STATISTICS SHOW ONE IN EVERY PERSON DIES, LET'S TALK ABOUT IT

A dissertation submitted to the Caspersen School of Graduate Studies
Drew University in partial fulfillment of
The requirements for the degree,
Doctor of Medical Humanities

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Madison, New Jersey
May 2017

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ABSTRACT

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Doctor of Medical Humanities by

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The Caspersen School of Graduate Studies
Drew University May 2017

Medicine has changed from generation to generation. Introduction of treatment options as well as technology influences have changed many facets of the medical field. These influences have greatly impacted how death occurs. Often death is now something that can be predicted and ultimately processed differently. Due to these changes, medical professionals now have a new opportunity to enhance the death experience for their patients and the patients' loved ones. This critical opportunity can be found in how death and dying wishes are discussed within the doctor/patient relationship. If the medical community obtained the skills to have better end of life dialogue, both emotional and physical suffering of their patients can be minimized. The history of end of life care and the modern care abilities play a role in how we should move forward with this challenge. There are certainly influential factors, such as gender, religion, marital status, and culture, to name a few, that make the end of life conversation complex. This paper will discuss those factors and highlight how important it is to remain sensitive to them. It will support how crucial this opportunity is to ultimately make death, which is now often a process, a more positive, peaceful experience. Education and skill abilities are a focus of this paper

as a means to bettering the medical environment’s role in the death experience. We as medical professionals need to actively improve how we talk about death and the tools which can be offered to assist in this development. Death is an event all humans will encounter, both with loved ones as well as their selves. Medicine will continue to grow and change, but we must strive for growth in all aspects of medicine, especially regarding the end of life process and death conversation.

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Acknowledgments

This paper would not have been possible without the unconditional love and support from my entire family and loyal friends. It is necessary that I take the opportunity to personally thank those special individuals who made the extra effort which allowed me to truly follow through this journey all the way to the end.

First I must thank each of my hospice and palliative care patients and their families. Without their inspiration the entire concept of this paper would not exist. It was their struggles and the love they showed for each other and life, that drove me to want to fight for better end of life communication. With that, I must address the end of life professionals I have had the pleasure of working with throughout my career. It has been through their passion, compassion, and strength that I have learned to be the professional I am today. A special thank you to my mentor, Laura Entwistle. You sought me out, so many years ago, and started me on this journey. It was your ability to see my potential and your unwavering confidence in me that started me on this beautiful path. It has been through your experience and through your constant teaching that has allowed me to flourish in this field.

To my advisor, Dr. Philip Scibilia, for directing me down the scary dissertation road and trusting that I had the ability to find my own way.

To my readers, Dr. Phil Linfante and Dr. Nicole Safonte Strumolo, I am beyond grateful for the time you took to share your knowledge and expertise with me. Nicole, thank you for jumping on board when I needed you most. Both of you not only read this paper, but also made sure to have the same level of pride in it that I do. I have always

admired your accomplishments and intelligence and today I find you inspire me even more.

To my editors, Luisa Frey and Michele McKenna, thank you for allowing me to benefit from your craft and for taking the time to help me perfect this paper. I knew that by putting it in your hands, I need not worry out the outcome.

It is impossible to list those I am grateful for during this process and always without mentioning my family. I start with my father, John Longo. You have always had this amazing ability to use your endless confidence in me to encourage me to grow and challenge myself. I look at your many life accomplishments and success and see that you are the foundation of my drive to be better. I thank you from the bottom of my heart for never giving up on me.

To my beautiful mother, Janet Longo, for always being behind me not only as my cheerleader but to pick me up every time I fall. I thank you for seeing me at my deepest levels and helping me to be proud of all of me. Thank you for believing there is nothing I can’t do.

To my brother, Nicky Longo, I thank you for being my constant reminder to find my own confidence and always show honest pride. For all those times when I am blind to the positive, you always find a way to pull me back to reality while pushing me to where I need to be.

Thank you to my loving and loyal husband, David Stellato, for standing strong beside me and for being there to wipe my tears, calm my nerves, and deal with my frustration. Thank you for your love and for our family that drives me to want to be a better version of myself. I know there is no one else that is as happy as I am that this paper is completed, even if it is because you will no longer have to deal with my dissertation anxiety!

During tough experiences, I have learned that it isn’t only blood relatives who define family. So, to my soul sister, Melissa Carsillo Malfettano, I am grateful for the constant inspiration you share with me. I thank you for listening and always knowing just what to say, for believing in me when I can’t believe in myself and for being my strength when I can’t seem to find mine.

Finally, to my precious baby girl, Adelaide Jane, may you always reach for the furthest stars, remember to use your love, passion, heart, and pride everyday as you touch those dreams. Never forget that I will forever be in your corner as your number one fan. May you find your happiness and remember to live it always.

Introduction

Life is full of events and experiences that build our character and shape the individuals we become. Life events such as first steps, our first kiss, graduation, moving out of our childhood home, getting married, and starting a family are some of many such events. Each of these experiences require us to individually process these events and make subsequent decisions. Some of these decisions take time and thus, our morals and values are challenged. The decisions we choose to make, influence our being as well as impact our life experience. Some of these events are truly what some of us live for. How many people have you heard say, “My children are my life,” or “My education started my career which provided me the life that I love?” No matter what decisions we choose to make throughout our lives, there is one event we all will experience; one that I did not mention in my short list above. That event is our death. Each of us, no matter what age or where we are from, no matter what our education, marital status, wealth, etc., will be faced with death at some point. I don’t know about you, but I have yet to meet anyone who has made it out of this life alive! This paper will focus on death, the dying process, and how medical professionals must gain knowledge to help improve how patients and families experience death. It will highlight the roles that medical professionals, as well as timing, play during this delicate process. I will discuss how thorough, appropriate conversation regarding individual death wishes can enhance the dying process, as well as avoid unnecessary physical and emotional suffering. To support my arguments, I will address the generational changes in medicine and how we die today. Supportive research surrounding influential factors such as culture, gender, religion, ethnicity, and marital status will also be included. I will address the impact of end of life care options and service supports. Finally, I will emphasize the importance of proper end of life education for all medical professionals and the current need for great improvement in this field.

Knowing that every human will die in their life begs the question of why we don't put emphasis on the decisions that impact that experience. Like other life experiences, our death can too allow for growth and individual choice. This becomes a very interesting concept when today's generation of medicine is added to the equation. Treatment, medicine, and care options have truly developed and greatly influenced the event of death. Due to these factors, the idea and experience at the end of our lives is much different today than one hundred years ago. In my opinion, death has gone from a straightforward event to a complex process. Yet I believe these changes allow for a positive influence. This allows us as humans to often be an active part of our death and how it may transpire over time.

Society has even created documents to allow for our individual wishes to be stated, written, and hopefully followed through with as the end is near. Through the years, legal documents like living wills, advance directives, and DNRs have been an additional factor in the end of life equation. I feel the implementation of such documents supports the belief that our deaths should be directed by us individually, just as the rest of our life has always been.

As a hospice counselor, the issue of death as a process is a passion of mine. I have advocated for many individuals to become an active part of their dying process. I continue to witness so many patients suffer more because they were not given the appropriate opportunity to be included in the decisions being made at the end of their lives. I have observed a number of reasons behind this exclusion. Those reasons range from religion and culture, to family control and emotional denial; but there is one cause that I feel impacts the end of life process more than any other factor. I believe that it is our lack of end of life conversations with each other that shadows over most end of life experiences. I believe that there are a number of individuals who have a responsibility to join the end of life discussion, including the patient themselves and their family and friends. However, the individuals who I consider to be the most responsible are the medical professionals. I truly feel that as a trained medical professional, especially physicians, it is our duty to appropriately initiate these difficult but crucial dialogues. The word dialogue in end of life narrative is exactly what this exchange should be.

I also believe that it is only fair and right to start this dialogue with the patient. Like each of the decisions that have created their life experience, the decisions made in regard to their end of life process should start and end with them. I believe it is our human right to be given a choice in how our end of life experience proceeds if the situation allows.

Of course there are situations where death is sudden, unexpected, and rapid. For the purpose of this paper and my argument I will be referring to chronic and terminal illness when discussing the end of life process. However, it is important for me to note that even if death occurs abruptly, for example a car crash or heat attack, I still believe it is the duty of the medical professionals to have the end of life wishes conversation long before such an event. Perhaps such a discussion should be part of the professional’s first assessment during the patient’s first encounter with them. It can even be a topic discussed by primary physicians during yearly physicals. Resolution does not have to be part of the initial conversation and there may be a large number of individuals who don’t feel comfortable with this initial conversation, especially if they are fairly healthy. End of life wishes should still be a part of a medical professionals' interest, because sick or healthy, we don't ever know when a patient will have an accident or become sick. Starting this dialogue gives the patient the human opportunity to just think about their wishes, whether the initial discussion transpires to clear choices or not.

When it comes to chronic illness and terminal diagnoses, my opinions become even stronger. In my experience, I have observed that end of life conversations absolutely occur too late. With today's technology and medical advancements, professionals have a clearer basic understanding of disease and a disease course.[1] For that reason I believe there is no valid excuse for why end of life conversation occurs so late.

I also believe that a negative consequence that comes from this lack of discussion is the risk of avoidable suffering for the patients, and subsequently their loved ones. I have witnessed a large number of individuals suffer a greater degree because of their limited knowledge of their disease and its typical disease course. This limited knowledge strongly influences how they will cope with the end of their life. For example, how can we expect one to properly facilitate closure with their loved ones if they don't have the truthful facts about the time they have left on this earth? If a patient believes that they have years, instead of months to live, because the medical professionals have not been clear and honest, the patient may not take the appropriate time to make plans and share

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[1] Cathy Siebold, *The Hospice Movement: Easing Death's Pain*. New York: Twayne Publishers, 1992.

their personal emotions and wishes. Those plans can range from traveling to the one place they always wanted to visit, writing individual letters to their children, settling their finances, or even prearranging their burial wish. These are just a few of many actions that I believe must be faced if one is going to have a positive, peaceful end of life experience. I know you are probably saying "positive death experience," is there really such a thing? Absolutely, death is hard, it is painful; it is painful for the loved ones, the patient, sometimes even the medical professionals who have undoubtedly built meaningful relationships with the patient and family. Talking about death is not going to eliminate all pain and suffering, but I believe that it can and will decrease the emotional residuals. Death can be experienced with dignity, strength, and most importantly peace, but I truly feel the only way to fulfill this potential is to TALK about it.

Bear with me here: since I'm a visual learner, I feel it necessary to colorfully illustrate a hypothetical example of how end of life dialogue can influence all parties when death is imminent.

One spring afternoon George and his sister Becca were sitting at the dinner table discussing the tragic death of Rob, a childhood friend who recently died after a brief, grueling six month battle with pancreatic cancer. Becca was discussing the details of their friend's treatment and how difficult the decision was for him to discontinue the aggressive route and accept end of life care. He had a wife and two young children he was terrified to leave behind. He attempted to get his affairs and finances in order as best he could at the young age of forty-four. Becca recalls the conversation she had with him regarding these affairs and the legal process. She explained to George how important Rob's medical wishes became, especially at the very end. Rob's wife frequently verbalized that she would not be able to just “let him go,” without attempting resuscitation. Rob spent many hours gently explaining to his wife why she needed to accept his wishes and let him die with dignity. He illustrated a picture of his children witnessing him receiving CPR on their living room floor. He knew that a sight like that would burn a permanent picture in the minds of his nine and seven year old boys. He also felt the masculine pressure to show them true strength, and instead leave a lasting fatherly impression on their young minds. Rob continued to remind his wife that resuscitation does not equal life and living. In his mind he knew his body was failing and he knew his time was near, and prolonging it was not going to help anyone, nor was it going to undeniably provide him a second chance at a full life. Fortunately, with the support of his friends and family, Rob’s wife was able to accept the idea of letting him go. He was admitted to the hospital with an infection, fully aware that it was his time to move on to what he believed to be the next life. Rob chose to enter the hospital and take his last breaths there to protect his wife and children. It was his hopeful that he would go at night once his wife had returned home to keep her from witnessing the end. Rob’s wishes all came true. He left this world peacefully and comfortably. Though, he was not alone, he was in the company of one of the finest oncology nurses he could have asked for.

This detailed, emotional, real conversation between George and his sister really opened George’s eyes to the reality that life can be short and fleeting. George is a healthy, active young man. He truly has never had any real reason to think about his future death experience. Outside of knowing that one day he would die, he chose not to think about it. In his mind he would hopefully one day fall in love, have a family, travel, get old, and die when he was elderly and ultimately good and ready. What we know about death is its inconsistency with this narrative.

Becca watched George’s focus slip from their original conversation and she couldn’t help but ask him where his mind was. George openly stated that he realized he needed to make some vital decisions and take appropriate legal action to make sure his wishes would be followed through with, if, God forbid, anything was to happen to him. At this time George was a single man and he was dating a young woman but the relationship was very new. He realized that if anything was to happen, legally, the medical decisions would fall on his parents. George knew that his distraught mother and father would not know how to proceed with critical medical decisions. He also believed that just having a verbal discussion with them would not be sufficient enough.

George felt very strongly about his wishes. Deep in his heart he knew that under no circumstance would he want to be left on any machines to live for him. George was a man’s man! He was a construction foreman, he boxed as a way of keeping in shape, and always enjoyed a good intellectual conversation, especially about politics. George knew that if he could not live the life he lives today, he would want to be let go. George shared all of his personal feelings and wishes with Becca that day, in great detail. Becca even shared her feelings about what she thought her medical wishes would be. She did not have as clear cut feelings the way George did but she respected her brother’s decisions. She knew that George likely would not be happy if he could not physically squat 200lbs or challenge someone’s naïve political views! George knew right then and there that Becca would probably be the best person to appoint as his medical proxy.

Shortly after their conversation George made a routine doctor's appointment. Rob's fate really made George feel the pressing need to get himself checked out as well as discuss his wishes with his longtime family physician. At the start of the visit Dr. Yong went about his common physical examination. He appeared to understand George's need to complete a checkup after the recent young loss of his dear friend. But when George mentioned his interest in creating a living will and appointing a medical POA, Dr. Yong stated that George was too young to be stressing himself with this stuff, especially because he was so healthy. Dr. Yong informed George that if he truly wished to go further with it he could discuss the paperwork with the RN who would be in to take his blood. Again, George mentioned it to the nurse who quickly informed him that a POA form could be obtained from the receptionist at the front desk. However, she also reported that if he was that serious about it he was better off meeting with a lawyer. George did stop at the front desk and received a copy of the POA form from the receptionist as he left the office that day. He stuck it in his glove compartment of his truck and did not read it for another few days.

Once George did read the form he realized that not only was it vague, it also required a witness who is not the appointed guardian, to sign the form before it was valid. At that time George realized that it would be too difficult for his parents to be witnesses while he appointed his sister to POA. He was also concerned it would cause possible relationship issues since he was sure they would be disappointed that he did not choose them. At that time he decided to forget the POA form. George would just make an appointment with the family's attorney.

Weeks went by, George and Becca kept telling each other they needed to make time to sit with the family attorney and both write out their detailed wishes properly. Those weeks turned into months; next thing they knew it was Christmas. Once the holidays came around setting up this meeting was no longer the immediate priority for either George or Becca. George made the decision to push it back until after the craziness of the winter holidays were over. Eventually, it was over a year since the initial conversation he had with his sister.

On a summer Friday night George was out for a sunset motorcycle ride. He thought how amazing life is… how it could change so fast and for the better. George found out three weeks prior that he was going to be a father and proposed to the same “new girl” he was seeing when Rob passed away. George could not be happier when all of a sudden, everything went black.

Becca will never forget the call she received from her father that Friday evening. “Honey, something has happened George. He was in a bike accident, and it’s bad.” Becca rushed to the nearest trauma center where George was taken. She needed to see him and find out what happened.

Becca learned that a young couple, who had been speeding, cut across the center lane around the big bend on the quiet road. George swerved to miss the car, lost control and flipped his bike. The injuries he sustained were severe and medical staff reported that he was in critical condition. Hours went by before Becca was able to see her brother. By then the entire family sat in the waiting room, including George’s new fiancé Ann. So many questions were asked of Becca’s parents and she could see their heads were spinning. By the next day George’s condition was touch and go. He was intubated and connected to a ventilator to breathe for him. Due to severe bone and vascular damage he lost his left leg from the knee down and there appeared to be a very limited amount of brain activity.

Becca was an emotional mess for so many reasons. Her mind was racing just as fast as her heart. Becca knew that George would be so angry if he saw himself in this condition. She still carried hope that things would turn around but as the days went by and the family was pulled into a number of meetings to discuss his condition and the treatment plan, Becca's hope began to disappear and she began to become fully aware that George would never be the same. That's when she knew what she needed to do.

Becca attempted to share George's wishes with her parents, the medical professionals, and his fiancé. She realized that they all listened but no one actual HEARD what she was saying. Eventually, she became frustrated that none of George's loved ones were respecting his wishes. Her mother and father were the legal decision makers and when they did not see eye to eye with Becca's feelings, they began to exclude her from the medical meetings and decisions.

Months went by, George survived a tracheotomy procedure to place a trach in his throat which would remain connected to the ventilator to breathe for him and he had an invasive surgery to have a feeding tube placed. The damage done to George's brain was permanent. He was unable to wake, speak, eat, or breathe on his own. Becca's heart broke every time she thought about George's current state and that vital conversation she had with him a year and a half ago. Becca's parents refused to disconnect George from any of the machines. Eventually George's son was born, George Junior of course. But George was never able to open his eyes and see the perfect little angel he helped create.

Years went by, Becca remained close with Ann and George Junior, and though she continued to see her parents, their relationship was greatly strained. George lived in a nursing home, he underwent a total of fifteen surgeries for a number of complications. All of his hard earned savings and financial support that he would have wanted to go to his family was used for his care. Three years after George's devastating accident he suffered severe complications during a procedure and died on the operating table.

If George had seen his death he would have been devastated with its undignified nature. He would have considered his last three years as just breathing and in no way would George had considered it living. George's parents grew old fast, having to make such difficult decisions. Witnessing their son's decline and death, truly took a toll on them. Becca went through the motions of her life, but she carried such a heavy weighted guilt that left a lasting pain with her the rest of her life. Becca thinks about how different George's end of life would have been if only they took the time to write his wishes down.

Though the above vignette is fairly detailed and demonstrates many of the common concerns with living wills (i.e., the vague documents that exist and the patient responsibility to complete it,) I feel it is important to provide an alternative illustration coloring a very different example of end of life planning. To be fair, it will have a more positive outcome but I need to make it clear, that in my experience, the positive outcomes are not as common as I believe they should be in today's medical climate.

Sharron was a sixty-four year old stay-at-home wife/mother who was known for her volunteer efforts and philanthropist nature. She had a husband of forty years, three adult children, and seven loving grandchildren who were truly the apples of her eye. Sharron was healthy for most of her life. When she was in her late forties she was diagnosed with stage II breast cancer in her right breast. Sharron was advised by her physicians not to be overly concerned. They recommended a lumpectomy and a few rounds of chemo to eliminate the cancer cells. But Sharron was a realist, and what I would call a “tough cookie.” She informed her medical staff that she had too much life to still live and she didn’t feel like messing around. So she opted for and essentially pushed the doctors to agree to do a double mastectomy.

Sharron was well read when it came to modern medicine. She had an interest in medicine ever since she was a little girl. In fact, if she had not gotten pregnant so young she would have become a nurse. However, thanks to a successful husband and her belief in the importance of personally raising her children, she never felt the need to follow her career dreams. Sharron knew that it was less likely for her cancer to return if extreme measures like a mastectomy were taken. Sharron weighed all the pro and cons out before making her decisions. She knew that her body would drastically change and Sharron did consider herself an attractive woman. She also thought her friends and community members would likely judge her appearance. Sharron recognized that some of the people she surrounded herself with were quite vain, but that was not going to stop her from following her strong, educated gut reaction. She also knew that her husband would love her no matter what and she would likely plan for breast reconstruction.

Sharron underwent the procedure. It was successful and she recovered like a true champ. She prepared herself for the next stages of skin expansion and reconstruction. A few weeks after her initial procedure Sharron stood in the mirror. She cried when she realized that she was a different woman. Her cancer was gone and all test results were promising, but she was definitely a very different person. On that day Sharron made the decision that she would not have the reconstruction surgery. She gratefully accepted this new person and felt her current physical appearance was a constant reminder of her life struggles and the strength she knows she has inside. Up to that moment Sharron spent hours processing her life, condition, future, health, and so on. She frequently thought of her wishes but never felt the pressing need to write them down.

Twenty years went by and Sharron's life continued to be happy and fulfilled. She never had another serious medical concern until her sixty-fourth birthday. Sharron knew her body pretty well and consistently felt a throbbing pain and pressure in her abdomen. Sharron knew because of her medical past and cancer history she needed to get it tested right away. She was not at all surprised to learn that she had a cancerous tumor in her colon. True to form, Sharron was ready to fight. Again she opted for the removal of the diseased section of the colon. She also knew that she would not get away without a few rounds of chemo. This time around, she endured three full rounds of chemo. She needed further procedures including an irreversible colostomy. Sharron faced it all with her unwavering strength and faith. She still had life to live. Yes, that life changed in so many ways but she would look into the eyes of her children and grandchildren and knew that she must fight.

Sharron now decided it was time to discuss her end of life wishes which had changed in the past twenty years. During her original diagnosis she would have chosen to limit her aggressive fight, she knew she did not want to be sustained by medical equipment nor would she have chosen to endure what she had already endured. But this time, her family, especially her grandchildren, made her want to fight harder.

Sharron was due for some follow up tests at the local hospital, so she knew she had to play this right from the first step. She asked her primary physician, oncologist, and surgeon as well as their medical assistants and/or nurses to schedule a meeting with her and her family. Sharron knew this was not a common occurrence but she had a great relationship with these individuals and she also was quite persistent. Therefore, Sharron was not surprised when all physicians, physician's assistants, her three children, and husband were present. Nor was she unprepared.

Sharron candidly and firmly reported what her wishes were. She wanted to fight. She was aware of what her future might hold and that specific treatments may not provide her with the life she would have initially chosen. She was not about to sign a DNR, nor was she going to stop the aggressive treatment, even if she only had months to live. After this detailed patient driven conversation, Sharron went straight to her attorney to write out her will and wishes. She also made sure all necessary medical documentation was completed before the meeting adjourned.

Next Sharron started to plan the next chapter of her life so that she had no regrets. Again, the cancer found ways to affect that life map, but Sharron was not giving in. She planned a family trip to Europe but she suffered rounds of chemo right before the trip, causing some brutal side effects on the trip. But the family never heard Sharron complain, because she was not ready to stop living her life. Sharron lost tens of pounds during her battle, and her cancer spread. She became weak, frail, and susceptible to the tiniest of infections. Sharron kept up the fight, but two weeks before her granddaughter's high school graduation, Sharron went into respiratory distress. The physicians told her she needed to be intubated and it was very likely she would never be able to breathe on her own again. They discussed her wishes briefly, but knew Sharron was not ready to let go.

Sharron was intubated and two weeks later, reluctantly she used a wheelchair down the aisle to watch her granddaughter graduate. Sharron would regularly speak with individuals who asked her why she still fought if life was going to be so difficult. Her answer was “because life is still worth living.” Sharron knew that when she had had enough, and life was no longer worth the discomfort, then it would be her time to let go.

Months went by and Sharron was still fighting, but eventually her love for her life was being outweighed by the pain and suffering. Sharron was at her weakest and all the doctors began to recommend comfort measures and to stop all aggressive treatment. Sharron fought them for one more round of chemo. She knew it would be her last but she needed just a little more time. She did make the decision to sign a DNR after her oncologist reported that ethically and personally, he did not have the heart to resuscitate her again, knowing she would not survive the intervention a second time.

On that day Sharron sat down on her back porch and began to write a letter for each of her family members. She still had so much she needed to share with them, and for her grandchildren there were lessons she needed to teach. She knew that writing them down was the only way they would learn these lessons from her, because their future together was soon to come to an end. It took Sharron one day to write a letter for each child and grandchild, and two days for her husband’s letter. On the thirteenth day, she placed them in a shoe box and informed her husband that after she was gone he was to hand them out. On that day Sharron enjoyed her coffee with her husband, watched her favorite shows, and hugged her children and grandchildren a little harder. She laid in bed next to her husband, held his hand, told him she loved him, and thanked him for the perfect life they made together. She shut her eyes in pure peace. Sharron had not one regret; she actively took what she knew was her last breathe and consciously let go.

The next day all of her loved ones as well as her medical caregivers learned of her passing. Ironically, no one was sad. A few days later all of Sharron's friends and family joined together at the local bar (one of her favorite spots). They drank pitchers of cheap beer (also her favorite), they danced and sang to the jukebox and they truly celebrated Sharron. Don't think she didn't have a hand in that celebration, because she included the details of that event (including a cash down payment for the room) in her letter to her husband.

As you can see every story is different when it comes to one's end of life experience, but that does not mean that everyone should not have the same opportunity to play a role in their end of life process. I can write story after story, each with a different angle as well as different outcome. The above examples are hypothetical, but very realistic depictions of what can happen. Yes, there are a number of factors that will ultimately affect each dying process.

As shown in story number one, the medical professionals dropped the ball and it eventually had a tragic result. The physician and the RN were handed a perfect opportunity to facilitate a crucial end of life discussion with not only the cooperation, but honest participation of the patient. It is my guess though that this may not be common for the patient to initiate this conversation as openly as George attempted. So when it does happen, it is imperative that medical professionals, no matter what their personal belief, be willing and able to participate in this conversation. Their role can have such a positive impact on the process. Dismissing a patient's interest in this conversation, as well as the importance of the discussion can and will have drastic results. This conversation is never an easy one no matter which role is being played, but in today's medical climate it is vital to assist in a peaceful death.

In the second story, the medical professionals stepped up to the plate and joined in Sharron's end of life planning. Of course knowing Sharron's character it was unlikely she was going to let them off the hook. The important fact to highlight here is that Sharron is the one who initiated the discussion. I am always a supporter of a patient controlling their treatment but I still believe that it is the medical professional's responsibility to start having this conversation. I feel it is the most beneficial when the conversation is addressed by the medical professional for the simple fact that their education and knowledge of medicine should allow them to have appropriate tools to begin a dialogue. Once the discussion has begun, how the patient engages with it will direct the path of the professional's continued end of life discussion efforts.

