A BETTER DEATH
DOES HAVING AN ADVANCE DIRECTIVE MAKE A DIFFERENCE AT THE END OF LIFE?

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by
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ABSTRACT

Death is inevitable, and research indicates that 80% of Americans wish to die at home. Does anyone know those wishes? Advance directives outline those wishes and personal decisions. Do advance directives make a significant difference in the experience of death for the patient, loved ones, and clinicians? Through interviews with loved ones of those who have died, as well as legal representative and a physician, this thesis examines the benefits and obstacles of having an advance directive, as well as the issues that have a high impact on whether and why an advance directive is written. Policy recommendations, business tactics, and community-based solutions are proposed to address these issues. It is clear that access to healthcare and the clinical professionals who can discuss end of life issues has a major impact on whether an advance directive is considered by the patient, along with health literacy skills and knowledge.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

You are going to die. I am going to die.We will all die at some point in time. How would you feel about having a role in the path to your own death? If you could, would you like to provide your caregivers: doctors, nurses, family, and friends with instructions on how to care for you and what care you would or would not like throughout your dying process? Only about one third (37%) of American adults have an advance directive (National Institute on Aging), a document that informs your medical and personal caregivers what treatment you want or do not want and when you want it. As stated by Steinbock and Menze,

Since the 1960s, there has been increasing acceptance in American law and society of the right of individuals to participate in and, within limits, control medical treatment. Such participation and control reflect a rejection of medical paternalism and support for autonomy and respect for persons (palliative.stanford.edu).

Research shows that 80 % of our fellow Americans would prefer to (palliative.stanford.edu) die at home. Would you? Who knows your decision? If you have an advance directive that contains this vital information and shared it with your primary doctor, friends, and loved ones, more people would know, and you would have a better chance of your wishes being honored. You could also choose someone to share your

written wishes for care if you were unable. Whom you chose depends on their ability to: speak on your behalf, are comfortable speaking with medical professionals, and can remain calm in the face of any adversity that may occur as a result of your illness or end of life choices.

I believe having an advance directive makes a significant difference to the patient, their loved ones, and the staff that care for the patient at end of life. First, I will discuss what brought me to this topic, both professionally and personally. I will move onto the national history and an overview of advance directives at Temple University Hospital Inc. (TUH). I will discuss barriers to and concerns involved in completing an advance directive. Through interviews with loved ones of those who have died, I will examine the benefits of having an advance directive for the patients and their loved ones. Based on the work of authors such as Atul Gawande, MD and, Jessica Nutzik Zitter, MD, I will examine how having an advance directive helps medical caregivers provide care that is better aligned with patients' values and lifestyles. A lawyer and a physician were also interviewed in an attempt to represent the full spectrum of this topic at an urban academic teaching hospital. I will also explore the impact of not having an advance directive on the patient, family, and medical caregivers and explore reasons why people do not have an advance directive. Having an advance directive needs to be normalized, I will share some steps on how this can be achieved.

Several people shared the story of their loved one’s death. These interviews presented both the good and bad of our health care system at the end of life. The various interviews presented opportunities to learn how to better prepare for death

and how to decrease the burden of difficult decision making during difficult times. The majority of interviews show that being prepared for your death allows both you and your loved one's time to be more present during the end of life.When people know how you feel about an issue, it frees up time for more genuine conversations and allows everyone to focus on the time that is left instead of making decisions, difficult decisions. In Being Mortal, Atul Gawande states;

> People who have substantive discussions with their doctor about their end of life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish (p.177).

The information I gathered during these interviews demonstrated, in most cases that those who understood the importance of and took the time to develop an advance directive with clear plans for end of life care and shared it with their family and caregivers leave behind loved ones who are grateful to have not had to make difficult medical and care decisions during stressful times. Loved ones were able to "live" the dying process with their family member, instead of having to worry about care decisions. As shared in one interview, I conducted,

> I am grateful to my mother for making her own decisions while she still could; it enabled me to be able to lay with my mother and hold her till the end rather than be worried I made the wrong decision at any time (Dr. H).

This interviewee believes that the fact that her mother made all her own healthcare decisions and informed all her doctors and children helped them provide the appropriate care. They miss her every day but have no regrets about her care at the end of her life.

PERSONAL HISTORY

This topic is very personal to me. I clearly remember being in the 6th grade and my parents completing their last will and testaments, the one known to most people for what happens to what you own once you die; these frequently contain instructions for burial as well. I cried and begged my parents not to complete their will because I thought it meant they were preparing to die. I had a horrible fear of death and a significant lack of understanding about wills. My parents tried to explain to me that they were not going to die any time soon, but I remained fearful for a long time after that night.This was the spring of 1978.

Four years earlier, my cousin, Rose, was in a life-altering accident. Her accident and recovery greatly influenced my early views on death, dying, and health care delivery. While driving to Atlantic City with her husband, they were in a horrible accident. He fell asleep while driving, and their small car became wedged under a tractor-trailer on the Atlantic City Expressway. He needed eight stitches, and she was in a coma with a severe brain injury and several broken bones. She spent four months in a Philadelphia, PA area hospital, most of those in a coma.

