

End of Life Care in the ICU

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This is to acknowledge that David Finklea, MD has disclosed that he does not have any financial relationships or other relationships with commercial concerns related directly or indirectly to this program. Dr. Finklea will not be discussing off-label use of FDA- approved drugs.

Purpose:

The goal of this talk is to provide a broad overview of end of life care in the intensive care unit (ICU). The presentation will focus on both the challenges and what is the best practice for end of life care in the ICU.

Educational Objectives:

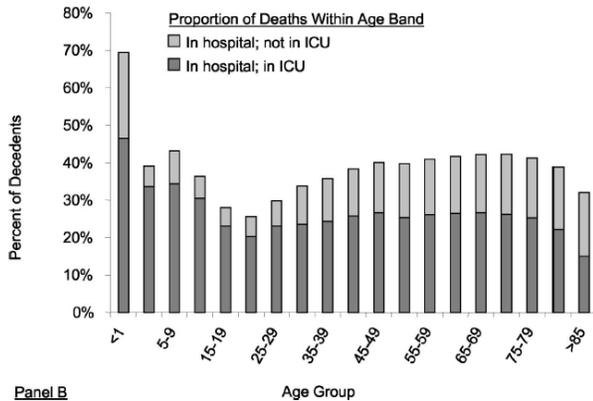
1. Discuss the epidemiology of end of life care in the ICU.
2. Review the different challenges in end of life care in the ICU.
3. Discuss the role of palliative care in the ICU.
4. Describe currently recommended best practice guidelines regarding end of life care in the ICU.
5. Explain what current methods are utilized at the University of Texas Southwestern regarding end of life care training

Biosketch

Dr. Finklea is currently an Assistant Professor of Internal Medicine in the Division of Pulmonary and Critical Care Medicine at the University of Texas Southwestern Medical Center. He has been a member of the faculty since 2012. He graduated from Centenary College in Shreveport, Louisiana. He then went and graduated from medical school at the University of Texas in Galveston, Texas. Following this he trained in internal medicine at Scott and White in Temple, Texas. He completed his pulmonary critical care fellowship at Emory University in Atlanta, Georgia. His clinical interests involve cystic fibrosis, critical care medicine, and end of life care in the intensive care unit.

Additionally, he has been awarded from the Cystic Fibrosis Foundation the Program for Adult Care Education, and he is also the Associate Adult Cystic Fibrosis Program Director.

One of the most difficult challenges in critical care medicine today is end of life (EOL) care. During this time, patients and families are faced with confronting the fears of death and at the same time feeling the pressure to make life changing decisions. The following paper will discuss the epidemiology of EOL care, the challenges in EOL care in the intensive care unit (ICU), palliative care support, the family meeting, treatment trials, best practice recommendations for EOL care, and the current state of EOL care at University of Texas Southwestern (UTSW).



