

A GOOD DEATH

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ABSTRACT

While death is surely inevitable, the timing and circumstances of our deaths may vary widely and are likely to be negotiable in response to the changing needs of patients and families for physical, emotional and spiritual support as their diseases and illnesses evolve. Patients and families need to become aware of specific care options and supports that are available for them so they can be accessed in order to achieve their own “good death”. The professional health care team is obliged to assist patients and families become knowledgeable about potentially appropriate resources to assist them to become more comfortable with their roles thus more effectively supporting the patient as well as each other. Through literature review and interviews with diverse stakeholders, I will explore what a good death means from the divergent perspectives of patients, families and the clinicians who provide care for hospitalized dying patients.

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CHAPTER 1: INTRODUCTION

In this document I will explore and discuss key issues that help inform and achieve a good death in three sections beginning with advance care planning. Specifically, why effective planning for end-of-life is so important, advance care planning as a vehicle to facilitate effective patient and family autonomy, barriers and facilitators for effective end of life discussions and the consequences of inadequate planning and discussion. Discussion of bioethical considerations of dying as a function of social justice and the relevance of self-determination, autonomy and beneficence are woven throughout the narrative. Second, utilizing a framework for a good death, I will discuss good deaths and weigh priorities to achieve a good death from the perspectives of patients, families and other patient advocates, and from members of the health care team with discussion of how concepts of dignity and futility might influence our own ideas about good deaths. Third, after discussion about barriers, facilitators and priorities in achieving a good death, I will propose practical strategies to help inform end-of-life decision making to the benefit of hospitalized patients who are approaching the end of life, their care providers and the institutions in which care and deaths occur. In addition to extensive readings and discussions with clinicians, my thoughts and perspectives are informed through 35 years of clinical and administrative experience as a professional nurse including 10 years of professional practice at Temple University Hospital, by my educational experiences in the Urban Bioethics Master's program at the Lewis Katz School of Medicine, and by the needs and concerns of our North Philadelphia community and neighbors.

CHAPTER 2: PLANNING TO DIE WELL

Advance care planning occurs as a series of discussions about an individual's health status and issues, their options for care, and which options best support their values and priorities. Although specific details vary from state to state, two basic elements of advance care planning are establishing a decision-making surrogate known as the Durable Power of Attorney for Health Care and an advance directive, also known as a Living Will. Deciding who the proxy medical decision-maker shall be is a personal decision. Then, certifying that individual to act on the patient's behalf is a legal process. The written advance directive is a personal statement that establishes the individual's values, priorities and wishes regarding care at the end of life against the time they are unable to speak for themselves (Benson & Aldrich, 2012). The document helps to provide direction to health care providers about an individual's preferences for care at the end of life. "Advance care planning [helps] ensure that the care people receive during periods of serious illness is consistent with their stated preferences and values" (Hall, Rowland, & Grande, 2019, p. 312). "The presence of advance care planning and an advance directive enhances quality at the end of life by providing clear direction to clinicians regarding the patient's preferences for end of life care while relieving the family's burden for decision making" (Hong, Yi, Johnson, & Adamek, 2018, p. 1278).

Ideally, planning conversations to support development of the advance directive with the advice and consent of key supporting friends and family members occurs while individuals are in stable or optimal health in their community and includes care providers to contribute factual information to facilitate well-informed decision making. Minimally,

an advance directive includes directions about resuscitation and life support, typically to apply in the setting of terminal illness when chances of meaningful recovery are nil. A more comprehensive living will would include thoughts about avoiding hospitalization, pain management, and potential treatments to be sought or avoided such as chemotherapy, feeding tubes, renal dialysis and intubation for respiratory failure. By providing instruction and making the patient's personal wishes known, the advance directive eliminates ambiguity and provides direction for care providers. The advance directive can be updated and amended at any time reflecting its function as a fluid document that reflects initial and evolving patient values and needs (Detering & Silvera 2019). As previously mentioned, advance care planning discussions may begin in the community, at home or in a primary care provider's office. The impact of the advance directive may not be felt until some point in the future when issues concerning health care services need to be addressed expeditiously to avoid unwanted treatment.

Advance directive instructions are archived in writing to clearly and unambiguously communicate the individual's plan to establish limits and direction about care to be received and avoided. The written advance care directive is shared with health care providers who then use the document to provide direction to the plan of care to ensure that their direction is consistent with the patient's clearly expressed personal goals and values.

Ideally, trusted care providers open and facilitate a series of discussions as an element of routine care in an office visit that culminates in a written document, but

ultimately the responsibility for developing a personal advance care plan rests with the individual. The reality is that everyone involved in the process of developing an advance directive – patients, families and health care providers – has personal needs, concerns and judgements that may facilitate or hinder developing and fulfilling the plan of care and achieving a “good death”.

Individuals who are financially and structurally disadvantaged do not have an equitable chance of achieving a good death when contrasted with those individuals who are fully health-literate with financial and social resources to support them. The social determinants of health including education, income, health care insurance coverage, and stable housing are influential in limiting and obscuring awareness of the gamut of potential resources to assist in end of life, as well as the ability to access those resources. As a result, “racial and ethnic minorities receive more intense, non-beneficial healthcare at the end of life” (Brown et al., 2018, p. 1309).

Thus, achieving a “good death” is not equitably accessible to all members of society. Economically and educationally privileged individuals have a much better chance of achieving an optimal death than people who are educationally, financially and structurally disenfranchised. Effective communication about end-of-life is essential for patients, families, and for the healthcare team, too. When adequate end-of-life planning does not occur, the results often have unfortunately predictable and unnecessary

consequences. But, with appropriate planning and forethought, end-of-life quality can be vastly improved for the benefit of patients, their informal caregivers, and for the healthcare team.

Temple University Hospital is simultaneously a tertiary and a community hospital and an academic training facility located in an impoverished North Philadelphia community. The systematically structurally and financially disenfranchised population struggle with the social determinants of health, predictably experiencing poor overall health status and outcomes. The median annual household income in the two primary zip codes in which the majority of Temple University Hospital patients reside (19140 and 19132) are \$18,600 and \$18,918, respectively. Approximately 46% of local households have incomes below the federal poverty line (U.S. Census Bureau 2017). Violence is an endemic public health concern in the community. From 1988 through 2016 there were 1990 homicides in North Philadelphia with 1650 (83%) by firearms. In 2016 there were 247 firearm homicides in Philadelphia with 32% occurring in the areas with the lowest median income; 75% among non-Hispanic blacks; 25% among people aged 20-24 years and 95% were males. In 2016 there were an additional 988 non-fatal shootings in North Philadelphia (Philadelphia Department of Public Health 2017). Life expectancy in areas of concentrated poverty in North Philadelphia (64 years) is significantly lower than those observed in wealthier areas of Philadelphia (87 years) (Philadelphia Department of Public Health 2018), just a few miles to the south where residents benefit from the advantages of higher income, stable housing, adequate nutrition, lives free from endemic violence and unfettered access to primary preventive health care.

As fairness eludes the basic issues that frame access to health care and determine health status, inequity also defines the process of dying. Reimer-Kirkham et al. (2016) describe death and dying through a social justice lens. People experiencing structural inequities and financial deprivation need focused, intentional interventions so that they might learn about the resources that are available to them to promote more equitable access to those services. Only then can they become knowledgeable about and access appropriate palliative care at the end of life to alleviate pain and suffering, and so their humanity, dignity and health care needs may be recognized and honored when they are at their most vulnerable; when they are dying.

Reimer-Kirkham et al., (2019, p. 297) also rightfully state that “Health care is a commodity that fails to uncover the underlying causes of health inequalities”. The long-term inequities in health status and outcomes are associated with issues including lack of appropriate nutrition, inadequate housing, poor primary preventive care and under-treatment of chronic health conditions that contribute to overall poor health status that collectively carry over into potentially unmet needs at the end of life. The authors describe individuals whose lives have been experienced in a state of chronic deprivation requiring assistance with both fundamental living conditions and with palliative care if they are to have a chance of achieving a good death (Reimer-Kirkham et al., 2016). While acknowledging that health care is a commodity as Reimer-Kirkham et al. posit, health care is simultaneously a basic human right, including appropriate care at the end of life. Thus, barriers to accessing health care services at the end of life must be explicitly identified and

managed to allow everyone, including those with few resources to equitably obtain optimal services in the most appropriate, desired setting.

In an interesting retrospective study linking inpatient hospital death certificates with electronic health records, Brown et al. (2018) reviewed deaths between 2010 and 2015 that were associated with a single Washington, Seattle area health system for relationships between the intensity of health care received in the last 30 days of life with racial and socioeconomic factors. Utilizing treatment in an intensive care unit, mechanical ventilation and cardiopulmonary resuscitation as markers for high intensity care, and focusing on nine common, chronic health conditions, they established a clear relationship between racial and ethnic minority status, lower income and less educational attainment with higher intensity care at end of life with most of the differences accounted for by racial and ethnic minority status alone. The authors suggest a causal explanation for this disparity is that long-term racially associated distrust of health care providers adds to a preexisting milieu of inadequate communication, making well-informed advance care planning unlikely. “This lack of trust and increased concern about receiving appropriate medical care may lead patients to view advance directives as a means of further excluding them from health care rather than as a way to increase their control over future medical care and decision making” (Brown et al. 2018, p. 1314).

Given the documented lack of trust and concern about their ability to receive the best and most intense health care possible among racial and ethnic minorities, have the authors – from their position as privileged, wealthy, educated individuals who

fundamentally represent the interests of the health care system - juxtaposed favorable and unfavorable outcomes? Although the authors perceive CPR, ICU utilization and mechanical ventilation as unfavorable outcomes, it is entirely reasonable to suggest that members of racial and ethnic minority groups view these care markers as the best and most appropriate care to which they are entitled. This disconnect contributes to reluctance among some Black individuals who perceive completing advance directives as another attempt to systematically exclude them from access to the best, optimal and most appropriate services readily available to other members of the community.

