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Why End-of-Life Discussion Matters: A Systematic Literature Review

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Abstract

End-of-life (EOL) discussions are a challenging yet vital topic of conversation in intensive care units (ICU) between healthcare providers, patients, and their families. There is great disparity in where, when, and how EOL discussions take place, but the consequences of neglecting their importance can be devastating physically, psychologically, and financially for all parties involved. Multiple inadequacies in the EOL discussion process have not only contributed to a personal and societal financial burden but an unacceptable quality of death for many ICU patients. A literature review was performed to determine what practice and policy changes could be made to improve EOL discussion between healthcare providers and their patients. A total of seven articles met criteria. Main findings revealed deficits in areas including provider education, congruence of care, and clear communication. Advance care directives, prognostic estimators, and early and structured communication played a role in some improvement in these inadequacies. These findings have the capability of guiding us toward improved EOL practices including shared decision-making with patients and their loved ones, early discussion and documentation of wishes, and the ability to advocate for formal training in EOL care for all healthcare providers. Further research is necessary to determine how these techniques would affect ICU resource utilization and length of stay.

Keywords: end-of-life discussion, end-of-life communication, structured discussion, early discussion, intensive care unit, critical care, critical care unit, length of stay

Why End-of-Life Discussion Matters: A Literature Review

End-of-life (EOL) discussions can be a challenging topic to address with patients and their families. Topics such as withholding (i.e. not using some type of life support) and withdrawal of (i.e. providing comfort care and sedation while discontinuing) life support are often broached (Kryworuchko et al., 2012). There is much diversity in preference for, expectancy of, and timing of these conversations between both healthcare providers and patients and their loved ones. There are approximately four million intensive care unit (ICU) admissions each year in the United States, with the mortality rate ranging from 8-19% yearly, or up to 500,000 deaths annually in ICUs (Kruczynski, 2015). The United States devotes more money to healthcare than any country in the world, making up 16% of the gross domestic product (Kruczynski, 2015). Critical care accounts for over 13% of hospital costs and over 4% of national expenditures, much of which can be attributed to length of stay (LOS) (UCSF, 2021). Despite our massive expenditure of resources directed toward healthcare, we continue to lag behind 20 other nations in life expectancy and fall behind the majority of developed European nations in measures of quality of death (Kruczynski, 2015). ICUs represent one of only a few environments where EOL negotiations take place, however, almost 40% of Medicare enrollees visit an ICU in their last six months of life, and roughly one-fifth of all Americans die during an ICU stay, while others do so in the weeks or months after discharge (Shapiro, 2015). We live in a time in which science has evolved into being capable of seemingly limitless technological advancements, yet somehow, we as a society still struggle with the idea that death is inevitable. Due to the lack of effort and willingness to accept, research, study, and implement appropriate intervention in regard to death and dying, we've found ourselves providing an unacceptable and appalling quality of care in the last few days, weeks, or months of a patient's life. Not only does this cause extreme financial burdens for caregivers but also lasting psychological issues (Kruczynski, 2015).

Background

EOL can be defined as the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. In the case of patients with chronic or malignant disease, this period can be years. It may also be very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma (Henderson et al., 2018).

Often, patients who are living with a life-threatening illness express readiness to discuss EOL before their healthcare provider introduces this issue, and these discussions take place very close to death, in the last week of life. Thus, although patients may have thoughts about what EOL care looks like for them, the communication and documentation of their wishes is inadequate (Bergenholtz et al., 2020). These discussions regarding planning for EOL care can occur in outpatient settings as well as acute care settings and ideally include the completion of an advance directive that is added to the medical record. An advance directive is a written or verbal set of instructions that is recognized by state law that can be referenced if an individual becomes incapacitated and is unable to voice their own wishes regarding medical care in the future. Two main types of advance directives exist: (1) proxy directives that designate one or more persons to make health-related decisions on their behalf (e.g. durable power of attorney) and (2) directives that offer guidance on preferences on type and amount of medical treatment desired (e.g. living will) (Shapiro, 2015). According to Tejwani et al. (2013), those with advance directives are much more likely to receive care consistent with their end-of-life preferences; over 83% who requested limited care received it and over 97% who requested comfort care received it.

Additionally, there is a reduction in resource utilization seen in those patients who have advance directives (Tejwani et al., 2013). Despite the decreased use of life-sustaining treatments, greater use of hospice care, and reduced likelihood of terminal hospitalization, perceived quality of EOL care is not diminished (Tejwani et al., 2013). In fact, patients that remain engaged in EOL planning have a significantly increased life expectancy. Despite the positive impacts that EOL discussion and planning have been shown to have, it is estimated that only 20%-30% of Americans have put their healthcare wishes into written form or a legal document such as an advance directive. Advances in technology have provided the ability to prolong the length of time until death, however, often these interventions have little benefit to the patient. This literature review aims to determine the question: *For adult patients at the end of life, does early and structured discussion about end-of-life planning reduce intensive care unit resources and length of stay?* The purpose of this review is to increase understanding of the EOL discussion process and where it can be improved upon.

Methods

This literature search was completed on January 15th, 2021. Databases searched include CINAHL, Medline, and PubMed. General search subjects covered by database, date range, and search restrictions can be viewed in Table 1 of the attached appendix. Key words included in the database search include “end of life discussions” or “end of life communication”, “intensive care unit”, “ICU”, “critical care”, “critical care unit”, and “length of stay.” Search restrictions included full text available, English language, and peer reviewed articles. Dates included in the search included articles from year 2010-2020. Articles included in this review were those that included “end of life discussions” or “end of life communication” and “intensive care unit” or ICU” or “critical care” or “critical care unit” and “length of stay” in the article. See Table 3 for full references included. A total of 7 articles were included in the final review after exclusion criteria was determined.