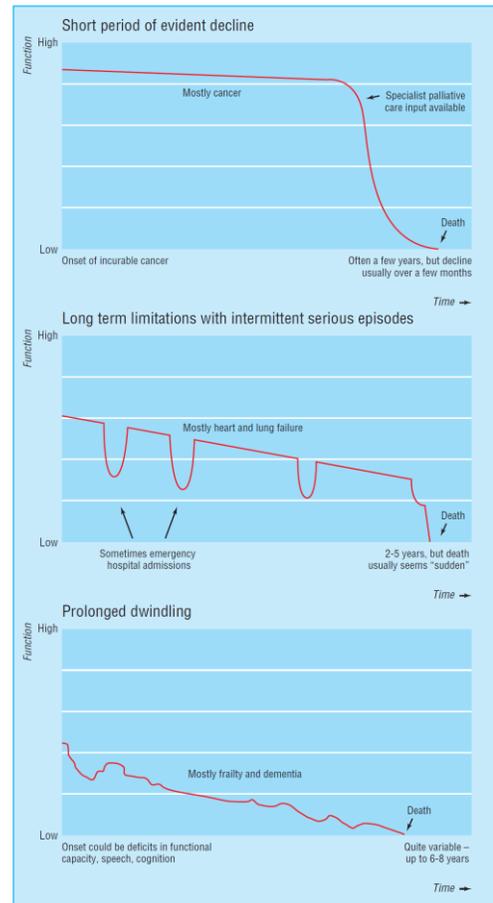
Panel B

countries' hospital systems. The US systems had the fewest deaths in acute care hospitals (22% in the US vs 29-52% in other countries). Patients died in the ICU at a rate of 27.2% in the US. Other countries in comparison had a lower death rate of 3.5-11.1% in the ICU.[3] This suggest in general that the US medical system is more aggressive regarding care prior to death than other countries. These statistics are concerning, because adults 65 in older in the US population are expected to double by 2030. If the population growth holds, physicians need to either triage beds in the ICU, make major philosophical changes to EOL care in the US population, or exponentially expand the number of available ICU beds.[1]

Many times patients will come into the ICU and the question arises, "will treating this patient result in a positive outcome for all parties involved?" There are four scenarios the physician will typically see regarding this question. The first one is the patient who has an acute decompensation without preexisting illnesses. Many of these patients will recover over several months and return to a relatively high functional status. Cancer patients; however, can die over a relatively short period of time (Figure 2, Short period of evident decline). The second type is classically seen in patients with heart or lung failure. The patient will have several hospital admissions with significant decompensations over 2-5 years (Figure 2, Long term limitations with serious episodes). Most will recover clinically, but with each episode they are unable to return to the previous level of functional status. Eventually, they will die due to end organ

Epidemiology

As the United States (US) population ages, critical care physicians consistently are asked to provide care for patients with more advanced diseases. The likelihood of one dying inside the ICU remains at a relatively high level until patients reach an advanced age (Figure 1).[1] In 2012, 15.1% of ICU admissions died that were in hospitals in the state of Texas while the national average was 15.4%. [2] The US as a whole spends more money during the last 180 days of one's life in comparison to other developed

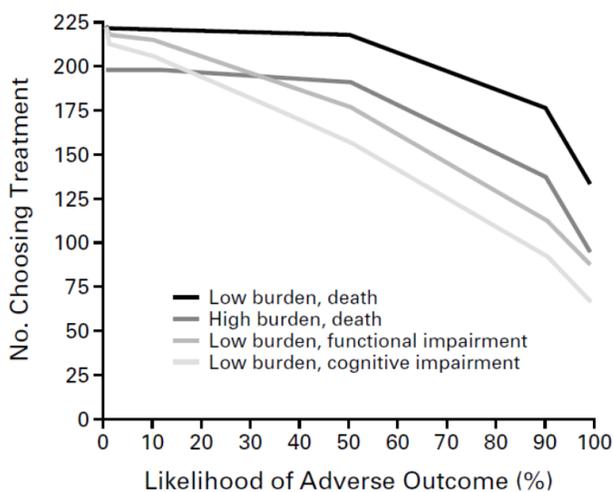


failure. The last one is seen in patients with dementia who have a slow gradual decline over a number of years followed by dying (Figure 2, Prolonged dwindling).[4] The challenge patients and families are frequently faced with is deciding if this episode is a temporary change in clinical status with a partial, but fairly functional recovery or is this episode so severe that they cannot recover resulting in death.[4]

Challenges in End of Life Care

When a patient acutely decompensates in the ICU many lose their ability to speak for themselves, and the medical team must rely on surrogate decision makers to make these choices. This typically occurs in 95% of ICU patients due to their illness or sedation needs. [5, 6] Physicians then must determine the best treatment plan with the family providing guidance into what type of care their loved one desires. The family frequently has several preconceived notions regarding their loved one's care. Many families are biased towards unrealistic outcomes based on television, having expectations of returning to one's previous level of quality of life post ICU discharge, struggling with the emotional distress involved in making EOL decisions, and finally all this can lead to conflicts with the medical team.

Television over the last 40 years has had a major influence on the American culture. In medical dramas and reality based medical programs the post cardiac survival ranges from 46-77%.[7, 8] As one would expect, there is discrepancy in the survival data based on national registry data. In 2009, the survival immediately after cardiac arrest was 42.9%. The survival to hospital discharge declined to 22.3%.[9] Unfortunately, television rarely follows a patient after arrest, or if they do it tends to highlight survival bias of patients with positive clinical outcomes. Finally, television does not capture the potential severe disability associated with surviving a cardiac arrest that occurs in some patients.



