

ETHICS AT THE BEDSIDE: ADVOCACY FOR PATIENTS AND THE COST

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ABSTRACT

As a healthcare professional at the bedside, it has been very difficult to advocate for the patient while all parties involved cannot respect what the patient wants. Four out of five Americans do not have an advance directive. The history and court cases that have led the country to make patient's right to make their own healthcare decisions has been decades in the making, yet still bring daily challenges within the healthcare system. When a patient's wishes are not being honored, medical futility may lead to moral distress and compassion fatigue. Institutions provide multidisciplinary teams to address these issues, but if a patient's capacity or competence is in question, their voice may not be heard. The toll on the healthcare provider and the patient can be permanently damaging, causing many nurses to leave the profession all together. I will attempt to determine the barriers to implementing the patient's wishes, address the syndrome of moral distress among healthcare professionals, and attempt to offer solutions to promote well rounded, patient-centered care.

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CHAPTER 1: INTRODUCTION

Healthcare professionals have the daily task of caring for people that have a multitude of medical, psychological, and social issues. Patients from all walks of life present to the hospital in need of care, and their diagnoses can be life-altering or life-threatening. In many cases, patients do not make their wishes known to their families or healthcare providers before they are admitted into the hospital. The reasons vary from their age (the young may not think about the end of life or the old may not want to confront their end), cultural (belief systems may not align with planning for death by illnesses), uneducated by medical staff (people are simply unaware or do not understand they have the right to choose how their care is directed). Any of these reasons can disrupt the delivery of care, and cause unexpected negative outcomes to become medical dilemmas that affect the patient, their families, and the bedside caregivers as well. The lack of advance directives may prolong unnecessary suffering for patients; contribute to feelings of helplessness and guilt for healthcare providers, and confusion, mistrust, and/or conflict from families and support systems. By not addressing a very integral part of the healthcare continuum, healthcare providers can experience moral distress, which leads to burnout, compassion fatigue, and mass exodus from bedside care or even the profession. Witnessing patients who have poor outcomes, unable to voice their wishes and needs to the decision makers of the healthcare team, is both frustrating and disturbing. Patients should be able to adjust their care at any point during their illness, and not be held to a signature on a piece of paper allowing consent for treatment.

CHAPTER 2: THE HISTORY OF CREATION OF ADVANCE DIRECTIVES AND THE PATIENT SELF DETERMINATION ACT

Advance directives began to be developed in the US in the late 1960s. In 1967, the concept of living wills began. The concept of a living will was to create “a document that provided instructions about the use of extraordinary medical procedures to prolong human life.” (Sparks, 2019). A Chicago attorney named Luis Kutner, a United States human rights activist who also co-founded Amnesty International in 1961, suggested the first living will's goal was to facilitate "the rights of dying people to control decisions about their own medical care." In 1968, the first living will legislation was presented to Florida state legislature. Walter F. Sackett, a doctor elected to the Florida legislature, introduced a bill that would allow patients to make decisions regarding the future use of life-sustaining equipment. The bill failed to pass. In 1973, Sackett reintroduced the bill and it was again defeated. While Dr. Sackett worked to lobby for living wills in Florida between 1972 and 1974, California Senator Barry Keene presented similar bills in the California legislature. Keene's interest in living wills was based on his personal experience with end-of-life issues. His mother-in-law was unable to limit medical treatment for a terminal illness even after having signed a power of attorney, and in turn suffered unnecessarily against her wishes. Keene was elected to the California State senate in 1974. The living will legislation he designed was defeated that same year. In 1976, Keene reintroduced the bill. In September 1976, California became the first state in the nation to legally sanction living wills. By 1977, 43 states had considered living will legislation and seven states had passed bills. Advance directive legislation has subsequently progressed state to state.

The first court decision to validate advance directives was at the state level. The landmark court decision which Chief Justice Judge Robert Hughes of the New Jersey Supreme Court, ruled was the request by Joe Quinlan to make legally binding health-care decisions for his daughter, Karen Ann Quinlan (who was in a persistent vegetative state after a drug and alcohol overdose). As a result of the case, Karen Ann Quinlan was gradually weaned and removed from mechanical ventilation. Quinlan lived another 9 years until her death in 1985 secondary to respiratory failure and pneumonia. The decision was handed down by the New Jersey Supreme Court in 1976. In Case 70 N.J. 10, 355 A 2nd 647, Chief Justice Hughes upheld the following judicial principles:

1. If patients are mentally unable to make treatment decisions, someone else may exercise their right for them.
 2. Decisions that can lead to the death of a mentally incompetent patient are better made not by courts but by families, with the input of their doctors.
 3. All patients have the right to refuse treatment, even if their decisions hasten their death
 4. Decisions about end-of-life care should take into consideration both the invasiveness of the treatment involved and the patient's likelihood of recovery.
- (Nabili, Sheil, 2019).

A second landmark case involving Nancy Cruzan was heard by the United States Supreme Court in 1990. Cruzan was also in a persistent vegetative state as result of an anoxic brain injury (lack of oxygen to the brain after cardiac arrest) from a car accident.

After sufficient evidence was presented to the court supporting Cruzan's wishes to not have her life artificially sustained, the Supreme Court ordered for her feeding tube to be removed. Cruzan was in a persistent vegetative stage for 8 years, but once the feeding tube was removed, Cruzan died after 12 days, in 1990.

Between 1990 and 1991, the US Congress and the Supreme Court began the process of making a federal law, after the Supreme Court agreed on the legality of advance directives and Rep. Sander M. Levin of the House of Representatives drafted a bill, which passed, known now as the Patient Self Determination Act (PSDA). In 1992, all 50 states, as well as the District of Columbia, had passed legislation to legalize some form of advance directive. (Nabili, Sheil, 2019).

In both cases of patients medically determined to be incapacitated or unable to make their own medical decisions, the judicial system ruled in favor of their families, based on expressed wishes prior to their injuries. These cases established separate, but complementary, legal rights: the ability to appoint a health care proxy/decision maker (Quinlan) and the right to execute a binding living will (Cruzan).

CHAPTER 3: PROBLEMS ASSOCIATED WITH ADVANCE DIRECTIVES

In the United States, four out of every five adults has no advance directive. When patients come in contact with the healthcare system, it occurs through these 3 common ways: 1. A patient is admitted into the hospital for an elective surgery; 2. A patient is already in a hospital to be treated for a problem; 3. A patient enters the hospital through the emergency department, sometimes with a life-threatening situation. Throughout any of these healthcare interactions, a patient should be approached with information addressing the plan of care, or in other words, information about an advance directive to notify all healthcare providers and family members of the patient's plan of care in case they become unable to speak for themselves. The patient coming into the hospital for an elective procedure has the perfect opportunity to be given information to complete an advance directive, but this step is oftentimes missed; the patient already admitted in a hospital and has a sudden change in status, requiring an increased level of care (ICU), may not be able to discuss their level of care due to change in mental status, or they are unresponsive; the patient entering the emergency department may also be unresponsive due to trauma or severe decline of a chronic disease process. "In 1950, about half of Americans who died did so at home. Now, about 85% of Americans die in a health-care setting: a hospital, a nursing home, or a rehabilitation center. At least 12% die in an intensive-care unit." (Nabili, Sheil, 2019). All these patients' default code status would be "full code", or every life saving measure that can be provided, will be performed as required by law. Whether a patient expresses that they do not want to be kept alive artificially or they don't want the hospital "experimenting on them", in the absence of an advance directive, the assumption is to provide all life-sustaining efforts, the hospital is

legally obligated to perform all life-sustaining measures due to their legal and moral duties. This comes from federal law:

“The law [H.R.4449 — 101st Congress (1989-1990)] clearly states that an adult patient or authorized surrogate has the right to refuse any medical treatment, whatever the consequences. The converse, however, is not true. The patient or surrogate does not have the right to demand and receive any desired treatment. The default position is no treatment unless authorized by the physician. CPR, however, has become one of the few exceptions in medicine in which the default response is to provide the treatment unless the patient explicitly declines it. The Patient Self-Determination Act of 1990 allows patients to specify, among other things, whether, and under what circumstances, they desire CPR. Should CPR, or any treatment, be considered futile or of no benefit to the patient, however, the physician is ethically obligated not to perform it, despite the patient's desires.” (Putman, 2003, para 10).

Although a patient may have verbally expressed a wish to “do not resuscitate to their family members, once the patient become unresponsive or cannot express their wishes, healthcare professionals are bound to preserve life rather than withhold life-saving treatments. Families can override advance directives if a patient becomes unresponsive or lacks the capacity to make decisions, and healthcare professionals are morally and legally bound provide care. This is the ultimate dilemma for patients because there is always a possibility that they will endure a form of suffering they were trying to avoid by expressing their wishes ahead of time.

