibly address palliative care during rounds as part of a checklist when deemed appropriate
Retention strategies. Turnover rate in nursing is very high. High turnover = (decreased) pt. outcomes
Rounding - Intensivists + Fellows round separately
symptom control; setting realistic goals of care
The attendings need to round with the intensivist team. Palliative on this unit is virtually D.O.A. until physician communication improves

Coronary ICU

(Increase) family rounding/participation; discussion of goals of care earlier than later
Adequate support staff from 0700-2300 so RN does not have to spend excessive time away from patients answering phone and doing ADLs
Automatic inclusion of palliative care on pt's with multiple readmits for "end stage" problems
Better management of sedation in mechanically ventilated pts. Sorry, you probably wanted me to say something about EOL issues but this I feel would make the bigger impact.
Early conversations about Futile care
Ensuring communication is open + honest from all team members. Avoid confusion with communication.
I think it would be wonderful if we could have someone from palliative on rounds with our heart failure patients at least to help them with their symptoms and to help change the culture in the hospital and with the patients and their families. I think it also would help to where it wouldn't seem so scary to have you on board.
I would change the language and the "way" MDs update patients and their families. They are typically too brief, or use complicated medical jargon to discuss situations. We are all human beings and MDs should learn to talk to patients like they would talk to a friend. They should sit down, make eye contact, and use regular language. inform pt of their true poor prognosis early on. Not instill false hope.
involve palliative care at an earlier time no matter what the situation
More nurse aids to assist in pt attention & comfort
nurse to patient ratio
palliative care consult on admission to ICU especially for Heart failure pts.
REDUCE NUISANCE ALLARMS (sic) AND OVERALL ALARM VOLUME

Neuroscience ICU

Better staffing
Changing opinion that consulting them early is giving up on them.
clearer role delineation btw primary surgical services + ICU team (or closed ICU)
Educating Families @ Palliative care...
Education as to: all services, palliative providers
Faster transition to palliative care/comfort measures
improved communication between teams
Increased communication b/t team members and then to families
More focus on Advance Directives earlier on
Open discussion of end of life care
Palliative consults happen timely.
Quicker palliative referral/consult
Staffing ratio
Usage/availability of more spiritual resources (and how to bring this up with families).

Medical ICU

(Increase) staffing, more goals of care discussions, (increase) pt/Family education regarding their illness, better pain control plans
adding more Nurses
All have palliative care consults unless suspected to recover fully within 48 (hours)
Be able to provide 1 on 1 care to really sick pts
Better pain management
Better sleep environment!
Bring palliative care in more quickly.
Education and involvement of family during entire process.
Ensure adequate nursing staff + a float nurse
Have palliative care services utilized earlier on in patient care when appropriate.
I wish we did a better job at communicating with patients and family with a language (sic) barrier
I would like to see us better elicit patient and family goals and expectations early in ICU stay, and then consistently communicate progress (or lack of it) to meet that outcome.
Include palliative care consult member on MICU rounds at least 2x weekly.
INVOLVING PALLIATIVE CARE MORE FREQUENTLY AND EARLIER IN PT CASES - REMOVING THE STIGMA FROM CONSULTING "PALLIATIVE CARE" SO WE CAN BETTER ADVOCATE FOR PT'S PAIN AND PT FAMILY INVOLVEMENT
More frequent, frank discussions with family members regarding disease progression/chance of recovery/return to baseline level of functioning
More nurses! Make education for families on code status, health info (hard to do)
Nurse screening tool for palliative consult.
Palliative care discussed during First 24 hours.
Palliative care is explained earlier with patients and their families.
Palliative on board sooner
Staffing; so we could be more attentive to our patients + not be as spread thin
Team members who aren't team players
TWO THINGS - PALLIATIVE INVOLVED MORE FREQUENTLY & EARLIER, FORMAL RN EDUCATION