After a cardiac arrest or a prolonged hospitalization, the burden of functional impairment can be quite severe. In a small study of 226 patients over 60 years of age with a limited life expectancy from cancer, COPD, or CHF were asked whether they would continue treatment based on the likelihood of an adverse outcome. The patients in this study generally declined aggressive care as the likelihood of a positive outcome decreased. This was most pronounced when patients were faced with increasing amounts cognitive or functional impairment. Despite a high percentage chance of a poor outcome some patients

still elected to continue aggressive care (Figure 3).[10]

Even the most astute patients fail to discuss these EOL scenarios with close family members. This leaves the families with a difficult decision to make if their loved one is admitted to the ICU. This causes a significant amount of anxiety and possible depression for the surrogates as they are trying to understand the EOL issues. [11, 12] Surrogate decision makers developed post-traumatic stress disorder (PTSD) 33% of the time after their loved one had an ICU admission. The rate of PTSD increases when the family felt the information was incomplete or lacked clarity during the family meeting (48.4%); their relative died in the ICU

(50%); their relative died after EOL discussions (60%); or if the family shared in the EOL decision (81.8%).[13] Currently, this is an area that more research needs to focus on.

The emotion of EOL event inherently brings conflict between members of the medical team, the family and the medical team, and between family members. The conflict occurs between members of the medical staff 48% of the time, between the staff and the family 48% of the time, and 24% of the time within the family itself.[14] The majority of the conflict is over poor psychological support for the family and the difference in opinion between the medical team and the family regarding life sustaining measures.[15, 16] Compounding this issue is many families feel information is poorly communicated when there is a language barrier or when the physician attempts to explain the medical illness or severity of the prognosis.[16] Emotions during EOL events continue to trigger conflict and as a whole physicians need to continue to work on improving communication.

EOL care has unique challenges when crossing races. In general most people desire to live as long as possible, but at some point they realize this is not possible. In 2012, the state of California published the attitudes of the state's population regarding death and dying. Interestingly, Latino and African American had similar attitudes regarding EOL care. Approximately 60% of Latin and African Americans wanted to die a natural death and another 30% were unable to make a decision regarding how to die. Surprisingly, these same cultures wanted to live as long as possible and simultaneously wanted to avoid burdening their families with EOL decisions. In stark contrast, Asian and White Americans were less concerned with living as long as possible and the potential burden they may place on their family regarding EOL decisions.[17] Regardless of the race EOL care can place an enormous burden on the family.

As difficult as the emotional stress involving EOL decision for the family is; it can be just as daunting for the physician. Physicians must initiate a difficult conversation regarding one's potential death. They have prognostic models that are not perfectly predictive for EOL decisions, are poorly trained in EOL care, must control their own emotions involving EOL care, and find quality time for family meetings in the ICU while managing multiple other critically ill patients.

One of the first landmark trials involving EOL care in the ICU was in 1995, the SUPPORT Trial phase 1 consisted of a two year observation period of EOL care from 5 different academic hospitals finding that only 47% of physicians were aware of the patients desire to have do-not-resuscitate (DNR) orders. In the phase II portion, the physician were randomized to the control or the intervention group. The intervention group was informed of the patient's likelihood of survival at 6 months and additionally they had a nurse whose main objective was to improve the dialogue between the medical team and the patient. The control group using the standard of care for EOL care. Unfortunately, when comparing the control group to the intervention arm there was no statistical differences regarding: median time till a DNR order was completed, patient to physician DNR agreement, the use of hospital resources, and having the patient survive in a perceived undesirable state (requiring greater than 8 days of mechanical ventilation or a comatose state).[18] Despite the negative results of this study, EOL care was pushed to the forefront and this study led to multiple subsequent studies over the last 20 years.

