Access to Palliative Care in Intensive Care Units and the Role of Nursing in its Promotion

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Palliative care is health care provided by an interdisciplinary team with the primary goal of relieving patient and family suffering through treatment of a patient’s physical, emotional, intellectual, and spiritual needs (Dahlin, 2013). Palliative care can be appropriate for any patient at any stage of serious illness that is in need of symptom relief without regard for prognosis or the nature of the relevant symptoms. While palliative care has an important role in end-of-life care, it is not reserved for patient and family support in the dying process, nor is palliative care preclusive of curative treatment (Dahlin, 2013). Palliative care utilization decreases costs and resource utilization without increasing mortality for hospitalized patients (Creutzfeldt et al., 2015; Morrison et al., 2008).

It is established in the end-of-life care literature that surveys of the United States show that a majority of people would prefer to die at home if terminally ill (Nathan Cummings Foundation, Fetzer Institute, & George H. Gallup International Institute, 1997). A 2010 report from the National Center for Health Statistics seems to show a gradual shift in health care towards this preference. The percentage of people 65 and older dying at home is up from 15% in 1989 to 24% in 2007. Deaths in nursing homes increased by 7% while deaths in acute care hospitals decreased by 14% (National Center for Health Statistics, 2010). Simultaneously, the use and availability of hospice care and palliative care services has expanded (National Hospice and Palliative Care Organization, 2015). However, “site of death” is not the only relevant factor in one’s dying process, nor is it the only factor considered in one’s expressed wishes surrounding one’s death.

A 2013 review of Medicare beneficiary records found that while fewer Americans are dying in acute care hospitals, rates of ICU hospitalization and the average number of “potentially burdensome transitions” between health care facilities are both on the rise
(Teno et al., 2013). Additionally, while hospice utilization increased from 21.6% in 2000 to 42.2% in 2009, the percentage of hospice stays less than 3 days has increased from 22.2% in 2000 to 28.4% in 2009 with 40.3% of these decedents having experienced an ICU hospitalization preceding hospice admission (Teno et al., 2013). A 2015 report from the National Hospice and Palliative Care Organization (NHPCO) shows that 35.5% of hospice patients die within a week of admission and over half die within 14 days (National Hospice and Palliative Care Organization, 2015). Patients with short hospice stays receive fewer services, and are less likely to benefit from the collaborative input of the interdisciplinary hospice care team (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). Decedent’s families who perceive that their loved one’s hospice referral was late report greater concerns with the quality of care, lower overall satisfaction, and higher rates of unmet needs than those families who perceive a decedent’s referral as “at the right time” (Teno et al., 2007). It is worth noting that an earlier hospice referral is not always possible. It has been estimated that one in three hospice referrals that occurred within seven days of death could not have happened earlier in the disease process either because the patient refused services or because of an acute event and rapid decline ending in death (Teno, Casarett, Spence, & Connor, 2012).

Patients are being treated more aggressively at the end of life. While the number of hospice referrals is increasing, and there is ample evidence supporting the benefit of even short hospice stays (Teno et al., 2007, 2011; Waldrop & Rinfrette, 2009), these referrals are coming late in the disease process and patients are not able to receive the full benefits of hospice service while also undergoing increasingly burdensome medical treatment. Access to palliative care in the ICU is associated with increased rates of formal advanced
directives, increased hospice enrollment, less utilization of futile and burdensome life-sustaining therapies, lower costs of care, and decreased length of ICU stay (Hua, Li, Blinderman, & Wunsch, 2013; Morrison et al., 2008).

Barriers to palliative care in the ICU are well known and documented in the literature, and there is ample research on how to increase referral rates to palliative and hospice care in the ICU in general. However, none of these interventions will change patient care if there is not a desire to employ them that comes from an understanding of the importance and value of good end-of-life care. Necessary to developing this understanding is openness to talking about death not just as professionals, but also as individual persons. We must accept the ineluctability of death as a personal as well as a professional reality so that we might appreciate the value of end-of-life care. A reflection on patterns of end-of-life care in and around the ICU provides an opportunity to reflect on attitudes surrounding death so that nursing can, as a profession, be conscientious of the role it needs to play in advocating for quality end-of-life care in the ICU and change how it educates new nurses accordingly.

