

Ethical Considerations in End-of-Life Discussions

Heidi Mason^{1*}, Mary Beth Derubeis¹, Natasha Mason¹ and Francis Worden¹ MD

¹Clinical instructor, Department of Health Behavior and Biological Sciences, University of Michigan School of Nursing, USA

*Corresponding author

Heidi Mason, Clinical instructor, Department of Health Behavior and Biological Sciences, University of Michigan School of Nursing, USA, Email: hmason@med.umich.edu

Submitted: 23 Feb 2018; Accepted: 02 Mar 2018; Published: 09 Mar 2018

Abstract

Every person deserves a dignified death. What this entails varies dramatically from patient to patient. Most people, however, never discuss their wishes regarding the care they desire for this very personal, final journey. As technology improves, as well as the ability to successfully treat almost any condition, both patients and clinicians alike have begun to ignore the reality of death. In this paper, the term clinicians will refer to doctors and nurses. In our present culture discussing death has become taboo. Patients may think about the end of their lives but are unsure or uncomfortable broaching the topic with their medical staff and families. Additionally, many clinicians are uneasy with end-of-life (EOL) discussions and, consequently, avoid them entirely. It is, however, the ethical responsibility of health care providers to address their patient's wishes regarding EOL care. Clinicians need to take the initiative to begin the conversation regarding prognosis and care choices. They need to make the patients feel that they can comfortably discuss this delicate issue without fear of judgment, pressure, or the possibility of abandonment. Ethical dilemmas are common when caring for a dying patient, often a direct result of avoiding or delaying difficult, EOL conversations [1]. By not adequately preparing patients for the dying process, clinicians are in danger of ignoring the ethical principles of autonomy, justice, beneficence and non-maleficence. Nurses and physicians alike share this responsibility, although nurses have historically shied away from this obligation. The American Nurses Association (ANA), the premier nursing organization representing registered nurses throughout the U.S., leaves no doubt that it is nurses' ethical duty to assure that patients have a dignified death - one that respects their spiritual, emotional, and physical needs, as well as those of their families. This duty is spelled out in the Nursing Code of Ethics. Nurses are called on to identify barriers that prevent early EOL discussions with patients so that they may work to eliminate them and ultimately improve the patient's ethical rights to a good death. Nurses should challenge themselves to break through these barriers to ensure that patients are able to die in a manner consistent with their beliefs and values.

Introduction

According to Borowske, a good death entails freedom from all avoidable distress and suffering for patients, their families, and their caregivers [2]. Furthermore, it is one aligned with the patient's wishes and reasonably consistent with clinical, cultural and ethical standards. Although the literature demonstrates diminished quality of life for patients who die in the ICU or hospital, many patients experience ICU visits within 30 days of death [3, 4]. If patients do not have specific information regarding their prognosis and are consequently unable to make decisions regarding their care goals prior to an emergency, a trip to the ER becomes the default. Additionally, aggressive and futile treatment at the EOL is not only contributing to the ever-increasing cost of health care, but is also depriving patients of the ability to die with dignity. More often than not, patients who are aware of a bad prognosis will choose less aggressive treatment at the end of life [5]. Regardless, the medical culture is reluctant to abandon the "fix and solve" mentality. As nurses, we have an ethical responsibility to treat our patients with compassion, respect, and dignity. We are charged with assuring

that every patient has the best possible care at the end of their life, one that does not prolong the dying process. It is our responsibility as clinicians to avoid unwarranted, unwanted, and unnecessary treatment. Patients must be our number one priority and it is our duty to assure their safety, avoid unnecessary suffering, and provide competent and compassionate care [6]. A "fix and solve" mentality is one of the barriers to effectively discussing EOL care. That mentality, coupled with a lack of confidence and education on how to approach the subject often leads to a complete avoidance of this discussion. Frequently, clinicians are uncertain about when they should begin to address EOL care and even fear upsetting their patients or dispelling hope. Furthermore, lack of education in EOL care prevents clinicians from overcoming these barriers. Nurses feel ill-equipped to discuss EOL issues and can be uncomfortable when their values differ significantly from their patients [7]. This is a direct result of lack of education and hands-on experience. Anstey found that, at the present time, education designed specifically for nurses who work with dying patients in nursing homes is not adequate, even though education is known to be the most important avenue for improving

end-of-life care [8]. According to Glover et al, 85% of BSN students did not feel properly prepared to care for dying patients prior to their exposure during clinical rotations [9]. Furthermore, Sinha states that EOL education is lacking in the nursing curriculum [10]. The end result is nurses who do not possess sufficient knowledge or skill to discuss and assist patients as they formulate their end-of-life goals. When nurses lack these skills, the result is more distress, unwanted and often futile aggressive treatment, prolonged suffering, survivor guilt, and overall dissatisfaction with EOL care.

