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A pilot study of palliative care provider self-competence, ethical concerns and priorities for
education and training in Kenya

By

Rebecca Sedillo, RN

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

NURSING

Dedication and Acknowledgments

This Master's Thesis is dedicated to the memory of my grandmother, Margie Sedillo, who passed away in March 2014 while I was writing my thesis. She believed in my global health work as a nurse and I always admired her work ethic and integrity. I will hold her in my heart as I move forward with my palliative care nursing work.

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A pilot study of palliative care provider self-competence, ethical concerns and priorities for education and training in Kenya

Rebecca Sedillo

Abstract

Introduction: The purpose of this study was to explore palliative care provider self-competence, ethical concerns and priorities for education and training in an inpatient hospice setting in Kenya. Momentum is building in sub-Saharan Africa to improve the provision of palliative care services. However, provider perspectives are poorly understood. We hypothesized that mean self-competence and ethical concerns scores would differ according to provider type. **Methods:** A descriptive, cross-sectional study design was piloted at Kimbilio Hospice, a 26-bed, rural, inpatient facility in Kenya. A quantitative survey instrument entitled, “Self assessment of clinical competency and concerns in end-of-life care,” was adapted for this setting and administered to participants by two research interviewers. Survey responses were collected from clinical staff, caregivers and support staff. Self-competence scores were reported as means for each variable in the Clinical Care and Patient and Family Interactions categories. Ethical concern scores were grouped by clinical scenario and ethical concern type. Data was analyzed using Kruskal Wallis to compare between means according to provider type. **Results:** The sample included 24 providers, with five clinical staff, 11 caregivers and eight support staff. Kruskal Wallis testing revealed statistically-significant differences between mean scores in five self-competence variables: performing a basic pain assessment, use of oral opioid analgesics, assessment and management of nausea/vomiting and constipation, and discussing an end-of-life prognosis with a patient’s family member ($p < 0.05$). The highest mean self-competence score for clinical staff was 4 for the use of oral opioid analgesics. The lowest scores were 2.8 for discussing inpatient

hospice referral, use of IV opioid analgesics and assessment of pain in pediatric patients.

Palliative care staff had the highest mean ethical concern score that withdrawing ventilator support from a dementia patient at the request of a family member would violate ethical norms of the community (mean=3.29, SD=1.04). Sixteen providers (21%) selected pediatric palliative care as their top priority for future education. **Discussion:** Our results support the hypothesis that palliative care providers have varying levels of self-competence. Improving educational and training programs to build palliative care competencies in pediatric palliative care and ethics in sub-Saharan Africa are recommended based on these findings.

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Access to palliative care in developing countries is a newly identified challenge in global health. The World Health Organization (WHO) describes palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, 2014). While palliative care in high-income countries is well characterized in the literature, palliative care in sub-Saharan Africa has only recently emerged in research and practice. The WHO Public Health Palliative Care Strategy and the Venice Declaration in 2007 proposed strategies to develop national palliative care provider education, expand service provision, and improve the quality of services (Powell, Downing, Radbruch, Mwangi-Powell, & Harding, 2008; Stjernsward, 2007).

An estimated one in every 200 individuals in Africa has a need for palliative care each year, highlighting the compelling case to address these service gaps quickly (World Health Organization, 2004). Unfortunately, the combination of resource constraints and a healthcare worker shortage complicate the delivery of high-quality palliative care services to underserved patient populations in the region (Harding et al., 2008; Volmink & Dare, 2005). Alleviating the suffering of patients with life-threatening illnesses, and their family members or caregivers, requires the implementation of palliative care services in sub-Saharan Africa. Research in the region has focused on palliative care patients, but few studies have investigated perspectives of palliative care providers. Input from palliative care providers, especially nurses, is crucial in designing effective interventions to scale up the availability and quality of evidence-based palliative care in this region.

In Kenya, palliative care services are coordinated through the Kenya Hospices and Palliative Care Association (Kenya Hospices and Palliative Care Association, 2012). Momentum is building to expand the provision of inpatient and outpatient palliative care throughout Kenya. However, few research studies have been conducted in the country and none apart from descriptive studies have assessed scope of practice, competence or perspectives on palliative care services among non-physician palliative care providers (Powell et al., 2008).

The purpose of this study was to explore self-competence, ethical concerns and priorities for education and training related to palliative and end-of-life care among palliative care providers and hospice staff in the Rift Valley Province in Kenya. Our specific aims were to: (1) assess palliative care provider self-competence in both clinical care and patient and family interactions, (2) assess ethical concerns among all palliative care staff, and (3) assess provider priorities for education and training. We hypothesized that self-competence and ethical concerns would differ between three groups of palliative care providers (clinical staff, support staff and caregivers) in an inpatient hospice setting.

Background

Global Palliative Care

Globally, an estimated 600 million people will experience negative health effects from untreated pain, demonstrating the need to improve palliative care access worldwide (Taylor, 2007). Pain is the most common reason that people seek medical care. However the availability to address pain in a palliative care setting is limited in lower and middle-income countries due to poor healthcare infrastructure, healthcare worker shortages and inequalities in opioid availability (Fishman, 2007; King & Fraser, 2013). Chronic pain is also a significant cause of disability. In developing countries, the high disease burden of cancer, HIV/AIDS and other terminal

conditions contributes to high rates of chronic pain and other symptoms that interfere with activities of daily living (International Association for the Study of Pain, 2013). Both acute traumatic pain and chronic malignant pain contribute to morbidity and mortality, causing socioeconomic and psychological consequences like reduced participation in the workforce, depression, and caregiver dependence (King & Fraser, 2013). Along with pain, life-threatening illnesses create further symptom burden for patients from shortness of breath, fatigue, mental health conditions, cognitive decline and spiritual distress that impact quality of life (Garrison, Overcash, & McMillan, 2011). Palliative care is increasingly regarded as a universal human right, although the implications of this paradigm are still being explored (Brennan, 2007; Gwyther, Brennan, Obs, & Harding, 2009). In order to give all people equal, equitable access to palliative care services and alleviate suffering, patient-centered palliative care must be scaled up worldwide, especially in resource-constrained settings.

Palliative care in sub-Saharan Africa

Palliative care services have existed in sub-Saharan Africa since 1979, when the first hospice in Africa opened in Zimbabwe (Di Sorbo, Chifamba, Mastrojohn, Sisimayi, & Williams, 2010). The East African nations of Kenya, Uganda, and Tanzania led the advancement of palliative care services, along with South Africa and Zimbabwe (Clark, Wright, Hunt, & Lynch, 2007). Under the umbrella of the pan-African advocacy organization, the African Palliative Care Association (APCA), and national associations including the Kenyan Hospice and Palliative Care Association, coordinate clinical education, health policy advocacy and mentorship for national governments and local palliative care providers (Kenya Hospices and Palliative Care Association, 2012).

Palliative care is a crucial yet neglected public health approach to treatable yet incurable diseases such as HIV and cancer (World Health Organization, 2002). The disease burden from HIV in sub-Saharan Africa is substantial, with 25 million adults and children living with HIV and 1.5 million HIV-related annual deaths (UN Joint Programme on HIV/AIDS (UNAIDS, 2012). Thus far, the majority of palliative care literature has focused on patients with HIV/AIDS rather than patients with cancer, leading to disparities in evidence-based cancer-related services (Jack, Kirton, Birakurataki, & Merriman, 2011). In sub-Saharan Africa, the epidemiologic transition of an aging population with a substantial burden of life-threatening illness highlights the need for an expansion of palliative care services. Based on WHO estimates, in 2020, 70% of new cancer cases will be in the developing world and half a million people will die from cancer each year in sub-Saharan Africa (International Agency for Research on Cancer, 2012). Moreover, although 80% of cancer diagnoses in sub-Saharan Africa are incurable due to lack of treatment access and late diagnosis, at least 88% of cancer deaths with moderate to severe pain occur without pain management, in part due to a lack of opioid availability (O'Brien et al., 2013; Ramsay, 2001).

Palliative care patients in sub-Saharan Africa have experiences at the end-of-life and throughout their disease courses that are simultaneously similar and distinct from those of other palliative care populations. In a multi-centered, cross-sectional study of a South African and Ugandan cohort, spiritual well-being was rated as a higher priority than physical well-being (Selman et al., 2011). In the same cohort, participants reported a high prevalence and burden of symptoms in advanced cancer with pain (87.5%), lack of energy (77.7%), sadness (75.9%), drowsiness (72.3%) and worry (69.6%) as the most prevalent symptoms (Harding et al., 2011). A five-country WHO study in sub-Saharan Africa revealed that dying patients suffer from physical,

psychological and spiritual problems that are often unaddressed in the course of their illness (Sepulveda et al., 2003). Pain is widespread, reported in 80-98% of advanced HIV patients in East Africa, and has a negative impact on quality of life (Norval, 2004; Solano, Gomes, & Higginson, 2006). Understanding the symptom burden and quality of life indicators for African patients receiving palliative care is an emerging field in palliative care research, as self-defined patient outcomes may differ from outcomes used in developed countries (Harding et al., 2011).