During this time, doctors advised my Aunt Bett, (my mother's sister and Rose's mother), that she should unplug her daughter from the machines keeping her alive as her life would never be what it once was and she would require more care than my aunt was able to provide. My aunt refused. One day, Rose began to wake up and continued to improve. Rose and her mother spent nine months at a physical and cognitive

rehabilitation center in Colorado, where Rose learned to walk and talk again. While my cousin was recovering, she was able to recall many of the conversations that the doctors had with her mother in her hospital room, including discussions about removing her from life support. Rose was very grateful that her mother had refused! Rose and her husband, Stuart, had three small girls at the time of the accident. Rose was never able to care for her children again, and my aunt moved in with them to care for Rose and her children. This story of Rose and her seemingly miraculous recovery is legend in my family. No one in my extended family believes in advance directives, limiting care, or withdrawing any medical care due to Rose and her recovery. My mother had 14 siblings; she was the only one to have had an advance directive at the time of her death in 1984, her primary reason was to not suffer in any way, she wanted "no heroic measures." I have six siblings, and only two of us have an advance directive.

This personal history, coupled with my thirty-plus years of working in various health care settings as a Certified Therapeutic Recreation Specialist, has dramatically shaped my views on advance directives and end of life care. I have witnessed many patients and families struggle to make difficult decisions and live with the uncertainty of knowing if they made the right decision at the right time. The premise of this thesis is not just about advance directives and end of life care. It reflects an entire career spent witnessing inconsistent or the complete lack of information and productive discussion between medical professionals and patients and families. In the absence of honest and understandable information about their medical situation, patients and families are deprived of the ability to make informed decisions. This omission by the medical field

strips patients and families of opportunities for justice and autonomy and does not allow for a comprehensive decision weighed with risks and benefits.

My views have also been shaped by the course work required to obtain a master's in Urban Bioethics. My first class was Dying in the 21st Century, completed in the summer of 2017. My desire to attend this class came from witnessing patients and families struggle with understanding medical language and then needing to make life-altering decisions. The knowledge gained during this class enabled me to identify better and articulate the disparities of care and health literacy and increased my knowledge of available resources for my urban patients. Subsequent classes and assignments helped shape my thoughts and provided resources for this paper and the care I provide patients and their families.

A senior citizen health expo that I participated in as part of my Community Engagement class allowed me to see firsthand the significant deficits in health care literacy in the community served by TUH. Health literacy is defined as "the degree to which an individual can obtain, communicate, process, and understand basic health information and services to make proper health decisions." (Rasu, et al. 2015, p.2). This experience significantly increased my desire to find ways to assist this community in increasing its health literacy surrounding advance directives. The ability to know if one wants an advance directive requires practical knowledge on the “what, how, and why” of advance directives and at least a basic understanding of some medical terms, such as CPR.

CHAPTER 2

HISTORY

History of Advance Directive in the U.S.A.

In 1969 a lawyer named Luis Kunter proposed that people should be able to put medical wishes in writing just as they do a last will and testament for personal property. He initially used the term “living will” to describe this process and suggested that the document be notarized and have at least two witnesses that confirm the person making the document was of sound mind and perusing their autonomy in executing the document. The Euthanasia Society of America embraced Kutner's idea and, in 1972, printed the first version of a living will. The form stated that if there was no reasonable expectation of recovery that the signee should be allowed to die and not kept alive "by artificial means or heroic measures." At this time, there were no laws supporting living wills; these requests were seen as an appeal to the graces and moral compasses of those providing care. Florida was the first state to introduce a bill to allow patients to make their own decisions about end of life care in 1968; the bill did not pass. At the same time, California was presenting similar legislation. In September of 1976, California became the first state in the country to allow living wills legally. Within one year of this landmark decision, 43 other states had attempted to pass legislation in support of living wills, only seven succeeded. By 1992, the entire nation had passed some form of legislation to acknowledge an advance directive, with many states having their own additional

allowances or requirements within the legislation. Pennsylvania was the first state to allow the possibility of a healthcare proxy into law in 1983. (Lacks, 2014)

Some of the confusion about advance directives and living wills comes from the fact that one can contain part of the other, and some states use different terms. An advance directive is a legal document that explains what type of medical care you want if you are unable to speak for yourself. Some advance directives contain living wills and health care proxy. Each state has different requirements; some require witnesses, some required notarized documents, some do not. In general, a living will and advance directive are used interchangeably, and this is acceptable for the essential autonomy of self-directed care. It gets more complicated when you need to select others to be your voice if you cannot remain autonomous or do not wish to make your own decisions and select a health care proxy. Health care proxy is also called different things in different states: health care surrogate, durable power of attorney for health care, and a few others depending on where you live. In California, for example, it is called the California Advance Healthcare Directive, which contains a power of attorney for healthcare.

The need for advance directives is highlighted by both Karen Ann Quinlan and Terri Schiavo. While both of these women are frequently championed by the right to die movement, they both galvanized the need for advance directives in their time. Also, they highlight the difficulties faced when loved ones and medical providers have no written documentation of plans for end of life care.

Karen Ann Quinlan collapsed in April 1975 at the age of 21 when advance directives were not yet the norm nor accepted in her home state of New Jersey. Her

parents wanted to remove her from a ventilator, the facility she was in, did not. Her case went as far as the Supreme Court on New Jersey in order to declare her father her decision-maker. Had there been an advance directive stating her desires for end of life care and appointing her father or anyone else as her decision-maker much anguish could have been avoided for her family and caregivers (Warraich, 2017). This tragic case helps emphasize that even young people need to have conversations about what medical treatment they would or would not like to receive.