Age is a factor: Pediatric and Young Adults

In the introduction, I gave a brief example of why end-of-life decisions are often left undiscussed and finalized in the younger population. Since I am not a pediatric nurse, I rarely see children suffering from chronic illnesses. My encounters with younger patients are few, but the age of these patients are mainly young adults (18-24). This population of patients tend to not have advance directives for many reasons; they may have been admitted to the hospital secondary to a traumatic event (burns, gunshot wounds, motor vehicle accidents, stabbings or blunt force trauma from assaults), chronic illnesses that have aged these patients from the pediatric setting (type 1 diabetes, cystic fibrosis, heart failure-acute and chronic, or a cancer diagnosis that was discovered as an incidental finding). In every case with children or young adults, there is more than the patient to consider. There are the patient's family and support network of extended family and friends that the patient relies on for reassurance and peace of mind. Sometimes, when their hospitalization becomes unbearable or their diagnosis is life-threatening, the discussion of end-of-life care or plans for ending treatment when it comes clear that treatments are not effective, some young patients and their families react as if death was never a possibility. These two examples of pediatric patients, at very young ages, show just how complicated life-threatening illnesses and end-of-life care discussions become-for the patient, the family, and the healthcare professionals.

“A national push to have end-of-life discussions before a patient is too sick to participate has focused largely on older adults. When patients are under 18 and do not have legal decision-making authority, doctors have traditionally asked anguished parents to make advanced-care choices on their behalf. More recently, providers have

begun approaching teenagers and young adults directly, giving them a voice in these difficult decisions, though parents retain legal authority for underage patients. But shifting from hushed talks with parents to conversations that include young patients has met some resistance. Many doctors lack training about how to raise these topics with teenagers. Until recently, most clinical teams believed that adolescents would not understand the implications of end-of-life planning and that they might be psychologically harmed by such talk. Sometimes when providers do make the attempt, parents or patients may abruptly change the subject, fearful that by joining in, they are signaling that they have abandoned hope.” (Hoffman, 2015)

Daniel Hauser, who was 13 at the time of his diagnosis of Hodgkin’s Lymphoma, was given a 90% percent survival rate with chemotherapy versus a 5% chance of survival without it. He and his family choose to start chemotherapy, but after one round, Daniel became very weak and ill. Daniel told his family he did not want to continue with another round of chemotherapy, having been made aware of the grave consequences by the medical staff. Daniel insisted on not continuing and his family made his wishes known to his healthcare team and the controversy ensued. The fact that Daniel was 13, according to his Native American tribal belief system and customs, Daniel is considered an elder at the age of 13, and therefore considered old enough to make adult decisions, and he and his family were relying on their religious beliefs to heal Daniel from his cancer. The hospital filed a case with Child Protective Services to override Daniel’s parents’ decision to honor his wishes and rely on their religious faith to heal, stating that discontinuing chemotherapy was medical neglect based on the high survival rate when patients are treated with chemotherapy (Lavagnino, 2009). The court ruled in favor of the medical

staff, citing that health and well-being of the child or the “interest of the state” outweighs the wishes of the parents or “the constitutional right to freedom of religious freedom” (State of Minnesota v. The Parents of D. Hauser May 2007). If Daniel was 5 more years older, he could have legally stop his treatments and live out his days as he wished. Daniel Hauser is alive and cancer free today.

There is a pediatric case of autonomy that involves a much younger child, who chose to end her suffering at age 4. Her name was Juliana Snow, born with an incurable, neurodegenerative disease (Charcot-Marie-Tooth disease); she had spent every day of her life with a breathing machine, very limited mobility, in and out of hospitals, constantly being stuck for bloodwork or given IV fluids or medications. Juliana’s parents (her mother a neurologist and her father an Air Force fighter pilot) asked her what she wanted to do if she became sick again and needed to the hospital, and Juliana said she would rather “go to Heaven”. On her last hospitalization at Doernbecher Children’s Hospital in Portland, Oregon, one of her nurses expressed that Juliana should be included in her healthcare decision-making and allowed her to be asked what her wishes were. Between her medical team and her parents, Juliana wanted to “go to Heaven” instead of living every day in her current state and to not be taken back to the hospital if she became sick again. The form of her disease had a very poor prognosis, and her condition was deteriorating. The medical staff agreed that Juliana’s wishes should honored, even though she was so young (not an emancipated minor or 18 and over); Dr. Chris Feudtner, bioethicist, pediatrician, and pediatric palliative care physician at Children’s Hospital of Philadelphia, believed that Juliana should at the very least be involved in making the decisions concerning her future, because she was the one experiencing it. As the patient,

she had to endure the pain of procedures, testing, and the constant need for artificial support, such as mechanical ventilation. Not all ethicists believe the same view. Dr. Art Caplan, director of Medical Ethics at New York University's School of Medicine and world renowned bioethicist disagrees strongly that a child that young should be able to make such a final decision, such as end-of-life. He stated that a 4 year old "might be capable of deciding what music to hear or what picture book they might want to read. But I think there's zero chance a 4-year-old can understand the concept of death." (Flowers, 2015, para 2). Caplan's stance is that children are incapable of understanding that death is final until the age of nine or ten. Although Juliana may have thought she would rather die than be treated, Caplan believes she probably did not understand death is forever. When Dr. Caplan was asked recently his opinion about Julianna Snow he stated, "She was a remarkable little girl... She taught me and others that even a child can become very knowledgeable about a challenging illness and can convey thoughtful and remarkable feelings about her illness and her ideas." (Cohen, 2016, para 6).

These two cases are not unique; thousands of children suffering from chronic or terminal illness and their families are faced with the critical decision to continue or withdraw treatment on a daily basis in pediatric hospitals all over the world. No parent wants to decide to stop treatments that potentially could save their child's life, but if the amount of suffering is too much to bear for the child, that child should be able to express their wish to end suffering when medical treatments become futile. In these cases, the decisions that were made based on the age of the patient could have been reversed to support the argument for the patient and family or the medical team. In Daniel Hauser's case, he was deemed "too young" to make his choice to end his treatments, and his

suffering. Caplan's view of when a child can understand the finality of death could have helped in Daniel's argument and he would have been able to practice his beliefs and possibly passed away, free from suffering. According to Caplan, Daniel was 13 years old, past the age of understanding as it pertains to life and death, but the court in his case would have prolonged suffering in Juliana Snow's case based solely on her young age. If Julianna was a patient in the same hospital as Daniel, although her prognosis was very poor, the court more than likely would have chosen not to continue her treatments and suffering because the medical staff stepped in as they did in Daniel's case. Julianna may have been still alive, but not living. At her age, the court would have ruled against her and prolonged her life. No one could have determined how long her life would have been, but the daily life she experienced was too much for her to bear and her wishes, as any other human being, should be at the very least taken into consideration.

Age is a factor: The Elderly

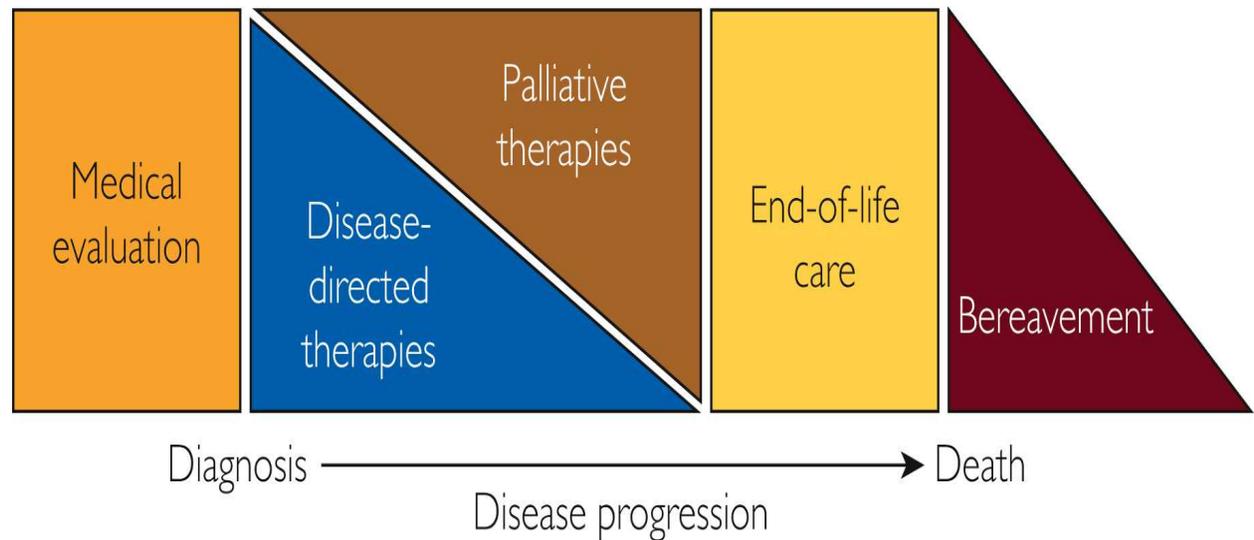
In the elderly patient, I have countless examples of conflicting and competing interests related to end-of-life issues, but I choose to speak about a patient on a personal level, my grandmother. Diagnosed with stage 4 lung cancer with metastasis the brain on January 21, 2019 (the same day as her first born child, my father), she was told there was no treatment that would be beneficial to her at this stage. The news came as an incidental finding after an emergency room visit due to a fall at home. My grandmother was experiencing flu-like symptoms and the doctor ordered an X-ray to rule out pneumonia. After her X-Ray results any fractures were ruled out, but the radiologist saw spots on her lungs. She was admitted and received fluids and antibiotics and stated she felt much better. Then the news of lung cancer in its terminal stage was given. She did not flinch