**Barriers to Palliative Care**

The growing importance of palliative care in the ICU is hampered by barriers that are well documented in critical care and palliative care literature. Some of these barriers are individually held misconceptions about medical care in the ICU. Individual patients, families, and even clinicians often have unrealistic expectations for the outcomes of intensive care therapies and patient prognosis (Nelson, 2006). Indeed, while existing prognostic systems are generally accurate at the population level, they are of limited clinical utility when prognosticating for individual patients as physicians are systematically
over-optimistic (Christakis, Smith, Parkes, & Lamont, 2000; Hua et al., 2013). Other barriers are individually held misconceptions about palliative care such as conflating palliative care with hospice care, concern that incorporation of palliative care hastens death, and thinking that palliative and curative care are mutually exclusive (Aslakson, Curtis, & Nelson, 2014; Nelson, 2006). Consequently, clinicians may not be educated on the different roles and qualifications for palliative and hospice care. They may be unfamiliar with the requirements for each service and consequently unable to refer their patients at the appropriate time. These kinds of impediments create an environment that is predisposed to choose aggressive, curative treatment as opposed to palliative treatment, even in situations where palliative treatment is clearly indicated either instead of or in conjunction with the intense, curative treatment that is proper to an ICU and that intensive care clinicians are trained to deliver.

Other barriers to palliative care in ICUs are those factors that prevent clinicians from addressing the aforementioned misunderstandings in themselves and in their patients and families. Patients are often unable to participate in conversations about their care in the ICU. They often don't have pre-existing advance directives outlining their wishes (Nelson JE et al., 2006). Thus, it becomes the difficult role of the family to make end-of-life decisions. Families are under duress and often unaware of the details of the situation and different options available to them. Competing demands for a physician's time, insufficient physician training in communication, and even lack of a physical space in which to have end-of-life conversations contribute to the common complaint from patients, families, and clinicians alike that there is ineffective communication surrounding end-of-life care and options in the ICU (Aslakson et al., 2012; Nelson JE et al., 2006). A 2014 systematic review
of studies conducted in North American and European Adult ICUs found that communication between physicians and families is often fragmented and delayed. When family meetings do happen with physicians there is often insufficient time to mutually share perspectives and concerns about the patient’s goals and values. Patient families may still harbor unrealistic expectations of recovery. Physicians may not be aware of the need to further educate on the unfiltered details of what can reasonably be expected, so a conversation about palliative or end-of-life care may not even begin. These break downs in communication can cause families to be too emotionally distressed to absorb and integrate the relevant information needed for good surrogate decision making (Aslakson et al., 2014).

Lack of communication and palliative care education in the ICU is also reflected in hospice research. Families of decedents report poor communication of prognosis and viable treatment options as a common cause of self-described “late” hospice referrals (Teno et al., 2012). Those factors contributing to this lack of communication include prognostic uncertainty, “silos” of disciplines preventing interprofessional dialogue, competing time demands, and a cultural aversion to acknowledging death (Aslakson et al., 2012; Nelson, 2006). These barriers to palliative care are widely documented and interventions to address them have been developed and published.

**Solutions**

Interventions to improve access to palliative care in ICUs often center on creating an opportunity for interprofessional communication about specific patient’s needs and treatment goals. This begins with provider education on how to identify those patients on a unit at risk for unmet palliative care needs. The implementation of screening tools offers a
system to consistently determine which patients are at risk for unmet palliative care needs and objectively trigger either a palliative care consult or a more detailed assessment and interprofessional conversation about those potentially unmet needs. The Improving Palliative Care in the ICU (IPAL-ICU) Advisory board, a segment of the Center to Advance Palliative Care (CAPC), conducted a systematic review about the use of screening criteria to engage palliative care consultants in a critical care context and determined that the use of specific criteria to trigger palliative care consultation increases involvement of palliative specialists in the ICU and reduces utilization of ICU resources without changing mortality (Nelson, Curtis, et al., 2013). There is also a need to ensure that clinicians are aware of what the differences between the available services are. If clinicians are unaware of the necessary criteria for hospice admission or abilities of palliative specialists, it is not reasonable to expect that they will leverage those services to their full potential merely because they implement a screening tool. Implementation must be done in conjunction with continued education on what to do for a patient and family with unmet palliative need.