Although the integration of palliative care into sub-Saharan African healthcare systems has improved in the last 20 years (Grant, Downing, Namukwaya, Leng, & Murray, 2011), barriers to the expansion of services still exist (Harding et al., 2008). Infrastructural challenges are compounded by the inaccessibility of rural palliative care facilities due to poor roads, and poor communication between academic and clinical palliative care communities (Powell et al., 2008). Palliative care facilities are typically community-based rather than hospital-based and lack funding for supplies and medications, including essential pain medications (Harding, Selman, Powell, Namisango, Downing, Merriman, Ali, Gikaara, Gwyther & Higginson, 2013).

Palliative care provider and staff competency in sub-Saharan Africa

Some palliative care studies have assessed patient needs and preferences in sub-Saharan Africa, but few have assessed the needs, preferences or competencies of providers, especially in relation to education and training programs (Powell et al., 2008). Competence is crucial; without it, poor quality of care and symptom management for patients may occur and moral distress or anxiety among providers is likely (Desbiens, Gagnon, & Fillion, 2011; Fillion, Saint-Laurent, & Rousseau, 2003; Mallory, 2003). Due to a lack of palliative care curricula or certificate programs in developing countries, palliative care staff reported feeling inadequately trained to provide care to patients in pain or at the end of life (Sheehan & Malloy, 2010).

Nurses have more contact with palliative care patients in sub-Saharan Africa than other healthcare workers; thus, it is imperative to improve nurses' competency in providing services to patients with life-threatening illnesses (Ferrell, Grant, & Virani, 1999; Fillion et al., 2003; Fitzpatrick, While, & Roberts, 1992; Mallory, 2003; Smith, 2003). In East Africa, however, nurses have insufficient professional training to provide end-of-life care (Sepulveda et al., 2003; Uys, R. & Social, D., 2003). As a result of the gap between professional education and clinical practice, the WHO recently recommended that palliative care become a core component of nursing training and continuing professional education (Davies & Higginson, 2004; World Health Organization, 2014). A literature review of 15 studies in developed countries evaluated competence-building activities in palliative care in-home care and nursing homes, showing that educational programs improved health providers' knowledge and skills while the impact on practice was less clear (Raunkiaer & Timm, 2013). Identifying feasible, evidence-based interventions for the provision of palliative care will be the next step for improved service-delivery in developing countries, especially in sub-Saharan Africa.

In South Africa, a mixed-methods study was conducted in 2008 to assess the competence of doctors enrolled in a distance-learning palliative care education program (Ens et al., 2011). A total of 85 medical students and physicians who had graduated from the program were evaluated on their competence in five areas: (i) palliative care activities, (ii) pain, (iii) assessment, (iv) changes in management protocols, and (v) general palliative care concepts. Physician graduates scored higher than current students, with significant differences in almost all domains and students' perception of confidence and competence improving over time. The lowest scores reported by participants were in end-of-life care and symptom management. Participants indicated that a hospice rotation would be beneficial for their learning and that their knowledge

and confidence improved over time. Findings from this study demonstrate that palliative care education influences practice.

Palliative care provider education and training in sub-Saharan Africa

A survey of end-of-life providers in sub-Saharan Africa revealed that service expansion through lay and professional education and training, especially in pain management and palliative care for all advanced diseases, was ranked as a high priority for service providers (Harding, Stewart, Marconi, O'Neill, & Higginson, 2003). Additionally, Ugandan healthcare professionals identified pediatric palliative care as an important education topic, including pediatric communication, pain management and psychological issues as their top three priorities (Amery, Rose, Byarugaba, & Agupio, 2010).

Some notable international palliative care training programs provide guidance for the development of provider competency-based training and frameworks. The End-of-Life Nursing Education Consortium Curriculum (ELNEC) launched an international team to train oncology nurses from over 60 countries in palliative care knowledge, expertise and tools, including role plays and symptom management didactics, to improve patient care and educate others (Paice, Ferrell, Coyle, Coyne, & Smith, 2010). The ELNEC pilot in Tanzania reported high levels of provider satisfaction at four months following the training of 39 nurses, who disseminated the ELNEC curriculum by giving lectures to a total of 242 Tanzanian healthcare professionals. However, pre- and post-test data measuring the impact of the training on nursing knowledge and practice were not reported. Another ELNEC training was conducted in Kenya over 5 days with similar levels of satisfaction among 49 providers, but without an evaluation of knowledge change (Malloy et al., 2011). Recommendations for improving basic palliative care education for all care providers include interdisciplinary teams, advocacy, reliable supply chains for opioids and other

pain medications and palliative care curricula for nursing and medical education programs (Shamieh, Jazieh, & MENA Cancer Palliative Care Regional Guidelines Committee, 2010).

Palliative care provider ethical concerns in sub-Saharan Africa

Few studies have assessed the ethical concerns of healthcare providers in sub-Saharan Africa. An ethnographic study of 24 Ugandan nurses revealed that nurses are very committed to high quality care for patients yet lament the lack of resources that threaten patient safety and health outcomes (Harrowing, 2010). Moral distress in nursing has been characterized as the emotions nurses experience in situations in which they feel compelled to take some moral action but are constrained by institutional, cultural or other barriers or limitations in their desires to minimize harm (Corley, 2002; Jameton, 1984). Even in situations that do not evoke moral distress, nurses are confronted by a variety of ethical issues in their daily clinical practice that have not been well-articulated (Austin, Lerner, Goldberg, Bergum, & Johnson, 2005). Little research has been conducted on ethical or moral distress among nurses in sub-Saharan Africa (Fournier, Kipp, Mill, & Walusimbi, 2007; Hanna, 2004), and no studies have investigated the ethical curricula in medical and nursing schools.

Palliative care in Kenya

Palliative care in Kenya is improving through public, private and non-governmental organizations. In 2012, 30,000 patients received palliative care services through 70 service providers throughout Kenya (Kenya Hospices and Palliative Care Association, 2012). However, in Western Kenya, the majority of hospitalized patients continue to experience acute pain and lack access to chronic-malignant pain management (Huang et al., 2013). While advocacy and collaboration are facilitating the growth of palliative care infrastructure in Kenya, poor access to care remains a formidable challenge.

Much of the palliative care research that has been conducted in Kenya focuses on pain management, both related to patient experiences of pain and the assessment and management of pain. One study evaluated a pain management program designed to improve knowledge and attitudes among 27 Kenyan nurses (Machira, Kariuki, & Martindale, 2013). The study authors found that pain management significantly improved after nurses received a focused educational program. In another study of HIV outpatients and their palliative care providers, Selman et al. (2013) found that patient pain and distress were not routinely assessed and effective pain medications were unavailable at the Kenyan clinics. Finally, three field evaluation studies in Uganda, Kenya and Malawi were conducted to determine the efficacy of palliative care programs throughout the region (Grant, Brown, Leng, Bettega, & Murray, 2011). In this study, Kenyan patients and families stated that barriers to care included the lack of skilled nurses and the distance from patients' homes to the site, which caused the Maua Hospital palliative care team to rely heavily on volunteer community health workers. Although the community's reported understanding of palliative care increased, knowledge of cancer-related palliative care was significantly less than knowledge of HIV/AIDS-related palliative care needs.

Theoretical Framework

The concept of self-competence in palliative care is derived from a shared theory proposed by Desbiens, Gagnon and Fill that combines Bandura's social cognitive theory (SCT) with Orem's Self Care Model (Bandura, 1986; Desbiens et al., 2011; Orem, 2001). This theory examines both nursing and patient concepts in palliative care, including nursing competence, nursing self-competence and nursing interventions, all of which impact the therapeutic relationship between nurses and patients with life-threatening illness (Dobrina, Tenze, & Alvisa, 2014). A functional definition of competence is the actual capability of an individual to utilize

various sub-skills (e.g. emotional and cognitive skills), knowledge, values and attitudes into an action that serves a specific purpose (Desbiens et al., 2011). Competence is differentiated from knowledge, talent or performance in that it is acquired through experience and effective training in a particular field. Self-competence denotes an individual's perception of his or her competence. Desbiens' shared theory argues that nurses with higher self-competence provide better care than nurses with lower self-competence (Dobrina et al., 2014).