Inclusion and Exclusion Criteria

Topics included:

- adults at the end of life
- early and structured discussion
- discussion regarding resources, length of stay, and outcomes
- discussion of standardized tools for prognosis/communication
- discussion of shared decision-making regarding end-of life
- discussion of advanced directives in ICU setting

Topics excluded:

- pediatrics
- specific data on medications or interventions
- populations outside of the ICU
- focus on RN role in EOL documentation
- letter to the editor

A full description and rationale for inclusion and exclusion are included in attached Table 3.

Literature Review

The seven articles chosen for this review consisted of two Level I studies, including systematic review and meta-analysis, three Level II studies, including critical appraisal and two retrospective observational studies, a Level III observational study, and a Level V expert opinion.

Establishing Clear Goals of Care

Preserving quality of life for those with advanced disease processes is an often-difficult goal for patients and their loved ones (Walling et al., 2012). Communication regarding goals of care is necessary for all patients, however, it is critical for those with advanced illness who may require ICU care. Jenkins (2011) describes a Stanford health study that clearly showed the most common request from families of patients who had died in their health system was clearer communication. This includes more information about their loved one's health condition(s) and prognosis. The Stanford study reported that nearly 50% of families felt they had received either contradictory or conflicting recommendations from health care providers (Jenkins, 2011). These mixed messages inhibited families' ability to make informed decisions and ultimately increased distress surrounding their loved one's hospitalization.

Daily rounds have been implemented in many institutions in an effort to improve these communication gaps. ICU teams are able to meet (typically at the patient bedside each day) and discuss, along with the patient and the family, the patient's status and determine an agreed upon plan of care; palliative care consults can also be placed as requested (Jenkins, 2011). Since implementing daily care teams in an effort to avoid vague or fragmented prognostic information (e.g. the likelihood of life saving measures changing a patient's long-term outcome), Stanford was able to decrease their average length of stay by half (Jenkins, 2011).

Effect of Do Not Resuscitate Consent

Do Not Resuscitate (DNR) orders have come into focus more in recent years and expanded outside the realm of terminal cancer patients to a broader context, particularly in ICUs. DNR status is defined as written orders from a physician telling health care staff not to attempt cardiopulmonary resuscitation (CPR) if a patient's heart stops or if they stop breathing. In other words, DNR orders instruct the healthcare provider not to manually perform the work of the heart and lungs via chest compressions and mechanical breathing, but to instead, allow death to occur naturally (Brigham and Women's Faulkner Hospital, 2021). In a study of adult patients hospitalized with sepsis and/or pneumonia in the critical care setting who were receiving mechanical ventilation at the time, the overall rate of survival to hospital discharge was 12.5% (Girotra et al., 2020).

Advocating for the use of DNR orders helps to avoid futile medical intervention, enhance patient autonomy, and make death more humane (Huang et al., 2010). A retrospective observational study that took place between 2003 and 2006 in a Taiwanese surgical intensive care unit looked at a total of 14,698 patients (Huang et al., 2010). The authors explain that its aim was to survey the aspects of DNR orders, determine the factors that influence DNR consent, and assess the impact that DNR status has on treatment in the ICU setting. Huang et al. (2010) explains that although EOL decisions are almost always difficult and complex, this difficulty likely increases in the surgical ICU setting due to major operations being part of an effort to sustain life and reverse critical illness. In this study, most palliative care discussion was initiated by intensivists rather than surgeons. Additionally, older age was associated with a higher rate of DNR consent as was the presence of impaired consciousness (e.g. post-cardiac arrest, brain death) (Huang et al., 2010). Ultimately, this study found that early DNR consent (within the first twenty-four hours of admission) was correlated with shorter ICU stays than the comparison group of non-DNR patients (Huang et al., 2010). Since DNR was signed only after other treatments options had been exhausted, the authors recommend early initiation of DNR discussion to promote reduced length of stay in the ICU. Huang et al (2010) goes on to explain that those with DNR consent received less aggressive treatments and received more sedatives and pain medicine near the time of death than those patients who did not have DNR status.

Interestingly, this study did not reveal any difference in DNR status and the use of mechanical ventilation though over 90% of the patients admitted to the surgical ICU were receiving invasive ventilation. In Taiwan, law states that this treatment can only be withdrawn by patients themselves, not by their family, so unless they had already signed the DNR consent themselves, they would have remained with mechanical ventilation at the time of death, increasing the utilization of resources in this population (Huang et al., 2010). In countries where the withdrawal of life-support is permissible by surrogate decision-makers, many therapeutic interventions are withdrawn as well (e.g. vasoactive drugs, supplemental oxygen, diagnostic procedures, lab work).

Improving Communication with Shared Decision-Making

It has been well-established that the use of a shared decision-making (SDM) approach is what delivers the best outcomes in regard to end-of-life care (Kryworuchko et al., 2012). These difficult decisions require careful consideration of a multitude of individualized factors such as diagnosis, prognosis, experience of illness, values, beliefs, hopes, fears, and moral and ethical obligations (Kryworuchko et al., 2012).

> “In addition, a wide variability exists in the intensity of care provided to similar types of patients at the end-of-life that is not explained by patient preferences. For example, patient preferences about life support were not at all congruent with the treatment they received. In these and other instances, poor communication contributes to the neglect of patient preferences resulting in distress and dissatisfaction amongst both healthcare professionals and family members in ICU” (Kryworuchko et al., 2012, p. 3).