or weep, but simply said, I just want to be at peace. Her physician tried to hold back her tears as she delivered the horrible news along with no options for treatment at this advanced stage, as the lung cancer had metastasized to her brain. She was released and sent home with in-home hospice care, and made it clear she did not want to be poked and prodded. That's when the trouble started. She refused to accept the diagnosis and began make excuses and questioned the obvious. "How do they know I have cancer if they didn't do any biopsies? Why didn't they see any of the cancer when I was here (in the same hospital) for my heart attack six months ago? I think all those tests and CAT scans and X-Rays gave me that cancer! I'm not in pain, so how do I have cancer?" All these questions and statements I answered thoroughly and repeatedly, but she either could not or would not accept her fate. We asked her what did she want or what are her wishes? She didn't want to talk about it. She initially would not address any end-of-life plans for the reasons listed above and many unspoken ones as well. This woman has lived through the days of Jim Crow South Carolina, picking tobacco as a child and young adult, becoming a mother at age 16, married at 18, mothering 9 children, grandmother to 20, great-grandmother to 30, and great-great grandmother to 2; the hardships she had overcome, becoming a widow, burying her oldest daughter, surviving a stroke and a heart attack, has now been given life-ending news. This woman who raised her children practically single-handedly, traveled, provided, and was always independent was now bedbound and dependent. The only decision she made was to be buried in South Carolina, her birthplace and ironically with my late grandfather and her husband whom she despised. Once her children came from down south, her feelings and outlook changed from no treatment and comfort care to "I want a second opinion..." This really

infuriated me. Being a RN for as long as I have, I felt that I explained everything to her and she seemed to understand, but since her children spoke to her and told her to “fight”, she set up her own appointment for a second opinion. After my mother (her daughter in law for 46 years) and I spoke to her primary care physician, Dr. Carson, she paid her a home visit. Dr. Carson explained to my grandmother her entire health picture-being a smoker for over 60 years has yielded this result, but if she wanted to go through the process of biopsies, blood work, and radiological testing, that was her choice. Testing was explained as being invasive and will make her uncomfortable. She declined the second opinion.

“The principle of respect for patient autonomy that places substitute judgment first has become increasingly important in American medical ethics over the past 30 years, often clashing with the existing paternalistic model in which physicians did what they thought was in the best interests of the patient. Now, the pendulum has swung in the other direction, and it is the patient's wishes that often are considered paramount. Justice Benjamin Cardozo of the New York State Supreme Court expressed the legal foundation for this viewpoint as early as 1914, when he wrote, “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.” This right is passed on to the patient's health care proxy or, failing that, to his or her next of kin if the patient is no longer able to exercise it.” (Putman, 2003, para 8.).

Figure 1.



Disease progression and the transition from palliative care to end-of-life care.

(The Organ Transplant Imperative. Santivasi, Wil L. et al. Mayo Clinic Proceedings, June 2017. Volume 92. Issue 6, 940 – 946).

As I am writing about my grandmother, she is actively dying, at home, with her loved ones. She has declined so rapidly, none of my family was prepared for this. In-home hospice has been an uneasy and fearful experience. The “comfort care” box containing the necessities of hospice (medications for nausea, vomiting, constipation, agitation, excessive oral secretions, but most of all, MORPHINE) is handled like a bomb—anything in that box can potentially “end my grandmother’s life”, but as the RN, I should know better. When she complains of pain, there’s long conversation whether to give her the morphine or the Tylenol...I know she needs morphine, but giving it to her makes me feel like I’m hastening her end. I feel very torn because she is my grandmother, but as a

medical professional, I am ashamed because I know Tylenol isn't going to relieve her pain. I have had to give my patients morphine at very high doses for end-of-life comfort care and think nothing of it, but since this is my grandmother, I am hesitant and apprehensive. My entire family is watching me, asking questions, and depending on me to direct her care, when all I can do is try to fight back the tears watching my "Mom Mom" fade away. She will probably have passed away by the time this thesis is submitted. I wanted to share this story because there is a misconception of healthcare professionals. Even though we may see death and dying more often than the average person, it becomes extremely difficult to handle when it is your own loved one. Even though we see death more often than the average person, the dying process and death is very hard to witness and overcome. When patient are dying in the hospital, we as healthcare providers have to be strong for the patient, the doctors, and the families who look to us for comfort and stability in an extremely difficult time. No one knows that the nurse could be crying in the clean utility closet or the bathroom and we are alone to deal with constant grief and sadness. In some cases, nurses are unable to cope with the constant death and dying processes, and choose to leave their positions in certain units, or leave the profession of nursing all together.

CHAPTER 4: IMPLEMENTING PRINCIPLES OF BIOETHICS

We have described here the pilot year of a longitudinal service-learning requirement integrated into the medical school curriculum. Students were assigned to one of six community sites in cohorts and were required to complete a total of eight hours of service at that site during their first year and four during their second. Each semester, they completed a one-page reflective essay. Here we discuss the qualitative evaluation of these reflection essays written by the students about their experiences. We will seek to integrate this discussion into the framework of how physicians construct their own identity and protect their sense of self when they encounter difficult or even traumatic experiences in their professional roles.

We hypothesized that by engaging with their future patients in a non-medical context through an integrated, longitudinal, required service-learning experience, students would develop and retain more favorable attitudes towards the underserved during their clinical years. Alternately, this experience might have no impact on attitudes towards the underserved, or might have a negative effect.

Medical school is a highly organized undertaking with a rigid social structure and well-defined norms. As they prepare to become physicians with clearly defined roles, Medical students become accustomed to living within these rigid norms, and are often unsettled by change. We anticipated that students would be unsettled by the different, often looser structures of their partner community organization. We considered that by learning to “sit with the discomfort” of this experience, might ultimately increase empathy and understanding of their future patients.

A longitudinal approach to service learning has many advantages. It makes a program more sustainable, requires less time to run (Stewart 2014), and enables efforts to build over the years. It can prevent repeated needs-assessment and ‘reinventing the wheel’ each year (Seifer 1998), in short – it provides the benefit of continuity. We believe that this approach is valuable, as our goal is to approach community organizations not as places solely in need to whom we can give help, but instead as collaborators and partners in building the health of our community. They in turn can be a part of teaching medical students skills that will serve them well as physicians as well as potentially shield them from some of the cynicism and loss of compassion towards the underserved that often occurs in the clinical years. We hoped that by encountering our neighbors in their element rather than as patients in the hospital, we might insulate our students from the loss of humanism in how they view their patients in the hospital.

By working with the same organization for four years, students attain continuity without an overly burdensome hours requirement each semester. This allows for trust and long-term relationships to develop between students and community members. This type of long term outcome may not be apparent initially, and there are at times unavoidable external factors that make true continuity and partnership difficult to achieve, such as we experienced with one site turnover during this pilot year.

Making service learning a requirement for all medical students was a highly intentional choice. Precisely because it is unpopular, this feature points to the crux of the difference between volunteering and service learning. Service learning is not comfortable; by definition it involves challenge and change. Students who might not be

interested in volunteerism are required to engage, cope with, and learn from uncomfortable situations, just as they will in the clinic and in the hospital.

The written reflections offer a fascinating snapshot of the mind of the developing physician, into the process of *becoming*. This experience is exciting, but also difficult and even painful for many students. Students respond to challenges to their sense of self in dramatically differing ways.

Overall, our results showed that the service learning program was acceptable to students. The vast majority of students had a positive experience and perceived a positive impact of this service. Students learned valuable skills, including clinical skills and communication skills, and were able to place academic concepts such as the social determinants of health in a real-world context. They also practiced invaluable but hard to quantify “soft skills” such as improving communication, learning about their patients and reflecting on their role in society as a future physician. A significant number reflected on the formation of their professional identity, with some more explicitly noting clinical skills gained or reflections on specialty choice.

Some students had visceral reactions to the discomfort of this new, undefined experience. Responses included feelings of otherness, feelings of guilt, and awareness of a student's own privileged position or privileged background. Some, on experiencing these feelings of discomfort, described freezing and not knowing what to do in an unfamiliar setting. Some responded to a classroom of rambunctious children by disengaging and talking with other medical students, or responded to a poorly attended vaccination booth at a harvest fair by talking with other students. On the other hand, some students adapted and responded resourcefully and creatively to challenges. At the

same fair, some students decided to read to children, and two went out into the community to invite passers-by to come to the fair, and these students reached a deeper understanding of why some community members might be distrustful of physicians and vaccination. The most common criticism of the requirement was that the 4 hours per semester requirement was simply not enough to develop continuity. A small number chose to do additional hours of service of their own volition.

