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Moral Distress of ICU Nurses and Palliative Care in the ICU

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Moral Distress of ICU Nurses and Palliative Care in the ICU

by

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Moral Distress of ICU Nurses and Palliative Care in the ICU

Krista L. Wolcott

Abstract

Background: ICU nurses, who care for patients at end of life, have reported high levels of moral distress. Moral distress is experienced when one is unable to deliver the care believed due to a patient and is associated with nurse burnout and patient care avoidance behaviors. Previous studies have linked ethical climate and nurse empowerment with moral distress. No previous studies have directly assessed the relationship between access to palliative care in the ICU and the nurse moral distress. Palliative care has been shown to improve patient care, but is still inconsistently available to ICU patients.

Aim: The primary goal of this web-based survey of ICU nurses was to evaluate relationships among moral distress, empowerment, ethical climate, and having access to palliative care in the ICU. Additionally, the study aimed to describe current delivery models of palliative care in the ICU and explore primary palliative care education of ICU nurses and possible relationships between palliative care education and moral distress.

Method: Participants were recruited via email and social media through a national database of ICU nurses. Descriptive, correlational, and multiple regression analyses were done on data from several validated instruments including: Moral Distress Scale-Revised (MDS-R), Moral Distress Thermometer(MDT), Hospital Ethical Climate Scale(HECS), Psychological Empowerment Index(PEI), and one questionnaire that was developed for this study to assess palliative care access and utilization.

Results: Of the 288 ICU nurses who initiated a survey, 238 completed the surveys and were included in the study. The sample was primarily Caucasian, female and had bachelor's degrees. They represented a range of ages and years' of experience in nursing and in the ICU, they worked in a variety of ICU settings and they represented an even distribution of geographical regions in the U.S. Negative correlations were found between MDS-R and HECS, and a curvilinear relationship was found between MDS-R and PEI. Additionally, those who reported access to a full palliative care team (73%) scored higher on the MDS-R than those without access to a full palliative care team. Multiple regression analysis showed ethical climate, ethnicity, number of beds in the unit, access to a palliative care team, and educational degree explained 37.7% of the variance of moral distress. Palliative care teams varied in how present they were in the unit, with social workers reported as the most frequently identified team member, and other disciplines (physician, nurse practitioner, clinical nurse specialist, spiritual care practitioner) were reported present by less than half of the participants. Highest ranked unmet palliative care needs included: psychological support for patients, family support, and goals of care conversations. The most common triggers for a palliative care consult included: prognosis/goals of care/futility conversations, pain/symptom management, imminently dying patient, family support/conflict resolution. The majority of participants reported having had some education on palliative care topics (e.g., management of pain, depression and anxiety, communication about prognosis, goals of care, suffering and code status). For each topic (except communication about code status) those who reported having had palliative care education scored lower on both the MDS-R and Moral Distress Intensity (MDI) than those who did not have education. There was no difference in moral distress levels between those who had code status education and those who did not. No difference was found in MDT for any educational topic.

Conclusion: Moral distress is present among ICU nurses related to end of life care, and is related to ethical climate and empowerment. Highly empowered nurses working in a positive ethical climate are likely to experience less moral distress. The existence of palliative care teams does not equate with adequate utilization or well-integrated palliative care delivery. Primary palliative care education for ICU nurses may contribute to less moral distress when combined with well-integrated care teams and positive ethical climates. The findings from this study highlight the need for the promotion of organizational team-building, enhanced palliative care education for ICU clinicians, and development of standardized palliative care delivery methods in the ICU.

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Chapter 1

Many patients die during, or soon after discharge from the Intensive Care Unit (ICU). The transition from aggressive life-sustaining treatment to comfort-driven treatment and care can be challenging not only for family members, but for the nurses who care for dying patients (King & Thomas, 2013; McCallum & McConigley, 2013). ICU nurses, while caring for patients at the end of life have reported high levels of moral distress (Corley, Elswick, Gorman & Clor, 2001; Gélinas, Fillion, Robitaille & Truchon, 2012; Hamric & Blackhall, 2007). Moral distress, defined as "…painful psychological disequilibrium that results from recognizing the ethically appropriate action and not taking it," (Corley et al., 2001, p. 250) was first identified and described in the 1980's (Jameton, 1984), and since that time the scientific literature has grown exponentially. In the last three decades, national and international conferences, symposia and focus groups of experts have convened to develop strategies to alleviate or diminish moral distress among nurses (ANA, 2013; ASBH, 2013; Hamric, 2012; Pauley, Varcoe & Storch, 2012).

Background and Significance

Moral distress has been identified as a factor in nurses' health, job retention, and delivery of quality care to patients. In addition, moral distress has been found to be associated with patient care disengagement, decreased patient care quality, nurse burnout, and nursing attrition (Corley et al, 2005; Gutierrez, 2005; Hamric & Blackhall, 2007; Pauley et al, 2009; Wilkinson, 1988). Experts have suggested that education to enhance nurses' awareness of moral distress may provide coping skills to minimize the negative effects of moral distress (AACN, 2004). However, these strategies have not yet been demonstrated to improve levels of moral distress

(Hamric, 2012) suggesting that the issue of moral distress is larger than the individual nurse. A joint effort between healthcare organizations, individual nurses, and providers is needed to address the problem of moral distress among nurses (AACN, 2004; ANA, 2011).

Landmark studies in 1995 identified that the U.S. health care system was not adequately meeting the needs and expectations of patients and family members at the end of life (Connors et al., 1995). Advancements in palliative care services have been partially in response to the challenge of inadequate end of life care. While palliative care has expanded to address a much broader patient population than just the actively dying, increasing access to palliative care services has been recommended as a way to improve end of life care for critically ill patients (Nelson et al., 2012).

ICU palliative care services should include aggressive symptom management, clarification of treatment goals, enhanced communication of patients' needs and wishes, and identification of ethically challenging situations. Palliative care experts regard their services as an added layer of support for patients, family members and providers (CAPC, 2004). Recommendations from the Center to Advance Palliative Care (CAPC) call for a palliative care provider team in ICU that includes: physicians, nurses, social workers and spiritual care practitioners (CAPC, 2004). Recent efforts to integrate palliative care services into the ICU have been shown to be feasible and beneficial, but the access to and utilization of palliative care is not universal or consistent across all ICUs (Mosenthal et al., 2010; Nelson et al., 2012; Penrod et al., 2012).

Experts suggest that moral distress may be influenced by both organizational and individual ICU nurse factors. However, there is limited data available about the relationship between organizational and individual nurse factors and ICU nurse moral distress on a nationwide scale. In addition, whether access to palliative care is associated with decreased moral distress is not known. A conceptual model was developed to better understand the issues and context of the study concepts (Figure 1). The overall goal of this study was to address the knowledge gap about factors that affect variance in moral distress and provides not previously known information about how palliative care influences the experience of ICU nurses.

Study Aims

This study addressed four **primary research questions**: 1) Is there a relationship between organizational/nurse factors (ethical climate, and empowerment) and moral distress in ICU nurses? 2) Does this relationship among factors depend on access to and utilization of palliative care in the ICU? 3) How is palliative care delivered in the ICU? and 4) How much education do ICU nurses receive in primary palliative care, and is there a relationship between palliative care education and levels of moral distress of ICU nurses?

<u>The specific aims for this study among ICU nurses were to:</u>

1. Evaluate the relationship between empowerment and moral distress and assess if this relationship depends on the access to and utilization of palliative care;

2. Evaluate the relationship between ethical climate (collaboration) and moral distress and assess if this relationship depends on access to and utilization of palliative care;
3. Evaluate the relationship between moral distress of ICU nurses and access to palliative care;
4. Describe access and utilization of specialist palliative care services in the ICU;
5. Evaluate primary palliative care education of ICU nurses, and the relationship between primary palliative care education and moral distress.

Impact

The findings from this study may inform the future development of palliative care programs that serve ICU patients. In addition, organizations may develop policies and procedures that foster improved communication of patient needs through greater collaboration resulting in improved quality and greater patient and family member satisfaction. Evidence of organizational factors that decrease the moral distress of nurses may support the development of interventions to promote healthy work environments.

Currently, there are no standards for healthcare organizations to provide palliative care in ICUs. Previous studies of palliative care in the ICU have demonstrated the feasibility of integrating a palliative care team into the standard services provided for ICU patients and improved patient and family satisfaction with quality of care. This study set out to report current practices of palliative care services in ICUs nationwide. The findings of this study suggest that support is needed to continue the pursuit of primary palliative care education for ICU nurses, and the development of organizational level team integration of palliative care services into ICU care teams.

Innovation

The study examined two important issues in health care research: moral distress and palliative care in ICU. In one study of ICU nurses, moral distress was briefly discussed in relation to the presence and absence of palliative care services (Hamric & Blackhall, 2007). However, the authors did not design their study to allow for a deeper analysis of palliative care factors. No study, to date has evaluated the potential relationship between ICU nurse moral distress and palliative care. This study contributes necessary information to improve care delivery models for dying patients that simultaneously improves the health of nurses and contributes to healthy work environments. This study draws from a nationwide population of ICU nurses that allows for a wide geographic distribution of participants who practice in numerous organizations. The use of a web-based approach with an online survey, contributes to the development of a broad and diverse national sample without the expense of personal interviews. This approach allowed for the investigation of both individual factors with a relationship to moral distress (empowerment, demographics, education), and organizational/environmental factors (ethical climate, collaboration). This would not have been feasible with a single or smaller multi-site study.

Moral distress is not unique to ICU nurses. Nurses are the largest segment of the US healthcare workforce, are a critical element of the healthcare team, and have a significant leadership role in the transformation of the US health care system

(IOM, 2012). This study provides evidence for the development of interventions to alleviate moral distress, and suggests that further inquiry is needed in order to address palliative care needs across specialties and settings.

The Relationships between Palliative Care, Ethical Climate, Empowerment, and Moral Distress Among ICU Nurses

This paper is the initial report for this study, with descriptions of data collection, analysis and interpretation of primary research questions that addresses the relationship between moral distress, ethical climate, empowerment and access to palliative care in a regression analysis model. Instruments used in this study included the Moral Distress Scale-Revised (MDS-R), the Hospital Ethical Climate Scale (HECS), the Psychological Empowerment Index (PEI), were used with permission, and were described in detail. A questionnaire was developed for this survey: Palliative Care in ICU: Access, Utilization and Barriers. It included 50 questions about how palliative care is delivered in the ICU. This questionnaire generated data that was used in all three papers. Several items from the questionnaire are included in this report. This paper has been submitted to the American Journal of Critical Care.

Intensive Care Unit Nurses' Perspective of Access and Utilization of Palliative Care: A Descriptive Study

This second paper includes a report of the descriptive analysis of palliative care delivery in the ICU setting. This study answers questions related to process of access and utilization of specialist palliative care services (SPCS) from the perspective of ICU nurses, and provides information about how SPCS gains access to

ICU patients, and how accessible SPCS are to support ICU nurses in the delivery of palliative care. Additionally this paper identifies unmet needs related to palliative care for ICU patients and common triggers for palliative care consults. This paper reports on data collected as part of the palliative care questionnaire developed for this study. This paper will be submitted to the Journal of Hospice and Palliative Nursing.

Primary Palliative Care Education Among ICU Nurses:
A Report from a Recent Study

The third paper included here is a report of primary palliative care education that ICU nurses have received. Specifically this study reports on palliative care education topics: management of pain, anxiety and depression; communication around prognosis, suffering, goals of care and code status. Analysis of levels of moral distress for nurses who reported having education on each topic compared with moral distress levels of nurses who reported having no education on each topic. Data for this analysis was taken from the Moral Distress Scale-Revised, the Moral Distress Thermometer, and items from the palliative care questionnaire developed for this survey. This paper will be submitted to American Journal of Critical Care.

Summary

This study adds to the knowledge of palliative care in the ICU and moral distress of ICU nurses. These three papers are submitted as partial completion for requirements of the doctoral dissertation at University of California, San Francisco, School of Nursing, Graduate Division. Completion of a public oral defense of this dissertation will finalize the dissertation process. Dissertation chair is Dr. Janine

Cataldo, and the dissertation committee includes Dr. Jill Howie Esquivel, Dr. Adam Cataldo, and Dr. Lucy Selman.

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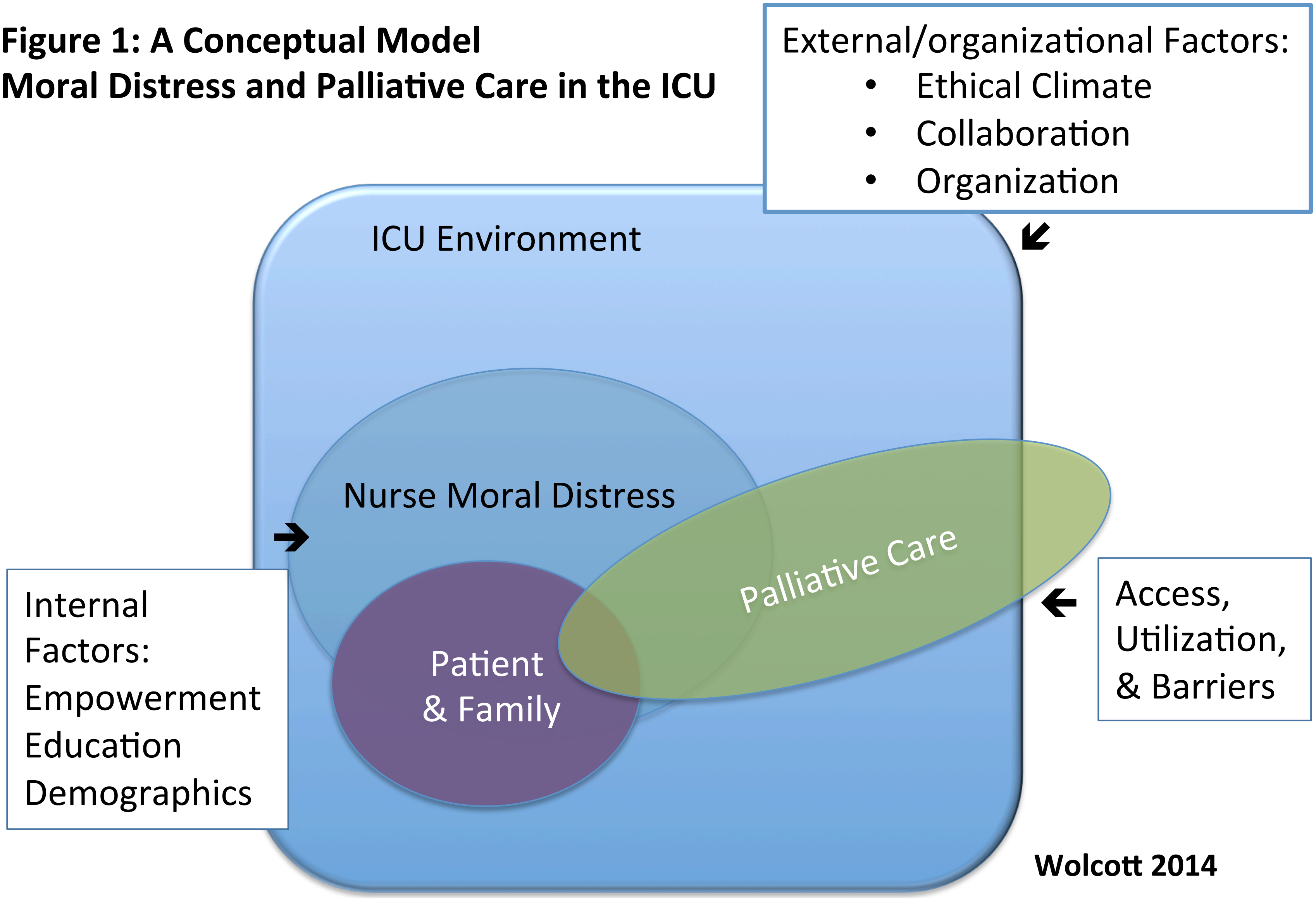
Figure 1: A Conceptual Model
Moral Distress and Palliative Care in the ICU



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Chapter 2

Abstract

Background: ICU nurses experience moral distress when they feel unable to deliver ethically appropriate care to their patients. Moral distress is associated with nurse burnout and patient care avoidance behaviors.