Surgical-Trauma-Burn ICU

Being involved in team meetings/family meetings. With unit acuity, sometimes a bedside RN are unable to attend these meetings.
Being more proactive instead of reactive to symptom management.
communication loop closure: streamlining process of ownership of ICU teams vs. "primary" teams
Communication with family members
Complex care patient rounds continue, maybe even more frequently
consult palliative early and often.
Consulting palliative sooner
Doctors being honest about possible patient outcomes + giving families ALL the options starting early in the patients course of stay
early convo about options/realistic expectations/better pain mgmt
Early, realistic conversations about real risks, statistics, probabilities about QUALITY Patient outcomes
Education of staff & early intervention of multidisciplinary team (including Palliative) for my pt population
Further incorporate best practice decision trees in ordering process (EMR).
I'd change the practice (sic) of futile care when at all feasible, and in a more timely manner.
Improving quality of sleep for patients

palliative should be brought in sooner - if it wasn't looked @ as a negative consult - as a potential direction the patient might go in (being critically ill). Having a game plan if/when they get worse - it would be a smoother process
the open communication w/ the team bout family needs + concerns for pt. well being even through night shift

Table 16

*Additional Sources of Moral Distress, Free Text Responses by Unit***Coronary ICU***Allowing families to dictate care – even when futile**Had to call moral distress day after ethics consult 2nd full week of Sept. Feel as though some of the issues/intensity of feelings are still lingering a month later**MDs think palliative team = death team. When I ask for pain consult in rounds, not well received***Medical ICU***LACK OF SUPPLIES B/C OF BUDGETING; THE “NIGHT SHIFT” THINKING PROCESS WHEN THINGS LIKE PAIN CONTROL ARE LEFT TO “DAY TEAM TO DECIDE” SO YOU HAVE TO WATCH YOUR PT SUFFER ALL NIGHT.**Research indicates shift rotations a risk to health (actually, detrimental to health. One study concluded rotating 1x month for 6 years reduced lifespan by 7 years (Circulation, ~ 1992).**UVA could (increase) night shift pay to attract an all night shift staff, reduce rotating shifts and increase health of employees (does this research cause moral distress for those making (financial) decisions?***Surgical-Trauma-Burn ICU***Surgeons refusing to “give up” on a patient and not allowing use of appropriate resources i.e. palliative*

Appendix D

IRB-HSR Exemption

For IRB-HSR Use Only

IRB-HSR # 18307

Protocol Title : Critical Care Nurses' Perceptions about Palliative Care and Moral Distress: Implications for Practice

The IRB-HSR confirms that this project meets the criteria of research which is exempt from federal regulations under 45CFR46.101 (b)(4).

The study includes only de-identified health information, therefore HIPAA regulations do not apply.

If you need to modify the procedures in this project you must notify the IRB-HSR first to determine if the project continues to meet the criteria for exempt research.

For additional information regarding educational resources for research see <http://www.virginia.edu/vpr/irb/hsr/education.html>

Signed *Sharon Hoffman* Date 7/29/15
IRB-HSR Staff Member

<small>Website: http://www.virginia.edu/vpr/irb/hsr/index.html Phone: 434-924-2820 Fax: 434-924-2932 Box 800483</small>
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Appendix E

Author Guidelines for Submission to the *Journal of Hospice & Palliative Nursing*

Journal of Hospice & Palliative Nursing

Online Submission and Review System

Author Resources

[Instructions for Authors \(this page\)](#)

[Copyright Transfer & Disclosure \(PDF\)](#)

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INSTRUCTIONS FOR AUTHORS

For more information, contact Betty Ferrell, PhD, FAAN, Editor in Chief

Last updated: July 2015

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Purposes of the Journal:

Purposes of the Journal: *JHPN* is designed as a forum for advancing the professional practice for nurses in hospice and palliative care. As a refereed journal, *JHPN* is a vehicle for the publication of high-quality, relevant, and timely articles on a variety of topics related to promoting excellence in palliative care, nursing practice, education, research, and administration. Articles in *JHPN* are selected to promote the highest professional standards of hospice and palliative nursing, dissemination and research leading to improved nursing practices, fostering the professional development of nurses, and encouraging nurses to practice in the fields of hospice and palliative care.