Many students had not previously spent time in the neighborhood of their assigned site, and responses ranged from curiosity to fear to deep discomfort. Numerous students mention feeling nervous in the neighborhood of their site, or refer to the area as ‘shady,’ or as the ‘inner city.’ One student even reported that they were forced to take a taxi to a site easily accessed by subway and multiple bus lines. Turning again to our reflections on the use of language by physicians and medical students, we see students in their reflections subconsciously use language that others and separates themselves from their patient population to protect their sense of wellness and wholeness. As they are called on to witness the full spectrum of human pathos, physicians may react by detaching their sense of self from the frailties they see in the human bodies of their patients. We saw this most notably as students wrote about their expectations, impressions, and thoughts leading up to their service-learning experience. There are mentions of the “dangerous” neighborhood, of the “inner city,” of a school that “looks like a prison,” of discomfort with public transit and “safely,” in the city. This language is at times racially tinged, and suggests the subconscious biases that students may carry with their expectations for this experience. But as students engage in activities at their community site, they let their guards down and are surprised by the connections they

make and the commonalities they find: the kids are kids, just like their younger siblings. Moms care about their kids and are just doing their best. Teenagers are standoffish but quickly become fun, silly, and sincere. There were moments of profound connection, belonging, and recognition of the fundamental similarities. A number of students describe a moment in which they realized their commonality with someone they previously saw as very different from themselves, or a moment in which they feel suddenly at home in area they previously felt very separate from.

A small number of medical students reported a very different experience of connection and disconnect: three students wrote about growing up in North Philadelphia or in a similar neighborhood in another city, and reported feeling deeply hurt by how their classmates spoke about these places, and felt an increased sense of alienation from their peers, most of whom grew up in comfortable circumstances, and many of whom are supported financially by their families into adulthood. The service learning experience brought them closer to the community but simultaneously alienated them from their classmates and made them feel other within their ostensible peer group.

Our community partners had largely positive experiences, and felt that students became more useful and valuable as the year went on, logistics came together, and they learned how to utilize the students most effectively.

On the medical student side, we identified areas for improvement and implemented these where possible, such as briefing students beforehand on what to expect and how they might be most helpful and get the most from the experience. We also learned how best to keep open lines of communication between students, community sites, and administration. Additionally, tallying student responses was quite valuable and

assists in implementing changes based on majority opinion rather than on the experience of a small number of vocal students.

There are clearly a number of limitations regarding this pilot year study. We cannot yet comment on the effects on attitudes towards the underserved, as the students have not yet entered their clinical years. Additionally, the data is muddled by a disproportionate number of negative responses from one college that had a late change in site.

This study is unique and significant in several regards. While many studies (cite) have reported on the effects of service learning and volunteering on student attitudes towards underserved patients, none have extended this as a structured requirement for all medical students. By requiring all students to engage in service learning, we avoid bias from self selection: there may be inherent differences in interest, temperament, and prior experience among those who choose to engage in service in their free time: these patients may have existing interests, prior experience, or different specific interests and specialty inclinations. If service-learning is not required, those without inclination will choose not to engage, and will not have the opportunity to have their assumptions challenged and to grow from this new experience. Those who might have the most to gain by engaging in an experience they had not previously considered would likely chose to not engage. Additionally, students who are concerned about their academic performance might chose to not engage out of concern that the time ought to be spent studying. Of course, it is difficult to measure the impact of four hours away from study mterials, but many initially reluctant students reported feeling unexpectedly energized and motivated by the

experience, and brought them back to the roots of their motivation for entering medical school.

The longitudinal nature of the service learning curriculum allows for continuity without an overly burdensome time commitment on the part of each student: there is continuity within each college, so students get to know their site more each time they visit. The site has a steady influx of students and is able, through trial and error, learn how to best utilize the students. Over time, the interaction becomes smoother, students and site leaders all pass on their knowledge and it becomes a more useful and enjoyable experience on both sides. All of this is facilitated by the community engagement specialist, the point person for both community sites and medical students, who plays a critical role in this interface.

We hoped that by encountering their patients in their own neighborhood, rather than in a medical setting in which students are more comfortable, that students might experience a role reversal that would allow them to connect with the neighborhood and patients on a personal level. With continuity, students might carry this sense of connection and increased understanding of their patients' lives into the clinic and see their patients more fully, enabling them to provide better care and feel more professionally satisfied.

In the reflections, there were moments when students had a sudden realization of similarity and fundamental sameness. There were also moments where increased exposure instead widened the perceived gap. Many students are fearful of the neighborhood, and left with varying impressions. The question is of course, how does this development of empathy and alignment affect students down the road? Distancing

functions as a protective mechanism, but in the long run, it is anything but. Physicians who use distancing to cope with the difficult things they see each day are able to put their emotions aside and act in the moment, in the long run they are not coping with the emotions that arise in these difficult situations, but rather setting them aside. Substance abuse, depression, anger (cite) are rife among physicians, as these emotions are avoided rather than addressed. By seeing your patient as a whole person, as you see yourself as a whole person, perhaps physician wellbeing will improve with this type of relationship building as well. Other-ing can be a protective mechanism employed by students when a situation becomes too personal, heavy, or challenges their sense of self. It allows the professional to function efficiently in the moment, and allows the student to carry on without identifying too closely with each patient.-

From a bioethical standpoint, it is essential to see one's patients clearly as fellow people and partners in their health. This promotes wholeness and wellbeing, and respect for patient autonomy. The principle of justice tells us that our patients, who we learn from and practice with, should benefit from this, and should be seen as fully realized people and partners in teaching us and in their own health. Helping students see themselves, their teachers, and their patients as fellow relatable humans may help instill feelings of wholeness to each, and allow them to acknowledge their own humanity.

We hope that the opportunity to feel a part of and embraced by the community on the part of the students and to feel cared for, appreciated and acknowledged on the part of the community, may help restore feelings of wholeness and trust in the medical profession, feelings that health is a partnership, and that the community is entrusted in the teaching of the students who will care for them as part of a reciprocal relationship, and

less that they are offering up their body, without agency, for students to “practice on.” The doctor-patient relationship is sacred in the medical profession, and feeling a part of the community may go a long way in treating and seeing this relationship with the reverence it deserves. Patients are not just a body, and physicians are not just a mind. There are still many medical problems that cannot be cured or even treated effectively. Even today, physicians ease suffering where they can, but most fundamentally, we bear witness to suffering and joy, and it is perhaps this human connection that is most healing.

In conclusion, we have described here the pilot year of a longitudinal, integrated service-learning requirement that seeks to help students retain their idealism and more positive views of poor and underserved patients. We show here that such a program is largely acceptable to students, and that it provides a valuable opportunity for experiential learning. This provides a hands-on way for students to learn about the social determinants of health and to practice communication skills, teaching skills, and clinical skills. It gives students an opportunity to reflect on where they wish to fit in to the healthcare system and how they may wish to practice medicine. We hope with time that this opportunity to work collaboratively and learn reciprocally with local community members will insulate our students from negative attitudes and assumptions about medically underserved populations as well as promote their own wellbeing as physicians.

CHAPTER 5: CULTURAL CONSIDERATIONS

Here, we have observed students' internal and external responses to a mandatory, longitudinal service learning curricular component. We found that it was largely acceptable to students, though there were many logistical and organizational hurdles along the way. We posit that learning to deal with this uncertainty and discomfort is useful to students entering the very foreign world of medicine

Broadly, student responses tended to fall into one of two categories: either an increased sense of connection to their community or fellow students, or with feelings of alienation from their community or their fellow students. These reactions were not always uniform: several students who wrote about growing up in a poor community felt a sense of increased connection with the community, but felt increased alienation from their peers following this activity. Many students were profoundly unsettled by the experience, regardless of whether they experienced alienation or connection. These responses are interesting in the context of considering how physicians construct their patients and the coping mechanisms that allow physicians to act swiftly in stressful, life threatening, and often heart wrenching situations. This may have implications in considering the most effective ways to build resilience and promote mental health in a field that may often encourage a "carry on at all costs" approach. I propose that building connection to patients and community, both with the physical neighborhood that surrounds the hospital, and also between physicians, trainees, and students may have a protective effect. Post-mortem analyses often cite shame and isolation as contributory factors in physician suicides. If we can build connection and community between physicians in training, their patients, and their colleagues, perhaps we can begin to build a

system in which patients, physicians, and colleagues see the humanity in each other. That said, the impulse of “other” is both deep and ancient. It allows for detachment and objectivity, and it may not be desirable or possible to completely counteract this. However, awareness of one’s biases and perspectives may itself prove useful to the physician examining their own objectivity and role.