In the same systematic review, the IPAL-ICU affirms that "existing data and resources can be used in developing such criteria, which should be tailored for a specific ICU, implemented through an organized process involving key stakeholders, and evaluated by appropriate measures" (Nelson, Curtis, et al., 2013). Since the patient populations, culture, resources, and therefore barriers to palliative care vary from unit to unit; the interventions to address those particular barriers should also vary. There is not a single, proven screening tool that works best for all ICUs. However, the IPAL-ICU has published a tool to guide ICU leadership through the process of developing screening criteria to "identify patients with a high likelihood of unmet palliative care needs" on a particular unit
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(Nelson, Campbell, et al., 2013). The tool is designed to be used by an multidisciplinary committee composed of both ICU and palliative care staff to develop particular screening criteria for a specific unit through local consensus, outline a pathway to implementation that coincides with current unit structure and flow, include occasions for assessment and revision of screening criteria and their implementation, and negotiate common and particular barriers to the implementation of the program. The tool is designed to be customizable to the needs, resources, and barriers of a particular unit.

While there is no single set of criteria that works for all units, as seen in the literature on barriers to palliative care, there are characteristics common in those patients at high risk for unmet palliative care needs. These characteristics include: distressing physical and psychological symptoms, social and spiritual concerns, poorly understood prognosis/unrealistic goals of care among family, significant disagreements or uncertainty among family and or staff concerning major treatment decisions, and frequent hospitalizations (Weissman & Meier, 2011) The Center to Advance Palliative Care has developed and published a set of checklists that broadly screen for these common characteristics (Weissman & Meier, 2011). The checklists are not tailored to a specific unit or level of acuity, but they outline those issues most commonly seen in patients in need of palliative care. The system is composed of two checklists, one to be used upon unit admission, and one to be used for daily screenings during patient rounds during the course of a patient’s stay. Each checklist has primary and secondary criteria to facilitate ease of implementation. Primary criteria are more general indicators of palliative need; they are the most important factors and represent the minimum criteria that hospitals should use to screen patients. Secondary criteria are more particular indicators of a high likelihood of
unmet palliative need and should be incorporated into a screening system if possible or relevant to a particular floor (Weissman & Meier, 2011). Thus, while composed of evidence-based criteria that are broadly relevant, the tool remains customizable to the needs of a particular.

These tools are designed to either trigger a basic palliative care needs assessment by the primary care team, or a specialty-level palliative care consultation depending on the extent of the need indicated by the screening tool and the resources available on a particular unit (Nelson, Campbell, et al., 2013; Weissman & Meier, 2011). Because specialty-level palliative care consultation remains a relatively scarce resource, the CPAC concludes that consultation should be reserved for the most complicated cases of unmet palliative need while routine palliative need should be actively managed by all primary care teams in the same way that “routine cardiac problems are handled by primary care physicians, rather than cardiologists” (Weissman & Meier, 2011). Proper implementation of a screening tool presupposes or concomitantly necessitates integration of basic palliative care into everyday clinical operation and education of health care staff. Where a particular unit falls on the spectrum of a “consultative model,” wherein palliative concerns are referred to specialists, to an “integrative model,” wherein palliative concerns are dealt with by the primary care team, depends on the consultative resources available, the level of palliative care education in the primary care team, and the unit culture. There is evidence to support the efficacy of models all along this spectrum (Aslakson et al., 2014). Given the complex palliative needs encountered in an ICU, there is need for a consultative element. Likewise, given the already complex structure and risk of fragmented communication in an ICU, there is a need for an integrative element. A detailed discussion on the risks and
benefits of different models of palliative care is beyond the scope of this paper, but it is reasonable to conclude, as has been asserted by the CPAC, that effective ICU palliative care should be designed on a unit-to-unit basis and include both integrative and consultative elements.