The importance of self-competence can be explained in part by SCT, the theoretical framework that conceptualizes a provider's perceived efficacy and confidence in clinical practice (Bandura, 1986). The core tenet of SCT posits that one's perception of his or her efficacy directly influences the attainment of that efficacy, a term which Desbiens considers to be conceptually equivalent to competence (Bandura, 1990; Francois, 1998; Schunk & Zimmerman, 2006). Orem's Self Care Model, the other theory in the shared theory, describes the need for nursing care when patients have a self-care deficit, which is applicable in palliative care scenarios since patients are dependent on nursing staff for some or all of their care (Orem, 2001). These two theories intersect in the shared theory, which posits that palliative care provider self-competence is crucial for the nursing actions leading to patient and family outcomes. Nursing self-competence impacts the quality of nursing interventions, as discussed by Orem, that are directed towards patients' self-care deficits (Dobrina et al., 2014).

Desbiens, Gagnon and Fillon's shared theory adds empirical explanations and predictions of palliative care nursing phenomena, for "the more competent the nurses feel in a given field, the more they commit to it and persevere in the face of difficulties; this brings success and strengthens the motivation to act" (Desbiens, Gagnon & Fillion, 2011, p. 2115). In the shared theory, both competence and self-competence are crucial for the provision of high-quality

palliative care services, regardless of whether these services are provided by nurses, social workers, chaplains, caregivers or other clinicians. The importance of self-competence is that service providers will regulate their behavior and actions based on how they judge their own competence. Self-competence reflects the capability of a nurse or other clinical staff to make decisions about how to provide high-quality, effective services in a variety of settings or clinical scenarios. People who trust their professional competencies will act more adeptly, leading to higher performance, goals and perseverance in challenging situations; whereas people who are not confident in their capabilities will avoid difficult scenarios and decisions, experiencing them more as a threat than an opportunity (Bandura, 1997).

Self-competence also has implications for staff retention, communication in multidisciplinary teams, patient-provider communication and patient satisfaction. In order for palliative care services to be provided in an evidence-based, competent fashion, training and education programs must incorporate strategies to boost resiliency, confidence and decision-making in challenging scenarios for any and all clinical personnel (Desbiens et al., 2011). The shared theory enables an extension of both theoretical concepts, enabling palliative care self-competence in nursing or other clinical fields to be considered a determinant of quality palliative care.

Self-competence is a helpful theoretical concept for understanding the relationship between palliative care provider competence and the quality of palliative care services. Not only does the shared theory of SCT and Orem's conceptual model provide an interpretation of how self-competence improvement could lead to better nursing interventions and enhance patient quality of life and outcomes, but it also delineates a framework to design and evaluate palliative care training programs (Desbiens et al., 2011). The application of the shared theory to the

palliative care field reveals that palliative care providers with higher self-competence will demonstrate better performance in providing care to patients living with life-threatening illnesses and their family than palliative care providers with low self-competence (Desbiens et al., 2011). Based on the principles of this shared theory, a survey instrument assessing palliative care provider self-competence was selected to address the study aims.

Methods

We conducted a descriptive cross-sectional study to assess palliative care provider self-competence, ethical concerns and priorities for education and training.

Setting

Kimbilio Hospice is a rural, palliative care facility located approximately 200 miles north of Nairobi, Kenya. This 26-bed hospice was opened in 2010 through the Kenyan non-governmental organization and 501(c)3 called Living Room International to provide quality palliative care services to adults and children living with life-threatening illnesses. Kimbilio Hospice (Kiswahili for “refuge”) provides free inpatient hospice services to patients who are admitted based on referrals from local hospitals or clinics or who have documented diagnoses of life-threatening illnesses. The interdisciplinary team of palliative care providers and staff includes three registered nurses, two clinical officers, a chaplain, three social workers, three community health workers, two physical therapists, twelve nursing assistants and other support staff including cooks and administrators. Clinical officers hold a similar role to physicians in Kenya, since Medical Degree programs are expensive and only at major universities. Kimbilio Hospice has access to morphine to provide effective management to their patients and provides holistic services including pain and symptom management, physical therapy, psychosocial, spiritual and social support, nutritional support, HIV medication management, wound care, and

bereavement support. An outpatient clinic will be opened in summer 2014 on the same campus as Kimbilio Hospice to expand palliative care access for patients who are not candidates for inpatient services.

Sample

Clinical staff from Kimbilio Hospice participated in the survey. The research team from the UCSF School of Nursing met with the Living Room International (LRI) management team in December 2013 to discuss the study and the recruitment of eligible Kimbilio Hospice clinical staff. All hospice staff who provided palliative care services were recruited for participation in this study, a total of 25 participants. Study inclusion criteria were: adult (at least 18 years old), staff that provided palliative care services at Kimbilio Hospice based on scope of practice and job descriptions (clinical officers, nurses, social workers, chaplains, social workers, physical therapists and caregivers), able to give informed consent, and able to speak English fluently. The only exclusion criterion was the need for an interpreter from English to Kiswahili, due to the lack of professional interpretation services in the village. The management team at LRI identified eligible participants. Demographic data collected included: gender, number of years worked in palliative care, role at Kimbilio Hospice, and whether or not the participant had received formal training in palliative care outside of LRI.

The Committee on Human Research at UCSF reviewed and approved the study. Although an ethics review board does not exist at LRI, the management team was involved in the design of the study and approved the final version of the survey. Informed written consent was obtained from each participant prior to the survey.

Data Collection

Two research investigators (MO and RS) conducted surveys during December 2013 and January 2014. Surveys were conducted with each individual participant in a private room. The WHO definition of palliative care was read to each participant (World Health Organization, 2014). The same investigator asked the questions out loud and recorded the survey answers in writing. Audio recording was not used. Anonymous completed surveys were given to the first author (RS) for analysis.

Instruments

Researchers completed the “Self assessment of clinical competency and end-of-life concerns in end-of-life care” survey with each participant (Appendix 1). The survey instrument was adapted from a questionnaire, “Clinical Competency and Concerns in End of Life Care,” developed by Weissman et al. (Weissman, Ambuel, Norton, Wang-Cheng, & Schiedermayer, 1998). This questionnaire was originally administered to physician trainees in the United States to assess competency and ethical concerns, and to design future palliative care educational training programs. In the original survey, four palliative care topics were assessed: (1) competencies and comfort in end-of-life communication topics, (2) management of end-of-life medical issues, (3) comfort with treatment withdrawal, and (4) ethical concerns in common end-of-life scenarios (Weissman et al., 1998). The instrument is used in medical curricula for monitoring and evaluation but has not been validated in clinical research. We decided to adapt this instrument because to our knowledge, there are no instruments that survey palliative care providers in developing countries or sub-Saharan Africa. A section eliciting providers’ priorities for future education and training had been added to the original survey in a later version and was preserved in the survey used for this study.

Section I of the survey measured palliative care provider self-competence. In this section, Domain I assessed Clinical Care (Questions 1-12), describing all tasks performed by clinical personnel (e.g. assessment and management of nausea). Domain II assessed Patient and Family Interactions (Questions 13-21), describing tasks that could be performed by clinical and non-clinical personnel (e.g. conducting a family conference). A Likert scale was used to assess self-competence (1= need further basic instruction, 2= competent to perform with minimal supervision and coaching, 3=competent to perform with team consultation, 4=competent to perform independently). A “Not Applicable to my Role” answer choice was included based on consultation with LRI staff since not all items tested were within the job descriptions or scope of practice of all study participants.

In Section II of the survey, ethical concerns in common end-of-life scenarios were assessed in five clinical scenarios (Decisions A-E). Participants were asked to rank their concern that ethical principles were being violated in the following areas: Medical Practice Standards, Ethical Norms, and Personal and Religious Ethical Beliefs. A Likert scale was used to record participant responses (1=not concerned, 2=somewhat unconcerned, 3=somewhat concerned, 4=very concerned).

In the last section of the survey, Section III, participants were asked to rate their priorities for ten palliative care education and training topics using a Likert scale (1=not at all a priority, 2=somewhat a priority, 3=a priority, 4=definitely a priority). Once participants had completed the questions, they were asked to highlight their top three priority topics for future education and training.

In order to adapt Weissman’s survey to a rural inpatient hospice setting in Kenya, the LRI management team reviewed and piloted survey drafts so that questions were contextually

appropriate. For instance, the word “physician” was removed from the survey since there are no Medical Doctors who work at Kimbilio Hospice. After the survey was piloted, the original survey response choice of 3, “Competent to perform with minimal supervision,” was replaced by “Competent to perform with team consultation,” since Kimbilio Hospice staff are instructed to perform many tasks through team consultation in their job descriptions. In the ethical concerns section, the original survey contained the response choice, “this violates state law,” which was removed from the adapted survey since there are no state or regional laws regulating palliative care practice in Kenya. Questions about pediatric palliative care were added to Sections I and III, because these were found to be important to providers. All four original topics from the original instrument were preserved in the survey. The topic that covered comfort with treatment withdrawal was incorporated into Sections I and II on self-competence and ethical concerns. Prior to the survey administration, the researchers agreed upon a set of standardized definitions of complex terms or phrases (e.g. urosepsis), so that participants could understand the terms and reliability of the data could be maintained.