About the Journal: *JHPN* began in 1999 as a quarterly publication of the Hospice and Palliative Nurses Association, and is now published bimonthly. *JHPN* is published by Lippincott Williams & Wilkins of Philadelphia and indexed by Thomson Reuters (Science Citation Index Expanded [SciSearch], Current Contents, and Journal Citation Reports). *JHPN* is also indexed in CINAHL and the International

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- Represent an original idea;

- Appropriate to the level and interests of palliative nursing;
- Organized, logically developed, complete, clear and grammatically correct;
- Tables, figures and illustrations are easy to follow, clearly designated , relevant and adequately captioned.

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- Chapter in a book
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Appendix F

Manuscript Submitted to the *Journal of Hospice & Palliative Nursing*

Palliative Care and Moral Distress in the Intensive Care Unit:

An Integrative Literature Review

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Abstract

Moral distress is a harmful emotional experience that often afflicts healthcare providers who care for dying patients. First described among nurses, morally distressing situations are particularly common in critical care, where nurses and other providers can feel forced to prolong their patients' death and suffering in pursuit of curative treatment. Meanwhile, the role of palliative care in the ICU continues to evolve, necessitating inquiry about how access to palliative care might affect the moral distress of ICU clinicians. The purpose of this review was to examine the relationship between palliative care and moral distress among healthcare providers in the adult ICU. An integrative review methodology was used to examine theoretical and empirical literature from six databases. Four studies – two qualitative and two quantitative descriptive studies – met final criteria for inclusion. Overall, inadequate palliative care appears to contribute to moral distress in ICU clinicians, and palliative care education alone is not sufficient to prevent moral distress in nurses and other providers. Further research is needed to examine how specific palliative interventions impact healthcare provider moral distress and to determine the effects of clinician moral distress on ICU patient outcomes and satisfaction.

Keywords: moral distress, palliative care, critical care, ethics

Palliative Care and Moral Distress in the Intensive Care Unit:

An Integrative Literature Review

Death and suffering are not uncommon in the intensive care unit (ICU). Despite significant decreases in ICU mortality over the last quarter-century,¹ at least one in five Americans dies in the ICU,² and the overall mortality rate for adult patients is estimated between 10 to 29 percent.³ Many adult ICU survivors remain chronically critically ill and are prone to functional and cognitive impairment, severe symptom burden, and increased mortality risk.⁴ As the risk of death and the “burdens of survivorship”^{4 (p.2419)} have become increasingly recognized, so too has the role of palliative care in the ICU. However, inadequate access to palliative care in the ICU may result in costly, painful, and protracted courses of treatment for seriously ill patients and their families, as well as significant moral distress to those providing care.

Background

Palliative Care

Palliative care is an interprofessional approach that focuses on optimizing the quality of life of seriously ill patients and their families.^{4,5} In the ICU, the key domains of palliative care include patient and family-centered decision-making; team member, patient, and family communication; continuity of care; emotional, spiritual, and practical support for patients and families; symptom management and comfort care; and support for ICU clinicians.⁶ Although palliative care is the fastest-growing subspecialty in the U.S.,⁷ the Institute of Medicine⁸ has emphasized that “all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management”.^{8 (p. 4)}

The last decade has seen a groundbreaking paradigm shift in the role of palliative care in the ICU, evolving from a mutually exclusive or sequential alternative to critical care into an essential component of quality critical care for all patients, regardless of prognosis.^{9,10}

Numerous critical care professional organizations have endorsed early initiation of palliative care concurrently with life-prolonging intensive care⁴ as well as at the end of life. In 2010, with support from the CAPC and the National Institutes of Health, the Improving Palliative Care in the ICU (IPAL-ICU) project was launched to help clinicians effectively integrate palliative care into the critical care setting.¹⁰

Despite these advances, significant barriers to palliative care exist. Studies have exposed significant knowledge gaps in palliative and end-of-life care competencies among ICU clinicians.¹¹⁻¹³ Additionally, Aslakson, Curtis, and Nelson⁴ summarized a number of other specific barriers that have prevented effective integration of palliative care and critical care: unrealistic patient, family, and clinician expectations of ICU treatment; misperception of palliative care and critical care as mutually exclusive or sequential; conflation of palliative care with end-of-life care or hospice; concern that palliative care will hasten death; insufficient clinician training; competing clinician demands; and failure to apply effective approaches for system or culture change.⁴