**Determining Palliative Need**

Before actively addressing palliative need in a specific ICU, one must determine the appropriate scope of one’s efforts to expand palliative service. Estimates of unmet palliative need vary greatly depending on palliative scope. A 2013 retrospective cohort study out of Columbia University determined that “13.8% of ICU admissions met one or more primary triggers for palliative care consultation.” A more comprehensive model that used multiple sets of triggers increased this number to 19.7% (Hua et al., 2013). Compare this estimate of palliative need, between 13.8% and 19.7%, to the results of a 2015 parallel-group prospective cohort design QI project out of the University of Washington to estimate palliative need in a Neuro ICU. This study used a screening tool to identify unmet palliative need in 62% of patients (Creutzfeldt et al., 2015). This massive disparity can be accounted for by looking at the screening criteria used.

The Colombia University study used mostly objective criteria to estimate morbidity and mortality. Their primary triggers were “(1) ICU admission following a hospital stay greater than or equal to 10 days, (2) Age greater than 80 with 2 or more life-threatening comorbidities, (3) diagnosis of active stage IV malignancy, (4) status post cardiac arrest, (5) diagnosis of intracerebral hemorrhage requiring mechanical ventilation.” These criteria were designed to be used within 72 hours of ICU admission, and “an initial evaluation of their implementation was associated with a decrease ICU length of stay” (Hua et al., 2013).
The secondary criteria were both objective and subjective, but remained focused on mortality and physical morbidity. These included declared futility by medical team, death expected during same ICU stay, ICU stay >1 month, and multisystem organ failure or 3 or more systems (Hua et al., 2013). While efficient and evidence based, these triggers “do not capture patients for whom palliative care consults are appropriate for other reasons, such as psychological, emotional, or spiritual support, family request, and mediation between family and the care team” (Hua et al., 2013).

The Washington University study used a palliative care need screening tool in a Neuroscience ICU consisting of only 4 questions: “(1) Does the patient have distressing physical or psychological symptoms? (2) Are there specific support needs for patient or family? (3) Are treatment options matched with patient-centered goals? (4) Are there disagreements among teams and family? (Creutzfeldt et al., 2015)” This tool was designed to be used during morning rounds and its implementation was associated with more documented family conferences and palliative care consultations when compared to a similar population that did not use the tool. (Creutzfeldt et al., 2015). Notably, these criteria are entirely subjective, yet, those patients that met these criteria were found to be more likely to die in the ICU or be transferred into comfort care, and they also had longer lengths of ICU and hospital stay. This validates that the subjective screening tool accurately identifies “patients at a higher risk of death and prolonged ICU and hospital stay (Creutzfeldt et al., 2015).” These criteria are also distinct from those used in the Columbia University study because they encompass those patients who may be appropriately served by palliative care consults for reasons other than physical morbidity or foreseen mortality. Indeed, the most commonly identified needs were social support (53%) and establishing
goals of care (28%) (Creutzfeldt et al., 2015). The goal of this screening tool was not to chart symptom prevalence, but rather “to prompt the ICU team to think about whether there were ongoing symptoms or needs that should be addressed (Creutzfeldt et al., 2015).”

The role of palliative care is broad. It is not particular to palliative care specialist physicians, but rather is a necessarily interdisciplinary effort of physicians, nurses, chaplains, social workers, mental health counselors, and any other resource that may ameliorate the distress associated with death or the death of a loved one. One of the central tenants of good palliative care is establishing common goals of treatment between the family and medical team; nurses, as the closest member of the health care team to the patient and their family, are essential to the communication necessary to establish these goals. This initiative must involve realistic and frank conversation about what can reasonably be expected from continued medical treatment. Thus, palliative care, while not exclusive of curative care, is also a natural conduit to timely hospice and end-of-life care from the inpatient setting. Further research ought to analyze the effect of increased palliative care utilization in ICUs on median hospice length of stay and family perceived timeliness of hospice referral.