Objectives: This study aimed to evaluate relationships among moral distress, empowerment, ethical climate and access to palliative care in ICU.

Methods: ICU nurses in a national database were recruited via email and social media to complete an online survey. Descriptive, correlational, and regression analyses were done using the Moral Distress Scale-Revised (MDS-R), Psychological Empowerment Index (PEI), Hospital Ethical Climate Scale (HECS) and a palliative care delivery questionnaire.

Results: Of 288 initiated surveys**,** 238 were completed. Participants were nationally representative of nurses by age, years experience, and geographical region; a majority were Caucasian, female, and had a bachelor's degree. The MDS-R was moderately high, and correlations were found with PEI (r= -.145,p<.05), and HECS (r= -.354,p<.05). Neither relationship between MDS-R and PEI, nor MDS-R and HECS were affected by having access to palliative care. Those reporting access to a palliative care(73%] had higher MDS-R scores than those without palliative care access. In multiple regression analysis education, ethnicity, size of unit, access to full palliative care team, and ethical climate explained 37.7% variance of MDS-R (r^2= .377, p<.01).

Conclusions: Poor ethical climate, un-integrated palliative care teams and empowered nurses are associated with increased moral distress. Findings from this

study highlight the need to promote palliative care education and well-integrated palliative care teams into ICUs.

Moral distress among nurses was initially identified in the 1980s. Since then, moral distress has been investigated among physicians, social workers, chaplains, respiratory therapists and nurses in a variety of settings (Allen et al., 2013; Corley, Elswick, Gorman, & Clor, 2001; Gordon, Ridley, Boston, & Dahl, 2012; Leggett, Wasson, Sinacore, & Gamelli, 2013, Whitehead et al., 2015). Originally defined by Jameton (1984), moral distress has been defined more recently as "a form of distress that occurs when one knows the ethically correct thing to do but is prevented from acting on that perceived obligation" (Wocial & Weaver, 2013, p.167). Moral distress is related to, but distinctly different from a moral or ethical dilemma. In an ethical dilemma there are two or more ethical principles in conflict, leading to more than one equally justifiable choice and the challenge is to choose the correct course of action. Whereas, in moral distress, an individual holds a belief or perception about what the ethically correct action is, but is prevented from acting upon that belief, leading to a loss of personal integrity. Negative consequences, such as burnout, moral residue, and avoidance behaviors in patient care settings have been associated with accumulated, unresolved moral distress (DeVillers & Devon, 2012; Hamric, 2012; Varcoe et al., 2012; Epstein & Hamric, 2009).

Recent data indicate that of the 4 million individuals admitted annually to an ICU, there are 500,000 deaths (SCCM, 2012; UCSF, 2012); and over 500,000 nurses work in an ICU. Issues faced during end of life care continue to rank highly as triggering scenarios for moral distress of nurses, and are associated with both internal (individual) and external (environmental) factors (Whitehead et al., 2015, Browning, 2013, Allen et al., 2013, Hamric et al, 2012; Hamric & Blackhall, 2007).

Decades of study continue to reveal high levels of moral distress without evidence of effective interventions, despite suggested strategies (Allen et al., 2013; Beumer, 2008; Browning, 2013; Rushton & Westphal, 2004, Hamric, 2014, Epstein & Hamric, 2009). While certainly not unique to ICU nurses, moral distress continues to pose a barrier for ICU nurses to offer the quality of care they are committed to providing. ICU nurses remain the frontline care providers to critically ill patients, and as the health care system focuses on improving care for the dying, ICU nurses can play a pivotal role.

Palliative care has been evolving as an interdisciplinary field aiming to improve quality of life for seriously ill patients through collaborative models that include high-level communication, goals of life clarification, and aggressive symptom management. In 1995, a landmark study, the Study to Understand Prognosis and Preferences for Outcomes and Risk of Treatment (SUPPORT), reported poor quality end of life care (Connors et al., 1995). Recent efforts have been made to include palliative care in standard ICU treatment plans (Mosenthal et al., 2012; O'Mahony et al., 2010). Although inconsistently available across ICUs, individual organizations have reported successful integration of palliative care services into their ICUs (Mosenthal et al., 2012). The Center for the Advancement of Palliative Care (CAPC) has developed a model that provides an ICU-focused team to further the integration of palliative care into ICUs. The CAPC provides structured guidelines and ongoing reports on the progress of palliative care initiatives (CAPC, 2011). Given the interdisciplinary nature of palliative care, the intended collaborative approach, and focused quality communication to individualize patient care plans, having access to a palliative care team may be associated with an improved organizational ethical climate and lower levels of moral distress. Organizational ethical climate can be described as an organization's practices around support for ethically challenging situations and opportunity for engagement with individuals on ethical issues (Olson, 1998).

No studies to date have directly evaluated the relationship between access to palliative care services and the experience of ICU nurse moral distress. The overall goal of this study among ICU nurses is to evaluate the relationships among nurse moral distress, perceived psychological empowerment, ethical climate of the ICU, and access to palliative care.

Study Aims

The hypotheses in this study include: 1a) Increased levels of moral distress are associated with decreased ethical climate. 1b) Access to palliative care affects the relationship between ethical climate and moral distress. 2a) Increased levels of moral distress is associated with decreased empowerment. 2b) Access to palliative care affects the relationship between moral distress and empowerment. 2c) A curvilinear relationship will be found between moral distress and empowerment. 3) Access to palliative care is associated with lower levels of moral distress. We also assessed additional demographic characteristics of both the nurses' and the nurses' work environment, (i.e., type of facility, size of unit, patient rounding practices), in relationship to moral distress.

Methods

A nationwide web-based survey was conducted via the American Association of Critical Care Nurses' (AACN) e-newsletter. Potential participants included critical care nurses who receive the e-newsletter or who have access to AACN's social media pages. Criteria for participation in the survey included: ICU nurse, currently employed either full-time or part-time, provide direct patient care in an adult ICU, and cared for a dying patient in the past 6 months. Because the sampling approach made it impossible to track all individuals who may have received, read or opened an email, or viewed the social media site with the study invitation, a response rate is not reported. The invitation was open to anyone receiving the AACN newsletter or viewing their social media site and was not restricted to AACN members. A total of 288 potential qualified participants opened the survey and agreed to the informed consent; 235 participants completed the survey, thereby yielding an 82% completion rate. Three other participants completed a majority of the survey, including questions regarding the key variables, and these participants were kept in the study, yielding a total sample size of 238. No significant differences in demographics were identified between those who did and who did not complete the survey. Demographics did not vary significantly from the demographics of AACN membership. The study was open for one week, in March 2015, to achieve goal sample size of at least 222. Power analysis was conducted, and in a multiple regression analysis with up to 20 variables in the model, to detect an R^2 change for one variable of at least 3% at alpha = 0.05 and a power of 80%, a sample size of at least 222 was recommended. Ethical approval for the study was obtained through the University of California, San Francisco (UCSF).

Measurement

The survey included three standardized instruments and one questionnaire developed specifically for this study. The Moral Distress Scale-Revised (MDS-R) (Hamric, Borchers & Epstein, 2012) provides a definition of moral distress, and includes 21 items describing specific scenarios. Participants are asked to rate each item from 0-4 for frequency and intensity of moral distress. Scores of frequency and intensity are multiplied for each item and then summed for a total MDS score with a possible range of 0-336 (higher scores indicating higher levels of distress).

The Hospital Ethical Climate Scale (Olsen, 1998) is a 26-item scale with 5 domains of nurse relationship to patients, peers, physician, managers, and the hospital. Each item is rated from 1-5 and mean scores were calculated. A HECS score of greater than 3.5 is interpreted as a positive ethical climate.

The Psychological Empowerment Index (Spreitzer, 1995) is a measure of perceived empowerment within the work environment and includes 12 statements rated from 1-7 on the extent to which the statement accurately describes the participant's self-perception. Mean scores were calculated with higher scores reflecting greater perceived empowerment.

A questionnaire was developed for this study to assess access, utilization and barriers to palliative care in the ICU. Questions were created based on input from previous studies, palliative care researchers, ICU nurses, and palliative care clinicians and was piloted on a small group of ICU nurses. This questionnaire was designed as a descriptive instrument to gather information on specific topics of access, utilization and barriers to palliative care in the ICU setting, from the nurses' perspective The questionnaire included triggers for consultation, method for palliative care inclusion in a patient's care team, and the level of nurse education on some palliative care topics. Focus for this study includes questions primarily related to palliative care access.

Data Collection and Analysis

Data were collected with the survey platform Qualtrics, LLC (2015) that was administered through UCSF, reviewed, and then imported into SPSS version 22.0 for analysis. All participants' responses were analyzed anonymously, but some participants provided identifying information and received a gift card for their participation. Any identifying data received was stored separately from study data analysis in encrypted, locked files.

Instrument scores were analyzed for reliability using Cronbach's alpha for each instrument: MDS-R = 0.971, HECS = 0.934, and PEI = 0.889; good internal reliability across instruments was found. Frequencies and descriptive statistics were reviewed and distributions assessed. Correlations were assessed among primary independent variables and demographic characteristics, and were evaluated in relation to moral distress. Variables that were found to be significantly associated with moral distress were included in a multiple regression model. Categorical variables were dummy-coded as dichotomous variables with designated reference variable for analysis in the regression model.

Also included in the regression model, despite lack of independent statistical significance, was number of years in ICU. Early studies on moral distress and discussions on cumulative effects of moral distress suggested that years of experience may be a meaningful factor, although recent studies have not consistently found it significant (Elpern, et al., 2005, Epstein & Hamric, 2009, Corley et al, 2001, Hamaideh, 2013). Thus, the variable of years experience in the ICU was included as a potentially meaningful factor in the overall regression analysis.

Results

Study participants were primarily Caucasian (82%) and female (90%) with a Bachelor's degree in nursing (62%). Geographic representation was equally distributed across the U.S. Census Bureau defined U.S. regions: West, South, Midwest, Northeast. See Table 1 for specific demographics of study participants and description of facilities. A broad range of facility type and size of facility unit were represented. Seventy-nine percent of participants reported that they were confident to describe palliative care in the ICU setting. Seventy-five percent (175 of 235) of participants reported having routine interdisciplinary patient rounds in their units, and 92% (161 of 175) of these included the bedside nurse. Twenty-eight percent (67 of 235) of nurses could obtain a palliative care consult without a direct physician order.

The Moral Distress Scale-Revised (MDS-R) scores ranged from 0-225 with a mean MDS-R score of 96.5 (SD= 55.8) where a higher score reflects greater distress. The Hospital Ethical Climate Scale (HECS) scores ranged from 1.96 – 5, with a mean score of 3.9 (SD= 0.5), higher scores indicate a positive ethical climate. PEI scores ranged from 1-7 (possible 1-7), with mean scores of 5.3 (SD= 0.8), with higher scores indicating greater perceived empowerment. Access to a full palliative care team was defined as Specialist Palliative Care team members including: Physicians, Nurses, Social Workers, and Spiritual Care practitioners. Seventy-three percent (n=171) of participants claimed access to a full palliative care team.

Moral distress was negatively correlated with empowerment in a linear relationship (r= -.145, p=.016). Analysis of a curvilinear relationship between empowerment and moral distress was found to be statistically significant (R^2 Change= 0.02, F= 4.866, p=.028) in regression analysis, with participants scoring lower on the PEI scale also having lower MDS-R scores, and participants scoring highest on the PEI scale having lower MDS-R scores, while participants scoring moderately high on the PEI had higher MDS-R scores. Both the linear and the curvilinear associations were small but statistically significant. MDS-R subscales for frequency (MDF) and intensity (MDI) were analyzed for a relationship to the PEI. A negative correlation (r= -.188, p = .005) was found between MDF and PEI. Participants with higher empowerment scores had lower moral distress frequency scores. No significant relationship was found between MDI and PEI. These findings support study hypotheses. Contrary to study hypothesis, no moderating effect of access to palliative care in the relationship between empowerment and moral distress was found, by testing the possible interaction in a regression analysis.

Moral distress and ethical climate were negatively correlated (r= -.354, p<.001), with moral distress levels lower in a positive ethical climate thereby supporting the study hypothesis. The association between ethical climate and moral distress was not influenced by access to palliative care as assessed by regression analysis.

There was a weak but significant correlation between access to palliative care and the experience of moral distress (r=.196, p=.004). Nurses reporting access to a full palliative care team reported higher levels of moral distress. T-test analysis found a mean MDS score for participants who reported having access to a full palliative care team was 102.3 (SD = 57.2), a difference of 22.5 when compared to those who did not have access to a full palliative care team (MDS = 79.8, SD= 49.4).This finding is contrary to study hypothesis.

Multiple regression findings are summarized in Table 3, where 218 participants were included for this analysis due to list-wise deletion. Factors that significantly contributed to explaining the variance in moral distress included: ethical climate, access to a full palliative care team, number of beds in the unit, ethnicity, and educational degree. Ethical climate provided the largest unique contribution to the variance in levels of moral distress ($sr^2 = .120$, $p<.001$). Several factors that had independent significant associations with moral distress did not demonstrate a significant unique contribution to explaining moral distress variation in the presence of the other factors; these were empowerment and facility type (academic, teaching, non-teaching; tertiary referral center).

Discussion

The novel findings of this study are that moral distress has an inverse relationship with ethical climate, a curvilinear relationship with empowerment, and a positive relationship with access to palliative care. Each relationship contributes to the larger picture of the moral distress experience in ICU nurses. Education, ethnicity, and number of beds in the unit were found to be important factors for nurses' experience of moral distress, but ethical climate was the most important.

Moral Distress and Ethical Climate

Ethical climate has been evaluated with moral distress in many studies; findings in this study validate and support consistent data reflecting an inverse relationship where participants who work in an ethically supportive environment experience lower levels of moral distress (Corley et al., 2005; Hamric & Blackhall, 2007, Whitehead, et al., 2015). In further support for the proposition of integrated collaborative teams contributing to lower moral distress, a follow up analysis found a small but significant correlation between levels of moral distress and the inclusion of nurses in daily patient rounds, which may reflect a collaborative work environment(r=.2, p=.004) in which nurses who participated in routine patient care rounds experienced lower moral distress. This is consistent with moral distress theory in which positive ethical climates and collaborative work environments contribute to less moral distress (Corley, 2001; Corley et al., 2005; Hamric, 2012, Hamric & Blackhall, 2007).