Systematic distrust manifests as the lack of therapeutic, trusting relationships with primary care providers. Without that therapeutic professional relationship, there are lost opportunities for discussions about priorities, preferences and end of life care options before the end of life, before the patient is hospitalized, when patients have capacity and families may be more willing to engage in discussions for the purpose of becoming informed. With inadequate communications about options for care at the end of life, some patients and their families remain unaware of alternative care options, including hospice and palliative care. Lack of access to primary and palliative care specialists precludes a thorough, systematic assessment of patient and family preferences for end of life issues (Stajduhar et al. 2019, p. 2).

John Rawls' Principles of Justice (1985) argue that the principles of Liberty and Equality describe individuals' rights and privileges in society. The Liberty Principle declares that each individual member of society has equal rights to basic liberties. The

Equality Principle describes distributive justice as the fair distribution of social goods and resources. Together, these positions argue for fair equality of opportunity so the lives of the worst off become materially better as a result of the (re)distribution of value. I interpret value as the access to human and health services that preserve life and optimize health status (Shinefeld, 2018). These interpretations support the argument that universal access to healthcare, for the benefit of both the individual and society, as a basic human right rather than a privilege. The construct of the Liberty Principle equates equal rights and basic liberties while Distributive Justice emphasizes fairness in access to social resources. Therefore, building upon the concepts of liberty and fair distribution of essential resources including access to health care, in this case, at the end of life, is a rational perspective.

In Kant's view, rationality is more important than individualism (Beauchamp & Childress, 2001). Denial of the basic human right to health care at the end of life is an irrational proposition. Since rationality is superior to individualism, it follows that universal access to health care during and at the end of life is just and appropriate.

In the case of the disadvantaged and disenfranchised citizens of North Philadelphia, guaranteed access to appropriate and equitable health care would begin to address the effects of the social determinants that contribute to overall lower health care status of impoverished individuals than to those individuals without food insecurity, who do have secure housing and ready access to primary preventive health care. A rational extension of this argument suggests that equitable access to optimal nutrition and safe, secure housing is also a basic human right. As John Rawls describes political arguments regarding the just

distribution and access to fundamental social resources, it needs to be acknowledged that the political will to mitigate poverty and the structural causes of endemic violence simply does not exist. The necessary resources to establish and sustain equitable access and utilization of health care have not been described in municipal, commonwealth or federal budgets. Budgets are statements of political financial priorities; the lack of dedicated, adequate and sustained budgetary funding clearly states that improving the health status of disenfranchised residents is not the current or previous administration's priority.

Continuing with Rawls' social justice perspective, "A good death ... would mean that all individuals are entitled to define what a good death means to them and [they would] possess the information, the agency and the opportunity to choose what helps them achieve their definition of a good death" (Tate & Matlock, 2019, p. 2). It then would become the responsibility of professional health care providers and those who manage health care organizations to support patients in their right to self-determination at the end of life. Derse (2015, p. 51) describes self-determination as autonomy: "The right to choose which treatments to accept, refuse or request, even if those choices mean death will probably or certainly result." Health care providers have the responsibility to support the patient's and family's considered requests that do not conflict with their professional ethics. The American Medical Association (2019, section 5.4) declares that "Personal value judgments should not obstruct implementation of the patient's decision." The objectionable neo-political use of religious barriers to hinder delivery of the professional care that licensed providers swore an oath to provide is a topic beyond the scope of this paper, other than to acknowledge its existence and relevance.

Johnson, Butow, Kerridge, and Tattersall (2017) conducted a series of semi-structured interviews with eighteen Australian oncologists and palliative care physicians to determine their understanding of patient autonomy and its influence on end-of-life care. Four distinct themes emerged that reflect “a profound disconnect” between “physicians’ concept of autonomy as freedom from interference and their clinical practices in end of life decision making” (Johnson, Butow, Kerridge, and Tattersall, 2017, p. 565) as well as professional cynicism about patient values and desires within the framework of autonomy. First, in the context of healthcare it is acknowledged that autonomy with capacity confers agency to determine one’s own health care. However, physicians expressed gaps between their professional practice and respect for patient autonomy with quotes like “I respect patient autonomy ... but would do whatever they can to influence the patient’s choices including cajoling them where necessary” (Johnson, Butow, Kerridge, and Tattersall, 2017, p. 567). Second, these physicians see clear limits to patient autonomy. Patient wishes are not honored when they are deemed futile, inappropriate, excessive or inconsistent with the doctor’s recommendations. The participants did not acknowledge the subjectivity of concepts of futility and excessiveness. Third, oncologists leveraged professional relationships with their patients to influence discussion and increase adherence to their recommendations. By developing long-term trusting relationships with their patients, the patients are more likely to trust the physicians’ advice in a crisis. This subterfuge is in contrast to acknowledging patient autonomy with respect to informed medical decision-making. Fourth, advance care planning was seen as a “sometimes-necessary paperwork

exercise” rather than advancing patient interests at the end of life. (Johnson, Butow, Kerridge, and Tattersall, 2017, p. 566).

The most important thing is truth-telling by the providers to patients and families. Deaths do not need to be tragic. People need time for goodbyes ... and to know that it is time to start saying goodbye. We leave families traumatized by not telling the truth and by setting unrealistic expectations. I don't think this is necessarily deliberate. I wonder about my colleagues' motivations – cultural, religious, spiritual, lack of education? They don't see the tortured families and sometimes patients who are left behind. It is compassionate to their colleagues but a disconnect with patient needs and end of life issues. (see Appendix A)

Stajduhar et al. describe the challenges that the Canadian poor and homeless encounter in a British Columbian city while attempting to access appropriate health care at the end of life. Their ethnographic study that included in-situ observations and interviews and ultimately identified five systematic categories of barriers to accessing end of life care: “1) Survival imperative; 2) Normalization of dying; 3) Problem of identification; 4) Professional risk and safety management, and 5) Cracks in a siloed system” (Stajduhar et al., 2019, pp. 7-10). The survival imperative refers to the need to work hard for basic subsistence so that seeking health care becomes less important than eating. When many people living in deprivation are accustomed to being at palpable risk of death on a daily basis, dying becomes normalized and being given a terminal diagnosis or definite time frame until death from a known reason is expected. Unless members of the homeless and deprived population formally enter the health care system, it is difficult to identify those who are at risk of dying imminently and who would benefit the most from rapid palliative interventions. In this Canadian study as well as in Philadelphia, there are limitations on

where palliative services can be delivered outside the hospital. For example, people living in boarding homes or who are homeless are typically ineligible for home hospice. Finally, medical models, behavioral health models and caring for patients with substance use disorders may conflict with each other and preclude access to specific care. For example, a patient with a substance use disorder may be ineligible for placement in a nursing home. Stajduhar concludes that poor and disenfranchised populations experience these formidable barriers to accessing care that persist in the face of both their terminal illnesses and their social vulnerabilities.

This poignant observation and the barriers to end-of-life care Stajduhar identify are readily applicable to our North Philadelphia population. Further, while these barriers are not unique to the poor and homeless, they appear to be “amplified” by the structurally and financially challenging circumstances commonly experienced in North Philadelphia. As end-of-life needs are highly individualized, the specific factors facilitating and inhibiting access to health care also vary depending on individual circumstances and structural context. The issues causing or associated with structural vulnerability limit individuals’ capacity and agency to access care and achieve optimal health-related outcomes. Critically, while individuals’ criteria for desired outcomes are subjective, the concept of optimal outcomes and the means to achieve them may not be widely known by those who are most impaired and who then are promised to be least likely to be able to achieve them (Stajduhar et al, 2019).

The predominant vehicle to communicate end-of-life plans is the advance directive. Ideally, this written document is formulated, developed and formalized by individuals when they are in their homes and communities, in optimal or stable health. In a prospective cohort study, Mack et al. (2012, p. 4392) identified that “Patients who had end-of-life discussions with their physicians before the last 30 days of life were less likely to receive aggressive measures at end of life, including chemotherapy, acute care or any aggressive care”. Conversely, “Aggressive end-of-life care was more common among patients whose first end-of-life discussions took place in the inpatient setting” (Mack et al. 2012, p. 4392).

Two conclusions may be inferred from these data. First, there is an implicit assumption in these statements that less aggressive end-of-life care is a desirable characteristic of a good death. While this statement is true among some populations, it may not be a universal truth. Previously, we discussed how advance directives may be seen as an attempt to ration desirable health care by people who have suffered from long term impaired access to those modalities. Second, for optimal effectiveness, end-of-life discussions that ideally result in an advance directive and a plan for end of life care need to occur prior to final trajectory of terminal illness while patients still have capacity and agency and there is time to gather information from care providers to inform the advance directive, to validate the terms of the advance directive with family and informal caregivers, and to execute the document, making it part of the medical record.

In a related study, Yefimova et al. (2020) studied the use of perioperative palliative care and its relationship to family reported end of life experiences of patients who died

within 90 days of a high-risk surgical procedure. They identified that perceptions of having received excellent overall care in the last month of life as well as communications and general support were significantly higher among recipients of palliative care than the reported experiences of those who did not receive palliative care. In addition to demonstrating the value of palliative care in terms of improved perceptions of end of life, it may be inferred that the timing of palliative interventions is also important to support decision making and establish well-considered, individualized goals of care prior to engaging in high risk procedures (Yefimova et al. 2020).