I also believe it is imperative to have these discussions as early as possible. I feel timing is important because this is a conversation that requires time to be processed healthily. New questions and concerns will likely arise as the discussion progresses. That does not mean that the first conversation is the final conversation. I actually believe the exact opposite. I feel that though the initial discussion may be morbid and uncomfortable, it allows for a very specific and special relationship between the medical professional and the patient. It should allow for a comfort level so that as one's feelings and wishes may change, one feels easier about having further discussions. The other argument regarding early end of life conversation is illustrated pretty clearly in George's case; it's simply because we don't have a crystal ball; we don't know what the future will hold for any of us. Yes, as one's medical condition changes, it is very likely, so will their wishes, like Sharron's wishes changed as her life continued and her family grew. The importance isn't always to have a definitive clear answer to all the end of life questions. Rather it's the dialogue and thoughtful process that is essential.

I think it is easy for individuals to believe that most people just don't think about their death, never mind think about the role they may play in it. Maybe it's my career experience that makes me feel differently about that. I think whether it is openly or secretly, we all have thought about it at some point in our adult lives. We may even have allowed the idea of death to filter into our minds as children. My argument focuses on adults because most young children may not have the life experience or maturity to make these decisions alone. That is not to say if a child is chronically or terminally ill that they should not be included in their end of life experience. I absolutely think that as long as the patient is old enough to form an opinion, and has the capacity to participate, they should be involved in their care decisions. When it comes to adults, I can't say I know any who have not suffered a loss or witnessed death whether personally or indirectly. Even if the death was of their favorite character in an action movie, I believe that when one encounters death, however it is encountered, it is perfectly human to think about their own death. As I have stated earlier and I'm likely to state again, most of us when we think of our death go as far as hoping it is natural, at an old age, and after a fulfilling life is lived. That is my hope for myself and my loved ones, but I'm also a realist. I know that illness and disease are real and common. The world has changed and all of these strides in medicine have curved the path of death, so what's wrong with discussing it?

This is important since today we can direct our end of life road differently than we could have one hundred years ago.

This paper started with very colorful illustrations of only two of millions of end of life stories. I hope I got your attention enough to accept my argument that as medical professionals in this generation of medicine, it is truly our job to appropriately broach the very real dialogue about the dying process. Not only must we be educated on the importance of the conversation, but we must also engage in the process of starting and actually having these conversations in a comfortable manner. Our patients rely on us to help them live the best way possible. They also look to us to help them die the way they choose. It is likely one of the hardest parts of a medical professional's job, but difficulty should not be an excuse. I strongly argue this is a crucial job of any medical professional and it should be a significant focus in the world of medical ethics. Finally, and maybe even most importantly, we need to find a positive and effective way to implement this education, with useful tools to assist our professionals in this daunting task, and with this significant responsibility.

Chapter 1

The History of Hospice and Palliative Care

In this chapter, death and the changes that have occurred with the dying process and with medicine itself will be discussed. It is necessary to highlight the past to help clarify how time and knowledge can affect how we view life, death, and medicine as well as how we experience it. Again I feel an experiential story can help to illustrate the representation of today's dying experience and how different generational factors have influenced the medicalization of death.

Six years ago when I began my career in end of life care I remember having a specific encounter with a family that truly made me think about how modern medicine has greatly affected the dying process. As a hospice social worker I was consulted on an end of life case to offer emotional support and hospice education to the family of a hospitalized eighty-three year old African American woman. The woman had been suffering from metastatic liver cancer and she had been through multiple rounds of palliative chemotherapy. The woman also suffered from a history of minor strokes. During one of the many rounds of chemotherapy she received, she suffered a massive stroke that resulted in full paralysis of the right side of her body and a significant case of dysphasia limiting her ability to swallow. As a result of this neurological event, she was hospitalized and spent a short time intubated and connected to a ventilator. While the patient remained intubated, the family opted to surgically place a gastrostomy tube to provide her with food and nutrition. The patient had not appointed a medical power of attorney prior to her incapacitated condition to make her medical decisions, so all treatment decisions required her four adult children to agree before proceeding with any further medical intervention. It is also important to add that the patient and her family had a very strong Baptist faith.

After the patient was removed from the ventilator her condition stabilized, but she remained lethargic with minimal response, was bedbound, and continued to receive nutrition through the g-tube. After the medical staff's recognition of the patient's slow recovery and limited improvement they felt that her current medical status would most likely be the extent of her recovery and she was ready for discharge. The patient was discharged home with her family who planned to provide her with all her care needs. One month into her care at home the patient, who remained unresponsive, bedbound, and partially paralyzed, became febrile and upon being readmitted to the hospital was diagnosed with pneumonia. During this second admission process it was also discovered that the patient's condition included skin break down and a stage II wound to her sacral area.

This is where I came in. It became clear to the medical professionals that the patient's body was failing her and the feeding tube that was meant to keep her nourished was now most likely causing her declining condition. I was asked to meet with the patient's children to not only offer them emotional support but also to attempt to educate them on the dying process, as well as the negative impact that the feeding tube technology was having on her failing body.

After having multiple family meetings with the children where emotional support and medical/end of life education were key components, the children all agreed to put the patient's health "in God's hands." They did not wish to remove or even decrease the patient's current tube feedings. As a result the patient continued to suffer from increased fluid in her lungs and extreme edema of her arms and legs. After a week, including multiple discussions, the family finally agreed to allow the team of hospice professionals to join the patient's care team and provide comfort measures, but they were still unwilling to stop or decrease the g-tube feedings. The fluid in the patient's lungs continued to increase as well as the swelling of her extremities, causing the patient respiratory distress and extreme discomfort. The patient was placed on a morphine drip for symptom management and after six days on the drip, ranging from three to six milligrams per hour the patient died.

I distinctly remember watching this woman appear to suffer unnecessarily as a result of modern medical technology. I remember asking myself what the family meant when they stated that they wished to leave her fate "in God's hands." How could it still be in God's hands if this patient's life was being unnaturally prolonged because of the aggressive, artificial medical technology used to sustain her existence? I asked myself if this truly was this woman's fate, her life quality was not only limited, but her level of suffering appeared to increase with the consequences of the modern measures implemented to sustain her. Furthermore, the use of technology appeared to increase her suffering, forcing the medical staff to further utilize additional aggressive medical measures; for example more morphine was used to counteract the consequences of the feeding tube intervention. Therefore, I pose this question: does our current medical system and modern technology truly allow for a natural death?

Hardwig looks at the changes society has seen within the dying process by focusing on common death within different generations, with the hopes to get a better view of today's conventional death experience. He highlights that "historically people died in childbirth, war, of accidents or infectious diseases."[2] He continues to report that these deaths where usually amongst the younger generation and were not long, painful experiences.[3] Those who escaped the young tragic deaths died of a failing body normally being taken by what he calls the "old man's friend" also known as pneumonia.[4] The process of these death experiences was cut short due to a lack of treatment for illnesses like pneumonia. These deaths also customarily occurred in the home of the dying individual surrounded by loving family and friends who were all aware and prepared for the passing of the patient.[5]

Today's common death is very different. Hardwig highlights how increased medical knowledge and technology allow for a longer dying process.[6] As a society, we see more "debility, chronic disease, dementia, and terminal illness" as a result of modern medicine/technology.[7] Goh agrees with Hardwig that it is because of these advances in medicine that not only is the dying process different, but the environment where death occurs has also changed. A majority of deaths in today's environment occur in facilities and hospitals.[8] Goh continues to discuss the main purpose of care received in a facility which is to "fix" medical problems and "restore health."[9] The concern with this philosophy at an individual's end of life is that often at this time most of these medical

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[2] John Hardwig, "Going to Meet Death: The Art of Dying in the Early Part of the Twenty-First Century." *Hasting Center Report* 39, no. 4 (2009) 38. doi:10.1353/hcr.0.0151.

[3] Hardwig, "Going to Meet Death," 38.

[4] Hardwig, "Going to Meet Death," 38.

[5] Hardwig, "Going to Meet Death," 38.

[6] Hardwig, "Going to Meet Death," 38.

[7] Hardwig, "Going to Meet Death," 38.

[8] Cynthia Goh, "Medicalization of Dying: Are We Turning the Corner?" *Journal of Palliative Medicine* 15, no. 7 (2012) 728. doi:10.1089/jpm.2012.9579.

[9] Goh, "Medicalization of Dying,"728.

problems are no longer "fixable."[10] In my experience I believe one crucial end of life problem lies here within the focus of treatment. As a medical society, I do not believe that we take the end of life process seriously until we have exhausted all aggressive treatments. Not only do I feel that this care method influences the dying process, I also wonder if these interventions speed the dying process up while resulting in further, unnecessary suffering.

In connection to death and dying in today's medical environment, it is very important to discuss the difference in the definition of death. Prior to 1959, the definition of death was based on the classification of cardiac death. An individual was labeled dead once they no longer had a cardiac rhythm, in other words, their heart stopped.[11] Today there is an additional definition of death: brain death. The Harvard committee defined brain death as "an irreversible coma" in 1968.[12] This new definition strongly influences the dying process and adds a large medicalized component. One of the main reasons for using brain death criteria with a comatose individual is because of the utilization of the medical technology of organ donation. "Heart-beating, brain-dead donors provide the majority of organs for transplant."[13] The medical ability to transplant healthy organs to appropriate recipients has influenced the need for this alternate definition of death.[14]

The medical ability to transfer a healthy organ from one brain-dead individual to another patient in need of this healthy organ is the motivation behind many of the

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[10] Goh, "Medicalization of Dying," 728.

[11] Richard Arbour, "Brain Death: Assessment, Controversy, and Confounding Factors." *Critical Care Nurse* 33, no. 6 (2013) 28. doi:10.4037/ccn2013215.

[12] Arbour, "Brain Death: Assessment, Controversy," 28.

[13] Arbour, "Brain Death: Assessment, Controversy," 28.

[14] Arbour, "Brain Death: Assessment, Controversy," 28.

aggressive treatments performed on brain-dead individuals.[15] If that isn't an example of the medicalization of death, I don't know what is. Just the medical criteria used to determine brain-death alone can cause medical professionals to execute a number of medically motivated techniques and interventions.[16] I believe it important to state that though the process of determining brain-death influences the dying process, and in my opinion eliminates a natural death, I do personally support the use of brain death in relation to the organ donation process. But Arbour makes sure that he highlights in his article that the process of deeming someone brain-dead does take time and may cause increased emotional suffering to the loved ones of the individual and isn't always a failsafe process.[17] He features a case study of a gentleman who was diagnosed as brain dead but by the seventh day after he met the criteria for brain death he was not only awake and alert but following the commands posed by the medical staff.[18] This case illustrates an example of how death is medicalized today and how uncertain our modern process can be when a life is wavering between life and death.

In relation to brain-death, it is important to include a discussion regarding the use of CPR related to the dying process. Timmermans believes that the act of resuscitation alone is the ultimate example of how death has become medicalized and influenced by technology.[19] In his research, Timmermans focuses on CPR related to sudden death situations, but my experience allows me to believe that CPR may also be an influential factor in chronic and terminal illness as well. As Timmermans reports, the research in

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[15] Arbour, "Brain Death: Assessment, Controversy," 28.

[16] Arbour, "Brain Death: Assessment, Controversy," 28.

[17] Arbour, "Brain Death: Assessment, Controversy," 35-36.

[18] Arbour, "Brain Death: Assessment, Controversy," 36.

[19] Stephan Timmermans, "Resuscitation Technology in the Emergency Department: Toward a Dignified Death." *Sociology of Health and Illness* 20, no. 2 (1998): 144. doi:10.1111/1467-9566.00095.

this field is limited but he reports statistics from Cummins' et al. research that "the current estimate suggests that no more than 1-3% of out of hospital cardiac arrest victims live to be discharged from the hospital," and it is believed that "the true percentage is probably even less.[20]

Cummins' et al. belief influences my opinion on how medicalization of death has eliminated the natural dying process.[21] This low statistic references how the dying experiences of these resuscitated individuals are prolonged by the implementation of resuscitation efforts. Though these efforts affect the dying process for the individual and may even increase their individual suffering, there may be a positive side to this medicalized act. Timmermans uses his research on CPR to highlight how the use of these medical treatments may allow for a better acceptance and grief process for the patient's family and loved ones.[22] By prolonging the dying process, the family and loved ones are not only offered the time to emotionally accept the loss of their loved one but they are even provided the opportunity of being a positive influence in their passing.[23] Timmermans discusses how more hospitals today are allowing the family and loved ones to be present during the resuscitation efforts.[24] Here the loved ones are able to be present with the patient allowing an opportunity for conversation, reflection, and emotional closure. Timmermans believes that though the patient may experience an unnecessarily prolonged life, the benefits of allowing for closure is a strong positive influence for the

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[20] Richard Cummins et al., "The Chain of Survival Concept." *AHA Medical/Scientific Statement* 83, no. 5 (1991): 1832. doi:10.1161/01.CIR.83.5.1832.

[21] Cummins et al., "The Chain Survival Concept," 1832.

[22] Timmermans, "Resuscitation Technology Emergency Department," 162.

[23] Timmermans, "Resuscitation Technology Emergency Department," 160.

[24] Timmermans, "Resuscitation Technology Emergency Department," 160.

grief process of those left behind.[25] He also believes there is an individual sense not only from the loved ones but from the medical staff as well that all efforts were conducted to save this individual human life.[26]

As a professional who spends time and energy on the emotional process that comes with human loss I can feel the positive influence of Timmermans' research. When focusing on the survivors and the loved ones it is hard to eliminate the assistance CPR has on the acceptance of and grief that comes with death. But I cannot help but wonder if the patient experiences a level of suffering and pain that can be avoided by removing extreme resuscitation efforts from the equation of death. In my field I feel the need to advocate for the patient's needs and a common wish is to limit themselves from experiencing unnecessary discomfort.

In reference to resuscitation and heroic measures it is significant to include the importance and societal promotion for individuals to complete personal medical advance directives. An advance directive is a document intended to allow individuals to provide directions for their medical care, specifically in end of life situations. The purpose of an advance directive document is to allow a patient to choose the care they wish for, prior to the time when they are not mentally capable of making personal medical decisions.[27] Advance directives have a dual purpose. The first role of the document is to put an individual's personal care wishes in writing regarding multiple medical circumstances. The second role is to provide an alternate spokesperson to assist with medical decisions

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[25] Timmermans, "Resuscitation Technology Emergency Department," 162.

[26] Timmermans, "Resuscitation Technology Emergency Department," 153.

[27] Dan Morhaim and Keshia. Pollack, "End of Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis." *American Journal of Public Health* 103, no 6. (2013): 8-9. doi: 10.2105/AJPH.2013.301316.

when an individual is mentally or physically unable to execute the proper decision making process.[28] These documents can even include afterlife wishes, for example, burial requests, as well as desires regarding organ and body donation.[29] However, Morhaim and Pollack's study exposes that although "60% of individuals 18 and older want their end of life wishes respected, only 1/3 of them have completed advance directives."[30]

In my opinion the simple fact of the current expectation to have an advance directive reveals the power medical influences have on end of life care and end of life care decisions. The focus of the form is inspired by the medicalization component of the modern environment surrounding death. By having an advance directive we as a society are either stating individually that yes, we would like our death to be natural, or no, we wish for it to be manipulated by medical treatment options. When medicine was in its beginning stages there was no need to document our treatment wishes because our options were limited and a natural death was truly our only choice. Even our current medical terminology is changing to bring back the basic understanding of what a natural death is. Morhaim and Pollack report that many facilities are transitioning their Do Not Resuscitate documentation to a document now labeled Allow Natural Death.[31]

It is also essential to discuss the additional motive behind the current push for advance directives. Within the medicalization of death there is also a cost component. Not only is there an increase in facility death rates but there is also an increase in end of life care costs due to the technology advances and the inappropriate use of treatment in

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[28] Morhaim and Pollack, "End of Life Care Issues," 8.
[29] Morhaim and Pollack, "End of Life Care Issues," 8.
[30] Morhaim and Pollack, "End of Life Care Issues," 8.
[31] Morhaim and Pollack, "End of Life Care Issues," 9.

patients with limited hope for realistic recovery.[32] Furthermore, “nearly 30% of all Medicare spending is for the last year of life and more than 50% of that is in an acute care hospital.”[33] This statistic supports the level of influence that current end of life treatments have on what should be a natural process. This statistic also triggers me to wonder if medicine is truly just prolonging the inevitable, especially if such a high percentage of our care costs are seen within the last year of life.

I think it’s evident that I may be leaning toward the side of the argument that I believe the natural process of death is on the decline in the current medical climate of end of life care. However, what about the impact of services like palliative and hospice care? Could the weight of these services be influencing the pendulum closer to the natural death direction? I’m not sure a definitive answer to that question is possible. However, I will always be in continued support of the dying patient, and I do believe these services to be beneficial to the patient and their loved ones during the end stages of disease.

The reason for my ambivalent feelings regarding palliative and hospice care is not because I don’t feel the care is positive. However, I remain fearful that these levels of care also have a medicalized component that impacts the natural process of death. To clarify, the purpose behind palliative care services is to provide medical and emotional interventions to decrease suffering while improving comfort and care at the end of one’s life.[34] The concept of palliative care began to grow in the beginning of the 1950s with the hope to influence a “gentler” medical response to the dying process while accepting

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[32] Morhaim and Pollack, “End of Life Care Issues,” 9.

[33] Morhaim, and Pollack, “End of Life Care Issues,” 9.

[34] David Clark, “Between Hope and Acceptance: The Medicalization of Death.” *BMJ* 324 (April 2002): 905. doi:10.1136/bmj.324.7342.905.

the process and providing patients with a sense of dignity and meaning through their terminal progression.[35] In my personal experience palliative care differs from hospice in that under the guidelines set by Medicare, hospice does not cover aggressive forms of treatment in the end stages while palliative care coverage will. In my professional experience the common form of palliative care that I see is within the population of terminal patients. These individuals have incurable diseases but continue to receive aggressive treatment measures to slow the dying process down. For example, a stage IV lung cancer patient may continue to receive radiation, not to cure the tumor but to keep it from growing rapidly. The palliative radiation will hopefully stunt the growth which will possibly provide the patient with more time while also attempting to alleviate the level of pain the patient experiences.

Hospice, on the other hand, though similar in its mission, which is to provide comfort in the end stages of disease progression, does not financially support aggressive treatment.[36] The reason behind this belief is that often many forms of aggressive treatment in the end stages of a disease are believed to be viewed as “cruel or inhuman.”[37] This belief is significant in response to human value in death and our medical society’s focus on how treatment impacts the “moral integrity of health care.”[38] When the dignity and respect of a dying patient is removed from the equation for the sake

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[35] Clark, “Between Hope and Acceptance,” 905.

[36] Melissa Aldridge-Carlson et al., “Hospices’ Enrollment Policies May Contribute to Underuse of Hospice Care in United States.” *National Institute of Health* 31, no. 12 (2012): 2690. doi:10.1377/hlthaff.2012.0286.

[37] Shan Mohammed and Elizabeth. Peter, “Rituals Death and the Moral Practice of Medical Futility.” *Nursing Ethics* 16, no. 3 (2009): 293. doi:10.1177/0969733009102691.

[38] Mohammed and Peter, “Rituals, Death Moral Practice,” 293.

of medical advancement I personally believe that the natural process of dying is greatly infringed upon.

In connection to the issue of palliative care it's important to include research support. Kon, and Albin believe that the term palliative care itself affects the medically influenced mind of our current society.[39] It is their position that the term "care implies that what is done is being good natured and meant to help a patient, however "care" generally does not require specialized knowledge."[40] It is their belief that due to society's current medical environment and the medicalization of death it is very important that the term "palliative care be replaced with palliative treatment."[41] In Kon and Albin's view, patients and families may have a different, more positive reaction to the term palliative treatment because it may allow them to feel more hope and comfort, not only with who is providing the level of service, but it will also provide them with a sense that they are still actively fighting the terminal disease.[42] In other words they will feel that they are still living, and fighting, not just giving up.

David Clark highlights his position on this issue. He reports much like Kon and Albin that palliative care is just another form of medicalized treatment. Clark highlights that as palliative care has grown, its focus has transitioned from supporting a better quality of life to a concentration on physical suffering and symptom management.[43] He feels that through the medicalization of palliative care the palliative professionals just

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[39] Alexander Kon and Arthur Albin, "Palliative Treatment: Redefining Interventions to Treat Suffering Near the End of Life." *Journal of Palliative Medicine* 13, no. 6 (2010): 643. doi:10.1089/jpm.2009.0410.

[40] Kon and Albin, "Palliative Treatment Redefining Intervention," 643.

[41] Kon and Albin, "Palliative Treatment Redefining Intervention," 644.

[42] Kon and Albin, "Palliative Treatment Redefining Intervention," 644.

[43] Clark, "Between Hope and Acceptance," 906.

become another specialist in the world of end of life medicine. The philosophy of life quality becomes once again a field of symptomology.[44]

The concern that Clark finds in the medicalized changes in palliative care is that soon the medical environment will forget the vital mission of a good death by defining a good death by the level of pain and symptoms that often occur within the dying process.[45] Of course physical comfort is crucial during the dying process but it must also be remembered that quality of life is also influenced by one's emotional and spiritual sense. The other fear here is that the gap between the patients that can be cured and the patients who are dying will continue to expand. The reason for the growing gap is the result of medicalized palliative care.[46] Clark reports the results of a study done with palliative care patients where a number of subjects died while participating in the study. He quotes the researchers results, "Dying during the study period is a strong indicator of patients who entered the palliative care intervention in very poor health."[47] Clark emphasizes that this comment implies that those who died during the research process did something "wrong" while receiving this level of palliative care.[48] His key point when documenting this is that we must not forget the mission of palliative care which is to facilitate quality of life at the end of one's life.[49] His hope is that instead of a larger rift creating a distance between a cure and death, it's instead to remain focused on the true issue at hand, which is to assist with the process of dying. For it is not death itself that most are afraid of, it is

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[44] Clark, "Between Hope and Acceptance," 906.
[45] Clark, "Between Hope and Acceptance," 906.
[46] Clark, "Between Hope and Acceptance," 906.
[47] Clark, "Between Hope and Acceptance," 907.
[48] Clark, "Between Hope and Acceptance," 907.
[49] Clark, "Between Hope and Acceptance," 907.

the fear of the suffering within the process of dying that evokes fear.[50] My personal addition to Clark's view in regards to natural death is that with palliative/hospice care we continue to allow medicine and medical techniques to participate in the dying process, which contributes to erase the true natural course of death.

It is clear that there are a number of useful end of life interventions that assist with the dying process. Whether they are medicalized or not, it is evident that death comes with fears, symptoms, and a modern need to aid a commonly difficult progression. As these levels of care are advanced and developed, it is impossible not to discuss the direction that end of life care is moving toward. The current path is taking society in the direction of assisted suicide, also termed assisted death.[51]

Assisted suicide has been a concept within the field of end of life care for a long time but recently the level of acceptance toward this practice has changed. There appears to be an increase in education, research, and tolerance regarding assisted suicide. We have even seen the legalization of this action in the states of Oregon, Washington, and Montana.[52] Hardwig is one of many professionals who is not afraid to touch upon the subject of assisted suicide. He includes the importance of modern medicine, illness, chronic disease, terminal conditions, and advanced medical technology as reasons behind the need for assisted suicide.[53] Hardwig also stresses the common fear of death coming too late as an additional component behind assisted death.

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[50] Clark, "Between Hope and Acceptance," 907.

[51] Hardwig, "Going to Meet Death," 37-38.

[52] Morhaim and Pollack, "End of Life Care Issues," 8.

[53] Hardwig, "Going to Meet Death," 37-38.

Hardwig believes that there is such a thing as a death that came too late and he does not feel that it is restricted to just those who suffer from chronic or terminal illness.[54] In fact I wonder if he would agree that assisted death does not need to be triggered by a physical medical condition. He discusses the real fact of what quality of life truly is and how it can differ from person to person.[55] He is fully aware that in many cases a diagnosis, medical issue, and/or physical symptoms can easily encourage an individual to desire a speedy death, but he also acknowledges that lack of independence, intellect, and an individual need and inability to set goals and continue to try for accomplishments can also support one's wish for a timely death.

Hardwig believes that these human desires and moral values should allow us to individually choose when it is our time. He believes in a timely death for all and does not feel it needs to be attached to a medical diagnosis.[56] He fears however that we no longer have the right to choose the path of our death because of medicine's influence in the dying process.[57] He also documents the fears that medicine has placed on the course of death. It is the options and interventions that easily influence not only the patient's decisions but the family decisions as well. It is the medical climate that pushes us to believe that though life may be prolonged by aggressive treatment it may also be the cause of an undignified, long dying experience.[58]

Though his article shows his support of assisted death it is important to emphasize that even the option of assisted death has a medical element and continues to remove the

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[54] Hardwig, "Going to Meet Death," 37.
[55] Hardwig, "Going to Meet Death," 38-39.
[56] Hardwig, "Going to Meet Death," 44.
[57] Hardwig, "Going to Meet Death," 44.
[58] Hardwig, "Going to Meet Death," 40-41.

nature from the event. In the examples of the legalized measures of Assisted Suicide in Oregon, the legislation requires a physician to be involved in the process and assist medically with this practice.[59] These policies continue to support the argument that even when an individual chooses to speed up their dying process it too is medicalized. Plus it goes without saying that assisted death completely removes nature from the dying process.

To conclude my argument regarding the natural dying process, I must first start with the fact that I don't believe all medical intervention used in the dying process to be wrong or unnecessary. On the contrary, I believe that in many of today's end of life situations, medication and the medical influence is the only way to provide an individual with a peaceful and dignified death. But as I have stated above these interventions, though supportive and often necessary, are not what I would personally consider natural.

From the push for an advance directive, to the common use of CPR, to palliative/hospice care, all the way to assisted suicide, it is evident that the historic natural dying process is no longer the common dying experience. Of course there are the exceptions to the more common examples of those who die under treatment and within a facility. These are those who die naturally in their sleep, but I would imagine there was some form of medical intervention prior to that death, in most cases. The medicalization of death is just another result of the current medicalization of today's society.

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[59] Jose Pereia, "Legalizing Euthanasia or Assisted Suicide: The Illusions of Safeguards and Controls." *Current Oncology* 19, no. 3 (2012): 38. doi:10.3747/co.v18i2.883.

The main struggle I have with the medicalization of death and the elimination of the natural process is not the influence of medical intervention, but the fears that come with the consequence of medical intervention. Medical intervention comes with a lot of positives, hopes, and even prolonged quality of life, but where is the line and how do we know when we have crossed it? And who is it who crosses the line; is it the patient who opted for continued treatment, the family who is not ready to accept death as a reality, or the medical professionals who are not ready to give up on the fight? Whoever it is, the procedure of dying today is just that, a procedure. When I hear that something as natural as dying, something we will all have to endure one day, can be considered a procedure or process I can't help but fear that it comes with unnecessary suffering. More importantly than the physical suffering that comes with modern medicalized death is what I have witnessed as an end of life professional. It is the eradication of dignity and pride that comes with today's generation of death. Due to the above details, we as a human race need to start a true and honest dialogue about death.