CHAPTER 6: MISTRUST IN THE HEALTHCARE SYSTEM

When I learned of Henrietta Lacks and her life experience, she inspired me to start a new chapter in my education and also shed a new light on the medical field and my nursing career. Her life and encounters with the institution of medicine has presents countless medical ethics debates and dilemmas. From the lack of informed consents for her many procedures, medical treatments that resulted in unnecessary pain and suffering, lack of patient and family centered care and decision making, and the profiting from a patient's misfortune and demise, the modern day medical ethics has changed for the better, but at the cost of Mrs. Lacks and her family.

“Among blacks, nonacceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. DNR orders may be viewed as a way of limiting expensive health care or as cutting costs by ceasing care prematurely. Historically, this perspective may stem from a long history of distrust of the white-dominated health care system. The Tuskegee syphilis study, in which infected black men were followed for 40 years but were not informed of the availability of penicillin treatment, is well known in the black community. The reluctance of blacks to formally address end-of-life care also may stem from a history of health care discrimination. Although individual studies vary, the preponderance of evidence indicates that nonwhites, even after controlling for income, insurance status, and age, are less likely to receive a range of common medical interventions such as cardiac catheterization, immunizations, and analgesics for acute pain. Although issues such as geographic patterns of medical care play some role in these disparities, mistrust of the health care system is likely to be a factor in the lower rates of organ donation among

blacks, as well as a reduced acceptance of hospice care. Blacks with colon cancer were more likely than comparably ill white patients to want artificial nutrition, mechanical ventilation, and cardiopulmonary resuscitation. Similarly, black patients overall are about one half as likely to accept DNR status and are more likely than whites to later change DNR orders to more aggressive levels of care. These attitudes also carry over to black physicians, who are significantly more likely than their white colleagues to recommend aggressive treatment to patients with brain damage and known terminal illness. Similarly, black physicians are less likely to accept physician-assisted suicide as an acceptable intervention. In addition to a historical legacy of unequal care, black patients also appear to view suffering somewhat differently than whites of European background. While whites may be concerned about dying patients undergoing needless suffering, black physicians and patients are more likely to think of suffering as spiritually meaningful, and life as always having some value. Survival alone, even if it involves significant pain, may be an important demonstration of religious faith.” (Searight, Gafford, 2005, para 21-23.)

The Presidential Commission for the Study of Bioethical Issues under the direction of President Barack Obama, conducted 10 projects to address bioethical issues in the United States and abroad and provided recommendations to improve the health and well-being of all Americans. *Moral Science: Protecting Participants Human Subjects Research* is one of the bioethical projects I chose to reanalyze through the lens of urban bioethics. *Moral Science* provided 14 recommendations to increase and ensure human subjects in clinical research are protected and not exposed to unnecessary risks of harm. Although this project was conducted in 2011, a case of human subject research from the 1950s at Johns Hopkins University Hospital leads me to analyze the case of Henrietta

Lacks and her family. According to interviews conducted by Rebecca Skloot, author of the book *The Immortal Life of Henrietta Lacks*, Johns Hopkins Hospital in the days of Jim Crow segregation was rumored to frequently experiment on “colored” patients, earning the reputation of “The Night Doctors” (as African Americans would walk near the hospital at night, they may have been victims of abduction and medical experimentation, and never seen again.). The HeLa cell line is responsible for medical breakthroughs from the polio vaccine to the HPV vaccine to the Pap smear screening that has become a routine and most important part of a gynecological exam. The extraordinary case of Henrietta Lacks and her immortal cells has been documented, written about, and televised, but many people do not know how the woman behind the immortal cells was treated, and ultimately experimented on without a true informed consent. After her death, her family was also subjected to misinformation, misleading, and unethical treatment to obtain blood samples for research—all of which was not properly consented for, nor compensated. The HeLa cell line has produced billions of dollars in the medical research field, none of which was divulged or shared with her family (Skloot, 2001.). *Moral Science* has addressed the very issues that came to light from not only the case of Henrietta Lacks, but many medical research projects that have had horrifying details such as the Tuskegee Experiment that involved 600 African American men (1932-1972) and the Guatemalan Experiment that involved 5,128 Guatemalan men, women, and children (1946-1948); these groups of human subjects were selected in large part because of their uneducated and lower class living conditions. Although race and ethnicity was never explored as a reason these particular groups of people were chosen, it has been the underlying theme in these morally and ethically

absent experiments. Consents were either withheld due to an assumed lack of understanding, limited in explanation to conceal the real motive of collecting data, or racial bias because of the era in which this occurred. "...mistrust of many African Americans for organizations, health professionals, clinical investigators, and administrations...given the negative aspects of their experiences, African Americans should be anti-majoritarian [opposing to majority rule], anti-utilitarian [opposing the idea of the greatest good for the greatest number of people], antiscientific [opposing experimentation], and anti-situationist [opposed to the theory that behavior is chiefly response to immediate circumstances], and pro-family, pro-religion, and pro-tradition." (Pellegrino, 2007). African Americans have experienced medical experimentation during the years of slavery at the hands of their captors, to the point of mutilation and death, with impunity or fear of retribution. Centuries of medical mistrust within communities of people of color still effect patients' ability to seek treatment for chronic or acute medical issues and decision-making concerning their care, due to the lack of diversity in healthcare professionals and underlying fear that still exist today.

Informed consent relates to the basic principles of bioethics in a very complex, and sometimes contradictory way. Since all patients aren't on the same level playing field, as far as education, health literacy, health access, and/or socioeconomic status, it is difficult to create a consent form that can be universally utilized. Although current forms are said to be written on a grade-school reading level, they are lengthy, and at a critical moment someone is making a life changing decision, it can be overwhelming. It is up to the healthcare provider to ensure the patient understands the risks and benefits of a pending procedure and respect the decision made. My institution uses a consent form that

is in 8 parts with several subsections, spaces for the doctor/surgeon/patient can fill in specific information, making sure that all bases are covered. Although the consent form is very thorough, it can be intimidating. Our doctors and surgeons are the people delivering the consent, explaining the procedure and attempting to obtain consent. In my opinion, it depends on the actual person who is delivering the information within the consent that will affect whether a patient agrees to receive treatment or not. For example, if a surgeon is asking for consent to perform surgery in the patient's room, the patient has some time to discuss the information with their support people, if they so choose, but asking a patient to sign a consent in the OR suite may leave a patient how has had apprehensions about the procedure feeling obligated to allow the surgeon to proceed because the operating room is ready to go forward. "It is now clear that the changing demography of America requires that practitioners and students of all health professions develop cultural competence and communication skills. Emphasis on empirical studies is requisite concomitantly if cultural competence is not to be based on caricature and stereotypes." (Pellegrino, 2007.)

In relation to autonomy (individual freedom or one's right to make decisions without being coerced/self-rule), the informed consent process is the patient's opportunity to decide whether to accept or reject treatment. When a healthcare professional approaches a patient, the sole intent is to receive consent for a pending procedure; many times the consenting process takes place when the patient is in the prep-and-hold area. How can a patient feel empowered to refuse treatment when the surgeons are practically standing over them waiting for the green light? The concept of informed consent is to allow patient autonomy to exist, not just a piece of paper to legitimize a

procedure. In relation to beneficence (action that is done for the benefit of others, also can be taken to help prevent or remove harm or simply improve the situation of others) informed consent is tool to illustrate the benefits of a procedure, such as a heart transplant or cancer removal. Healthcare providers enter the profession to help or benefit people (morally obligated to, but often healthcare professionals see the refusal of treatment or essentially choosing harm, as a direct contradiction to why patients come to the hospital in the first place. Beneficence implies more than just avoiding doing harm, but if a procedure does not provide a positive outcome or even death, this principle has been violated. In relation to non-maleficence (non-harming or inflicting the least harm possible to reach a beneficial outcome) informed consent explains how a procedure will either terminate the harm of a disease process or prevent future harm. There is no greater intention of a surgeon or doctor than to relieve harm or pain from their patient, but in the process of “doing no harm”, harm can be inflicted. On my institution’s consent form, there is a section stating that “medicine, surgery, and dentistry is not an exact science and no guarantee about outcome can be made”, also there are subsections for “risks and consequences”/”benefits”/”alternative courses of treatment”/”risks and consequences of these alternative courses of treatment”/”risks if no treatment is rendered”. As a patient, reading this form before a pending procedure or surgery, I would be thinking the worst. In relation to justice (individuals should be treated the same, unless they differ in ways that are relevant to the situation in which they are involved) informed consent is complicated. In the healthcare system, no one can be treated the same. No individual is the same, nor are disease processes. As far as treatment and care are concerned, healthcare should be provided to all, as in equal access-distributive and procedural

justice. In relation to social justice (providing people what they need equitably, not giving everyone the same no matter where they start from) informed consent can offer minimal to maximum levels of treatment. Depending on the individual patient need, procedures can be consented for care-whether it is a scheduled procedure or an emergency, life-saving surgery. The informed consent does not address the aftercare aspect of surgeries and procedures. If a patient needs a life-saving cardiac device and agrees to it, the aftercare and family support is not addressed. Many times, these procedures and operations aren't offered to patients who do not have the socioeconomic or social support of caregivers to assist them, which leads to injustice and inequity. In relation to solidarity (the willingness to share the burden to assist others that are less fortunate or vulnerable and strive for equity for all) informed consent does not address this aspect. The only common ground that an informed consent provides is the patient and the doctor want a good end-result with minimal to no suffering involved. The problems start when the patient and the doctor have conflicting views about what treatment and care the patient should receive. Solidarity should be recognized and discussed to ensure the patient's wishes are respected.