There are many other barriers to effectively discussing a patient's end-of-life wishes. According to Pavlish, physicians and nurses have very different philosophies of care [11]. Physicians are taught to function in a "fix and solve" mode, while nurses rely on a holistic care approach that includes helping patients attain a good death. More often than not, there is a clear hierarchy of leadership in medicine with physicians being placed at the top. Even when there is not a hierarchical relationship, nurses and physicians will often work parallel to each other, but not as a team [12]. When they are not working as a team, nurses feel unable to advocate for their patients. They often remain silent, even if they disagree with the physician's plan to continue aggressive treatment [7, 13]. Lack of interdisciplinary work, especially in EOL care, results in an over-reliance on the medical model, thereby ignoring the nursing component of addressing the patient's and family's response to treatment and illness, ultimately resulting in less comprehensive and holistic care.

Additionally, there are plenty of administrative barriers to productive EOL discussions. Advance directive, or living will, documents are beneficial, but they have little meaning if the provider does not understand and respect the values and meaning behind them. Moreover, if the patient has not discussed their wishes openly with their clinician and their family, these documents may not be utilized or interpreted correctly, especially in an emergency situation [14]. It has become too common for patients to receive advance directive materials without a meaningful discussion. Because many institutions stress efficiency, there has been a severe decrease in time allotted for EOL discussions [11]. In addition to stressing efficiency, care rotations are frequently the norm in a busy hospital setting. This translates into the patient and family having several changes in their care team throughout their hospitalization. The result can be a decrease in continuity and personalized care. When clinicians are unable to develop a meaningful relationship with their patients, the culture of avoidance is perpetuated [11]. Additionally, Barbor notes that clear guidelines regarding how and when to discontinue aggressive treatment are lacking at most institutions, further complicating the transition to palliative care [15]. As discussed above, the hierarchical culture in many institutions can also lend itself to a lack of open communication among providers. When difficult EOL situations arise, poor communication among clinicians can lead to ethical dilemmas which then accumulate over time. As a result, clinicians may begin to lose perspective and eventually experience compassion fatigue [1, 16]. EOL conversations take time, patience and empathy. They can be difficult and emotionally charged. So, for a clinician who is experiencing compassion fatigue, a conversation of that nature can be extremely difficult.

Patients, families and clinicians can all present as to timely EOL discussions. According to Barbor, when patients are unaware that they have a poor prognosis and lack understanding regarding the

complications of life-sustaining procedures, they are more apt to push for aggressive care that may be deemed futile by clinicians [15]. Furthermore, patients and families may not be ready to accept a poor prognosis which can lead to unrealistic expectations. This is especially true when they have not been given honest information regarding the situation. Clinicians may back away from a difficult discussion if the patient begins to talk about their will to live and desire to do whatever is necessary for a cure or longer life. Additionally, when the patient has multiple services involved in their care, they may receive varying facts on their condition. Providers may disagree on prognosis and treatment, leaving the patient trying to decipher which information is accurate. Instead of guiding patients through difficult decisions, clinicians can add to the barriers that already exist.

There are four basic ethical principles that must guide nursing practice, as well as the role they play in EOL preparation. The first of these is autonomy. According to this principle, patients should maintain maximum control over their lives and their values. This reflects our respect, as clinicians, for the patient's ability to form their own decisions, as well as our duty not to treat them in a patronizing manner. According to Davies and Higginson, autonomy is a basic right and should be a core ethical value, regardless of how complicated or difficult the situation may be [17]. Patients cannot direct their own care if they are unclear about their prognosis, treatment and care options. This is why it is essential to start these EOL discussions early on, presenting patients with all the relevant information necessary to make informed choices regarding their care. Clinicians often wait for patients and their families to broach the subject of death rather than initiating it themselves. And, more often than not, the patient is unsure of when, or even how, to ask some of these questions [18]. Morgan et al found that the majority of terminal patients would choose to opt out of aggressive treatment when they have a full understanding of their prognosis [5]. In order for a person to exercise autonomy, they need to be able to think through all of their choices in order to make an informed decision, therefore, discussions need to begin as early as possible to avoid the cognitive changes that are frequently seen with progression of disease and may even lead to the patient's inability to make these decisions [19]. Providers often fear harming their relationship with patients by bringing up EOL issues and possibly destroying the patient's hope [11, 31]. Many clinicians also feel unprepared to confront the vast range of emotions related to patient and family grief. Anger, tears, pleading, all normal stages of grief, can be difficult to handle and will often cause the provider to avoid discussing a poor prognosis [20, 21]. All of these factors, combined, will lead to further delay in honest and open discussions, leading to additional suffering for patients and families, as well as the loss of their ethical right of autonomy. Nurses have an ethical obligation to safeguard their patient's autonomy.