Moral Distress

Among ICU clinicians, barriers to palliative care may contribute to moral distress, a phenomenon in which an individual knows the right action to take but is constrained from taking it.¹⁴ Moral distress is distinguished from an ethical dilemma, where an individual is conflicted by two or more ethically justifiable actions that could be taken, each with its own downsides.¹⁵ Common among nurses,^{16,17} moral distress can have damaging effects on these providers that

may eventually lead to departure from a nursing position or the profession altogether.¹⁸ Corley¹⁶ extrapolated the major sources of nurse moral distress: “harm to the patients in the form of pain and suffering, the treatment of patients as objects when meeting institutional requirements, medical prolongation of dying without letting the patient or family know about choices concerning care, the definition of brain death, inadequate staffing, and the effects of cost containment”.¹⁶ (p. 639) Moreover, ICU nurses and physicians have reported that the highest moral distress situations are those in which caregivers are pressured to continue unwarranted aggressive treatment.¹⁹

The noticeable overlap between reported sources of moral distress and the domains of palliative care indicates that better access to palliative care in the ICU could help mitigate sources of clinician moral distress in the ICU. Recent evidence-based reviews have highlighted the significant effects of palliative care interventions on reducing ICU and hospital length of stay without affecting mortality,^{20,21} improving clinician, patient and family decision-making, and decreasing resource utilization and cost.²² However, additional evidence synthesis is needed to determine how the delivery of palliative care affects clinicians in the ICU, namely in the area of moral distress. A recent integrative review²³ evaluated the relationship between palliative care and nurse moral distress in the neonatal ICU, but this relationship has not yet been examined in adult critical care, supporting the need for further evidence-based review.

The purpose of this integrative literature review was to examine the relationship between palliative care and healthcare provider moral distress in the adult ICU setting. The following research question was addressed: How do palliative care interventions for critically ill adults, compared with no palliative care, relate to moral distress among healthcare providers in the adult ICU?

Conceptual Framework

In 2010, clinicians and researchers from the IPAL-ICU Project produced a framework that is an ideal model to conceptualize modern palliative care delivery in critical care. According to the IPAL-ICU framework, the incorporation of palliative care into the ICU is achieved using two main models: consultative and integrative.²⁴

In a consultative model, palliative care is provided for patients and families by expert consultants via referral from ICU clinicians.²⁴ Significant efforts have been put forth to improve access to consultative palliative care for ICU patients. Nelson et al.⁹ reviewed published screening criteria (also known as “triggers”) that have been used to proactively identify patients who are appropriate for a palliative care consultation. Overall, the use of screening criteria for palliative care consultation appeared to increase the involvement of palliative care specialists and reduce ICU length of stay and utilization without affecting mortality.⁹

A second approach, the integrative model, describes palliative care that is directly provided by ICU clinicians who have integrated core principles of palliative care into their daily practice.²⁴ The palliative needs of all critically ill patients and their families have become increasingly recognized, yet continued shortages in the palliative care workforce may limit the reliance on a consultative model,²⁵ underscoring the need for ICU clinicians to integrate palliative care into their everyday practice. In an integrative model, efforts to improve palliative care in the ICU focus on two main areas: improving systems of care and development of palliative care knowledge and skills for ICU clinicians. Examples of interventions to improve systems of care include the implementation of palliative care checklists and decision supports, proactive family meetings, and the development of comfort care order sets for ICU patients receiving end-of-life care.²⁴ Improving ICU clinician knowledge and skills is typified by

educational initiatives specific to critical care, such as the End-of-Life Nursing Educating Consortium (ELNEC)-Critical Care program, and training programs that increase clinician communication skills.