CHAPTER 7: NURSES EXPERIENCING MORAL DISTRESS: THE COST

“Moral distress occurs when one knows the ethically correct action to take that action. Research on moral distress among nurses has identified that the sources of moral distress are many and varied and that the experience of moral distress leads some nurses to leave their jobs, or the profession altogether...considers both moral distress and moral residue, a consequence of unresolved moral distress.” (Epstein, Delgado, 2010, para 1).

The anomaly of moral distress is described by Andrew Jameton, PhD, a Public Health professor and biostatistician, in 1984 as the occurrence in which “one knows the right action to take, but is constrained from taking it. Moral distress is different from the classical ethical dilemma in which one recognizes that a problem exists, and that two or more ethically justifiable but mutually opposing action can be taken. Often, in an ethical dilemma, there are significant downsides to each potential solution.” (Epstein, Delgado, 2010, para 3). Jameton further describes moral distress “as painful feelings and/or the psychological disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot follow through with that action because of institutional obstacles...more broadly, to healthcare professionals moral distress may be felt when a professional (who has taken an oath to serve the good of the patient) believes he or she knows the ethically correct but cannot follow that action because of some constraint whether interpersonal, regulatory, or legal.” (Houston, Casanova, Leveille, Schmidt, Barnes, Trungale, Fine, 2013.) Another definition characterizes moral distress as “a well-documented phenomenon with negative consequences that may be experienced by nurses and other clinical care providers...the definition of moral distress has evolved over the years, but at its core it is a form of

distress that occurs when one knows the ethically correct thing to do, but is prevented from acting on that perceived obligation. . . .moral distress is a concern for nurses worldwide as evidenced by the attendance of 73 participants from Sweden, England, Norway, New Zealand, Canada, the USA at an International Symposium on moral distress, convened in September 2010. . . .moral distress has been shown to be related to burnout, errors in patient care, distancing from patients and consideration of leaving a position or the profession all together.” (Wocial, Weaver, 2012, page 167, 168). Nursing burnout has become more and more prominent, especially in a high acuity area, such as an ICU. I conducted a quick survey of my colleagues from the Cardiac Intensive Care Unit, where I have been employed for the last 13 years, and asked one simple question, “Have you experienced a feeling of moral distress within the past month of your career?” I work with 65 RNs and I asked this question to 40 nurses. Using a modified tool called the Moral Distress Thermometer developed by the Fairbanks Center (www.fairbankscenter.org), nurses from less than 1 year experience to 20-30+ years at the bedside, only 5 out of 40 nurses answered “no” they did not experience moral distress within the last month. Although the tool did not leave room for explanation, the nurses wanted to qualify their statements-they wanted to state that they have experienced moral distress during their careers (whether they were new nurses or seasoned RNs). The results showed me that there is very little nurses can do to avoid moral distress. By defying a doctors’ order, we can and will face discipline. Our job description in any state is to be a patient and family advocate, and many hospitals are moving toward the “patient and family centered care model”, to foster trust and advocacy for the patient, as well as the community as a whole. In the original study conducted using the Moral Distress

Thermometer, Lucia D. Wocial PhD, RN and Michael T. Weaver PhD, RN concluded that participants who had left or considered leaving the profession of nursing was due to moral distress. Moral distress can be experienced by any and all members of the healthcare team, not just nurses. Although nurses come in contact more often and for longer periods of time than any other members of the multidisciplinary team, moral distress has been experienced by doctors, nursing assistances, respiratory therapists, physical, recreational, and speech therapists, social workers and case managers, dietitians, and/or chaplains. "Nurses have long reported that their work conditions are not conducive to providing patient-centered care that is safe and of high quality. The relationship between nurses' working conditions and patient safety was recognized by the IOM report *Keeping Patients Safe: Transforming the Work Environment of Nurses*. Indeed, researchers have suggested that the work environment and staffing levels for nurses affect both nurse burnout—which is characterized by feeling extremely overextended and depleted of one's emotional and physical resources in response to chronic job stressors—and job satisfaction, and are also associated with patients' satisfaction with care." The feeling of medical futility and unnecessary suffering due to a goal set by competing interests can lead healthcare professionals to resent their jobs, because in my personal opinion, the amount of suffering involved to reach a preconceived goal can be devastating to the patient and all that care for the patient. Commercials and hospital advertisements show the success stories: happy people who were cured from life-threatening illnesses or a doctor who gives the perception of caring and warm; but the reality, in most cases, is that the patient has now become a medical record number whose diagnosis needs an intervention that possibly may supersede their

wishes, advanced directives and/or religious beliefs. This is the heart of the problem, in my opinion; treating specimens and symptoms instead of the person as a whole. “Moral distress has been described as a phenomenon predominantly among nursing professionals...studies on moral distress suggest the phenomenon is significant across multiple professional healthcare disciplines. Healthcare professionals should be sensitive to situations that create moral distress for colleagues from other disciplines. Policy makers and administrators should explore options to lessen moral distress and professional burnout that frequently accompanies it.” (Houston, et al, 2013).

CHAPTER 8: RECOMMENDATIONS

There are several approaches to combat end-of-life decision-making and alleviate nursing burnout/moral distress. Nursing scholars have conducted studies in both issues and comprised multiple solutions for healthcare professionals to assist their patients into making the right decision for their lives. Dr. Shaida Talebreza and Dr. Eric Widera in the published article “Advance Directives: Navigating Conflicts between Expressed Wishes and Best Interest”, have comprised a list to aid healthcare professionals with the advance directive process. Here is an example in which healthcare facilities can utilize with their patients:

1. Advance care planning involves meeting with patients and their surrogates to ensure a shared understanding of diagnosis, prognosis, treatment options, and relevant values and goals, and to establish plans for future treatment that work toward a patient’s goals.
2. Advance directives are the written expression, recorded on any type of document, of a patient’s preferences for medical care at the end of life.

There are two general categories of directives:

1. Substantive directives, such as living wills, communicate patients’ stated values and treatment preferences should they become incapacitated.

2. Process directives, such as health care proxies (also known as health care power of attorney, durable power of attorney for health care, etc.), are used by patients to state whom they choose to make their decisions should they become incapacitated.

(Talebreza, Widera, 2015)

Information to be given to the patient in advance of capacity:

POLST (Physician Orders for Life-Sustaining Treatment or code status) paradigm is an approach to end-of-life planning emphasizing conversations and shared decision making about the care a patient would like to receive at the end of his or her life. A POLST form then translates the shared decisions into actionable medical orders. Only patients with serious illness or frailty who are unlikely to live longer than one year should have one. An advance directive is more appropriate to make future end-of-life care wishes known.

Surrogate decision maker is an advocate for a patient who lacks decision-making capacity. This can be someone the patient has appointed in a durable power of attorney for health care document or, if the patient has not appointed someone, a default person according to a hierarchy usually specified by state law.

(Talebreza, Widera, 2015)

By implementing these steps, patients, their families, and healthcare providers would be on the same page as it pertains to the care and overall outcome of the patient.

Oftentimes, a patient assumes their family members are able to make a life-changing

decision on their behalf, but some family members cannot or choose not to be the sole decision-maker when serious choices need to be made. A phone call in the middle of the night whether to intubate or continue a “code blue” on their loved one can be shocking and difficult to do when there is no preparation in place. Making a patient’s plan of future care the priority can quell patient’s anxiety over the uncertainty of their future, gives clear instructions to healthcare providers on how to proceed if the patient’s outcome is not favorable as per the expressed and written wishes, and gives the patient and their families peace of mind in knowing their healthcare providers are working toward their best interest.

Dr. H. Russell Searight and Dr. Jennifer Gafford in the article “Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians”, offer important recommendations to address the cultural considerations when advance directives and end-of-life care decisions need to be determined: 1. Emphasis on individualism versus collectivism, 2. Definition of family (extended, nuclear, nonblood kinship), 3. Common views of gender roles, child-rearing practices, and care of older adults, 4. Views of marriage and relationships, 5. Communication patterns (direct versus indirect; relative emphasis on nonverbal communication; meanings of nonverbal gestures), 6. Common religious and spiritual-belief systems, 7. Views of physicians, 8. Views of suffering, 9. Views of afterlife. (Searight, Gafford, 2005.)

“Understanding that every culture has their own specific views and beliefs on illness, death and dying, and the afterlife, can shed new light on how to approach patients and their families with respect and maintain their dignity. Working in an urban, level 1 trauma center, I have had the pleasure of caring for patients of many different backgrounds and have learned to not assume everyone thinks, feels, or believes the same way I do. By actively listening to the concerns and answering questions openly and honestly, a trust can

be built and maintain, even if a patient's prognosis is not favorable. Families will respect the institution and its employees more when honesty and trust is established well in advanced. (Searight, Gafford, 2005.)