Although autonomy is a basic right, information regarding prognosis must also be given within the boundaries of the patient's desire and emotional ability to hear and process that information. The second principle, non-maleficence, states that harm should not be inflicted upon patients. All EOL discussions need to be done with sensitivity and honesty. Depending on what state emotionally, spiritually or physically, the patient is in, it may be necessary for clinicians to re-evaluate the amount of information the patient is ready to hear. More importantly, it is not just the information the clinician is giving to the patient, but the manner in which it is delivered. These discussions must be done in a way the patient is able to receive and

understand, otherwise they can ultimately cause harm. While they take patience and time, these conversations must be had because patients need vital information, as well as appropriate time to provide informed consent [19]. Wilson et al discusses the clinician's responsibility to discuss a poor prognosis in a manner that attempts to minimize undue distress [22]. This may require a longer process, one that allows patients enough time to reflect on and adjust to the information they are given. Conversely, when clinicians withhold information or avoid conversations due to their own discomfort, lack of education, or because they simply feel that they do not have the time, they are in fact, perpetuating maleficence. Maleficence also entails subjecting patients to aggressive, non-beneficial treatments that can cause unnecessary suffering and prolongation of the dying process. When patients are deprived of the right to die as they wish or the right to die in a dignified manner, the principle of non-maleficence has been ignored.

The next principle is beneficence. This principle calls for promoting what is best for the patient. In other words, it is the opposite of non-maleficence. Beauchamp and Childress define beneficence as not causing harm, but preventing harm, removing harm, and promoting what is best for the patient [23]. As a result, nurses have the ethical duty to advocate for the best possible medical treatment with the least possible harm. Before consenting to any treatment, patients need to understand three things: their prognosis, the risks of treatment, and the benefits of treatment. They need to know about all possible treatment options, including the option of no treatment. Again, this means that clinicians need to be honest and clear about the patient's condition even when these discussions are uncomfortable. The objective is to find the best way to balance quality of life with potential treatment options, while still maintaining the EOL goals set by the patient. According to a study by Downey et al, clinicians were more apt to err on the side of being more aggressive than their patients necessarily wanted [24]. The study concluded that costly, unwanted treatment could result when providers made treatment decisions based upon their perception of what the patient wanted rather than what the patient actually wanted. When nurses discuss EOL goals with the patient and their family, they are able to promote what is in the best interest of the patient. Generally speaking, those discussions are often associated with less aggressive care, which improves the quality of life for patients and concurrently improves adjustment for bereaved family and loved ones. Unless the clinician asks, there is no way to know the patient's wishes for their EOL care. Nurses have an ethical responsibility to assure that their patients have the best possible care, safe from unnecessary risks and suffering. Doing this will allow them to uphold the principle of beneficence.

The last principle, justice, mandates fair and equitable treatment of all patients. How resources are utilized, especially when health care costs are skyrocketing, can be placed under this principle. Is aggressive treatment for dying patients an ethical use of health care resources? Donley and Danis discuss the ethical implications for talking to patients about EOL cost [25]. Aggressive EOL care can be very costly and patients do not always understand what aggressive care at the EOL entails or what the costs are. Loved ones can be left with huge bills for treatments that were not of any value to the patient. Extensive cost for futile care may not be the most effective approach. However, there are many concerns about having these discussions. For example, poorer patients may opt for less treatment to avoid these costs, even when there may be benefit. Additionally, less-educated patients may not be able to effectively argue for

treatment that is justifiable yet costly. They may not understand when to switch to palliative care versus when to fight for continued aggressive treatment. Another concern with discussing the cost of EOL care is the risk of overwhelming patients at a time when they are already under extreme duress. Many clinicians believe this is an aspect of care that patients should not be worried about. According to Beauchamp and Childress, the concept of justice is centered around the allocation of services and treatment, which should be based on need and merit [23]. On the opposite side of things, there are patients who wish to continue with aggressive treatment, even when their clinicians know that it is futile and potentially harmful. Yet, Morgan et al found that this happens more often when the patient and their family do not fully understand the prognosis, risk, benefits, and alternatives to treatment [5]. Some oncologists view late chemotherapy as a way to maintain hope and treat emotional distress in the patient or family [26]. Aggressive care at the end of life is often patient-driven, frequently based on lack of knowledge regarding what their choice entails, as well as what alternatives are available. Avoiding EOL discussions does not treat emotional distress or maintain hope. Unfortunately, it can often do the exact opposite by causing more pain and suffering at the end of life. The misallocation of services and treatment due to the lack of EOL discussions does not promote the principle of justice. When nurses are able to break past this barrier, they can begin to uphold the principles as outlined in the nursing code of ethics.