We evaluate how people function in the world. Assess their physical, emotional and spiritual resources. Their challenges and strengths. Ascertain their values. What's important to them in the world. What's important in terms of their medical issues and options for care. Help them determine what will work best for them with respect to the medical and surgical options for care. Curative and palliative. Inexperienced care givers with fewer options to offer may perceive that conversations will take longer than they need to. People leading the discussion need a toolbox of skills and they need to be comfortable using the skills. Teams don't collaborate or communicate effectively. Not knowing, not understanding and not knowing that they don't know. All this leads to fragmented care. For example, a patient being treated in outpatient oncology, cared for by inpatient medicine or hospitalist groups who have not communicated effectively with each other ... inhibits downstream communication with the patient and informal caregivers about end of life and goals of care. Lack of clarity about prognosis, treatment plan while the care teams disagree about basic issues like prognosis or about the information that is to be shared with family as well as recommendations. We see this with transplant services. (see Appendix B)

When patients are admitted to an inpatient health care facility, there is an implicit assumption that all the curative, life-saving resources of the health care organization will be brought to bear upon the patient (Derse, 2015). Absent clarity about the patient's and

family's known wishes to the contrary, the hospital's default tactic is full resuscitation including fluids and antibiotics through peripheral or central access, cardiopulmonary resuscitation with medications, chest compressions and mechanical breathing devices. In some cases, invasive devices to support circulation and oxygenation may also be utilized. Insufficient discussions prior to critical illness and lack of an advance directive with a plan of care about end of life care predictably result in more care and more aggressive, invasive care than the patient or family may have desired, if there had been an opportunity to discuss these issues beforehand. Clearly, improving communication to help patients clarify their thoughts and make their wishes about end of life care well known helps reduce unwanted and unnecessary procedures at the end of life (Sinuff et al. 2015).

The purpose of the advance directive is to communicate patients' preferences for care at a time when the patient lacks capacity to speak for themselves. It is important that end of life discussions occur with a trusted health care provider and family and support system to fully inform and communicate the substance and meaning of the advance directive. The health care provider is a subject matter expert who can offer information, insight and context for the advance directive. Family and supporting individuals, particularly the health care proxy, will be tasked to advocate for the patient to uphold the plan set forth in the advance directive, so it is important that they are aware of its existence and what the patient has specified and requested in the document. At the conclusion of these discussions, there will be a shared understanding between the patient, family and support system about their care preferences so that when the patients' wishes are discussed

with the patients' care providers, they can be supported by written evidence of the patients' wishes to help inform an appropriate plan of care (Sinuff et al. 2015).

Ethically, advance care planning and well-informed advance directives support the concept of patient autonomy (Singer & MacDonald 1998). With this written document, patients and their designated surrogate decision maker(s) are able to declare the intent to withdraw or withhold certain treatments with the certainty of knowledge that they are supporting the informed, expressed wishes of the patient. Ikonomidis and Singer (1999) also argue that advance care planning supports a liberal concept of autonomy in which the rational individual expresses their self-determination via vehicles such as advance directives.

Advance directives that demand specific technologies or treatments present situations that are less clear, especially when the judgement of the health care professionals caring for the patient determines that their application would be inappropriate, or even harmful. Futility, or medically non-beneficial care within the context of end of life, represents a subjective determination by the health care providers that further curative interventions will not be useful or restorative, perhaps even harmful. The determination of futility is subjective because the clinical course (life expectancy) often cannot be precisely predicted and interpretation varies between providers. However, in many cases quality of life may be enhanced through fewer interventions or with palliative care that is directed at enhancing quality of life through emotional and spiritual support and relief of symptoms of terminal illness.

Responsible stewardship of scarce and expensive health care resources is both a medical and an organizational business survival necessity. As patients are on a deteriorating trajectory, their care providers may find themselves in a situation with conflicting interests. As care providers for the patient, they are in a position of directing care that consumes resources to accomplish the goal of saving a life or improving health status or saving a life. However, at the same time they have a responsibility on behalf of the hospital and health system to use scarce and expensive resources judiciously. This scenario raises two clear professional challenges for the care provider. First, the physicians' duty for beneficence, that is to do more 'good than harm' is called into question when the specter of futility, or, medically non-beneficial care presents, particularly from consultants or other external sources. Physicians work within professional and organizational guidelines regarding the appropriate use of scarce and expensive resources. Thus, the concept of beneficence is informed through evolving guidelines and standards. Determining futility represents the tension in determining what resources will be expended in the course of treatment that is believed will not restore health or function. This tension may be between the organization and the provider, or between providers with diverging clinical and fiduciary frameworks (Baily, 2011).

The second challenge manifests when the clinician has a responsibility to be a steward of hospital resources. Associating medically non-beneficial care directly with the issue of resource stewardship places the care provider in an untenable position where their fundamental duty to treat is potentially compromised by nonclinical financial

considerations. The clinician's primary duty and responsibility is to the patient, within the framework established by the health care organization, set forth by the medical executive committee and Board of Governors. It is the shared responsibility of the organization and the clinician to satisfy the duty to treat appropriately in a manner that allows the organization to continue to provide appropriate care for the most patients. This balance cannot be attained unless the organization remains financially viable (Karnik & Kanekar, 2016). "Our societal priorities are misplaced. Patients can't access inexpensive, preventive care like colonoscopies but society is willing to spend hundreds of thousands of dollars on chemotherapy and surgeries for hopelessly advanced cancers and futile treatment". (Appendix C)

Two specific examples of conflicts about resource utilization include situations where patients or their advocates want "everything" done, but the requested treatments are deemed inappropriate or ineffective for a patient who clearly will not benefit from their application. The hospital's imperative to remain financially viable is compromised when resources are expended inappropriately, in contravention of established medical standards and criteria. A second specific example may occur when critically ill patients are transferred from a lower level of care to a hospital that can provide a higher level of care, presumed to be potentially lifesaving. At Temple University Hospital, a pre-screening process was put into place to ensure that patients were not too sick to benefit from advanced therapies and that the proposed care could not be provided equally at the sending facility. After a year of screening approximately 20% of ICU to ICU transfers were found to be inappropriate and were declined for one of these reasons resulting in improved quality

indicators and financial outcomes. Most significantly, we are no longer subjecting critically ill patients to ground or air transportation or giving false hope to families when futility is all but certain.

Physicians have a duty to provide care for the patient and simultaneously a duty to the survival of the organization for whom they work. From a consequentialist perspective, organizational policies that strictly determine the general care of patients with a specific illness or constellation of symptoms benefit the organization by limiting use of potentially useful, expensive medical technology enhance its financial viability, therefore also enhancing its ability to provide care to the greatest number of additional patients. Simultaneously, the policies would also protect patients from potentially inappropriately applied therapies by defining guidelines for the utilization of advanced therapies. The use of guidelines opposed to rules-based criteria allow practitioners to utilize their clinical judgement with the patient and the organization's best interests at heart.

Similarly, rules-based criteria may be unable to accommodate patient-specific needs, requests and expectations of individualized care. From a deontological viewpoint, each patient is treated as a unique individual with decisions about use of any or all available care being made on a case by case basis. Realistically, this means utilizing all the technologies that are available and clinically defensible. Again, the unrestricted application of expensive technologies may compromise the financial sustainability of the health care organization, implicitly impairing its ability to continue to exist to provide care for all patients. This demonstrates that the use of expensive technology is ultimately self-limiting,

if not managed through responsible clinical criteria that offer guidelines to practitioners to support clinical decisions. Deontology supports physician and patient autonomy by ensuring that all available resources may be used for each patient based on rational clinical judgement. However, just because we can use advanced therapies does not necessarily mean that we should apply them as technology seeking a clinical application.

This line of reasoning offers support for the argument that the best strategy to support patient and physician autonomy and optimal clinical outcomes while promoting sustainable financial viability is a combination of deontological and utilitarian approaches. A reasonable approach is to utilize guidelines and algorithms that recognize and support the organization's financial imperative while empowering health care providers to use professional judgement regarding which treatments are most useful on an individual basis with objective guidelines for decision support. A criteria-driven rationale for application of technology to protect patients and the organization with room in the algorithm for clinical and humanist judgement also supports patient autonomy by increasing the likelihood that if a treatment is rational and appropriate, then it will be utilized.

With autonomy, there are implications for everyone involved in formulating the advance directive, for family and surrogate decision makers who advocate for the advance directive and for the care providers who determine and implement the plan of care to support the advance directive. Clearly, the advance directive supports patient autonomy by assisting them to identify priorities and values at the end of life and by providing a vehicle so their wishes regarding issues of self-determination are known when they cannot

participate in discussions or express themselves. As discussed below, patient autonomy may be compromised in several potential methods. Family members and surrogate decision-makers have autonomy and have chosen to advocate for the patient vis-a-vie the advance directive. Health care providers have autonomy and a duty to the patient and to the health care organization. These demands may cause a potential conflict of interest and compromise. Physicians are not necessarily obligated to provide treatments they believe are “ineffective or potentially harmful” (Kraemer, 2019, Grand Rounds Presentation).

The advance directive acts as informed consent in setting a plan of care to support patient wishes in motion. Physicians have responsibility to raise the subject about end of life care issues; patients’ responsibility includes making decisions based on the facts that physicians set forth. Ideally, patients make decisions with the advice and consent of family members who become familiar with patients’ wishes and the advance care document. As with any informed consent, the quality of the decision making depends on the facts presented and the individuals’ willingness to openly consider options. Advance care planning is best as a series of discussions to elicit thoughtful consideration of the patient’s values, desires and fears and to educate about available care options. Optimally, this discussion happens over a period of time when the patient has capacity to fully engage in informed discussions and decision making (Hall et al., 2019).