Statistical Analysis

Analysis of responses among the providers were aggregated into three groups: clinical medical staff (including nurses and clinical officers), support staff (including social workers, chaplains, physical therapists and community health workers) and caregivers, who provide assistance with activities of daily living to patients in a role similar to Certified Nursing Assistants in the United States. We calculated the means and standard deviations for each question in each domain. Composite scores were also calculated, including the categories of Clinical Care (total possible score ranged from 12-48) and Patient and Family Interactions (total possible score ranged from 9-36) in Section I and ethical concern in Section II (total possible

score ranged from 3-16). We assessed self-competence score and mean ethical concern scores score differences among the three groups of palliative care providers using the non-parametric Kruskal-Wallis one-way analysis of variance. We used an alpha level of < 0.05 to determine statistical significance in all statistical tests. Ethical concerns were analyzed by calculating the means and standard deviations for the total ethical concern scores for each clinical scenario and also for each type of ethical concern (medical, ethical and personal or religious). The top three priorities for education and training were tallied for each participant and the sums and percentages of variables chosen most frequently were calculated.

Findings

Demographic Data

The sample included 24 palliative care providers and staff out of the 25 eligible participants at Kimbilio Hospice. One caregiver did not speak English and was therefore excluded. Participants included five clinical staff (21%), eight support staff (33%) and 11 caregivers (49%). The majority of participants were female (54%) with seven female caregivers, four female clinical staff and two female support staff. The majority of participants reported formal training (e.g. nursing school, certificate programs, other programs or training outside of Kimbilio Hospice) in palliative care (58%), including 80% of clinical staff, 63% of caregivers and 38% of support staff. The median amount of time that staff had worked in palliative care was 2-3 years, with a clinical staff median of 0-1 years, a support staff median of 2-3 years and a caregiver median of 3-4 years.

Self-Competence Scores

Mean self-competence scores grouped by provider type for Domains 1 and 2 in Section I are shown in Table 1. Across all provider types, the total mean self-competence score for

Clinical Care was 2.9 ($SD=0.84$) and the total mean self-competence score for Patient and Family Interactions was also 2.9 ($SD=0.94$) on a scale of 1-4. The mean self-competence composite score (total possible range = 12-48) in the clinical care category across all providers was 26.4 ($SD=11.1$). The mean self-competence composite score in the patient and family interactions category (total possible range = 9-36) was 22.3 ($SD=6.7$). Clinical care mean self-competence scores were higher for clinical staff as compared to caregivers or support staff. The mean self-competence scores for Patient and Family Interactions were the same for clinical and support staff, and only slightly lower for caregivers (Figure 1).

For clinical staff, the five highest mean self-competence scores were the use of oral opioid analgesics ($M=4.0$), performing a basic pain assessment, and the assessment and management of nausea and vomiting, diarrhea and constipation (all with $M=3.8$). The three lowest mean self-competence scores were discussing inpatient hospice referral, the use of intravenous/injectable opioid analgesics and the assessment of pain in the pediatric patient (all with $M=2.8$). Clinical staff answered Clinical Care category questions with a response of 3 or 4 (3=Competent to perform with team consultation, 4=Competent to perform independently) 92% of the time, compared with 75% of the time for support staff and 70% for caregivers. In the Patient and Family Interactions category, clinical staff responded with a 3 or 4 response 91% of the time, compared with 89% of the time for support staff and 66% for caregivers. All clinical staff responded to the questions in both Clinical Care and Patient and Family Interactions categories by choosing from the 1-4 Likert Scale and did not select "Not applicable to my role" for any question. Out of eleven caregivers, "Not applicable to my role" was answered 31 times out of 132 possible responses (23%) in the Clinical Care category and 17 times out of 99 possible responses (16%) in the Patient and Family Interactions Category. Out of eight support

staff, “Not applicable to my role” was answered 43 times out of 96 possible responses (45%) in the Clinical Care category and 19 times out of 72 possible responses (26%) in the Patient and Family Interactions category.

There were statistically significant differences between palliative care provider types in five of the 21 self-competence variables: performing a basic pain assessment (Kruskal Wallis $H(2)=7.220, p=0.027$), use of oral opioid analgesics ($H(2)=8.366, p=0.015$), assessment and management of nausea and vomiting ($H(2)=7.730, p=0.021$), assessment and management of constipation ($H(2)=7.034, p=0.030$), and discussing an end-of-life prognosis with a patient’s family member ($H(2)=7.794, p=0.020$). In all of these variables, clinical staff were more likely to report higher self-competence than support staff and caregivers. The sixteen remaining self-competence variables were not found to be significantly different based on palliative care provider type.

Ethical Concerns

The clinical scenario causing the lowest ethical concern for all provider types was providing maximal pain relief throughout the course of a patient’s illness ($M=4.8, SD=2.63$). The clinical scenario causing the highest ethical concern was withdrawing ventilator support from a dementia patient at the request of their family member ($M=9.5, SD=3.20$) (Figure 2). None of the clinical scenarios showed statistically significant differences in total ethical concern by provider type.

When grouped by type of ethical concern, clinical staff, support staff and caregivers overall had the highest mean ethical concern scores about withdrawing ventilator support from a dementia patient at the request of a family member, stating that it would violate the ethical norms of the community ($M=3.29, SD=1.04$), their personal and religious ethical beliefs ($M=3.08,$

$SD=1.28$), and medical practice standards ($M=3.08$, $SD=1.18$) (Figure 2). Mean scores were on a scale of 1-4, with 4 representing the highest mean ethical concern. Providers also had high concern that withdrawing antibiotic medication from a dementia patient with urosepsis would violate medical practice standards and represent malpractice ($M=3.14$, $SD=1.25$) and would violate the ethical norms of the community ($M=3.00$, $SD=1.02$).

Across all palliative care provider groups, the type of ethical concern that caused the highest mean composite ethical concern score was that the various scenarios violated the ethical norms of the community ($M=12.7$, $SD=4.67$). Concerns that the scenarios violated medical practice standards or personal and religious ethical beliefs showed similar mean scores of 11.4 ($SD=3.79$) and 11.5 ($SD=4.35$), however differences among these three concerns were not statistically significant when analyzed according to provider type.

Priorities for Education and Training

The majority of participants rated all categories as either a priority or definitely a priority for future education and treatment, with a total mean score of 3.4 out of a total possible range of 1-4, with 4 representing “definitely a priority for future education and training” ($SD=0.83$). Sixteen providers (21%) selected pediatric palliative care as their top priority for education and treatment, 14 (19%) chose pain assessment and management, 11 (15%) chose spirituality in end of life care, 10 (13%) chose hospice care (the who, why, when and where), and 6 (8%) chose end of life communication skills. No providers selected the assessment and management of nausea and vomiting as a top priority.

Discussion

Our study is the first to elicit palliative care provider self-competency and ethical concerns for non-physician palliative care staff in sub-Saharan Africa. Our results support the

hypothesis that self-competence scores differ according to palliative care provider type. Some of these differences were expected given the scope of practice of nurses and clinical officers compared to that of non-clinical staff. For instance, for clinical skills like performing a basic pain assessment and the assessment and management of constipation, one would expect that clinical staff have higher self-competence and competence compared to non-licensed caregivers. However, clinical staff surprisingly did not show higher self-competence in the use of parenteral opioid analgesics, use of adjuvant analgesics, assessment of pain in the non-responsive or confused patient, or the assessment and management of pediatric pain, terminal delirium, terminal dyspnea or fatigue when compared to other staff. All these areas are crucial for symptom management and end-of-life care and warrant further investigation into why clinical staff did not perceive themselves to be more competent than non-clinical staff in these management topics. Adjuvant analgesics (e.g. tricyclics, steroids, anticonvulsants) are rarely used at Kimbilio Hospice, nevertheless the lower competency scores in these clinical care skills identify possibilities for further training topics. Finally, support staff disclosed significantly higher self-competence in performing a basic pain assessment and discussing an end-of-life prognosis with a patients' family member than caregivers.

Clinical staff responded 3 ("Competent to perform with team consultation") or 4 ("Competent to perform independently) on over 90% of survey questions in both Clinical Care and Patient and Family Interactions. The survey response choice of 3, "Competent to perform with team consultation," was created for this pilot study to replace "Competent to perform with minimal supervision", since teams of interdisciplinary palliative care providers often make decisions collaboratively (de Haes & Teunissen, 2005; Remke & Schermer, 2012). Support staff and caregivers also had high rates of answering a 3-4 in Domains 1-2, with many caregivers

selecting response 3 in both categories. However, a caregiver's interpretation of the assessment and management of diarrhea with team consultation is most likely different from how a support staff or clinical staff would interpret that same team interaction, for example. This raises the question of whether palliative care self-competence and competence should be evaluated based on independent skills versus on the successful collaboration and shared decision-making of an interdisciplinary team. Even so, the clinical implications of high self-competence are encouraging, since healthcare providers who trust their professional competencies will act more competently, leading to higher performance, goals and perseverance in challenging clinical scenarios (Desbiens et al., 2011). In the rural setting of Kimbilio Hospice, staff perceptions of their competence are critical for decision-making, quality of care and patient outcomes. During night shifts for instance, when only one clinical staff works at the hospice at a time, self-competence is critically important for patient care.