Nurses have an ethical responsibility to prepare their patients for the dying process, as evident in the ANA Nursing Code of Ethics [6]. Nursing practice is built on the foundation of holistic care and the premise that health is not simply the absence of disease. Margaret Newman's theory of health as expanding consciousness was developed with a focus on those patients for whom absence of disease or disability is not possible [27]. Nurses care for patients facing uncertainty, debilitation, loss, and eventual death on a daily basis. Newman's theory claims that every person, regardless of their physical, psychological, or social situation, is part of the universal process of expanding consciousness. She defines it as a process of becoming more of oneself, finding greater meaning in life and reconnecting or connecting more deeply with their loved ones [27]. All patients should be given this opportunity in the final stages of their lives. Nurses, especially bedside nurses, develop strong relationships with their patients and families. Their day-to-day care increases their awareness of the family dynamics, values, and EOL wishes. Nurses are also in a key position to notice the subtler signs that a patient is making the transition away from aggressive treatment and into palliative care [28]. Because of the role they play in their patient's care and lives, nurses are perfectly situated to aid in this transition. Both Lewis and Adams et al note that the nurse serves as care provider and educator as well as patient advocate [29, 30]. They are in the best situation to help facilitate discussions between patients and their doctors, establishing an acceptable EOL plan that respects the patient's autonomy and promotes beneficence, non-maleficence, and justice. It is clear that nurses should play a vital role in EOL discussions, care planning, and the care of the dying patient.

The real question, then, is how can these barriers to a timely and dignified EOL discussion be eliminated? Communication actually helps decrease anxiety. Often patients and their families will worry more about what is not said, believing that the physician may not be able to face the truth. Clayton found that open discussions, utilizing

truth and compassion, are a more beneficial way to build hope, as opposed to disguising the truth [31]. The literature supports that early and open discussions regarding EOL can empower patients, improve hope and quality of life, and help relieve families from making hard decisions on their loved one's behalf [31-34]. Decisions regarding life support or discontinuation of aggressive care should be made with the patient's input so that family members are not forced to make them on their own. Improving interdisciplinary communication between nurses and physicians is also important. Successful communication allows nurses to feel as though their input regarding the patient's plan of care is valued. Since medicine and nursing approach patient care from different perspectives, integrating the two views will allow for a more holistic plan of care. Larabee and Friese both found that improved nurse-physician communication, plus collegial working conditions, translate into increased patient satisfaction and improved quality of care [35, 36]. Additionally, interdisciplinary education helps to promote better communication and collegial practice. One way to enhance nurse-physician communication is by implementing interdisciplinary education opportunities for medical students and nursing students. Having these two groups work together in simulated scenarios will allow them to begin to understand how their roles can be synergistic.

Education is another method of breaking down the barriers to timely EOL discussions. This is especially important because many nurses feel ill-equipped to address prognosis and EOL goals with patients [7]. Milic et al conducted an eight-hour workshop with ICU nurses. Nurses were able to practice communication skills during simulated experiences, followed by time for reflection. Burnout and self-care issues were also discussed. Following the workshop, participants described improved confidence and skills in assessing a patient's understanding of their prognosis and goals of care, as well as addressing their patient's emotional concerns. Additionally, they were able to actively participate in family meetings [37]. It is clear that when nurses feel comfortable with their ability to discuss end-of-life goals with patients, they can begin to participate more fully in their patient's care. This will ultimately improve EOL care, as well as overall nursing satisfaction. Gillett and Bryan developed a program called Quality End of Life Care for All (QELCA). This program involves bedside nurses shadowing hospice nurses and then engaging in six months of EOL training. Nurses who participated in this program stated that it had a significant impact on their practice. They felt more comfortable discussing EOL goals and caring for dying patients. They were more apt to initiate changes to improve their ability to begin timely discussions regarding a patient's goals of care [38]. Glover et al conducted an End-of-Life Nursing Education Consortium (ELNEC) core course with BSN students. This course resulted in students with an improved knowledge of EOL care [9]. Gillan et al found that having nursing students participate in simulated end-of-life scenarios, followed by reflection, was beneficial in improving their comfort with EOL discussions [39]. According to Coombs et al, education in EOL care decreases the clinician's distress and improves their decision-making and communication skills. It also enhances teamwork at the bedside, while promoting patient-centered care [40]. Clearly, education in EOL care is vital in improving the comfort level of nurses as they care for the dying patient. Not only will nurses begin to take on a larger role in planning their patient's care, but they will also begin to implement a more holistic approach to EOL care.