EOL prognostication is classically done at the time of ICU admission and uses only objective clinical information. These prognostication test fail to account for clinical judgement.[19] In two recent studies researchers attempted to account for the importance of clinical judgement in predicting outcomes. The study asked providers one simple question, "Do you think this patient will die in the hospital or survive to be discharged?"[20] The physicians were only accurate 52% of the time in predicting "death before discharge." The prediction improved to 66% of the time when the medical team predicted death before discharge on more

than one day. If the entire team (attending physician, fellows, residents, and registered nurses) all predicted death before discharge the percentage rose to 84%.[20] Several years later the same investigative group repeated the study and then evaluated the survival of the patients 6 months after admission. The study found that 93% would die in 6 months if the medical team had agreement on predicting death before discharge. Additionally only 4% of this initial population were able to function with a Barthel index score greater than 70 six months after discharge.[19] A Barthel index is scored 1-100. The index determines their ability to do activities of daily living (ADL) with a higher score suggestive of a more independent state and patients with a low score requiring increasing dependence for their ADLs.[21, 22] These studies suggest that although physician may be able to predict short term outcomes poorly; they are much better at predicting survival at 6 months with a reasonable quality life.

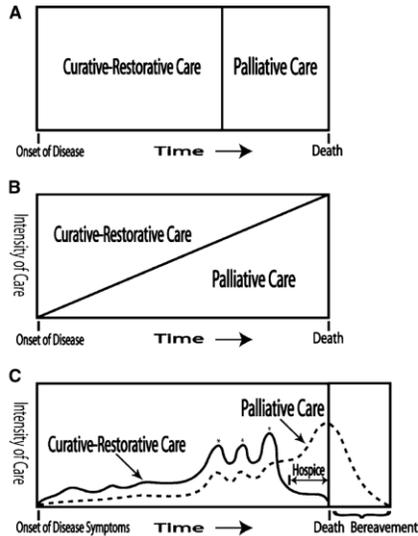
Physicians at all levels use euphemism to express one is dying. Families commonly hear anything from they are: "passing away to they are getting worse." It is difficult for physicians to openly use the word dead or dying.[23] This simple nuance of EOL discussions seems so mundane to physicians, but in reality it is extremely important to be honest with the family ensuring there is clear communication about their loved one's condition.

EOL discussion are difficult to initiate, providers found themselves frequently speaking slowly, searching for words, and trying to manage the stress they are experiencing when all eyes are on them. Adding to the stress is the difficulty in being completely honest about the patient's condition. They fight back personal emotion from prior experience relating to their own family members. Finally, physician try to find a balance between being personal and remaining objective.

The question is why is EOL discussion so difficult? Could it simply be that lack of training? An unpublished study found that 90% of trainees are supervised by attending level physician when performing invasive procedures; however, only 6% of EOL discussion were monitored by a senior level resident or their faculty.[24, 25] Another study surprisingly demonstrated resident generally will discuss information involving one's code status, but have difficulty discussing more complex issues such as advanced care planning.[26]. It may be that determining code status is a required conversation for all patients being admitted, but discussing advance care planning has multiple levels of complexity and due to limited time it is avoided. As medical training continues to evolve EOL care will need to become more prominent in medical education.

EOL care is very time consuming. One small study compared the time expert physicians spent on talking to patient about their advanced directives to community physicians on (AD) in a clinic setting. The expert physician group consisted of nationally recognized experts in medical ethics, physician-patient communication, or experts in both while the community physicians consisted of local general internist. On average, the expert physicians spent 14.1 minutes where the community physicians spent 8.1 minutes discussing ADs. The expert physicians focused more on building a partnership with the patient, focusing on one's psychosocial needs, and less on the biomedical information.[27] Although this data is suggestive, this data does not reflect the time required to discuss a crisis situation that physician are faced often with in the ICU. One way to improve EOL discussion is to consult palliative care.

Palliative Care



Physicians frequently request palliative care assistance as it becomes clear the patient is entering the EOL stage. In the traditional model, palliative care (Figure 4A) would only be consulted once the patient reached a stage where restorative measures were felt to be ineffective. The overlapping model (Figure 4B) occurs when palliative care becomes more involved as the possibility of curative care becomes less likely. Today, most hospital systems use an integrative system of care (Figure 4C)[28] combining both palliative and traditional care simultaneously as the symptoms progress or resolve. If restorative care cannot be achieved, aggressive care is stopped, and one is transitioned to comfort care or hospice.[28] Palliative care is extremely helpful, but the overall number of programs across the country are relatively small in number. In 2015 in the state of Texas, out of 198 hospitals, only 85 (42.9%)

had programs. This limited resource requires ICU physicians to request assistance in the most advanced cases, thus requiring them to provide a basic level of palliative care.