Moral Distress and Empowerment

A key component of the operational definition of moral distress for this study includes: "….prevented from acting on a perceived obligation…" (Wocial & Weaver, 2013, p. 167). Findings from this study add to previous study findings (Browning, 2013) that found an inverse relationship between empowerment and moral distress levels. Nurses in the ICU environment are often expected to make autonomous decisions on behalf of the patient and also function in a hierarchically lower position than physicians. Education in leadership and systems level navigation can support nurse empowerment and action on patient behalf regardless of agreement with other team members (Macphee et al., 2012). However, findings from this study suggest that just gaining knowledge and feeling confident is not sufficient to prevent moral distress. The delivery of optimal care and the personal integrity of nurses around intentions and perceived obligations are at stake (Corley, 2001; Epstein & Hamric, 2009; Hamric, 2012; Hamric, Borchers, & Epstein, 2013). Individual nurse empowerment has been a target of educational interventions, particularly related to end of life care and team building (Beumer, 2008; Gordon et al., 2012). Browning's study found an inverse correlation between moral distress frequency and empowerment of nurses; when moral distress was high, perceptions of empowerment were low (2013). Findings in this study initially support this finding with participants who scored higher in the PEI reporting lower total moral distress scores, and experienced moral distress less frequently.

Our findings suggest that a curvilinear relationship between moral distress and empowerment exists. Perceived obligations of individual nurses are a major component of the moral distress experience. The curvilinear relationship found in this study suggests that participants who perceive very low empowerment and very high empowerment have lower moral distress scores than nurses who perceive moderate empowerment. Nurses with very low perceived empowerment scores may also experience a lesser sense of moral obligation for the care they feel a duty to deliver and in turn experience less moral distress, while those with very high empowerment scores may be able to deliver their desired level of care despite obstacles in their work environment. These findings support the recommendations from AACN that moral distress must be addressed at both individual and organizational levels (AACN, 2008).

Additionally, when in the presence of the ethical climate variable, empowerment lost its significant unique contribution for explaining moral distress. This finding suggests that nurses who are somewhat more empowered may have an increased sense of obligation related to ethical delivery of patient care. But in the face of less supportive ethical environments, and thus not fully empowered to act as they believe correct, they may experience higher levels of moral distress.

Moral Distress and Access to Palliative Care

Palliative care is intended to provide additional support for patients with complex serious illness. The study hypothesis that proposed nurses with access to palliative care resources would experience less moral distress, was not supported. In fact, participants who reported having access to a palliative care team experienced higher levels of moral distress. Factors that need to be considered include the level of integration of the palliative care teams into the ICU team, and clinician beliefs and attitudes about palliative care. Collaboration and integration of care delivery teams is thought to affect moral distress (Corley, 2001; Hamric & Blackhall, 2007; Epstein & Hamric, 2009). While the stated goal of palliative care includes interdisciplinary collaboration (CAPC, 2015), if there is not a sufficient integration of teams, nurses may experience more conflict than support. Previous literature reflects the inconsistent presence of palliative care in the ICU (Mosenthal et al, 2012). Researchers in this study found that 75% of participants reported routine daily interdisciplinary patient care rounds, and of those, just 30% (n=52 of 173) included a palliative care team member. This may reflect the need for further integration of palliative care teams in the ICU. An alternate possible interpretation of the inverse correlation between moral distress and access to palliative care may be the elevated expectations of care for dying patients, since there is a palliative care team, but unless the palliative care team is active in the unit, these expectations may face barriers. For example, if a nurse has received education regarding palliative care contributions to quality of patient care, and works at a facility that has a palliative care team on staff; but this team is not well integrated in the ICU, this may lead to increased moral distress. This explanation is consistent with Whitehead and colleagues' (2015) findings related to change in the understanding of obligations, and dissonance between care teams related to beliefs of best practice for delivery of quality care. Another possible explanation lies in some potential gaps in clinicians' understanding of the goal of palliative care and agreement about whether or not it is appropriate for ICU care. Seventy-nine percent of the participants reported they were confident in describing palliative care in the ICU. This suggests that over 20% of ICU nurses did not feel confident to describe the basic concept of palliative care. That identifies a gap in understanding about palliative care and identifies an opportunity for education.

There are challenges that can arise due to conflict between stated and unstated goals of patients, families and clinicians in relation to end of life care. Working toward divergent goals inevitably leads to conflict. Goals of palliative care practitioners are to assist in the clarification of treatment goals and communication about patient quality of life and to raise consciousness about palliative care alternatives (HPNA, 2015; CAPC, 2015). While these goals are being pursued, care plans for dying patients may not always reflect a smooth delivery process across care teams. The majority of palliative care services in the ICU setting are provided on a consultant basis that requires a specific consultation request for care strategy recommendations (Mosenthal et al., 2013). This study supports prevalence of the consult model by finding that only 28% (67 of 235) of nurses could obtain a palliative care consult without a direct physician order. By nature, when a consult service requires a physician order there will be occasions when clinicians do not agree on a need to request palliative care. This sets up potential for conflict among clinicians and ultimately the process defaults back to the hierarchical structure where one physician (or team of physicians) makes the final decisions about how care is delivered and who is involved. Without established, standardized consult triggers, consistent referral patterns will be lacking, which leaves individual nurse and physician expectations for the palliative care referral process open to variation and may create conflict among the team members. To facilitate clear expectations and establish a more integrated team approach, it is recommended that institutions develop a standardized approach to referral and utilization of palliative care.

Strengths and Limitations

Limitations to this study include the inability to link participants to specific facilities, which limits the ability to compare individual organizations other than within broad categorizations. Self-selection bias of study participants who are more knowledgeable or interested in palliative care may be present. This may limit generalizability to the population of ICU nurses. Additionally, no information was gathered in this study about physician or other practitioners' knowledge or beliefs about palliative care in the ICU.

The strengths of this study include the broad sample from ICU nurses in the AACN nationwide database, that provides a range of perspectives across geographical and practice settings. The anonymity present in a web-based survey may have encouraged more honest responses to sensitive questions about work environment and experiences around moral distress. Using updated, validated instruments contributes to the growing knowledge about moral distress and related factors. Novel findings of this study contribute to knowledge and understanding about nurse empowerment, experience of moral distress and the integration of palliative care in the ICU.

Summary

Discussions about moral distress continue to underscore the need for well-integrated teams to respectfully collaborate and communicate goals and strategies for individualized patient care. There remains a lack of understanding on the part of nurse clinicians of the role of palliative care for patients in the ICU thereby creating a gap that optimizes the benefits of a palliative care approach. Individual empowerment remains a meaningful concept for ICU nurses, but not more important than the nurse's relationship to team and unit. Study findings support the incorporation of organizational support and inclusion of entire team for any attempted changes in a care delivery process when planning educational interventions for improving end of life care in the ICU. For a sustainable change to be effected, all levels of management and staff are required. Education is necessary, and contributes to the individual's ability to work within the upgraded expectations, but all change must be actively supported by administrative and clinical teams, and challenges must be addressed at a system as well as individual level.

Recommendations for further study include assessment of collaboration and integration of palliative care teams in the ICU setting. Qualitative studies may provide more insight into the role of palliative care in the ICU and relationships with moral distress of nurses. Also, exploring other components of access and utilization of palliative care services from a primary palliative care and specialist palliative care perspective may give insight into the support available for nurses delivering end of life care in the ICU.

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Table 1: Description of Study Participants and Facilities

Demographics (N=238)	%(N)	Mean(sd,range)
Individual		
Female	90(214)	--
Race		
Caucasian	82(194)	--
African American	10(23)	--
Asian	6(13)	--
Other/Decline to State	3(8)	--
Ethnicity Hispanic	12(29)	--
Age	--	38(11, 20 - 70)
Years Experience as RN	--	12 (11, <1 - 49)
Years Experience in ICU	--	8(9, <1 - 43)
Education Degree		
Diploma	8(19)	--
Associates	16(39)	--
BSN	62(148)	--
MSN and beyond	13(32)	--
Shift Worked		
Dayshift	50(119)	--
Evenings	6(15)	--
Night	23(55)	--
Mixed	21(49)	--
Hours Worked in 2 weeks	--	66(22,<1 - 120)
Facility		
Geographic Region		
West	23(39)	--
South	26(62)	--
Midwest	29(70)	--
Northeast	22(52)	--
Community/Public Hospital*	79(187)	--
Academic Medical Center	33(79)	--
Teaching Non-Academic	27(65)	--
Non-Teaching Facilities	40(94)	--
Tertiary Referral Center	45(107)	--
# Beds in the unit	--	24(25, 1 - 180)

RN, Registered Nurse; ICU, Intensive Care Unit; BSN, Bachelor's of Science in Nursing; MSN, Master's of Science in Nursing.
* versus Private Hospital

Table 2: Correlations with Moral Distress (Total MDS-R Score)

Independent Variable (N=218)	r	p-value*
HECS	-.354	<.001*
PEI	-.145	.016*
BEDS in unit	.251	<.001*
ACCESS to Full Palliative Care Team[1]	.196	.004*
Race[2,3]	-.264	<.001*
Facility: Tertiary Referral Center	-.166	.007*
Education Degree[3]		
Associate vs. Diploma	-.120	.038*
BSN vs. Diploma	.231	<.001*
MSN and beyond vs. Diploma	.060	.189 (NS)
Facility:[3]		
Academic MedCtr vs. Non-Teaching	.169	.006*
Teaching Non-MedCtr vs. Non-Teaching	.040	.281 (NS)
Years Experience in ICU	.061	.185 (NS)

ICU, Intensive Care Unit; BSN, Bachelor's of Science in Nursing; MSN, Master's of Science in Nursing; MDS-R, Moral Distress Scale-Revised.

1. Full Palliative Care Team = Specialist Palliative Care: Physician, Nurse, Social Worker, Spiritual Care.

2.African American vs. Caucasian/Asian/Other

3.Categorical variables Dummy-coded for regression analysis into sets of dichotomous variables with a reference variable.

**P-Value<.05 is statistically significant. NS, Not Significant.*

Table 3: Regression Analysis; Dependent Variable: Moral Distress (MDS-R)

N=218	R^2	Beta	R^2change (sr^2)	df	F	P*
Overall	.377	--	--	12,205	10.337	<.001*
HECS (Hospital Ethical Climate Scale)		-.379	.120	1,205	39.589	<.001*
PEI (Psychological Empowerment Index)		.024	.000	1,205	.138	.710
ACCESS to Full Palliative Care Team[1]		.152	.021	1,205	6.791	.010*
BEDS in unit		.229	.047	1,205	15.335	<.001*
Race[2,3]		-.193	.031	1,205	10.317	.002*
Years Experience in ICU		.000	.000	1,205	.000	.996
Educational Degree[3]		--	.054	3,205	5.932	.001*
Associate vs. Diploma		.238	.023	--	7.431	.007*
BSN vs. Diploma		.425	.053	--	17.530	<.001*
MSN and beyond vs. Diploma		.258	.027	--	8.874	.003*
Facility [3]		--	.005	2,205	.859	.425
Academic MedCenter vs. Non-Teaching		.084	.004	--	1.199	.275
Teaching Non-MedCenter vs. Non-Teaching		.080	.004	--	1.438	.232
Facility: Tertiary Referral Center		-.031	.001	1,205	.209	.648

MDS-R, Moral Distress Scale-Revised. ICU, Intensive Care Unit; BSN, Bachelor's of Science in Nursing; MSN, Master's of Science in Nursing

1. Full Palliative Care Team = Specialist Palliative Care: Physician, Nurse, Social Worker, Spiritual Care.

2.African American vs. Caucasian/Asian/Other

3.Categorical variables Dummy-coded for regression analysis into sets of dichotomous variables with a reference variable.

**P-Value<.05 is statistically significant.*

Chapter 3

Abstract

Background: Palliative Care has been found to improve the care of critically ill ICU patients. There has been inconsistent access and utilization of palliative care in ICUs in the U.S. Active efforts to promote palliative care have contributed to increases in the prevalence of palliative care teams, however access to and utilization of palliative care delivery vary across ICU settings.

Objectives: Study aims were to describe access to and utilization of palliative care in the ICU, as perceived by ICU nurses.

Methods: As part of a larger web-based national survey of ICU nurses, participants completed a questionnaire on topics of access and utilization of palliative care. Descriptive analyses were reported.

Results: The majority of participants reported having a palliative care team in their organization, but less than half reported a consistent presence of palliative care clinicians in the ICU. The majority reported having consult models of palliative care. Most frequently reported triggers for a palliative care consult included: prognosis/goals of care/futility, pain/symptom management, imminently dying patient, and family support/conflict resolution. Psychological distress needs were most frequently unmet. Other highest ranking unmet needs included: goals of care conversations, family support, symptom (non-pain) management, and spiritual distress. Majority felt sufficiently supported around pain management, care of imminently dying patients, and treatment individualization.

Conclusions: Access does not necessarily translate into utilization of palliative care. Areas for improvement include psychological needs of patients, goals of care

conversations and family support. Utilizing palliative care to address psychological needs is recommended, however, it was low on the list of reported consult triggers, and high on unmet need rankings. Goals of care conversations are a frequent trigger for a palliative care consult, yet still reported as an unmet need. To optimize palliative care in the ICU, further education for clinicians on palliative care, and organization based team-building to improve integration are recommended.

Palliative care has been evolving as a specialist field in medicine and nursing since 1988 (AAHPM, 2015). Palliative care uses an interdisciplinary approach to care for seriously ill patients that requires core skills in communication, psychosocial assessment, and symptom management for incorporation into standard primary practitioner care (Higginson et al., 2013; Penrod et al., 2012). The Center to Advance Palliative Care (CAPC) is an organization in which palliative care is promoted and analyzed for effectiveness in the intensive care unit (ICU) (Mosenthal et al., 2012).

There is evidence that palliative care adds value and quality to the ICU patient experience, therefore, an important area of inquiry is to assess how palliative care is delivered in ICUs across the U.S. Both integrative and consultative palliative care delivery models have been described in recent reports (Nelson & Hope, 2012; Mosenthal et al., 2012, Campbell, Nelson & Weissman, 2015). While both models have benefits, a combination of models is recommended for optimal delivery of palliative care in ICU (Nelson, Bassett, et al., 2010). In both models, access to and utilization of palliative care in the ICU are key elements to understanding the quality of end of life care. To our knowledge, there are no current studies that assess the accessibility and utilization of palliative care in U.S. ICUs. To address this gap, the aims for this study were to describe access and utilization of palliative care in the ICU, as perceived by ICU nurses.

Background

Palliative Care

Worldwide, palliative care has varying roles in healthcare and differing methods in which it is implemented. In some instances palliative care is focused exclusively on end of life care for terminally ill patients, when all curative care has been abandoned (Schindler, 2006; Nelson & Hope, 2012). For other patients, palliative care may be integrated into the treatment plan for any seriously ill individual who may benefit from aggressive symptom management related to complex disease, and may include active rehabilitation (KCL, 2015). The goal of palliative care at any stage of care is to improve function and quality of life to optimal levels within the limitations of disease (KCL, 2015; AAHPM, 2015; CAPC, 2015; Nelson & Hope, 2012). In the U.S. there is no consistent agreement and understanding of the scope of palliative care (Mosenthal et al., 2012; Nelson & Hope, 2012; Penrod et al., 2012, Curtis et al., 2008). The American Association of Hospice and Palliative Medicine (AAHPM) currently defines palliative care as "focused on improving a patient's quality of life by managing pain and other distressing symptoms of a serious illness…[and] should be delivered along with other medical treatments" (AAHPM, 2015). They specify that hospice is a form of palliative care that is delivered in the last year of life. The Hospice and Palliative Nursing Association (HPNA) propose that palliative care should be delivered across the continuum of care for patients with "actual or potential life-limiting illnesses" (HPNA, 2015, p3). Official position statements from these two organizations agree that palliative care should go beyond care of the imminently dying patient.