There are several issues to consider that may compromise the perceived and expected integrity of the informed consent / advance directive process. Since effective advance directives are written in advance of final stages of terminal illness, but without

known specific issues, conversations are largely hypothetical. End of life determinations need to be placed in the context of specific scenarios but the actual granular circumstances cannot be known until or near the final stages of illness. Patient and family awareness of end of life issues is based on information provided by health care practitioners regarding what might be ‘reasonably’ or ‘usually’ predicted to occur. This can easily be inconsistent with the reality of any individual’s specific end of life scenario. This strains the appropriateness and credulity of the advance directive process and document. Thus, advance care planning can be a poor proxy for focused discussion with specific and tangible concerns (Karnik & Kanekar, 2016). Additionally, patients may change their minds about terms of their advance directives as their needs and values change, especially when formerly hypothetical scenarios become more concrete as illnesses advance (Hall et al., 2019).

Each patients’ “threshold for transitioning from curative to palliative intent” (Emanuel & Scandrett, 2010, p. 7) varies. It is unlikely that these individualized tolerances can be known when advance directives are contemplated and written. Further, even with the best of intentions, there may be inadequate discussion about end of life to inform the advance directive. Discussions that happen in advance of the actual scenario cannot anticipate all possibilities. This uncertainty and lack of information compromise the informed consent concept of advance directives.

It often becomes the responsibility of family members or other surrogate decision makers to advocate for the patient by upholding their expressed wishes. Responsibilities of

individuals tasked with advocating for the patient include situations when their loved one's advance directive may be inconsistent with their own value system and with their understanding of the present reality. They may not fully understand what the patient wanted and might not have been present when the advance directive was developed, signed and implemented. These factors may compromise their ability and desire to advocate for the patient's expressed values. (Karnik & Kanekar, 2016).

Surrogate decision-makers may have very limited experience with end of life situations. If they have any experience at all in mediating the death of a loved one, it may be based on sub-optimal anecdotal scenarios without adequate support, guidance or understandable and useful information so they may easily feel ill prepared to engage in discussion and potential disagreement with professional care team members. This scenario is particularly intimidating because their loved one is dependent on the healthcare team for their life. Given the challenges of variable trust in the health care establishment, it is easy to imagine how substantive disagreements may engender or exacerbate feelings of potential distrust. Finally, patient and surrogate involvement in decision-making may cause the health care team members to feel compromised by needing to consult and take direction from the lay-public. Delayed medical decisions leading to unintended outcomes can compromise the intent of the advance directive and the integrity of the healthcare team (Baily, 2011).

O'Neill (2003) notes additional relevant limitations to the informed consent concept of advanced directives. One is the obvious concern that only competent individuals

can give consent, that is, can formulate and commit to an advance care plan. In class discussion about the limits of self-determination with respect to the movie *Still Alice*, the care team and family may be confounded when confronted with an advance directive written by someone who has since lost capacity and is unable to recapture the thought, consideration and expressions of personal values that went into its formulation, especially when they are directed towards a plan of care that runs counter to their personal value system and professional standards of care. As Cees, Hertogh, Dröes & Eefsting (2007) discuss, as we lose capacity, there may not be the opportunity for to affirm with the patient that this is what they want, or the implications of their wishes.

Another nuanced concern is that even “competent individuals cannot consent under emotional duress or constraint, when they are less able to refuse others’ demands” (O’Neill, 2003, p. 5). Thus, determinations about crucial issues like resuscitation, intubation and other end of life limitations or demands for specific treatments that are actually made under the stress of imminent end of life are compromised. Patient autonomy depends on well informed and considered decisions to identify options and determine personally relevant and important priorities of care. Therefore, decisions that are made under duress, without time for thought and adequate contemplation, and quite possibly without the patient’s involvement clearly do not support patient or proxy autonomy. This issue lends credence and support to the work of Yefimova et al. (2019) and others who advocate for palliative interventions prior to the final stages of illness.

For hospitalized patients, by the time end of life care decisions are made in the absence of an advance directive, potentially unwanted, aggressive care that is difficult to reverse has already occurred. This scenario is even more likely to occur when the patient with a life-threatening condition is admitted to a critical care unit. Therefore, timely pre-illness advance directive discussions are even more relevant and important to affirm the integrity of the decision-making process and to effectively direct care. When advance care planning happens over a series of discussions before a life-threatening health crisis has occurred, there is the luxury of time for thoughtful, contemplative discussions and decisions that allow the future patient to be involved when they have full capacity to determine what care they wish to receive and then to make their wishes known. If advance care planning waits until admission to a hospital is imminent or has already occurred, it is too late to be considered “advanced”. While appropriate timing is obviously essential, unfortunately there is no single method to determine the best time to engage in advance care planning discussions (Hall et al., 2019).

CHAPTER 3: A GOOD DEATH: BARRIERS AND FACILITATORS

The concept of a “good death” seems oxymoronic. Death is sad, tragic, the end of the line, perhaps representing the culmination of a series of failures or failed expectations in clinical diagnosis, management and treatment. Death may be sudden and premature, or perhaps, long, painful, alone and protracted. So, under what circumstances can a death be described as good? Simply, a good death can be achieved when the circumstances of dying meet the needs, expressed values and desires of the dying patient and their family members.

Approximately a year ago, there was a Buddhist patient who had arrested several times, for whom death was clearly imminent. After rounds, there was angry discussion among team members about why the family would not make the patient a DNR. Then, a Buddhist monk came to the hospital and conducted an end-of-life service with family members present at the patient’s side, and the patient died peacefully. We helped her to have a beautiful, good death (see Appendix D).

The process of dying and individuals’ priorities of care and coping are unique. Therefore, there is no single unified description or definition of exactly what a good death should look like (Meier et al., 2016) and consequently, care preferences are individualized with innumerable variations about a good death (Mack, Weeks, Wright, Block & Prigerson, 2010). Concepts of a good death depend on “what patients, families and health care practitioners view as important at the end of life” (Steinhauser et al., 2000, p. 2481) and are based on their needs, desires and personal values. I suggest that for patients and families, achieving a good death begins with their awareness of their own needs and

priorities for care including where they want to die, in the hospital or at home. Will their death be natural and peaceful or will it be framed in the metaphors of war? When are treatment and intervention appropriate and when is it time to acknowledge that additional treatment would be medically non-beneficial? Those involved – patients, families, health care professionals - in framing the dying experience need to become aware of these issues and of the options for comfort and support of spiritual, emotional and physical needs during the end of life process.

From the patient's and family's perspectives, the barriers to developing an advance care plan and implementing an advance directive to facilitate a good death can be formidable and include many socioeconomic determinants of health including ethnicity / race, income, and education. As the issues that negatively influence access to primary preventive health care, it makes unfortunate sense that they are equally influential in determining equitable access to optimal care at the end of life too.

Krikorian, Maldonado and Patrana (2019) performed a literature meta-analysis and developed a useful conceptual framework to consider elements included in a good death. They identified the core elements of a good death that include “pain and symptom control, preparation for death, the subjective feeling of closure at the end of one's life, clear decision-making, and contributing to others” (p. 7). They also recognize that values, preferences and decisions are largely determined as “culture, religion, age, life circumstances, disease, and financial issues” (p. 10). While there is not consensus about

defining a good death, these and similar findings are reported in additional literature reviewed for this paper.

In an ethnographically informed study of advance care planning among ethnic and racial minorities in the United States, Hong et al. (2018) synthesized findings from prior research that identified better educated individuals with higher income and more education as more likely to participate in advance care planning than less educated, poorer and less health literate individuals. With respect to race, almost twice as many white individuals completed advance care plans compared to ethnic minorities (18% vs. 34%). Latinos demonstrated the least engagement among non-white groups. This disparity continued even after admission to a hospital where more whites than ethnic minorities discussed or participated in advance care planning discussions (Hong et al. 2018). Specifically, Hong found four categories of barriers and enablers to advance care planning experienced disproportionately by ethnic minorities. First, socio-demographic factors including education and income with higher income and educational attainment associated with greater care planning participation. Second, poorer health status and low health literacy including lack of awareness of health issues and lack of access to social and health care supports contributed to less engagement in pre-planning activities. Mistrust toward health care organizations based on prior experience was identified as an issue inhibiting advance care planning among Blacks. Third, cultural values strongly influenced participation. Family centered decision-making models as seen in Latino and Asian families is associated with negative attitudes towards advance care planning. Finally, spirituality, or belief in God may be also associated with less participation in advance care planning, particularly among

Blacks and Latinos. In a broad generalization, Blacks were identified as using religious beliefs to guide end of life decisions while Whites consider religion as a factor in decision making.

Nobody told me about the expected disease progression or options to assist with end-of-life. I had to learn about them by reading. Then he developed kidney failure. Still not informed by the care team. He became debilitated and confused. Still, the care team said nothing. During one of many hospitalizations that Spring, he was intubated – but still no conversation about end-of-life with the care team. I feel strongly now that the team made assumptions about my ability to participate in informed decision making and excluded me from the process. That summer he was intubated for 10 days and towards the end of the 10 days I had the first conversation with the team. Options were DNR or not DNR. I chose DNR. My son and I had little time to prepare ourselves or our home to care for him. Still, nobody told me about Palliative Care. He was home 5 days and needed to be readmitted once more. He died 2 days later. There was plenty of time for discussion. Maybe they (ed. the care team) were afraid they would take hope away. But it would have been better to have known what to realistically expect. Not knowing made things so stressful for me and my family. The team lacked empathy. They had a sterile appearance and were ignorant of my religious beliefs and practices. I included his mother in the decision because he was her son longer than he was my husband. (see Appendix E)

It took me years to become comfortable having these discussions with patients and families. We are never completely certain how things might have turned out if other options had been selected. On one hand, frailty in aging and disease is nature's way of saying it is time. Still, families have a hard time understanding and believing that this is the end. The pain that stems from ill-conceived procedures falls on the physician too. It's hard. (see Appendix C)

Periyakoil, Neri and Kraemer (2015) reported on empirically identified barriers experienced by multiethnic patients and families in receiving high quality end of life care in five California cities. They identified and validated six key barriers to high quality end

of life care among their target population. Barriers included financial and insurance issues, physician behaviors / communication gaps between doctors and patients, family beliefs and behaviors, health system barriers and cultural / religious barriers. Periyakoil et al. also found that educational attainment independently influenced end of life care choices. Periyakoil's findings overlap with the Hong analysis, and together both support Krikorian's framework.