According to the authors, nine essential elements must exist in the SDM process: (1) define/explain the problem that needs addressing; (2) present available options; (3) share perspectives on relative benefits, risks, and costs of the options available; (4) obtain patient/family values, concerns, and expectations; (5) discuss patient's ability/self-efficacy to follow-through with a plan; (6) explain existing knowledge of provider given situation at hand; (7) clarify understanding; (8) decide to formulate or explicitly defer the decision; (9) schedule follow-up (Kryworuchko et al., 2012). Although we know that families prefer to be involved in the decision-making process, it is much more of a challenge to ensure this happens in real-time, and current practice remains inadequate. A study done at a teaching hospital in the United States reported that none of the patients that subsequently died in their ICU ever had a palliative or hospice care consult upon admission, giving them no alternative to the use of life support (Kryworuchko et al., 2012). This systematic review identified that in three of the four trials reviewed, by incorporating EOL communication and using a SDM approach, a reduction in length of stay was recorded, and two of the four trials showed a decrease in use of life-support technologies and mechanical ventilation (Kryworuchko et al., 2012). Ultimately, length of stay in the ICU is dependent upon the health of each individual patient, the context of their illness, and what their values and preferences for care are (Kryworuchko et al., 2012).

Effect of Structured Communication Tools

Many people approaching the EOL would choose to limit aggressive treatments and instead opt for a more comfortable approach if asked, however, often these preferences are not documented in the medical record (e.g. advance directive, living will, power of attorney) (Oczkowski et al., 2016). According to Shapiro (2015), 85% of directives do not request heroic measures under most circumstances.

> "To understand the role of advance directives in medical decision making, it is critical to examine the process during which they are invoked, ignored, interpreted, reinterpreted, or

> disputed over, day after day, as a medical crisis plays out and decisions— both momentous and routine—are made and remade and shape and constrain the next set of decisions that surrogates speaking for the patient necessarily face" (Shapiro, 2015. P. 490).

Because of this lack of early documentation, end-of-life discussions instead tend to take place at the bedside at or sometime after the time of admission to the ICU. Shapiro (2015) explains that despite one of the purposes of advance directives being to minimize burden on loved ones of the patient, advance directives alone do not seem to make a difference in the associated guilt, remorse, conflict, or resentment that is often experienced by loved ones during the EOL. Given the high stress conditions these discussions take place in as well as the medical and moral complexity they can manifest, communication tools have been developed to help assist health care providers with EOL decision-making (Oczkowski et al., 2016). These tools are often directed toward a surrogate decision-maker, as frequently, the patient is too ill to participate in meaningful dialogue in the ICU setting. The systematic review and meta-analysis done by Oczkowski et al. (2016), determined that the use of structured communication tools did have a positive impact on resource utilization (e.g. duration of mechanical ventilation, length of ICU stay, number of hospital days, and financial costs of care), however, this was low-quality evidence and there were limited studies available evaluating these processes. Furthermore, Oczkowski et al. (2016) concluded that structured communication tools were not found to affect the number of patients with documented code status or decisions to withdraw/withhold treatments.

Prognostic Estimation and Outcomes

Literature shows that many critically ill patients receive life-supportive technologies in the last few days of their life, however, this is often not congruent with what they would prefer (Basile et al., 2019). Often times, prognosis is estimated based upon the health care provider's subjective clinical experiences rather than via protocolized assessments (Basile et al., 2019). This information passed to patients or their surrogate decision-makers often stems from information bias depending on clinical experience, subspecialty of the health care provider, and amount of time spent caring for the patient (Basile et al., 2019). The authors go on to explain that the risk for bias increases for those of advanced age who do not have multiple comorbidities due to the fact that they are likely to have positive outcomes when treated with life-sustaining therapies during an acute illness. While prognostic calculators are available to assist with determining survivability in the ICU, there is some discrepancy about which method is more accurate. The authors suggest that the combination of mathematically based prognosticators with subjective estimates may allow for higher accuracy of outcomes than either method used alone. Furthermore, literature has suggested that sharing these estimates with patients and their families or surrogate decision makers may help to improve outcomes via a shared decision-making (SDM) process (Basile et al., 2019). "Importantly, we should investigate whether patients/families are aware of the source of prognostic estimates communicated by their ICU clinicians and palliative care/ethics consultants" (Basile et al., 2019, p. 9). Interestingly, 66% of surrogate decision-makers in the ICU stated that quantitative prognostic indicators could be helpful in their decision-making process if followed by experiential opinion, while only 12% of physicians felt these numeric estimates would be helpful (Basile et al., 2019). A systematic review of over 10,000 articles was done with an aim to decipher how protocolized prognostic estimations (versus clinical experiential-based estimates) affected patient and caregiver outcomes in the ICU setting. Of the articles identified, seven were chosen in this review based on criteria of inclusion of prognostic calculations/guidelines (Basile et al., 2019). The most common outcomes measured within these guidelines were hospital mortality, DNR status, and medical ICU length of stay. Upon analysis, there was a correlation between guideline-based prognostic estimation and decreased ICU stay as well as increased DNR status, however, there was no obvious difference in hospital mortality.

Another study done at UCLA Health measured quality indicators in a group of 118 advanced cancer patients who were admitted to the ICU between April 2005 and April 2006 and ultimately died in the hospital (Walling et al., 2012). The purpose was to identify which aspects of care had room for improvement. The study used the Assessing Symptoms Side Effects and Indicators of Supportive Treatment (ASSIST) measures, which cover assessment and treatment of pain and other symptoms as well as information and care planning. Of the decedents receiving care prior to their passing, only 16% received or were offered a palliative care consult (Walling et al., 2012). For these patients with advanced cancer, a surrogate decision-maker was documented in the medical record 78% of the time, and discussions about goals of care were documented 64% of the time within 48 hours of admission to the ICU and 69% of the time within 48 hours of initiation of mechanical ventilation (Walling et al., 2012). It is reasonable to assume that the higher percentages of patients with documented goals of care were in part attributed to the less acute hospitalization in the advanced cancer patient population, compared to that seen in trauma or cardiac arrest, for example.