However, as a result of lingering perspectives that ICU and palliative care are mutually exclusive sequential treatment plans, ICU standards of care have been slow to integrate palliative care (Nelson & Hope, 2012; Penrod et al., 2012, Mosenthal et al., 2012, CAPC, 2015).

Specialist palliative care practitioners primarily consult on care for ICU patients who are imminently dying (Mosenthal et al., 2012; Perrin & Kazanowski, 2015; Visser, Deliens, & Houttekier, 2014). Despite current assertions from numerous professional organizations (e.g., medicine, nursing, critical care, and palliative care) that palliative care should be incorporated early in treatment plans regardless of prognosis (Dahlin et al., 2009) in the ICU, it remains primarily an end of life intervention. Some ICU clinicians view palliative care as giving up, a failure, or a betrayal to patients (Mosenthal et al., 2012). Intensive care requires that team members utilize high level communication skills within the ICU setting to facilitate understanding of patient goals, coordinate across healthcare teams, individualize care plans, and optimize the ICU experience for patients and families (Carter & Wocial, 2012; Mosenthal et al., 2012; Perrin & Kazanowski, 2015). The interdisciplinary approach of palliative care that provides with aggressive symptom management and skilled communication, has been shown to improve quality of care and enhance the experience of patients and families in the ICU (Nelson, Puntillo, et al., 2010, Penrod et al, 2012).

Access to Palliative Care in the ICU

Access to palliative care primarily describes models of delivery, such as a consult model or an integrated palliative care service model (Mosenthal et al, 2012, Nelson & Hope, 2012). There is limited discussion of the interaction of ICU nurses with palliative care services. Access, as defined in this study, is the ability of nurses to approach or communicate with specialist palliative care practitioners when needed. Recommendations for a palliative care service include a multi-professional model consisting of at least: a specialist palliative care physician, a specialist palliative care nurse, a social worker and a spiritual care practitioner (CAPC, 2015). Hospitals may have a palliative care service that includes all the requisite team members, but case loads can include patients from the entire organization or multiple organizations, which limits availability of services to an individual department. The question of how accessible are palliative care teams to ICU nurses, remains unanswered.

Utilization of Palliative Care in the ICU

Just establishing the existence or availability of palliative care services is not adequate to assess palliative care in the ICU, whereas, an assessment of how these services are utilized is necessary. Data regarding utilization of palliative care in the ICU primarily describes what indications, or triggers, are present when a palliative care consult is requested (Penrod, et al., 2012, Mosenthal, et al., 2012, Higginson et al., 2013). Utilization, in this study, is defined as the frequency and process of palliative care used in the ICU. Assessment of utilization of palliative care in the ICU includes: 1) A review of the need for palliative care; 2) Identification of unmet palliative care needs; and, 3) Assessment of the support nurses have to provide palliative care in the ICU. A factor closely associated with utilization, is the process used for connecting ICU patients with palliative care services. In consult models, clinicians need a reason (i.e., trigger) for including specialist palliative care on the patient care team. Although explored in a few studies, standardized triggers for palliative care consult have not been established (Penrod, et al., 2012, Mosenthal, et al., 2012, Higginson et al., 2013). Integration of palliative care into standard ICU care may include a palliative care representative present at patient rounds (Mosenthal et al., 2006, Higginson et al., 2013). Nurses provide valuable contributions to the decision-making processes in palliative care including information about patient preferences regarding treatments and goals of care (Puntillo & MacAdam, 2006; Nelson & Hope, 2012). A recent study found an association between ICU nurse moral distress and the existence of a palliative care team, with those reporting access to palliative care having higher levels of moral distress. This may be related to the lack of integration between palliative care teams and ICU teams (Wolcott, Howie-Esquivel, & Cataldo, 2016). Because the existence and availability of palliative care services does not necessarily translate into use of the services, studies are needed to identify how often ICU nurses are included and how supported they feel in the process of palliative care delivery.

Methods

Design

This was a web-based, cross-sectional descriptive nationwide survey of ICU nurses. This study is part of a larger study that explored moral distress of nurses, ethical climate, empowerment, and access, utilization, and barriers of palliative care services available to ICU nurses that is published elsewhere (Wolcott, Howie-Esquivel, & Cataldo, 2016).

Sample

ICU nurse participants were recruited through the American Association of Critical-Care Nurses' (AACN) e-newsletter and social media sites, and was available to AACN members and non-members. They completed a web-based survey designed to describe access, utilization and barriers to palliative care resources. During the second week of March 2015, 288 ICU nurses responded to the study invitation, indicated that they met study criteria, and completed the informed consent process to begin the survey; 235 respondents completed this portion of the survey, yielding an 82% completion rate. Ethics approval was obtained from the University of California, San Francisco (Wolcott, Howie-Esquivel, & Cataldo, 2016).

Data Collection

Survey Questionnaire

Questions developed for the survey in the larger study incorporated input from palliative care clinicians, ICU clinicians, palliative care researchers, and previously published literature on palliative care in the ICU (Penrod et al., 2012; Mosenthal et al., 2012). The overall questionnaire included a section on palliative care: access, utilization, and barriers. For the present study we explored access and utilization.

Access Assessment

Access to specialist palliative care was assessed as a multi-layered concept: 1) Do palliative care teams exist in the organization and/or in the ICU? 2) What disciplines are included in the palliative care teams? and 3) How often are the teams and/or practitioners present in the ICU? Figure 2 outlines these concepts and describes how they were assessed.

Access questions focused on presence and availability of specialist palliative care providers in the ICU, and the process in place for palliative care practitioners to participate in patient care in the ICU. To measure access to palliative care, the survey first asked a general question: "Do you have access to a full specialist interdisciplinary palliative care team (defined as: Specialist Palliative Physician, Specialist Palliative Nurse, Social Worker, and Spiritual Care Practitioner)?" This question was designed to explore the prevalence of palliative care services in the hospital as perceived by nurses. Follow-up questions included: How much time do each member (i.e., by discipline) of the palliative care team spend in the ICU? Five palliative care practitioners (i.e., physician, nurse practitioner, clinical nurse specialist, social worker, spiritual care) were rated on a frequency scale of 1-5, five representing the most time (i.e., never, rarely, occasionally, frequently, most all of the time). This provides context to understanding the complex landscape of palliative care resources that are available to ICU nurses. A calculation was conducted to condense these responses into a broad overview of presence and access of palliative care in the ICU. If a participant rated at least three listed practitioner types as present frequently or most all of the time (i.e., 4 or 5 on the scale), they were designated as having a palliative care team present in their unit.

Utilization Assessment

Utilization questions were developed first to assess integration of palliative care into standard ICU care by asking about routine rounding practices. The survey also explored: the involvement of nurses in consult practice; nurse perceived palliative care needs of patients; and whether or not those needs were met. A list of specific palliative care needs (e.g. goals of care conversations, pain and symptom management, family support, etc) was rated unmet on a scale of 1-5, from least to most (i.e. never, rarely, as often as not [sometimes], frequently, most all of the time). If items were rated 3, 4, or 5, they were designated as unmet. Participants were then asked how supported they felt in providing care in core palliative care areas (e.g., care of imminently dying patients, ethical concerns around withdrawal or withholding treatments)rated on a scale of 1-5, from most supported to least, (i.e., most all of the time, usually, as often as not [sometimes], rarely, never). If the specific item was scored 1 or 2 out of 5 (i.e., frequently or most all of the time), they were designated as sufficiently supported. In addition, questions were designed to explore the presence of other staff nurses with palliative care skills, and the inclusion of bedside nurses in family care conferences. In consult models, clinicians need a reason, or trigger, for initiating palliative care. A list of potential triggers for consult was explored among participants who had been involved in requesting palliative care for their patients. Participants were also given the opportunity to describe other reasons for requesting palliative care.

Data Analysis

For the purposes of this exploratory study, a univariate descriptive analysis was run on all variables using SPSS version 22.0. Composite overviews were calculated for the variables related to the concepts of access and utilization. Figure 2 shows the culmination process for the concept of access.

Results

Study participants (N=235) were primarily Caucasian and female, with more than half having a Bachelor's degree in nursing. This sample comprised a broad range of ages from 20-70, though overall it was a fairly young group of nurses, with a mean age of 38. As seen in Table 1, geographic representation was equally distributed across the U.S. Census Bureau defined regions (2013): West, South, Midwest, and Northeast, and a wide range of facility type and size were represented. A majority of nurses in this study (79%, n=185) reported confidence in their ability to describe palliative care in the ICU setting.

Access

In response to the question, "Do you have access to a full palliative care team?" 73% (n=171) of the participants said yes. Presence (i.e., frequency of time) of individual specialist palliative care practitioners in the ICU was assessed, with 48% (n=112) reporting palliative care teams present in their ICU (Table 2). Additionally, 54% (n=127) of participants reported a nurse co-worker with palliative care skills as an available resource.

Utilization

Routine patient care rounds, as a primary indicator of utilization and integration, were reported by 75% (n=175) of participants, with 92% (n=161) of those including the bedside nurse, and 30% (n=52) including a member of the palliative care team. According to 64% (n=150) of participants, the bedside nurse was routinely included in family care conferences and 28% of all participants (n=67) reported that a nurse could directly request a palliative care consult without an order from the primary physician. Seventy-one percent (n=167) of participants reported requesting palliative care for a patient and 70% (n= 165) report that primary ICU physicians do initiate palliative care consults when requested by nurses. (These statistics were previously reported as part of larger study, Wolcott et al., 2016). Ranking of issues that were triggers for palliative care consults were: Futility/goals of care/prognosis discussions; Pain and symptom management; Imminently dying patient; and Family support/conflict resolution (Table 3). Patient or family initiated requests for palliative care were reported by a small number of participants. There was no significant difference among these topics between geographical regions represented.

Palliative Care Needs Assessment

When asked about palliative care needs, 64% (n=150) of participants reported having cared for a patient in the past six months whom they believed would have benefited from, but did not receive, palliative care. Regarding specific palliative care areas, unmet needs were reported by the majority of participants related to psychological or emotional distress, and conversations about goals of care (Table 4). Approximately half of the participants reported unmet needs relating to: pain management, management of other symptoms (e.g., dyspnea, thirst, fatigue, depression), spiritual distress or religious needs, cultural or linguistic needs, and family support needs.

The majority of participants reported sufficient support for: pain and symptom management, care of imminently dying patients, and treatment individualization (Table 5). Approximately half of the participants reported sufficient support for goals of care, prognosis discussions, and communication about end of life topics with patients and families. However, most participants did not feel sufficiently supported around ethical concerns regarding withholding or withdrawal of treatments.

Discussion

This study is novel because the literature has no previous descriptions of: 1) The presence of palliative care practitioners in the ICU, 2) The inclusion of palliative care in routine patient care rounds, 3) Nurses' interactions with the ICU team regarding palliative care resources, and, 4) Nurses' perceptions of the adequacy of care for patients with palliative care needs. The findings that describe triggers for consult add a perspective of how palliative care might be initiated in the ICU. We have found that while nurses report having access to palliative care, specialist palliative care team members spend very little time on the unit and are not well integrated into standard care in ICUs. Goals of care and prognosis discussions, pain and symptom management, and care of imminently dying patients were the most frequent triggers for palliative care consult; while palliative care teams were rarely called for cultural, spiritual, or psychological/emotional needs. In addition, psychological and emotional needs were ranked as the highest reported unmet needs. This is of interest because social workers and spiritual care practitioners were the ones most frequently reported as spending the most time in the ICU.

While study findings did show that the majority of study participants reported having specialist palliative care teams in their facilities, less than half of the participants reported that palliative care team members were routinely present in their ICU. Some palliative care practitioners, primarily social workers, were present in the units represented in this study, but not consistently; and few patient care rounds routinely incorporated specialist palliative care input. No previous studies were found that described the presence of a palliative care team in the ICU. The majority of facilities represented in this study functioned on a consult model requiring a physician to request specialist palliative care, which is consistent with previously reported data (Mosenthal et al., 2012). This study's findings support previous discussions of the inconsistency of palliative care in ICUs across the country (Mosenthal et al., 2012, Penrod et al, 2012). In this study, patient care rounds occurred in the majority of ICUs, which suggests interdisciplinary collaboration and a structured intention to provide individualized patient care that includes the nursing perspective for patient care decisions. Presence of this interdisciplinary approach may reflect primary palliative care approaches not directly assessed in this study, such as collaborative pain and symptom management, input from multiple disciplines to clarify and address specific patient goals, and ongoing evaluation of treatment effectiveness. However, the noted absence of specialist palliative care team members during patient rounds suggests that palliative care is not well integrated into the standards of care for these ICUs.

Triggers for palliative care consults included requests for assistance with goals of care conversations and issues related to futility, pain and symptom management, imminently dying patients, assistance with complex families, and ethical challenges related to withdrawal or withholding of life sustaining treatments. These triggers reflect the primary stated goals of palliative care organizations and suggest some consistency in the components of palliative care that are provided in the ICU. Patients and families requesting consults may reflect general knowledge in the community about palliative care. These requested consults were well distributed across geographical regions, which may suggest that no one region is more or less educated about palliative care.

The area of psychological and emotional distress stands out as a significant issue. Although not frequently cited as a reason to call for palliative care, it was identified by nurses as an unmet need. As an explanation, there may be a disconnect between understanding that palliative care resources can be helpful to support psychological and emotional needs, or perhaps current palliative care services do not have the ability to address these issues adequately. The possibility exists that social workers and spiritual care practitioners actually do address these needs without the knowledge of nurses. Consistent with findings in this study, previous reports suggest that trigger criteria are not optimally utilized for palliative care consults in the ICU (Mosenthal et al., 2012).

Strengths and Limitations

A limitation of this study is that there were no data to link participants to specific facilities. This limits the ability to compare individual organizations other than by broad categorizations. The relatively young age and Caucasian majority of participants in this study may also influence study findings, and may reflect different perspectives and experiences than the total population of US ICU nurses. There may also be some self-selection bias of study participants who are more knowledgeable or interested in palliative care that may not reflect the total US population of ICU nurses. This bias may lead to overestimating areas where knowledge and attention to palliative care are innately reflected in the survey responses. The strengths of this study include the broad sample from a nationwide database of ICU nurses, which provides a range of perspectives across geographical and practice settings. In addition, the anonymity present in a web-based survey may have encouraged more honest responses to sensitive questions about work environment and personal experiences. The novel findings of this study contribute to knowledge about access and utilization of palliative care in the ICU, and the experiences of the nurse related to palliative care delivery in the ICU.