Sometimes a physician must discuss EOL care in an emergent condition, for example when a patient decompensates with acute respiratory failure. In this scenario, the physician must complete an EOL discussion in minutes and truncate what normally takes 30 minutes to an hour, followed by allowing several days for the patient to comprehend the discussion and to ultimately reach a decision. As the medical condition progressively deteriorates, many lose the ability to make decisions. The transition from having decisional capacity to having it impaired can occur quite quickly in the ICU setting. In this emergent situation, the physician must respond quickly and answer two basic questions:

1. "Does the patient have adequate decision-making capacity?"
2. "Are requirements met for the practitioner to provide emergency treatment without informed consent?"[29]

Capacity is ultimately a clinical term that addresses one's ability to make a decision. The most commonly used tools for decision capacity are the MacArthur Competence Assessment Tool for Treatment and the Hopkins Competency Assessment Test. They are helpful in low acuity scenarios and when there is no critical time constraint.[30, 31] These tools have limited value for ICU physicians. One tool that can be used in emergent situations is CURVES (Choose and Communicate, Understand, Reasons, Value, Emergency, Surrogate).[29]

CURVES provides a quick assessment to determine capacity. One must ask and answer six basic questions.

Choose and Communicate- Is the patient able to communicate his choice?

Understand- Does the patient understand the consequences of the proposed intervention or treatment plan?

Reason- Can the patient explain his or her reason for accepting or declining the proposed intervention?

Value- Does the patient's decision fall in line with their personal values?

Emergency- Does an emergent procedure need to be performed to prevent death or serious injury?

Surrogate- Is a surrogate decision maker present?

If the patient is unable to answer the questions then the provider must determine if the situation is emergent or can wait for a surrogate decision maker to arrive. These questions can be asked quickly and are useful in a time of crisis in the ICU.[29]

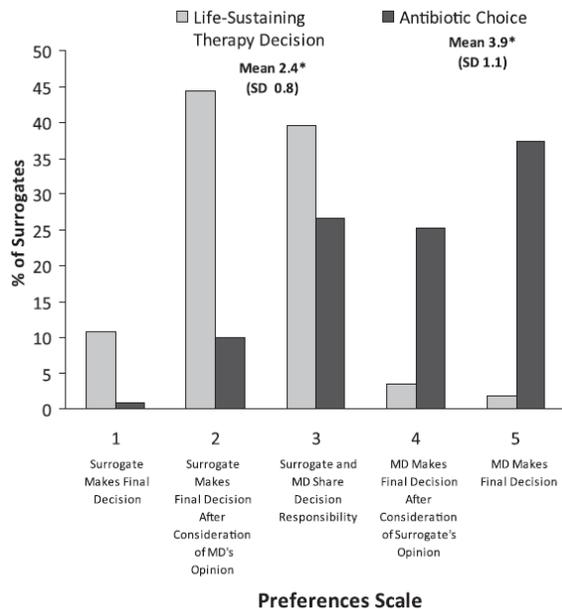
Family Meeting

After the crisis scenario, the medical team must rely on the family to be the primary decision maker. The discussion primarily takes place in the family meetings. In the meeting, the physician begins building trust by coordinating a timely meeting with the appropriate medical teams, discussing the specifics of their loved one illness, understanding the patients' values and preferences, and determining the goals of care.[32]

Frequently as an ICU physician, the provider desires to focus on the patient's medical condition near the EOL, arrange an appropriate medical plan, and then evaluate the next critical patient. Families prefer the physician to focus on the loved one as a person and not treat them as a person with a medical disease. As the patient census in the ICU expands this becomes more challenging. Unfortunately as one would expect, physicians only discussed 37% of the time with the family the patients previously expressed values and preferences regarding EOL care. In 30% of the cases neither values nor preferences were discussed. Physicians fail 88% of the time to discuss the patients, "longevity, maintaining bodily integrity, symptom palliation, autonomy, independence, emotional well-being, relationships, maintaining physical function, maintaining cognitive function, adhering to religious or spiritual beliefs." [33] One mnemonic that can be helpful in discussing the patient as a whole is VALUE. It stands for: "Value family statements, Acknowledge family emotions, Listen to the family, Understand the patient as a person, and Elicit family questions." [34] This technique ensures the patient is treated as a whole person and not Mr. Smith with some type of metastatic cancer.