**Recommendations and Conclusion**

The current divide between intensive medical care and appropriate palliative and end-of-life care is one that nursing is most perfectly poised to bridge. The underlying goal of those screening tools and interventions designed to optimize patient access to palliative care is to create a space in which the interdisciplinary health care team can discuss and
determine what interventions might be appropriate to address those unmet needs of that patient. These screening tools differ in scope, sensitivity, and specificity, but are only successful insofar as they raise the awareness of the health care team to patient family need so that it might be better addressed. This is a kind of patient advocacy. Patient advocacy is among the oldest and most central nursing virtues, so it follows that the push for the implementation of these systematic changes ought to be led by nursing.

Nurses’ presence at the bedside and opportunities to build relationships with patients and families uniquely positions them to assess patient and family needs, become aware of futility, and consequently facilitate end-of-life decision making conversations between the patient, family, and the rest of the health care team (Adams, Bailey Jr., Anderson, & Docherty, 2011). Whether used as part of team rounds or as an independent nursing assessment, screening tools can serve to objectively and systematically create the space for discussions about unmet palliative need and end-of-life care if necessary. In either case, this should be a nursing initiative and the nursing process can be used as a model to elucidate the role of the bedside nurse.

The particular form that a palliative care access initiative would take on a particular unit should be determined by the culture, need, and structure of that unit. This initiative could be a nursing QI project or the initiative of a shared governance committee to implement a pre-existing palliative need screening tool. It could begin as a bedside nursing assessment in which palliative need is assessed on a particular unit and data surrounding that need is gathered before presenting the discovered need to larger, interdisciplinary committees in an effort to change how rounds are conducted. The most comprehensive intervention would be nursing leadership leveraging evidence from the literature and data
from their unit to advocate for an interdisciplinary team to be assembled and tasked with working through the IPAL-ICU tool to design and implement a screening tool customized for that particular unit. Regardless of the route taken to implement the aforementioned interventions, palliative access is a matter of patient advocacy, and thus, a nursing responsibility. Prior to and in conjunction with these system changes, nursing teams and individual nurses should be educated on how to fit palliative access into the nursing process, especially into the nursing assessment.

The focus of the nursing “palliative need assessment” of the patient should be on those with distressing physical, psychological, or spiritual symptoms that have proved intractable or might be further helped by additional action on the part of the medical team or a palliative care consult. Crucial to this assessment is the input of the patient themselves and giving them the opportunity to express those aspects of their disease or treatment that are the most distressing for them. A nurse does not assess merely the objective reality of a disease and treatment process, but rather also has the duty to assess the phenomenological reality of that disease and treatment process. The nurse is equally accountable for the assessment of how a patient is experiencing and perceiving every aspect of disease and care. The focus of the nursing assessment of the patient-family unit should be on those areas where the literature shows common family barriers to palliative care. These include unrealistic or unclear goals of care, poor understanding of current treatment, and conflicts with the medical team (Creutzfeldt et al., 2015; Weissman & Meier, 2011). Upon a thorough assessment, the bedside nurse ought to diagnose distinct aspects of the current course of disease and treatment that are either directly causing patient distress or impeding the relief of patient distress. With these nursing diagnoses, the bedside nurse is in a position to
plan an intervention with the medical team. This intervention should leverage the
appropriate available resources. If the nursing diagnosis was “unrealistic patient and
family goals,” an appropriate intervention could be arranging a family meeting with the
medical team to determine more realistic set of goals and the most appropriate action to
achieve them. If the nursing diagnosis was intractable pain, nausea, or other physical
symptom, an appropriate intervention could be a change in medication or a consult to
palliative care services. The implementation of the planned intervention should involve the
family as much as is appropriate, as should the evaluation of the intervention. Continued
assessment as the patient and treatment changes is essential. The primary roles of the
nurse are to advocate for the patient, facilitate care, and communicate between the medical
team and the patient-family. Teaching how to integrate palliative care into the nursing
process would preferably happen in nursing school but could also be part of continuing
education or the focus of an internal nursing education project. This is a role of nursing at
every level of care, like all nursing initiatives: beginning at the bedside.