Recommendations for Future Research

Further research is recommended to better understand the challenges related to psychological and emotional needs of patients in the ICU, and how palliative care services may be better utilized to support these patients. Also further studies that assess the primary palliative care delivered by staff nurses and primary providers in the ICU is needed. This should explore the scope of primary palliative care knowledge, skills, and attitude, and include assessment of efficacy. It would also be useful to explore the education that nurses receive for core palliative care skills. An additional area to explore is barriers and obstacles for increased integration of palliative care into the ICU. Correlational studies related to patient outcomes and access to palliative care teams, structure and format of patient care rounding practices, and primary palliative care knowledge and skills would build on this study and contribute to knowledge in the field.

Implications for Practice

For the assessment of unmet palliative care needs of ICU patients, it is important to explore how much palliative care is really needed. Responses to questions in this survey suggest that present levels of palliative care are inadequate and perhaps more comprehensive palliative care delivery is needed. However, more in depth assessment should be conducted that includes multiple perspectives from clinicians, patients and families. Other investigators have begun to assess the need for palliative care in the ICU, and findings from this study support the recommendation that need for more integrated palliative care persists (Curtis et al., 2008; Nelson, Puntillo et al., 2010; Nelson & Hope, 2012; Montagnini et al., 2012). Findings from this study suggest that the key areas of unmet patient and family needs are related to psychological and emotional distress and that having more goals of care conversations, increased family support, addressing end of life topics with patients and families, and supporting nurses with ethical concerns around withholding or withdrawal of treatments is needed.

Several areas for improvement in delivery of palliative care in the ICU have been identified. Nearly all identified palliative care area needs were reported as unmet by approximately half of the study participants, with the exception of discharge planning (this may reflect the infrequency that discharge is included in ICU standard care). Since the landmark study in 1995 (Connors et al., 1995) highlighted poor quality end of life care, a focus has been on the improvement of palliative care. Numerous papers have been written discussing why, despite prevalence of death in the ICU, the challenge remains to provide high quality care for seriously ill and dying patients (Nelson & Hope, 2010; Nelson et al., 2010; Mosenthal et al., 2012, Reinki, et al., 2008). The "rescue mission" to keep death at bay and the covenant relationship some surgeons and intensivists have with their patients to endure complications, defy odds, and maintain hope in dire circumstances, sets up a belief that inclusion of palliative care may be a failure to meet expectations, and a betrayal of promises made by clinicians to patients (Mosenthal et al., 2012; Cassell et al., 2003, Nelson, Azoulay et al., 2012).

The shift in the culture of intent for palliative care from a process exclusively for actively dying patients, to a model where palliative care is available for all patients in the ICU has been partially successful for reframing the utilization of palliative care resources (Nelson, Azoulay et al., 2012; Nelson & Hope, 2012); but some clinicians, particularly those who have not received palliative care content during training, are not ready to view palliative care as a collaborative process appropriate for ICU patients (Mosenthal et al., 2012). However, current literature recommends palliative care as a beneficial component of delivering quality care, and suggests that it should be available for all ICU patients (Nelson, Azoulay et al., 2012, Penrod et al., 2012, Dahlin et al., 2009).

Primary areas of unmet needs identified in this study were related to goals of care conversations and psychological/emotional support. Increased integration of a palliative care team member in routine patient care rounding may improve patient care in these areas. Quality assessment measures of palliative care in the ICU (Mularski et al,, 2006) included specific offerings of psychosocial and spiritual support to patients and families. Prioritizing psychosocial and spiritual needs, and incorporating them into standard ICU care may result in better patient care outcomes. While improving basic palliative care skills of primary clinicians in the ICU may eventually enhance quality of care, presently there are unmet palliative care needs, as perceived by ICU nurses. For the delivery of palliative care, these challenges need to be addressed at a system level.

Conclusion

This study sought to describe the presence and accessibility of palliative care for ICU nurses, and to evaluate palliative care patient needs and support experienced by nurses. While nurses claim to have access to palliative care, there are still many areas of improvement needed in palliative care delivery in the ICU. There is an opportunity for improvement and further integration of palliative care resource availability in the ICU. Palliative care remains on the fringe of most ICUs and is often sought only at the very end of life, or for very complex physiological or ethically challenging situations. To optimize benefits that can improve quality of life for patients and improve overall patient, family, and nurse experiences, further integration of palliative care into ICUs is needed. . Additionally, the exploration of barriers to palliative care in the ICU is needed. Further studies may focus on interventions to enhance integration of palliative care teams into the ICU, and incorporate palliative care principles (i.e., goals of care, interdisciplinary team approach, psychosocial and spiritual support) into standards of care.

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Table 1. Description of Study Participants and Facilities

(N=238)	%(N)	Mean (sd, range)
Individual		
Female	90(214)	--
Ethnicity/Race		
Hispanic*	12(29)	--
Caucasian	82(194)	--
African American	10(23)	--
Asian	6(13)	--
Other/Decline to State	3(8)	--
Age	--	38(11, 20 - 70)
Experience as RN (years)	--	12 (11, <1 - 49)
Experience in ICU (years)	--	8(9, <1 - 43)
Education Degree		
Diploma	8(19)	--
Associate	16(39)	--
BSN	62(148)	--
MSN and beyond	13(32)	--
Shift Worked		
Day shift	50(119)	--
Evening shift	6(15)	--
Night shift	23(55)	--
Mixed	21(49)	--
Hours Worked in 2 weeks	--	66(22,<1 - 120)
Facility		
Geographic Region		
West	23(39)	--
South	26(62)	--
Midwest	29(70)	--
Northeast	22(52)	--
Community/Public Hospital	79(187)	--
Academic Medical Center	33(79)	--
Teaching Non-Academic	27(65)	--
Non-Teaching Facilities	40(94)	--
Tertiary Referral Center	45(107)	--
Beds in unit (total number)	--	24(25, 1 - 180)

RN=Registered Nurse, ICU=Intensive Care Unit, BSN= Bachelor's of Science in Nursing, MSN= Master's of Science in Nursing *Question asked independently.

Table 2 – Presence of Palliative Care Practitioners in the ICU by Discipline

Palliative Care Team Member Present: Calculated Present if scored 4 or 5 1=Never , 2=Rarely, 3=Occasionally, **4=Frequently, 5= All of the time**		
N=235	**Present (n)**	**%**
Social Worker	149	63
Spiritual Care	131	56
SPC Nurse Practitioner	118	50
SPC Physician	102	43
SPC Clinical Nurse Specialist	78	33
SPS = Specialist Palliative Care		

Table 3- Triggers for Palliative Care Consult in the ICU

N=186	**N**	**%***
Futility/Goals of Care/Prognosis discussions	132	71
Pain/Symptom management	109	57
Imminently dying	102	55
Family Support/Conflict resolution	94	51
Patient/Family requests palliative care	67	36
Ethical concerns around withdrawal/withholding treatment	60	32
Psychological/Emotional distress	47	25
Discharge planning	38	20
Spiritual distress/Religious need	29	16
Cultural/Linguistic	10	5
**Participants could select any that applied, so does not equal 100%*		

Table 4 – Unmet Needs in Palliative Care Areas

Unmet Need if scored 3,4 or 5 on scale from 1-5 1=Never, 2=Rarely, **3=Sometimes (as often as not), 4=Usually, 5= Most all of the time**		
N = 234	N	%
Psychological/Emotional distress	163	70
Goals of care conversation	144	62
Family support	132	56
Other symptom management (i.e., dyspnea, thirst, fatigue, depression, etc.)	123	53
Spiritual distress/Religious needs	119	51
Cultural/Linguistic issues	118	50
Pain management	115	49
Discharge planning	95	41

Table 5 – Sufficient Support for Palliative Care Areas

Sufficient Support if scored 1, or 2 on scale 1-5 **1=Most all of the time, 2- Usually,** 3=Sometimes (as often as not), 4 = Rarely, 5=Never		
N = 234	N	%
Pain/Symptom management	177	76
Imminently dying patients	160	68
Treatment individualization	149	64
Goals of care and prognosis discussions	127	54
Communication about end of life topics with patients/families	121	52
Ethical concerns about withholding or withdrawal of treatment	110	47

Figure 2 - Concepts: Access to Palliative Care in ICU

Term	**Definition**	**Assessment Strategy**
Access to Palliative Care Team	The existence of a full palliative care team in the facility. Includes: SPC Physician, SPC Nurse, SW, Spiritual Care Practitioner.	Yes or No
Team Time Spent (of each individual SPC practitioner)	Time spent in the ICU by each member of a SPC team (Physician, NP, CNS, SW, Spiritual Care)	Rate for Frequency of time spent in ICU 1-5; 1=Never, 5=Most all of the time.
Overview of Presence	Overview of palliative care team availability, related to time spent in ICU	Calculated by at least 3 practitioner team members rated as present at least frequently or most all of the time (4 or 5 out of 5).

SPC= Specialist Palliative Care, SW= Social Worker, NP = Nurse Practitioner, CNS = Clinical Nurse Specialist,
ICU= Intensive Care Unit

Chapter 4

Abstract

Background: Numerous organizations have promoted palliative care education among practicing clinicians in an effort to improve end of life care. Given the consistently high mortality rates in intensive care units across the United States, efforts have been focused on ICU nurses. The End-of-Life Nursing Education Consortium and Center to Advance Palliative Care have provided structured educational programs that have reached thousands of nurses. However no evaluation of primary palliative care education across the U.S. population of ICU nurses has been published.

Objectives: This study sought to explore the primary palliative care education of ICU nurses, and to investigate possible relationships between palliative care education and moral distress among ICU nurses.

Methods: As part of a larger web-based national survey of ICU nurses, questions on topics and modalities of palliative care education, and two moral distress measures were assessed. Descriptive and comparative analyses were reported.

Results: The majority of participants had some education on palliative care topics in management of pain, anxiety and depression, and communication about prognosis, suffering, goals of care and code status. Consistent with previous studies, moral distress levels of participants were moderate to high. MDS and MDI were less for those who had palliative care education (i.e., pain, anxiety and depression management, and communication around prognosis, goals of care and suffering). No difference was found in MDT for any educational topic.

Conclusion: Primary palliative care education, including management of pain, anxiety and depression, communication about prognosis and goals of care conversations, may assist in strategies to improve end of life care and to decrease moral distress among ICU nurses, when other organizational strategies are taken into account. An increase in palliative care education for ICU nurses is needed.

Palliative care is an approach to patient-centered care that involves multidisciplinary collaboration to individualize and optimize patient and family experience when faced with serious illness (WHO, 2016, CAPC, 2015). Dame Cicely Saunders, named the founder of hospice and palliative medicine, initiated a movement beginning in the 1940's, to enhance end of life care, and to combine research and clinical efforts in this area (KCL, 2016). End of life care has been and continues to be provided across multiple settings including community clinics, hospitals, and private homes. This study focuses on hospital-based palliative care, which includes the intensive care unit (ICU). Hospital-based palliative care programs in the U.S. began in the 1980's (Davis, 2015). In 1995 the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) revealed a need for improved end of life care (O'Connor et al.,1995). SUPPORT findings highlighted poor communication about prognosis and treatment options in primary care and hospital-based settings, and reported a discrepancy between patient preferences and actual treatments received (O'Conner et al., 1995). As a result, palliative care was promoted as part of the strategy to improve end of life care. In 2002, the National Consensus Project for quality palliative care, an interdisciplinary group of advisors, was formed to develop guidelines for clinical practice of palliative care across all settings (Davis, 2015).

In 2009, the NCP established the Center to Advance Palliative Care (CAPC) (Davis, 2015) and due to high mortality rates in ICUs (SCCM, 2015) the CAPC created workgroups with a focus on improvement of palliative care in ICU (IPAL-ICU). CAPC offered palliative care leadership training programs for clinicians across the country (Dahlin et al., 2009; CAPC, 2015b, Grant, 2009). During the same time, the Robert Wood Johnson Foundation

(RWJF) created workgroups to develop quality measures for palliative care in the ICU (Mularski, Curtis, Billings et al. 2006). As a result of these efforts, specialist palliative care teams are increasingly included in hospitals, and ICUs, across the U.S., with 67% of hospitals with 50 or more beds having a palliative care team (CAPC, 2015a, Nelson, et al., 2010). In addition to increasing presence and awareness of specialist palliative care to provide an added layer of support for critically ill patients, agendas have included the enhancement of palliative care knowledge and skills for clinicians (Nelson, Bassett, et al., 2010, AAHPM, 2015).

Palliative Care Education

Recent discussions on improving end of life care have included an intention to educate and train clinicians to incorporate palliative care principles and approaches into standard care (Dahlin et al., 2009, AACN, 2015, Higginson et al., 2013). The inclusion of basic palliative care skills into standard care in any setting delivered by primary clinicians is referred to as primary or general palliative care (Dahlin et al., 2009). In addition, there has been a strong educational movement to improve nursing knowledge and skills in end of life care, including the American Association of Colleges of Nursing's collaborative project on End-of-Life Nursing Education Consortium (ELNEC) national initiative to improve palliative care, and the CAPC palliative care leadership training centers (AACN, 2015; Higginson, et al., 2013, Treece, et al., 2006, Shannon, Long-Sutehall, & Coombs, 2011, Puntillo & McAdam, 2006, Grant, 2009).

The American Association of Colleges of Nursing requires that baccalaureate undergraduate nursing curricula include palliative and end of life care training, stating that graduates must be able to "implement patient and family care around resolution of end-of-life and palliative care issues such as symptom management, support of rituals, and respect for patient and family preferences" (AACN, 2008, p.31). Topics of continuing education in palliative care include pain management, management of anxiety and depression, and communication skills (AACN, 2015; Davis, 2015; Puntillo & McAdam, 2006; Higginson et al., 2013; Krimshtein et al., 2011). While not an exhaustive list of palliative care skills, education in these areas may contribute to improved quality of care for critically ill patients (Mularski et al., 2009; Mularski et al., 2006, Curtis et al., 2015, Krimshtein et al., 2011, Mosenthal et al., 2012). Recent reports suggest a gap in optimally managing pain and other symptoms for ICU patients (Mularski, et al., 2009, Puntillo et al., 2014).

A recent report highlights self-perceived deficiencies in competency for delivering end of life care in the ICU, specifically related to communication, decision-making and continuity of care (Montagnini, Smith & Balistrieri, 2012). Because quality communication is an important aspect of end of life care in the ICU, in recent years, several educational interventions related to communication have been implemented. (Liaschenko et al, 2009, Higginson et al., 2013, Krimshtein, et al., 2011, Gordon et al., 2012, Curtis et al., 2015, Rushton et al., 2009, Puntillo & McAdam, 2006). Some key topics of communication particularly relevant for critically ill patients include conversations about goals of care, prognosis, suffering, and code status (Higginson et al., 2013, Puntillo & McAdams, 2006, Shannon, Long-Sutehall, & Coombs, 2011, Kirchoff, Conradt, & Anumandla, 2003). Nurses faced with unmet patient-care needs, or conflicts in how care is delivered, have reported experiencing moral distress (Corley et al., 2001, Gutierrez, 2005, Hamric & Blackhall, 2007, Hamric, Borchers & Epstein, 2012, Allen et al., 2013).