During the meetings, physicians must determine the best way to communicate EOL discussions with the family. The four communication styles are: informative, facilitative, collaborative, and directive. A recent study, evaluated what communication style physician used when evaluating a simulated patient with metastatic gastric cancer who has life threatening hypoxia. Most physician communicated using a facilitative role (49%), while 37% used a collaborative role, 12% were directive, and 1% were informative. Most families prefer either facilitative or collaborative communication styles, but in crisis scenarios physicians may need to provide a more directive role.[35]

Often the medical team is faced with uncertainty in determining the patients' prognosis. The family looks to the medical team to determine the prognosis. A recent study stated that up to 87% of surrogate prefer to discuss prognosis even in uncertainty. The families' state: uncertainty regarding prognosis is unavoidable, the physician is the only source, this allows families to have realistic hope, increases trust between the doctor and the family, and provides an opportunity to begin preparation for bereavement. [36] Interestingly families are indifferent in regard to whether a physician should provide a recommendation to surrogates regarding their opinion about limiting life support. Based on this, physician should ask if the family would like the physician's opinion in regard to continue life sustain measures.[37] The degree of shared



decision making varies in surrogates based on the type of decision. Regarding life sustaining therapy, surrogates prefer to either make the decision in conjunction with the physician or receives the physician's opinion and then make a final decision. When it comes to more basic decisions such as antibiotic choices they generally desire much less involvement (Figure 5).[38] Finally, these discussions require excellent communication to prevent unneeded suffering and to provide the best care for their loved one.

Most major breakdowns in communication during a family meeting occur beginning with the prognosis. Studies have found that 54% of family fail to understand the diagnosis, prognosis, or treatment plan. A little less than the majority of the families' (43%) were unable to comprehend the

prognosis. To make matters worse patients coming from the hematology floor or those with acute respiratory failure patients have the worst comprehension regarding EOL discussion.[39] Family members are unwilling to accept the prognosis, and are unable to grasp the limitation of life sustaining therapies. Additionally medical providers fail to recognizing the families inability to understand the medical information.[39] One of the most interesting aspect is 79% of surrogates' state that if the physician or nurse had provided more information about the current condition they would have made different choices regarding EOL for their family member.[40] These breakdown in communication provide multiple opportunities for improvement.

Treatment trial

As patients with advanced age, multiple end stage medical problems, or malignant neoplasms clinical condition deteriorates providers frequently have reluctance of transferring them to the ICU due to perception there may be no benefit. Families feel threatened when the providers offers either to continue aggressive care or comfort care. One alternative is to provide three options: continue to pursue aggressive care, a treatment trial, or comfort care. The treatment trial is where one continues aggressive care for a predefined number of days normally consisting of anywhere between 3-7 days.[41] This provides family comfort in that there was an attempt to save their life, but if the patient's medical condition continues to decline they can transition to comfort care preventing prolonged care and reducing unnecessary suffering. Current treatment trials have been studied in a limited fashion.[42, 43] In one study of 72 family conference a treatment trial were offered in only 15% of the meetings.[43] These trials are generally offered in the context of EOL discussion. They provide a pathway for the surrogates to determine if the medical therapy can quickly change the direction of the patient's clinical condition. The largest trial evaluating this was completed in oncology patients. The researcher's goal was to determine the optimal length for treatment trials in cancer patients. They developed a probability model using cohort data from a quaternary hospital in Boston base on the type of cancer and sequential organ failure assessment (SOFA) to determine the optimal duration of a treatment trial in comparison to time unlimited trial. The data was then validated using 3 external quaternary hospitals showing that patients with hematological malignancies or with lower SOFA scores benefiting from longer treatment trials. Patients with poor prognosis from solid tumors and high SOFA scores generally can have shorter treatment trials consisting

of just 1-4 days.[42] Treatments trials provide families solace in that they provided their loved one a chance at improving, but limits suffering if the patient's condition did not improve.