In addition to the current climate of death, it is now necessary to really venture back through the factual details of how we got here today. I feel it is imperative to understanding the growth and changes of what is now called the end of life experience. Generations of medicine, education, and many influential individuals have helped to put end of life, hospice, and palliative care on the medical map. The conversation I feel that is so very crucial to have, has been influenced by this historical process.

As it has been mentioned in this paper, death has been around as long as life has been around, but the culture of end of life care has not. In reference to the current end of life climate it is important to discuss the origins of end of life care and its history. The best way to define this history for this paper is to focus on the journey of palliative and hospice care. It may even come as a surprise as to how young hospice and palliative care are, especially outside facilities and within the community.

It is relevant to document the changes in medicine prior to discussing the birth and growth of palliative and hospice care. In the seventeenth century humans were viewed as "machines."[60] This influence was greatly affected by the new theories suggested by Isaac Newton. His understanding of "gravitational physics" helped to create the belief that if matter made up all of nature then we as humans can be labeled as machines.[61] The influence of these thoughts allowed for more of an objective approach from physicians. The idea of assessing a medical condition from a quantitative approach, for example, "the feel of the pulse, taste of urine, sound of breathing, and appearance of skin and eyes," continued through the eighteenth century.[62] As the nineteenth century progressed so did the technique of medicine. Thus the use of patient experience was no longer considered useful. Physician and patient relationships became less important in the science of illness.[63] The patient's physical experience of their personal symptoms were now replaced by the "machines and technical expertise" within the assessment process.[64] Data, numbers and visual observation seen by the physicians became the new model of medicine. This new generation of medicine was soon supported by the systems of hospital settings, medical laboratories, and university involvement.[65] As an end of life

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[60] Milton Lewis, *Medicine and Care of the Dying.* New York: Oxford University Press, 2007.
[61] Lewis, *Medicine Care Dying*, 44.
[62] Lewis, *Medicine Care Dying*, 44.
[63] Lewis, *Medicine Care Dying*, 44.
[64] Lewis, *Medicine Care Dying*, 45.
[65] Lewis, *Medicine Care Dying*, 45.

professional I can only wonder if this shift in medicine is what continues to affect the lack of physician/patient end of life conversation?

Apparently I'm not the only professional with that thought. Lewis states that the influence of modern medicine is believed to have decreased the "humanity" in how we care for our dying population.[66] He reports that the need for a scientific cure has replaced the need for compassion and appropriate palliative care when a cure is no longer an option.[67] The climate continued to change in the world of medicine. In the mid-1900s the pendulum began to swing the other way. This change was seen in the field of medicine in both Britain and the United States. This change was greatly influenced by the field of psychiatry and the need to support mental health with the understanding of psychiatric illness and depression. These factors were found to be affected by the individual mind, relationships, and social influences.[68] The cost of medicine during this time also helped in support of this change. Ivan Illich opened discussion about the medicalization of "problems of living in his theory. It was thought that physicians often prompted the idea of illness within the patient by this heavy influence of medicalization.[69] In 1977, George Engel's biopsychosocial model greatly influenced how disease was seen. Again his theory highlighted the importance of the need to include the impact of environment, social, psychological and biological factors when diagnosing and treating illness.[70] This is when illness and treatment began to be seen as a combination of natural influences as well as environmental factors. Of course, due to

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[66] Lewis, *Medicine Care Dying*, 49.
[67] Lewis, *Medicine Care Dying*, 50.
[68] Lewis, *Medicine Care Dying*, 52.
[69] Lewis, *Medicine Care Dying*, 53.
[70] Lewis, *Medicine Care Dying*, 53.

medicine and treatment options, the result of illness and death were also changed during this time. [71]

All of the above changes impacted the culture of death. The medicalization of death had begun. The journey of life and death was now viewed from the angle of body control as well as outside environmental factors. It is important to highlight how ethics and the humanities impacted this critical period.[72] Human values were now being seen as a working factor in medicine and especially death. The individual who obtained great recognition for this influence is Edmund Pellegrino. Pellegrino's influence with the use of the Journal of Medicine and Philosophy as well as the involvement of the Institute of Human Values in medicine encouraged a new vessel of education. This broadened the conversation within the field of "medical humanities, bioethics, and philosophy."[73] This shift in the view of illness and medicine began to influence medical practice in the 1970s. In the U.S, Callahan and Cassell were also focused on a resurrection of caring in the world of medicine.[74] Callahan expressed concern that the climate of "economic sustainability" has placed pressure on the technology and hospital based medical environment which has decreased the care expressed to patients.[75] It was believed by Callahan that caring needed to be the starting point in medicine. Caring could be expressed in both a general and particular fashion, but caring should be a requirement in illness either way. On the general level there are four specific factors, "caring for the patients' feelings that are evoked by their condition, meeting the patients' needs to be

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[71] Lewis, *Medicine Care Dying*, 53.
[72] Lewis, *Medicine Care Dying*, 60.
[73] Lewis, *Medicine Care Dying*, 60.
[74] Lewis, *Medicine Care Dying*, 60-61.
[75] Lewis, *Medicine Care Dying*, 61.

understood regarding how their minds work, responding to what they value in life, and trying to understand how they relate to others."[76] Caring for a patient on this particular level is what makes the experience real for them. Patients need to be seen as their own individual, with their own particular needs and that is where the caring needs to be seen.[77] I believe that in the sphere of end of life care, it is the particulars that will enhance the dying experience, but they are also the factors that can damage the unique experience of death. My consistent reminder is that we all get to die only once in our lives, so as professionals let us try not to ruin it for our patients. As a professional in the end of life field, I'm not sure I would have gotten to this above conclusion without the influences of the historic individuals mentioned above.

The concept of value based medicine, as stated by Little, is where the shift has occurred and needs to remain a focus. This standard requires the influence of our "principle based ethics of medicine, respect for the autonomy of others, beneficence, nonmaleficence, and justice" and should direct us to first evaluate the patient as a human and not just the diseased part of them.[78] It is important to highlight here that much of this change in direction is a result of the changes in population growth, disease growth and change which has undeniably affected "mortality and morbidity."[79] Here is a statistic that will paint a clear picture of how the world of end of life is different in just the simple life expectancy pattern. In the "U.S the life expectancy in 1800 was 33, increased to 49.7 in 1900, and continued to increase to 68.7 in 1950!"[80] According to the National Vital

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[76] Lewis, *Medicine Care Dying*, 61.
[77] Lewis, *Medicine Care Dying*, 61.
[78] Lewis, *Medicine Care Dying*, 62.
[79] Lewis, *Medicine Care Dying*, 63.
[80] Lewis, *Medicine Care Dying*, 63.

Statistics Report in 2013, the average age of death in the United States is now 78.8.[81] This life expectancy increase has occurred alongside the transition of diseases, from being a death sentence to a chronic survivable illness. This distinct medical change requires a unique response, not just from the scientific world of medicine but also in the levels of care that medical professionals are capable of offering. This is where I would like to transition to the supportive care programs that have influenced and continued to influence medicine, disease, and death.

I feel the best place to start when it comes to the history of dying comfortably is from the religious and spiritual perspective. I feel this is necessary because of the great influence that comes from these realms long before the term hospice was related to the structure of end of life care. Siebold clearly documents that Christianity, over other religious groups, taught that the "care of both the sick and dying were sacred duties."[82] It was preached that Jesus himself followed this belief profoundly and it was encouraged that the Christian community find this level of care to be of individual importance. During the end of the fourth century, Western medicine was greatly controlled by the Church, which had great influence on the establishment of hospices for the poor, sick, and homeless populations.[83] The role of the spiritual healer "was not only to cure but to help save their patient's soul."[84] In connection to illness, Christian followers found both the anticipation of death, including its preparation, as well as life after death, to be handled with respect. For it is the life and struggles one experiences that create their

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[81] Jiaquan Xu et al. "Death: Final Data for 2013." *National Vital Statistics Report,* 64 no. 2 (2016): 1-2. https://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf.

[82] Siebold, *The Hospice Movement*, 68.

[83] Siebold, *The Hospice Movement*, 14.

[84] Siebold, *The Hospice Movement*, 14.

afterlife. In the Christian beliefs, sacrifices in the living world can influence the soul on the other side. The pain and suffering that comes with death also allows for the patient to find peace, and the church took responsibility for encouraging this growth. Religious figures, for example Bishops, were encouraged to accept sick travelers into their homes or locate community homes where they could implement these care services.[85] Eventually rulers began to create facilities where these services could be carried out appropriately.

These facilities could be found across European countries though the illustrations of the accommodations varied. A famous version of this early hospice could be found in Rome in A.D. 475. The Port of Rome was ruled by Fabiola who was a "matron and disciple of Jerome."[86] It was her experience at the "monasteries in the Holy Land" that allowed her to structure and provide hospice level of care.[87] Like many of these facilities she not only accepted the sick and dying but also housed travelers in her shelters. As mentioned above, travelers could often be found in these accommodations for they were often weak and weary from their long travels and need of supportive care.[88]

Like the Christian faith, Muslims too saw caring for the sick and dying as a religious duty and they too built their own versions of hospices. These care centers were much like those built for the sick, dying, and travelers. Their difference was in the high level of medical knowledge and care that could be found within these facilities.[89] It is believed that their medical knowledge was gained from the ancient Greeks. The Greek

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[85] Siebold, *The Hospice Movement*, 15.
[86] Siebold, *The Hospice Movement*, 15.
[87] Siebold, *The Hospice Movement*, 15.
[88] Siebold, *The Hospice Movement*, 15.
[89] Siebold, *The Hospice Movement*, 16.

understanding served as a foundation for what they built upon with great "emphasis on scientific principles.[90]

The historic event of the Crusades had a great influence on hospice history. Hospice structures grew popular during this time period which is likely when people became accustomed to the term and their services. These institutions were structured for fatigued travelers and crusaders and by the thirteenth century, England was the home to 750 of these structures.[91] These centers provided care for both men and women and continued with the goal of providing comfort, lodging, and care for those on their journey home. The health care services given throughout these facilities during the Crusades were mainly provided by religious figures. Their lack of medical knowledge and experience, as well as their focus on saving the soul did not help decrease disease and infection, nor did it assist with the physical component of pain.[92] For example, surgery was seen as violation of the soul and was not supported. During the era of the Reformation there was a transition from the medicine having a religious influence to it becoming the territory of scientists.[93] Leaders began to "encourage intellect" in the medical world.[94] Though there was the acceptance that many diseases did not have a cure there was a new emphasis on understanding the "physiological and pathological" factors as influences on the care practices. It was this transition that transformed what

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[90] Siebold, *The Hospice Movement*, 16.
[91] Siebold, *The Hospice Movement*, 16.
[92] Siebold, *The Hospice Movement*, 16.
[93] Siebold, *The Hospice Movement*, 17.
[94] Siebold, *The Hospice Movement*, 17.

was originally termed hospices into scientifically influenced structures that we now call hospitals.[95]

Even with the leaps and bounds in the scientific world of medicine, including the increase of university-trained physicians joining the staff of these hospitals, there still remained places where illness progressed and death occurred. To help clear up their reputations and community respect, hospital physicians began to discourage terminal and chronically ill patients from utilizing the hospital setting for care.[96] It was reported that those levels of care were no longer in their scope of responsibility. Death was seen as a "threat" to the physician's role and respect.[97]

I feel it necessary to interject here because my honest opinion is that even though we have made many positive steps regarding end of life care, I can't help but feel that we haven't made the strides we want to think we have. I personally feel the negative connotation of death continues to effect the reputation and statistics of medical professionals, especially physicians. There is still a sense of failure found when a patient dies. Even in the field of oncology, infection disease, and chronic conditions, I feel the professionals continue to exude a sense of failure when a patient who is likely expected to die, does. I'm sure the continued influence of technology and treatment growth influences this feeling of failure. Our technological growth in medicine has provided us with a number of treatment options that may allow the professional to believe they are defeating chronic and life threatening diseases. For example if a patient is tolerating treatments like chemo and radiation it can be perceived that they are beating the disease.

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[95] Siebold, *The Hospice Movement*, 18.
[96] Siebold, *The Hospice Movement*, 19.
[97] Siebold, *The Hospice Movement*, 19.

I fear it isn’t just the patients who often have that perception but the physicians as well. Another form of technology that may also fall in this category is the use of a feeding tube. Again, artificial nutrition can sustain life, but at what cost. Due to the fact that artificial nutrition exists, I fear professionals may use this intervention to avoid the feelings of failure. My concern here is that sentiment of failure can take away from the experience and dignity that should come with death. The physicians sense of failure can and will influence the patient and family’s acceptance of death. I can’t help but think that this is an avoidable negative emotional impact.

I also believe that the factor of failure comes from the same foundation it did hundreds of years ago. As technology and treatment expanded it became easier for professionals to succeed in a cure, but it continued to allow for failure to be experienced. We as a medical culture no longer accept disease progression as the norm or as part of life. It is now a puzzle that we must figure out no matter what. We believe that we have all the pieces to this puzzle and if we don’t, we must use our great knowledge to reconstruct the missing piece. Unfortunately, sometimes no matter how hard we try that piece just doesn’t fit correctly. The place where I feel we are misdirected is when we realize this piece will never fit right; instead of acceptance and supporting death we see ourselves and sometimes the patient as a failure.

I believe that my personal opinion, built off of my professional experiences, is essential because as we have come so far in so many aspects of medicine, I find it compelling and disappointing that today’s medical culture, in regards to our attitude toward death, has not taken the same vital steps. I think this is seen clearly in the failure outlook as well as our current inability to draw a fair treatment line. When I talk about a fair treatment line I mean knowing, when instead of feeling like a failure and pushing harder, we respect the frailty of life and give our patients the dignity to die without the pressure of aggressive treatment. I respect palliative treatment in the form of containing a symptom from progressing into further pain and suffering, but I also feel that there is a fine line that treatment itself can be the exact action that causes a similar level of pain and suffering. For some reason, many professionals feel that the simple element of attempting to beat an unbeatable disease makes us feel we are doing the right and just thing for our patient. Sometimes we are waiting for them to hold up the stop sign. I feel it must be our responsibility as medical professionals to educate our patients and families on non-aggressively treated death as an option. We have come so far from the foundation of medicine in so many positive ways. However the one aspect where we did it better in the past is the acceptance of death and the acceptance that medical professionals are only human, even with all their new medical weapons and technology.

As time progressed so did medicine and the technology aspect of medical treatment. The eighteenth century began the beginning of the biomedical model of medicine and it continued to grow into the nineteenth and twentieth centuries.[98] The introduction of "technologies like the X ray and radiation therapy," added to this biomedical growth.[99] Illness and disease were now seen from a new perspective. Siebold's statement explains this change perfectly: "disease was defined as a deviation from certain physical and biomedical norms." This new vision of medicine further changed the doctor/patient relationship. This relationship placed an importance on the

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[98] Siebold, *The Hospice Movement*, 19.
[99] Siebold, *The Hospice Movement*, 19.

diagnosing process, treatment efforts, and ultimately a cure for disease. The physicians now began to see a patient more and more as a diagnosis with a possible cure instead of the human being they should be seen as.[100] Medical specialties were created and focus remained on the concept of cure which indirectly had an obvious effect on the terminal population. A focus on the dying patient and the death process disappeared, and up until the 1950s, was no longer considered a teaching point for physicians, students, and other medical professionals.[101]

I would like to clear up some terminology here. "Historically the terms hospice, hospital, hotel, and hostel were used interchangeably."[102] Hospice referred to care services offered to "the sick, the indigent, and the traveler."[103] As the history above illustrates, this care morphed through the years to become facilities that eventually pushed the terminal and dying patients away.[104] These structures became what we likely today call hospitals. We know that with the creation of hospitals we have not done completely away with hospice. Today hospice continues to exist with a new structure. Prior to today's modern version of hospice, which we will get to soon, hospice was revived in the nineteenth century.[105] In Europe, hospital facilities turning away terminal and dying patients, as well as the potato famine in Ireland, influenced the new foundation for hospice care. These two factors influenced ill and dying patients being encouraged to utilize other institutions for their needs, many which were run by religious figures.[106] In

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[100] Siebold, *The Hospice Movement*, 19.
[101] Siebold, *The Hospice Movement*, 19.
[102] Siebold, *The Hospice Movement*, 14.
[103] Siebold, *The Hospice Movement*, 14.
[104] Siebold, *The Hospice Movement*, 19.
[105] Siebold, *The Hospice Movement*, 20.
[106] Siebold, *The Hospice Movement*, 20.

1879, Our Lady of Hospice in Harold Cross, Dublin, Ireland provided comfort care to the dying population. This facility was inspired by work done by Sister Mary Aikenhead and her belief that "death is to be life's final pilgrimage," and she utilized the term hospice to name her facility.[107] Sister Mary's vision was illustrated many years before the facility came to life but her hope to provide care for the terminally ill became a philosophy that caught attention quickly.[108]

Hospices could now be found in "England, France, Australia, and the United States."[109] In France, these homes provided care services for the dying indigent. In Australia, as an answer to the hospice trend, the Sacred Heart Hospice of Australia opened in 1890. The building of hospices continued to grow in England including the Hostel of God that continues to operate today.[110] In 1893, Saint Luke's House of the Dying Poor was opened in London, and unlike others of its kind, was run by a physician. Dr. Howard Bassett treated his patients as a "human microcosm, with its own characteristics, its own life history, intensely interesting to itself and some small surrounding circle."[111] It was here that Cicely Saunders, whom I will discuss later, gained her first hospice experience as a volunteer. Saint Luke's House for the Dying's goal was to provide appropriate end of life care to individuals free of charge. These individuals were admitted to the facility after the medical officer deemed the patient suffering from a disease that will likely take their live in the not so distant future.[112]

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[107] Siebold, *The Hospice Movement*, 20.
[108] Siebold, *The Hospice Movement*, 20.
[109] Siebold, *The Hospice Movement*, 20.
[110] Siebold, *The Hospice Movement*, 20-21.
[111] Siebold, *The Hospice Movement*, 21.
[112] Siebold, *The Hospice Movement*, 21.

The United States' medical care and hospice care followed in the footsteps of the European movement. Like European hospitals, the U.S. utilized their hospital facilities for the curable and for those who could fund their treatment. Hospices in America were also built to provide better care for dying patients as well as the poor community in the nineteenth century. The impact the United States had on historic literature is limited. These limits were related to the fewer number of facilities open in America versus the widespread level of hospice care in Europe as well as the negative attitude that came with the termed "death houses".[113] The American understanding of original hospices were that all treatment was concluded and they saw this opportunity in hospice growth as a catalyst for a foundation for a new treatment method.[114] As hospice grew both in Europe and the U.S., so did the minds of individuals who were in the world of this care as so the modern hospice movement began.

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[113] Siebold, *The Hospice Movement*, 22- 23.

[114] Siebold, *The Hospice Movement*, 23.

Chapter 2

The Modern Hospice Movement

The historic background of hospice constructs a solid foundation for what we call today the modern hospice movement. This movement created the vision of hospice that we see today and it would not have transpired without the crucial influential of one individual, Cicely Saunders.[115] Cicely Saunders was a social work employee in the 1940s when she was influenced by a dying patient named David Toma. Cicely's relationship with David grew and continued through his disease progression.[116] During their time spent together they frequently discussed the process of death and how, if possible, the care could focus on easing the distress of the experience. He provided a monetary donation to be used toward the goal of providing the facility with a room that had a glass window. This window was to be used by the terminal patients to gaze out of as a way of providing them with an outlet during their struggling time.[117] It was this relationship and experience that drove Saunders to enter medical school to become a physician, with the hopes of giving appropriate care to the dying population.[118]

Prior to the start of her medical schooling Saunders decided to expand her experience by volunteering at Saint Luke's Hospice. Here she gained knowledge from the nuns who were the primary caregivers. She recognized their specific round the clock medication administration. This concept of, as needed medication management, was

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[115] Siebold, *The Hospice Movement*, 21.
[116] Siebold, *The Hospice Movement*, 68.
[117] Siebold, *The Hospice Movement*, 68.
[118] Siebold, *The Hospice Movement*, 68.

intended to alleviate, manage, and hopefully control pain and discomfort before it became unbearable.[119]

This focus on pain control encouraged Cicely to join a research group as a fellow medical student that concentrated on pain and pain management. Her multiple experiences helped her to be a part of the development of an analgesic research trial to enhance symptom control in the dying population.[120] After the completion of her medical education, she graduated as a physician where she then became a medical officer employed at Saint Joseph's Hospice.[121]

Through her multiple experiences with the dying, Saunders created her own philosophy on hospice care and the dying experience. She recognized the gap in care of the actual dying individual. Saunders felt that professionals missed the mark when it came to comfort needs. She believed that we as professionals should first listen to the patient and the complaints that they verbalize. Also Saunders found that her focus on physical positioning, dietary requests, and massage were a few simple tasks that should be implemented with the goal of comfort.[122] Just as important as the physical comfort, Saunders encouraged emphasis on the patient's personal values, spiritual health, and emotional needs.[123] I view her philosophy as treating the whole person first by seeing the depths of their character, soul, life, and wishes before seeing their disease and just treating the symptoms. As a professional I easily recognize the importance of physical

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[119] Siebold, *The Hospice Movement*, 68.
[120] Siebold, *The Hospice Movement*, 68-69.
[121] Siebold, *The Hospice Movement*, 69.
[122] Siebold, *The Hospice Movement*, 69.
[123] Siebold, *The Hospice Movement*, 69.

suffering, but I also believe that if the other levels of personal suffering are not treated, I feel the physical symptoms actually worsen.

Saunders' continued experience built a foundation for her philosophy and she recognized the need to educate professionals on this level of end of life care. Cicely was awarded a grant in 1963 from Saint Thomas Hospice to travel to the United States and present her beliefs. During this visit she had the opportunity to share her viewpoint with eighteen different facilities.[124] To say she was received with great enthusiasm is an understatement. She was invited again and again to continue to educate on this new care standard. It is important to add here that as grateful as the American medical culture was for Saunders' directives, the medical climate in America definitely had barriers in front of this way of caring that the British model of care did not have. This will be discussed later on.[125]

Evidently, changes were occurring during this influential growth period, and more knowledge about end of life as a process was becoming a major focus in medicine. With this growth there was a factor of the dying experience that should not be overlooked: the influence of grief and how grief truly affects death for both the patient and their loved ones. It is important to highlight the work of psychiatrist Elisabeth Kubler-Ross at this time. Kubler-Ross was researching the social and emotional response to terminal illness and grief. Kubler-Ross is known for her work on social responses to grief and her theory of the five stages of grief: denial, anger, bargaining, depression, and acceptance.[126] Kubler Ross's research is greatly recognized in the field of psychiatry as well as the

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[124] Siebold, *The Hospice Movement*, 69

[125] Siebold, *The Hospice Movement*, 70.

[126] Siebold, *The Hospice Movement*, 73.

culture of end of life care. Ross reports in her research and experience that patients often know of their condition and prognosis and frequently wish to talk about it.[127] Because of this understanding, Kubler-Ross emphasizes open conversation about death and learning to face it with an inner peace.[128] As a social worker in the field of end of life care, I must credit the impact Kubler-Ross's theory continues to have on this field today as well as how I conduct my care with patients and their loved ones. It remains a staple in the education of end of life care and is a consistent theory in my own personal therapeutic regiment.[129]

During this developmental stage in end of life and hospice care, Saunders and Kubler-Ross could be found lecturing and sharing their new views with the medical world. They were invited to speak at Yale University Hospital by another influential figure, Florence Wald, who was a driving force in the discussion of end of life care in the United States.[130] It was Wald who brought together in her home the minds of Saunders, Kubler- Ross, and Parkes who were all very influential in the movement.[131] During these open dialogues, Kubler-Ross found herself becoming increasingly interested in the atmosphere of hospice care as it relates to the grief process. She found herself frequently agreeing with Saunders' beliefs, knowledge, and values.[132]

In 1967, not long after Saunders' presentation at Yale University Hospital, the first inpatient hospice unit opened in England due to her influence. Two years later

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[127] Siebold, *The Hospice Movement*, 73.
[128] Siebold, *The Hospice Movement*, 73.
[129] Siebold, *The Hospice Movement*, 73.
[130] Siebold, *The Hospice Movement*, 65.
[131] Siebold, *The Hospice Movement*, 65.
[132] Siebold, *The Hospice Movement*, 73.

Saunders found herself as an employee at St. Christopher's inpatient unit. This unit was located in South East London and contained fifty-four beds.[133] Saunders along with a team of end of life medical professionals actively worked hard for the terminal community in south-east London. Their patients and experiences ranged, but a majority of her patients died within the facility walls. In 1969, after serving the dying community for two years, St. Joseph had a case that in my mind changed the field of end of life care permanently, for the better.[134]

A female patient was admitted to St. Joseph's unit at the end stages of her condition with the goal of managing her symptoms and allowing for a comfortable death on the unit. This patient verbalized her wishes to die in the comfort of her own home.[135] After extensive plans were made and an appropriate supply of medication was provided for comfort in her home, this patient was discharged. After being home for ten days the staff at St. Joseph's were contacted by this patient's husband. He notified the staff that his wife was in excruciating pain and she was immediately re-admitted to the facility.[136] Shortly after her re-admission the staff learned that the patient's General Practitioner made a home visit and was appalled by the morphine doses recommended and provided by St. Joseph's. This physician quickly came to his own understanding that St. Joseph's was exercising euthanasia as a form of end of life treatment. This fear caused him to rapidly reduce the morphine dose and eventually discharge the drug completely.[137]

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[133] Mary Baines, "The Origins and Development of Palliative Care at Home." *Progress in Palliative Care* 18, no. 1 (2013): 4. doi:10.1179/096992610X12624290276223.

[134] Baines, "Origins and Development," 4.

[135] Baines, "Origins and Development," 4.

[136] Baines, "Origins and Development," 4.

[137] Baines, "Origins and Development," 4.

Once back under the care of the hospice professionals on St. Joseph's unit, this patient was again medicated appropriately to an appropriate physical comfort, but she continued to hold her desperate wish to die at home with her family. Unfortunately, her prior terrifying home care experience prevented her from being willing to return to her home again. This woman was kept comfortable until she died within the facility days later.[138]

This event and this specific individual drove Dr. Saunders to question end of life care and the possibility of providing it to the community in their very own homes. The social worker side of her knew that emotionally, being at home may alleviate many struggles and fears for both the patients and their loved ones. She recognized that the comforts found within one's home were elements that could not under any circumstance be recreated in a unit setting.[139] As a professional in the field I have visited a number of hospice units, nursing facilities, and end of life rooms within hospital settings. Though they can be lovey, warm, comforting, and even home-like, they are still not home. It isn't always a matter of the space, but instead the pictures hung, the soothing pastel colors of the walls, and/or the soft texture of the comforter. What I have seen is that it is the memories contained in the home, the familiar smell, the view outside the bedroom window that is a common peace. It is the peace that the sick individual feels when they enter the door to their home and the comfort that their loved ones experience while visiting them there. I truly believe these factors are real and do greatly affect the emotional comfort experienced at the end of life.