To address and combat the syndrome of Moral Distress and offer solutions for nursing burnout/compassion fatigue, these are some suggestions by Donna Wood, RN:

“1. Support the nursing code of ethics: The ANA Code of Ethics presents a framework for practice. Nurses should be familiar with the code and use it on a daily basis, Turner said. Hospitals should incorporate behavior consistent with the code of ethics into job descriptions and consider that during annual performance reviews. 2. Offer ongoing education: Ethics, like most other disciplines, must be learned. Ethics is not intuitive or just ‘being good. New employee orientation and all educational programs should include ethics content, with specific examples of how to apply theoretical principles to concrete issues. 3. Create an environment where nurses can speak up: Having a practice environment that supports nurses in raising ethical questions and empowering them to address those concerns also is vital. Ethical issues are complicated and everyone brings their own experiences and values to the situation. 4. Bring different disciplines together: Physicians and nurses experience shared suffering. Working together could prove beneficial in addressing moral distress. Nurses and physicians don't realize how helpful they can be to one another. Clinical ethics rounds often are helpful in addressing concerns. Nurses also should be included in discussions about patient goals. 5. Provide ethics experts: On-site nurse ethicists or other ethics professionals who clinicians can confidentially talk with are valuable in helping people look at the situation from other perspectives. 6. Add unit-based ethics mentors: Everyday ethical issues need to be addressed. Hospitals could develop unit-based ethics mentors, who could help their colleagues with those day-to-day concerns that come up. 7. Hold a family conference: Family conferences bring everyone together and should be planned, with clinicians thinking through uncertainties and recommendations before the meeting. The importance of getting the family involved in developing the plan of care. Hold advance care planning meetings with families and the interdisciplinary team to discuss options for changing the goals of care, such

as enrolling in hospice or continuing more aggressive treatment. 8. Sponsor ethics journal or book clubs: Book clubs and journal clubs offer an opportunity to focus on ethics. Hospitals often can organize them, so participants can obtain continuing education credits. Reading articles helps nurses to realize other people have experienced similar feelings. A journal club can make it safe to talk about, because the discussion starts with the article, although it can move into personal values. Many nursing journals include an ethics column. The journal *Nursing Ethics* is dedicated to the topic. ANA publishes articles about ethical issues the *Online Journal of Issues in Nursing*, which is online and available at no cost. The National Institutes of Health, Hastings Center, the Institutes of Medicine and the President's Council on Bioethics provide online information. The World Health Organization offers an international ethics perspective. 9. Reach out to professional associations: Professional associations often provide resources to assist with training and handling of ethical issues. The ANA offers more than a dozen online ethics continuing education programs. AACN has developed practical resources about identifying and addressing moral distress, including "4 As to Rise Above Moral Distress," a handbook that guides clinicians through four steps when confronting moral distress: ask, affirm, assess and act. They're available to any health professional free of charge at www.aacn.org/moraldistress. Organizations, such as the American Society of Bioethics and Humanities, which has an affinity group for nurses, hold annual conferences. ANA co-sponsors the National Nursing Ethics Conference. 10. Offer employee counseling services: Nurses especially troubled by an ethical issue--perhaps relating to something happening in their personal lives or how the current situation rekindles past events--may benefit from individual sessions with a counselor from an employee assistance program (EAP)." (Wood, 2014.)

"Our challenge isn't to eliminate moral distress; it is becoming part of our new normal and not going away, so our new goals have become learning how to recognize and address it effectively. Healthcare leaders can start by helping clinicians learn how to recognize moral distress and point them to resources to help address it." (Wood, 2014.)

During my coursework in Urban Bioethics, a challenge was given to the students to offer solutions to inpatient issues of code status and informed consent. My colleague Michaela Kinloch and I created a potential position within the health system called “Advance Directive Navigator”. We presented and submitted our recommendations to the “Death and Dying” class and posted the information on the Center for Bioethics, Urban Health, and Policy’s Medium blog. This is what we recommended:

“We propose that hospitals create a position on their staff for someone who will “navigate” the patient through the process of creating an Advance Directive for themselves, and navigate the Directive itself through its correct implementation. Advance Directive documents should enable the patient, not the health care providers or others, to determine their care, with particular concern over care at the end of life, to be able to determine for themselves in advance when enough is enough. But do the documents in fact function that way? One of us, in direct clinical experience, has often noted many instances in which advance directives are not followed. Too often at the very moment in which the patient’s Advance Directive should become functional, they are ignored or countermanded by decisions of family or care givers, exactly what the Advance Directive is intended to prevent. The Directive becomes an exercise in violation of the principle of patient autonomy.

Why does this happen? The circumstances are multiple: The tasks of finding out if a patient has provided an Advance Directive, understanding it, and seeing that all who should know of it do in fact know of it, can be tasks that are not assigned to anyone in particular, not anyone’s specific job, but merely left up to whoever might be around and

available. It is an example of “if it’s everybody’s job it becomes nobody’s.” Doctors can, and do at times avoid following the Directive. In an emergency situation the MD’s default is, quite rightly, to attempt to preserve life, even if may seem futile. Even when time is less pressing they can still see following the Directive as time consuming. They can see the Directives as interference in their work, feeling that they know what is best for the patient. Doctors may have an interest in medical research and experimentation, but those are not the same as treatment. While the horrors of the Tuskegee experiments are long past, we must remain ever vigilant against even the smallest violation of ethics in this matter. There is the possibility of patient care being influenced by, distorted by, the interest in learning more about a condition. The patient has the right to say they do not wish the doctors to “learn on me” if that is going to affect their care in ways they do not want. Doctors and other clinicians do not always fully inform patients to enable them to make the best decisions for themselves, or do the same for family or appointed surrogate decision makers. Rather, they may edit what they say, speaking of what they believe, sincerely, is in the patient’s best interests. Unfortunately, this is almost inherent within the structure of health care, for without the massive knowledge base of a physician, how can a patient even know what questions to ask, let alone what to make of what they are told; how can they know what it is they are not being told. If clinicians, perhaps only intending to encourage, downplay negative outcomes, then the patient cannot be expected to make the best decisions.

Consent is often done at the last moment, when patient is least able to deal with the issue, most vulnerable, such as when they are “hostage to surgery.” For example, the lung transplant patient, fully prepped by the team for surgery, who was told that such soft

tissue transplants are not considered curative, but only a means of extending life for a limited span, but was told this only moments before surgery. Might they feel a pressure to carry through with the procedure even as their first doubts arise? R.N.s at the bedside have little time to explain or assist in creating Advance Directives, especially in the early stage of admission, and they may or may not have the necessary documentation available to them. Sadly, it must be recognized that in the current fee-for-service environment doing more does in fact generate greater revenue than doing less. Without some change to the system of the use of Advance Directives in hospitals it is likely the problem will only worsen. An aging population will have greater end-of-life care needs. As the cost of health care is already in large part a function of the political climate, and budgets are under increasing stress, adherence to what may be seen as non-essential elements of care, perhaps peripheral to core medical matters, is less likely to be maintained. The key is a fully informed honest assessment about the patient's condition, prognosis, and all potential outcomes, not downplaying the harsh outcomes of death, disfigurement, disability, or dependence upon mechanical devices, but how does this come about? We are proposing the creation of the Advance Directive Navigator staff position. The Navigator's duties include, but not limited to:

1. Educate the patient to available options.
2. Assist the patient in understanding what to expect with a possible negative outcome and end-of-life decisions.
3. Assist the patient in the process of creating an Advance Directive document.
4. Ensure the institution and its staff are aware of the patient's wishes, including entering the Advance Directive in the Electronic Medical Record (EMR).
5. Advocate for the patient's wishes to be honored.

To avoid the phenomenon of “if it’s everybody’s job it becomes nobody’s,” make this a specific position with recognized title, responsibilities, and authority. This is not to be a mere add on to an existing position, but a position in its own right. The patient would be connected to the Navigator at the earliest opportunity, possibly even before admission if the situation warrants, such as at pre-admission testing or during office visits. The Navigator researches the patient’s situation and determines their desires. From this the Advance Directive document itself is created in collaboration with the patient. The patient’s health care team is informed of the Directive, through all possible channels. The Navigator carefully observes the process of the patient’s care, always being aware of the patient’s condition and who might be involved in their care. They would also stay in contact with the patient, continuing to inform and advise, so long as that is possible. The Navigator will inform the team of the provisions of the patient’s Directive, and do all that might be necessary to see that directives are followed, including reference to ethics consults. The Navigator would serve as a bridge between the Ethics Committee and the Palliative Care team. The Navigator, or a delegate, would be on call for needs as they arise.

In order to function this way the Navigator would need to be given certain authorities:

1. They must have full access to patient’s records and unrestricted access to patient themselves.
2. They must be allowed to speak with any member of the health care team.
3. They must be allowed to round with the team.