Best Practice

Since the Support Trial in 1995[18], research in the field of EOL care has provided physicians a systematic method to provide a best practice. Things that both the family and patient find important: are being honest when discussing the medical issues, listening carefully, remaining sensitive as one gives bad news, encouraging questions, and being willing to discuss dying.[44] As the discussion continues with the family, the medical team should be willing to allow periods of silence as the family processes the information, and recognize and explore the emotions occurring at the time of the meeting. As the physician continues to discuss EOL decisions their goal is to: discuss prognostic information, determine decision-making preferences, understanding one's long term fears of death and goals for life, balancing treatment tradeoffs, and the extent of family involvement.[45] This model provides the ideal framework for end of life care.

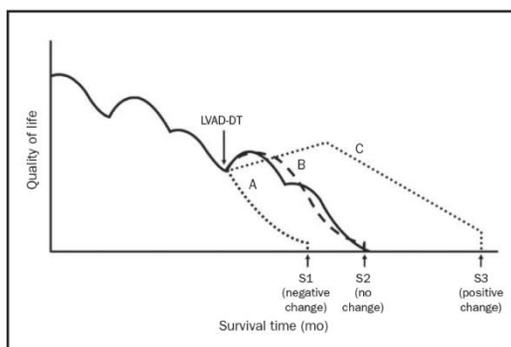
UTSW is currently working to integrate this extensive EOL care research into their health care system. Many medical teams are already actively using the research recommendation in their practices.

CF Clinic

Currently the UTSW Cystic Fibrosis Clinic screens all patients understanding of EOL care with FEV1% predicted under 40% using a simple questionnaire. From the testing, we determined that patients frequently confuses the terms living will and AD. This process has allowed the providers to transition the simple questionnaire into a talking point for this difficult discussion regarding EOL care. Currently, 32% of our patients have advance directives. Several patients have not completed the AD packet, but despite the failure to complete the formal paperwork our team is able to determine who the surrogate decision makers will be and begin an informal process in establishing goals of care. This begins a lengthy process that normally allows the patient and the team to collaborate in making an informed decision regarding EOL care.

Heart Failure

As medical therapies have advanced there are many disease states where patients greatly benefit from the new breakthroughs. One of these is the placement of a left ventricular assist device placement (LVAD) for severe systolic heart failure. After placement of the LVAD patients frequently proceed in 1 of 3 pathways. Some of them unfortunately decline at faster rate till death (line A), others gain no benefit and continue to decline (line B), and most have a positive outcome living several years with the LVAD (line C) (Figure 6).[46] Currently the heart failure team at UTSW, based on this data and recent national guidelines from the American College of Cardiology recommend all patients that are evaluated for advanced heart failure therapies have a palliative care consultation.[47] The goal of this meeting is to prepare the family and the patient for the potential outcomes that can arise following the initiation of advanced therapies.[46]



Oncology

In the world of cancer, palliative care has long had a foothold in patient care as the disease progresses. In a landmark trial in the *New England Journal of Medicine* 2010, patients with metastatic lung cancer were randomized to either standard of care with chemotherapy or to chemotherapy and the addition of early palliative care. The standard care group survived 8.9 months compared to the early palliative care group surviving 11.6 months (95% CI 6.3 to 11.4; $p=0.02$ log-rank test).[48] At UTSW, the palliative care team has established a role in a multidisciplinary cancer clinic where they are able to build trust, control symptoms, and begin the discussion about advance care planning.

Billing End of Life Care Discussion

Starting on January 1, 2016, the Centers for Medicare and Medicaid Services (CMS) have opened two codes for advance care planning. The first code is 99497 and provides 1.5 RVUs for the initial 30 minutes of discussion. An additional code 99498 is available for each additional 30 minutes of time spent providing 1.4 RVUs.[49] These two codes will provide reimbursement to physician for the extensive time spent in discussing EOL care.

EOL discussion will continue to occur for all providers regardless of your medical specialty. The major key for successful EOL discussion is communication prior to the crisis situation. These repetitive discussions during clinic visits can begin the framework for later conversations hopefully prior to a crisis situation arising. If the crisis occurs before a decision is reached the medical team needs to take time with the family: to discuss and understand the patient's value system from the families' perspective, discuss the clinical condition, explain to the different medical options available for their loved one, and explain to them the team will be there for them. Finally allow them time to make a decision. EOL care will remain a challenging subject for all, but as providers refine their skills it can reduce the burden on making an emergent decision if one acutely decompensates.

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