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[138] Baines, "Origins and Development," 4.

[139] Baines, "Origins and Development," 4.

Of course it is important to add that returning home for the end of one's life can and will increase some anxieties at first. The unknown factor of the care they will receive and fear of suffering in an environment not structured for medical care is likely a common thought that may impact the patient and family's final decision. Saunders was very aware of these common fears, and her career changing experience with the patient described above helped her to have a clear understanding of these common reservations. Dr. Saunders also became aware of the outside factors, especially the involvement with the community physician. This specific case reminded her that education and communication with the following community physician must be clear and open for the idea of hospice to work in one's home.[140]

Like the community physicians who don't have the knowledge or understanding of traditional hospice care, Dr. Saunders had to admit that she had no previous experience with community home care. This is when she created an appropriate team of individuals to provide her with the knowledge and experience that she lacked. She included Mary Baines, a General Practitioner, and Barbara McNulty, a ward sister and unit nurse.[141] Before they began to build what they believed to be an ideal, much needed form of end of life care, they wanted to be sure that other medical professionals agreed with their sentiments and plans. In line with the team's hopes, the medical community, General Practitioners, and community nurses welcomed the idea of home hospice. They too felt that not only was pain control a major goal of end of life care but just as important is the element of emotional support for the patient and for all the involved family, friends, and

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[140] Baines, "Origins and Development," 5.
[141] Baines, "Origins and Development," 5.

care givers. The common request from most community practitioners and nurses was to remain involved in the patient care, because the physicians wished to continue to direct the patient care.[142] After their homework was completed and Saunders and her team felt they had the foundation they needed to begin this journey, the official first home hospice program was created in 1969.[143]

The philosophy behind the foundation of home hospice care started with the dual care goals of pain control/symptom management and emotional counseling support for patients and their loved ones. Saunders and her team prioritized the care around patient wishes and the needs and suggestions from the professionals who were already actively caring for patients in the community. Community district nurses were included in the care process as well as the creation process of home hospice care.[144] The basic philosophy was the easy part of the equation. The actual structure of community care and the operation details included great thought and problem solving skills. Questions such as the geographical area coverage and to the hours of staff availability were just a few of the starting issues. To work through these issues the team that consisted of two nurses, a part time social worker, and a general practitioner, met as a group to attempt to work through the structural issues. Together they made decisions and each individual using their specific education and influence to hopefully create a well-rounded program.[145]

Referrals were to come from general practitioners or hospital doctors. It was a requirement that all community referrals be initiated by a physician. Once the referral

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[142] Baines, “Origins and Development,” 5.
[143] Baines, “Origins and Development,” 5.
[144] Baines, “Origins and Development,” 5.
[145] Baines, “Origins and Development,” 5.

was received and permission given by the physician, a nurse scheduled a home visit. The team felt it important that a nurse be the first in person contact for the patient and family.[146] It was thought that trust and rapport would start to be built in the first meeting. In this session the community hospice nurse would not just take a detailed medical history and assess current symptoms, but they were also required to evaluate both the patient and family's emotional status, social needs, and spiritual concerns. The information obtained in the initial visit was then brought to the hospice team where a multidisciplinary care plan was created. Prior to the implementation, this plan was discussed thoroughly with the primary physician.

As time went by, the team, as well as the care, began to flow easier. Difficulties were worked out and care roles were more defined. Both the district nurses, as well as the hospice nurses, had their specific duties but there remained a flexibility between the team professionals in order to provide the patient and family with the most appropriate care. The team began to work as just that, a team.[147] Due to the unique relationship between the district nurse and hospice nurse roles, proper education and training became a necessity. Ideal training would have consisted of all nurses having additional training in both community care as well as palliative care. In the first stages of the community program it was not possible to provide all with this level of care. Thus the focus was on the community nurses who were required to spend time on the hospice wards where they obtained clinical experience in symptom management and pain control. It is important to

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[146] Baines, "Origins and Development," 5.
[147] Baines, "Origins and Development," 5.

note that inpatient hospice nurses who were interested in home hospice care were also provided with appropriate community training before entering the patients' homes.[148]

No healthcare program or organization is created without difficulty and home hospice had its own set of rocky foundations. One of the major struggles in the initial stages of home hospice care was found when setting the area limits of where care can be provided. Being a new program, area limits were important so that the hospice professionals were able to provide the most appropriate level of care to their patients and families. A six mile radius was defined as the geographical restriction.[149] Services outside of that radius were limited and telephone contact was provided to the patients who were still physically able to travel to outpatient clinics.[150] I trust these restrictions allowed for the hospice staff to provide the critical patients with their time and attention.

Another decision to be determined was the hours of operation in the community. It was initially clear to the team that dying patients needed access to care support twenty-four hours a day.[151] As I frequently tell my patients and families, the process of death does not limit itself to a daytime hour schedule of nine to five. In my experience it is the evening hours that tend to be the most difficult for patients. There are a number of reasons behind that experience including lack of daily distraction, fears of being alone, and fears of not waking up once asleep for the night. Consequently, the fact that pain and suffering can and often does arise after hours, the hospice team had twenty-four hour on call services. These services allowed patients and families to contact a nurse via

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[148] Baines, "Origins and Development," 5.
[149] Baines, "Origins and Development," 5.
[150] Baines, "Origins and Development," 5.
[151] Baines, "Origins and Development," 5.

telephone. If the patients' discomfort could not be alleviated over the phone, the on-call nurse was willing to provide a home visit. An on-call physician was also always available to support the nurse as needed.[152]

Having a twenty-four hour service was costly but the commitment of the nurses, specifically Barbara McNulty, allowed for the program to provide this very crucial level of care. More than anything this level of care provided the patient and families with a better quality of life.[153] As Baines documents, being the on-call nurse was never easy, especially when they were getting up in the middle of the night to visit an unmanaged patient who was suffering. She believed that a midnight visit was better than finding out in the morning that a patient, whose only wish was to pass away in the comfort of their own home, was unfortunately admitted to a hospital or hospice unit because their pain and symptoms could not be managed in the home during the evening.[154]

As the program grew and time assisted the team in solving their starting problems, the staff also grew. The team worked closely with the Marie Curie Memorial Foundation who helped to provide night nurses. St. Joseph's developed and progressed through the years. During its first year, over 300 patients were cared for in the community, thirty were discharged while thirty-four died in their homes.[155] By 1989, nineteen years into its journey, the number of patients cared for increased. It is believed that the development of palliative care teams in hospital settings who directed the referral process was greatly

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[152] Baines, "Origins and Development," 5.
[153] Baines, "Origins and Development," 6.
[154] Baines, "Origins and Development," 6.
[155] Baines, "Origins and Development," 6.

responsible for these increases. In 2008, statistics show that 1,900 patients were cared for through this program, with 48% of these individuals dying within the home.[156]

It is important to conclude with the inspiration that followed this initial patient care program. The initiation and construction of community hospice care allowed other medical settings to test the waters with their own home hospice programs.[157] Some of the following care programs were the Macmillan Unit for Cancer Care which opened a twenty-five bed inpatient unit as well as a community program in 1975. Also in 1975, St. Luke's Nursing Home in Sheffield created a hospice service which utilized volunteers to drive hospice patients to the unit where their symptoms could be assessed and managed. The first home care program outside of the UK was initiated after a response to a lack of funds for an inpatient unit in New Haven, Connecticut in 1974 run by medical director Dr. Sylvia Lack.[158]

Today the National Hospice and Palliative Care Organization reports that the hospice care goal in America remains to provide "quality, compassionate care for people facing life limiting illness, by providing expert medical care, pain management, and emotional and spiritual support."[159] The team members consist of "physicians, nurses, spiritual counselors, social workers, bereavement counselors, homes health aides, therapists, and volunteers."[160] These support networks not only support the terminal patients, but their family members and loved ones as well. In 2011, there were "5,300

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[156] Baines, "Origins and Development," 6.

[157] Baines, "Origins and Development," 6.

[158] Baines, "Origins and Development," 7.

[159] National Hospice and Palliative Care Organization Facts (February 2017) http://www.nhpco.org/sites/default/files/public/Statisitcs_Research/2015_Facts_Figures.pdf.

[160] National Hospice and Palliative Care Organization Facts 2012 (February 2017) http://www.nhpco.org/sites/default/files/public/Statisitcs_Research/2015_Facts_Figures.pdf.

active programs located in all fifty states including the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands."[161] Through these programs, approximately 1.65 million patients utilized hospice services in 2011; 1,059,000 of those individuals died while receiving hospice care. At the end of 2011, of the original 1.65 million, 313,000 remained on hospice services while 278,000 were discharged alive.

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[161] National Hospice and Palliative Care Organization Facts (February 2012) http://www.nhpco.org/sites/default/files/public/Statisitcs_Research/2015_Facts_Figures.pdf.

Chapter 3

Cultural Influence

End of life in the field of medicine continues to be an unresolved issue. There are a number of factors that influence the complexity of the subject of death and dying in today's medicine. One of these powerful factors is the influence of culture. The impact of culture can come from a number of different directions when related to end of life care. One form of cultural influence is found in an individual's cultural background which shapes their beliefs and decisions during the end stage of their disease process.[162] The cultural experiences and moral beliefs of the medical professionals involved in the patient's treatment can also impact the care provided and the decisions that are made. [163] The systems and environment in which the care and treatment decisions are being made also assist the direction of the level of care and care decisions at hand. It is crucial to incorporate the culture of American medicine when highlighting the systems and environments involved in end of life care.[164] This chapter will elaborate on these cultural factors while highlighting specific values such as religion, language, moral influence, education, race, and gender as other powerful standards that stimulate end of life care and decisions.[165]

As previously stated, it is difficult to discuss the subject of end of life without first discussing the magnitude that patient physician communication plays within this stage of

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[162] Megan Jane Johnstone, "Bioethics, Cultural Differences and the Problem of Moral Disagreement in End of Life Care: A Terror Management Theory." *Journal of Medicine and Philosophy* 37 (2012): 182. doi:10.1093/jmp/jhs009.

[163] M. Larochelle et al., "Hospital Staff Attributions of the Causes of Physician Variation in End of Life Treatment Intensity." *Palliative Medicine* 23 (2009):462 doi: 10.1177/0269216309103664.

[164] Johnstone, "Bioethics, Cultural Differences," 182-183.

[165] Sonia Duffy et al., "Cultural Concepts at the End of Life." *Nursing Older People* 18, no. 8 (2006): 10. doi:10.7748/nop.18.8.10.s8.

illness. Communication involves the medical professionals as well as the patients and their family members. Montgomery defines this form of communication as the "patient narrative."[166] These "narratives" are influenced greatly by the patients who are experiencing them and presenting them.[167] For example, the patients tell their stories based not only on their physical experience but from their personal values that impact this experience. During this explanation it is important to note that the physician's previous professional personal experience, listening abilities, and education will penetrate their professional/medical version of the patient's story.[168] The individual, personal dynamics known as cultural influences of both the patient and the medical professional will serve as the origin and structure of the creation of this unique narrative. As this story is told by the patient, family, and medical professionals it will change and certainly grow.

It is the values and beliefs of the individuals involved that highlight the details of the story that build a foundation of the disease. During end of life cases it is the communication of these values between the parties involved that create the end of life process.[169] It is the opportunity for the patient to openly speak their experiences, wishes, and needs. It is the ability of the health care professionals to hear the spoken and unspoken words provided by the patient and family. It is allowing the loved ones to share their concerns and possibly help both the patients and professionals to understand one another. It is all the individuals who are involved in the care's responsibility to recognize their personal cultural beliefs and values that may influence their role in the

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[166] Kathryn Montgomery-Hunter, *Doctor's Stories: The Narrative Structure of Medical Knowledge.* Princeton: Princeton Univ. Press, 1991.

[167] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 5.

[168] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 5.

[169] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 8-14.

end of life process. The difficult influential component of these stories is the simple fact that it is a human story and that story is coming to an end. The emotion and pure fact that it is the end complicates this already complex struggle. Because of our differences as humans and the struggle of facing end of life issues, our natural ability to communicate openly as patients and professionals may be limited. The unfortunate part of this limit is that we only get one shot at dying; unlike curative medicine, we don’t get a do over or another try at a different treatment. As humans, we all get to die once and if culture/beliefs are not understood during the end of life process, the patient may lose their chance at obtaining the moral value of closure and peace.[170]

To show the complexity of the issue of culture at the end of life it is important to start with some of the struggles seen by physicians in the American field of medicine. Using an American doctor is essential to this explanation because of the diversity of the population they will deal with in their medical career. Unlike physicians in other countries, those employed in the United States will need to have knowledge and the preparation for encounters with many different ethnic cultures, religious morals, and even language barriers. The multifaceted dynamics of cultural competence in medicine continues to be a hurdle as the American melting pot of diversity grows. The patient’s values, beliefs, and culture should be the foundation of their end of life experience. These values are influenced by their experiences, their race, religion, cultural upbringing, age, and education level. Each of these specific factors will influence their end of life treatment, their decisions, and the care they receive during the end stages of their disease. Duffy highlights five cultural examples and their end of life beliefs in her research. The

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[170] Montgomery-Hunter, *Narrative Structure Medical* Knowledge, 124.

five groups that Duffy focuses on are Arab Muslim Americans, Arab Christian Americans, Hispanic Americans, Black and White Americans.[171] She elaborates on the individual factors that influence end of life decisions within these specific populations.[172]

Duffy begins her research with her findings in the Arab community. She finds her results are very similar between both the Muslims and Christian Arabs.[173] Her first focus of discussion is on the importance of the caregivers within this population. Though there were minor differences between male and female perspectives within this group she does not emphasize these disparities. The Arab sample emphasized the importance of family members remaining the primary care givers.[174] They do not believe in placing loved ones into long term care facilities at the end of their lives due to the issues surrounding values of respect and dignity. Nursing home placement in the Arab community is "perceived as the most awful thing that could happen."[175] In fact the benefit of even hospice is unfamiliar to the Arab population and is rarely used as a level of care for their loved ones.[176] In regards to their wishes about open communication toward their disease process and prognosis, many admit to wanting to be told of their impending death but it is a common practice that most end of life concerns are withheld from the patient by the family.[177] It is believed by the family that patients, especially females, cannot emotionally handle their dying status, though they hold the concept of personal closure and peace in high regard. During their end stages of life the Arab

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[171] Duffy et al., "Cultural Concepts End of Life," 11-12.
[172] Duffy et al., "Cultural Concepts End of Life," 11.
[173] Duffy et al., "Cultural Concepts End of Life," 13.
[174] Duffy et al., "Cultural Concepts End of Life," 13.
[175] Duffy et al., "Cultural Concepts End of Life," 11.
[176] Duffy et al., "Cultural Concepts End of Life," 11.
[177] Duffy et al., "Cultural Concepts End of Life," 11.

community chooses to focus on their individual “life accomplishments” while also concentrating on getting their finances in order.[178]

Hispanics, like the Arabs, focus on the importance of dignity and care while believing it is the duty of the family to provide end of life care. On the other hand they were more open and educated on hospital and hospice care.[179] Although Hispanic women were open to alternative treatment options, they were specifically opposed to feeding tubes; to quote one subject “If I can’t eat tortillas no more, forget it. Let me go!”[180] On the contrary, Hispanic men “wanted the least amount of intervention” at their end stages of their disease process, even considering the extreme of “assisted suicide” despite the convictions of their religion.[181]

There were significant differences between Black males and females when it came to their end of life care wishes. Black women were against assisted suicide and opted for all aggressive treatment due to the fear that their physicians could have made a mistake and they had more time to live. However, Black males verbalized their support for assisted suicide, going as far as to say that “Dr. Jack Kevorkian was *the man*, and equated him with *bravery*.”[182] Unlike the previous populations discussed, both Black males and females were vehemently opposed to patient end of life care in the home and preferred care provided in a facility. They believe that end of life care is strenuous and would choose not to be a burden to their loved ones.[183] Though the Black male community favored institutional care they shared a common feeling of distrust in

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[178] Duffy et al., “Cultural Concepts End of Life,” 11.
[179] Duffy et al., “Cultural Concepts End of Life,” 11.
[180] Duffy et al., “Cultural Concepts End of Life,” 11.
[181] Duffy et al., “Cultural Concepts End of Life,” 11.
[182] Duffy et al., “Cultural Concepts End of Life,” 12.
[183] Duffy et al., “Cultural Concepts End of Life,” 12.

physicians referring to them as “the worst bandits in the world who were all about money, money, money.”[184]

The White population within this study shared similar thoughts to the Black population when it came to who was to care for them at the end of their lives. Though they did not feel their end of life care was the responsibility of their family members, and hoped for professional care, they did however, hope to receive their end of life care in their home where family could be close.[185] They were knowledgeable of hospice care and not opposed to receiving the benefit at the end of their life. They had strong beliefs in open communication regarding their disease process and the importance of executing an advance directive.[186] The White population stressed the significance of being free from pain, limited suffering, and having the ability to make personal choices with regards to their end of life care. An interesting difference between White males and females is that the male research subjects verbalized more interest in aggressive treatments than the women. Both genders opposed life support in reference to ventilators.[187]

Duffy included an open ended question on her survey related to medical discrimination to show examples of prejudices that each group may have personally experienced or feared in reference to their care at the end of their lives.[188] Arab Muslim men did not fear discrimination based on their feelings that the care they would receive here in American is drastically superior to the care they would be given in their countries.[189] Christian Arab females did not specifically feel discriminated against but

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[184] Duffy et al., “Cultural Concepts End of Life,” 12.
[185] Duffy et al., “Cultural Concepts End of Life,” 12.
[186] Duffy et al., “Cultural Concepts End of Life,” 12.
[187] Duffy et al., “Cultural Concepts End of Life,” 12.
[188] Duffy et al., “Cultural Concepts End of Life,” 13.
[189] Duffy et al., “Cultural Concepts End of Life,” 13.

shared feelings of discomfort with the importance of remaining covered and respected in hospital settings. They shared their fear of medical professionals entering their room at any time and the anxiety attributed to the need to be fully covered during those occasions.[190] They also shared frustration with hospital visiting hours and how the hours are often not conducive to their family lifestyle mainly because their spouses tend to be store owners and keep very late hours.[191] Black men had limited personal experiences with discrimination but were able to highlight historical references while Black women were more concerned about the AIDS/HIV discrimination toward Black males.[192] White men feared age discrimination and a concern that emergent care is often given to younger individuals first. White women were the only population to directly connect their discrimination fear to end of life care. The fear they shared was that once they are deemed terminal their care would then be neglected.[193]

Duffy's research only highlights five specific communities and their wishes for their end of life care. It is clear just by referencing her study how truly diverse the American population is in regard to health care and specifically end of life care. Duffy did not focus on the aspect of language as a cultural influence but it must be an additional factor to be mentioned. As noted thus far, America is a diverse country and with the large numbers of different immigrants comes a large number of different languages.[194] It is important to highlight language as a cultural aspect in the end of life process because communication can and does play an important role in understanding the patient's story

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[190] Duffy et al., "Cultural Concepts End of Life," 13.
[191] Duffy et al., "Cultural Concepts End of Life," 13.
[192] Duffy et al., "Cultural Concepts End of Life," 13.
[193] Duffy et al., "Cultural Concepts End of Life," 13.
[194] Lavera Crawley, "Racial, Cultural, and Ethnic Factors Influencing End of Life Care." *Journal of Palliative Medicine* 8 (2006): 64. doi:10.1089/jpm.2005.8.s-58.

as well as informing them of their diagnosis/prognosis and assisting them in the dying/healing process.[195] From my own experience I know that the death and dying conversation is never easy, but it can be made even more complex when there is a language barrier. The United States Department of Health and Human Services has even created a specific set of guidelines mandating linguistically appropriate services in health care settings.[196] The importance of these services is to provide patients and families with access to individuals who speak their native language. These services are a crucial component to making end of life conversations easier and also eliminate the use of family members as translators. Using family to translate end of life conversation can put the patient at risk for not absorbing the information and/or having their personal decisions swayed by their loved ones.[197]

Cultural differences are not only found in the patient and their families but they can also be found in the belief system of the physicians and medical professionals. It is not only important for our medical professionals to have cultural competency regarding the individuals they treat, but they must also have a true grasp of their own culture, individual beliefs, and personal values.[198] They must have the ability to recognize their personal beliefs, culture, and values but they must also have a basic understanding of how these factors will affect them in their job as a medical professional and how best to remain as neutral as possible in spite of that.

It is crucial for medical professionals to have this basic personal understanding, but they need to be in tune with their feelings regarding death and the dying process. As

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[195] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 124.

[196] Crawley, “Racial, Cultural, Ethic Factors,” 64.

[197] Crawley, “Racial, Cultural, Ethic Factors,” 64.

[198] Duffy et al., “Cultural Concepts End of Life,” 14.

a professional in the end of life field, it has become apparent in my experience that personal knowledge, emotional awareness, and personal end of life beliefs can and will affect the care one provides to their patients and their families. It is essential to comprehend personal feelings during end of life care as a professional in order to provide the appropriate care the patient and families need and deserve.

Hegedus, Zana, and Szabo used their research to study the effects of end of life education on personal perspectives of medical students and health care workers. It was their belief that increased education within this population will not only positively affect the care these individuals provide but will also influence their understanding of their own perception and/or fears of end of life issues.[199] This study highlighted "death anxiety" within a sample of medical students and health care professionals with the use of the "Multidimensional Fear of Death Scale" used to measure the given anxiety within the individual subjects.[200] After the anxiety levels were measured the subjects attended a course pertaining to death and end of life care issues.[201]

The death anxiety measures showed significant levels of fear around many areas of death. The most significant results were seen in the fear of death amongst significant others and fear of the death process. Both of these anxiety levels decreased after the completion of the educational course.[202] Women showed a significantly higher measurement for their death anxiety overall, while the older subjects reported lower levels of death anxiety.[203] Overall the educational death course provided a decrease in

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[199] K.Hegedus, A. Zana, and G. Szabo. "Effect of End of Life Education on Medical Students' and Health Care Workers' Death Attitude." *Palliative Medicine* 22 (2008): 265. doi:10.1177/0269216307086520.

[200] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 265.

[201] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 265.

[202] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 265.

[203] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 268.

death anxiety. These results show a significant importance surrounding the need for both education around death and dying as well as the importance of medical professionals' awareness of their personal feelings surrounding these issues.[204] It is clear that medical professionals need to recognize their own attitude toward death and dying and Hegedus et al. believe that personal awareness with proper education will provide our professionals with the needed tools to provide appropriate end of life care. Their findings support the understanding that when professionals experience death with patients they are forced to face their own death anxieties.[205] They not only recommend education, but after discussing their research results, they go on to advise case discussions amongst professionals to support their coping skills and mental health status.[206]

The above study is a reminder to the medical field of the great impact that death and dying have on our treating professionals. It is important to acknowledge that physicians and medical professionals still remain human, and death and dying is a scary, emotional part of being a human. As a professional in the field, it is something I try to keep in mind daily as I provide the best care I can. I know that not only does my knowledge and understanding affect how I do my job but so does my upbringing, culture, religion, and especially my own personal fears. Though my experience is anecdotal I know that continued education, discussion, and analysis of my experience and awareness of my coping process help me to provide better non-biased care to my patients and their families, who only deserve the best.

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[204] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 268.
[205] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 268.
[206] Hegedus, Zana, and Szabo, "Effect of End of Life Education," 268.

I fear that our current culture of medicine and end of life has isolated the physician's and medical professional's emotions from the equation of the care they provide. This may be a colossal flaw in the American dynamic of medicine, or should I say, the current medical culture. Not only does the individual professional's culture play a part in the end of life care they provide but it is the culture of today's medicine that also affects end of life care in America today. The culture of end of life care is influenced by a number of factors ranging from the availability and knowledge of treatment options, the re-imbursement of these benefits, the communication skills of the medical professionals, the minimal use of advance directives and DNRs, and even the fear of legal ramifications. These factors take the term "culture" to a different level. Outside of the diversity of the American melting pot, medicine itself has created its very own culture and end of life care has its very own role in it. The next section of this chapter will illustrate the facets of end of life care within the culture of American medicine today and how some of those facets may be approved upon to continue to enhance the benefits of appropriate end of life care to all.

Consent is a household word in the field of American medicine. It is no longer a concept but a regulation and right of the patient to be given complete information in regards to their health care condition.[207] The right to individual autonomy has become a strong dynamic in all care but can become especially important during the end stages of life. The influence of patient autonomy is a simple example of how our medical world has created its own culture. It has become an individual moral right in the eyes of American medical professionals. However, is autonomy a moral right believed by all

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[207] Tom Beauchamp and James Childress. *Principles of Biomedical Ethics.* 6th ed. New York: Oxford University. Press, 2009.

other non-American populations who happen to receive their medical care here in the states? Midgley terms this dynamic "the imperial model of ethics."[208] This model describes the American cultural belief that our moral values are not only superior but they are placed on others as a right.[209] As Duffy illustrated in her research, American rights are not universal and other subcultures may not share similar values. There are many populations who believe that withholding medical information from their loved ones is the correct action to take and is the highest sign of respect.[210] Johnstone elaborates on the significant need for current medical ethics in America to find a balance between "cross cultural" views/wishes prior to imposing the American way.[211] She believes that only when we are able to accept others' differences, especially at the end of their lives, can we truly say we are providing the most meaningful, deserved medical care.[212]

Johnstone goes further to explore the concept of end of life fear and the terror experienced prior to death as a sense of harming the patient.[213] In the field of medical ethics we also stress the principle of nonmaleficence, otherwise known as doing no harm.[214] It is possible that there are individuals who feel harm from their fear of death and the knowledge that their death is near. Not allowing an open discussion about these innate fears can result in the suffering of unnecessary pain for these patients. Johnstone expresses personal concerns regarding the use of the moral principles of bioethics alone to answer questions at the end of life. She argues that medical professionals need further

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[208] Johnstone, "Bioethics, Cultural Differences," 183.
[209] Johnstone, "Bioethics, Cultural Differences," 183.
[210] Duffy et al., *"*Cultural Concepts End of Life*,"* 12.
[211] Johnstone, "Bioethics, Cultural Differences," 183.
[212] Johnstone, "Bioethics, Cultural Differences," 183.
[213] Johnstone, "Bioethics, Cultural Differences," 183.
[214] Beauchamp and Childress*, Principles Biomedical Ethics, 153*.

engagement with cross cultural values if they are going to provide culturally appropriate end of life care.[215]

Johnstone's focus can be attributed to many levels of illness but her attention to death and dying is essential because of the natural terror of the death process and the mere fact that death is a human condition.[216] It is a significant human process that all individuals will face, for both their loved ones and themselves. Death provides individuals with "worth and moral significance."[217] Death occurs everywhere and it is not fair to believe that American medical philosophies are the only appropriate way to confront the struggle of the dying process. To impose unknown views on an individual can enhance an already difficult process.[218] Research supports that neglecting cultural views not only affects the dying process but it also results in "inferior" patient care.[219]

It is important to note that there may not be a clear answer to the question of how to deal with the American culture and other beliefs, but tools have been created to assist with the diversity of individual end of life wishes. Examples of those tools are advance directives, living wills, DNRs, and POLST forms. These documents are influential factors in the culture of American medicine since they are structured to assist the medical professionals in providing the care in line with the patient's wishes.[220] Some of these documents alone aren't even widely used in other countries. For example, the use of advance directives in Ireland is limited and not a focus of the medical professionals in

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[215] Johnstone, "Bioethics, Cultural Differences," 183.