Clinical and support staff had similar mean composite self-competence scores in the Patient and Family Interactions category. The support staff category included both licensed and unlicensed staff, as well as clinical and non-clinical personnel. Interestingly, support staff had a higher rate of 45% in answering "not applicable to my role" in the clinical care category compared to 22% among caregivers, demonstrating that support staff might have higher role clarity than caregivers. Another interpretation could be that since caregivers have the most frequent contact with patients compared to clinical and support staff, they may try to advocate for their patients by providing care outside of their formal job descriptions. Regardless, since the clinical staff response rate was 100% in both domains, the trends in their responses are the most reliable and useful for the understanding of palliative care provider self competence based on this pilot study.

Across all provider types, the similar mean self-competence survey response scores in Patient and Family Interactions and Clinical Care ($M=2.9$ in both categories) suggest that the Kimbilio staff team as a whole has similar self-competence in both clinical and psychosocial aspects of patient care. It is within everyone's scope of practice to communicate with patients and families, whether independently or as a team, which is a strength of the Kimbilio Hospice palliative care providers. Clinical staff felt highly competent in many areas, with mean scores above three for all variables except for inpatient hospice referral, the use of intravenous/injectable opioid analgesics and the assessment of pain in the pediatric patient.

The entire sample of palliative care providers at Kimbilio Hospice was invited to participate in this study, and only one caregiver was excluded from the study based on eligibility criteria. Interestingly, the providers who had less than one year of palliative care experience had higher self-competence than those with more experience across all provider types. One likely explanation for this is that four clinical staff members who have had formal training in palliative care reported less than one year in the field yet had higher self-competence in general than caregivers, who had a median of three to four years working in palliative care. Self-competence in palliative care, therefore, could potentially be attributed to education and training rather than years of work experience. However, this phenomenon could also be influenced by hubris, making the case that validated indicators for true palliative care competence, along with self-competence, should be studied and described to ensure patient safety and outcomes. Providing high-quality, evidence-based palliative care to patients in an inpatient hospice setting requires a distinct set of skills and experiences compared to providing care at the bedside in a hospital setting. Effective methods of improving the competency of palliative care providers must be further investigated.

Pediatric pain assessment was a self-competence area in which all staff reported low competence and pediatric palliative care was most frequently selected as a topic for future education and training. This finding was consistent with a previous study in which Ugandan healthcare providers identified communication with children as a top priority for palliative care education (Amery et al., 2010). Based on competency training interventions in the United States (Raunkiaer & Timm, 2013), educational programs designed to improve knowledge and skills have the potential to build self-competence among palliative care providers in rural hospice or palliative care settings in East Africa. Policymakers and directors of palliative care institutions must consider competency training to strengthen the quality of patient care and minimize moral distress among providers. Future education and training programs at Kimbilio Hospice and at hospices throughout Kenya must focus on pain management, pediatric palliative care and spiritual care, based on the results of this study and others (Amery et al., 2010; Harding et al., 2003).

Although ethical concerns did not vary significantly among provider types, trends in ethical concerns were identified. Ethical concern scores based on the clinical scenario showed larger differences between providers than based on the type of concern (medical practice, ethical or personal and religious). When ethical concerns were averaged across all clinical scenarios, providers reported their highest concern was that ethical norms of the community were being violated. Since community norms seem to be the most important tool to assess ethical issues of palliative care provider staff at Kimbilio, a future study could survey the community members about their ethical concerns with palliative care to inform clinical practice. The ethical grey areas of most concern to Kimbilio Hospice providers involved the withdrawal of antibiotics from patients with urosepsis and the withdrawal of a ventilator from a dementia patient at the request

of their family member. Although all participants were familiar with the use of a ventilator, Kimbilio Hospice does not have a ventilator. The ethical concern in this scenario highlighted the importance of patient autonomy to Kimbilio providers, which the management team noted was a part of their training.

In the original Weisman study, all the ethical scenarios included in the survey were legal in the state of Wisconsin yet controversial (Weissman et al., 1998). Conversely in Kenya, medical malpractice and litigation are rare. In our study, therefore, these scenarios that elicited the highest ethical concern highlight the need to implement ethically-relevant training, debriefing and values clarification for staff and management that are specific to the Kenyan legal, medical and community setting. Additionally, ethical training should be specific to the scope of practice of the various providers. Providers must be equipped with strategies to assess common ethical dilemmas they may encounter while providing care within their job descriptions and licenses.

Limitations of the study include subject bias, particularly in Section III that assessed providers' priorities for future education and training. Although the intentions of the study were made clear to the entire staff team and future education and training opportunities were not discussed or promised as a part of this project, participants may have responded to the questions based on expectations that the researchers would be able to fund future training at the hospice. Statistical conclusion validity is poor in this study, based on the small sample size. Type II error is possible, since this study was insufficiently powered to detect changes in the dependent variables. Furthermore, a high percentage of study participants answered "Not applicable to my role" in Section I, influencing the power of the statistical analysis and the generalizability of the results to the inpatient hospice staff. Given the nature of this pilot study, however, it provides preliminary data to inform future studies. While the original survey instrument has not been

validated in the United States or in developing countries, the measurement reliability over time and over raters was stable. Although the results of our study are not generalizable beyond the setting of Kimbilio Hospice, this pilot study could be replicated by administering the survey at other hospices and palliative care services throughout Kenya and sub-Saharan Africa to assess larger trends in palliative care provider competencies and training needs.

Our results provide compelling initial evidence that Kenyan palliative care providers and staff have varying levels of self-competence that merit additional educational and training programs to build competencies and skills in clinical care, patient and family communication and ethics. Continuing this research would be in line with the Declaration of Venice, which highlights the agenda for global palliative care research and education in developing countries by responding to the specific needs of patients within their geographical and socio-economic and cultural contexts (Powell et al., 2008).

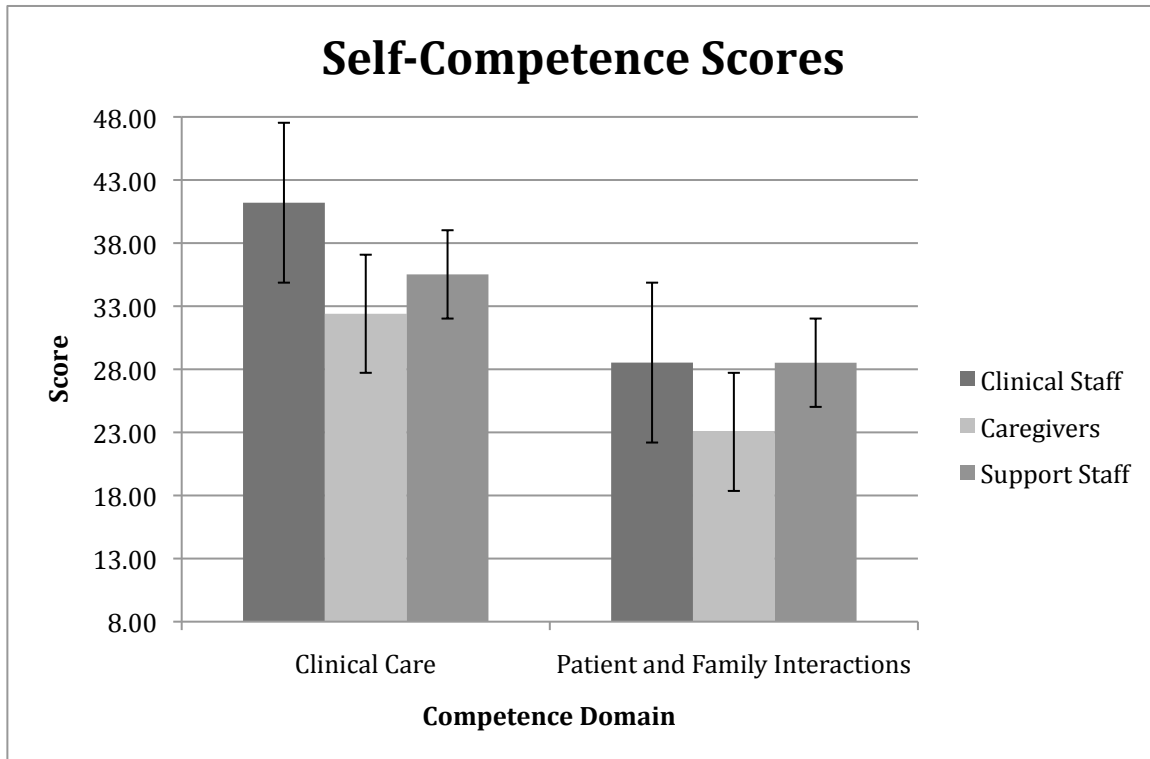
Table 1: Mean self-competence scores by palliative care provider type, Domains 1-2.