In England, Hall et al. (2019) performed a less ethnically informed review of literature published between 2017 and 2018. Nevertheless, their findings are similar to Periyakoil's and Hong's. Older, white, well-educated women had the best chance of engaging in advance care planning discussions with care providers. Ethnic minorities, less educated and poorer people, as well as those with intellectual disabilities, had fewer discussions. Hall also identifies tension between standardized end-of-life practices and discussions compared with those who advocate a more flexible approach to honor the need for patient and family centered discussion of specific preferences and concerns. In all likelihood, there needs to be a balance between the two approaches so that key issues are consistently addressed in culturally and personally appropriate ways.

There are clear opportunities to intentionally extend advance care planning to minorities so that their wishes and needs can become known and so that the end of life care they receive is more likely to meet their individual choices. By promoting informed choices at the end of life, health providers reinforce autonomy among disenfranchised populations, supporting the view that advance care planning should be initiated in the primary practice

by the providers with whom the patient has an established relationship in a series of conversations rather than as a single discussion and as a routine part of the office visit. With chronically advancing diseases like dementia and chronic obstructive pulmonary diseases it is especially important to initiate discussions early when patients have capacity. Appropriate timing is essential but there is no “formula” to determine the “best” time to engage in advance care planning discussions.

In their systematic literature review and meta—ethnography, Rodriguez-Prat, Monforte-Royo, Porta-Sales, Escribano, and Balaguer (2016) identified dignity as a marker for an individual’s sense of autonomy and control as well as the quality of their life and death. First, dignity is positively associated with a sense of control and usefulness. Second, dignity is positively associated with personal identity, so that loss of dignity is associated with a loss of personal identity. And third, perceived autonomy reinforces personal perceptions of dignity. These findings are similar to Derse’s (2015) description of self-determination as autonomy: The individual’s right to select which treatments to choose and accept, refuse or request, to influence and determine the conditions of their own death.

At Temple University Hospital, analysis of demographic data reveals that patients arrive with advance directives in about 2 – 2.5% of inpatient admissions. It has been observed that some families bring these documents to the hospital after admission. Although these numbers are difficult to quantify, this is not reported to be a frequent or regular occurrence. Through the admission process, the vast majority of inpatients (97-98%) are identified as not completing an advance directive prior to admission. Having

established the value of timely and effective end of life conversations about advance care planning as well as barriers to these conversations from the patient's and family's perspectives, it is reasonable to examine the care team's perspective for reasons that these conversations do not occur more often prior to the actual end of life as well as general barriers to effective communication at the end of life.

One issue to consider is the nature of the terminal illness or disease. Hospital deaths may be characterized as anticipated or unanticipated. Anticipated deaths typically occur in the presence of chronic health conditions with a predictable clinical progression towards end of life that may include issues like cancer, heart disease and lung disease. Death may also be anticipated in the setting of high-risk elective, planned surgical procedures. Ideally, patients who have anticipated deaths will have advance care plans that direct their end of life care. Unanticipated deaths occur infrequently among patients who expire unexpectedly while hospitalized. More commonly, severely injured trauma patients who were in good health immediately prior to their unforeseen injuries may expire unexpectedly while hospitalized. When critically-ill trauma victims arrive in the Emergency Department, they receive all appropriate and available care to save and sustain their lives including intubation, transfusions and operative and other invasive procedures. The presence or absence of advance care plans is not an initial consideration when attempting to save lives among this patient population. Interventions are performed with regard only for their clinical needs. Decisions about the direction and extent of subsequent care typically happens later when there is time for discussion with family members. These discussions are difficult. Family members are anxious and grieving and sometimes the decisions that

need to be made are extremely time sensitive. This timing issue clearly conflicts with wider decision-making models that are observed to be favored by some families. In other clinical scenarios, the trauma team is able to support the family's need for time and wider discussion before making critical decisions.

Western culture has unrealistic expectations about what medicine can do for people. Sometimes they want everything done even when it is clear that the situation is hopeless. If I am ever in that situation, just let me go. Time is a major barrier. These discussions need to happen in the primary care office, not wait until an inpatient crisis. (see Appendix F)

A major barrier is unresolved family dynamic issues that are expressed in stressful situations. Our residents are inexperienced and try to use data and statistics in conversations. It doesn't work well to use statistics in end of life conversations. There's not enough focus on quality of care and quality of life; too much emphasis on survival related whether or not to do procedures and interventions. Health literacy is a major barrier in non-trauma end of life discussions. End of life discussions are usually much more straightforward in trauma patients with injuries that are undeniable. We have to earn trust. Spend time and show you care ... and you have to care. People believe in miracles and so do I. (see Appendix G)

In a telephone survey of primary care physicians and specialists who care for patients aged 65 and older, the vast majority (99%) of 736 respondents agree on the potential value of advance care planning. However, despite Medicare reimbursement for patient-provider end-of-life care planning discussions, only 14% of providers with Medicare fee for service patients reported billing for this service. This gap suggests that barriers exist among providers that interfere with engaging in end-of-life discussions with their patients (PerryUndem 2016). They summarize the identified barriers into structural and attitudinal categories. Structural barriers include practices and health care systems not having formal processes in place to assess patients' end of life preferences and goals for

care, the electronic health record not supporting advance care planning by identifying patients with advance directives or making it possible to see the advance directive. 71% of respondents have not had formal training about end-of-life conversations. These issues dovetail into physicians feeling unprepared for end of life discussions, managing disagreements among family members and patients and not knowing the right time to have end of life conversations. “The primary motivations to have these conversations are honoring their patients’ values and wishes and reducing unnecessary or unwanted hospitalization at the end of life” (PerryUndem, 2016, p. 5). Physicians with formal training and access to formal assessment systems are much more likely to appreciate the value of end-of-life care planning discussions.

Brighton and Bristow (2016) identify that patients and families wait for clinicians to initiate end-of-life discussions while clinicians wait for patients and families to raise the topic. They identify specific reasons that clinicians hesitate to begin discussions including “prognostic uncertainty, fear of causing distress, navigating patient readiness and feeling unprepared for these conversations” (Brighton and Bristow, 2016, p. 467-468). Prognostic uncertainty refers to the timing of end of life discussions. Patients need to have capacity to participate in their own end of life decision making. It can be inferred then that it is useful to engage in these discussions in the outpatient, primary care setting while patients are in stable and hopefully optimal health, including the patient’s usual care providers to determine end of life values and preferences. Establishing preferences about end-of-life care preferences prior to the end of life is associated with desirably less aggressive end-of-life care. In turn, surviving families report less distress with less aggressive care. This cycle

results in increased use of palliative care and hospice, fewer unwanted hospitalizations with fewer unwanted interventions and better compliance with the patient's expressed wishes. Thus, when end of life discussions are well planned and implemented in advance of end of life, outcomes for patients, their families and health care organizations are improved.

There are so many barriers (in the primary care setting) to having discussions about what patients want at the end of life. Residents' awareness of likely prognosis. Patients and families don't want to talk about it. We need to clarify values with patients and their decision makers; what is important to them. Routine counseling in the primary care setting. Normalize end of life discussion in the primary care setting. I don't counsel every patient, every visit. There's not enough time and there are other priorities during that visit. Doctors are not always comfortable in that situation, when they don't have a relationship with that patient. I need work-life balance. There are superstars in the organization who are so good at these conversations. (see Appendix H)

Brighton and Bristow's findings are remarkably similar to those of Periyakoil, Neri and Kraemer (2015) who identify that 99.9% of physicians (N=1040) practicing in Stanford Hospital and the VA System in Palo Alto, California reported barriers to effective end-of-life conversations with their patients. Ineffective patient physician communication results in the failure to elicit patient preferences and values early in the disease process causing ethnic patients to be more likely to consume ineffective and burdensome and expensive high-intensity treatments and less likely to utilize desirable hospice services at the end of life. Data analysis shows that physician ethnicity is significantly associated with physician reported barriers to conducting effective end of life conversations with Asian physicians reporting the most struggles (91.3%) followed by African American doctors (85.3%), then Caucasian doctors (83.5%), then Hispanic Latino doctors (79.3%). They identify six

barriers to conducting effective end-of-life conversations. Most of the barriers are associated with patients' cultural differences reflected in language, beliefs and practices around death and dying, and collectivistic family decision-making. The sixth barrier is limited health literacy among patients and families. In one item, physicians acknowledge their lack of awareness of patient values. Therefore, five of the six identified barriers are patient-centered rather than focused around professional physician practices. This study effectively blames patients of diverse cultures and backgrounds for the physician and health care system's collective failures to deliver culturally appropriate care at the end of life. Nevertheless, these health care professionals have identified these items as barriers to effective communications around eliciting end of life values and preferences from their diverse patient population. (see Appendix I)

Barriers identified by Nedjat-Haiem, Carrion, Gonzalez, Ell, Thompson and Mishra (2017) include delayed communications about end of life until patients have lost capacity to engage in discussions, gaps in provider-patient communication negatively impact the effectiveness of advance care planning, and role confusion when teams poorly coordinate communications between themselves and patients and families as barriers to effective and timely end of life communication. It may be uncertain who will initiate the conversation resulting in missed opportunities to engage in needed discussions.