Discussion

Establishing clear goals of care is of utmost importance when communicating about EOL decision-making. Ideally, these conversations begin outside of an acute illness or ICU admission and when the patient is of sound mindset to be able to voice and document their wishes without the use of a surrogate decision-maker. Due to that fact that that these pre-hospital conversations oftentimes do not occur, healthcare providers must ensure that frank conversations regarding patient wishes are not only discussed but documented and added to the patient's medical record in the event they are hospitalized. Without clear guidance on what a patient's values, goals, and wishes are, care will default to the most aggressive life-saving therapies available. "Clear communication is critical for patients and their family members to make informed decisions, managing valuable resources in health care, and for the appropriate utilization of the ICU" (Jenkins, 2011, p. 24).

As described previously, families and healthcare providers are required to make difficult decisions about the use of life support and end-of-life goal planning on a daily basis, especially in ICUs (Kryworuchko et al., 2012). While SDM proves optimistic for improving the decision-making process within the ICU setting, little is known about what framework of interventions may make this process more deliverable (Kryworuchko et al., 2012). There is much diversity between each individual patient and also between healthcare providers, therefore more work should be done to establish clear guidelines and topics to, at minimum, make the discussion for consistent, clear, and less abrupt. Overall, more high-level studies are needed to determine whether structured communication tools improve outcomes that are important to patients and their families. Oczkowski et al. (2016) speculates that it may be more effective to implement the use of structured intervention tools earlier in the course of the patient's care, giving the patients and their families a greater opportunity to create documented care plans, allowing for better harmony between the care they receive and the care they wish to receive. When DNR status is discussed early in the hospital stay, futile treatments are reduced, resources can be allocated more appropriately, and end-of-life care is improved (Huang et al., 2010).

Part of the difficulty in approaching and producing clear and consistent goals of care is the sheer lack of training that most healthcare providers have in this area, especially those working outside of the ICU. Fewer than 10% of medical schools offer specific education on the process of death and dying to their students and fewer than 18% of medical students and residents have received formal EOL education (Kruczynski, 2015). According to a survey of physicians who had recently finished their residency, 39% felt unprepared to address their patient's fears about death, and nearly 50% felt unprepared to manage their own feelings about it. Furthermore, 40% reported that in their training, they did not feel that dying patients made for good learning and that meeting the psychosocial needs of dying patients was not considered a core competency (Kruczynski, 2015). We must shift our current focus of treating illness first and the individual second to one that is more able to "explore, understand, respect, and implement each individual patient's desires" prior to severe illness (Kruczynski, 2015, p. 196). Hospital culture must change to allow this to be attainable. Ideally, healthcare providers should be able to spend the time with their patients and their loved ones in the ambulatory care setting discussing these important topics. Alternatively, they must be available and willing to be present at the bedside of their patients to broach these topics, answer questions, and offer the chance to improve not only their patient's but their loved ones EOL experience. "Open and frank discussion of death and dying including EOL care options, approach to futile treatment, caring and bereavement should be encouraged within the profession and in the wider community" (Henderson et al., 2018, p. 1).

Many patients receive intensive therapies during hospitalization despite poor prognosis, therefore, early and more frequent palliative care consultation could lead to better alignment of aggressive therapies with prognosis (Walling et al., 2012). Furthermore, default care is aggressive care, and in those patients with poor prognosis, this lack of communication is likely to result in potentially unwanted life-sustaining therapies. Individual preferences can only be elucidated with open and early communication with the patient and/or family. Interventions such as clinical reminders based on standardized measures may improve inpatient care for ICU patients. Prognostic calculators could help health care providers to provide tailored and accurate estimates to individual patients as well as help minimize the risk of clinician bias. By doing so, health care providers' prognostic estimates would become evidence-based, rather than relying on subjective experience, which in theory, could make the risk of bias in decision-making lower and would ensure that patients are getting objective estimates regarding risks and benefits of ICU treatments, no matter where they choose to seek care. After objective estimation is completed, subjective expertise could then be used to solidify or modify these prognostic estimates (Basile et al., 2019).

While it is apparent that communicating protocolized prognostication estimates to patients and their families and/or surrogate decision-makers does decrease LOS and increases DNR status, these findings also showcase the need for additional studies to determine in which context these estimates are relayed to these groups, and what their reactions are. In order to provide our patients with the right to unbiased information so that they can make informed decisions, we must also ensure that the methods we use for prognostication are unbiased, which will lead to increased autonomy (Basile et al., 2019).

Barriers

Barriers to initiating EOL conversations can include lack of competency of the healthcare provider (including inadequate communication regarding prognosis), perceived discomfort of the patient or family, underestimating the need for information, and fear of taking away the patient's hope (Tejwani et al., 2013). These barriers can result in late initiation of EOL conversations, meaning many patients may become hospitalized (and even die) without their EOL wishes ever being discussed. This leaves the burden of their healthcare decisions to their next-of-kin (Tejwani et al., 2013). Differing perspectives and experiences from one healthcare provider to the next may over or underestimate prognosis and contribute to confusion among the patient and their loved ones (Walling et al., 2012). The stressful and ever-changing environment that an ICU can bring may result in fragmented communication between care teams and families, decreasing the likelihood that a clear EOL discussion and plan is taking place (Jenkins, 2011). Poor understanding of the role of palliative care services is often a barrier to what their services could provide in the ICU (Jenkins, 2011).

Limitations

The limitations of this review include the number of studies available, small sample sizes, and unique environments such as the ICU. ICUs represent only one of several venues where EOL decisions take place and have a disproportionately high number of patients unable to make their own medical decisions. Additional limitations include narrow search criteria, population limitations (i.e. adult only), and potential for low amount of data due to potential lack of documentation of patient's actual (vs surrogate) preferences.