Self-Competency Question	Clinical Staff	Support Staff	Caregivers
Conducting a basic pain assessment	3.8 (0.45)*	3.7 (0.52)*	2.7 (0.95)
Use of oral opioid analgesics	4.0 (0.00)*	2.0 (0)*	2.3 (1.16)*
Use of IV opioid analgesics	2.8 (0.84)	NA	1.75 (0.96)
Use of adjuvant analgesics	3.4 (0.55)	NA	2.2 (1.10)
Pain in the unresponsive, demented or confused patient, Assessment	3.2 (0.55)	2.9 (0.38)	2.7 (1.00)
Pain in the pediatric patient, Assessment	2.8 (0.45)	3.2 (0.41)	2.6 (1.03)
Terminal delirium, Assessment and management	3.2 (0.45)	2.8 (0.41)	2.6 (0.67)
Terminal dyspnea, Assessment and management	3.4 (0.55)	2.8 (0.75)	2.5 (0.97)
Nausea and vomiting, Assessment and management	3.8 (0.45)*	2.8 (0.41)*	2.4 (1.07)*
Diarrhea, Assessment and management	3.8 (0.45)	2.5 (0.58)	2.5 (1.13)
Constipation, Assessment and management	3.8 (0.45)*	2.5 (1.29)*	2.2 (1.25)*
Fatigue, Assessment and management	3.2 (0.84)	3.4 (0.79)	2.8 (0.79)
Conducting a family conference	3.2 (0.45)	3.1 (0.38)	2.9 (0.83)
Giving bad news to a patient or family member	3.0 (0.00)	3.0 (1.10)	2.4 (1.13)
Discussing inpatient hospice referral	2.8 (0.84)	3.3 (0.46)	2.6 (1.17)
Discussing a shift in treatment approach	3.0 (0.00)	3.00 (0.82)	2.0 (0.93)
Discussing treatment withdrawal	3.2 (0.84)	NA	2.4 (1.19)
Assessing patient decision-making capacity	3.2 (0.84)	3.4 (0.79)	2.7 (0.79)
Assessment and management of adult patient grief	3.6 (0.55)	3.5 (0.55)	2.7 (0.90)
Assessment and management of pediatric patient grief	3.0 (0.00)	2.7 (0.52)	2.5 (0.82)
Discussing an end-of-life prognosis with a patient's family member*	3.6 (0.55)*	3.3 (0.52)*	2.6 (0.52)*

* = **Kruskal-Wallis test <0.05**

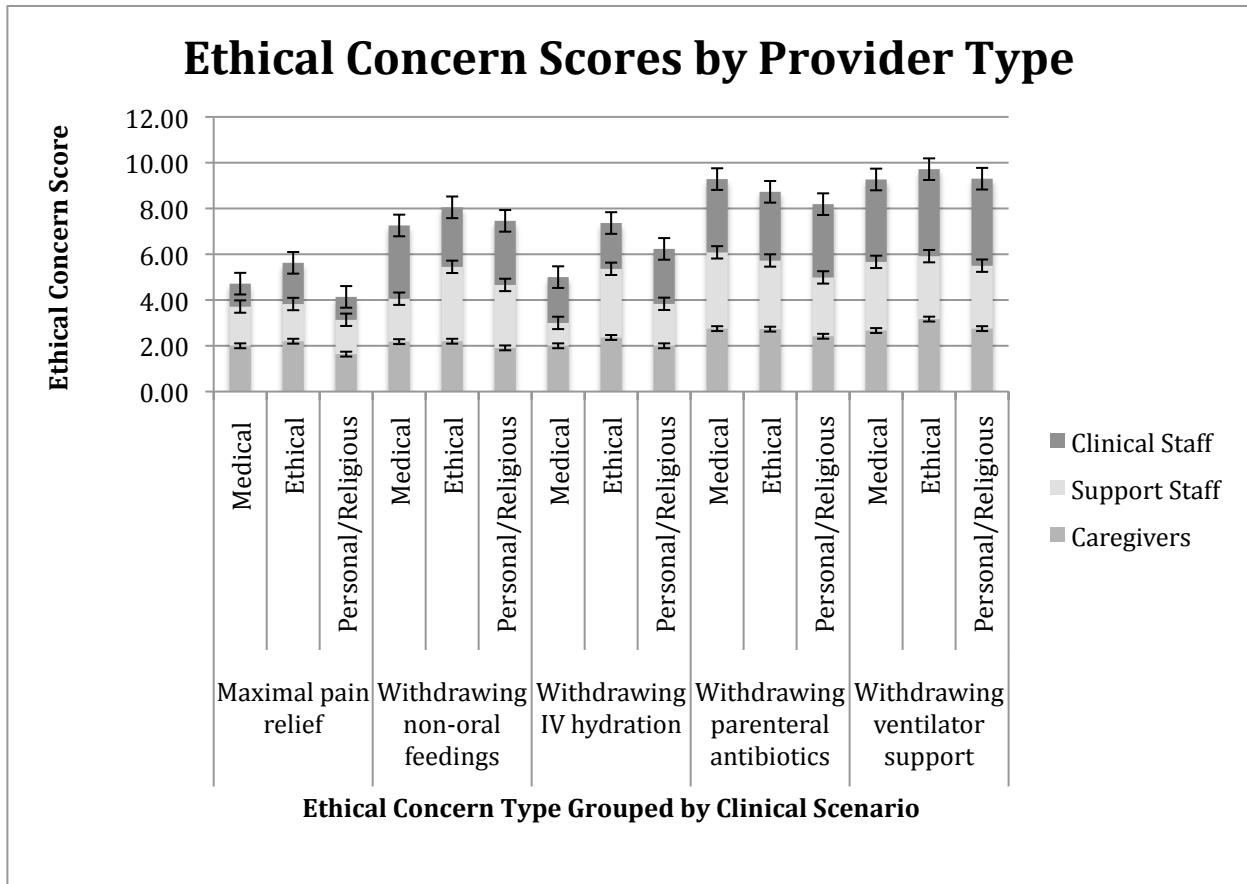
NA= "Not applicable to my role" answered by all participants in group

Figure 1: Mean composite self-competence scores in Clinical Care and Patient and Family Interactions categories by palliative care provider type.



Clinical Care total possible score range: 12-48
 Patient and Family Interactions total possible score range: 9-36
 (see Appendix 1)

Figure 2: Mean ethical concern scores identified by providers in five palliative care clinical scenarios.



Ethical concern score total possible range = 3-12

Medical = “This violates medical practice standards and represents malpractice”

Ethical = “This violates accepted ethical norms”

Personal and Religious = “This violates my personal religious or ethical beliefs”

(see Appendix 1 for full clinical scenario descriptions)

References

- Amery, J. M., Rose, C. J., Byarugaba, C., & Agupio, G. (2010). A study into the children's palliative care educational needs of health professionals in Uganda. *Journal of Palliative Medicine, 13*(2), 147-153. doi:10.1089/jpm.2009.0153; 10.1089/jpm.2009.0153
- Austin, W., Lerner, G., Goldberg, L., Bergum, V., & Johnson, M. S. (2005). Moral distress in healthcare practice: The situation of nurses. *HEC Forum, 17*(1), 33-48. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Bandura, A. (1990). Reflections on nonability determinants of competence. In R. J. Sternberg, & J. J. Kolligan (Eds.), *Competence considered* (pp. 315-362). New Haven, CT: Yale University Press.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman.
- Brennan, F. (2007). Palliative care as an international human right. *Journal of Pain and Symptom Management, 33*(5), 494-499. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Clark, D., Wright, M., Hunt, J., & Lynch, T. (2007). Hospice and palliative care development in Africa: A multi-method review of services and experiences. *Journal of Pain and Symptom Management, 33*(6), 698-710. doi:10.1016/j.jpainsymman.2006.09.033
- Corley, M. C. (2002). Nurse moral distress: A proposed theory and research agenda. *Nursing Ethics, 9*(6), 636-650. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Davies, E., & Higginson, I. J. (2004). *Palliative care: The solid facts*. The World Health Organization.