In 1990, Terri Schiavo was 37 when she had a heart attack at home and was left in a persistent vegetative state. From 1990 to her final death in 2005, her parents and her husband waged a battle about her care in the courts and the court of public opinion, with even then-president George W Bush weighing in. Terri's husband wanted her feeding tube removed; her parents did not. The Quinlan case helped courts eventually decide that Terri's husband was her legal guardian and could make decisions on her behalf (Warraich, 2017). Terri's case again emphasized the need for people to speak to their loved ones about care at the end of life and their desires. If Terry had had an advance directive, her husband and parents may not have spent years in court disagreeing about her care.

These cases call attention to the need for everyone, young and old, healthy and sick to have at least a conversation about end of life care. Completing an advance directive needs to be normalized. Even young people in the prime of their lives can succumb to tragedies that leave their loved ones with little to no direction on how to proceed with difficult care decisions.

Advance Directive at Temple University Hospital, Inc.

Temple University Hospital Inc., main campus, is a 576 bed, urban, academic teaching hospital in one of the poorest sections in Philadelphia, Pennsylvania. According to the 2018 Census Bureau data, the median income for the area surrounding the hospital zip code, 19140, is $30,984, compared with the median income for Pennsylvania at $47,329 and the United States median income of $50,936 (Census, 2018).

Less than 2% of patients admitted at TUH on any given day have an advance directive (EPIC, 2020), compared with a third of our fellow Americans (National Institute on Aging). Why so few? Could there be a correlation between the lack of access to health care and health literacy in urban settings and the lack of an advance directive? I would say yes. If people do not seek out medical care, then they will not learn about the importance of an advance directive. This lack of access to care and with so few people having an advance directive can lead to a lack of autonomy and agency for our most vulnerable patients. This can only lead to missed opportunities for beneficence and non-maleficence.

A small sampling of people's knowledge was taken at a senior citizen exposition at Temple University in fall 2019.

These are the results:

- 52% state they know what an advance directive is
- 62% do not have an AD; 5% don't know if they have an AD
- 11/17 (65%) of respondents who stated they have an AD have shared with their physicians

- Respondents
    - 62% were 61-65; 66-70 years
    - 83% female
    - Zip code 19121 (Broad Street – Schuylkill River; Girard Ave – Dauphin St.)

Various barriers to completing an advance directive were also noted:

1. Need more information (8/27)
2. Have never been asked to complete (6/27)
3. Not ready for EOL planning (4/27)
4. Never thought about EOL planning (4/27)
5. Family knows their wishes (3/27)

The most concerning result for me is that people were never asked about an advance directive. After an eighty-nine-year-old man who had been shuttling back and forth from the nursing home to the hospital as he became more critically ill was finally asked about his wants and needs as the end of his life drew near stated "No one ever asked me what I wanted. I have lived for eighty-nine years in this country, and this is the first time that anyone has ever asked me what I want" (Volandes, 2015, p.140).Why? One reason is that physicians, for the most part, are not trained to have these important conservations with patients. Another reason is that patients fear that they will not get the care they desire if they complete an advance directive. Some people do not complete an advance directive due to fear. Those who conducted this small sampling had the desire to ask follow-up questions, but time did not allow such critical conversations to occur in this

setting; however, we were able to provide the TUH approved advance directive form to all who desired one. While this was a small sample, we had to start somewhere; this survey was part of a larger project for a masters' level Community Engagement class at the Lewis Katz School of Medicine at Temple University, Urban Bioethics section. This group of masters' students consisted of adult learners with vast health care experience, from a Certified Therapeutic Recreation Specialist to a medical researcher and several other professions in between who were charged with discovering why so few TUH main campus patients have an advance directive and how that number could be increased.

During an Interview with John O'Donnell, JD he explained the TUH approved advance directive form, which contains three parts:

*Living Will - which describes your wishes for your healthcare in the event you can no longer do so – in the event of near-death/terminal illness, permanently unconscious or in a persistent vegetative state

*Durable Power of Attorney – Choose your medical decision-maker for when you are unable to speak for yourself

*Surrogate instructions – Give your surrogate a sense of your wishes so they can carry them out

Three types of surrogate healthcare decision-makers are acceptable: Agent, Guardian, and Health Care Representative.

An Agent is someone who is selected by the patient when they have capacity.

> A Guardian is someone who is appointed by the Court to make decisions on behalf of an incapacitated person. A Guardian will have a court order designating them as the Guardian for the person who lacks capacity.
>
> A Health Care Representative must be at least 18 years old and may make a health care decision for an individual whose attending physician has determined that the individual lacks capacity. (O'Donnell, 2020)

All of the above make it easy to see why some people may be reluctant to complete an advance directive: it will not be a quick discussion with either a doctor or family members, many decisions need to be made, and medical and legal terms need to be understood by all parties. Lost in this reluctance is the opportunity for autonomy and justice for the patient. The complex nature of the various terms that need to be understood in order to complete an advance directive only emphasizes the need for increased health literacy, not only at TUH but across all health care settings. The importance of making an advance directive does not only fall to the patient. Doctors and all medical professionals have a responsibility to ask and educate patients about an advance directive and how important they are to end of life care. I have only been asked about an advance directive once in my life: before surgery this past June. I have one, and I shared it with my doctor. I believe everyone should be asked at every appointment, be it the primary care doctor or the cardiologist. It should not be left to time down the road when a difficult diagnosis has been delivered, and many other important decisions need to be made. Many different

resources exist on a national, state, and local level. Some resources are better than others, and some are difficult to understand, others have too many pages and use too much medical language. Some are too simplistic.