Moral Distress

Moral distress, first identified by Jameton (1984) as “a form of distress that occurs when one knows the ethically correct thing to do but is prevented from acting on that perceived obligation” (Wocial & Weaver, 2013, p.167). Moral distress is frequently associated with end of life care challenges in the ICU (Corley et al., 2001, Hamric & Blackhall, 2007, Allen et al., 2013, Wolcott, Howie-Esquival & Cataldo, 2016) Many factors are associated with moral distress, including, but not limited to: education level of the nurse, empowerment, ethical climate of the organization, collaboration and teamwork (Hamric, 2012, Browning, 2013, Allen et al., 2013, Corley et al., 2001, Hamric & Blackhall 2007, Wolcott, Howie-Esquival & Cataldo, 2016, Whitehead et al., 2015). Evidence based strategies for addressing moral distress among nurses include educational interventions (Beumer, 2008), unit level team building programs (Gordon et al., 2012), a moral distress consult service (Epstein & Delgado, 2010), and guidelines for nurses to follow during morally distressing situations (Rushton et al., 2004). A recent study found that ICU nurses who report having access to a palliative care team in their hospital actually experience higher levels of moral distress than those who do not have access to a palliative care team (Wolcott, Howie-Esquivel & Cataldo, 2016). One suggested interpretation was a lack of integration among clinicians that may reflect inadequate communication between care teams (Wolcott, Howie-Esquivel & Cataldo, 2016).

Effective communication skills are associated with improved patient care, improved patient and family satisfaction, and less conflict among clinicians (Curtis et al., 2015, Krimshtein et al., 2011, Mosenthal et al., 2012). Some key elements of communication in palliative care approaches are having conversations about prognosis, goals of care, suffering and code status (Mosenthal et al., 2012). Additional core palliative care skills, such as the management of pain, anxiety, and depression have also been identified as nursing education goals (Puntillo et al.,2014, CSI, 2015, AACN 2015). To our knowledge, at the time of this study no previous studies examining associations among moral distress of ICU nurses and primary palliative care education have been reported.

Study Aims

The purposes of this study were to: 1) Describe ICU nurses' primary palliative care education experiences (e.g., specialized workshop/class, informal discussions, readings, none) on palliative care topics (e.g., management of pain, anxiety and depression, and having conversations about prognosis, goals of care, suffering, or code status); 2) Investigate associations among nurses' education in primary palliative care topics and a.) overall cumulative levels of moral distress; and b) moral distress frequency and intensity scores; and c) current levels of moral distress. Study hypothesis is that more primary palliative care education will be associated with lower levels of moral distress related to end of life care.

Methods

This study was part of a larger study reported in detail elsewhere (Wolcott, Howie-Esquivel & Cataldo, 2016). This was a cross-sectional study with a web-based survey of ICU nurses from across the U.S., accessed through the AACN's e-newsletter and social media sites. The study obtained IRB approval through the University of California, San Francisco, and informed consent was embedded in the survey. A total of 238 ICU nurses completed the larger survey and due to missing data, the sample size for analyses was 230-235.

Measurement

As part of a larger palliative care assessment questionnaire, one section of questions addressed the nurse's education received on primary palliative care topics (i.e., management of pain, anxiety and depression, having conversations about prognosis, goals of care, suffering, or code status). For each palliative care topic, participants were queried about palliative care education delivery modes (i.e., specialized workshop/class, informal discussion, readings, or none). They could select any modality that applied for each topic. Given that participants could select multiple options for educational topics, variables for analysis were created to reflect any mode of education compared to no education on each topic.

Moral Distress was measured with the Moral Distress Scale-Revised (MDS-R) and the Moral Distress Thermometer (MDT). The MDS-R (Hamric & Borchers, 2012), yields a total moral distress score, with sub-scale scores of moral distress frequency (MDF) and moral distress intensity (MDI). The instrument contains 21 items that are scored from 0-4 for frequency and for intensity, with higher numbers reflecting higher levels of distress. A total moral distress score is calculated by the multiplication of frequency times intensity for each item and summed up for a possible MDS-R total score to range 0-336. Moral Distress frequency and intensity scores are summed for each item, yielding a possible range of 0-84 for each sub-scale. This instrument reflects a cumulative experience of moral distress (Hamric, Borchers & Epstein, 2012). The Moral Distress Thermometer (MDT) was developed to assess a current level of moral distress in the clinical setting (Wocial & Weaver, 2013). This instrument is a single item, visual analog scale asking participants to reflect on levels of moral distress experienced within the past week and rate levels of distress between 0-10, with zero being no distress and 10 being a very high level of distress. Validity was previously established for use in this population (Wocial & Weaver, 2013).

Analysis

Descriptive statistics were explored for primary demographics, educational topics and moral distress. Analyses included t-tests to assess difference in mean scores of the overall moral distress scale-revised (MDS-R), moral distress frequency (MDF), and moral distress intensity (MDI); each educational topic was rated for each modality, then calculated none vs some for each topic (Tables 2-4). Participants who had selected both none and another modality of education were excluded from subsequent analyses, and this is reflected in the total sample size difference between the overall descriptive statistics reported and the reported t-test analyses. However, all responses were left in the overall report as they may contribute to the discussion of study findings. Confidence intervals, at a 95% level, were included to reflect the range of possible differences in mean moral distress scores for each educational topic.

Results

Demographics

As shown in Table 1, the sample was primarily female ICU nurses, Caucasian, with a Bachelors degree, and dispersed almost evenly across four geographic regions in a wide variety of ICU settings, and with a mean of 12 years of nursing experience (range <1 – 49) and mean of 8 years of ICU experience (range <1 – 43). Descriptions of facilities include a range of hospitals that are community/public or private, and organizations that are academic medical centers, teaching non-academic centers or non-teaching facilities. Additionally, nearly half of the facilities are tertiary referral centers (Table 1).

Primary Palliative Care Education

The majority of participants reported receiving some education on all primary palliative care topics (Table 2). Categories for different educational modalities included specialized workshop or class, informal discussions, readings, or none. Education topics included management of pain, anxiety and depression, and having conversations about: prognosis, goals of care, suffering, and code status. As shown in Table 2, over 20% of participants reported no education on topics of anxiety/depression, prognosis, goals of care, and suffering. In addition, no education on conversations about code status was reported by 18% of the participants. Most participants (92%) reported receiving some form of additional education on pain management.

Moral Distress and Education

Results for moral distress yielded an overall MDS-R mean of 96.5(SD=55.8), MDF mean of 32.5 (SD=15.3), MDI mean of 53.1(SD=20.6), and MDT mean of 3.52(SD=2.5). For each t-test conducted, Levine tests were assessed, and equal variance was not assumed for any of these analyses. Results for t-tests, as shown in Table 3, revealed that participants who reported having some form of education in topics related to management of pain, anxiety and depression, and communication around prognosis, goals of care and suffering all had less overall moral distress than those who reported no education on these topics. Only those who reported education on the topic of communicating about code status failed to show a significant change in moral distress scores compared to those who had not received education on this topic. Mean MDS scores were 19-26 points lower for those receiving education on these topics, compared to those who did not receive education on these topics (Table 3). Those who received education on conversations about goals of care revealed the greatest difference in MDS levels, with at least 12.9 points less and up to 40.3 points less moral distress for those reporting education on this topic, as compared to those with no education on this topic (Table 3).

Analysis of MDF did not reveal any significant differences for participants who reported some education in any of the topics as compared to those who reported no education. However, when evaluating levels of MDI, participants had 10-13 points lower mean MDI scores related to reported education for all listed topics, except conversations about code status, as compared to those with no education reported. (Table 4). Those who received education on conversations about prognosis had the greatest difference, with at least 8.9 points less on the MDI and as much as18.6 points less than those with no education on this topic (Table 4). Also, those reporting education on anxiety and depression management had at least 6.9 points less on the MDI and as much as 17.3 points less than those with no education on this topic (Table 4). The MDT scores were not significantly different for those who received education on any topic as compared to those who received no education on these topics.

Discussion

Novel findings in this study include descriptions of primary palliative care education received by ICU nurses, and associations between education topics (i.e., management of pain, anxiety and depression, having conversations about prognosis, goals of care, suffering, or code status) and experiences of ICU nurse moral distress. Associations were found for both total moral distress levels and intensity of moral distress related to education topics (i.e. management of pain, anxiety and depression, having conversations about prognosis, goals of care, suffering). No associations were found between frequency of moral distress or the moral distress thermometer scores and any education topic.

Descriptions of Primary Palliative Care Education

Almost 80% of the study participants reported having some type of education for most primary palliative care topics (i.e. management of pain, anxiety and depression, having conversations about prognosis, goals of care, suffering, and code status). Type of education included workshop/class, informal discussions, and readings. If educational experiences were thought to be inadequate they may have been reported as “no education” on the topic. Of nurses who voluntarily self-selected to participate in this study, many (8-28%) reported no education on palliative care topics included in the survey. According to ELNEC and CAPC reports, approximately 0.2% of critical nurses in the U.S. (1,115 critical care nurses, ELNEC; 1,005 nurses, CAPC) have completed critical-care –focused end-of-life or palliative care trainings (Grant, 2009, SCCM 2015, ELNEC 2015). These published reports only include formal workshop training offered by CAPC and ELNEC and do not include individual classes offered locally for nurses. Findings in this study about continuing primary palliative care education may be indicative of the active agendas of various organizations to increase primary palliative care knowledge and skills for bedside nurses (e.g., CAPC, RWJF, AACN). Findings in this study include a variety of types of education on palliative care topics that a nurse may have received, and shouldn’t be directly compared to published statistics from ELNEC or CAPC. However, all currently available data indicate a need for further education. While many nurses in this study did report receiving education on palliative care topics, a need for an emphasis on palliative care education continues.

Levels of Moral Distress and Education Topics

Total Moral Distress and Education Topics. Overall moral distress levels reported in this study are similar or higher when compared to several recent published studies focused in individual facilities or regionalized organizations. (Hamric, Borchers, Epstein, 2012, Allen et al., 2013, Leggett et al., 2013, OConnell, 2014). Findings in this study support the hypothesis that having some education in primary palliative care topics (management of pain, anxiety and depression, having conversations about prognosis, goals of care, suffering) is associated with lower levels of moral distress. Overall moral distress levels were consistently lower for those who had palliative care education as compared to those who reported having had no education; in particular, those whose education focused on communicating about goals of care. These findings are in contrast to the findings of recent studies that reported continuing education in pain management and end-of-life care were associated with higher levels of moral distress overall and higher frequency of moral distress among healthcare team members (Browning, 2013, Whitehead et al., 2015). An explanation for these findings is not clear, however, we do know that no single factor independent of environment is consistently responsible for moral distress levels (Corley, 2001, Hamric 2012, Hamric, Borchers & Epstein, 2012). Unfortunately, previous reports on education and moral distress levels (Browning, 2013; Whitehead et al., 2015) did not specify what was included in end of life continuing education. Perhaps there is a meaningful distinction between the primary palliative care education described here, and the end of life care continuing education reported in previous studies. Moral distress theory (Corley, 2001) does suggest that increasing knowledge about alternative treatment options and improved communication skills, could be achieved through palliative care education and may contribute to lower moral distress levels. Thus, if the nurse is not also faced with environmental obstacles to deliver an enhanced version of end of life care, as is suggested by Whitehead and colleagues (2015), moral distress may be diminished with increased palliative care knowledge and skill.

The findings from this study are consistent with previous reports that moral distress is related to whether there is effective communication among team members around end of life care planning (Hamric, Borchers & Epstein, 2012, Whitehead et al., 2015). This study also supports previous findings that when nurses consistently offer meaningful and valued input in the process of goals clarification and individualization of patient care they experience less moral distress (Hamric & Blackhall, 2007). The possibility exists that increased exposure to nursing palliative care education may contribute to increased interdisciplinary collaboration in the ICU. Studies are needed to explore if nurses who receive palliative care education engage more frequently with ICU team members.

Another key education topic associated with less moral distress for nurses, was management of anxiety and depression. This supports previous findings from a palliative care assessment survey that reported psychological and emotional needs of patients were frequently unmet (Wolcott, Howie-Esquivel & Cataldo, 2016b). In addition, previous studies of moral distress report that patient care is compromised when nurses avoid morally distressing situations (Hamric, Borchers, Epstein, 2012, Gutierrez, 2005). Nurses in this current study, who reported having been exposed to more education on the management of palliative care challenges (i.e., management of pain, anxiety and depression, goals of care conversations), reported less moral distress,. Although not directly assessed in this study, less moral distress, is known to be associated with improved patient care.

No significant association was found between moral distress and communication about code status. This may be a reflection of a possible belief by nurses that having conversations about code status isn't included in their perceived obligation of patient care to provide. On the other hand, this finding may reflect that nurses who have developed skills in having code status conversations outside of education modalities named in this study aren't significantly different from those who reported having received specific education on the topic.

Moral Distress Frequency and Intensity and Education Topics. No education topic in this study was found to be associated with frequency of moral distress, yet most education topics were associated with less moral distress intensity. This suggests that while overall moral distress is influenced by environmental factors (Hamric,Borchers & Epstein, 2012; Wolcott, Howie-Esquivel & Cataldo, 2016; Hamric & Blackhall, 2007), primary palliative care education may not change the frequency of exposure to morally distressing experiences for nurses. Education may contribute to decreased moral distress intensity experienced in end of life situations. Previously identified factors that contribute to moral distress include situations where the nurse does not understand the whole picture, and nurses' lack of knowledge of alternate treatment options (Hamric, Borchers & Epstein, 2012). Further research is needed to explore the role of primary palliative care education as a strategy to address moral distress factors.

Moral Distress Thermometer and Education Topics. In this study, no association was found between primary palliative care education and current levels of moral distress as measured by MDT scores. In consideration of findings related to the MDS-R and MDI associations, this MDT finding suggests that palliative care education may not directly affect a single experience, but may enhance a nurse's foundational ability to more consistently resolve moral distress situations throughout one's career. The MDT is a time-specific measure of current moral distress levels, in comparison to the MDS-R which includes a cumulative level of distress (Wocial & Weaver, 2013). These study findings support this distinction and suggest that palliative care education may help to address moral residue, which is the lingering feelings of distress that accumulate over time (Epstein and Hamric, 2009).

Strengths and Limitations

An inherent limitation in a cross-sectional survey is that causative associations can not be established. In addition, online surveys may limit selection to participants who can access the internet. Nurses who self-selected to participate in this study may have more interest, knowledge, or experience with palliative care than the general population of ICU nurses. This bias may lead to an elevated level of reported educational experiences. However, a strength of this study is that an anonymous online survey may encourage more honest responses about work environment and sensitive topics. Strengths of this study also include the broad representation of geographical regions and varied work environments in the sample of ICU nurses. Novel findings include a direct evaluation of moral distress levels in relationship to education on primary palliative care topics, and an overview of primary palliative care education currently reported by ICU nurses. However, it is noted that most studies on moral distress report significant contributions of organizational and environmental factors that were not in the scope of this study (Corley et al., 2001, Hamric &

Blackhall 2007, Hamric, Borchers & Epstein 2012, Whitehead et al., 2015, Wolcott, Howie-Esquivel & Cataldo, 2016), . Findings from this study should be viewed as one piece of a much larger complex picture of moral distress of ICU nurses.