- de Haes, H., & Teunissen, S. (2005). Communication in palliative care: A review of recent literature. *Current Opinion in Oncology*, 17(4), 345-350. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Desbiens, J., Gagnon, J., & Fillion, L. (2011). Development of a shared theory in palliative care to enhance nursing competence. *Journal of Advanced Nursing*, 68(9), 2113-2124. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Di Sorbo, P. G., Chifamba, D. D., Mastrojohn, J. 3., Sisimayi, C. N., & Williams, S. H. (2010). The zimbabwe rural palliative care initiative: PCI-Z. *Journal of Pain and Symptom Management*, 40, 19-22. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Dobrina, R., Tenze, M., & Alvisa, P. (2014). An overview of hospice and palliative care nursing models and theories. *International Journal of Palliative Nursing*, 20(2), 75-81. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Ens, C. D., Chochinov, H. M., Gwyther, E., Moses, S., Jackson, C., Thompson, G., & Harding, R. (2011). Postgraduate palliative care education: Evaluation of a South African programme. *South African Medical Journal*, 101(1), 42-44. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Ferrell, B. R., Grant, M., & Virani, R. (1999). Strengthening nursing education to improve end-of-life care. *Nursing Outlook*, 47, 252-256. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Fillion, L., Saint-Laurent, L., & Rousseau, N. (2003). Stressors related to nursing practice in palliative care: The views of nurses. *Les Cahiers De Soins Palliatifs*, 4(1), 5-40. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Fishman, S. M. (2007). Recognizing pain management as a human right: A first step. *Anesthesia and Analgesia*, 105, 8-9. doi:10.1213/01.ane.0000267526.37663.41

Fitzpatrick, J. M., While, A. E., & Roberts, J. D. (1992). The role of the nurse in high-quality patient care:

A review of the literature. *Journal of Advanced Nursing*, *17*(10), 1210-1219. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed>

Fournier, B., Kipp, W., Mill, J., & Walusimbi, M. (2007). Nursing care of AIDS patients in Uganda.

Journal of Transcultural Nursing, *18*(3), 257-264. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed>

Francois, P. H. (1998). Self-efficacy and competences: A social cognitive approach. *Education*

Permanente, *135*, 45-55. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

Garrison, C. M., Overcash, J., & McMillan, S. C. (2011). Predictors of quality of life in elderly hospice

patients with cancer. *Journal of Hospice & Palliative Nursing*, *13*(5), 288-297. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed>

Grant, L., Downing, J., Namukwaya, E., Leng, M., & Murray, S. (2011). Palliative care in Africa since

2005: Good progress but much further to go. *BMJ Supportive and Palliative Care*, *1*, 118-122.

Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

Grant, L., Brown, J., Leng, M., Bettega, N., & Murray, S. A. (2011). Palliative care making a difference

in rural Uganda, Kenya and Malawi: Three rapid evaluation field studies. *BMC Palliative Care*,

10(8). doi:10.1186/1472-684X-10-8; 10.1186/1472-684X-10-8

Gwyther, L., Brennan, F., Obs, D., & Harding, R. (2009). Advancing palliative care as a human right.

Journal of Pain and Symptom Management, *38*(5), 767-774. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed>

Hanna, D. R. (2004). Moral distress: The state of the science. *Research & Theory for Nursing Practice*,

18(1), 73-93. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

- Harding, R., Selman, L., Agupio, G., Dinat, N., Downing, J., Gwyther, L., . . . Higginson, I. (2011). The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. *European Journal of Cancer*, *47*, 51-56. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Harding, R., Stewart, K., Marconi, K., O'Neill, J. F., & Higginson, I. J. (2003). Current HIV/AIDS end-of-life care in sub-Saharan Africa: A survey of models, services, challenges and priorities. *BMC Public Health*, *3*, 1-6. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Harding, R., & Higginson, I. J. (2005). Palliative care in sub-Saharan Africa. *Lancet*, *365*(9475), 1971-1977. doi:10.1016/S0140-6736(05)66666-4
- Harding, R., Powell, R. A., Downing, J., Connor, S. R., Mwangi-Powell, F., Defilippi, K., . . . Alexander, C. (2008). Generating an African palliative care evidence base: The context, need, challenges, and strategies. *Journal of Pain and Symptom Management*, *36*(3), 304-9. doi:10.1016/j.jpainsymman.2008.04.008; 10.1016/j.jpainsymman.2008.04.008
- Harrowing, J. N. (2010). Moral distress among Ugandan nurses providing HIV care: A critical ethnography. *International Journal of Nursing Studies*, *47*(6), 723-731. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Higginson, I. J., & Bruera, E. (2002). Do we need palliative care audit in developing countries? *Palliative Medicine*, *16*(6), 546-547. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Huang, K. T., Owino, C., Gramelspacher, G. P., Monahan, P. O., Tabbey, R., Hagembe, M., . . . Vreeman, R. C. (2013). Prevalence and correlates of pain and pain treatment in a western Kenya referral hospital. *Journal of Palliative Medicine*, *16*(10), 1260-1267. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

International Agency for Research on Cancer. (2012). GLOBOCAN 2012 fact stats. Retrieved February 8, 2014, from http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx

International Association for the Study of Pain. (2013). *Unrelieved pain is a major global healthcare problem*. Washington, D.C.: International Association for the Study of Pain.

Jack, B. A., Kirton, J., Birakurataki, J., & Merriman, A. (2011). 'A bridge to the hospice': The impact of a community volunteer programme in Uganda. *Palliative Medicine*, 25(7), 706-715.
doi:10.1177/0269216310397566; 10.1177/0269216310397566

Jameton, A. (1984). *Nursing practice: The ethical issues*. Englewood Cliffs, New Jersey: Prentice Hall.

Kenya Hospices and Palliative Care Association. (2012). Kenya hospices and palliative care association annual report 2012. Retrieved October 6, 2013, from <http://kehpc.org/wp-content/uploads/Annual-Report-2012.pdf>.

King, N. B., & Fraser, V. (2013). Untreated pain, narcotics regulation and global health ideologies. *PLoS Medicine*, 10(4), e1001411. doi:10.1371/journal.pmed.1001411

Machira, G., Kariuki, H., & Martindale, L. (2013). Impact of an educational pain management programme on nurses pain knowledge and attitudes in Kenya. *International Journal of Palliative Nursing*, 19(7), 341-346. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

Mallory, J. L. (2003). The impact of a palliative care educational component on attitudes toward care of the dying in undergraduate nursing students. *Journal of Professional Nursing*, 19(5), 305-312.
Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

- Malloy, P., Paice, J. A., Ferrell, B. R., Ali, Z., Munyoro, E., Coyne, P., & Smith, T. (2011). Advancing palliative care in Kenya. *Cancer Nursing, 34*(1), E10-3. doi:10.1097/NCC.0b013e3181ea73dd; 10.1097/NCC.0b013e3181ea73dd
- Norval, D. A. (2004). Symptoms and sites of pain experienced by AIDS patients. *South African Medicine, 94*, 450-454. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- O'Brien, M., Mwangi-Powell, F., Adewole, I. F., Soyannwo, O., Amandua, J., Ogaja, M. O., . . . Merriman, A. (2013). Improving access to analgesic drugs for patients with cancer in sub-Saharan Africa. *Lancet Oncology, 14*, e176-e182. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Orem, D. E. (2001). *Nursing: Concepts of practice* (6th ed.). St. Louis, MO: Mosby.
- Paice, J. A., Ferrell, B., Coyle, N., Coyne, P., & Smith, T. (2010). Living and dying in East Africa: Implementing the end-of-life nursing education consortium curriculum in Tanzania. *Clinical Journal of Oncology Nursing, 14*(2), 161-166. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Powell, R. A., Downing, J., Radbruch, L., Mwangi-Powell, F. N., & Harding, R. (2008). Advancing palliative care research in sub-Saharan Africa: From the Venice Declaration, to Nairobi and beyond. *Palliative Medicine, 22*(8), 885-887. doi:10.1177/0269216308098094
- Ramsay, S. (2001). Raising the profile of palliative care for Africa. *Lancet, 358*, 734. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Raunkiaer, M., & Timm, H. (2013). Interventions concerning competence-building in community palliative care services: A literature review. *Scandinavian Journal of Caring Sciences, 27*(4), 804-819. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>

- Remke, S.S. & Schermer, M.M. (2012). Team collaboration in pediatric palliative care. *Journal of Social Work in End-of-Life and Palliative Care*, 8, 286-96. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Schunk, D. H., & Zimmerman, B. J. (2006). Competence and control beliefs: Distinguishing the means and ends. In P. A. Alexander, & P. H. Winne (Eds.), *Handbook of educational psychology* (pp. 349-367). Mahwah, NJ: Erlbaum.
- Selman, L., Siegert, R. J., Higginson, I. J., Agupio, G., Dinat, N., Downing, J., . . . Harding, R. (2011). The MVQOLI successfully captured quality of life in African palliative care: A factor analysis. *Journal of Clinical Epidemiology*, 64(8), 913-924. doi:10.1016/j.jclinepi.2010.12.013; 10.1016/j.jclinepi.2010.12.013
- Sepulveda, C., Habiyambere, V., Amandua, J., Borok, M., Kikule, E., Mudanga, B., . . . Solomon, B. (2003). Quality care at the end of life in Africa. *BMJ*, 327, 209-213. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Sheehan, D. K., & Malloy, P. (2010). Nursing education. In B. R. Ferrell, & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 1193-1210). New York: Oxford University Press.
- Smith, S. A. (2003). Developing and utilizing end of life nursing competencies. *Home Health Care Management and Practice*, 15(2), 116-122. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal of Pain and Symptom Management*, 31, 58-69. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Stjernsward, J. (2007). Palliative care: The public health strategy. *Journal of Public Health Policy*, 28(1), 42-55. doi:10.1057/palgrave.jphp.3200115