Although the IPAL-ICU framework does not ascribe preference to either model, its authors suggest that a combined approach that adopts elements of both models may be best in some settings.²⁴ In the planning of palliative care initiatives in the ICU, the IPAL-ICU framework calls for “careful and realistic assessment of available resources, attitudes of key stakeholders, structural aspects of ICU care, and patterns of local practice in the ICU and hospital”.²⁴ (p. 1769)

Methods

The integrative review methodology was used to perform this review because it encompasses the broadest type of review methods that allow for inclusion of numerous types of research to understand a phenomenon.²⁶ Moreover, it was hypothesized prior to the undertaking of this review that high-level quantitative evidence pertinent to the research question would be lacking, thus necessitating inclusion of diverse types of research. The CINAHL, Ovid MEDLINE, PsycINFO, Web of Science, Joanna Briggs Institute (JBI), and EBSCOhost databases were individually searched, using the keywords “*moral distress*”, “*palliative care*”, “*palliative treatment*”, “*end of life*”, *end-of-life*, “*intensive care unit*”, *ICU*, and “*critical care*”. These keywords were combined with suggested major subject headings in each database. Ancestry searches of the reference lists of relevant articles were also performed. Inclusion criteria were the following: (1) primary research articles; (2) publication year between 1984 and 2015; (3) addressed staff moral distress; (4) described elements of palliative care as an intervention. The restricted publication years reflect the original description of moral distress by

Jameton in 1984. Exclusion criteria included the following: (1) non-English language; (2) articles that did not report on adult ICU settings; (3) case studies, case series, commentaries and editorials.

In total, there were 266 articles between all databases, with 7 additional titles added during the ancestral reference search. After eliminating duplicates (n=59), 147 articles failed to meet inclusion criteria during title, abstract, or full text review. The abstract or full text was not accessible for 5 articles; therefore they could not be retained. Forty-nine remaining articles did not report on the adult ICU and were thus excluded from further analysis. Nine articles were excluded as case studies, case series, or commentaries. Among included articles, the strength and quality of evidence was rated using the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Tool.²⁷ A final illustration of included and excluded articles can be found in Appendix A.

Results

Four studies met criteria for final inclusion in this review. A literature table summarizing pertinent findings of the included studies can be found in Appendix B.

Study Designs

Two of the included studies employed a qualitative design. Seeking to understand moral distress among critical care nurses, Gutierrez¹⁷ used an open-ended but guided interview format to obtain qualitative data on moral distress from 12 nurses in a surgical ICU. The interviews included broad questions focused on three moral concepts: moral conflict, moral judgment, and moral action. The author facilitated and audiotaped all interviews and recorded field notes, reading them to the participant in order to validate and correct the data.

Ferrell²⁸ also aimed to explore moral distress among nurses, but within the context of providing treatments that were perceived by nurses as medically futile. Moreover, this study included, but was not limited to, ICU nurses. A written survey entitled “Moral Distress and Futility”^{28(p. 925)} was distributed to 108 nurse participants in two end-of-life nursing education courses. This survey intended to elicit responses from nurses about their experiences providing treatments they believed were futile, and how these experiences related to their moral distress. All narratives were entered into a word processing program, coded to the setting and type of conflict, those involved in the conflict, cultural, spiritual and religious factors involved, the patient’s diagnosis, and the nursing response and emotion. Each narrative was then coded to capture elements of the experience of moral distress among the nurse respondents.

The two remaining studies were quantitative, non-experimental, descriptive studies. Browning²⁹ sought to examine relationships between moral distress, psychological empowerment, and demographic characteristics of critical care nurses caring for adults at the end of life. The 277 study participants were recruited from the American Association of Critical-Care Nurses’ email newsletter list. Participants had to be critical care staff nurses with experience in caring for dying adults in the critical care setting prior to the survey. Two validated and reliable survey instruments – the Moral Distress Scale (MDS) and the Psychological Empowerment Instrument – were used to assess the primary variables of interest. Moral distress intensity and moral distress frequency, which are both measured by the MDS, were treated as two separate dependent variables. Demographic data, including previous end-of-life care training, were collected using a third survey. Relationships between variables were analyzed using correlational statistics, and associations between moral distress and predictor demographic and psychological empowerment variables were assessed using linear regression.