Recommendations for Practice and Future Research

Primary palliative care education can improve end of life care delivery experienced by nurses and in turn may improve quality of patient care. The findings from this study support the need for continuation of current agendas to improve palliative care education for ICU nurses. In order to give insight into the effectiveness of educational and institutional strategies to provide improved end-of-life care, future research needs to focus on changes in moral distress over time and situations using longitudinal and qualitative designs. In addition, further assessment of nursing knowledge, skills and attitudes in areas of palliative care in the ICU with specific patient outcome data would allow for evaluation of effectiveness of training reflected in patient care.

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Table 1: Description of Participants and Facilities

Demographics (N=238)	%(N)	Mean (sd,range)
Individual		
Female	90(214)	--
Ethnicity/Race		
Caucasian	82(194)	--
African American	10(23)	--
Asian	6(13)	--
Other/Decline to State	3(8)	--
		--
Age	--	38(11, 20 - 70)
Years Experience as RN	--	12 (11, <1 - 49)
Years Experience in ICU	--	8(9, <1 - 43)
Education Degree		
Diploma	8(19)	--
Associates	16(39)	--
BSN	62(148)	--
MSN and beyond	13(32)	--
Shift Worked		
Dayshift	50(119)	--
Evenings	6(15)	--
Night	23(55)	--
Mixed	21(49)	--
Hours Worked in 2 weeks	--	66(22, <1 - 120)
Facility		
Geographic Region		
West	23(39)	--
South	26(62)	--
Midwest	29(70)	--
Northeast	22(52)	--
Community/Public Hospital	79(187)	--
Academic Medical Center	33(79)	--
Teaching Non-Academic	27(65)	--
Non-Teaching Facilities	40(94)	--
Tertiary Referral Center	45(107)	--
# Beds in the unit	--	24(25, 1 - 180)

RN, Registered Nurse; ICU, Intensive Care Unit; BSN, Bachelor's of Science in Nursing; MSN, Master's of Science in Nursing.
sd, Standard Deviation.

Table 2: Education of ICU Nurses for Palliative Care Topics

N=235	Reported n(%) *Participants could select multiple modalities*			
Modality Education Topic	Specialized Workshop/Class	Informal Discussion	Readings	None
Pain Management	102(43)	109 (46)	132(56)	19(8)
Management of Anxiety and Depression	58(25)	87(37)	113(48)	50(21)
Having Conversations about:				
Prognosis	52(22)	89(38)	93(40)	63(27)
Goals of Care	62(26)	110(47)	93(40)	54(23)
Suffering	58(25)	84(36)	94(40)	65(28)
Code Status	63(27)	117(50)	95(40)	41(17)
ICU= Intensive Care Unit.				

Table 3: T-tests for Palliative Care Education Topics and MDS-R Scores

Some Education as compared to None: (N=231)	Mean (sd) MDS-R	T (df), p-value	Mean Difference in MDS-R	95% CI
Pain Management (213)	94.6(57.6)	-2.3(24.7), 0.03*	-21.8*	-2.3, -41.2*
Anxiety/Depression Management (183)	91.3(58.9)	-3.4(111.0), 0.001*	-23.9*	-9.8,-37.9*
Conversations about:				
Prognosis (169)	90.6(59.7)	-3.0(157.4), 0.003*	-21.2*	-7.5, -35.0*
Goals of Care(178)	90.2(59.0)	-3.8(129.4),<0.001*	-26.6*	-12.9, -40.3*
Suffering(167)	90.9(60.3)	-2.8(170.7), 0.005*	-19.4*	-5.8, -32.9*
Code status(191)	94.7(59.8)	-1.4(105), 0.169	NS	NS
*P-values <0.05 considered significant. *Significant. NS= Not significant. sd= Standard Deviation. df = Degrees of freedom. CI=Confidence interval. MDS-R= Moral Distress Scale-Revised (Total).*				

Table 4: T-tests for Palliative Care Education Topics and MDI Subscale Scores

Some Education as compared to None: (N=230)	Mean (sd) MDI	T (df), p-value	Mean Difference in MDI	95% CI
Pain Management(212)	52.2(21.1)	-3.1(25.1), 0.005*	-10.5*	-3.4, -17.6*
Anxiety/Depression Management(182)	50.5(21.4)	-4.6(107.0),<0.001*	-12.1*	-6.9, -17.3*
Conversations about:				
Prognosis(168)	49.3(21.5)	-5.6(164.4),<0.001*	-13.8*	-8.9, -18.6*
Goals of Care(177)	50.4(21.8)	-4.8(139.5),<0.001*	-11.1*	-6.2, -16.0*
Suffering(166)	50.1(22.0)	-4.2(172.4),<0.001*	-10.6*	-5.6, -15.5*
Code status(190)	52.1(21.8)	-1.89(84.9), 0.062	NS	NS
*P-values <0.05 considered significant. *Significant. NS= Not significant. sd= Standard deviation. df = Degrees of freedom. CI=Confidence interval. MDI= Moral Distress Intensity Subscale.*				

Chapter 5

The purpose of this study was to 1) explore relationships among moral distress, organizational ethical climate, nurse empowerment, and access to palliative care, 2) to describe delivery of palliative care in the ICU, and 3) to assess primary palliative care education received by ICU nurses, and identify relationships between palliative care education and moral distress. This is the first study to explore a relationship between having access to palliative care and moral distress among ICU nurses. The major findings of this study include: negative correlations between the Moral Distress Scale-Revised (MDS-R) and the Hospital Ethical Climate Scale (HECS), between MDS-R, Moral Distress Intensity (MDI) and primary palliative care education; a positive correlation between MDS-R and access to palliative care; and a curvilinear relationship between MDS-R and empowerment (PEI). Additionally, a description of palliative care delivery in ICU and a needs assessment revealed opportunities for improvement that included: goals of care conversations between patients/families and clinicians, and psychological/emotional support for patients and family.

Discussion of Results

Moral Distress of ICU Nurses, Empowerment, Ethical Climate and Access to Palliative Care

This study found significant relationships between moral distress (MDS-R) and empowerment (PEI), MDS-R and ethical climate (HECS), and between MDS-R and palliative care access. Palliative care access did not influence the relationships between MDS-R and PEI, or between MDS-R and HECS. A curvilinear relationship was found between PEI and MDS-R, with those nurses who scored very high and very low on empowerment having lower moral distress scores. Those with higher (more positive) workplace ethical climate (HECS) had lower MDS-R scores. And those who reported having access to a full palliative care team scored higher on the MDS-R. A regression analysis showed ethical climate as the most significant predictor of moral distress, with other contributing factors identified as: number of beds in unit, access to full palliative care team, and nurse demographics of race, and educational degree. Empowerment, while individually correlated with MDS-R, did not offer a unique significant contribution to MDS-R in the presence of the other variables in the multiple regression model.

Intensive Care Unit Nurses' Perspective of Access and Utilization of Palliative Care: A Descriptive Study

Palliative care delivery in the ICU was assessed with descriptive measures. Beyond reporting on access to a palliative care team, this study evaluated the presence of specialist palliative care practitioners in the unit, described the consult process of delivering specialist palliative care to ICU patients, and assessed patient care needs for palliative care. Palliative care practitioners were reported present 30-63% of the time, with social workers reported most frequently present in the ICU, and nurse practitioners, physicians, and clinical nurse specialists were reported present in the ICU by less than half of participants. The majority of nurses in the study were not able to directly request a consult for palliative care. However, they reported that consults did occur the majority of the time if primary physicians were asked for a consult order. The most common reasons for triggering a palliative care consult were: situations of futility/goals of care conversations/prognosis discussions, pain/symptom management, and imminently dying patients.

Palliative care needs assessment revealed several opportunities for improvement, with psychological and emotional support for patients and families, and having goals of care conversations as top ranking unmet needs. Only 25% of participants named psychological/emotional distress as a reason for calling a palliative care consult. This marks a need for further education about palliative care utilization in the ICU.

Primary Palliative Care Education Among ICU Nurses

Findings from aim one showed that ethical climate was the most significant predictor of moral distress of ICU nurses, and nurse empowerment was meaningful, yet not independent of climate. This aim described what types of education nurses have received on palliative care topics, and explored how having had some education correlated with nurses' experience of moral distress. The majority of nurses reported receiving some education in the palliative care topics of: management of pain, anxiety and depression, and communication about prognosis, goals of care, suffering, and code status. Additionally, those who reported receiving some education in each of these areas (except communicating about code status) scored lower on overall moral distress (MDS-R) and moral distress intensity (MDI). There was no difference in MDS-R or MDI scores for those who reported education about code status. There was also no difference in MDT scores related to education received on any topic. This supports the proposition that education alone does not affect an isolated incident of moral distress, but may assist the nurse in managing morally distressing situations over time.

Limitations

Cross-sectional studies have inherent limitations in that causality or evaluating change over time cannot be determined. In addition, a web-based study may introduce bias by limiting participation to only those with internet access. Additionally, because this study surveyed ICU nurses who did not have access to organization or patient outcome data, direct evaluation of organizational factors and patient care outcomes was not possible.

Strengths

Broad geographical representation allowed for evaluation of nationwide palliative care delivery and experiences of moral distress outside of a specific organization. The web-based survey format allowed for anonymity that may have enhanced participants' willingness to report sensitive information about workplace environment and patient care provided. This is the first study to provide a comprehensive description and analysis of factors related to palliative care delivery in ICU across the U.S., and evaluates factors contributing to moral distress.

Implications for Nursing

Nursing education currently includes some minimal components of end of life care, but the newest recommendations call for more comprehensive and standardized nursing education in palliative care (AACN, 2016). Primary palliative care education and skill-building are recommended for nurses both pre-licensure and at the clinical practice level. Organizations are encouraged to promote team-building, collaborative and ethically supportive environments, and work to integrate palliative care teams into the ICU setting. This will enhance patient care, and contribute to health of nurses.

Summary

In conclusion, nurses continue to experience moral distress related to end of life care in the ICU, as has been reported for decades. Organization ethical climate is a significant contributor to moral distress, and additional significant factors are individual nurse knowledge and empowerment. Palliative care has previously been shown to improve patient care in ICU settings, yet remains inconsistently available. This study supports the goal of increasing availability of palliative care in the ICU, and developing a standard for how this palliative care is delivered. Well-integrated palliative care teams are better equipped to meet the needs of patients, and can contribute to positive communication among clinicians and a decrease in moral distress of ICU nurses. Recommendations include further work toward educating clinicians about palliative care, implementing standard palliative care procedures for ICU patients, and incorporating team-building approaches for all ICU teams. Future research should focus on evaluating moral distress over time in longitudinal and qualitative studies, and assessment of educational and team-building strategies for improving collaboration and integration of palliative care into ICUs.

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Appendix A

MDS-R
Nurse Questionnaire (ADULT)

Moral distress occurs when professionals cannot carry out what they believe to be ethically appropriate actions because of internal or external constraints. The following situations occur in clinical practice. If you have experienced these situations they may or may not have been morally distressing to you. Please indicate how frequently you experience each item described and how disturbing the experience is for you. If you have never experienced a particular situation, select "0" (never) for frequency. Even if you have not experienced a situation, please indicate how disturbed you would be if it occurred in your practice. Note that you will respond to each item by checking the appropriate column for two dimensions: *Frequency* and *Level of Disturbance*.

	Frequency					Level of Disturbance				
	Never				Very frequently	None				Great extent
	0	1	2	3	4	0	1	2	3	4
1. Provide less than optimal care due to pressures from administrators or insurers to reduce costs.										
2. Witness healthcare providers giving "false hope" to a patient or family.										
3. Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient.										
4. Initiate extensive life-saving actions when I think they only prolong death.										
5. Follow the family's request not to discuss death with a dying patient who asks about dying.										
6. Carry out the physician's orders for what I consider to be unnecessary tests and treatments.										
7. Continue to participate in care for a hopelessly ill person who is being sustained on a ventilator, when no one will make a decision to withdraw support.										
8. Avoid taking action when I learn that a physician or nurse colleague has made a medical error and does not report it.										
9. Assist a physician who, in my opinion, is providing incompetent care.										
10. Be required to care for patients I don't feel qualified to care for.										
11. Witness medical students perform painful procedures on patients solely to increase their skill.										

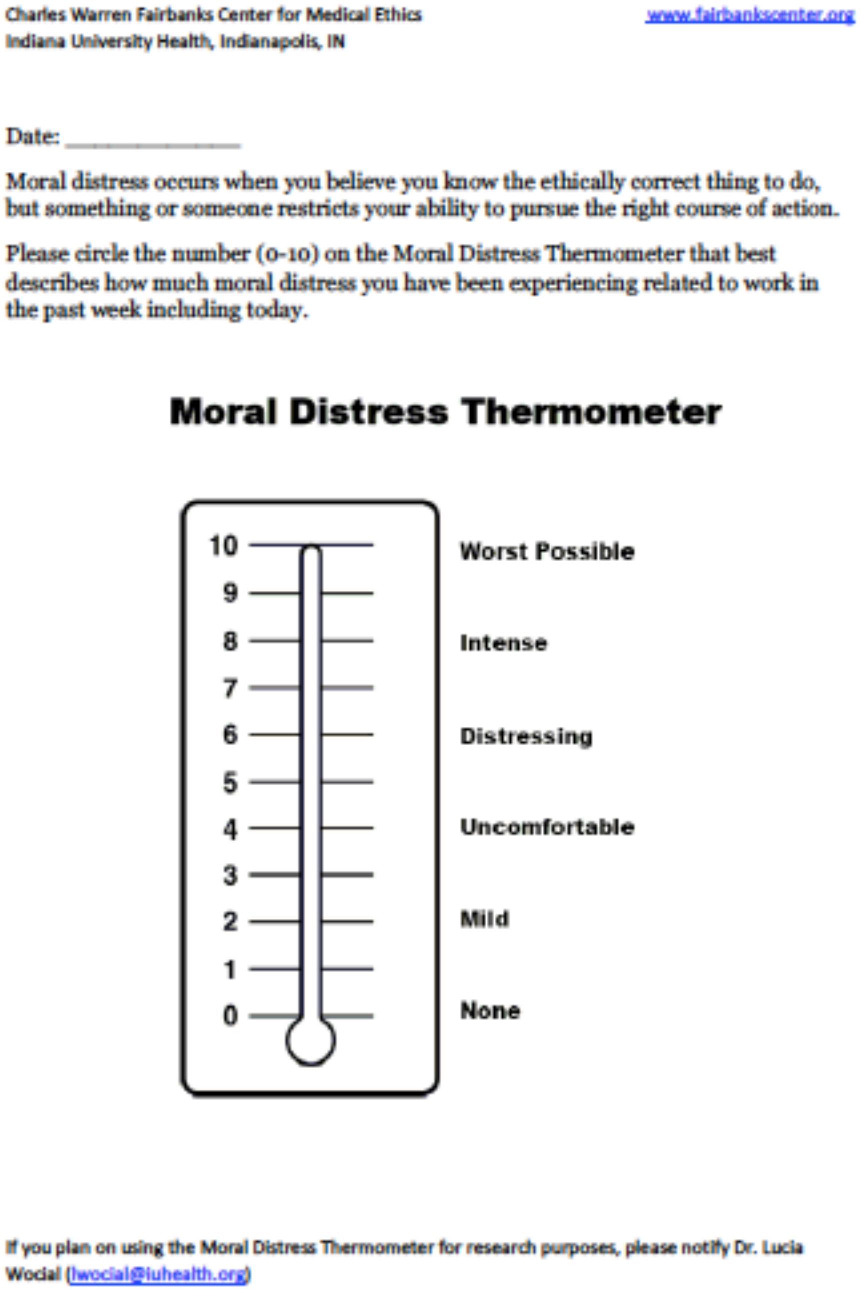
(MDS-R Page 2)	Frequency					Level of Disturbance				
	Never				Very frequently	None				Great extent
	0	1	2	3	4	0	1	2	3	4
12. Provide care that does not relieve the patient's suffering because the physician fears that increasing the dose of pain medication will cause death.										
13. Follow the physician's request not to discuss the patient's prognosis with the patient or family.										
14. Increase the dose of sedatives/opiates for an unconscious patient that I believe could hasten the patient's death.										
15. Take no action about an observed ethical issue because the involved staff member or someone in a position of authority requested that I do nothing.										
16. Follow the family's wishes for the patient's care when I do not agree with them, but do so because of fears of a lawsuit.										
17. Work with nurses or other healthcare providers who are not as competent as the patient care requires.										
18. Witness diminished patient care quality due to poor team communication.										
19. Ignore situations in which patients have not been given adequate information to insure informed consent.										
20. Watch patient care suffer because of a lack of provider continuity.										
21. Work with levels of nurse or other care provider staffing that I consider unsafe.										
If there are other situations in which you have felt moral distress, please write them and score them here:										

Have you ever left or considered quitting a clinical position because of your moral distress with the way patient care was handled at your institution?