Implications and Areas for Further Research

Practice Implications

With further research examining and improving the decision-making process regarding EOL in the ICU, we will be able to implement the interventions that provide the best clinical and patient/family support. An example of this is an ethics or palliative care consult at the request of healthcare providers or family. As touched on previously, structured family conferences show promise in reducing stress, anxiety, and depression in families, help to meet the family's need for information, and increase the focus on what the preferences of the patient would be in a given circumstance (Kryworuchko et al., 2012). Focusing more effort on these communication tools earlier in the patient's care trajectory (i.e. ambulatory care) would also likely have a positive impact on patient outcomes. After further evaluation of whether structured communication tools ultimately aid in reducing cost and ICU length of stay, this author would recommend collecting data on how these improvements affect caregiver attitudes/morale/burden, in addition to their effects at the system, family, and patient-levels. As mentioned previously, it would also benefit us as healthcare providers to focus more of our efforts on not only the completion and documentation of EOL wishes (i.e. advance directives), but on the importance of early, intentional, and explicit communication with effective surrogates. Educating our patients to choose a surrogate decision-maker that not only knows their values and priorities (versus automatically assuming this role to the closest family member) but that will be able to process ever-changing information at the bedside and stand-up for their loved ones wishes if necessary is of utmost importance.

Health Policy

Advance directives show only limited promise in having a positive effect on patient outcomes, ICU resource utilization, and length of stay. As discussed above, this is not only due to the lack of advance directive documentation and verbal discussion about wishes with loved ones, but also the lack of clear understanding about alternative treatment options. Early and explicit discussion regarding what treatment options are available to patients if and when they become hospitalized, what those treatments may entail, (including hypothetical prognosis), and what their wishes would be given their prognosis must become a requirement moving forward in healthcare. By requiring EOL care documents be completed outside the hospital setting, we will not only be able to more easily honor the values that patient's hold sacred but prevent the larger detriment that poor EOL planning has on society as a whole.

Education Implications

This author recommends that implementation of a curriculum in all health care provider programs (e.g. medical schools, advanced practice registered nursing and physician assistant programs) be required to ensure healthcare provider literacy and increase comfort in EOL discussion and care. By increasing the discussions that occur around these topics, research shows that not only does quality of death improve for the patient, so does bereavement for their loved ones (Kruczynski, 2015).

Areas for Further Research

Areas of research that could further benefit the understanding of the EOL discussion process and where it could be improved upon include the lack of long-term, high quality studies. Future studies would benefit from a more transparent framework that helps to not only guide the healthcare team and family through the EOL decision-making difficulties, but also offers an approach to specific interventions and evaluation of outcomes to determine how these tools affect length of stay and use of resources (Kryworuchko et al., 2012). Evidence also suggests that more high-quality randomized trials are needed to determine whether the use of structured tools to assist surrogate decision-makers and clinicians with EOL decision making has a major effect upon outcomes that are important to patients (Walling et al., 2012). Perhaps what would be more useful is focusing studies on how structured communication tools affect those that need more assistance with EOL decisions such as those in conflict over goals of care or those making decisions for long-stay ICU patients (Oczkowski, 2016).

Conclusion

Discussing the plans for the end of our lives is an often uncomfortable and stressful topic to imagine. Avoiding it, however, not only diminishes our likelihood and preference for a comfortable and humane death, but it also has the potential to create an immense personal and societal financial burden. Early planning, transparent conversations with healthcare providers and loved ones, and clear documentation regarding our wishes for our EOL care allows us more freedom to choose what our last days will look like. Unfortunately, intensive care units have no shortage of heartache and suffering when it comes to caring for those at the EOL, but there is hope for a better way of dying that results in better outcomes for patients, families, and healthcare as a whole.

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Walling, A. M., Asch, S. M., Lorenz, K. A., Malin, J., Roth, C. P., Barry, T., & Wenger, N. S. (2012). The quality of supportive care among inpatients dying with advanced cancer. *Supportive Care in Cancer*, *20*(9), 2189–2194. https://doi-org.ezproxy.mnsu.edu/10.1007/s00520-012-1462-3

Appendix

PIO:
For adult patients at the end of life, does early and structured discussion about end-of-life planning reduce intensive care unit resources and length of stay?

Table 1

Database Search Description

Database (or Search Engine)	Restrictions Added to Search	Dates Included in Database	General Subjects Covered by Database
1. CINAHL	Full Text; English Language; Peer Reviewed	2010 through 2020	Cardiopulmonary technology, emergency service, health education, medical/laboratory, medical assistant, medical records, occupational therapy, physical therapy, physician assistant, radiologic technology, social service/health care, and more.
2. PubMed	Free Full Text; English Language; Systematic review	2010 through 2020	Medicine, nursing, dentistry, veterinary medicine, the healthcare system, and preclinical sciences.
3. Medline	Full Text; English Language; Peer Reviewed	2010 through 2020	Research, clinical practice, administration, policy issues, and health care services.

Table 2

Data Abstraction Process

Date of Search	**Key Words**	**Results in CINAHL**	**Results in PubMed**	**Results in Medline**
1.15.21	End of life discussions or end of life communication	1301	434	1656
	Intensive care unit or ICU or critical care or critical care unit	29,980	3665	32,069
	Length of stay	11,598	1752	10,041
1.15.21	End of life discussions or end of life communication AND			
	intensive care unit or ICU or critical care or critical care unit			
	AND length of stay	**11**	**5**	**10**

***BOLD** = articles reviewed for match with systematic review inclusion criteria (parentheses indicate those articles meeting inclusion criteria)

Table 3

Characteristics of Literature Included and Excluded

Reference	**Included or Excluded and Document**	**Rationale**
Allingstrup M, Wetterslev J, Ravn FB, Møller AM, Afshari A. Antithrombin III for critically ill patients. Cochrane Database Syst Rev. 2016 Feb 8;2(2):CD005370. doi: 10.1002/14651858.CD005370.pub3. PMID: 26858174; PMCID: PMC6517014.	Excluded	Article is specific to antithrombin III use in critically ill patients