Whitehead and colleagues³⁰ did not examine psychological empowerment, but sought to assess and compare levels of moral distress, its causes, and its relationships with perceptions of ethical climate, intent to leave, and education in end-of-life care and pain management, across different types of healthcare providers. Web-based surveys were distributed to all healthcare professionals at one medical center, with 592 participant surveys retained for analysis. The authors used a revised version of the MDS (the MDS-R) to assess and compare levels of moral distress among different types of healthcare providers. A second reliable and valid tool, the Hospital Ethical Climate Scale-Shortened, was used to assess and compare perceptions of ethical climate. Demographic data were also collected, including age, race, gender, position, care setting, years of experience, and training experience in end-of-life care and pain management. Two-way and three-way ANOVA were used to compare MDS-R scores between groups. Relationships between perceptions of ethical climate, moral distress, and demographic variables were analyzed using correlations and Fisher's exact test.

Pertinent Study Findings

Qualitative Findings

In the study of surgical ICU nurses by Gutierrez,¹⁷ two-thirds of the study participants identified providing supportive care only or refraining from resuscitative therapies as the appropriate action that should have been taken in the conflict they described. Overall, 92 percent of the nurses in this study described conflicts related to overly aggressive medical treatment that increased the burden of suffering. Similarly, the study by Ferrell²⁸ found that instances of moral distress related to treatment perceived by nurses as futile most predominantly involved conflicts of "aggressive care denying palliative care",^{28(p. 926)} as nurses described how patients who died in the ICU often did so painfully, in the absence of family, and with inadequate attention to their

physical and spiritual needs. Half of the participants in the study by Gutierrez described conflicts in which physicians gave incomplete or inaccurate information to patients and families, leading to nurse moral distress. These findings were consistent with the study by Ferrell, with multiple narratives describing conflicts in which nurses felt patients were receiving incomplete, unclear, or misleading information from a physician.

Quantitative Findings

In an online survey of critical care RNs caring for patients at the end of life, Browning²⁹ found moderate overall moral distress frequency but high overall moral distress intensity among participants. There was a weak but significant negative correlation between nurse collaboration in end-of-life patient care conferences and frequency of moral distress related to deception ($p = .007$). Additionally, there were weak but significant positive correlations between ELNEC training and total moral distress frequency score ($p = .02$) and moral distress frequency item “not in patient’s best interest” ($p = .006$). In fact, the presence of ELNEC training was a significant predictor of nurse moral distress frequency ($p < .01$), with ELNEC-trained nurses having, on average, 21.5% higher scores of moral distress frequency.

In the institutional survey of healthcare providers by Whitehead and colleagues,³⁰ mean moral distress frequency was not directly reported. However, nurses had significantly higher overall MDS-R scores than physicians ($p = .001$), and ICU nurses had higher overall MDS-R scores than non-ICU nurses ($p = .008$). Among all ICU groups, a commonly cited source of moral distress was continuing to treat a hopelessly ill patient when no one will make a decision to withdraw support. Providers with end-of-life care training had higher mean levels of moral distress than those without end-of-life care training ($p = .005$). A similar but non-significant trend was found among staff members with advanced pain management training.

Discussion

This review aimed to review current evidence describing the relationship between palliative care and healthcare provider moral distress in the ICU setting. Only four studies were identified that met all inclusion criteria for this integrative review, all of which were appraised as level 3 evidence. Despite an absence of experimental studies in this area, four major themes were identified. The following themes illustrate how palliative care relates to clinician moral distress in the ICU: the impact of end-of-life care education, collaboration and participation in end-of-life care, perceptions of aggressive care or inadequate palliative care, and the effects of moral distress on care provided by clinicians.

The Impact of End-of-Life Care Education

The aforementioned gaps in palliative care education continue to serve as a barrier to quality palliative care in the ICU. However, in the study by Browning, critical care nurses who had received end-of-life care education, such as ELNEC training, experienced greater frequency and/or intensity of moral distress items than providers who had not received such training. While education may precede empowerment,²⁹ the similarity of findings among a larger cohort of nurses and other healthcare providers in the study by Whitehead and colleagues is concerning. The observed associations between end-of-life care education and moral distress in these studies suggest the possibility that nurses and other healthcare providers who have training in best practices in end-of-life care may be challenged to incorporate this education into clinical practice.³⁰ Therefore, palliative care education, while remaining a serious necessity in the ICU, is not alone sufficient to ensure appropriate patient access to palliative care and to mitigate sources of moral distress. This review suggests that in the absence of institutional mechanisms that will

support palliative care best practices at the bedside, the provision of palliative care education for staff may exacerbate their moral distress.