4. They must be allowed to report all violations of the Advance Directive to upper management levels.
5. They should be able to function independently. To facilitate this, the position should be created as not reporting to any one clinical department, but rather to a neutral office such as that of Patient Relations.

Who would the Navigator be? Certainly the successful Navigator would require some very strong skills. We would suggest looking at those with clinical experience, ideally some in a palliative care setting, while also having training in bioethics. An understanding of the hospital organization will be essential, as will strong communication capabilities. There are certainly going to be barriers to instituting this, and it is therefore necessary to consider what can be done to counter the objections.

Certainly the cost of another hospital staff position would be raised in objection. However, it should be noted that, since the functions of the position are restricted, even a larger institution may need only one or a very few people in such a position, their time shared over many patients. The actual capacity may vary by institution, based on patient population, and would have to be determined by each institution for itself. The position may be seen as not really part of the health care team but rather “on the patient’s side” in an adversarial situation. This need not be. The institution and members of any health care team should be trained to see this as a means by which the patient’s wishes can be better understood and more readily followed. Unless the attitude of a team member is essentially ‘anti-patient,’ simply not respecting patient autonomy—in which case there is a much larger problem—then this should be possible. They may even come to see it as a

means by which they are relieved of a difficult and worrisome task. In any event, it has already been largely accepted that an R.N.'s job can require them to function as a patient advocate, so the principle is already in place (even if not always respected.)

The objection can be made that it is yet a further complication in patient care. Admittedly, this is true, but it is a necessary refinement, or enhancement, one might say, because following the patient's wishes is a core element of the care.

There may be the opinion that existing procedures and documentation are doing the job quite adequately. It would be necessary for each institution to carry out a critical self-examination to establish if that is really the case. There can certainly be issues of trust within the patient community. Might the position be seen as a means of serving the institution's wishes, or those of the physicians, and not the patient's? This could be difficult to overcome except through demonstration of success. Members of the patient's family may have the interest of 'keeping them alive no matter what must be done,' which can be, even with best of intentions and founded in love, in conflict with the Advance Directive, and the situation can become quite volatile, with the family's anger focused very specifically, personally even, upon the Navigator. However, that anger could well exist in any event, and might it not be better to relieve the clinical care members of the team from facing it, and so give them a better chance to do their work? This may in fact be a benefit, in that those members will be less likely to avoid adhering to the provisions of the Advance Directive if they do not have to face emotional family members on the matter.

No solution is perfect, and there are weaknesses still.

Does the creation of such a position in effect this lessen the responsibility of health care team to be active in following patient directives? That is, it becomes someone else's job, and therefore the Advance Directive becomes if anything less visible? That may be how it could develop, but the very fact of the position should, if properly implemented, keep the Advance Directive very much in the foreground. Much would depend on how the position is managed, how it is staffed. No job is immune to poor fulfillment of its duties. Might it be functionally restrained in scope by existing institutional Advance Directive documentation? It must be clear that such form documentation is only suggestive to the patient, not a requirement or a limitation, and individual needs and desires must be accommodated.

Overall we believe that the creation of such a position would do much to ensure that patient's wishes at the end of life, as expressed in their Advance Directives, are followed.

REFERENCES

- Beaty-Edwards, D., Kinloch, M., “*The Advance Directive Navigator: A catalyst for change and better care.*” Medium blog (Urban Bioethics) August 29, 2017
<https://medium.com/@CBUHP/the-advance-directive-navigator-a-catalyst-for-change-and-better-care-7f55af738ac0>
- Talbreza, S., Widera, E., *Advance Directives: Navigating Conflicts between Expressed Wishes and Best Interests* American Family Physician 2015 April 1: 91(7): 480-484
- Hoffman, J., “*Teenagers Face Early Death, on Their Terms*” March 28, 2015
<https://well.blogs.nytimes.com/2015/03/28/teen-advance-directive-end-of-life-care/>
- Putman, A., “*Do I Have to Resuscitate This Patient Against Her Wishes?*” American Family Physician 2003 May 1: 67(9) 2025-2028
- Searight, H, Russell, Gafford, J., “*Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*” American Family Physicians 2005 February 1: 71(3): 515-522
- Houston, S; Casanova, M; Leveille, M; Schmidt; K; Barnes, S; Trungale, K; Fine, R.
“*The Intensity and Frequency of Moral Distress among Different Healthcare Disciplines.*”
- The Journal of Clinical Ethics 24, no. 2 (Summer 2013): 98-112
- Wocial, L; Weaver, M.,”*Development and psychometric testing of a new tool for detecting moral distress: the Moral Distress Thermometer.*” Journal of Advanced Nursing 69(1), 167-174.

Epstein, E., Delgado, S., (Sept 30, 2010) “Understanding and Addressing Moral Distress”
OJIN: The Online Journal of Issue in Nursing Vol. 15, No 3, Manuscript 1.

Prograis, L, Pellegrino, E. 2007. African American Bioethics; Culture, Race, and Identity. Georgetown University Press, Washington, D. C. Pg. xiii

H.R.4449 – Patient Self Determination Act of 1990, 101st Congress (1989-1990)

<https://www.congress.gov/bill/101st-congress/house-bill/4449>

Frank, Arthur. 1995. Chapter 1: When Bodies Need Voices. The Wounded Storyteller: Body, Illness, and Ethics. Chicago: University Of Chicago Press. Pg. 1-26.

Flowers, M. *Who Should Make Treatment Decisions for Terminally Ill Children?*

Medium blog March 20, 2017

<https://medium.com/@mflower2/navigating-end-of-life-decisions-for-children-together-11ed7cef8c99>

Lavagnino, J. *The Matter of Daniel Hauser: Parents’ Right to Refuse Medical Treatment for their Kids*. Find Law (blog) May 15,

2009 https://blogs.findlaw.com/law_and_life/2009/05/the-matter-of-daniel-hauser-parents-right-to-refuse-medical-treatment-for-their-kids.html

Cohen, E. *Heaven over hospital: 5-year-old Julianna Snow dies on her terms* CNN .com

(blog) June 20, 2016 <https://www.cnn.com/2016/06/14/health/julianna-snow-heaven-over-hospital-death/index.html>

Shiel, W. *Medical Definition of Patient autonomy* Medicine Net (blog) January 25, 2017

<https://www.medicinenet.com/script/main/art.asp?articlekey=13551>

Santivasi, W, Strand, J, Mueller, P, Thomas J. Beckman, J. T. *The Organ Transplant Imperative* Mayo Clinic Proceedings. N June 2017; 92(6):940-946 n

<http://dx.doi.org/10.1016/j.mayocp.2017.03.005> www.mayoclinicproceedings.org

Gerrek, M. *Getting Past Dax* AMA Journal of Ethics

<https://journalofethics.ama-assn.org/article/getting-past-dax/2018-06> June 2018

Skloot, R. *The Immortal Life of Henrietta Lacks*. 2011. Broadway Books, New York, New York.

“*Ethically Impossible*” STD Research in Guatemala from 1946 to 1948. Presidential Commission for the Study of Bioethical Issues, September 2011.

“*Moral Science*” Protecting Participants in Human Subjects Research. Presidential Commission for the Bioethical Issues, December 2011.

U.S. Public Health Service Syphilis Study at Tuskegee Timeline. Centers for Disease Control and Prevention. December 2015.

<https://www.cdc.gov/tuskegee/timeline.htm>

Wood, D. *10 Best Practices for Addressing Ethical Issues and Moral Distress*. American Mobile Nurses Healthcare (AMN Healthcare) March 3, 2014.

<https://www.amnhealthcare.com/latest-healthcare-news/10-best-practices-addressing-ethical-issues-moral-distress/>

Maslach C, Schaufeli WB, Leiter MP, *Job Burnout* Annual Rev Psychol. 2001; 52():397-422.

Institute of Medicine. Keeping patients safe: transforming the work environment of nurses. Washington (DC): National Academies Press; 2003.

McHugh, M, Kutney-Lee, A, Cimiotti, D, Aiken, L. Nurses' *Widespread Job Dissatisfaction, Burnout, And Frustration With Health Benefits Signal Problems For Patient Care.*

[Health Aff \(Millwood\). 2011 Feb; 30\(2\): 202–210.](#)

doi: [10.1377/hlthaff.2010.0100](#)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3201822/>

Nabili, S, Sheil, W, *Advance Medical Directives (Living Will, Power of Attorney, and Health-Care Proxy)*

https://www.medicinenet.com/advance_medical_directives/article.htm#advance_medical_directive_facts

Sparks, K, *Luis Kutner* Encyclopædia Britannica February 25, 2019

<https://www.britannica.com/biography/Luis-Kutner>

FIGURE 1. Disease progression and the transition from palliative care to end-of-life care. (The Organ Transplant Imperative. Santivasi, Wil L. et al. Mayo Clinic Proceedings, June 2017. Volume 92. Issue 6, 940 – 946).