Reference	**Included or Excluded and Document**	**Rationale**
Basile, M., Press, A., Adia, A. C., Wang, J. J., Herman, S. W., Lester, J., . . . Hajizadeh, N. (2019). Does calculated prognostic estimation lead to different outcomes compared with experience-based prognostication in the ICU? A Systematic Review. *Critical Care Explorations, 1*(2). doi:10.1097/cce.0000000000000004	Included	Discussion of use of tool to estimate survivability vs experience-based prognosis
Bloomer, M., Lee, S., & O'Connor, M. (2011). End of life clinician–family communication in ICU: A retrospective clinical study—Implications for nursing. *Australian Critical Care, 24*(1), 66. doi:10.1016/j.aucc.2010.12.034	Excluded	Focuses on role of nurse in documentation of end-of-life discussion with family
Bloomer, M. J., Tiruvoipati, R., Tsiripillis, M., & Botha, J. A. (2010). End of life management of adult patients in an Australian metropolitan intensive care unit: A retrospective observational study. *Australian Critical Care : Official Journal of the Confederation of Australian Critical Care Nurses, 23*(1), 13-19. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1016/j.aucc.2009.10.002	Excluded	Addresses end of life processes, not length of stay or resource use
Boss, R., Nelson, J., Weissman, D., Campbell, M., Curtis, R., Frontera, J., . . . Hays, R. (2014). Integrating palliative care into the PICU: A report from the improving palliative care in the ICU advisory board. *Pediatric Critical Care Medicine : A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies, 15*(8), 762-767.doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1097/PCC.0000000000000209	Excluded	Pediatric ICU
Brooten, D. (2016). Cause of death of infants and children in the intensive care unit: Parents' recall vs chart review. *American Journal of Critical Care*, *25*(3), 235–242. https://doi-org.ezproxy.mnsu.edu/10.4037/ajcc2016233	Excluded	Pediatrics
Das, A., Bharti, B., Malhi, P., & Singhi, S. (2019). End-of-life milieu of critically sick children admitted to a pediatric hospital: A	Excluded	Peds

Reference	**Included or Excluded and Document**	**Rationale**
comparative study of survivors versus non-survivors. *Indian Journal of Palliative Care*, *25*(4), 550–555. https://doi-org.ezproxy.mnsu.edu/10.4103/IJPC.IJPC_60_19		
Feeney, J. M., Jayaraman, V., Spilka, J., Shapiro, D. S., Ellner, S., Marshall, W. T., & Jacobs, L. M. (2012). Prehospital HMG co-A reductase inhibitor use and reduced mortality in hemorrhagic shock due to trauma. *European Journal of Trauma and Emergency Surgery : Official Publication of the European Trauma Society, 38*(2), 171-176. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1007/s00068-011-0144-z	Excluded	Addresses use of HMG Co-A reductase inhibitor specific to hemorrhagic shock due to trauma
Fuller, G. W., Goodacre, S., Keating, S., Perkins, G., Ward, M., Rosser, A., . . . Cooper, C. (2018). The ACUTE (ambulance CPAP: Use, treatment effect and economics) feasibility study: A pilot randomized controlled trial of prehospital CPAP for acute respiratory failure. *Pilot and Feasibility Studies, 4*, 86. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1186/s40814-018-0281-9	Excluded	Specific to CPAP use in respiratory failure
Huang, Y., Huang, S., & Ko, W. (2010). Survey of do-not-resuscitate orders in surgical intensive care units. *Journal of the Formosan Medical Association = Taiwan Yi Zhi, 109*(3), 201-208. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1016/S0929-6646(10)60043-5	Included	Addresses use of resources in regard to DNR order as well as ICU length of stay
Jenkins, T. (2011). The BMT/ICU utilization project: end-of-life decisions and goals of care in the bone marrow transplant unit. *Stanford Nurse*, *31*(1), 22–24.	Included	Discusses improvements in communication between patients/family & care providers to assist in end of life planning

Reference	**Included or Excluded and Document**	**Rationale**
King, A., Botti, M., McKenzie, D. P., Barrett, J., & Bloomer, M. J. (2020). End-of-life care and intensive care unit clinician involvement in a private acute care hospital: A retrospective descriptive medical record audit. *Australian Critical Care : Official Journal of the Confederation of Australian Critical Care Nurses,* doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1016/j.aucc.2020.10.010	Excluded	Addresses measures to improve quality of care via use of "ICU outreach teams", but does not address length of stay or use of resources
Kisvetrová, H., Školoudík, D., Joanovič, E., Konečná, J., & Mikšová, Z. (2016). Dying Care Interventions in the Intensive Care Unit. *Journal of Nursing Scholarship*, *48*(2), 139–146. https://doi-org.ezproxy.mnsu.edu/10.1111/jnu.12191	Excluded	Does not address length of stay or resources used in regard to early discussion of end of life care
Kryworuchko, J., Hill, E., Murray, M. A., Stacey, D., & Fergusson, D. A. (2012). Interventions for shared decision-making about life support in the intensive care unit: A systematic review. *Worldviews on Evidence-Based Nursing, 10*(1), 3-16. doi:10.1111/j.1741-6787.2012.00247.x	Included	Addresses how shared decision making affects both length of stay and resource use
Leede, E., Fry, L., Crosby, L., Hamilton, S., Ali, S., & Brown, C. (2020). Impact of geriatric trauma service on the outcome of older trauma patents. *Geriatrics & Gerontology International*, *20*(9), 817–821. https://doi-org.ezproxy.mnsu.edu/10.1111/ggi.13979	Excluded	Addresses length of stay, however, it is specific to use of geriatric trauma service in trauma patients and not specific to end of life
Meert, K. L., Keele, L., Morrison, W., Berg, R. A., Dalton, H., Newth, C. J. L., . . . Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care, Research Network. (2015). End-of-life practices among tertiary care PICUs in the United States: A multicenter study. *Pediatric Critical Care Medicine : A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies, 16*(7), e231-e238.	Excluded	Pediatric