Collaboration and Participation in End-of-Life Care

In the qualitative study by Gutierrez,¹⁷ nurses reported that their concerns or suggestions were often criticized, dismissed, or excluded by physicians, resulting in feelings of powerlessness among the nurses and a decreased likelihood of nurses to act as moral advocates for their patients. Conversely, nurse collaboration in end-of-life patient conferences was associated with increased psychological empowerment and decreased moral distress frequency in the study by Browning.²⁹ The limited evidence presented in this review suggests that nurse collaboration in end-of-life care and decision-making is essential, both to mitigate sources of nurse moral distress and to embolden nurses to act as moral agents and protect seriously and terminally ill patients from undue harm.

Perceptions of Overly Aggressive Care or Inadequate Palliative Care

The qualitative studies presented in this review describe inappropriate medical treatment with inadequate palliative care as significant sources of conflict leading to moral distress among nurses.^{17,28} Moreover, Ferrell notes that as palliative care expands, moral distress may become even more prominent if patients are not provided access to these services. Overall, the limited evidence in this review suggests that the aggressive critical care provided to some patients without sufficient attention to their palliative care needs may contribute significantly to moral distress in clinicians.

Effects of Moral Distress on Clinicians

Three of the four studies included in this review described the effects of moral distress on nurses. The qualitative studies by Gutierrez¹⁷ and Ferrell²⁸ illustrate the anger; sadness,

frustration, helplessness, hopelessness, and discouragement that morally distressed nurses may endure when palliative care is not sufficient. Only the study by Whitehead and colleagues³⁰ examined the moral distress of physicians and other healthcare providers in addition to nurses. Overall, healthcare providers who were considering leaving or who had left a position due to moral distress had higher reported moral distress.³⁰ The evidence presented in this review suggests that moral distress among nurses and other clinicians has deleterious effects on clinicians, but the potential consequences of moral distress on clinical patient outcomes is unknown.

Limitations

There are several important limitations of this review. A small number of non-experimental studies were the only studies included in the final analysis, and the heterogeneity of samples, sample sizes, variables of interest, and instruments used among the included studies reduce the overall generalizability of this review. Furthermore, the major headings and search terms used in each database could have adversely affected the search result. For instance, other keywords such as *moral conflict*, *supportive care*, and numerous terms for specific palliative interventions were not used.

Recommendations

Despite the limitations, this integrative review presents compelling evidence that palliative care is closely related to staff moral distress in the adult ICU in several important areas, including end-of-life care education, collaboration and participation in end-of-life care, perceptions of aggressive care or inadequate palliative care, and the effects of moral distress on care provided by clinicians. Although palliative care education and training for ICU clinicians remains crucial, education interventions should be implemented with careful consideration for

how such an intervention might affect moral distress without concomitant efforts to improve access to consultative and integrative palliative care. A collaborative approach is recommended to manage the palliative needs of ICU patients, align treatment goals between healthcare providers, the patient, and family, and prevent healthcare provider moral distress that could erode patient care. Further research is recommended to address how specific consultative and integrative palliative care interventions affect healthcare provider moral distress and to determine the effects of clinician moral distress on ICU patient outcomes and satisfaction.

Conclusion

Palliative care is now considered an essential component of comprehensive care for patients in the ICU. Barriers to optimal palliative care may contribute to poor outcomes for patients, families, and clinicians alike. This review informs nurses and other healthcare professionals that barriers to palliative care may ultimately contribute to healthcare provider moral distress. As the demand for critical care continues to grow together with the population of older Americans, no health system can afford to lose members of its workforce due to moral distress related to inadequate palliative care. More robust research is critically needed to evaluate interventions that will optimize palliative care access for critically ill patients and their families, and decrease the moral distress of those who care for them.

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