[216] Johnstone, "Bioethics, Cultural Differences," 186.

[217] Johnstone, "Bioethics, Cultural Differences," 186.

[218] Johnstone, "Bioethics, Cultural Differences," 190.

[219] Harvey Bosma, Lars Apland, and Arminee Kazanjian, "Cultural Conceptualizations of Hospice Palliative Care: More Similarities than Differences." *Palliative Medicine* 24, no. 5 (2010): 510. doi:10.1177/0269216309351380.

[220] Johnstone, "Bioethics, Cultural Differences," 191.

that country.[221] There has been a focus on these documents and end of life care competency in medical settings and in medical education. This is to provide those in the field with a way to decrease the gap between the American culture of medicine and the diverse cultures receiving care in the United States.[222]

The focus on the documentation of end of life wishes is important. In addition, it is just as crucial for American medical professionals to be fully educated on the supports and benefits available for patients at the end stages of their lives. Both hospice and palliative care are treatment options available in the American medical culture. It is vital for our professionals to have a sound understanding of these options to be able to share their knowledge with their patients and recognize that many populations may not have a clear understanding of these options or the fact that they exist.[223] There are a number of reasons behind specific populations' limited knowledge and use of these services. Culture is surely one of them, as well as age, education, geographic location, and healthcare experience.[224]

As a professional in the field of end of life care, the concept of knowledge of end of life services amongst our medical professionals is important for me. It is a part of our American medical culture where I feel we are greatly lacking. I find that in my experience the understanding of appropriate end of life care services is limited by the medical professional's ability to discuss end of life issues in general. I agree with

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[221] Joan McCarthy, John Weaver, and Mark Loughrey, "Irish Views on Death and Dying: A National Survey." *Journal of Med Ethics* 36, (2010):454. doi:10.1136/jme.2009.032615.

[222] Bosma, Apland, and Kazanjian, "Cultural Conceptualization Hospice Palliative Care," 520.

[223] Bosma, Apland, and Kazanjian, "Cultural Conceptualization Hospice Palliative Care," 510.

[224] Susan Miesfeldt et al., "Association of Age, Gender, and Race with Intensity of End of Life Care for Medicare Beneficiaries with Cancer." *Journal of Palliative Medicine* 15, no. 5 (2012): 548. doi:10.1089/jpm.2011.0310.

Montgomery's feeling that our focus on treatment, diagnosis, and cure has pulled us away from patient/ physician conversation, especially at the end stages of a disease process.[225] From someone who has death and dying conversations daily, I believe that it is the emotional foundation of the conversation and its difficulty that places the limits on the medical professionals' initiation of the necessary conversations.

As the education surrounding these limits has increased in medical education, the level of education has remained focused on the American end of life process for some time and only recently included cross cultured "variations of the dying experience."[226] The educational focus very much remains motivated on providing our medical professionals with cultural competence. Though this is necessary knowledge, Doorenbos et al. share concerns regarding the intensity of the education provided.[227] These researchers concentrate on the value of having a deep, specific understanding of the diverse beliefs that can and will be found in the patients that medical professionals will encounter.[228] They highlight five factors they believe are necessary for proper care education to occur and to initiate growth within the culture of American medicine in order to provide its people with the care they deserve. The first is the element of not only the culture that the patient is currently living in, but the culture and environment that they were raised in.[229] Through educating professionals on the importance of this factor they will be able to construct a deeper foundation for the patient's story. The second educational factor is to acknowledge the culture that the patient has created around their

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[225] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 124.

[226] Ardith Doorenbos, Sherylyn Briller, and Elizabeth Chapleski, "Weaving Cultural Context into an Interdisciplinary End of Life Curriculum." *Educational Gerontology* 29 (2010): 406. doi:10.1080/713844358.

[227] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 406.

[228] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 406.

[229] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 406.

dying experience. Death can inspire change in the individual who is facing it, and it is crucial for the professionals to be aware that a patient's belief system could be influenced by their impending death alone.[230] Not only can an individual's belief system be an influence, but the environment where the patient chooses to receive care can also influence the culture surrounding their death, such as a patient newly placed into long term care or an inpatient hospice unit.[231] The third factor of education that was discussed earlier in this chapter but must continue to be a focus of medical education is the culture of the professional and the care staff they will be working with. The importance of this factor is to train the professionals to be in tune with their preferences and how their beliefs might affect the care they will provide to their patients.[232] It is also important to emphasize the need for the professionals to be willing to engage with other care providers who may have different values than themselves.[233] The fourth educational issue to be stressed within medical education is to have knowledge and awareness of the environment and culture of the setting they will be working in.[234] For example, from my personal experience, this could include working in a religious organization that has restrictions on end of life decisions, like removing an already placed feeding tube or restricting feedings in a dying patient. The final component of the American medical education is to be aware of the biomedical influence. It is imperative that medical education include the impact of treatment and technology as well as the medical ethics principles utilized in the field of medicine in American society.[235] However, it must be

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[230] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 406-407.
[231] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 407.
[232] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 407.
[233] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 407.
[234] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 407.
[235] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 407-411.

incorporated in this section of education that the principles of medical ethics may not be universally important to all.[236]

In connection to the limited conversation/education surrounding end of life care options in the American medical culture is the under use of the benefits like hospice and palliative care. The highest medical costs in America are a result from aggressive care at the end of life. Radwin, et al. documents that in 2002, 77% of healthcare costs of expired Medicare recipients were results of aggressive care received within the last year of the recipient's life.[237] While a more recent study, published in 2010, reports that "32 % of hospitalized patients over the age of eighty-five use intensive care services at the end of their lives."[238] The high numbers of aggressive care use in these statistics imply that necessary end of life conversation is not being had, nor are the appropriate patients being referred to end of life programs like hospice and palliative care. After reading the results of these studies I cannot help to wonder if it is our medical culture, with its professional lack of knowledge of end of life options, or the lack of appropriate honest end of life communication from our physicians, that causes such high costs at the end of life. I believe that both concerns do play a part in the issue of over treatment at end of life. I also question the limited access to end of life services due to insurance limitations, location of service providers, reimbursement for aggressive treatment, and limited coverage for custodial care, as other influences on the underutilization of hospice and palliative care services. Do we as professionals choose to limit the information on care

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[236] Doorenbos, Briller, and Chapleski, "Weaving Cultural Context," 411.

[237] Laurel Radwin et al., "Effects of a Patient/Family-Centered Practice Change on the Quality and Cost of Intensive Care: Research Protocol." *Journal of Advanced Nursing* 76, no. 1 (2010): 216. doi:10.1111/j.1365-2648.2010.05448.x.

[238] Radwin et al., "Effects Patient/Family Centered Practice," 216.

options to patients because those services may not be available to them as a result of limited funding, no insurance, and community access?

The benefit of hospice care is traditionally a Medicare benefit. My profession as a hospice employee has provided me with the education that though insurance coverage like Medicaid and commercial insurance policies provide versions of hospice care, it was Medicare which first implemented coverage for the service. Medicare has strict limitations around the care covered under the hospice benefit. Many of these regulations can be found in alternate insurance carriers who follow the footsteps of Medicare guidelines. One of the limitations that I find deters patients and their families from accepting the benefit of hospice is the limited aide care given to individual patients. Medicare will only provide coverage for personal care needs.[239] Unfortunately, in my experience, as a patient progresses through their terminal process they tend to need safety care also known as custodial care. Custodial care can be explained as care needs to assure patient safety. Many patients get to a status in their disease progression where they become confused and/or unsafe to be alone. Though the patient may not need constant personal care needs yet, they still need an individual present to maintain safety measures for them. Medicare does not consider this to be a necessary end of life need and does not cover any additional care for custodial needs. This places responsibility of custodial care on loved ones to either provide the care themselves or pay for it privately.[240] This can become a heavy burden for those individuals for a number of reasons. For example, my experience has confirmed that many of the caregivers in end of life situations are children and grandchildren, many of whom need to work to support

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[239] Crawley, "Radical, Cultural, Ethical Factors," 63.
[240] Crawley, "Radical, Cultural, Ethical Factors," 63.

their families financially. When they are caring for a terminally ill loved one it becomes very difficult to provide full time custodial care while maintaining a full time, even part time job.

Many of the studies included in this chapter have focused in part on end of life decisions in relation to the patient's reported wishes. Larochelle, Rodriguez, Arnold, and Barnato report that their research supports that treatment intensity in end of life situations are greatly influenced by the physician.[241] They found a number of influences that affect the physician's decision to continue treatment in terminally ill patients. These influences continue to highlight the culture of end of life care in American medicine. Some of their findings were supportive of previous findings discussed in this paper, for example the culture, values, religion, and beliefs of the physician but they also discussed other influences from the environment of American medicine today.[242] Those factors are "fear of failing as a physician, training, role perceptions, experience, and response to incentives."[243] In the culture of American medicine, physicians continue to acquire a great deal of respect in reference to their role as healers. To discontinue or withhold medical treatments at the end of a patient's life can not only be seen by the physician, but by their patient and patient's families, as failing to fulfill their duty.[244] In connection to the physician's fear of letting a patient down they may also see themselves playing a specific role in the patient's treatment story. These results illustrated a physician perception of themselves as the individual whose job is to promote treatment, technology,

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[241] Larochelle et al., "Hospital Staff Attributions," 460.
[242] Larochelle et al., "Hospital Staff Attributions," 464-465.
[243] Larochelle et al., "Hospital Staff Attributions," 465.
[244] Larochelle et al., "Hospital Staff Attributions," 465.

and medicine.[245] By terminating treatment, a physician may feel they are abandoning their duty, therefore abandoning their patient.[246] Both their training and past experience with end of life cases can also influence their ability to accept the terminal illness and resort to comfort measures. Through proper training and personal experience, physicians should learn the limitations of aggressive treatment and the trajectory of the disease progression. This knowledge may provide them with the comfort to share this knowledge with their patients while opting to cease futile treatments.[247]

The conclusion of this research also highlighted the concern of "incentives" versus "disincentives."[248] The incentives were described as the possible financial gains physicians may attain due to "fee for service" as aggressive treatments are continued.[249] The disincentives were illustrated by the common fear of legal ramifications of ending/withholding medical treatment.[250]

The latter two factors discussed in this study, in my opinion, are extremely relevant to the subject of the culture of American medicine. The matter of malpractice in medicine has grown to be a universal fear amongst not only physicians, but all medical professionals and medical organizations.[251] The system of malpractice in the field of medicine has two objectives: to provide compensation to a patient for undue harm and to attempt to minimize and prevent "careless behavior" by medical professionals.[252] With

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[245] Larochelle et al., "Hospital Staff Attributions," 465.

[246] Larochelle et al., "Hospital Staff Attributions," 465.

[247] Larochelle et al., "Hospital Staff Attributions," 465.

[248] Larochelle et al., "Hospital Staff Attributions," 465.

[249] Larochelle et al., "Hospital Staff Attributions," 465-466.

[250] Larochelle et al., "Hospital Staff Attributions," 465.

[251] Allen Kachalia, Niteesh Choudhry, and David Studdert, "Physician Response to the Malpractice Crisis: Defense to Offense." *Journal of Law, Medicine, and Ethics* 33, no. 3 (2005): 416. doi:10.1111/j.1748720X.2005.tb00509.x.

[252] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 416.

an increase in the number of medical law suits there has also been an increase in the need for liability insurance and an increase in the cost of this said insurance.[253] Malpractice concerns are absolutely not limited to end of life care cases but can be a common fear that drive the physician decisions to continue aggressive treatment.[254] The factor of the legal component to medical care and the current cost on availability of reasonable liability insurance has changed the physician response to a possible suit, from advocacy and lobbying to more extreme even unethical terms. Some physicians have chosen to "go bare," in other words, have chosen not to obtain adequate liability insurance.[255] "Protests and walkouts" have occurred with hopes to achieve a "malpractice reform."[256] An additional increase to patient fee charges have also been implemented as a way to offset the cost of increased insurance costs.[257] There was even a "plaintiff database" which included patient information of individuals who were known to sue for medical damages.[258] This database is no longer available after the ethical and legal concerns that arose with it. As noted here many of these responses seemed to toe the ethical line but the most extreme response is that of individuals who protested that physicians have the right to deny treatment to "plaintiff attorneys and their families" unless under emergent conditions.[259]

The concern of medical malpractice and the response to the circumstance of limited availability of liability insurance helps to highlight another subject of concern for the culture of American medicine. This concern is the financial element to the healthcare

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[253] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 416.
[254] Larochelle et al., "Hospital Staff Attributions," 467.
[255] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 419.
[256] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 423.
[257] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 425.
[258] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 425.
[259] Kachalia, Choudury, and Studdert, "Physician Response Malpractice Crisis," 419.

environment. The motivation behind legal suits, as well as the recent increase in malpractice insurance costs, both include financial gain in the equation. This leads to the discussion of the incentive illustrated in research provided by Larochelle, et al.[260] The incentive of financial gains, through the use of aggressive treatment that can be found in many medical situations, can be a frequent concern observed in end of life care. Wright and Katz focus on this issue with the use of physician perspective on treatment costs at the end of life. They highlight quotes from physicians discussing their personal frustrations with the limitations of end of life care benefits, such as hospice, which include their reimbursement. Wright and Katz quote Dr. Thomas Smith of the Virginia Commonwealth University-Massey Cancer Center in reference to his patients who opt for hospice care, "I can't do anything but adjust pain meds and hold hands. These are wonderful things, but they won't keep my office running."[261] They continue to report that interviews with numerous hospice directors imply that cancer physicians "abandon" their patients once they have opted for the benefit of hospice care and can no longer continue visiting the physician in the office.[262] Medicare's hospice benefit reimburses the hospice company with a minimal daily rate. That rate is to cover nursing, social work, personal care aide, and chaplain services as well as medication and medical equipment. With this limited daily rate barely covering these services it is up to the company to restrict the forms of treatment a patient can continue under the traditional Medicare coverage.[263] Some hospice companies are attempting to provide what is being

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[260] Larochelle et al., "Hospital Staff Attributions," 467.

[261] Alexi Wright and Ingrid Katz, "Letting Go of the Rope: Aggressive Treatment, Hospice Care, and Open Access." *The New England Journal of Medicine* 357, no 4 (2007): 324. doi:10.1056/NEJMp078074.

[262] Wright and Katz, "Letting Go Rope," 324.

[263] Wright and Katz, "Letting Go Rope," 324.

called “an open access hospice benefit” to make an effort to provide aggressive palliative treatment options available while including the involved physicians in an attempt to bridge the current care gap. The option of open access programs remain limited to the companies that are large enough to cover the financial loss of providing these extra levels of care, therefore they continue to be few and far between.[264] Based on the information reported by Wrights and Katz, the financial reason behind a physician’s decision to continue treatment at the end of life can be identified. It is also recognized that it may be a result of the culture of American medicine.

It connection to circumstance of continued aggressive treatment at the end of life, it is essential to elaborate on the dynamic of quality of life in the end stages. The importance of emphasizing quality of life can directly correlate to aggressive treatment. Treatment can cause additional physical suffering for the patient while forcing family to observe this further suffering and increasing patient care needs.[265] As medicine has progressed and treatment options increased, our understanding of the end of life condition has also changed. Studies have been implemented to attempt to measure an individual’s quality of life.[266] It is difficult to create a flawless tool to measure such a personally influenced topic. A project known as the “Toolkit” was completed in 2000. It highlights a number of factors that influence quality of life at the end stages.[267] The components found by this project to be of importance, with regard to quality of life at the end of life, are “pain management, functional status, sense of emotional well-being, sense of spiritual

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[264] Wright and Katz, “Letting Go Rope,” 325.

[265] Virginia Tilden et al., “Measurement of Quality of Care and Quality of Life at the End of Life.” *The Gerontologist* 42, no. 3 (2002): 72. doi:10.1093/geront/42.suppl_3.71.

[266] Tilden et al., “Measurement Quality Care,” 72.

[267] Tilden et al., “Measurement Quality Care,” 72.

fulfillment, and satisfaction with care quality."[268] The reason for including these findings of the Toolkit project is to highlight the variation between the quality components. Through my experience in the medical field, I fear that there is an unfair focus placed on physical comfort. Of course in the Toolkit list, pain is the first element to quality of life, but I feel it important to draw specific attention to the others. Even as a hospice professional I tend to refer to the hospice benefit as "comfort measures." But I realize there should be so much more to it. End of life care should encompass pain control as well as the other Toolkit facets such as emotional well-being, spiritual peace, and functional status. These have just as much barring on one's life quality as physical comfort does. The Toolkit is just the start of the advanced research in the realm of measuring the quality of life in its end stages. Tilden and her fellow researchers emphasize the great importance in the requirement for new and improved tools to measure life quality and to continue to utilize these tools particularly to better the lives of the terminally ill.[269]

The end stages of an individual's illness and life is a personal event and should be experienced in a private setting with their significant loved ones present if they wish. In the American medical environment, privacy and confidentiality should be critical features during the end of life experience. It is unfortunate to say that these factors are not always considered at the time of one's death. Medical situations such as learning of a terminal illness, to where we receive treatment, to where the dying experience occurs, can show us some of the limitations on privacy. Arthur Frank shares some of his experiences in his

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[268] Tilden et al., "Measurement Quality Care," 72.
[269] Tilden et al., "Measurement Quality Care," 71.

memoir “At the Will of the Body: Reflections on Illness.”[270] He describes one of his first admissions to the hospital prior to beginning his treatment. He realized his privacy was not a matter of importance when he learns that his serious diagnosis was posted on his hospital room door. The devastating element of that diagnosis, being placed under his name on his hospital room door, was not only that everyone else in the facility now knew his diagnosis, but it was actually the first time he learned of his diagnosis of lymphoma. Prior to reading that term on his door he was yet to be informed of his illness.[271] He even began to be referred to as the “specimen in room 53.”[272] These are just the start of this individual’s experience with his privacy being stripped away at a time when he needed it most. Throughout his specific story Arthur Frank continues to confront stages of his illness where he is reminded that his privacy is of no importance. He highlights the details of the treatment unit where he receives his chemotherapy. He finds himself behind a curtain meant to shield him from the rest of the patients. In his view the curtain did not do its job, especially when the medical staff interviewed him and his wife behind the magic curtain. These professionals did nothing to convince Frank and his wife that his privacy mattered. They asked personal, intimate questions of both Frank and his wife without lowering their voices. They absolutely did not provide the environment or the compassion of privacy necessary for this couple to answers these important questions honestly.[273]

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[270] Arthur Frank, *At the Will of the Body: Reflections on Illness.* Boston: Houghton Mifflin Company, 1991.

[271] Frank, *At Will Body,* 52.

[272] Frank, *At Will Body,* 52.

[273] Frank, *At Will Body,* 105-106.

Of course Frank's story is his memoir and personal memories but as a professional in this field I cannot believe that Frank is the only patient to confront the issue of privacy and inappropriate environmental settings within their illness experience. The addition of the end of life dynamic to this concern adds another level of discomfort to the problem. There is an additional element of different emotions that come with death and dying. This dynamic creates a concern for me, especially as a mental health professional. I believe that the lack of respect for human privacy specifically at the end of our lives can affect our ability to heal emotionally and reach the level of personal peace needed to die with personal respect and dignity. Even just the impact of the environment where an individual learns of their terminal illness can affect their ability to cope with their disease progression. Another example is from an additional memoir, "A Whole New Life: An Illness and a Healing," written by Reynolds Price who learned of his deadly spinal tumor while on a stretcher in the hall way of a crowded hospital unit.[274] I can only imagine the emotional factors that come with finding out devastating news as Price learned. I believe that by providing that shocking information in a setting where others can hear and subsequently watch your response must enhance those emotions, while probably adding feelings that could have been avoided by exercising a patient's right to privacy and confidentiality.

As this chapter continues, it is apparent that the experience of one's end of life process is most definitely influenced by experiencing it in the culture of American medicine. But even the concept of what is considered an end of life diagnosis is controlled by this said culture. Miesfeldt et al. focused their research on strictly end of

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[274] Reynolds Price, *A Whole New Life: An Illness and a Healing.* New York: Schribner, 1994.

life care in cancer patients. By focusing on patients with cancer there is an added element of treatment dynamics like chemo and radiation that are not components with other diseases.[275] When I share with people what I do for a living, I get many responses surrounding the topic of cancer. I can't help but think that our society focuses greatly on cancer as the main culprit of end of life diseases. In today's medical culture there are a number of other diseases that are also common causes of death such as cardiac conditions, neurological diseases, HIV/AIDS, and even failure to thrive.[276] It is also important to emphasize that what American medicine defines as end of life illness is very different from other cultures. For example, the use of "artificial feeding" is a very common treatment options for many medical conditions here in the United States while there are a number of countries that do not use tube feedings as a medical intervention.[277] Here in America a brain injured patient may not be seen as an end of life case because of our willingness to utilize a feeding tube in such a situation. In other cultures the condition of a brain injury may be seen very differently. What American medical professionals consider terminal conditions have a lot to do with the treatment options available and most medically defined treatments can be found here in the United States. The view of illness connected to treatment is influenced by our American medical culture and continues to influence what is considered end of life. It is also important to include that frequency of disease prevalence can be associated with the life style and culture of the individual. Many conditions are more prevalent in specific cultures. For example, African Americans are at a higher risk for illness like "diabetes, hypertension, end stage

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[275] Miesfeldt et al., "Association Age, Gender Race," 548.

[276] Robert Blank, "End of Life Decision Making Across Cultures." *Journal of Law, Medicine, and Ethics* 39 no. 2(2011): 202. doi:10.1111/j.1748-720X.2011.00589.x.

[277] Blank, "Decision Making Across Culture," 202.

renal disease, cardiac disease, and stroke."[278] The frequency of these diseases in this population can be linked to their genetics as well as their life style, insurance coverage, and geographical location.[279]

Before concluding this chapter it is critical to note that end of life care, though in a majority of research and interpretation above focuses on adults and the senior population, it unfortunately affects children and the pediatric field of medicine too. The culture surrounding pediatric end of life care is altogether different. We continue to lean on the principles of bio medical ethics to help medical professionals to provide the appropriate care for their patients. When the patient is a child the support gained from some of the principles change.[280]

The principle of autonomy is not as easily utilized in the care of terminal children. In America we provide the children's parents or surrogate the right to make medical decisions for the patient. Often because of the parent/surrogate's right, the child, who is suffering through the disease process, is left out of the equation.[281] There are a number of reasons why children are not often involved in the decisions regarding their end of life care. Those reasons range from the child's limited capacity to understand their condition and future, the parents own personal emotions and fears, the concerns over protecting the suffering child, the cultural beliefs of the family, and even concerns regarding the child's siblings.[282] When a child is suffering from a terminal illness there are a number of influences on others involved with the child and those influences hold a different weight

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[278] Eric Krakauer, Christopher Crenner, and Ken Fox. "Barriers to Optimum End of Life Care for Minority Patients." *JAGS* 50 (2002):186. doi:10.1046/j.1532-5415.2002.50027.x.

[279] Krakauer, Crenner, and Fox, "Barriers Optimum End of Life,"186-187.

[280] Joanna Whitty-Rogers et al., "Working with Children in End of Life Decision Making." *Nursing Ethics* 16, no. 6 (2009):744. doi:10.1177/0969733009341910.

[281] Whitty-Rogers et al., "Working with Children," 744.

[282] Whitty-Rogers et al., "Working with Children," 744.

than the burdens that come with adult end of life cases. The reason for that different power is simply because of the "human fact that a child should not die before a parent, it is an unnatural event."[283]

While autonomy becomes a tricky principle in end of life care with children, so does the principle of non-maleficence. By attempting to protect a child from the true understanding of their terminal illness, a care giver or provider can restrict the child from having the opportunity to voice their feelings toward their disease process, including their fears.[284] Parents/surrogates, even medical professionals, experience their own gamut of emotions, fears, and grief and their fear of placing similar feelings on a child compel them to withhold information and decision capacity from the sick children. Whitty-Rogers et al. report the harm that can come with silencing a sick child by taking their right to know and learn about their condition.[285] Not only is it necessary to allow them to cope and grieve in the manner they choose, knowledge of their condition also allows them the opportunity to share wishes for the end of their life and gain closure within their personal relationships.[286]

Whitty-Rogers et al. continue to stress the limits in the conversations we have with our terminally ill children. They highlight research that support having conversations about death with terminal children. The study investigated experiences of parents who had lost a child to a fatal disease. The results shared that the parents who chose to speak with their dying child about death prior to their death experienced no regrets while the families who did not stress this discussion wished they had prior to

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[283] Whitty-Rogers et al., "Working with Children," 746.
[284] Whitty-Rogers et al., "Working with Children," 750.
[285] Whitty-Rogers et al., "Working with Children," 746.
[286] Whitty-Rogers et al., "Working with Children," 752.

losing their child.[287] Whitty et al. stresses the importance of conversation and the discussion of end of life care issues with children. They also place a bulk of the responsibility of these conversations on the professionals caring for the children, especially the nurses.[288] As Montgomery might agree, the sick children in these cases have the right to help create the narrative of their illness especially at the end of their short lives.[289]

It is important to recognize in all of American medicine, that our current bio medical ethics are just a guide to providing appropriate care especially in end of life care situations. Whitty and her colleagues provide use with how gray our ethics really are when discussing the culture of American medicine and end of life care in children. The reality is that end of life care is affected by our current ethics, and though they may not give us all the answers, they do help direct us in helping care for our patients as best we can. It is important to utilize our ethics especially at the end of life because a patient's end stage disease process is their last experience and they deserve the right to complete it the way they chose.