No, I've never considered quitting or left a position _____
Yes, I considered quitting but did not leave _____
Yes, I left a position _____

Are you considering leaving your position now? Yes No

Moral Distress Thermometer



Charles Warren Fairbanks Center for Medical Ethics
Indiana University Health, Indianapolis, IN

www.fairbankscenter.org

Date: ______________

Moral distress occurs when you believe you know the ethically correct thing to do, but something or someone restricts your ability to pursue the right course of action.

Please circle the number (0-10) on the Moral Distress Thermometer that best describes how much moral distress you have been experiencing related to work in the past week including today.

Moral Distress Thermometer

If you plan on using the Moral Distress Thermometer for research purposes, please notify Dr. Lucia Wocial (lwocial@iuhealth.org)

Hospital Ethical Climate Survey (Part A)

Directions: Here is a series of statements relating to various practices within your work setting. Please respond in terms of how it is in your current job on your current unit. As you read and respond to each statement, think of some difficult patient care issues you have faced. For those items that refer to your manager, think of your immediate manager (nurse manager, assistant nurse manager, shift supervisor). It is important that you respond in terms of how it really is on your unit, not how you would prefer it to be. It is essential to answer every item. There are no right or wrong answers, so please respond honestly. Remember, all your responses will remain anonymous.

Please read each of the following statements. Then, select one of the numbers on each line to indicate your response.

		Almost Never True	Seldom True	Sometimes True	Often True	Almost Always True
1.	My peers listen to my concerns about patient care	1	2	3	4	5
2.	Patients know what to expect from their care	1	2	3	4	5
3.	When I'm unable to decide what's right or wrong in a patient care situation, my manager helps me	1	2	3	4	5
4.	Hospital policies help me with difficult patient care issues/problems	1	2	3	4	5
5.	Nurses and physicians trust one another	1	2	3	4	5
6.	Nurses have access to the information necessary to solve a patient care issue/problem	1	2	3	4	5
7.	My manager supports me in my decisions about patient care	1	2	3	4	5
8.	A clear sense of the hospital's mission is shared with nurses	1	2	3	4	5
9.	Physicians ask nurses for their opinions about treatment decisions	1	2	3	4	5
10.	My peers help me with difficult patient care issues/problems	1	2	3	4	5
11.	Nurses use the information necessary to solve a patient care issue/problem	1	2	3	4	5
12.	My manager listens to me talk about patient care issues/problems	1	2	3	4	5
13.	The feelings and values of all parties involved in a patient care issue/problem are taken into account when choosing a course of actions	1	2	3	4	5
14.	I participate in treatment decisions for my patients	1	2	3	4	5

15.	My manager is someone I can trust	1	2	3	4	5
16.	Conflict is openly dealt with, not avoided	1	2	3	4	5
17.	Nurses and physicians here respect each others' opinions, even when they disagree about what is best for patients	1	2	3	4	5
18.	I work with competent colleagues	1	2	3	4	5
19.	The patient's wishes are respected	1	2	3	4	5
20.	When my peers are unable to decide what's right or wrong in a particular patient care situation, I have observed that my manager helps them	1	2	3	4	5
21.	There is a sense of questioning, learning, and seeking creative responses to patient care problems	1	2	3	4	5
22.	Nurses and physicians respect one another	1	2	3	4	5
23.	Safe patient care is given on my unit	1	2	3	4	5
24.	My manager is someone I respect	1	2	3	4	5
25.	I am able to practice nursing on my unit as I believe it should be practiced	1	2	3	4	5
26.	Nurses are supported and respected in this hospital	1	2	3	4	5

Psychological Empowerment Instrument

Listed below are a number of self-orientations that people may have with regard to their work role. Using the following scale, please indicate the extent to which you agree or disagree that each one describes your self-orientation.

A. Very Strongly Disagree
B. Strongly Disagree
C. Disagree
D. Neutral
E. Agree
F. Strongly Agree
G. Very Strongly Agree

____ I am confident about my ability to do my job.
____ The work that I do is important to me.
____ I have significant autonomy in determining how I do my job.
____ My impact on what happens in my department is large. impact
____ My job activities are personally meaningful to me.
____ I have a great deal of control over what happens in my department. impact
____ I can decide on my own how to go about doing my own work.
____ I have considerable opportunity for independence and freedom in how I do my job.
____ I have mastered the skills necessary for my job.
____ The work I do is meaningful to me.
____ I have significant influence over what happens in my department.
____ I am self-assured about my capabilities to perform my work activities.

The scale is composed of 4 subdimensions: meaning, competence, self-determination, and impact. You may use the subdimensions on their own or take the mean of the 4 subdimensions to create an overall empowerment score. The validation of the instrument is described in Spreitzer (1995; 1996). The instrument has been used successfully in more than 50 different studies in contexts ranging from nurses to low wage service workers to manufacturing workers.

The validity of the instrument is very good. Test retest-reliability has been shown to be strong and validity estimates for the dimensions are typically around .80. More information on the empowerment profiles for different contexts and norm data for the empowerment dimensions can be found in Spreitzer and Quinn (2001).

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Translated into Chinese by JWS-Hong Kong. Translated into Dutch by Thema B.V.

Palliative Care Questionnaire
Access, Utilization and Barriers

ACCESS to Palliative Care Services

1. Do you have access to a full interdisciplinary palliative care team (Palliative care physician, Nurse, Social Worker, Spiritual Care Practitioner)? Y/N/IDK

2. Do you have access to the following in your ICU?	Never	Rarely	Occasionally	Frequently	Always	I Don't Know
a. Palliative Care Physician						
b. Palliative Care Nurse Practitioner						
c. Palliative Care Clinical Nurse Specialist						
d. Social Worker						
e. Spiritual Care Practitioner						

3. Does your unit conduct routine (daily or nearly daily) interdisciplinary patient rounds? Y/N/IDK
    a. If Yes, Does this include a member of the palliative care team? Y/N/IDK
    b. If Yes, Does this include the bedside nurse? Y/N/IDK
4. Are you, as a bedside nurse, able to request a palliative care consult (as opposed to needing a physician's order)? Y/N/IDK
5. Do physicians in your unit initiate a referral to palliative care when a nurse recommends it? Y/N/IDK
6. Have you had a patient in the past 6 months that you felt would benefit from palliative care, but did not receive it?
7. Have you made a palliative care referral (either requested directly, or requested through a physician) in the past 6 months? Y/N/IDK
8. If Yes, What triggered you to request palliative care? (Check all that apply)
    - ○ Pain/Symptom management
    - ○ Futility of active treatment/Goals of care discussions/Difficult conversations
    - ○ Spiritual/Emotional distress
    - ○ Discharge Planning
    - ○ Imminently dying patient
    - ○ Cultural/Linguistic Concerns
    - ○ Ethical concerns around withholding/withdrawing treatment
    - ○ Family Support/Conflict Resolution
    - ○ Patient/Family request for palliative care.
    - ○ Other, please describe:

9. Is the bedside nurse consistently included in family care conferences? Y/N/IDK

UTILIZATION of Palliative Care Services

10. In your unit, does any patient or family with palliative care needs not receive palliative care? Y/N/IDK

Rate how often your patients' needs are <u>unmet</u> for the following:	1: Most all of the time	2: Usually	3: As often as not. (Sometimes)	4: Rarely	5: Never
11. Pain management					
12. Other symptom management (dyspnea, thirst, fatigue, depression, etc.)					
13. Goals of care conversations					
14. Spiritual/Emotional distress					
15. Cultural/Linguistic issues					
16. Family support					
17. Discharge planning					
Rate how often you feel you have <u>sufficient</u> support for the following:					
18. Goals of care and prognosis discussions, treatment individualization					
19. Symptom/pain management					
20. Imminently dying patients					
21. Family support/conflict resolution					
22. Ethical concerns about withholding or withdrawing treatments					
23. Communication about end of life topics with patients/families					

EDUCATION/Training in Palliative Care Skills

Indicate any training/education you have received in any of the following?	Specialized Workshop/Class	Informal Discussion	Readings	None
24. Pain management				
25. Management of anxiety and depression				
26. Having conversations about:				
Prognosis				
Goals of care				
Suffering				
Code Status				

27. Do you work with ICU staff nurses who are knowledgeable or skilled in palliative care who can serve as a resource for you?

BARRIERS

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
28. Please rate your experience with the following potential barriers to accessing or utilizing palliative care:					
a. I'm unsure of my role in discussing prognosis, goals of care and palliative care					
b. I need more training in how to discuss prognosis, goals of care and palliative care					
c. I don't feel physicians support my involvement in discussions					
d. Physicians don't ask for my perspective on prognosis, goals of care and palliative care					
e. I don't have time for bedside discussions on prognosis, goals of care and palliative care					
f. I don't have time to attend family meetings					
g. It is hard to get coverage for my patients so I can attend family meetings					
h. My managers don't support my involvement					
i. I don't know when or where family meetings are occurring					
j. I'm not invited to family meetings					
k. Engaging in these discussions is emotionally draining					
l. I don't believe that palliative care is beneficial for my patients					
m. Families have negative reactions to palliative care					
n. Physicians have negative reactions to palliative care					
o. I don't know how to contact palliative care clinicians					
p. I don't know what palliative care resources are available					

Please describe any other factors that you feel limit your access to, or utilization of palliative care resources.

Appendix B

UCSF
University of California
San Francisco

Human Research Protection Program
Committee on Human Research

Notification of Expedited Review Approval

Principal Investigator	*Co-Principal Investigator*
Jill Howie Esquivel	

Type of Submission: Modification Form
Study Title: PALLIATIVE CARE IN THE ICU AND MORAL DISTRESS OF NURSES

IRB #: 14-15390
Reference #: 132228

Committee of Record: Laurel Heights Panel

Study Risk Assignment: Minimal

Approval Date: 03/06/2015 **Expiration Date:** 02/01/2018

Regulatory Determinations Pertaining to this Approval (if applicable):

IRB Comments (if applicable):

All changes to a study must receive CHR approval before they are implemented. Follow the modification request instructions. The only exception to the requirement for prior CHR review and approval is when the changes are necessary to eliminate apparent immediate hazards to the subject (45 CFR 46.103.b.4, 21 CFR 56.108.a). In such cases, report the actions taken by following these instructions.

Expiration Notice: The iRIS system will generate an email notification eight weeks prior to the expiration of this study's approval. However, it is your responsibility to ensure that an application for continuing review approval has been submitted by the required time. In addition, you are required to submit a study closeout report at the completion of the project.

Approved Documents: To obtain a list of documents that were approved with this submission, follow these steps: Go to My Studies and open the study – Click on Submissions History – Go to Completed Submissions – Locate this submission and click on the Details button to view a list of submitted documents and their outcomes.

For a list of all currently approved documents, follow these steps: Go to My Studies and open the study – Click on Informed Consent to obtain a list of approved consent documents and Other Study Documents for a list of other approved documents.

San Francisco Veterans Affairs Medical Center (SFVAMC): If the SFVAMC is engaged in this research, you must secure approval of the VA Research & Development Committee in addition to CHR approval and follow all applicable VA and other federal requirements. The CHR website has more information.

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Palliative Care in the ICU and Moral Distress among Nurses

This is a research study about moral distress of nurses, related to end of life care, and access to palliative care resources. The study researchers Krista Wolcott, RN, PhDc, and Jill Howie-Esquivel RN, PhD, from the UCSF School of Nursing are available to explain the study to you if you have questions.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you are an ICU nurse, currently practicing in direct patient care, and have cared for a dying patient sometime in the past 6 months.

Why is this study being done?

The purpose of this study is to learn more about how palliative care may affect the experience of moral distress of nurses in the ICU.

There are no financial or proprietary conflicts of interest for any of the investigators involved in this study.

How many people will take part in this study?

- About 220 people will take part in this study. Participants will be ICU nurses in the United States, from all across the country.

What will happen if I take part in this research study?

- If you agree, the following procedures will occur:
- First, you will be asked to give your consent by clicking below.
- Then you will be asked to respond to a series of questions in an online survey.

- **Study location:** All these procedures will be done at any computer you choose, that has access to the internet.

How long will I be in the study?

- Participation in the study will take a total of about 20-25 min.

Can I stop being in the study?

- Yes. You can decide to stop the survey at any time. Just exit out of the survey at any time before submitting.
- Also, the study researcher may stop you from taking part in this study if you do not meet the study criteria.

What side effects or risks can I expect from being in the study?

There are minimal risks involved in participating in this study. Possible risks may include unpleasant feeling when reminiscing about stressful or challenging experiences. If you wish to debrief with a mental health counselor following the study, you may contact the National Alliance for Mental Health to find a counselor near you. (www.nami.org).

For more information about risks and side effects, ask one of the researchers.

Are there benefits to taking part in the study?

There may be no direct benefit to you from participating in this study, however you may experience some satisfaction, or emotional closure in reviewing past experiences. Also, the information that you provide may help health professionals better understand/learn more about moral distress of nurses and about palliative care processes in the ICU.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you.

Will information about me be kept private?

We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. Your employer will not have access to research data and will not be given any indication of whether or not you participated in this survey. Personal information that you choose to share will be stored separately from survey data, and used only to provide you the gift card as a thank-you for your time.

Organizations that may look at and/or copy your research records for research, quality assurance, and data analysis include:

- American Association of Critical-Care Nurses
- The University of California

What are the costs of taking part in this study?

You will not be charged for any of the study procedures.

Will I be paid for taking part in this study?

In return for your time, and effort, you will be offered a $20 gift card for taking part in this study. At completion of the survey you will be have the option of accepting the gift card and will need to provide your mailing address so that it can be sent to you. You will be asked to choose either the Amazon or Starbucks gift card.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions, concerns, or complaints you have about this study. Contact the researcher Krista Wolcott RN, PhDc, at krista.wolcott@ucsf.edu.

If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Office of the Committee on Human Research at 415-476-1814.

CONSENT

You may print a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, please click through to the survey.

Publishing Agreement
It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

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I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Author Signature

5/31/16
Date