Community education is also necessary for a successful move to

earlier EOL planning. We are not a society that talks about EOL. Therefore, patients are unprepared when faced with the concept of death. Patients frequently rely on our medical system in times of crisis and often hold on to unrealistic expectations regarding the effectiveness of treatment. Many patients and their families view hospice or cessation of aggressive treatment as giving up, a sign of weakness. Some have even been told that a positive attitude and fighting spirit can overcome anything. Many books have been written on this concept and the patients who have overcome the odds are celebrated. Yet, this is not a realistic expectation since everyone will eventually die. Overcoming these unrealistic societal expectations may seem daunting. However, the early education of patients on all available options will allow the opportunity to do so. Coombs et al discusses the concept of societal education [40]. Since people do not have a clear picture of what dying in the ICU or ER looks like, it is difficult for them to accept the concept of hospice or palliative care. They do not always understand what resources are (or are not) available. When a patient is in the middle of a crisis situation it is too late to begin educating them. Rather, early intervention, education, and preparation gives way for patients to process the end of their life, and their EOL goals, in order to make an informed decision regarding their care. Accomplishing this will allow nurses to uphold all of the principles, autonomy, non-maleficence, beneficence and justice.

An ethically centered practice environment is also beneficial to improving EOL care. When clinicians are unable to voice concern or disagreement regarding their patient's care, they can experience ethical distress. This is especially true for nurses who often identify with the role of patient advocate. When these ethical struggles are ignored, they can build upon each other and affect the clinician's ability to make decisions. Additionally, as these conflicts are allowed the time to simmer, they can erupt suddenly, causing the clinician to experience emotional exhaustion and moral insensitivity [1]. Nurses feel more moral distress and have a more negative view of the ethical environment than physicians. Nurses are also less satisfied with the quality of their patient's EOL care. When nurses feel as though they are unable to advocate for their patients they experience anguish, compassion fatigue and distress [41]. Clinicians need a safe place to debrief and share their perspectives. This can allow nurses and physicians the opportunity to support one another and discuss strategies to navigate through difficult situations. Santiago and Abdool instituted a monthly ethical debriefing meeting. It resulted in team cohesiveness, as they were able to address concerns prior to a meeting with the patient and their family. Furthermore, they were able to establish a multidisciplinary plan that could be placed in the chart, allowing for improved consistency of care. It also allowed all parties involved to have a voice in the EOL plan [16]. Pavlish et al also describes the importance of establishing moral communities in the practice environment [1]. This establishes the expectation that all clinicians will have honest and timely communication with their patients. However, leadership that promotes an ethical environment must first be established. Readily available resources, as well as clinician awareness and willingness to use these resources, is also necessary. Patient-centered, holistic care should be the foundation of every practice and every decision. All ethical conflicts should be addressed swiftly and with open, respectful discussion.

Discussions regarding EOL care should begin early on and should not stop. It is essential that they continue throughout the entire care process, as patient's preferences may change as they grow nearer to death. As patients progress in their illness, they may lose their ability

to make competent decisions for themselves. If we want to preserve their personal autonomy, EOL discussions and decisions need to be initiated early on [42]. Patients and their families alike suffer when these decisions are not initiated. According to Lever, these early conversations not only improve the patient's personal integrity but will also help families as they deal with decisions regarding the terminal care of their loved ones [43]. When families are forced to make decisions without guidance or the reassurance that they are doing what their loved ones want, they can experience both guilt and emotional stress. Additionally, early and continued discussions may lead to the use of palliative care services much sooner. Palliative care services can help treat depression related to death, as well as improve hope, quality of life, coping skills, and dignity. Early palliative care may also increase the frequency of EOL conversations [33, 34]. Clinicians trained in palliative and hospice care understand that supportive care can make drastic improvements to a patient's physical, psychological, social, and spiritual functioning. Because hospice care concentrates on improving the quality of life of patients, patients often experience a longer life span when compared to those receiving aggressive treatment [44]. This is an important topic to discuss with patients when they are reluctant to stop aggressive therapy. It is evident that honest and early discussion throughout a patient's care allows palliative care or hospice to get involved sooner, consequently avoiding aggressive, futile treatments. The goal of all end-of-life care should be to enhance the quality of life of patients so that they may spend their final days as comfortable as possible, allowing them to pursue activities of their choosing.

Nursing theory and training in holistic care prepares nurses for difficult EOL discussions. Holistic care involves addressing the spiritual needs of patients which is important when working with terminal patients. When hope for a cure is no longer possible, hope needs to be redefined in the context of symptom management, inner peace, relationships, and faith or beliefs [31]. Spirituality is more than religion, it encompasses how people seek meaning in their lives [14]. Newman's theory of health as expanding consciousness describes the opportunity for patients to achieve health as they are dying. Even in the final stages of life, personal fulfillment and growth are still possible [27]. Advance care documents are more than just written guidelines, they reflect the beliefs, customs, and values of the patient and family. They are both personal and unique. Clinicians should strive to understand them through the eyes of their patient [14]. Every EOL plan of care needs to be individualized, taking into account the unique values, customs, spiritual beliefs, social, and economic circumstances of the patient [45]. Nurses are uniquely trained to engage in EOL discussions with their patients. They are prepared to care for each patient in a holistic and compassionate fashion.