Reference	**Included or Excluded and Document**	**Rationale**
doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1097/PCC.0000000000000520		
Metaxa, V., Anagnostou, D., Vlachos, S., Arulkumaran, N., Dusseldorp, I. V., Bensemmane, S., . . . Curtis, R. (2019). Palliative care interventions in intensive care unit patients – a systematic review protocol. *Systematic Reviews, 8*(1). doi:10.1186/s13643-019-1064-y	Included	Discussion of formal palliative care consult's impact on resources and outcomes in ICU settings
Naguib, A. N., Winch, P. D., Tobias, J. D., Yeates, K. O., Miao, Y., Galantowicz, M., & Hoffman, T. M. (2015). Neurodevelopmental outcome after cardiac surgery utilizing cardiopulmonary bypass in children. *Saudi Journal of Anaesthesia, 9*(1), 12-18. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.4103/1658-354X.146255	Excluded	Pediatrics
Oczkowski, S. J., Chung, H., Hanvey, L., Mbuagbaw, L., & You, J. J. (2016). Communication tools for end-of-life decision-making in the intensive care unit: A systematic review and meta-analysis. *Critical Care, 20*(1). doi:10.1186/s13054-016-1264-y	Included	Discussion about use of communication tools (vs ad hoc communication) and improvement of outcomes and resource utilization
Paolini, V., Faverio, P., Aliberti, S., Messinesi, G., Foti, G., Sibila, O., . . . Pesci, A. (2018). Positive end expiratory pressure in acute hypoxemic respiratory failure due to community acquired pneumonia: Do we need a personalized approach? *PeerJ, 6*, 1. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.7717/peerj.4211	Excluded	Specific to ventilator settings
Paul, G., Gautam, P. L., Mahajan, R. K., Gautam, N., & Ragavaiah, S. (2019). Patients leaving against medical advice--A national survey. *Indian Journal of Critical Care Medicine*, *23*(3), 143–148. https://doi-org.ezproxy.mnsu.edu/10.5005/jp-journals-10071-23138	Excluded	Specific to patient who leave against medical advice, not end-of-life.
Ram, P., Horn, B., & Siegel, A. (2018). An internal medicine residents' perspective on end-of-life discussions. Indian Journal of Palliative Care, 24(3), 388–389. https://doi-org.ezproxy.mnsu.edu/10.4103/IJPC.IJPC_11_18	Excluded	Letter to Editor/Opinion on end-of-life discussion and advanced directive usefulness

Reference	**Included or Excluded and Document**	**Rationale**
Reis AMD, Fruchtenicht AV, Loss SH, Moreira LF. Use of dietary fibers in enteral nutrition of critically ill patients: a systematic review. Rev Bras Ter Intensiva. 2018 Jul-Sept;30(3):358-365. doi: 10.5935/0103-507X.20180050. PMID: 30328989; PMCID: PMC6180475.	Excluded	Article specific to use of dietary fiber in critically ill patients
Shapiro, S. P. (2015). Do Advance Directives Direct? *Journal of Health Politics, Policy & Law*, *40*(3), 487–530. https://doi-org.ezproxy.mnsu.edu/10.1215/03616878-2888424	Included	Compares having an advanced directive vs not in ICU patients
Stawicki, S. P., Wojda, T. R., Nuschke, J. D., Mubang, R. N., Cipolla, J., Hoff, W. S., . . . Falowski, S. (2017). Prognostication of traumatic brain injury outcomes in older trauma patients: A novel risk assessment tool based on initial cranial CT findings. *International Journal of Critical Illness and Injury Science, 7*(1), 23-31. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.4103/IJCIIS.IJCIIS_2_17	Excluded	Specific to initial CT findings in TBI patients
Walling AM, Asch SM, Lorenz KA, Malin J, Roth CP, Barry T, Wenger NS, Walling, A. M., Asch, S. M., Lorenz, K. A., Malin, J., Roth, C. P., Barry, T., & Wenger, N. S. (2012). The quality of supportive care among inpatients dying with advanced cancer. *Supportive Care in Cancer*, *20*(9), 2189–2194. https://doi-org.ezproxy.mnsu.edu/10.1007/s00520-012-1462-3	Included	Discusses interventions to improve use of resources as well as patient/family outcomes dependent on prognosis

Table 4

Literature Review Table of All Studies Included

Citation	**Study Purpose**	**Pop (N)**	**Design/ Level of Evidence**	**Variables/ Instruments**	**Intervention**	**Findings**	**Implications**
Basile, M., Press, A., Adia, A. C., Wang, J. J., Herman, S. W., Lester, J., . . . Hajizadeh, N. (2019). Does calculated prognostic estimation lead to different outcomes compared with experience-based prognostication in the ICU? A systematic review. *Critical Care Explorations, 1*(2). doi:10.1097/cce.0000000000000004	To discover the impact of guideline based prognostics (vs experiential) and how these affect outcomes in the ICU	N=10,704 articles, n=10	Critically Appraised Topic/ Level II	n/a	n/a	Protocolized assessment of prognosis is associated with decreased ICU length of stay and increased DNR status but does not have a significant effect on mortality.	Future studies should explore how communicating these estimates to physicians changes behaviors including communication to patients/families and whether calculator/guideline based prognostication is associated with improved patient and family rated outcomes.
Huang, Y., Huang, S., & Ko, W. (2010). Survey of do-not-resuscitate orders in surgical intensive care units. *Journal of the Formosan Medical Association = Taiwan Yi Zhi, 109*(3), 201-208. doi:http://dx.doi.org.ezproxy.mnsu.edu/10.1016/S0929-6646(10)60043-5	Examines the epidemiology of do-not-resuscitate (DNR) orders, and the clinical factors influencing DNR consent. The impact of DNR on	N=14,698	Retrospective observational study/Level II	n/a	n/a	Older age was associated with DNR consent. DNR pt's had longer ICU stays, lower FiO2, less inotropic infusion, dialysis, transfusion, and lab exam/xray, but more use of sedative drugs, analgesics, and	Early initiation of DNR discussion should be promoted to improve end-of-life care and reduce futile treatments in the ICU.