This chapter started out with a focus on culture and how diversity affects medical care. We learned through Duffy how different populations handle end of life care in their families. Duffy only provided us with five subgroup examples.[290] Her research is just the beginning dialogue when it comes to the differences in culture, values, beliefs, and religion. Continued studies would provide us with details, not only on end of life acceptance in different cultures, but acceptance of medical treatment too.

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[287] Whitty-Rogers et al., "Working with Children," 751.
[288] Whitty-Rogers et al., "Working with Children," 754-756.
[289] Montgomery-Hunter, *Narrative Structure Medical Knowledge,* 124.
[290] Duffy et al., "Cultural Concepts End of Life,"10.

The direction that Duffy's research started within this chapter took a turn as I continued to elaborate on my knowledge of end of life care and the research that was found. I soon realized that outside of the impact of different cultures in medicine, America had its own version of culture in its medical structure. Though it is crucial for our medical professionals to have professional cultural competency in reference to the diverse people they will encounter, it is just as important to be aware of how our American culture influences our professionals.

American culture of medicine influences the populations we help in more ways than we realize. The structure of our medical environment has many outside influences that aren't even related to true medicine. We see those factors in the financial component of medicine, the legal influence, and the role of the organizations that provide medical care. There is a business segment to medicine that was not a part of medicine's history. This part appears to weigh heavy on the practice of medicine as we have seen in this chapter.

In my opinion the influence of the current American culture of medicine starts with our medical professionals. It starts with the person behind the stethoscope, the personal values, beliefs, religion, culture, education, and experience of that one person and those individual factors can and will affect the care decisions made for their patients. Their education and skills will either emphasize their values or hide them. Both can affect the patient either positively or negatively depending on the situation at hand. These professionals must not only have an understanding of the patient's culture and values, but they must be trained to identify and control for their own influences. If they are able to actively connect to the values that influence them as an individual, they will hopefully be able to use their beliefs to unite with the patient and provide a positive patient/physician relationship. Also they must be able to acknowledge their values well enough to step back from them, keeping in mind that it is the patient's values that come first.

There are a number of aspects of American medicine that should remain in place and will continue to assist us in providing the best care for our society whether it is end of life care or not. There are also a number of aspects that need work, or even to be eliminated from the current medical culture. This chapter highlights a number of the things we are doing right and wrong when it comes to patient care. I continue to hope for growth in education and knowledge of end of life care and care benefits, but if I could choose one aspect of end of life care that needs the most work I would need to agree with Montgomery. Our entire lives are our own stories and the end is just as important as how we go there. Sometimes I feel that because someone is at the end stages of their lives we forget that they are still important and so is their story. Sometimes it's just the process of telling the story and being heard that helps us heal from the fear of our life ending.[291]

I believe that there needs to be an increase in communication on all levels and again I think we need to start with the medical professionals. It is important that they are taught the skills of listening, hearing, interpreting, and supporting. These are tools that are critical to the end of life process, without each one the patient is at risk for missing out on their end ride. By listening to a story it starts as an outline, by hearing we are able as professionals to connect to our patients, by interpreting we have the ability to see past

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[291] Montgomery-Hunter, *Narrative Structure Medical Knowledge*, 124.

the details, and by supporting we remind the patient that not only are they human but so are we. If we start there I think we would see a positive change in the process of end of life care and see the healing process from Montgomery's stand point. Healing is not just a matter of being cured or physically feeling better, it's about being at peace with the lives, or should I say, stories we have lived.

It's important to report the role of culture both individually and medically and how each factor of culture has and continues to affect how we talk about death. For me, I feel that as part of our human rights we should have the opportunity to share our hopes and wishes for our death and our beliefs and values will influence that greatly. The medical culture and how it changes its view of death will ultimately change how we handle the dying process. It is necessary to continually open the lines of communication. Could possibly personal values and beliefs be the best way to start the conversation? It cannot go unsaid that the component of culture and its differences must be a talking point, with again the focus being on the word "talk." We cannot understand and grow as humans and medical professionals without opening lines of communication, and the end of life is a crucial moment to infiltrate these communication barriers. Talking about the dying process and the individual impact it has on our patients, families, and professionals will start a new culture surrounding death in the world of medicine.

Chapter 4

Gender Influence

As an end of life counselor I have had to learn skills and techniques to provide appropriate beneficial services to my patients and their families. End of life acceptance, wishes, and care services are inspired by a number of complex factors. As the years have passed and my experience has increased I have found a number of behavioral patterns within my case load. These patterns have affected my counseling skills and have helped me to understand my patients on a deeper level. Of course I have learned that every patient I work with is an individual and I must treat them as such, but I have seen gender components that impact the care that I offer. The personal experience I will include in this chapter will be used as an anecdotal reference. However, I'm hopeful to support my professional knowledge with the use of peer reviewed material. Included in both my skilled understanding and the research data, and as stated above, it is clear that gender alone cannot predict end of life acceptance but traits such as culture, religion, age, marital status, and physician gender also impact an individual's care wishes at the end of their life. It is important for me to state that though I have had a variety of experiences with a range of patient ages and a number of cultures, a majority of my patients are sixty-five and older coming from middle to lower class backgrounds. When discussing my experiences with end of life care in this chapter, this is the population I will be referring to.

The dynamic of gender influences has helped me to view gender behavior as a tool when initially evaluating my individual cases. Throughout my career I have observed that on average, men and women present specific gender behaviors especially during end of life situations. For example, as a hospice social worker I have observed an emotional struggle during the initial acceptance of an end of life diagnosis within the male gender. These men frequently request second opinions and opt for further aggressive treatment. They wish to continue the battle against their disease. Women tend to weigh the option of treatment and treatment side effects versus their belief of what quality of life is. Exploring the issue of their quality of life frequently influences the women's wish for end of life services and comfort measures over the alternative option of aggressive treatment. Though absorbing the knowledge that the end of their life is near is commonly emotional and difficult, women's acceptance of disease progression appears to occur more rapidly than a male's recognition. Women's fear of pain and suffering may also be an influential factor on their decision to initiate comfort measures more rapidly. It is recognized that generally women tend to experience more pain than men which can be an impacting factor on their decision to forgo further aggressive treatment and accept comfort measures.[292]

Witnessing this gender differential encourages the question of why women appear to be more accepting of their end of life condition than men. When offering emotional support to my male patients I almost always hear them discuss their fear of losing their independence and personal strength. The concept of male pride is another element I observe that may stimulate the emotional process at the end of the lives of my male

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[292] Duffy et al., "Cultural Concepts End of Life." 14.

patients. As their bodies decline and their condition warrants dependence on others, their emotional struggle appears to increase. It is the concept of losing their sense of "manhood" that results in an emotional conflict. While women will also struggle with the loss of independence it is their fear of being a burden to others that results in their specific emotional battle. I have found that there are more effective techniques to encourage a woman's acceptance of care giving assistance at the end stages of her disease progression than there are to assist a man through his physical decline process. After studying the history of both the male and female gender throughout generations, I cannot help but think that American culture's male gender role of strength, independence, and dominance serves as an influence that fuels a man's emotional struggle with his loss of independence at the end of his life. Furthermore, it is the historic female gender role as a nurturer and caregiver that may promote her fear of being a burden to her loved ones.

As mentioned earlier, the idea of quality of life can stimulate one's care decisions. A person's definition of the value of life can significantly alter his/her wishes at the end of their life. A studied completed by Bookwala and colleagues addressed life values in connection to end of life care wishes and how these values may be influenced by gender. Bookwala, et al. used interviews and surveys to illustrate gender differences between the relationship amongst particular life sustaining preferences and the influence of a person's life values as elements behind end of life care choices.[293] This research used "four life sustaining treatments (antibiotic medication, CPR, surgery, and artificial nutrition/hydration) in response to nine health specific scenarios (Alzheimer's disease,

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[293] Jamila Bookwala et al., "Gender Differences in Older Adults' Preferences for Life Sustaining Medical Treatments and End of Life Values." *Death Studies* 25 (2011): 130. doi:10.1080/07481180126202.

emphysema, coma with a slight chance of recovery, coma with no chance of recovery, stroke with a slight chance of improvement, stroke with no chance of improvement, cancer with no pain, and cancer with pain requiring constant use of medication)" with the use of life value as a correlation as motivation surrounding end of life care decisions.[294] The hypothesis of this study was that personal life value and what health means to a woman or a man does affect their end of life preferences. It is the researchers' belief that gender is very much an influential factor related to what as individual's meaning of life value is.[295]

It is important to note that Bookwala, et al. report that on average, women are more likely to use "preventative or curative medical services."[296] In other words women are more likely to see a physician prior to a diagnosis of chronic or terminal illness which may play a significant role in the importance women put on being healthy in comparison to health as an important factor to men.[297] This statement alone illustrates a difference in how men and women may see health and what they consider to be healthy. Men and women's views of health can influence their definition of what quality of life is; this can be especially significant in the situation of end of life care.[298]

The results found in this study did show a significant distinction between the preferences amongst men and women regarding end of life treatment.[299] The distinction demonstrated that it was men who wished for aggressive end of life treatments over

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[294] Bookwala et al., "Gender Differences Older Adults," 130.
[295] Bookwala et al., "Gender Differences Older Adults," 130.
[296] Bookwala et al., "Gender Differences Older Adults," 140.
[297] Bookwala et al., "Gender Differences Older Adults," 140.
[298] Bookwala et al., "Gender Differences Older Adults," 140.
[299] Bookwala et al., "Gender Differences Older Adults," 140.

women.[300] The researchers believe there can be a number of influences supporting these results. The first factor is that women may have a higher regard for a “healthy” life due to their more frequent use of health care services.[301] In connection to women’s more frequent use of health care services is their better knowledge of medical care, treatment options, and side effects that are a result of their regular use of medical services.[302]

The second influence discussed in this research is women’s fear of future pain and suffering as a crucial reason to withhold life sustaining treatments.[303] As Duffy reports, women are regularly more likely to experience pain.[304] That fact is associated with the possibility of their increased knowledge of medicine that can influence their fear that pain and suffering comes with end of life conditions.[305] There may also be a fear of emotional suffering due to the physical changes a woman’s bodies will endure and what would happen to her appearance with the utilization of life sustaining treatments.[306]

The third point stressed in the research that supports the gender results is women’s individual value of life and how physical limitations can affect this value.[307] Within these results women stressed the importance of being fully functioning and the idea of limitations with their physical and mental capacities rang to be more problematic for them than for men.[308] These limitations can impact a woman’s perception of her personal value of life.

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[300] Bookwala et al., “Gender Differences Older Adults,” 140.
[301] Bookwala et al., “Gender Differences Older Adults,” 140.
[302] Bookwala et al., “Gender Differences Older Adults,” 141.
[303] Bookwala et al., “Gender Differences Older Adults,” 141.
[304] Duffy et al., “Cultural Concept End of Life,” 11.
[305] Bookwala et al., “Gender Differences Older Adults,” 141.
[306] Bookwala et al., “Gender Differences Older Adults,” 142.
[307] Bookwala et al., “Gender Differences Older Adults,” 142.
[308] Bookwala et al., “Gender Differences Older Adults,” 142.

In my career I have observed the earlier a patient accepts their terminal prognosis the sooner they are willing to accept end of life care services. The faster the services are in place the more time I have to spend with them to help them through this challenging end of life process with the end goal of obtaining emotional peace. Due to an earlier admission to palliative or hospice care, my ability to build a strong rapport and trusting relationship with that patient is more probable. I find that due to their quicker acceptance of their illness women begin end of life services earlier in their disease process. The later a patient is referred to palliative/hospice care the less opportunity I have to use my skills to assist them with closure. It is especially difficult to motivate a male patient to open up with me regarding his own personal feelings. I believe that the culture of male gender roles in society influence the male inability to discuss personal struggles. I would be interested to see if a male therapist has similar struggles with their male patients that I, as a female counselor, experience with mine.

The difficult element of understanding end of life wishes/experience between genders is that gender alone is not the only impacting factor during this critical experience. It is just as important to look at the factors of race, age, religion, culture, and even marital status when exploring end of life care decisions, as well as personality, temperament, and past experiences of loss and grief. Much of the research included in this chapter examines these above factors in relation to gender. I believe that based on my encounters with the dying population, these dynamics can and do impact end of life experiences.

As discussed in the previous chapter Sonia Duffy reported on the cultural differences and influences that may affect death acceptance in different populations. In her evaluation of gender as a whole, Duffy found women respond more often to their cultural influence while being influenced by their spirituality and soothed by human touch.[309] They preferred to have awareness of their condition and feared unresolved business.[310] Women were more likely to have executed living wills and a power of attorney.[311]

In regards to Duffy's above findings it is difficult to separate culture, race, and religion from the gender component during end of life experiences and how each aspect can stimulate care wishes. My personal experiences illustrated in the start of this chapter focused mainly on the gender element I have encountered, but I can confidently say it is very difficult to separate the gender traits from the cultural power.

In reference to the many important additional factors that may influence gender preferences at a person's end of life, marital status can play a vital role in end of life decisions as well as end of life communication. Wachterman and Sommers used the National Mortality Followback survey from 1993 to examine end of life care services provided to deceased Americans with relation to their marital status at the time of death.[312] Results illustrated that there is a difference in end of life care services received by married and single individuals. Unmarried individuals were more likely to receive end of life care in a facility due to the lack of spouse support.[313] There was a higher level

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[309] Duffy et al., "Cultural Concept End of Life," 13.

[310] Duffy et al., "Cultural Concept End of Life," 13.

[311] Duffy et al., "Cultural Concept End of Life," 13.

[312] Melissa Wachterman and Benjamin. Sommers, "The Impact of Gender and Marital Status on End of Life Care: Evidence from the National Mortality Follow-Back Survey." *Journal of Palliative Medicine* 9 (2006): 343. doi:10.1089/jpm.2006.9.343.

[313] Wachterman and Sommers, "Impact of Gender," 343.

of women receiving facility care due to women's longer life span.[314] Women were also seen using Medicaid coverage more frequently at the end of their lives.[315] It is believed that their financial limitations and inability to obtain private coverage forced unmarried/widowed women to use Medicaid coverage at the end of their lives.[316] There was significant data present that when a male patient was married his spouse on average was his caregiver. Because women tend to live longer, when they are in need of end of life care it is common that their spouse is already deceased.[317] There was also a significant influence of financial stability and a gender component regarding Medicare/Medicaid/ private insurance coverage at end of life care. Women were more likely to need Medicaid coverage while men were more likely to have "other" forms of insurance coverage likely related to their income and career status.[318] It was evident through the results of this research that married men were the most likely to receive end of life care in their home and it is believed that their care in the home is a result of their spousal support.[319]

It is clear that there are a number of influential factors that may impact end of life care decisions. Up until now those factors have all been characteristics of the individual patient, but what about the gender influence of the physician/clinician communicating with the patient about their terminal illness? Do gender roles and personal acceptance of death and dying impact our abilities to communicate with our patients as clinicians?

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[314] Wachterman, and Sommers, "Impact of Gender," 343.
[315] Wachterman, and Sommers, "Impact of Gender," 351.
[316] Wachterman, and Sommers, "Impact of Gender," 351.
[317] Wachterman, and Sommers, "Impact of Gender," 349.
[318] Wachterman, and Sommers, "Impact of Gender," 349.
[319] Wachterman, and Sommers, "Impact of Gender," 349.

A study published by Palliative Medicine in 2008 highlighted the importance of personal acceptance and comfort with the idea of death found in male and female health care professionals as factors in end of life communication.[320] As noted in the previous chapter Hegedus, Zane, and Szabo used the Multidimensional Fear of Death Scale (MFDS) and an educational seminar as tools, to demonstrate the effect that death anxiety in health care professionals can have on end of life situations.[321] In the initial evaluation of the participants' fear of death, it was significant that male health care professionals had less fear of death based on results from the MFDS.[322] Though the males had lower levels of death anxiety prior to the seminar it was significant that the educational seminars decreased the anxiety in both the men and women samples used in this study.[323] The results of this research simply illustrate the important roles that education and personal understanding can play in end of life communication and that the gender of the clinician may also contribute to this issue.[324]

I believe that in the field of end of life care the importance put on who is receiving the information, for example, the patient, should not outweigh who is providing the information, for example, the physician. How the diagnostic information is absorbed can be greatly affected by the person who is presenting the information. Is that person comfortable verbalizing the prognosis and speaking words like terminal and death? Is that person capable not only to speak the difficult words but do it with empathy and compassion? Are they aware that hearing words like terminal and death can be scary for

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[320] Hegedus, Zana, and Szabo, "Medical Students' Health Care Workers'," 265.
[321] Hegedus, Zana, and Szabo, "Medical Students' Health Care Workers'," 265.
[322] Hegedus, Zana, and Szabo, "Medical Students' Health Care Workers'," 265-267.
[323] Hegedus, Zana, and Szabo, "Medical Students' Health Care Workers'," 267.
[324] Hegedus, Zana, and Szabo, "Medical Students' Health Care Workers'," 267.

a patient and that it may take multiple conversations with that patient before the information can be clearly understood? Does the gender of the clinician providing this information influence how the information is recognized and processed? As I asked earlier, I would be interested to see if a male therapist had a different experience communicating with a male patient. Would he experience the same struggles I feel I have encountered? Would he have a completely different experience with his female patients from what I do?

Hegedus, Zana, and Szabo don't answer all these questions directly but the underlying purpose of their research is a start finding answers to these exact questions. Not only can the personal anxiety of the clinician affect how end of life information is received but their gender and the gender of their patient are all influences affecting how the patient's end of life process is experienced.

When I first contemplated the topic of gender influences in end of life wishes and experiences for this chapter, I was confident that I would find answers or at least a significant direction toward what specific influences gender may have on end of life issues. As this chapter concludes it is clear that I don't have many answers; actually I think I have more questions about whether my experience and the techniques that I have built around my gender construction are relevant to the care I provide my patients. One of the questions I still have is whether my gender and my personal death anxiety have an influence on my patient's acceptance on their end of life condition. Another question is about the impact on a patient's understanding of end of life issues is based on who provides them with that information, and do their gender roles affect the patient's ability to grasp that crucial information. Finally, I still question whether gender can truly be a distinct influence to end of life care alone or must we consider culture, religion, age, and even marital status as connecting factors.

My personal conclusion is that yes, gender appears to have an influence on end of life care and end of life wishes but I don't believe that gender can be separated from other factors such as culture, religion, and marital status to name a few. My view has also been influenced by the idea of the gender component from the clinician perspective. Therefore, before gender as a direct decisional element is understood, we need to study the influences that other factors have on our gender roles.

Some of these questions may never get answered but I will repeat that without asking them we will never have a better understanding of them. So again, communication is necessary not just between the patient and the physician but amongst the field of professionals. The research needs to be executed so that we in the field of end of life care may be able to provide our professionals with the appropriate education on how to address the gender component with regards to end of life communication and acceptance. If in the future, research shows us that men receiving end of life information from another male significantly effects their acceptance and positively influences their emotional journey through out their death experience, then we can implement that as an active communication tool. Since the topic of death is so fragile, I believe that any assistance toward providing a better version of it is useful.

Chapter 5

The Importance of End of Life Conversation

How easy is it to get medical attention today? It is as simple as calling 911 and being transferred via ambulance to the local emergency room. What if a construction employee has a mishap with a piece of machinery that severs his arm, can we save his arm? Possibly, but he may need to be air lifted to the nearest trauma center. Can medicine save a premature baby who needs medical intervention to support her little, inexperienced lungs and provide her with nourishment until she is able to breath and eat on her own to survive? Again, the answer to those questions are yes to the treatment and very likely a yes to the baby's survival. Many of today's advancements in medicine allow the answer to the above questions to be yes. Prior to the current medical environment, the answer to each of these questions would likely be no and the lives of the individuals in question would be shortened due to a lack of medical treatment options. These interventions allow for additional living including an enhanced quality of life. However, with these medical developments and improvements that influence how we survive disease and trauma, we also see a fundamental change in what we understand death to be. Having to change how we see death should push us to change how we deal with it.

As medicine has progressed we as a population have found ourselves changing in a number of ways. The environment of medicine has forced us to treat illness differently than ever before. We now have levels of care, treatment, and life sustaining efforts that we have never had before. It not only has changed the climate that surrounds how we as humans can live, but it has also had an additional impact on the professionals in the field of medicine. Though the growth in medicine has allowed for positive influences on quality of life it has also had an impact on what death is in today's generation. Through personal experience I have observed that the field of death and dying has not truly caught up with the medical progression in relation to the humanistic value. What does that really mean? It means that we have failed to remain focused on the results of these environmental changes at the end stages of life. We are aware of the life sustaining properties of medicine, but is there a line where we should allow for death? I believe there is a line, but I also feel that these lines must be drawn by the individual patients themselves. I also believe these lines cannot be fairly illustrated without discussing the real issue at hand, which is death and how we chose to die.

Long before today's advancement in medicine, death was simple with very limited personal control. Hardwig illustrates the history of death by how it occurred without the impact of medicine. As stated earlier, prior to today's medical abilities individuals "died in childbirth, during a war, as a result of an accident or commonly of an infectious disease."[325] These deaths occurred quickly with very limited medical intervention; therefore to communicate about death during these events was much less an issue as it is today. Today each of these common natural end of life events can be manipulated by physicians and medical treatments.[326] These medical influences can be positive forces for quality of life but are we being fair to our population by not discussing the inevitable? Are we assuming that all individuals would chose to aggressively prolong their lives when facing a terminal situation?

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[325] Hardwig, "Going to Meet Death," 37.

[326] Hardwig, "Going to Meet Death," 38.

This is where we are falling short in the field of end of life care. We aren't having the much needed, essential conversations with both those who are sick and those who are healthy. I strongly believe that if we as medical professionals not only had these conversations, but started them earlier, our patients will have a better quality of life at the end of their life. Moreover, they will receive more appropriate care at the end stages of a disease progression.

I can't help but want to paint a picture of why this is such a crucial issue for our society at this time. Let us look at a common reality of an end of life situation in a way that is less often thought of. As a professional who has worked in the field of brain injury, I have witnessed the impact that an injury to the brain can have not only on the individual, but also on those around them. One of the many physical outcomes of a traumatic brain injury is the patient being left with an inability to naturally swallow. The current medical intervention for this symptom is to surgically place a feeding tube inside the patient to provide nutrition artificially. This treatment can prolong an individual's life but does not promise an increase in life quality.

Let me color this picture for you. An active, vibrant thirty-seven year old father is in a grave motorcycle accident. His traumatic brain injury leaves him with a number of life changing symptoms. He becomes bedbound, unable to speak, and can only communicate by blinking his eyes. He is also unable to eat or swallow on his own. He has no medical power of attorney or a written document stating his care wishes. After lengthy discussions with the medical professionals on his case, his family chooses to have a feeding tube placed with high hopes that he will recover with proper nutrition. After six months of all efforts being made, he unfortunately remains the same. Not only has his quality of life changed dramatically, so have the lives of his loved ones, especially his young children, who do not have the mature knowledge to understand that the magic tube is not going to bring their Daddy back.

The decision to place a feeding tube as well as to stop its use often needs to be made by a loved one. Stopping the use of a feeding tube in an individual who is unable to swallow can and will result in eventual death. The thought of being the individual who makes this decision can carry quite a heavy burden to the family members. What if the medical professionals and the loved ones asked this question of the patient long before this condition arose, would it have provided an easier decision-making process while still respecting the patient's personal wishes? We don't know the answers to this question because we don't speak of these issues often enough, nor do we have these appropriate dialogues in full.

In the above situation we don't know if this young man would have wanted to live this way, nor do we know if he wished for his children to remember him this way. But what if this gentleman's primary physician sat down with him on a routine appointment after his children were born and simply asked him about his medical wishes? Would his physician have learned that under no circumstance did this man want to be placed on a feeding tube? Would he have learned that this young father had thought about completing an advance directive and discussing his wishes with his wife but was too afraid and unsure of how to start the conversation? Would he have learned that the patient is a motorcycle enthusiast who frequently rides his bike without a helmet and opened a crucial dialogue about safety and this above event was therefore completely avoided? Or would his physician quickly learn that the patient had no interest in speaking about his wishes for end of life care at that very moment, but for the next six months, he thought at length about his care wishes and returned to the office to complete an advance direct with a professional in the physician's office?

This case is a fabricated example but I'm certain could be a real situation for many. It is also just one straightforward example of an end of life situation that can easily be compared to a number of other end of life situations. I chose this example instead of a terminal cancer example because it illustrates a form of end of life that we don't often consider as a common end of life circumstance. Our medical advancements can also allow us to see this case as a medical success instead of a tragic death. But the tragic sudden death version of this case may have avoided other levels of pain and emotional suffering. It also may have avoided the chance of defying this young individual's quality of life wishes.

We may still die tragically and young after being sustained with medical interventions. We may die slow and painful after rounds and rounds of torturous chemo and radiation. If we are lucky we can die in our sleep as a result of old age and maybe then we never need to use the results of the end of life conversation that we hopefully had with our medical professionals. So why don't we talk about dying, especially with the reality that today there are many possible ways that we may die?

I think it is safe to say that talking about our life ending is hard, depressing, and frightening but there is not one of us alive today who will not personally experience the event of death in their life time. This conversation is difficult to have for all those involved: the patient, their loved ones, and their medical professionals. Today's medical climate and disease options impact this conversation greatly. There are a number of specific barriers that may be reasons behind why these imperative discussions are not being had or are being had too late.

As a professional in the medical field we are taught to focus on curative treatment, intervention, and prolonging life. With these being the motivations behind medical education it is understood why end of life conversations and interventions are limited. We as professionals are rarely trained on the issues of end of life care. Maybe it is felt that these responsibilities should be left for the individuals who choose to work in the end of life field such as palliative and hospice care employees. The problem I see with this point of view is that only those who are admitted to these services benefit from communicating with these trained individuals. I also believe that if these are the only individuals providing these important conversations then this dialogue is also being had way too late.

Billings, et al. report that though "End of life care education is a requirement of the Liaison Committee for Medical Education, it remains inadequate."[327] Their research, surveying fourth year med students at sixty-two medical schools, validated that students are reporting inadequate education and training for end of life care, which includes end of life education.[328] The current lack of end of life training for physicians may influence the limited appropriateness of these conversations.[329] This concern seems to be common

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[327] Martha Billings et al., "Determinants of Medical Students' Perceived Preparation to Perform End-of-Life Care, Quality of End-of-Life Care Education, and Attitudes Toward End- of Life Care." *Journal of Palliative Medicine* 13, no. 3 (2010): 319. doi:10.1089/jpm.2009.0293.

[328] Billings et al., "Determinants of Medical Students'," 319.