Education about advance directive needs to be everyone in healthcare's responsibility. The more patients hear it, the apter they are to ask questions and hopefully complete one. Lack of education coupled with decreased health literacy about advance directive needs to be viewed by the medical field as an ethical issue, in that neglecting to speak with patients about it at every appointment is unethical and needs to change. Talking about advance directive needs to be normalized. I believe that being asked if you have an advance directive should be the same as getting your vital signs checked. Very few health care appointments begin without having your vital signs checked, very few appointments should end without being asked if you have an advance directive. More education for both patients and care providers is needed.

A woman I know who is pregnant with her second child shared with me that she is asked at every appointment now, even when she has blood drawn and was never asked when she was pregnant with the first child, who is now four. This gives me great hope that the message is being heard; that health care providers are being educated on the need to speak with patients about end of life care, patients need to hear it frequently and often to realize how important and necessary it is for their care.

TUH has had only 2% of admitted patients with a documented advance directive at any time in the past three years (EPIC). This number had not increased despite the efforts mentioned earlier. Why? One reason may be that approximately 40% of admitted

patients do not identify a primary care physician on file. While Medicaid assigned participants a primary care physician, most patients never seek out that assigned physician (Wells, 2020). Another contributing factor may be the high cancellation/no show rate. On average, 25% of all follow up outpatient visits are canceled by the patient, or the patient simply does not show up (Craighead, 2020). These two statistics represent crucial missed opportunities for patients and doctors to have conversations about end of life care. In neighborhoods such as those surrounding TUH, there is a deep distrust of hospitals and doctors and fear that completing an advance directive would lead to not receiving desired care is real. "Many people don't sign an advance directive because they worry they're not going to get any care if they say they don't want CPR, it becomes this very scary document that says, 'Let me die'" (Andrews, 2017 p. 3). It is vastly important to complete an advance directive at any age for all the reasons previously mentioned, what has not been mentioned is the fact that it is very difficult to know what care you would want at any given moment in your life. Novel treatments and advancements are made frequently in healthcare, and what was once end of life treatment can become a lifesaving treatment. As stated by Dr. Diane Meier, a geriatrician and the director of the New York-based Center to Advance Palliative Care, "In some ways, the public's lack of excitement about this is related to the reality that it's very hard to make decisions about the kind of care you want in the future when you don't know what it will be like." (Andrews, 2017 p. 3).

CHAPTER 3

GATHERING MORE KNOWLEDGE

In the fall of 2018, as part of my community engagement class, a survey was conducted at several TUH outpatient sites. All staff that interacted with patients was included in the survey, everyone from the front desk clerk to the physician. The survey included ten questions chosen to gather a baseline of provider's thoughts and knowledge and barriers surrounding advance directives. Fifty health professionals responded. Most listed lack of time as the number one barrier to discussing advance directives with their patients. To encourage more physicians to help people to plan for their care, the Medicare program began reimbursing them in January 2016 for counseling beneficiaries advance-care planning. The second barrier was that patients had a lack of understanding of advance directives. A few other barriers noted to completing an advance directive included: lack of resources to give to patients, health professionals not ready to discuss, patient not ready and patient/family mistrust of medical professionals.

These results demonstrate that more education is needed for both patients and providers. I believe that improvements can be made incrementally for education for providers and patients to decrease the amount of time needed during an appointment and increase the amount of time that patients and families discuss advance directives at home with each other and bring clarifying questions to the actual appointment. Ellen Goodman, a Pulitzer Prize-winning writer who founded The Conversation Project, states, "the most

important thing is to have the conversation with the people that you love around the kitchen table and have it early" (Andrews, 2017, p. 4).

My original thought when I began this thesis was that those who have an advance directive in place when they start the journey towards death have a better death, and their loved ones have a better experience as well. Those dying are more accepting of their mortal end and can focus on family and friends rather than care and the surrounding decisions. Their loved ones' experience less moral distress surrounding care decisions and are therefore able to be more present for their loved ones; they can let go and begin mourning without regret about care decisions. Opportunities to create final memories and say goodbye are readily present when the focus is on the dying loved one and not the care decisions surrounding the dying loved one. I did find that this was the case for all the loved ones I interviewed that had their loved one's advance directive honored. Issues arose when the advance directive was ignored or challenged. According to a June 2014 Advisory Board Daily Briefing, advance directives are ignored when patients fail to have meaningful conversations with their families about their decisions: patients chose ineffective proxies; family members disagree about the best treatment options and clerical errors. This briefing shared that the state of Oregon has had an electronic registry for the Physician Orders for Life-Sustaining Treatment (POLST) for nearly 30 years. A study of the registry in 2010 and 2011 showed that utilizing POLST resulted in patients' wishes being honor more frequently. Just 6% of patients who selected "comfort measures only" died a hospital, while 44% who selected "full treatment "died in the hospital (Advisory Board, 2014).

Currently, I am the POA for a friend, she has all of her wishes written down and has told me that it is my job to stand at the foot of her hospital bed and say," this is what Annette wanted," to her family, as many times as I need to say it. I hope I am up to the task if the day ever occurs. For me, this is the ultimate autonomy to get to say what and when it is permitted to be done to my body even if I am not wholly aware. Autonomy refers to an individual's "rational capacity for self-governance or self-determination- the ability to direct one's own life and choose for oneself" (Vaughn, 2019, p. 81).

CHAPTER 4

INTERVIEWS

The majority of those interviewed had only positive things to say about advance directives and the framework it provided for both medical care and guidance to loved ones. For some, it was too private a matter; for others, it was too new; others still did not want their story told. Many, many people I asked did not know what an advance directive was and were not interested in learning about one. This shows that mistrust still exists and health literacy remains a barrier not only to care but to planning for end of life issues. One would think that religious and cultural beliefs also play a role in some people's reluctance to both complete and advance directive and share any stories of loved ones who have passed.