Finally, in a multi-center Canadian study of academic medical facilities, You et al (2014) studied 1256 clinicians (512 nurses, 484 resident physicians and 260 staff physicians) to identify the most important barriers impeding communication and goals of

care decision making with seriously ill patients and their families. The clinical staff identified the patient and family's difficulty accepting a poor prognosis; understanding the limitations and complications of life sustaining treatments; disagreements about goals of care, and lack of patient capacity to make decisions as the most important barriers impeding communication and decisions around goals of care. Respondents perceived their own skills and system factors as less important than these patient centered issues. Importantly, they did concur that all groups of caregivers should participate in goals of care discussions. As observed with Periyakoil, Neri and Kraemer's report of barriers to effective end of life conversations, the issues identified by You et al are focused on patient factors rather than how these healthcare professionals understand, navigate and surmount these issues so that effective discussions about care at the end of life may occur.

CHAPTER 4: STRATEGIES TO INFLUENCE CLINICAL PRACTICE AND SUPPORT WELL-INFORMED PATIENT AUTONOMY

We have reviewed the importance of effective planning for care at the end-of-life and the use of advance care planning as a vehicle to promote patient autonomy. Many barriers and facilitators for effective end of life discussions and the consequences of inadequate planning and discussion have been described at length. Through discussion of bioethical perspectives, we have described death as a function of social justice, self-determination and autonomy. We have described good deaths from patient and caregiver perspectives including the concepts of futility and medically non-beneficial care with emphasis on barriers and facilitators to effective end of life discussions that result in actionable expression of patient wishes and values about what treatments are desired and those to be avoided at end of life. Finally, through review of literature about provider perceived barriers to end of life care planning, we established that care provider strategies and tactics are inconsistently aligned with principles of social justice and patient autonomy. Despite a clear roadmap and best intentions to develop and implement a plan of care for the end-of-life, we most often fail to accomplish this goal as evidenced by the relatively few patients who have advance directives and designated medical proxies. Advance care planning is theoretical. It begins in a health care provider's office against a time in the future when informed, time-sensitive decisions about important health issues need to be made. But we ask people to formulate literally their life or death response to a complex situation that is so difficult to conceptualize or envision.

The results of ineffective or absent care planning may be felt in the inpatient hospital setting. Successful decision-making requires patient and family focused communication that is sufficiently structured to facilitate informed decision-making (Shinefeld 2017). I believe that by using a structured communication model to inform thoughtful decisions, we can mitigate the effect of not considering end-of-life healthcare choices previously. We have established that patients wait for their providers to initiate discussions and many providers are uncomfortable starting discussions about end of life because they “frequently or sometimes feel unsure of what to say during conversations about end-of-life care” (PerryUndem, 2016, p. 4).

This avoidance may be due to the emotional distress these discussions cause among clinicians as well as to their not knowing what to say or how to say it. The Serious Illness Communication Guide (SICG) is based on research from the Dana Farber Serious Illness Communication trial establishing that trained clinicians were able to have earlier and more effective palliative care discussions to help inform their patients’ future care. With a scripted approach to facilitate difficult conversations, the SICG addresses potential anxiety to help clinicians and patients have meaningful conversations about topics such as prognosis and illness understanding, personal values and goals, fears and sources of strength, critical abilities that matter to their quality of life, and what they might be willing to go through for more time. (Paladino et al., 2019, p. 805). The innovative SICG has the potential to improve overall reliability of end-of-life cancer communications.

Scripted, focused conversation guides are shown to be an effective tool to mitigate clinicians' fears, concerns and perceived inability to conduct effective end of life conversations (Geerse et al. 2019). The result of the SICG intervention at Brigham and Women's Hospital is that end of life conversations happened almost 2.5 months earlier and that patients reported decreased anxiety and depression (Palladino et al., 2019, p. 805). For these reasons, the SICG is being considered for implementation in the Department of Medicine as a useful teaching and clinical tool especially for patients who did not have advance planning conversations prior to their illness or hospitalization. The SICG may prove to help mitigate the effects of social injustice that creates barriers to accessing primary preventive health care where advance care planning discussions should occur. (see Appendix J).

There continues to be disagreement about the role of surgery in an attempt to sustain life when death seems to be a certainty among the professionals who guide and participate in patient care. In the most recent 12-month review of mortality data, 45% to 54% of deaths were associated with a procedure near the end of life. In the same time period, 14% to 17% of those deaths were associated with futility. These data validate the perception that there is opportunity for improvement in terms of advocating for robust, well-informed patient decision making.

We don't make sane recommendations. Our default is that intubation, ventilation, circulatory support is the optimal strategy. We don't recognize other options. We don't recommend against coding the patient in favor of high-tech interventions. We traumatize patients, families and the healthcare team. We cross the line and cause emotional damage. (see Appendix A)

The Best Case / Worst Case framework is an intervention to teach surgeons to change their communication habits and utilize shared decision making during high stakes surgical decisions. “Best practice guidelines endorse shared decision making in the context of serious illness to present options, engage patients in deliberation about treatment outcomes, and integrate patient preferences into a recommendation” (Taylor et al. 2017). Traditionally, surgeons would offer risks of specific complications to inform decision making. While these discrete lists of complication risks are accurate, they do not begin to accurately describe the life altering outcomes that may be expected after major, high-risk surgery. The Best Case/Worst Case framework combines narrative with a graphic visual aid to illustrate and demonstrate anticipated post-operative realities. To promote realistic patient and family understanding and expectations of outcomes, the visual aid was used to show expected outcomes between the best- and worst-case possibilities – accompanied by a narrative description in lieu of statistics. The initial implementation study demonstrated that the “Best Case / Worst Case framework promotes shared decision making for frail older patients with acute surgical problems” (Taylor et al., 2017, p. 537). For this reason, it is being phased in for high risk surgical procedures to support well-informed decisions and enhanced patient autonomy (see Appendix K).

Both the Serious Illness Communication Guide and the Best Case/Worst Case framework support the three key teaching elements described in Towards an Effective Shared Decision Model (Shinefeld, 2017) for effective patient education and well-informed consent. The first element is structured communication for reliable and consistent

teaching (Taylor and Schwarze 2016). Both models structure communication for the benefit of the clinician to facilitate effective discussion and for the patient and family to facilitate learning. The second element is to meaningfully quantify the risks, alternatives and benefits associated with any potential course of action. Both models place likely outcomes in the context of personally relevant and meaningful patient perspectives. The third element of a framework for effective decision-making is the development and application of patient decision aids; evidence-based learning tools designed to help patients understand what issues are most important to them when they speak with their health care team about treatment options (Bae, 2015). Clearly, the Best Case / Worst Case graphic aid fits this description. Arguably, the Serious Illness Communication Guide also qualifies as a patient decision aid since it also offers a framework to focus discussion on specific, relevant issues.

CHAPTER 5: CONCLUSIONS

In this paper we have discussed the value of advance directives and the effects of social determinants of health on disenfranchised individuals' ability to access primary care where advance care planning is initiated as well as to the elements of care that make a "good death" possible. It is clear that current social and health care structures fail to support equity in accessing appropriate and necessary health care. Discussion of bioethical considerations supports a well-informed consenting process and interventions to support ethically informed decision-making preferences. We have reviewed facilitators and barriers to engaging in effective end of life discussion from the perspectives of patients and clinicians. Clinician priorities and agendas do not consistently align with patient needs and values. We have also discussed strategies to mitigate the impact of not having engaged in advance care planning through patient-centered educational frameworks. As timing of palliative care interventions is key, facilitating earlier supportive discussions is highly recommended. Most importantly, since discussion alone is insufficient to effect change, we are also beginning the work to implement educational initiatives and robust decision-making frameworks to support well-informed and sustainable patient autonomy through clinical conferences and enhancements to resident and student curricula.

My hope is that by normalizing discussion regarding end of life and rational care options, we can assist patients and families in making decisions that support their needs and values. Sometimes this may be reflected in increased utilization of advanced therapies. In many cases rational decision making may be reflected by fewer end-of-life

hospitalizations, fewer end-of-life curative procedures, and a change in the language associated with end-of-life from war and battle to grace and peace.

Thank you for the opportunity to explore this topic in depth. My reading, research and discussions resulted in awareness of multiple concerns and perspectives and a nuanced understanding of many alternate and contending issues regarding the end of life. While the inevitability of death is truly universal, our own beliefs and wishes are mostly unexplored and undiscussed. Opening the subject to forthright and earlier discussion through primary practices will help normalize the topic and encourage more robust conversation so that this may become a pathway to routinely negotiating the terms and conditions of our deaths.

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APPENDIX A: INTERVIEW WITH AN INTERNAL MEDICINE PHYSICIAN;
DECEMBER 2019; 16 YEARS PROFESSIONAL PRACTICE

Barriers to a good death and productive end-of-life discussions: Truth telling by providers; health care team (attending physicians) to patients and families. Deaths do not need to be tragic. Need time for goodbyes... and need to know it is time to start saying goodbye. We leave families traumatized by not telling the truth and by setting unrealistic expectations. Not necessarily deliberate. Motivation ... cultural, religious, spiritual, educational? They don't see the tortured families and sometimes patients who are left behind. Compassionate to their colleagues but a disconnect with patient centered end of life issues. We traumatize patients, family and the health care team. We cross the line and cause emotional damage

Residents are intimidated by "gag rule" - Please don't talk to my patient ... but I'm not going to talk to them either.

Families may need permission to ask questions and to push the care team for information, prognosis, end of life, to think about next steps. But sometimes we focus discussions on increasingly unlikely interventions with purportedly curative intent. "Let's try dialysis." Any insertion of a possibility of hope / cure / longer life and families tend to focus on that rather than what doesn't work.

Our default is to assume that intubation, ventilation, circulatory support are the optimal strategies. We don't recognize other options. We don't make "sane" recommendations. We don't recommend against coding the patient in favor of high-tech interventions.