[329] Quyen Ngo-Metzger et al., "End of Life Care: Guidelines for Patient Centered Communication." *American Family Physician* 77, no. 2 (2008): 167. http://www.aafp.org/afp/2008/0115/p167.html.

specifically for primary care physicians because they frequently feel that this responsibility is that of the specialists, for example the oncologists in cancer cases.[330] The important point to highlight here is that it is often the primary care physician who has the long standing, more comfortable relationship with the patient.[331] In the cases that there are a number of physicians actively working with a patient it is important for those professionals to work together as a team. A team approach allows for a more comprehensive approach for patient care and understanding of patient wishes.[332]

All professionals must be aware, when discussing end of life wishes, of the emotional status of the patient. It is important to recognize if the patient is emotionally ready to engage in this emotional conversation.[333] Just having an end of life discussion does not allow for it to be appropriate if the patient is not fully engaged or prepared. In my experience the inappropriate timing of this delicate conversation can be damaging and ultimately affect the result of this discussion as well as the patient's ability to cope with their disease. It can also affect the patient/physician relationship which can further influence the continuation of the end of life dialogue.[334]

The mental preparation behind having these conversations for both the patient and the professionals adds to my argument that we should be having these discussions prior to the patient's terminal status. In my opinion it is ideal to have this discussion long before a terminal diagnosis occurs. It is a hypothesis of mine that discussing end of life wishes

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[330] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 173.

[331] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 167.

[332] Lori Wiener et al., "When Silence is Not Golden: Engaging Adolescents and Young Adults in Discussions Around End of Life Care Choices." *Pediatric Blood Cancer* 60, no. 5 (2013): 715. doi:10.1002/pbc.24490.

[333] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 167.

[334] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 168.

prior to a terminal or even crucial diagnosis allows for the elimination of the patient's active fears and emotions. Furthermore it will decrease the medical professional's hesitancy to face the intense emotional component. I must insert here that though an individual chooses specific end of life wishes when they are healthy, it does not always mean their wishes will remain the same if they become crucially ill. The positive advantage to the early timing of having these conversations prior to a diagnosis is to allow for a more comfortable atmosphere. Both the physician and patient will have previous knowledge of how each other may react to the details of this dialogue. It is also important to emphasize here that these conversations take time and are not meant to be completed during one fifteen minute appointment. It is healthy for these dialogues to be ongoing throughout a number of patient/physician interventions.[335] This is another supportive argument to having these discussions early on in a patient's care. Starting earlier allows for questions to be formulated by the patient as well as the discussion of small issues that may weigh a lot to the individual, for example, the environment they choose to die in.

Another important factor that can affect the status of an end of life conversation, which is a heavy burden for the physician, is the issue of treatment expectations and containing hope. Hope is very much a part of end of life issues and often a terminal diagnosis is believed to eliminate hope from the equation.[336] The struggle that medical professionals may find when it comes to hope at the end of life is finding a balance between providing a false sense of curative hope versus a healthy form of end of life

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[335] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 167.
[336] Ngo-Metzger et al., "Guidelines for Patient Centered Communication," 170.

hope. You may ask yourself, in relation to a terminal illness, what kind of hope there is. As a professional in the field, I truly believe that there is absolutely a form of hope at the end of life. It is the hope that you can and will have the end of life experience that you choose. Of course we cannot plan the end of lives exactly, but we can be sure that many of our wishes be fulfilled. Some of those wishes may be to be kept physically comfortable, allow for appropriate family time, even putting a sense of closure to our financial concerns. The truth is when an individual is facing the end of their life, the above issues are very real issues and knowing that these concerns may be handled the way the individual chooses, can and will, provide a true sense of hope as well as necessary peace. These hopes may also change as the patient's condition changes which is another argument as to why the end of life conversation is to be had early and should be continuous.

As it has been stated, end of life conversation produces emotions and fears for both the patient and the medical professional, but it is also difficult for the family members and loved ones. The family's involvement or lack of involvement can also create a barrier when initiating an end of life conversation. There are a number of reasons why family members may obstruct this process. In many cases if a patient has not completed an advance directive directing one individual to assist with medical decisions, it can cause the discussion to become chaotic and complex.[337] Research supports that having a formal document instructing an individual with the right to make

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[337] Deborah Carr, Sara Moorman, and Kathrin Boerner. "End of Life Planning in Family Context: Does Relationship Quality Affect Whether (and With Whom) Older Adults Plan?" *Journal of Gerontology* 68, no. 4 (June 2013): 586. doi:10.1093/geronb/gbt034.

medical decisions while also documenting an individual's specific wishes allows for more effective conversation and advance care planning.[338] Having a number of different personalities, points of view, and opinions will cause for confusion. In my experience even if all members of the family agree on the decision to be made, their individual emotional status can and often affect the fluidity of the end of life decision making process.

It is important to highlight in this section how influential the quality of family relationships can be in respect to advance care and end of life planning. It has been assumed that the more positive the family relationship, the more likely that the communication efforts will occur with constructive results. Carr, Moorman, and Boerner's research supports this argument.[339] Their study supports the belief that better relationship quality between the patient and their spouse or family members increases the likelihood of that individual being chosen as the patient's durable power of attorney for health care.[340] These positive relationships are linked to the loved one's personal objective to maintain the patient's comfort while actively carrying out the patient's individual care wishes.[341] These positive relationship connections also minimize the decision making difficulty and "family-level conflict" during the decision making experience.[342] It is significant to draw attention to the study results illustrating that "only 2% of married parents appointed someone other than a spouse or child" as their durable power of attorney for medical care.[343] This small percentage limited the researchers from

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[338] Carr, Moorman, and Boerner, "End of Life Planning," 586.
[339] Carr, Moorman, and Boerner, "End of Life Planning," 590.
[340] Carr, Moorman, and Boerner, "End of Life Planning," 590.
[341] Carr, Moorman, and Boerner, "End of Life Planning," 590.
[342] Carr, Moorman, and Boerner, "End of Life Planning," 590.
[343] Carr, Moorman, and Boerner, "End of Life Planning," 588.

finding further significant data in relation to why these individuals chose alternate decision makers.[344] In relation to this statistic I cannot help but believe relationships such as spousal and parent/child are the most crucial in respect to end of life conversations. This allows me to think that we as individuals not only have common values, beliefs, and thoughts as our partners and children, but we also discuss subjects like medical care and death with these individuals. Furthermore, I agree with the researchers that it is likely that poor relationships with these individuals may decrease the frequency of these much-needed conversations.[345]

In addition to the barrier of family relationships concerning end of life conversation, it is essential to discuss the influence that specific culture, including religion, play in the course of these conversations. Our modern medical environment is currently Americanized, but that does not mean that all patients and their families believe in the common American values.[346] Values will differ from patient to patient and many of their beliefs toward medical intervention, as well as their individual wishes, are influenced greatly by their culture and upbringing.[347] These specific cultural differences were elaborated on in detail earlier in this paper but I feel it important to address the weight that culture plays in the end of life conversation at this time. I feel that there are times that culture, moral values, and religion can also trigger barriers during the end of life conversation. Many cultures do not believe in including the ill patient in these

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[344] Carr, Moorman, and Boerner, “End of Life Planning,” 588.
[345] Carr, Moorman, and Boerner, “End of Life Planning,” 590.
[346] Johnstone, “Bioethics, Cultural Differences,” 182.
[347] Larochelle et al., “Hospital Staff Attributions,” 462.

conversations and furthermore do not allow for medical professionals to inform an individual of their impending death.[348]

In connection to the influence of culture, it is significant to raise the matter of age at the end of life. It is often common to automatically think about end of life in the geriatric population. I know personally because of my career experience that is often the direction my mind goes since the majority of my patients are elderly or at least considered senior citizens. I have had a number of experiences with younger individuals but still most of them were legal adults with maturity and capacity to make their own decisions. But what about adolescent and pediatric cases - are they different? How should we handle them? When thinking of pediatric and adolescent end of life care communication a number of additional barriers arise.

Pediatric and adolescent end of life decisions can become difficult for a number of reasons. The issue that appears to frequently come first is that of the child's mental capacity to be involved in this emotional decision making processes.[349] Throughout the history of childhood end of life care it was often the legal component concerning the child's competency which ultimately designated the parents of the ill child as the responsible individual, to actively make decisions on their child's end of life care planning.[350] I believe that these cases are individually based and I would guess that most children under the teenage years may not have the emotional ability to appropriately make their end of life decisions alone. Furthermore, there is quite a bit of research

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[348] Duffy et al., "Cultural Concepts End of Life," 10.
[349] Weiner et al., "Silence is Not Golden,"715.
[350] Whitty-Rogers et al., "Working with Children," 743.

concentrating on some of the changes occurring within pediatric and adolescent end of life cases specific to the communication argument.[351]

Autonomy has become a factor is medicine since the 1970s when bioethics became a field of interest in the medical environment.[352] Autonomy has not only been awarded to adult patients but it is being seen as a right for young patients as well, including pediatric and adolescent patients. Whitty- Roger et al. have reported that when children have the capacity to understand their illness, treatment, and future, giving them a "voice" that can and will provide them with an increase in quality of life during end of life situations.[353] In connection to that belief Weiner et al. also emphasize that allowing the young patient, specifically adolescent age individuals, in the decision making process during end of life circumstances can even eliminate parental stress, conflict and "decisional regret."[354]

It is important to state here that all children will have different cognitive capacities allowing them to participate fully in these conversations. Whitty- Roger et al. recommend that based on Piaget's developmental theory and other developmental psychologist perspectives, children as young as twelve can cognitively be an active part of their end of life conversations.[355] With that being said, it is imperative that the medical professionals make every effort to understand their individual patient's knowledge, understanding, capacity, and awareness prior to initiating end of life conversations.[356]

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[351] Whitty-Rogers et al., "Working with Children," 743.
[352] Whitty-Rogers et al., "Working with Children," 745.
[353] Whitty-Rogers et al., "Working with Children," 743.
[354] Weiner et al., "Silence in Not Golden," 715.
[355] Whitty-Rogers et al., "Working with Children," 748.
[356] Whitty-Rogers et al., "Working with Children," 748.

Just allowing the young patient to be involved in their care discussions can eliminate a number of common barriers at the end of a young person's life. Some of these universal barriers are parental conflict, patient protection, sibling protection, patient decision manipulation, physician insecurity, and medical futility.[357] For example, the parents of the ill child will undoubtedly struggle with the decision to stop treatment and let their child die. For the reason of protecting their child from hearing dire news they may hesitate to discuss discontinuation of treatment with their sick child.[358] They also may be protecting themselves from the complicated experience of having to be the ones to share this devastating news with their ill child.[359] Parents will struggle with the idea of their child dying before them and the emotions that come attached to that concept will affect their ability to include the child in these difficult decision making processes.[360]

Often the ill child is not the only child in the family and the parents believe it their duty to not only protect the sick child, but the other children as well.[361] This can be an additional motivation behind keeping end of life information from their sick child. I feel it may also be one of the many reasons why there is conflict between the child's parents. Parents may have a difference of opinion regarding treatment options, discontinuation of treatment, and openly discussing end of life with the ill child.[362] Conflict between the child's parents is a common barrier to end of life communication.[363] This conflict will

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[357] Whitty-Rogers et al., "Working with Children," 755.
[358] Whitty-Rogers et al., "Working with Children," 744.
[359] Whitty-Rogers et al., "Working with Children," 748.
[360] Whitty-Rogers et al., "Working with Children," 748.
[361] Whitty-Rogers et al., "Working with Children," 744.
[362] Whitty-Rogers et al., "Working with Children," 746.
[363] Whitty-Rogers et al., "Working with Children," 746.

certainly impact the parent's relationship will each other as well their relationship with the ill child, the medical professionals and possibly even their other children.[364]

Medical professionals play a significant role in the culture of end of life care for pediatric and adolescent patients just as they do with adult patients. The professionals must be aware of the above barriers as well as how they too may become a barrier.[365] As we have discovered, end of life conversations with any individual are difficult for medical professionals, for a number of reasons. When working with a child the professional must remember to be aware of their own emotions. "Self-reflection" is crucial when building a safe environment with a young dying patient.[366] They must also be aware of their relationship with both the patient and the parents. It is common for a child to restrain from sharing their wishes when they feel their wishes may disappoint their parents or conflict with their parent's views.[367] In this example it is crucial for the medical professionals to allow the child to feel safe discussing their fears and wishes with them without the influence of their parent's hopes. The treatment nurses on the pediatric units often become the figures who are able to provide these needed relationships with these dying children.[368]

Medical professionals must also consider that their recommendations for the young patient may be different from what the child and the family wish for the patient's care. I could imagine that young end of life cases come with a higher intensity of emotions. I know when my elder patients are at their end stages of their lives I sleep

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[364] Whitty-Rogers et al., "Working with Children," 746.
[365] Whitty-Rogers et al., "Working with Children," 746.
[366] Whitty-Rogers et al., "Working with Children," 746.
[367] Whitty-Rogers et al., "Working with Children," 744.
[368] Whitty-Rogers et al., "Working with Children," 752.

easier knowing that they had a full life. When it comes to pediatric and adolescent end of life cases this peaceful feeling is not had. That may be one of the reasons why medical professionals often feel the need to keep fighting for their young patients.[369]

Medical futility is something that must be discussed here. It is not limited to young patients and can be a common concern in end of life care. Medical futility is "treatment that either, prolongs suffering, does not improve the patient's quality of life, or fails to achieve a good outcome for the patient."[370] Demonstrated throughout this paper, medical technology and medical advancement have given the medical environment opportunities to prolong life.[371] However, it has also been highlighted that these interventions not always allow for a better quality of life, especially in end of life cases. This becomes truthful for pediatric and adolescent cases as well. In these circumstances it is the responsibility of the medical professionals to recognize and communicate to the family of their young patients when treatment has reached the futile stage.[372] O'Brien, et al. like Whitty- Rogers et al. stress the important role of nurses in these specific situations.[373]

It is obvious that geriatric and adult end of life conversations, in relation to pediatric and adolescent patients, also carry a number of communication barriers. As I have hypothesized as a solution to this issue in the adult population, I continue to believe that beginning these dialogues early, as well as engaging in them often, is the best advice

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[369] Whitty-Rogers et al., "Working with Children," 753.

[370] Irene O'Brien, Anita Duffy, and Ellen O' Shea. "Medical Futility in Children's Nursing: Making End of Life Decisions." *British Journal of Nursing* 19, no. 6 (2010): 352. doi:10.12968/bjon.2010.19.6.47234.

[371] O'Brien, Duffy, and O'Shea, "Medical Futility in Children's," 352.

[372] O'Brien, Duffy, and O'Shea, "Medical Futility in Children's," 352.

[373] O'Brien, Duffy, and O'Shea, "Medical Futility in Children's," 352.

toward end of life conversation with pediatric and adolescent cases as well. Weiner et al. research supports this argument from many angles. They report that it is imperative to begin treatment and end of life discussion from the start of the young patient's care.[374] This allows for goals to be verbalized by the young patient, their parents, and the medical professionals.[375] The earlier this conversation is had the more time is given to have further discussion. The discussion of goals and wishes will provide the young patient the opportunity to generate questions and verbalize fears they may have.[376] It is hopeful that the frequency of these dialogues will build relationships and assure the young patient that their hopes are being heard.[377] It is important to recognize that young patients have not had a full life to experience everything they hope, so giving them time to understand that their life may be shortened allows them to work toward some of these accomplishments.[378] Peer relationships, specifically romantic relationships, are one of those important milestones that can affect a patient's life experience when they are considered terminal.[379]

Having end of life dialogue with young patients should include a team of professionals.[380] Much like Carr, et al. reports that relationships are significant factors in the end of life process of young individuals.[381] Young individuals may not have a number of substantial relationships due to the limited life they have lived. Having a number of professionals involved allows them to build these bonds and gives them

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[374] Weiner et al., "Silence in Not Golden," 715.
[375] Weiner et al., "Silence in Not Golden," 715.
[376] Weiner et al., "Silence in Not Golden," 716.
[377] Weiner et al., "Silence in Not Golden," 716.
[378] Weiner et al., "Silence in Not Golden," 716.
[379] Weiner et al., "Silence in Not Golden," 716.
[380] Weiner et al., "Silence in Not Golden," 716.
[381] Carr, Moorman, and Boerner, "End of Life Planning," 590.

options of individuals they can count on during this difficult process.[382] It is also important that young patients have the ability to speak with professionals confidentially due to their natural fear of disappointing or upsetting their parents.[383]

It is clear that all populations of end of life situations have barriers that impact the end of life conversation. Some may appear unique to the specific population, for example, the barrier of children wanting to protect their parents from further pain if they choose to discontinue their treatment.[384] But a common thread that I have witnessed in my career as well as throughout the research I have read for this paper is that there is a universal lack of patient knowledge regarding how to have end of life conversations.[385] It has been discussed that medical professionals are part of the equation and are very limited when it comes to knowledge and skills needed to have the appropriate end of life conversations.[386] Walczak's et al. report allows me to believe that the people of today's society are also quite limited in regards to this topic.[387]

The study by Walczak et al. is structured to provide education as well as a safe and compassionate environment for patients to learn how to navigate an end of life conversation.[388] They believe that one of the reasons behind limited conversation about end of life is because individuals are uneducated on how to have them and are

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[382] Weiner et al., "Silence in Not Golden," 716.

[383] Weiner et al., "Silence in Not Golden," 716.

[384] Weiner et al., "Silence in Not Golden," 716.

[385] Adam Walczak et al., "Discussion Prognosis and End of Life Care in the Final Year of Life: A Randomized Controlled Trial of a Nurse-Led Communication Support Program for Patients and Caregivers." *BMJ Open* 4 (2014): 2. doi:10.1136/bmjopen-2014-005745.

[386] Rachelle Bernacki et al., "Development of the Serious Illness Care Program: A Randomized Trial of Palliative Care Communication Intervention." *BMJ Open* 5, no. 10 (2015):1. doi: 10.1136/bmjopen2015009032.

[387] Walczak et al., "Discussion Prognosis End of Life Care," 2.

[388] Walczak et al., "Discussion Prognosis End of Life Care," 9.

uncomfortable initiating them. They have a number of feelings behind why this happens but believe that if patients are provided with education and coaching prior to having these conversations with medical professionals, the results may be more positive.[389]

This study supports my feelings that patients are both fearful and unsure of how to initiate an end of life conversation, though I believe that most people are interested in having this discussion. I believe that individuals are uncertain about what questions should be asked as well as feel insecure about some of their fears and worries. I also believe that there is a strong focus on diagnosis, treatment, and the medical components. I don't believe that patients are aware that they should also think about their life wishes. In my experience I have found that when I removed the issues of medicine from the conversation, initially the patient often becomes more comfortable discussing their hopes for life and what quality of life means to them. As these important issues were understood it becomes easier to add the medical/treatment factors into the conversation. I will be interested to see the results of Walczak et al. study with the use of a communication broker who essentially preps and supports a patient prior to their initial end of life conversation. I am hopeful that they will find positive results.

Finally I believe that one of the biggest impediments to end of life communication is the belief that patients do not want to have these discussions. Often it is the medical professional who believes the patient does not want to participate in an end of life discussion.[390] Medical professionals feel that patients are hesitant to engage in these

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[389] Walczak et al., "Discussion Prognosis End of Life Care," 9.

[390] Thomas McCormick and Becky Conley, "Patients' Perspectives on Dying and on the Care of Dying Patients." *West J Med* 163 (1995): 236. http://hdl.handle.net/10822/747247.

dialogues because they do not want their hope for recovery taken away.[391] Furthermore, I believe there is an understanding that patients will not fully understand their care options until their disease has progressed to its end stages. Waitzkin's research reports that patients revealed wanting to obtain as much information about their condition as possible and believe that having this crucial information would be helpful to them throughout their disease progression.[392] In addition, McCormick and Conley also conclude that patients consistently chose to want to know the details of their illness and impending death.[393] Moreover, these subjects hoped to learn about their disease progression and the researchers found that the subject's emotional discomfort was often related to their intuition that the physician was uncomfortable and struggling to engage in the difficult conversation.[394]

This chapter emphasizes that not only is end of life conversation a major topic in medicine today, but it also has a number of barriers that fundamentally affect this issue. Each of these barriers can be seen as their own individual focus and research can be done on each specifically. My point here is that we must start looking at these issues, whether it be individually or as a group because they all have a powerful impact on our end of life care. It's not about the cost of end of life care that concerns me, though correcting some of these issues may show a positive effect in cost decrease. My purpose in looking into these barriers is to illustrate that the population is suffering at the end of their life and their care wishes are being neglected because we continue to be controlled by

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[391] McCormick, and Conley, "Patients' Perspectives on Dying," 237.

[392] Howard Waitzkin, "Doctor-Patient Communication; Clinical Implications of Social Scientific Research." *JAMA* 252 (1984): 2441. doi:10.1001/jama.1984.03350170043017.

[393] McCormick, and Conley, "Patients' Perspectives on Dying," 242.

[394] McCormick, and Conley, "Patients' Perspectives on Dying," 243.

communication hurdles. These obstacles are keeping us as medical professionals from truly doing what medicine is supposed to do. In my opinion, medicine is supposed to increase one's quality of life, not just prolong it. It should be up to these individuals to help create the plans for their life, especially if their life is coming to an end. I believe that people old and young have a human right to and want to talk about their wishes and fears. The best way to help them do this is to knock down the current barricades that are keeping us from these human rights.

Chapter 6

How Do We Fix The Communication Problem?

Medicine has obviously evolved, as has end of life care as we have seen throughout the chapters of this paper. But have we learned to talk about death any better? Is there a way for us to implement this conversation into everyday medical care in a more influential way? Are their tools out there to assist with this need? Do they work? Can we build better tools? Who should be a part of the tool building? I think each of these questions is vital to the much needed growth in how we provide the best kind of end of life care.

As the history of medicine has evolved, technology and treatment options now allow for a longer dying process and including the idea of death prediction. Due to these influences the dying conversation has become very different. Prior to today's medical climate we did not have the decisions and options we have today regarding our death process. Death was often sudden, accident related, or a result of diseases as simple as pneumonia which did not have treatment options.[395] When facing this experience of death, the acceptance of death happened quicker because there were no other options. This situation allowed for a different conversation than is had today. I do feel that the conversations had during these times was likely healthier and maybe even easier due to the mere fact that the patient and loved ones had to accept the pending death and didn't have the pressure of choosing how the death would occur. I stated earlier that historically death was more natural and I feel that the conversation was too during that time period.

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[395] Hardwig, "Going to Meet Death," 318.

Today's conversation is different in many ways. It is less natural, more complex, and likely much longer, and more detailed. It allows for the patient and family to be involved in the actual dying process. Acceptance of death can be denied longer today than in historic situations because aggressive treatment allows for a different level of hope. These reasons themselves must be the crucial drive behind conducting end of life conversations better. The complexity and details of this dialogue today also influence the time it takes to allow for this critical conversation to be appropriately had and completed. Death does not often occur within a few days like it had in the past with pneumonia. While there continue to be sudden, unexpected, and short death experiences, for every one of those, there is a chronic disease or terminal process that allows us to open lines of communication.

Therefore, death has changed which includes a need for a new death dialogue. Where do we start with this process? I feel that it must start with the medical professionals. I strongly believe that if given the chance and the comfortable environment, patients would engage in this dialogue. Even if that discussion is short and limited, I do believe it is something most people have had even fleeting thoughts about. I feel that the medical professionals' comfort with this topic triggers the patients' and families' comfort with it. I use the term medical professional because I believe that all professionals in the medical environment should be prepared for such conversations. It never surprises me when a patient opens up to a nurse, a personal care assistant or even a physical therapist. It isn't always about the professional's education or expertise that prompts this discussion; it is the relationship and comfort the patient/family has with that individual that allows for such openness. However, I must put emphasis on the role that physicians play here.

Physicians are expected to have the knowledge about end of life situations and are often the most respected opinion regarding the decision-making process because of their education and expertise.[396] I don't believe that just because a person chooses to become a physician that they automatically should be prepared to have this conversation or even be interested in learning how to have it. Yet death is innately part of the job and now more than ever it needs to be focused on. Of course there are medical specialties where this conversation skill will likely be used more than others such as the field of oncology, infectious disease, or geriatrics, just to name a few. Again, I believe all professionals should have some level of education regarding this skill. Studies have supported this hypothesis and propose that the "greatest opportunities for improvement in end of life care pertain to the physician's role in the communication process."[397] Statistics show that improvement in the physician's ability to share crucial information, actively listen, and include the patient in their "decision making process" are believed to improve the current end of life climate.[398]

As a social worker who graduated with my master's degree ten years ago, I can't say I had that education within my curriculum structure. I was faced with experiences as an intern that allowed for some teaching from my supervisors, but it was limited and situational. Ten years ago I would have never pictured myself here, as an end of life

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[396] Amane Abdul-Razzak et al., "Conditional Candour and Knowing Me: An Interpretive Description Study on Patient Preferences for Physician Behaviors During End of Life Communication." *BJM Open* 4 (2014):1. doi:10.1136/bmjopen-2014-005653.

[397] Abdul-Razzak et al., "Conditional Candour and Knowing Me," 1.

[398] Abdul-Razzak et al., "Conditional Candour and Knowing Me," 1.

professional, practicing my craft in the world of hospice care. However, being placed in an educational environment structured around end of life communication may have been uncomfortable and maybe even scary, but it would have saved me from so many awkward experiences as a young professional.

As a young medical resident or nursing student, end of life conversation needs to be a crucial part of the education process and curriculum because their role is vital. I strongly believe they are the medical influencers who hold the great responsibility of making or breaking the beginning of the dying process. I recently had a conversation with a medical school graduate who is about to start her residency. She is in the field of genetics. We discussed her curriculum and she reported having no required classes focused on difficult conversations including end of life issues. I would think that the world of genetics is a very likely place where death and dying would often be a topic of necessary discussion. She explained that much of her education on difficult conversations was similar to mine, and came from intern experiences and was most likely learned behavior from her superiors.

Billings, et al. found significant support throughout their survey study that education and medical school experience, in the field of end of life care, is not sufficient. The findings indicated that medical students learn end of life care from three different learning modalities: formal curriculum, informal curriculum, and hidden curriculum. Formal curriculum is knowledge obtained from lectures and class room structured assignments.[399] Informal teaching is found in observing clinical situations, while hidden

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[399] Billings et al., "Determinants of Medical Students'," 319.

curriculum is found within behaviors or impressions conveyed from supervisors and the medical culture.[400] Billings, et al. reported that results showed fourth year medical students feeling unprepared, for a number of reasons, to provide appropriate end of life care.[401] The subjects reported receiving proper education within the formal setting but it was found that the level of preparedness the students felt was more closely related to the observations regarding end of life care.[402] The concern shared by the researchers with this evidence is the influence of hidden curriculum. The fear is that common attitudes portrayed by physicians and expressed in medical settings is negative toward the dying population. It is felt by this research team that physicians "model detached concern" for their dying patients which results in the depersonalization of the patient and impacts the sensitivity toward their dying experience.[403] It is also important to include the data that reports the students' expression of concern and being unprepared to deal with their own personal feelings when facing a patient's death.[404] I feel this is a crucial finding. How are we supposed to teach compassion and empathy to professionals if we are unable to help them recognize and cope with their own emotions?