I am eternally grateful to those who entrusted me with the story of their loved one's death. For some, it was the last act of letting go of their grief, and for others, it was the first opportunity to tell the details of the experience to an outsider. All gave generously of their time and provided thoughtful insight into the last days of not only their loved one but their families and our healthcare delivery system. Each story involved an opportunity for all to learn to plan better for death and care better for the dying and their families. Opportunities for justice for the dying as well as beneficence abound.

Be Prepared

Mr. Z and his daughter, G, who had 19 years' experience in healthcare at the time her father became ill. Mr. Z was married and had another adult daughter. Mr. Z died in 2008 of Mesothelioma, initially, he responded well to all treatment and life continued with few bumps Mesothelioma, initially, he responded well to all treatment and life continued with few bumps in the road until three years later when he suddenly became worse. He had a brief hospitalization for fluid buildup in his lungs. At a follow-up appointment with his wife and G, they were told there was “nothing else to do” for him. Essentially they were told to go home and enjoy life. G feels this news could have been delivered differently, at a minimum allowing time for the patient and family to absorb the news. She feels they were told, stunned, and pushed out the door. In the parking lot, Mr. Z proclaims: "I am done with hospitals!" The first week at home is good; he is able to remain independent and eat well, going up and down the stairs, still driving. Within a week, Mr. Z started eating less and sleeping on the couch, utilizing a commode in the living room. Quickly then he unable to get off the couch and needed a diaper and more hands-on care than his wife could provide. His daughters were able to help but did not live in the home with their parents. During this week, the family made several attempts to have more services provided within the home. Unfortunately, they hit many roadblocks to care. In speaking with a hospice company, the family was told they needed to have a doctor initiate hospice care, doctors' offices were not returning phone calls, and the families' frustration was growing. Within a week, Mr. Z. was unconscious on the couch, and G was out of town! A private ambulance company was called to take Mr. Z to

the hospital where G worked. His daughter called the hospital and let them know her father was on the way and that she was driving in from another state and would be there within 2 hours. G also let the hospital know that her father had end-stage cancer, and the family was hoping to be connected with services to get him back home with comfort measures only. The emergency department doctor called G and let her know that her father was not going to make it home. The doctor confirmed that they wanted comfort measures only. Other family members had arrived at the hospital, so her mom was not alone. G arrived in time for her father's last two heartbeats. He was 81.

What went well? G is grateful that the ambulance crew did precisely what was asked of them and took her father to the requested hospital. The care in the emergency department was appropriate, and G remains very grateful that the doctor double-checked with the family about the care her father wanted, she was the medical POA, and Mr. Z had and advance directive. The family feels when they were told there was “nothing to be done," the doctor should have handled it very differently. Key missing components from that visit included allowing the family time to live with the news, even for just 10 minutes. There was no mention of what Mr. Z’s quality of life would be like once home or the burden of care on elderly Mrs. Z. No mention of what to expect in the days ahead, no offer of palliative or hospice services. No offer of any additional help for her elderly parents. G thinks that this doctor thought his job was to prescribe chemotherapy, and when that was done, he was done.

With 11 years’ hindsight, G wishes that the cancer doctor had better prepared her father and the family for the impact the disease and the progression cancer would take. G

wonders if a more detailed plan would have helped her father and the family. She sees that a plan could have been made to fight cancer and then a plan to be comfortable as possible with cancer and then a plan for the end. G feels it was the cancer doctor's job to provide resources and direction to the family, not just dismiss her father when the "fighting" of the cancer was over. Mr. Z and his family's story provide clear examples and opportunities for bioethical principles to guide doctors and caregivers. Mr. Z clearly expressed his autonomy with" I am done with hospitals!" I am sure his wife and daughter would have preferred more discussion at the moment in time. Mr. Z's view may have been that he made an advance directive, and his wife and children knew his desires, and that doctor said he was done, so Mr. Z was DONE. G wishes there was more justice for her father in the entire process. She cannot help but feel that the end of her father's life could have been extended and less traumatic had they all been made aware of any resources available to them. Truly, ANYTHING! Not just "go home and enjoy life." A little beneficence would have gone a long way for this family, and their final journey with their dying loved one. G does believe that her father and her family were harmed if not physically, then emotionally, by the lack of offered services and support. In hindsight, she realizes that her mother's dementia was in the beginning stages during her father's dying and support services may have helped recognize this and lessened the burden of care for her mother and allowed her mother and father to have some quality time together while they both still could. Looking back, G wishes her father had shared more about how he was feeling, and if he was in pain or had any discomfort, she thinks he might

have opened up to the right support person who was not the person he had to be strong for like his wife and daughters.

All Done But the Dying

Mrs. H's story could not be more different from Mr. Z's. Mrs. H had an advance directive that was repeatedly not honored. Her family was given no justice, her autonomous wishes were ignored, and opportunities for beneficence were lost during Mrs. H's long dying process. Mrs. H died in her daughter's home surrounded by her family with her daughter in bed with her so she wouldn't be scared. It was a very long road to what sounds like a peaceful death. She had been sick for about eight years with senile dementia, type A, possibly Louie Body type; she had no comorbid conditions. She initially became confused and stopped taking care of herself, and changes in her behavior became evident. Over the next eight years, Mrs. H. moved through many levels of health care: from being cared for in her own home with aids, her daughter's home, assisted living, various nursing homes, on and off of hospice care and finally in her daughter's house where she died. Her daughter spent all of her extra money caring for her mother, cut back her work hours to care for her herself, and went without seeing her husband for many weekends while she cared for her mother. Mrs. H. went from eating normally to existing only on BOOST for a very long time. At the last nursing home, she suffered a hip fracture, shoulder fracture, and UTI; she was on morphine for pain shortly before she died.