Resident Education: What are we teaching residents about end of life? About truth-telling? Are they savvy enough to understand learn practice from us? Are we causing moral distress among our pulmonary residents?

Palliative care's job: Create shared understanding. Figure out where palliative care can help with decision making. Get to know the patients who can't be part of the discussion. Develop an understanding of the social context of the family: supports, how were they living before this final episode? Values? Priorities? Promote shared decision making. Supports patient autonomy by providing information for informed consent / advance directive determinations

APPENDIX B: INTERVIEW WITH A PALLIATIVE CARE SOCIAL WORKER;
SEPTEMBER 2019; 14 YEARS PROFESSIONAL PRACTICE

Role of palliative care: Evaluate how people function in the world. Assess their physical, emotional and spiritual resources. Challenges and strengths. Ascertain their values. What's important to them in the world. What's important to them with respect to their medical issues and options for care. Help them determine what will work best for them with respect to the medical-surgical options for care. Curative and palliative.

Who helps family make medical decisions? Have they already made decisions? How can the palliative care team add to that conversation? Translate medical options for them in lay terminology. Being specific and concrete with "if/then" scenarios: If that treatment, then what will their future likely look like in terms of ICU and hospital stay, discharge home or to a facility. Their predictable frailty.

Barriers Identified

Time element: Care givers, especially those who are less experienced and have fewer options readily available to them perceive that end of life conversations will take longer than they need to. People leading the discussion need the toolbox of skills to be comfortable using the skills.

Lack of collaboration between teams: Care teams not knowing, not understanding and not knowing that they don't know. Assumptions about roles and capabilities of other

teams and the resources available to assist in the care of the patient. Poor communication between teams even with the best of intentions leads to fragmented care, e.g., patient seen in outpatient oncology, cared for in the inpatient setting by medicine or hospitalist groups who have not communicated effectively with each other, inhibits downstream communication with the patient and informal care givers about end-of-life and goals of care.

Lack of clarity: About prognosis and treatment plans. Sometimes the teams disagree about basic issues like prognosis or about the information that is to be shared with family as well as recommendations. See this with transplant services and their survival metrics.

Time and logistics: Getting everyone to the table is challenging

Prioritization: End-of-life and goals of care are less important to some care teams than the patient's short-term survival. Some teams and team members are more comfortable and some are less comfortable having conversations.

Patient and families: Might not want to have end-of-life and goals of care conversations. When patient lose capacity and can't participate it puts family members in a difficult situation, especially when there have not been prior discussions about end-of-life and goals of care or the local decisions makers have not been present at those

conversations. Especially difficult when there is no surrogate and the patient has lost capacity necessitating administrative decision making.

Unrealistic expectations: Family wants to stop but the care team wants to keep going because they see the current situation as treatable. See this in high stakes surgeries especially transplants with the ultra-high value organ gift – and there is a perceived obligation to use all available treatment to survive.

Sometimes, the team wants to stop but the family wants to keep going. Palliative care helps teams and families / decision makers talk to each other about likely course and outcomes. Use Best Case / Worst Case framework in this situation to help families verbalize values and communicate them to the team who can then describe likely outcomes of intervention / non-interventions in lay terms that in turn helps families clarify their own thought processes in terms of what the patient would want or has previously expressed. Then Palliative Care can advocate appropriately.

Where do you get satisfaction? Patient advocacy. Family advocacy. Help them make decisions from a perspective of being respected as people – not as a clinical project. Informed consent is such an important framework. Talking to people as humans. Helping them feel understood and appreciated in a potentially fraught process. Working with so many different people and groups to work for something better than any of us could achieve separately.

Frustrations: When we don't listen to each other. Don't work together. Don't communicate with each other. Suspicious of each other's motives. Working in a big hospital leads to issues communicating due to the sheer number of people and teams involved in patient care.

Observations: Latino and African American patients and families may choose more medically aggressive care but in reality, it often does not happen that way. They may trust medical decision makers more because they simply do not know about palliative care options. Conversely, wealthier Caucasian patients and families may seem to have a sense of entitlement not observed in lower socioeconomic status groups. They may have prior knowledge and preconceived notions about palliative care; that palliative care equals end-of-life. They may ask more questions, demonstrate lower levels of trust.

Resident Training: Awkward conversations led by trainees can cause harm and distress. They need feedback to learn. Seems as though trainees who are less adept at EOL conversations are also less likely to accept feedback constructively. Recommend using the SIM lab to simulate conversations – deliver bad news in emotionally fraught situations, especially around brain death. Use of the SIM lab mitigates awkwardness of role playing and may make feedback easier to give and accept.

APPENDIX C: INTERVIEW WITH A SURGEON; SEPTEMBER 2019; 8 YEARS
PROFESSIONAL PRACTICE

Barriers:

Trust issues sometimes but not typically a major issue. Patient culture and unrealistic expectations. Misplaced societal priorities. Patients can't access inexpensive, preventive care like colonoscopies but society is willing to spend hundreds of thousands of dollars on chemotherapy for hopelessly advanced cancers and futile treatment.

Resident education - when consulting on cases with advanced cancers and other immediately life limiting conditions for potentially "life-saving" surgeries residents will lean towards recommending interventions rather than end-of-life / goals of care discussion. Trained and incented to do procedures.

Overcoming barriers: Took years to become comfortable having these discussions with patients and families. Never completely certain about how things might have turned out if other options had been selected. On one hand frailty in aging and disease is nature's way of saying it is time. Still, families have a hard time understanding and believing that "this" is the end of life. Seeing the pain stemming from ill-conceived procedures falls on the attending physician too. Residents are aware, sometimes. The fallout does really fall on the attending's shoulders. Advocates strongly for use of the Best Case / Worst Case scenario.

APPENDIX D: INTERVIEW WITH A HOSPITAL MEDICINE PHYSICIAN;
NOVEMBER 2019; 7 YEARS PROFESSIONAL PRACTICE

Approximately a year ago, there was a Buddhist patient who had arrested several times, for whom imminent death was clearly inevitable. After daily rounds, there was angry discussion among team members about why the family did not make the patient a DNR. Then a Buddhist monk came to the hospital and conducted an end-of-life service with family members present at the patient's side, and the patient died, peacefully. We helped her have a beautiful, good death.

A Good Death and a Bad Death

A good death is one that is prepared for; concerns and obligations are reconciled; a beautiful life, at peace with her own death.

A bad death is one that is unprepared, young, tragic, trauma; survivors may experience post-traumatic stress.

Barriers

Prognostication: We are not good at predicting how much longer people will live. This shortcoming is exacerbated when teams and caregivers rotate on and off services every week or two.

Absence of family and support network. Family is often not ready and not present ... perhaps to avoid discussion about end-of-life issues.

Personal views about end-of-life that are superimposed onto the therapeutic discussion.

Health literacy, for example the concept of brain death absent obvious trauma is difficult for some to comprehend, particularly in a young, otherwise healthy appearing individual.

Distrust of the medical establishment. Related to our poor prognostication, race relations, SDH related issues.

“I am a woman of faith – I believe in miracles. As a physician, I wouldn’t be surprised if had 4 weeks left” but that’s not enough time for family to process the dying or the death or to let go.

A young patient in pain wanted to stop dialysis. A family member couldn’t accept his decision, his request. But he was ready. This was not the way he wanted to live.

Resident Training

While there are didactic components to end of life curriculum, end-of-life education is typically on the job. Some people are better at these conversations than others. People

who gravitate to some of the specialties are typically not as good at having bad news or end-of-life discussions. Humanism in medicine with consideration of patient wants and needs. When to stop? When to continue? IM and ACGME components.

Terminology and language matters: “I’m here for you; I’m here with you” versus “I understand what you are going through”

Medical Training and Faith: Very few moral or ethical conflicts attributable to faith. Some obvious issues like birth control are easily negotiated. No conflict between faith and medical practice. Typically, medical training and faith concepts align. Always going to be difficult issues like Terry Schiavo – issues are often based around lack of shared understanding of language and meaning ... persistent vegetative state; brain death ... our obligation is to teach families. The church does not advocate extraordinary measures; faith and medical standards of care typically align.

Bioethical considerations: Autonomy; social justice; distributive justice; moral distress often around the social determinants of health that are inadequate to support needs. Patients with capacity but perhaps with limited decision making ability refuse care and leave against medical advice.

Withholding nutrition: PEG is not useful for a patient at the end of life but for someone on the border it can be a useful intervention and minimally invasive.

We serve the poorest of the poor; the neediest of the needy; a voice for those without voice is simply advocacy. A passionate calling.

End-of-Life discussion goals: Listen to the patient. Advocate for what they want. Raise important issues: Code status; hospice. Is continuing treatment appropriate or inappropriate? What are the patient's goals? Series of discussions to understand patient and family needs. Try to support what they want.

Entire life story: "So proud of you."

Towards a Good Death: Hear the patient. Advocate for the patient. Make reasonable accommodations with the family and patient. Provide education to support autonomy. Translate medical jargon. Create alignment. One good death can impact so many people.

One bad death can have the same but negative impact.

APPENDIX E: OCTOBER 2019; INTERVIEW WITH A SURVIVING SPOUSE AND
MOTHER.

Husband – liver disease, long standing diagnosis treated but relapsed. Developed confusion due to the liver disease. “Nobody told me about the expected disease progression. I had to learn about it by reading”. Then he developed kidney failure. Still not informed by the care team. Became debilitated and confused. She and her son were taking care of their husband / father at home.

She asked the care team about Palliative Care. She knew a little about Palliative Care from her own work experience. “He should have been headed to Palliative Care much earlier. Earlier communication would have helped patient and care givers in their preparation – family, home care arrangements; to allow preparation and closure for everyone”.