Citation	Study Purpose	Pop (N)	Design/ Level of Evidence	Variables/ Instruments	Intervention	Findings	Implications
	treatment and resource use in the surgical intensive-care unit (ICU) is also assessed.					nutrition support at time of death. DNR was common in ICU patients, but signed late in ICU course, when therapeutic options had been exhausted.	
Jenkins, T. (2011). The BMT/ICU utilization project: end-of-life decisions and goals of care in the bone marrow transplant unit. *Stanford Nurse*, *31*(1), 22–24.	To improve communication between families and health care team, in order to help patients and their families make decisions about their care	Adult ICU patients/ n=36	Expert Opinion/ Level V	n/a	Daily rounds followed by every 2-3 day check-ins on prognosis.	ICU length of stays decreased by 50%.	Shows benefit of clear and consistent communication to allow for patient and family awareness of prognosis as well as treatment options as well as appropriate ICU utilization)
Kryworuchko, J., Hill, E., Murray, M. A., Stacey, D., & Fergusson, D. A. (2012). Interventions for Shared Decision-Making About Life Support in the Intensive Care Unit: A Systematic Review. *Worldviews on Evidence-Based Nursing, 10*(1), 3-16.	To know what elements of shared decision-making had been tested to improve communication between healthcare professionals,	Adult ICU patients/ 3162 reports	Systematic Review/Level I	n/a	n/a	Upon review of three evaluated interventions, the interventions were not harmful; they decreased family member anxiety and distress, shortened intensive care unit stay, but did not	Interventions that include essential elements of SDM need to be more thoroughly evaluated in order to determine their effectiveness and health impact and to guide clinical practice.

Citation	Study Purpose	Pop (N)	Design/ Level of Evidence	Variables/ Instruments	Intervention	Findings	Implications
doi:10.1111/j.1741-6787.2012.00247.x	patients, and their families about decision.					affect patient mortality.	
Metaxa, V., Anagnostou, D., Vlachos, S., Arulkumaran, N., Dusseldorp, I. V., Bensemmane, S., . . . Curtis, R. (2019). Palliative care interventions in intensive care unit patients – a systematic review protocol. *Systematic Reviews, 8*(1). doi:10.1186/s13643-019-1064-y	The primary aim of this study is to compare the numbers and types of PC interventions in ICU, and their impact on patient and family outcomes	Intensive Care Units	Systematic Review/Level I	n/a	n/a	The models for providing PC differ according to geographic and cultural criteria, rendering the comparison of outcomes problematic.	To bring together the evidence behind diverse interventions and outcomes of palliative care interventions in intensive care. This will facilitate the identification of key interventions which are consistently associated with positive clinical outcomes
Oczkowski, S. J., Chung, H., Hanvey, L., Mbuagbaw, L., & You, J. J. (2016). Communication tools for end-of-life decision-making in the intensive care unit: A systematic review and meta-analysis. *Critical Care, 20*(1). doi:10.1186/s13054-016-1264-y	To determine the effect of structured communication tools for EOL decision-making, compared to usual care, upon the number of documented goals of care discussions,	N=5785 abstracts, n=168 articles	Systematic review & Meta-analysis/ Level I	n/a	n/a	Supporting evidence that structured communication tools may improve documentation of EOL decision making may result in lower resource use is low.	Further high-quality randomized studies of simple communication interventions are needed to determine whether structured, rather than ad hoc, approaches to end-of-life decision-making improve patient-level, family-level, and system-level outcomes.

Citation	Study Purpose	Pop (N)	Design/ Level of Evidence	Variables/ Instruments	Intervention	Findings	Implications
	documented code status, and decisions to withdraw life-sustaining treatments, in adult patients in the ICU						
Shapiro, S. P. (2015). Do Advance Directives Direct? *Journal of Health Politics, Policy & Law*, *40*(3), 487–530. https://doi-org.ezproxy.mnsu.edu/10.1215/03616878-2888424	Compares aspects of the medical decision-making process and outcomes by advance-directive status.	N=2216 n= 205/Conducted in 1 hospital within 2 ICUs	Observational study/Level III	n/a	n/a	There are few significant differences between patients without advance directives and those who claim to have them (the few differences pertain only to those directives in the hospital chart).	The article considers the implications if directives seemingly must be in hand to show even modest effects. there are few simple formulas or protocols to decisively guide our surrogates through the daunting course of life-and death decision making, especially in an ICU
Walling AM, Asch SM, Lorenz KA, Malin J, Roth CP, Barry T, Wenger NS, Walling, A. M., Asch, S. M., Lorenz, K. A., Malin, J., Roth, C. P., Barry, T., &	To apply novel quality indicators to measure the quality of supportive care	N=496 n=118 decedents with advanced cancer	Retrospective observational/Level II	All patients deceased before study	n/a	Only 16% of advance cancer patients received/were offered PC consult. Earlier and more frequent palliative	This set of quality indicators can evaluate the quality of supportive and end-of-life care provided to inpatients dying with advanced

Citation	**Study Purpose**	**Pop (N)**	**Design/ Level of Evidence**	**Variables/ Instruments**	**Intervention**	**Findings**	**Implications**
Wenger, N. S. (2012). The quality of supportive care among inpatients dying with advanced cancer. *Supportive Care in Cancer*, *20*(9), 2189–2194. https://doi-org.ezproxy.mnsu.edu/10.1007/s00520-012-1462-3	provided to patients with advanced cancer who died in a large university medical center.			initiation		care consultation in this population may lead to better alignment of aggressive therapies (such as hemodialysis and ICU admission) with prognosis.	cancer and identify aspects of care that need improvement