During one hospitalization, doctors wanted to place a feeding tube. Mrs. H.'s advance directive clearly stated that this was not in her wishes. Her family was told that her advance directive meant nothing and that the family needed to consent to a feeding tube. This made Mrs. H's daughter very uncomfortable and caused the family great distress. This has influenced her opinion about advance directives; she does not have one and has no plans to create one. Her experience with the doctor telling her that her mothers' advance directive meant nothing had left her feeling they are not necessary and why bother completing one when it will be ignored.

Two days before Mrs. H.'s death, her daughter noticed she was shutting down. Her daughter stayed in bed with her so she would know her family was nearby and not be scared. At some point the night before she died, her daughter noticed that she had a stroke and never fully regained consciousness. Mrs. H. was no longer making urine, and bodily functions were shutting down, she died surrounded by 4 of her daughters.

The daughter I interviewed, R, had many observations, the most striking to me was “one mom can care for seven children, but seven children cannot care for one mom.” R has no regrets surrounding being her mother's primary caregiver over the eight years it took her to die. She is forever grateful that her mother made her wishes know to her whole family, so there were no disagreements within the family when care decisions were needed. She remains sad, very sad that she was told her mother's advance directive meant nothing.

R had mourned her mother many years before her actual death and wishes that there were more services available sooner to those caring for ill loved ones. Long before

her mother required hospice care, she needed round the clock care for everyday activities, and R feels her quality of life could have been better had there been more services available. Some lessons R learned through this process: nursing homes with missions are generally better facilitates, Certified nursing assistants are a very important part of care delivery in our country and are undervalued and underappreciated.

Throughout the eight years from diagnosis to her mother's death, R had to learn that no new level of care lasted long, care needs were changing every 3 to six months, there needs to be a more comprehensive resource for family caregivers: like a state handbook or a resource manual when patients are first diagnosed with important information to help guide families for instance; R was unaware that nursing homes are allowed to discharge you when your money runs out.

Many times throughout Mrs. H and her daughters' story, there were missed opportunities for beneficence and justice. The indignity of being discharged from a care facility due to lack of money after having spent 18 months there as a patient was almost too much to bear. The lack of resources between diagnosis and hospice is vast and presented many missed opportunities for justice for both Mrs. H and her family. The ethics of care sees individuals as relational and interdependent (Vaughn, 2019); this interdependence was lost many times throughout Mrs. H's care. Had R been better educated about her mother's prognosis by her doctors or some other resources she may have been more prepared for the ever-changing levels of care needed and able to educate the physician who told them her advance directive would not be honored how important it is was to follow her mother's wishes. I personally am saddened that R. is now so

against having an advance directive due to this experience. I will continue to try and educate R about the need for and benefit of advance directives.

Not Prepared to Die

Mrs. Gonzales had a heart and lung transplant eleven years ago, and she considered this her second chance. She was able to go back to work as a teacher and was living life to its fullest, enjoying her dogs, her children, and grandchildren. During those ten years, she had the usual setbacks of a post-transplant patient; colds hit her hard, the fear of her body rejecting her new organ was ever-present, and she was not getting any younger at 65. While at her ten-year checkup, she shared with her doctor that she sometimes felt short of breath and that it was happening more often. Even though Mrs. G. had lived a long time after her transplant, she was nervous about going into rejection for her heart and lung transplant as it is always a concern. After the usual tests for rejection, the doctors ordered a CAT scan that showed a mass in her chest.

The diagnosis was cancer, which is common for transplant recipients. Her cancer turned out to be large and inoperable due to the location in her chest, pushing on her lungs and esophagus. After several rounds of chemotherapy, a palliative care consult was ordered. Mrs. G was devastated and had not considered anything but continuing to treat the cancer. It was explained that all treatment at this point would be palliative and not curative. Hospice was offered and rejected. An advance directive was discussed and left on her bedside table. She had been divorced for many years, and her last relationship had ended while she was waiting for her transplant. Her children were grown now with

families of their own and not able to help more than just popping in. No one in her family was financially stable enough to take any time off from work to care for her. Her oldest daughter was two thousand miles away in the midst of a divorce and custody battle and had yet to be told of her mother's diagnosis. Mrs. Gonzales had always been fiercely independent. The idea of giving up after having survived to wait for her transplant was foreign to her. She felt as though her medical team had given up on her, the transplant doctors didn't round on her anymore, and only the cancer doctor and the palliative team continues to see her. She was reluctant to share her current state with her children fully. While there were grown, they each had their own problems. After much thought and many conversations with her friend, she decided to fill out the advance directive and called the palliative care team to let them know. Her friend was with her and was named as her spokesperson should she not be able to speak for herself. Mrs. Gonzales shared with the palliative care team, a social worker and physician that she was feeling abandoned by the other care teams and that everyone had given up on her. The palliative team shared that they were here for her while she remained in the hospital and would help set up care for her at home.