- Taylor, A. L. (2007). Addressing the global tragedy of needless pain: Rethinking the united nations single convention on narcotic drugs. *Journal of Law and Medical Ethics*, 35, 556-511. doi:10.1111/j.1748-720X.2007.00180.x
- UN Joint Programme on HIV/AIDS (UNAIDS). (2012). *Global report: UNAIDS report on the global AIDS epidemic*. UNAIDS.
- Uys, R. & Social, D. (2003). Aspects of care of people with HIV/AIDS in South Africa. *Public Health Nursing*, 20(4), 271-280. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Volmink, J., & Dare, L. (2005). Addressing inequalities in research capacity in Africa. *British Medical Journal*, 331(7519), 705-706. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Weissman, D. E., Ambuel, B., Norton, A. J., Wang-Cheng, R., & Schiedermayer, D. (1998). A survey of competencies and concerns in end-of-life care for physician trainees. *Journal of Pain and Symptom Management*, 15(2), 82-90. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- World Health Organization. (2002). Minimum standard of care defined for HIV patients with cancer. 80, February 8, 2014, 176.
- World Health Organization. (2004). *A community health approach to palliative care for HIV/AIDS and cancer patients in sub-Saharan Africa*. Geneva: World Health Organization.
- World Health Organization. (2014). WHO definition of palliative care. Retrieved February 9, 2014, from <http://www.who.int/cancer/palliative/definition/en/>

Appendix 1: SELF-ASSESSMENT OF CLINICAL COMPETENCY AND CONCERNS IN END-OF-LIFE CARE ¹

My name is Rebecca Sedillo/Mia Openshaw and we are helping Kimbilio Hospice conduct a need assessment in preparation to open a new outpatient palliative care clinic in 2014. This brief survey is designed to assess your comfort and expertise in providing palliative care, your concerns about providing palliative care, and your priorities for education and training. But first, I would like to get to know a little bit about you. Please answer the following questions.

What is your role at Kimbilio Hospice? Please check the best answer.

Clinical Officer

Social Worker

Nurse

Caregiver

Other _____

How many years have you worked in palliative care? Please check the best answer.

Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, 2012).

0-1 years

1-2 years

2-3 years

3-4 years

More than 5

Have you completed any formal training in palliative care (example: nursing school, certificate programs, other programs or training outside of Kimbilio Hospice)?

Yes

No

What is your gender?

Male

Female

1. Adapted from: Weissman DE, Norton A, et al. A survey of competencies and concerns in end-of-life care for physician trainees. *J Pain Symptom Manage* 1998; 15:82-90

2. "WHO Definition of Palliative Care". World Health Organization. Retrieved December 23, 2012.

I. Please rank your degree of competence with the following patient/family interactions and patient management topics, using the following scale:

1	2	3	4	5
Need further basic instruction	Competent to perform with close supervision/coaching	Competent to perform with team consultation	Competent to perform independently	Not applicable to my role

Domain I

I.1. Perform a basic pain assessment

1	2	3	4	5
----------	----------	----------	----------	----------

I.2. Use of oral opioid analgesics

1	2	3	4	5
----------	----------	----------	----------	----------

I.3. Use of parenteral opioid analgesics

1	2	3	4	5
----------	----------	----------	----------	----------

I.4. Use of adjuvant analgesics (e.g. tricyclics, steroids, anti-convulsants)

1	2	3	4	5
----------	----------	----------	----------	----------

I.5. Assessment of pain in the non-responsive, demented or confused patient

1	2	3	4	5
----------	----------	----------	----------	----------

I.6. Assessment of pain in the pediatric patient

1	2	3	4	5
----------	----------	----------	----------	----------

I.7. Assessment and management of terminal delirium

1	2	3	4	5
----------	----------	----------	----------	----------

I.8. Assessment and management of terminal dyspnea

1	2	3	4	5
----------	----------	----------	----------	----------

I.9. Assessment and management of nausea / vomiting

1	2	3	4	5
----------	----------	----------	----------	----------

I.10. Assessment and management of diarrhea

1	2	3	4	5
----------	----------	----------	----------	----------

1	2	3	4	5
Need further basic instruction	Competent to perform with close supervision/coaching	Competent to perform with team consultation	Competent to perform independently	Not Applicable

I.11. Assessment and management of constipation

1	2	3	4	5
----------	----------	----------	----------	----------

I.12. Assessment and management of fatigue

1	2	3	4	5
----------	----------	----------	----------	----------

Domain II

II.1. Conducting a family conference to discuss important end-of-life decisions

1	2	3	4	5
----------	----------	----------	----------	----------

II.2. Giving bad news to a patient or family member

1	2	3	4	5
----------	----------	----------	----------	----------

II.3. Discussing inpatient hospice referral

1	2	3	4	5
----------	----------	----------	----------	----------

II.4. Discussing a shift in treatment approach from curative to comfort care.

1	2	3	4	5
----------	----------	----------	----------	----------

II.5. Discussing treatment withdrawal (e.g. antibiotics, hydration)

1	2	3	4	5
----------	----------	----------	----------	----------

II.6. Assessing patient decision -making capacity

1	2	3	4	5
----------	----------	----------	----------	----------

II.7. Assessment and management of adult patient grief

1	2	3	4	5
----------	----------	----------	----------	----------

II.8. Assessment and management of pediatric patient grief

1	2	3	4	5
----------	----------	----------	----------	----------

II.9. Discussing an end-of-life prognosis with a patient’s family member.

1	2	3	4	5
----------	----------	----------	----------	----------

II. Palliative care providers and staff often have concerns that certain medical decisions may either be contrary to accepted legal, ethical or professional standards or that they may be contrary to their own personal beliefs. For each of the situations listed below, please indicate the type and amount of concern you have, using the following scale:

- 4 = very concerned**
3 = somewhat concerned
2 = somewhat unconcerned
1 = not concerned

A. Decision: Providing maximal pain relief throughout a patient's illness, even before the terminal phase. Concerns:

1. ___ This violates medical practice standards and represents malpractice
2. ___ This violates accepted ethical norms
3. ___ This violates my personal religious or ethical beliefs

B. Decision: Withdrawing non-oral feedings (G-tube or NG tube) from a terminal cancer patient who asks for such feeding to be discontinued. Concerns:

1. ___ This violates medical practice standards and represents malpractice
2. ___ This violates accepted ethical norms
3. ___ This violates my personal religious or ethical beliefs

C. Decision: Withdrawing IV hydration from a terminal cancer patient, who can no longer take oral fluids and who is clearly dying. Concerns:

1. ___ This violates medical practice standards and represents malpractice
2. ___ This violates accepted ethical norms
3. ___ This violates my personal religious or ethical beliefs

D. Decision: Withdrawing parenteral antibiotics from a dementia patient with urosepsis. Concerns:

1. ___ This violates medical practice standards and represents malpractice
2. ___ This violates accepted ethical norms
3. ___ This violates my personal religious or ethical beliefs

E. Decision: Withdrawing ventilator support from a dementia patient at the request of their family member. Concerns:

1. ___ This violates medical practice standards and represents malpractice
2. ___ This violates accepted ethical norms
3. ___ This violates my personal religious or ethical beliefs

Please indicate which of the following topics you would like to have included in future education or training programs using the following scale:

	1	2	3	4
	Not at all a priority for future education or training	Somewhat a priority for future education or training	A priority for future education and training	Definitely a priority for future education and training
1. Pain assessment and management	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
2. Assessment and management of nausea and vomiting	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
3. Assessment and management of terminal delirium	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
4. Assessment and management of terminal dyspnea	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
5. Assessment and management of constipation	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
6. Pediatric palliative care	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
7. End-of-life communication skills—giving bad news, running a family conference, discussing prognosis, discussing treatment withdrawal				

	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
7. Hospice care: the who, why, when and where	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
8. End-of-life ethics and decision-making capacity	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
9. Use of intravenous hydration and/of non-oral feedings in end-of life care	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
10. Spirituality in end-of-life care	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority
11. Assessment and management of fatigue	1	2	3	4
	Not at all priority	Somewhat a priority	A priority	Definitely a priority

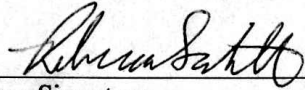
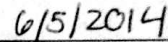
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