As previously discussed, those failures of intensive care to recognize and respond to
unmet palliative need are most often a failure of communication. Health care professionals
generally feel inadequately trained to know when and how it is appropriate to initiate
discussions on the end-of-life (Adams et al., 2011). Nursing education and research can
both benefit from renewed focus on evidence based ways to effectively approach difficult
discussions with family, especially those surrounding end-of-life. Physicians and nurses
need to be able to educate patients and families on the role of palliation in curative
treatment as well as the role of the health care team when further treatment is futile. These
conversations are undeniably difficult. Consequently, a study of ICU cultures shows that
such conversations often don’t occur until a do-not-resuscitate (DNR) order is discussed or the medical team proposes the insertion of a percutaneous endoscopic gastronomy (PEG) tube and a tracheostomy. These situations, many times, do not arise until prognosis is poor, the patient is on the verge of dying, and or the patient is unable to participate in the discussion (Adams et al., 2011). This pattern of delayed and fragmented communication directly contributes to the pattern of short hospice stays and unmet palliative care need. The aversion to broaching the subject comes from a gap in education. Studies show that a paucity of palliative care education and training contributes to poorer therapeutic communication skills, professional confidence, and coping skills regarding end-of-life care among healthcare workers that deal with terminally ill patients (Agustinus, 2013). It has been shown that the more conversations that healthcare workers have about death and the more palliative care education they have, the more positive their attitudes towards palliative care and working with terminally ill patients (Agustinus, 2013).

For these reasons, it is essential that palliative and end-of-life care be taught in nursing schools. This education should include:

1) The scope, services, and differences of palliative and hospice care as well as the evidence bases behind their need and benefit
2) How to integrate palliative care into the nursing process and routine nursing care
3) How to conduct a thorough palliative assessment of a patient and a patient’s family
4) How to communicate with patients and families about realistic goals of care
5) How to broach to topic of palliative care with patients in a variety of disease stages
6) How to broach the topic of end-of-life with patients and families without prognosticating or leaving the appropriate scope of nursing

7) How to broach the topic of unmet palliative need with providers

If possible, clinical rotations in hospice care offer the optimal venue to expose future nurses to the need for good end-of-life care, give them experience openly talking about and working with death, and ultimately prompt personal reflection and growth concerning the end of life. The skills of therapeutic communication, focused symptom assessment, and general poise around death come into their sharpest relief in hospice care. The evidence shows that nurses equipped with this experience will carry better attitudes about caring for dying patients into their various areas of practice (Agustinus, 2013). This educated willingness to talk about death and familiarity with the priorities of palliation will equip nurses to most effectively leverage those evidence-based tools to advocate for better and more appropriate palliative care in all areas of medicine, but especially in intensive care where the need for strong and systematic advocacy is the greatest. Thus so, nursing has a central role in introducing palliative care into the systems and cultures of intensive care units. This role needs to be brought to the forefront of nursing education and nursing care both to address the increasing need for palliative care and as a part of nursing's identity as the health care profession of patient care and advocacy.

Beyond the primary goal of providing more pertinent, cost effective care and empowering patients at all stages of disease to utilize those services available to relieve and help them cope with those areas of disease and treatment that are most distressing, ensuring timely access to palliative care will have profound effects for nursing as a profession. By instilling new nurses with a sense of responsibility for patient's access to
palliative care and further educating current nurses about how to most effectively advocate for palliative care, nursing as a profession will be empowered as the profession of patient advocacy. By asserting nursing’s role as patient advocate in the context of palliative and end-of-life care, nursing will further affix its identity as the conduit between patient needs and desires and the medical team’s services and priorities. On an individual level, education and training on effective advocacy surrounding palliative care, but even more so timely end of life care, can reasonably be concluded to increase job satisfaction due to ameliorated moral duress and increased comfort with caring for the terminally ill (Agustinus, 2013). Further research should be conducted to analyze the extent of this effect within a nursing staff that has employed palliative access interventions.

Palliative access is an essential element of healthcare economic sustainability, and more importantly an essential element of healthcare ethics. As intensive care becomes more aggressive and miraculous, nursing is responsible for advocating for patients and ensuring their understanding of and desire for every step in their experience of disease and treatment, especially those patients and families at the end of life. Access to palliative care is essential to this goal. Nursing is best poised to ensure it.
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