There were many tears after the team left her room. Tears of fear and hopelessness. Her friend later told me that Mrs. Gonzales felt that after fighting and never considering the end of her life due to getting a second chance with a transplant, she just would always fight whatever medical setback she had. Having no options for treatment had never occurred to her before this diagnosis.

Had Mrs. Gonzales' transplant team given up on her? Transplant patients do not routinely have an advance directive. If you are listed and waiting for a transplant, you are clearly opting to have everything done should you become sicker. Once you get your transplant, advance directives are not offered or discussed. Continued treatment is the only choice. I have witnessed this lead to very difficult conversations like Mrs. Gonzales'. Patients are stunned when continued treatment is no longer offered. Families are equally blindsided. To answer why this occurs would be another thesis. For now, I will just say that the consensus is that if you receive the gift of an organ transplant, continued treatment is the only acceptable plan.

Beneficence says that we should do good for others, and non-maleficence asks that we essentially do no harm. Mrs. Gonzales felt harmed by having never been asked her wishes for the end of her life, until the very end. Her friend felt she was harmed by no further treatment options and little time to consider the overwhelming diagnosis. This situation is a great example that education about advance directives needs to start much earlier in a patients' journey, be it for a transplant or the birth of a child. Information needs to be shared and repeated, so it is not so shocking when it is actually needed.

Mrs. Gonzales went home, initially without any hospice services. Her 21-year-old grandson moved in to care for her, and when he could no longer care for her, she went to an inpatient hospice and died within three days.

Hoped for More Time

Barbara was a very pragmatic woman with a plan for everything. In 2006, at the age of 56, when she was diagnosed with Non-Hodgkin Lymphoma, she and her husband, David, completed advance directives detailing the care they wanted at the end of their lives, thus assuring their autonomy. Throughout the 14 years, she was ill, and her cancer would come and go many times. It would be in remissions for years and then come back in new locations. She sought a variety of treatments from chemotherapy and radiation to a bone marrow transplant to the removal of most of her intestines.

Barbara and David had retired from New Jersey to Myrtle Beach, SC, while her son lived in PA, and her daughter remained in NJ. All of Barbara's cancer treatment was carried out in South Carolina. Looking back, her daughter, Kari, realized many inconsistencies about her mother's cancer treatment. First, for many years her mother was only getting blood work to see if the cancer returned, not any type of scan. Second, her parents were aging and possibly not hearing all the medical information, not hearing it correctly, or just plain not understanding it. Kari believes that if her mother had received care near her, in NJ, it would have gone differently, and she may have had more time with her mother, and her mother would have gotten to meet her first grandson instead of dying shortly before he was born. Once Kari realized the shortcomings of her mother's care, it was too late.

In April 2019, Kari and her family were visiting her parents for spring break. Kari knew when her mother was not at the airport to meet them that she must be in bad shape. The moment she saw her mother with a walker and legs so swollen she could barely

move them, she knew her parents had been keeping the progression of her mother's cancer from her. The next day, Barbara told her daughter, "I think I am dying." Barbara was more interested in cuddling with her grandchildren than speaking about her current medical condition. Barbara declared they are having Domino's pizza and Burger King for dinner as that is what she has a taste for, her family make fun of her as they considered these choices to be the worst possible for pizza and burgers. They ate, had a goodnight, and all went to bed fed and happy.

At 6 am, her father wakes her up and tells her he is taking Barbara to the hospital since she has been vomiting all night. The granddaughters were scared; they had lost several great grandparents in the last year. They knew about the cancer and had a ten and 13-year-olds understanding of it. Although in pain, Barbara rallied for her grandchildren and told them, "I'll be back by dinner." She did not come back. Around lunchtime, David called and told Kari that it was not looking good, there was a really big tumor, and they were consulting surgery to see what could be done. Later that day, David came home and told Kari that the surgeon said there was nothing that could be done for Barbara. At the time, Barbara was unaware of this news, as she was still recovering from surgery.

In the morning, she was told by her husband. She did not accept this information and was certain there was more that could be done. Unfortunately, the tumor was strangling what was left of her intestines and was too big to remove or operate. Barbara was stunned while she had no fear of death as she knew she was going to heaven. She just wanted more time with her granddaughters and to meet her first grandson, who was due to be born the next month. Her son and son in law had been called and were traveling

to SC, as was her sister and a few other family members. Her granddaughters were told, they were sad and scared. Barbara remained stunned, never thought it would happen so quickly, just wanted more time with her family, but took comfort that soon she would be pain-free and be with Jesus; this gave her great comfort.

After fourteen years of cancer treatment, hospice care was finally mentioned to Barbara and her family. It was explained that she required more care than could be carried out at home, and Barbara was adamant; she did not want her family to be her caregivers, her dignity was essential to her. They were still in denial that death would come quickly. Soon Barbara began to decline further; David signed papers to move her to an inpatient hospice facility.

Barbara was moved that evening. She perked up, wanted her daughter to make her favorite lasagna for her to eat. Barbara ate that lasagna with gusto and shared it with the hospice staff. Many more relatives arrived, some welcome, some not. Barbara seemed to rally for a second night, eating more lasagna and shrimp. Kari noticed her mother was starting to get confused and more tired. She began refusing care and not wanting to be bothered. Kari stayed the night with her mother, and it was the last time her mother was awake and aware. Morphine needed to be increased to keep the pain tolerable.

Barbara died two days later alone in her room while her family was in another room. In the preceding two day's family members came and went, all the while, speaking with Barbara even though she could no longer respond. They played worship music that Barbara loved, her son, daughter, and husband each had private time with her to say their final words.