May – June: Dementia, hospitalized repeatedly between brief amount of time at home. During one hospitalization, he was intubated with terminal illness but still no conversation about end of life.

She feels strongly that the team made assumptions about her ability to participate in informed decision making and excluded her from decision making.

He was intubated 10 days. Towards the end of the 10 days she had the first DNR communication with the team. She believes they were still hopeful until that time. Options presented were DNR or not DNR. She chose DNR.

She saw signs of life in her husband and eventually he was extubated and sent home once more. Still no discussion or information about Palliative Care. She and her son had very little time to prepare their home and her husband was home 5 days before he decompensated again. His outpatient lab work was abnormal and he was readmitted once more. He died two days later.

There had been plenty of time for discussions. Maybe they (the care team) were afraid they were going to take hope away. But it would have been better to have known what to realistically expect. Not knowing made things so much more stressful for the family.

Family needs a road map. Each visit, reiteration. Not the one-time advance directive conversation.

Questions are “what if”.

She felt included in the ultimate decision she had to make but not included in the larger conversation.

The care team lacked empathy. They presented a “sterile” appearance. Ignorant of racial and religious beliefs and issues.

She included her husband’s mother in decision making. “He was son longer than he was my husband”. Group decision making is important in her family. Every decision was made by the family at end of life There was a disconnect between the group decision making and the medical model.

Advance care planning is not a proxy for discussion. The advance directive helps the health care provider in the office but it does not help the patient or the family who need to be informed and have the chance to talk.

Language and cultural barriers:

The team needs to anticipate the need for group decision making. The opportunity for the patient and the family to think about what they want in the future. They take the conversation home with them.

APPENDIX F: OCTOBER 2019; INTERVIEW WITH SURGEON; 16 YEARS

PROFESSIONAL PRACTICE

Barriers to a good death and effective end of life discussions

Time from arrival to death for trauma patients. Western culture has unrealistic expectations about what medicine can do for people. Sometimes they (families) want everything done even when it is clear that the situation is hopeless. If I am ever in that situation, just let me go. Lack of clarity among family members. Lack of trust in physicians and in the hospital.

Overcoming barriers to a good death and effective end of life - Discussions should happen in primary care office, not wait until an inpatient crisis.

APPENDIX G: SEPTEMBER 2019; INTERVIEW WITH A SURGEON; 36 YEARS

PROFESSIONAL PRACTICE

Barriers: Unresolved family dynamic issues. Identifies no differences between families of varying race and ethnicity.

Residents: Inexperienced. Lack of understanding about likely outcomes. They try to use data and statistics in conversations – doesn't work well to use statistics in compassionate EOL conversations. Not enough focus on quality of care and quality of life; too much emphasis on survival related whether or not to do procedures and interventions.

Role playing > contrived discussion.

Scenario: data and survival; whether or not to recommend OR procedures; establish patient values

EOL discussions are labor intensive. Always slightly different outcomes. We use simulators for informed consent discussions; why not for EOL discussions?

Do not observe barriers and differences based on ethnicity and race. EOL GOC discussions are usually much more straightforward in trauma patients with evident injuries that are undeniable.

Health literacy is a barrier in nontraumatic EOL discussions – with insidious disease processes.

Role is keeping the focus on the patient's quality of life. "People believe in miracles and so do I". Trust is necessary – for families to take what we offer in a meaningful way. We have to earn trust. Spend time. Show you care ... and you have to care. Value their input and refocus the discussion where it needs to be. Personal

understanding and experiences. Value their opinions. Show you care about their loved one and about their feelings.

Recommends – exposing residents and younger faculty to scenarios.

Changing Services: Personal introduction of new colleagues to family. If it is perceived that the transition will be sub-optimal, then the outgoing doctor needs to stay involved with the patient's care and with the family.

Palliative Care Services: Questionable usefulness in the context of the surgical ICU. Tend to lead discussions and maybe reinforce the wrong ideas. Crucial to refocus the family on what they believe their loved one would want, and then assist them with decision making on that basis.

If a situation is hopeless but family want to stay the course, then agree to revisit the conversation in a few days – to look for interval improvement. “I don't agree but I respect your wishes”. Can't force a decision.

APPENDIX H: NOVEMBER 2019; INTERVIEW WITH AN INTERNAL MEDICINE
PHYSICIAN; 30 YEARS PROFESSIONAL PRACTICE.

Barrier to end of life discussions:

Denial: Patient, family. Care team too sometimes. Residents' awareness of likely prognosis. Patients and families don't want to talk about it (end of life).

Overcoming Barriers: Clarifying values with patients and their decision makers; what is important to them. Routine counseling in the primary care setting. Normalize the end of life discussion in the primary care setting

In practice: Not every patient, every time.

Time: Alternate priorities during that visit. Need for work life balance and the perception that the discussion will take too much time and infringe on personal time away from work.

Lack of comfort in that situation, with that patient. Often lack of a prior professional relationship.

There are some superstars in the organization: [identifies 2 physicians] who are really good at end of life discussions and who have much to offer our patients and their professional staff.

APPENDIX I: BARRIERS FACED BY CLINICIANS IN REGARD TO END OF LIFE

DISCUSSIONS

Brighton, LJ & Bristow K., (2016). Communication in palliative care: talking about the end of life, before the end of life. *BMJ Post Graduate Medical Journal*, 92, pp. 466-470. doi:10.1136/postgradmedj-2015-133368

Barriers Faced by Clinicians in Regard to End of Life Discussions

1. Accurately translating technical medical terms into other languages;
2. Patient and family religious and spiritual beliefs about death and dying that influence discussions and family decisions about end of life treatment;
3. Care providers self-identifying as being unaware of important cultural values around death and dying;
4. Cultural differences in truth telling and decision making;
5. Limited health literacy among patients and families, and
6. Patient and family mistrust of doctors and the health care system. This issue reinforces discussion about recommendations to limit futile health care interventions being misinterpreted as racial rationing.

APPENDIX J: SERIOUS ILLNESS CONVERSATION GUIDE

Geerse, OP., Lamas, DJ., Sanders, JJ., Paladino, J., Kavanagh, J., Henrich, NJ., Berendsen, AJ., Thijo JN., Hiltermann, TJN., Fromme, EK., Bernacki, RE., and Block, SD., (2019). A Qualitative Study of Serious Illness Conversations in Patients with Advanced Cancer. *Journal of Palliative Medicine*. Jul 2019.773- 781.
<http://doi.org.libproxy.temple.edu/10.1089/jpm.2018.0487>

Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2. Assess understanding and preferences

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6. Document your conversation

7. Communicate with key clinicians



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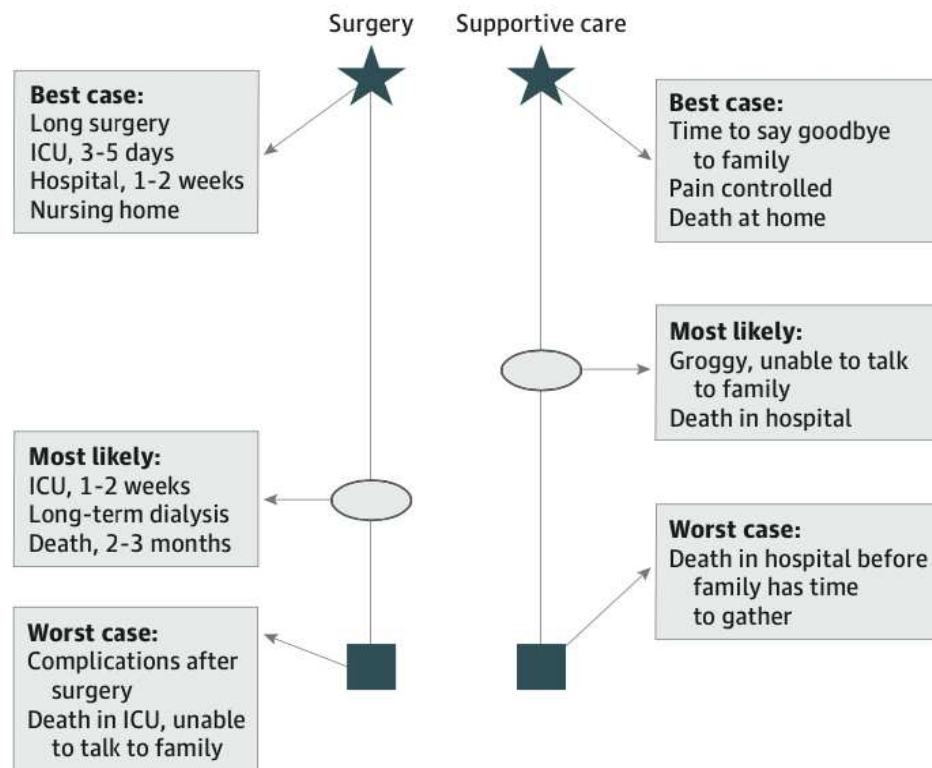
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APPENDIX K: THE BEST CASE / WORST CASE SCENARIO

Taylor, L., Nabozny, M., Steffens, N., Tucholka, J., Brasel, K., Johnson, S., Zelenski, A., Rathouz, P., Zhao, Q., Kwekkeboom, K., Campbell, T., & Schwarze, M. (2017). A Framework to improve surgeon communication in high stakes decisions - Best Case / Worst Case. *JAMA Surgery*, 152(6):531-538. doi:10.1001/jamasurg.2016:5674.

Figure 1. Best Case/Worst Case Graphic Aid



Example of a Best Case/Worst Case graphic aid that the surgeon would create and use during a decision-making discussion for an older patient with a serious surgical problem. The box represents the worst case scenario, the star represents the best case scenario, and the oval indicates the most likely outcome. ICU indicates intensive care unit.