Clinicians often fear that broaching EOL topics may have a negative effect on their relationship with the patient. They worry that their words may shatter any hope the patient and family may have. Yet, at the same time, it is the nurse's responsibility to advocate for their patient, safeguarding their autonomy. This is not possible without understanding their EOL goals. While having advance care documents in place is important, this does not replace open and honest communication between the provider, patient, and family [46]. Communication is a powerful and underutilized tool. Clayton found that avoiding the truth did not promote hope, and that, in fact, honest and empathic communication empowered patients, as well as increased their hope [31]. Additionally, the manner in which information is worded can be very potent. Carefully choosing words

can make a difference in how the patient receives the information the clinician is giving them. For example, the word "futile" implies that the patient is not worthwhile or that aggressive treatment is wasted on them. Using "appropriateness of care" relays the message but sounds more personal and caring [47]. Furthermore, the words "withdrawing care" may be misconstrued as no longer caring for the patient. Describing how a breathing tube would not improve the patient's status and may actually cause pain and discomfort can relay your ultimate concern with their loved one's well-being [48]. Care is never withdrawn, it is just redirected toward symptom management and comfort. Communicating that to a patient conveys that you, as a clinician, still care and are invested in their life. Poor communication is hurried with the healthcare provider doing all of the talking, typically using medical jargon the patient does not understand, while being distant and not engaged. Good communication is the opposite; it is not rushed, simple words are used, and clinicians listen more and talk less. Information is given in small bits at a time, following cues from the patient and family. Most importantly, the provider is empathetic and truly present [48]. This means turning the pager off or on vibrate, making eye contact, not typing or writing notes. To assure that the clinician has the time they need to engage in EOL discussions, they must utilize these same communication techniques with their colleagues. They may need to solicit other staff to cover their pager, have the clerical staff schedule the patient at the end of the day, or block out extra time in the schedule for these patients. EOL conversations need to be timely, honest, and planned [11]. Although waiting for the patient to initiate the discussion is not appropriate, the discussion does need to be based on the patient's ability and willingness to hear the information. It may need to be given over a period of time to allow the patient and their family to process it. According to Wilson, sensitivity and balance are required [22]. The goal is to allow autonomy while promoting beneficence.

Regrettably, planning for the EOL often occurs in the final days or even hours when, in actuality, it should be occurring over an extended period of time, with a trusted provider well-known to the patient. Nurses are in a unique role to initiate EOL conversations. While a physician's focus is on treatment and cure, the goal of nursing care is centered on improving the patient's quality of life and the ability to function as normally and independently as possible [22, 49, 50]. This perfectly positions nurses to take the lead in assisting patients as they transition to the final stage in their lives. The nursing code of ethics demands that nurses uphold the ethical virtues of autonomy, beneficence, non-maleficence and justice [6]. Hence, timely discussions regarding EOL goals and wishes of patients is important in order to deliver competent, compassionate and ethical care.

References

1. Pavlish C, Brown-Saltzman K, Jakel P, Fine A (2014) The nature of ethical conflicts and the meaning of moral community in oncology practice. *Oncol Nurs Forum* 41: 130-140. <http://dx.doi.org/10.1188/14.ONF.130-140>
2. Borowske D (2012) Straddling the fence: ICU nurses advocating for hospice care. *Crit Care Nurs Clin North Am* 24: 105-116. <http://dx.doi.org/10.1016/j.ccell.2012.01.006>
3. Zhang B, Nilsson M, Prigerson H (2012) Factors important to patients' quality of life at the end of life. *Arch Intern Med* 172: 1133-1142. <http://dx.doi.org/10.1001/archinternmed.2012.2364>
4. Teno JM, Gozalo PL, Bynum JPW et al. (2013) Change in end-of-life care for Medicare beneficiaries: Site of death, place of