Kari is very grateful that her mother completed an advance directive and that it was followed, no machines, no invasive surgery that would have only lead to more suffering. The family was grateful for hospice, but wondered why it took fourteen years to mention it and continue to wonder if services were provided sooner would Barbara have had a better quality of life and more life. They appreciate the hospice staff but were not prepared for the sights and sounds of Barbara's last days, and some family members continue to struggle with this. Kari wishes that there was more open communication with her parents throughout her mother's illness and more descriptive information from both the last hospital stay and hospice about what to expect during her last days. It appeared that the trajectory of her mother’s cancer was never fully explained or understood by her parents.

Policy Suggestions

I do not believe that education about advance care planning should be left just to the medical field; the more the public hears about advance directives, the more it will become familiar and be normalized. One way this can be accomplished is to make it a question on each states driver's license/identification card application, just like the question for organ donation. Once allowed, each state could have their approved Advance Directive form available for people who answered no, as yet another educational tool. People could be advised to follow up with their healthcare provider. I spoke with an emergency department nurse, and she shared that they do check the patient's driver's licenses to see if they are an organ donor if they are unable to tell the staff themselves. This behavior appears to be already normalized, and adding one more question should be easy. Now all I need is to find a legislator to take up the cause.

In January 2016, Medicare began reimbursing physicians for counseling patients about advance directives and end of life care. This billing code is underutilized, and some physicians I asked did not even know it existed. A study published in the Journal of the American Board of Family Medicine utilizing data from a single academic tertiary care center in Iowa from January 1, 2016, to September 19, 2018, showed that the CPT 99497 for initial advance care planning was utilized only 17 times in 33 months. I find it hard to believe that there were only 17 opportunities to speak with patients about end of life care at such a facility. Barriers noted in this study included a lack of time for such conversations and insufficient training for providers. A wider campaign needs to be

undertaken to increase physician's knowledge, and better training needs to occur to help physicians be more comfortable with these crucial conversations. This billing code also needs to be expanded so that other disciplines can utilize it, such as social workers and therapists. These steps would ensure that patients are hearing the same message repeatedly and understand the importance of their desires for end of life care be heard.

All health insurance companies should be mandated to provide advance directive information with all mailings sent to consumers, and every insurance website should have a prominent space for advance directives information with a live chat person available for questions.

National Healthcare Decisions Day began in 2008 by Nathan Kottkamp to provide clear, concise and consistent information on healthcare decision-making to both the public and providers/facilities through the widespread availability and dissemination of simple, free and uniform tools (not just forms) to guide the process (conversation project). It is only in the last few years that I had heard about National Healthcare Decisions Day, and this important initiative needs to be part of all new employee orientations, in particular in healthcare institutions. All employees should have at least a basic knowledge of this and be able to provide patients with resources.

At the local level, TUH could begin the system-wide campaign that was implemented with great success in La Crosse, Wisconsin. "In 1991, local medical leaders headed a systemic campaign to get medical people and patients to discuss end-of-life wishes. Within a few years, it became routine for all patients admitted to a hospital, nursing home, or assisted living facility to sit down with someone experienced in these

conversations and complete a multiple-choice form that boiled down to four crucial questions. At this moment in your life, the form asked:

1. Do you want to be resuscitated if your heart stops?
2. Do you want aggressive treatments such as intubation and mechanical ventilation?
3. Do you want antibiotics?
4. Do you want tube or intravenous feeding if you can't eat on your own?

This campaign could be instituted at TUH and other city hospitals, it would take time and effort and some money, but the benefits outweigh the cost. "Within five years, 85 percent of La Crosse residents who died has (sic) a written advance directive, up from 15 percent." (Gawande, 2014, p. 179). There were other benefits as well; caregivers knew their patients' wishes and families were much more receptive to end of life conversations, and much less money was spent on end of life care.

Community-Based Ideas

There is a growing movement called DEATH CAFES. These provide an opportunity for people to come together and discuss death. It is not meant to be an advice session but more of an exchange of ideas with likeminded people. Cafes are not always a physical location; they are more of a pop-up event. Death Cafes were initially started by Swiss sociologist Bernard Crettaz in 2004. However, Jon Underwood is credited with founding the Death Cafe movement in 2011. I was pleased to find many meetings available in the Philadelphia area. Death Cafes could be a great, non-threating way for

people to speak about their concerns and fears about death, and as mentioned in the article, the conversations frequently turn to how to live our best lives now (Magra, 2017).

Death Doulas are also a growing field for emotional support and education during the final stages of life. (Christianson, 2020) They are non-medical support for families and dying patients. They are often the eyes and ear for hospice workers. They can also offer grief support and education for families about the dying process. In my interview with Kari, she stated that she wishes she knew the sights and sounds of death. It was very upsetting to her and her family; they thought her mother was suffering. A Death Doula would have better prepared them and provided support.

CONCLUSION

Through my interviews and research, I have shown that having an advance directive does make the end of life better for the patients, loved ones, and the staff caring for the patient. Time and again, authors and my interviewees have shared that knowing the care loved ones do and do not want decreases moral distress for caregivers and increases opportunities for loved ones to be fully present during end of life.

What continues to be needed is greater access and knowledge for all. Providers need more education and training to increase knowledge and comfort level for these crucial conversations. Patients need greater access to care and that care needs to include opportunities to increase health literacy in general and specifically advance directives and all that goes into completing one.

Also required is access to healthcare providers who will take the time to ensure a complete understanding of the importance of sharing wishes and desires for end of life care.

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