- care, and health care transitions in 2000, 2005, and 2009. *JAMA* 309: 470-477. <http://dx.doi.org/10.1001/jama.2012.207624>
5. Morgan L, Howe L, Whitcomb J (2011) Improving communication and cost-effectiveness in the intensive care unit through palliative care. *Dimens Crit Care Nurs* 30: 133-138. <http://dx.doi.org/10.1097/DCC.0b013e31820d2114>
 6. American Nurses Association. Code of Ethics for Nurses with Interpretive Statements. Silver Spring, MD: NursesBooks.org; 2001.
 7. Costello J (1995) Helping relatives cope with the grieving process. *Prof Nurse* 11: 89-92.
 8. Anstey S, Powell T, Coles B, Hale R, Gould D (2016) Education and training to enhance end-of-life care for nursing home staff: A systematic literature review. *BMJ Support Palliat Care* 6: 353-361. <http://dx.doi.org/10.1136/bmjspcare-2015-000956>.
 9. Glover TL, Garvan C, Nealis RM, Citty SW, Derrico DJ (2017) Improving end-of-life care knowledge among senior baccalaureate nursing students. *Am J Hosp Palliat Care*, PMID: 28193106
 10. Sinha P, Murphy SP, Becker CM, et al. (2015) A novel interprofessional approach to end-of-life care education: A pilot study. *J Interprof Care* 29: 643-645. <http://dx.doi.org/10.3109/13561820.2015.1041585>
 11. Pavlish C, Brown-Saltzman K, Fine A, Jakel P (2015) A culture of avoidance: Voices from inside ethically difficult clinical situations. *Clin J Oncol Nurs* 19: 159-165. <http://dx.doi.org/10.1188/15.CJON.19-02AP>
 12. Curtis JR, Shannon SE (2005) Transcending the silos: Toward an interdisciplinary approach to end-of-life care in the ICU. *Intensive Care Medicine* 32: 15-17. <http://dx.doi.org/10.1007/s00134-005-2865-0>
 13. Malloy D, Hadjistavropoulos T, McCarthy E, et al. (2009) Culture and organizational climate: Nurses' insights into their relationship with physicians. *Nurs Ethics* 16: 719-733. <http://dx.doi.org/10.1177/0969733009342636>
 14. Churchill LR (2014) Embracing a broad spirituality in end of life discussions and advance care planning. *J Relig Health* 54: 759-764. <http://dx.doi.org/10.1007/s10943-014-9988-y>
 15. Barbor M (2016) Family/patient-related factors main barriers to end-of-life discussions. *Palliat Care* 6.
 16. Santiago C, Abdool S (2011) Conversations about challenging end of life cases: Ethics debriefing in the medical surgical intensive care unit. *Dynamics* 22: 26-30.
 17. Davies E, Higginson IJ. *Better Palliative Care for Older People*. Copenhagen, Denmark: World Health Organization, Regional Office for Europe; 2004. <http://apps.who.int/iris/handle/10665/107563>
 18. Barclay S, Maher J (2010) Having the difficult conversations about the end of life. *BMJ* 341: c4862-4862. <http://dx.doi.org/10.1136/bmj.c4862>
 19. Green D (2013) HSC 3048: Support individuals at the end of life—part 2. *Nurs Res Care* 15: 501-504. <http://dx.doi.org/10.12968/nrec.2013.15.7.501>
 20. O'Grady E, Dempsey L, Fabby C (2012) Anger: A common form of psychological distress among patients at the end of life. *Int J Palliat Nurs* 18: 592-596. <http://dx.doi.org/10.12968/ijpn.2012.18.12.592>
 21. Alexander SC, Pollak KI, Morgan PA, et al. (2010) How do non-physician clinicians respond to advanced cancer patients' negative expressions of emotions? *Support Care Cancer* 19: 155-159. <http://dx.doi.org/10.1007/s00520-010-0996-5>
 22. Wilson F, Ingleton C, Gott M, Gardiner C (2013) Autonomy and choice in palliative care: Time for a new model? *J Adv Nurs* 70: 1020-1029. <http://dx.doi.org/10.1111/jan.12267>
 23. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 5th edition. NY: Oxford University Press; 2001.
 24. Downey L, Au DH, Curtis JR, Engelberg RA (2013) Life-sustaining treatment preferences: Matches and mismatches between patients' preferences and clinicians' perceptions. *J Pain Symptom Manage* 46: 9-19. <http://dx.doi.org/10.1016/j.jpainsymman.2012.07.002>
 25. Donley G, Danis M (2011) Making the case for talking to patients about the costs of end-of-life care. *J Law Med Ethics* 39: 183-193. <http://dx.doi.org/10.1111/j.1748-720X.2011.00587.x>
 26. Bluhm M, Connell CM, De Vries RG, Janz NK, Bickel KE, et al. (2016) Paradox of prescribing late chemotherapy: Oncologists explain. *J Oncol Pract* 12: e1006-e1015. <http://dx.doi.org/10.1200/JOP.2016.013995>
 27. Newman, M. *Health as Expanding Consciousness*. currentnursing.com. http://currentnursing.com/nursing_theory/Newman_Health_As_Expanding_Consciousness.html. Updated November 14, 2011. Accessed June 08, 2017.
 28. McMillen RE (2008) End of life decisions: Nurses perceptions, feelings and experiences. *Intensive Crit Care Nurs* 24: 251-259. <http://dx.doi.org/10.1016/j.iccn.2007.11.002>
 29. Lewis K (2013) How nurses can help ease patient transitions to end of life care. *Nurs Older People* 25: 22-26. <http://dx.doi.org/10.7748/nop2013.10.25.8.22.e479>
 30. Adams JA, Bailey DE, Anderson RA, Docherty SL (2011) Nursing roles and strategies in end-of-life decision making in acute care: A systematic review of the literature. *Nursing Res Pract* 2011: 1-15. <http://dx.doi.org/10.1155/2011/527834>
 31. Clayton JM, Hancock K, Parker S, et al. (2008) Sustaining hope when communicating with terminally ill patients and their families: A systematic review. *Psychooncology* 17: 641-659. <http://dx.doi.org/10.1002/pon.1288>
 32. Larkin PJ (2010) Listening to the still small voice: The role of palliative care nurses in addressing psychosocial issues at end of life. *Prog Palliat Care* 18: 335-340. <http://dx.doi.org/10.1177/1743291X10Y.0000000002>
 33. Brown H, Johnston B, Östlund U (2011) Identifying care actions to conserve dignity in end-of-life care. *Br J Community Nurs* 16: 238-245. <http://dx.doi.org/10.12968/bjcn.2011.16.5.238>
 34. Greer JA, El-Jawahri A, Pirl WF, et al. (2016) Randomized trial of early integrated palliative and oncology care. *J Clin Oncol* 34: 104-104.
 35. Larrabee J, Ostrow C, Withrow M, Janney M, Hobbs G, et al. (2004) Predictors of patient satisfaction with inpatient hospital nursing care. *Res Nurs Health* 27: 254-268. <http://dx.doi.org/10.1002/nur.20021>
 36. Friese, CR (2005) Nurse practice environments and outcomes: Implications for oncology nursing. *Oncol Nurs Forum* 32: 765-772. <http://dx.doi.org/10.1188/05.ONF.765-772>
 37. Milic MM, Puntillo K, Turner K, et al. (2015) Communicating with patients' families and physicians about prognosis and goals of care. *Am J Crit Care* 24: e56-e64. <http://dx.doi.org/10.4037/ajcc2015855>
 38. Gillett K, Bryan L (2015) 'Quality End of Life Care for All' (QELCA): The national rollout of an end-of-life workforce development initiative. *BMJ Support Palliat Care* 6: 225-230. <http://dx.doi.org/10.1136/bmjspcare-2014-000816>
 39. Gillan PC, van der Riet P, Jeong S (2016) Australian nursing

- students' stories of end-of-life care simulation. *Nurs Health Sci* 18: 64-69. <http://dx.doi.org/10.1111/nhs.12233>
40. Coombs M, Long-Sutehall T, Shannon S (2010) International dialogue on end of life: challenges in the UK and USA. *Nurs Crit Care* 15: 234-240. <http://dx.doi.org/10.1111/j.1478-5153.2010.00408.x>
 41. Hamric AB, Blackhall LJ (2007) Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Crit Care Med* 35: 422-429. <http://dx.doi.org/10.1097/01.CCM.0000254722.50608.2D>
 42. Waterworth S, Gott M (2010) Decision making among older people with advanced heart failure as they transition to dependency and death. *Curr Opin Support Palliat Care* 4: 238-242. <http://dx.doi.org/10.1097/spc.0b013e328340684f>
 43. Lever JA, Seymour J, Gott M, Bellamy G (2005) 5 themes described the views of older people on advance care statements and their role in end of life care. *Evid Based Nurs* 8: 64-64. <http://dx.doi.org/10.1136/ebn.8.2.64>
 44. Temel JS, Greer JA, Muzikansky A, et al. (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363: 733-742. <http://dx.doi.org/10.1056/NEJMoa1000678>
 45. Code of Ethics for Registered Nurses: 2008 Centennial Edition. nurses.ab.ca. http://www.nurses.ab.ca/content/dam/carna/pdfs/DocumentList/EndorsedPublications/RN_CNA_Ethics_2008.pdf Accessed June 8, 2017.
 46. Piemonte NM, Hermer L (2013) Avoiding a “death panel” redux. *Hastings Cent Rep* 43: 20-28. <http://dx.doi.org/10.1002/hast.190>
 47. Storch J (2015) Ethics in practice: At end of life — part 2. *Can Nurse* 111: 20-22.
 48. Cramer, CF (2010) To live until you die. *Clin J Oncol Nurs* 14: 53-56. <http://dx.doi.org/10.1188/10.CJON.53-56>
 49. Pfeil TA, Laryionava K, Reiter-Theil S, Hiddemann W, Winkler EC (2014) What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key. *Oncologist* 20: 56-61. <http://dx.doi.org/10.1634/theoncologist.2014-0031>
 50. Valente SM (2004) End-of-life challenges. *Cancer Nurs* 27: 314-319. <http://dx.doi.org/10.1097/00002820-200407000-00008>

Copyright: ©2018 Heidi Mason, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.