As medicine has progressed I believe the professionals' attitudes and demeanor have followed it. Medicine is becoming more technical based, treatment oriented, and curatively based, therefore resulting in decreasing the focus and need for end of life conversations skills. Similar to the Billings, et al. study, Sullivan, Lakoma, and Block surmised comparable questions regarding the current quality of end of life education.

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[400] Billings et al., "Determinants of Medical Students'," 319.
[401] Billings et al., "Determinants of Medical Students'," 322.
[402] Billings et al., "Determinants of Medical Students'," 323.
[403] Billings et al., "Determinants of Medical Students'," 325.
[404] Billings et al., "Determinants of Medical Students'," 322.

They conducted a survey of medical students, residents, and faculty at sixty-two accredited medical schools within the United States. Results showed that less than 18% of the subjects reported having formal end of life education, 9% reported finishing a clerkship in an end of life field, 16% of residents completed a rotation in hospice or palliative care, and 17% of faculty conveyed teaching some aspect of end of life care to students in the last year.[405] These findings illustrate the pattern that is of concern. The most astounding result from Sullivan, et al. is that when asked about performing a clinical task such as a lumbar puncture, 71% completed this intervention, with only 2% reporting not being given feedback from their superior, while 53% of the subjects reported participating in a conversation regarding a life threatening illness including wishes and end of life values. Of that group 53% received no feedback regarding their dialogue.[406]

As this current climate continues, the older seasoned professionals are likely less capable of having these conversations, thus, limiting the knowledge they pass down to their interns and residents. I think it is safe to say that the historic physicians who were often open about death, because of their lack of care options and their subsequent comfort from difficult discussion experiences, are few and far between in today's medical environment. These young residents are not encountering physicians who are open and willing to engage in difficult conversations as well as teach this lost art. How are we expecting the next generation of professionals to knock down this vital barrier?

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[405] Amy Sullivan, Matthew Lakoma, and Susan Block. "The Status of Medical Education in End-of-Life Care." *Journal of General Internal Medicine* 18, no. 9 (2003): 688. doi:10.1046/j.15251497.2003.21215.x.

[406] Sullivan, Lakoma, and Block. "Status of Medical Education," 688.

This is where I feel it is our duty as ethicists to push for growth in this area. I think there is a very strong argument that a starting point is in the educational process and should be a requirement in medical school curriculums. I believe that education is where we start to make positive changes in the abilities to comfortably talk about death. It allows for medical professionals to get acquainted with it. As I reported earlier, I had some difficult experiences with the end of life conversation in my early career. Of course I believe those conversations directed me down my career path and even gave me the drive to write this paper, but they were not free of discomfort, pain, and even feelings of disrespect felt by my patients and their families. Now please understand, that no level of education can prepare you for every end of life encounter you will have as a professional, but it will allow for a level of human comfort with this subject. I think that human comfort influences a patient/family experience with the end of life conversation. I know that in my early experiences individuals felt my discomfort and fed off of it. Comfort is crucial for the patient and family while they are engaging in an end of life discussion. Comfort can come in many forms. Abdul-Razzak et al. reports how their subjects often shared that having known the physician a longer period of time allowed for a level of personal understanding that greatly influenced their level of comfort with the end of life conversation.[407] The subject of death itself can induce fear and discomfort. Abdul-Razzak et al. report the importance of the disease in question as a comfort component. For example, "evidence suggests the uncertain prognoses associated with non-cancer illnesses, as compared with cancer illnesses pose a barrier to end of life communication."[408] I feel this statement implies that not having a clear illustration of the

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[407] Abdul-Razzak et al., "Conditional Candour and Knowing Me," 4.

[408] Abdul-Razzak et al., "Conditional Candour and Knowing Me," 2.

disease expectations, treatments, and disease projection can and will affect the comfort that both the patient and physician will have with the difficult conversation surrounding it. Additionally, I would guess that Abdul-Razzak et al. would agree that the knowledge of cancer and how it affects the human body seems to come with a different awareness.[409] Personally, I wonder if it is even a cultural stereotype that many other diseases may not carry. I feel it important to note here that disease stereotypes are real and I believe they affect patients and families as well as medical professionals. I can imagine that they do create unnecessary barriers to difficult conversations.

It is also important for me to include the importance of patient readiness for this conversation to occur as a crucial factor when discussing comfort. I am aware that I have stated earlier that I believe we need to address death and dying earlier in the disease stages in order to have better outcomes. I continue to feel that we need to engage in end of life conversation earlier but I do not feel we need to do this at the risk of causing the patient/family additional, avoidable pain that will affect their acceptance of their condition. Abdul-Razzak et al. reports that their study suggested that engaging in the end of life conversation with individuals who are not emotionally and mentally prepared can be destructive to both the patient/family welfare as well as the patient/physician relationship.[410] Regarding this evidence I can’t help but wonder how that possible damage can affect future discussion opportunities and patient acceptance. Education within the end of life dialogue should also include and hopefully influence the

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[409] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 2.

[410] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 5.

professional's ability to assess the patient's readiness to engage in this conversation, for this continues to show another duty of the medical professional.[411]

I have experienced the result of this above situation more than I can count. I can remember my first experience with an unprepared, emotionally unsuspecting patient who was abruptly told that she was dying of end stage lung cancer. If you asked me to highlight one professional memory as a driving force behind this paper it would be this patient. As a sixty-seven year old, single, independent woman being treated for a persistent cough, she was blindsided by this fatal diagnosis. For starters, she was told by the oncology attending she had met only once before, alone in a hospital room that she, "must get her affairs in order, for she had less than six months left to her life." Of course, this is what she heard; I can't with 100% certainty tell you this is what was actually said or in the cold manner in which she implied it was stated. But I can say I had experienced this physician's lack of tact in the past, so her illustration of finding out about her prognosis could have been exactly how it occurred.

As far as I'm concerned, how she heard these words with the soul paralyzing fear that she heard them was very much a result of her not being emotionally prepared to hear that statement, no matter how it was worded. How she heard this crushing news absolutely drove the rest of her end of life experience. It forced her to become defensive and untrusting of the diagnosis. She became focused on getting a second and third opinion as a mere goal to prove this doctor wrong. Her immediate anger, and feeling more like a diagnosis than a person, triggered her to look past the diagnosis and

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[411] Ngo-Metzger et al., "Guidelines for Patient Centered," 167.

prognosis. She remained fixated on how inhumane she felt and thus the way she felt she was treated stunted her ability to cope adequately with her end of life. By the time she accepted her medical fate and moved passed her anger with the physician, her time for closure was greatly limited. Sure, I would agree that some of her anger was likely triggered by the disease and she transferred it to the doctor as a coping skill, but I can't help but wonder how her end of life would have been different if she was more ready to hear her fate. If I could, I would have changed a hundred things in that situation. I wasn't even able to perform my job appropriately because of the gaping wound left open by this poor executed end of life conversation.

I wholeheartedly understand the circumstances and the pressures that medical professionals encounter in end of life situations. I recognize that with death and dying, pain and suffering is unavoidable, both physically and emotionally, but this case is a perfect example of how if we, as professionals, just took a few moments to think it through and make specific aspects of end of life care a priority, we may be able to contain suffering. End of life is often a time sensitive issue and the time needed to create rapport with the patient may not allow for an ideal emotional readiness. Sometimes we need to try the little things to assist the patient in their readiness.

In this example, just sitting at the end of this patient's bed and asking about her support networks prior to having this discussion may have allowed for a different level of trust. If she did not have trust in the medical professional maybe a more stable trust could be found within her family support. Maybe allowing for the opportunity for her support network to be present, her anger could have been curbed, and her family would be the reminder she needed to remain focused on her prognosis and not her anger.

Maybe by having a social worker attempt a relationship first, this would have softened the blow. Maybe waiting for the evening shift so that her favorite nurse or aide could be present during the discussion, they may have held her hand and provided a tissue so she could have felt more like the independent, proud woman she was and less like the aggressive, dying, cancer patient. And yes, maybe, we as professionals, and I say we because we should work as a cohesive team, could have done all of this and the result may have been the exact same, but I have faith that one of these interventions for this woman could have changed her entire end of life experience.

Maybe the doctor not did have the emotional ability to ever carry this conversation out tactfully. Maybe after twenty-five years as an oncologist, he is jaded, a brick wall surrounds his heart protecting it from the pain of telling person after person, day in and day out, that they are dying. Maybe that is why he treats his patient as a diagnosis, a code number, a treatment option instead of a human. Maybe if he does connect it hurts too much. But that is why there should be a team. This pressure should not be on him and him alone. He has to be willing to share this duty with others even if that sharing is just a small gesture.

This is where an end of life policy and procedure may be of assistance. Just like how hospitals have code procedures and doctor's offices have structure and procedures to function with fluidity, why can't there be a death and dying code, an end of life conversation procure, where there are checks and balances? With this we may give medical professionals the opportunity to avoid this failure. When a patient suffers at the expense of us not being thorough enough, then we have failed them. As professionals we are taught to leave it at the door for our own well-being and that boundaries are necessary for our professional survival. However, our patients don't get the chance to leave it at the door. They are the ones who suffer despite the professional's failures. No code or policy will avoid all pain and suffering, but if it could just alleviate a portion of it then we as professionals perform our job better. I can't help but think about the possibilities that these steps may have had on my patient all those years ago.

This policy can be as detailed or simplistic as needed. Every medical environment is expected to have its own issues specific to its clientele. Possibly, this procedure would act as a tool to initiate a different thought process for medical professionals. Only having to review a short document prior to engaging in an end of life conversation may force us as professionals to remember the end goal. It's not about us getting out unscathed, it's about being humane. This code, as you may want to call it, could just be a few questions. For example:

- Has the patient been evaluated for emotional readiness to engage in end of life conversation? If so, who performed it: social worker, RN, physician's assistant, NP, or physician? If not completed in person, does the patient have a DNR, living will, or have they completed our questionnaire (another possible way to obtain vital information)?
- Is the patient aware that the end of life conversation is a possibility? Have they been educated on their diagnosis, treatment, and test results?
- Did the patient come in just for a yearly physical only to find there is something life changing going on?

- Has there been any type of end of life conversation through this facility in the past? If so, with whom? What was the level of that discussion? Who initiated it: patient, family, or professional?
- Does the patient have rapport with ANY staff members that may be able to offer a level of emotional support the physician may not be able to provide?
- Who are the patient's support networks, spouse, children, other family, and/or friends? If we are unsure, have we asked that question? If we are aware, should we ask the patient if they would like a support network present?

Obviously the above is just an example. It didn't take long to read this and likely after about ten patients, for most medical professionals the code will be committed to memory and a physical document may not even be needed as a reminder to perform it. After reading those six simple statements, did it force you to think differently about the topic? Did it make the importance feel stronger? Did you think of yourself and your future end of life experience? Did you think of a loved one who you hope one day is treated with the respect and time they deserve? I'm hopeful it did. If it did for you, then maybe my hypothesis is correct that implementing an end of life conversation procedure will allow for a change. It might just give us the moments we need as professionals to remind us of the importance of this experience and the great responsibility we as medical professionals have to being fair and caring to all of our patients, especially those with the burden of death in their near future.

I have to admit that my hypothetical example is not the only one of its kind and that I am not alone in this way of thinking. Dr. William Ventres discusses the idea of the "development of a pedagogy of dying."[412] In other words, he stresses the need to create a new format to assist the education of patients on how to approach and manage their death while still keeping their pride and dignity in place.[413] Ventres acknowledges that the growth from advance directives, living wills, and DNRs have absolutely set a foundation for addressing some end of life issues in the current medical climate. Though he feels this foundation serves as a guideline for physicians to follow, he too believes that these discussions still occur too late in the patients' disease progression which limits the possibility for the proper mindful discussion to occur.[414] He reports that it remains the responsibility of the professionals and focuses on the physician's duty to assist their patients with the exploration and acceptance of their "mortality."[415] Dr. Ventres reports that research suggests that there are already communication tools that support a "pedagogy of living," which include "models of structural clinical conversation and the dynamics of interpersonal engagement."[416] Furthermore, these studies support the belief that "motivational interviewing" promotes patient behavior change when it comes to medical care and that this change is encouraged by the doctor/patient relationship.[417] Ventres implies that if the research shows a significant positive result from the use of "pedagogy of life," why not try "pedagogy of death" to assist with easing the emotional battle of the end of life experience.[418]

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[412] William Ventres, "Educating Our Patients About Life and the End of Life: Toward a Pedagogy of Dying." *Journal of American Board of Family Medicine* 27 (2014): 713. doi:10.3122/jabfm.2014.05.130301.

[413] Ventres, "Educating Our Patients," 713.

[414] Ventres, "Educating Our Patients," 713.

[415] Ventres, "Educating Our Patients," 713.

[416] Ventres, "Educating Our Patients," 713.

[417] Ventres, "Educating Our Patients," 714.

[418] Ventres, "Educating Our Patients," 713-14.

Dr. Ventres suggests that we utilize a communication format similar to a coaching technique.[419] He constructs his idea as “short, specific, goal-oriented discussions that assess where patients physically are in their lives, where they figuratively want to be when death comes nearer, and how to prepare for that eventuality.”[420] This technique would be driven by the physician’s clinical creativity to open the dialogue on the topic of the patient’s death. This may be accomplished by pursuing emotional triggers, for example “the death of a loved one, colleague, or even a well-known personality.”[421] This structure will allow for the subject of end of life to enter the conversation. It can continue to become a more in-depth discussion or it can be gently ended to permit the patient to process their personal end of life hopes further on their own time. [422] While exploring Ventres’ suggestion, I can’t help but think of the details within the physician/patient relationship and how this simple act can benefit that connection. Ventres’ proposition of addressing death by sensitively broaching the subject with conversation about the patient’s loss experience, whether it be personal or of a common known individual, does more than just open end of life conversation. I see it also influencing the relationship outside of just being a doctor/patient relationship. By engaging in this dialogue the physician easily removes the relationship from just medical and creates a personal connection. The patient will likely feel less like a medical component in a medical environment and hopefully sense a more humanistic connection. The physician can display true interest in an aspect of the patient’s life that doctors most often do not show

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[419] Ventres, “Educating Our Patients,” 714.
[420] Ventres, “Educating Our Patients,” 714.
[421] Ventres, “Educating Our Patients,” 714.
[422] Ventres, “Educating Our Patients,” 714.

an interest in. This alone can change the dynamic of this relationship, allowing for a level of comfort that is necessary for end of life fears to be managed.

Ventres also reports that due to the fact that every physician, as well as their individual clients, each bring their own individuality, experience, and background to the relationship it will be difficult for any one specific standard of encounter to be expected.[423] Actually I see this as a positive; this interaction can and will provide the patient with the opportunity to identify their physician as a human and see a personal side to him/her simply by how they chose to approach this subject. Like any encounter there is a chance that it may result in a negative reaction if the physician is unable to allow a personal connection during this interaction, but it can also open doors to a new form of doctor/patient relationships. It may give the doctor-patient relationship the opportunity to grown beyond its already created limits.

It may be as simple as the physician starting the discussion with their own personal loss experience or death fears. Yes, this will mean that the physician (or any medical professional who enters this encounter) be open and vulnerable. That may also mean the possibility of the professional feeling more, having sadder, more difficult days, perhaps connecting in a deeper manner with their patients. Again, I don’t see this as a major problem but as the exact answer to why we aren’t able to talk about death better. It will insist on finding new coping skills for the medical professionals, because feeling more as a professional can make the job harder. However, knowing in the end that as a professional you were the driving force that allowed for a patient to be at emotional peace

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[423] Ventres, “Educating Our Patients,” 714,

at the time of their death should ultimately diminish the uneasy emotions that are very normal when death is a concern.

Ventres talks about the skill of listening when it comes to death. As professionals we must get to a place where our hearts and minds are open to a new way of dealing with death, but we must also allow ourselves to really hear what our patients are saying. We cannot hear their fears, hopes, and wishes if we do not allow for the conversation, but once it begins we must step back from our personal fears, hopes, and wishes to hear those of the individual we are trying to help.[424] It is Dr. Ventres' hope that simple questions and themes to consider while building our own "pedagogy of death" can facilitate our capacity to hear. He suggests there are five themes and supportive goals behind each theme.[425]

"Awareness," which generates the importance of the individual's "personal and cultural" influences that ultimately formulate their death process.[426] Some of the questions that may evoke awareness is to address our own "assumptions toward life and death," as medical professionals.[427] It is important that as professionals we recognize how our notions can affect those we are caring for.

It is just as important that patients be aware of their own concepts of their life and death which is where theme two comes in. "Recognition" allows for the professional to create their own understanding of how a patient and family perceives death. It is not easy to formulate appropriate care for an individual without an understanding of their view of

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[424] Ventres, "Educating Our Patients," 714.
[425] Ventres, "Educating Our Patients," 714.
[426] Ventres, "Educating Our Patients," 714.
[427] Ventres, "Educating Our Patients," 714.

life and death.[428] We may find ourselves asking questions about the patient/family's ideas regarding their death as well as how they wish to live their life up to the end.[429]

"Engagement" is likely my favorite of the themes.[430] It highlights the importance of communication tools to help promote a healthy end of life conversation. It instructs that one tool may not work for all and that as professionals we need to have an inventory of skills to make sure we accomplish our goals with our unique patient/family dynamics.[431] A question you may find yourself asking in support of this theme is what approach may best facilitate a conversation on the matter of death?[432]

"Synchronicity" provides the opportunity for the physician to view timing of this conversation as a value. It is essential to the positive outcome of this dialogue that this encounter happen when both the physician and patient/family are emotionally equipped to engage in the process.[433] As stated throughout this paper I have distinguished that though some disease progressions are time sensitive and allow for limited opportunity to engage in the end of life conversation, I have also found support that patient preparation and readiness is no doubt a crucial factor in the final acceptance of the dying process.[434] So we need to carefully ask ourselves as professionals, when is the best time to broach this topic while continuing to recognize that this circumstance also includes professionals' ability to listen as well.[435]

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[428] Ventres, "Educating Our Patients," 714.
[429] Ventres, "Educating Our Patients," 714.
[430] Ventres, "Educating Our Patients," 714.
[431] Ventres, "Educating Our Patients," 714.
[432] Ventres, "Educating Our Patients," 714.
[433] Ventres, "Educating Our Patients," 714.
[434] Ventres, "Educating Our Patients," 714.
[435] Ventres, "Educating Our Patients," 714.

The final theme is "equilibrium" which is the need to discover a balance between the actualities of death while still encompassing a form of hope. It is our job as professionals to strive to a place where we can assist our patient/families to gain acceptance of death as a normal life experience. It is crucial for inner peace to obtain the understanding that death is part of life while self-reflection of human mortality is a weight we must lessen.[436] I feel that it is hope itself that can lead this development. Dr. Ventres states it perfectly, "Life is at once both a recognition of reality and an uncovering of hope, seeking for and finding a balance between the two are important undertakings at whatever are in its cycle."[437] This is especially true as the end of a life is waiting in the wings.

As Dr. Ventres so poignantly documents there are absolutely ways for us to better our abilities to have end of life conversations and though there may not be a perfect standard, there are definitely models of how to accomplish this task. There are themes that should be included in this process as a way to push past the barriers that currently stand in the way of this work. As medical professionals we must remember it is a central part of our role, but it is vital that we also consider the role and responsibility of the patient/family. There are simple factors, that, if considered during the end of life process and even before, we may find a new, more effective way to alleviate the emotional suffering that comes with death.

I want to go back to my suggested thought points to quickly highlight another important factor that mustn't be overlooked. The last question on my example procedure

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[436] Ventres, "Educating Our Patients," 715.
[437] Ventres, "Educating Our Patients," 715.

asks about the patient’s support network. This has been proven to be an important factor in the patient’s engagement in this crucial conversation. Abdul-Razzak, et al. report that the participants of their study conveyed the positive impact that including their family in the end of life conversation had on their experience.[438] This study highlighted the role that family members often play in end of life care and the decision making process. Abdul-Razzak et al. and their research refer to this group as the subject’s family. I think it’s necessary to include friends as a part of the support network. I find that often patients don’t have blood relatives who are involved, but they do have some form of friendship networks. Often, even with family and relatives’ involvement, they still choose for their friends to be their alternate decision makers. Often it becomes the responsibility of the family/friends to assist or even make very crucial end of life decisions. By including them in the conversation appropriately it can allow for the alleviation of pressure on both the patient and the loved one.[439] The patient is given the critical opportunity to verbalize their wishes openly in the presence of their loved ones. This can decrease the pressure of their fears that their wishes will not be known or respected.[440] It also gives them the opportunity to share who they may wish to follow their wishes if they do not have the capacity. This should not only alleviate stress for the patient, but the open discussion should additionally allow the family to have a sense of peace with the patient’s wishes.[441]

It is hopeful that including the loved ones in the end of life conversation will be a positive experience, where support is given to the patient no matter what their wishes. As

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[438] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 3.
[439] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 4.
[440] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 4.
[441] Abdul-Razzak et al., “Conditional Candour and Knowing Me,” 4.

an end of life professional I can tell you that often it isn't that simple. End of life conversation comes with an intense emotional driving force and often in my experience the most intense emotions can come from the loved ones. I have found that though it is important to include family/friends when the patient requests it, often the loved ones struggle to cope with the patient's wishes when hearing them in this setting. Often the patient has accepted their fate and made peace with their death, but those who love them have yet to do that. If the patient is ready to be comfortable and forgo treatment, loved ones can often contest these wishes. This is another situation where I argue education can and will make a difference. Medical professionals should have knowledge and experience with dealing with these complex cases which occur all too often.

On the other side of this it can be the family/friends who are more accepting of the news than the patient. For example, the case of the sixty-seven year old lung cancer patient that I shared earlier may have had a different outcome if her son was present for the conversation. He may have be able to remain calm enough to absorb more of the conversation than the patient herself. I have been present for those conversations as well. Sometimes I think that when a patient hears the words, "end stage, fatal, or there is nothing else we can do," they shut down and hear nothing else from that statement on. It is often the loved ones in those cases who go into caregiving mode and they quickly become the ambassador of the patient's care. Again, education and experience can play a vital role in these cases too. With a better understanding of the many roles both patients and their loved ones can play, a medical professional can quickly assess the direction their discussion is going down and hopefully avoid further conflict or waste of conversation time.

Each of the above points illustrates the role that medical professionals have in the end of life conversation. It is likely that if the medical professional who opens the end of life conversation is not comfortable with the topic it will show and will influence the patient/family response to it. I feel the role of education regarding the end of life dialogue comes with many attributes, but most importantly, is to help and build a level of comfort with death. It allows for experience which is a crucial part of the comfort process. The open dialogue about death and the end of life conversation provides these individuals with the opportunity to understand how the idea of death affects them. So it only makes sense that as a medical professional, knowing your personal response, even your own personal fears, can and will likely influence how you have the end of life conversation with your patients.

Hurtig and Stewin discuss this exact influence in their research regarding the factors of personal feelings and fears toward death in a population of nurses. It was their goal to understand the impact that personal anxieties may play in a medical professional's ability to cope with end of life conversation as a professional duty.[442] It was their hypothesis that personal fears toward their death may negatively impact the subjects' ability to have an appropriate end of life conversation with their patients.[443] They also report that having awareness of their personal feelings and the ability to accept these feelings can and will allow them to have a more humanistic, personal, and affective end of life discussion.

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[442] Wendy Hurtig and Len Stewin, "The Effect of Death Education and Experience of Nursing Students' Attitude Towards Death." *Journal of Advanced Nursing* 15, (1990): 29. doi:10.1111/j.13652648.1990.tb01669.x.

[443] Hurtig and Stewin, "Effect of Death Education," 29.

Evidence supports that providing nurses with the opportunity and tools to face their own personal death fears will allow for more appropriate and helpful interaction with their dying patients.[444] "Those interested in improving the care of the terminally ill have concluded that, until nurses learn to cope with the spectre of death, they will be inclined to put a physical and social distance between themselves and the dying."[445] It is believed that death education courses can assist nurses in facing these issues with a positive influence on their work. In addition, research shows that the educational formats that approach the issue with a personal prospective tend to be more effective than those structured on just providing information.[446] It is important to note that Hurtig et al. reports that though "professional experience with death has not been shown as a significant positive influence on death attitude, personal experience with death may be an important factor."[447] Prior to their study Hurtig et al. reported that much of the research surrounding the influence of death education as an impact for nursing care was done in the 1970s. Some of these studies showed that as death education increased and with time, death anxiety amongst nurses did decrease.[448]

Hurtig et al. performed their study with nursing students who did not have clinical experience yet. The results showed that educational programs provided an opportunity for personal death awareness in their subject group. Furthermore, the study suggested that the experimental approach, which allowed for a more personal introspective method, also afforded a better chance for the subjects to encounter and confront their own feelings

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[444] Hurtig and Stewin, "Effect of Death Education," 29.
[445] Hurtig and Stewin, "Effect of Death Education," 29.
[446] Hurtig and Stewin, "Effect of Death Education," 30.
[447] Hurtig and Stewin, "Effect of Death Education," 30.
[448] Hurtig and Stewin, "Effect of Death Education," 30.

and emotions regarding death.[449] An instructed "guided life death fantasy" allowed for a more realistic environment for the subjects to relate to their personal thoughts about death.[450]

Though the students reported being more aware of their emotions toward death, they were not as willing to be open with the confrontation of these emotions.[451] Hurtig et al. results do not specify as to what may have caused the students to be resistant. Two thoughts are: the attitude that, as a medical professional, they must show strength; and the idea that unresolved emotions from previous personal experience with loss came to the surface.[452] Whether the student was willing to confront their death concerns or not, the results showed that death education in a nursing curriculum can impact awareness which can ultimately affect care provided at the end of a patient's life.[453]

As this study supports my argument that education can and does affect how we as medical professionals handle death and dying in our career, it also brings up another point that I feel necessary to discuss. Hurtig et al. hypothesized that one of the possible reasons the students did not want to express their personal struggles regarding death is due to the "be strong" perception.[454] It has become the culture of medicine that it is the job of the professionals to remain strong for the patient. We are not given the permission as a professional to show our emotions for the fear that it may influence the patient/family's emotional condition and/or imply we are not competent enough to do our

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[449] Hurtig and Stewin, "Effect of Death Education," 32.
[450] Hurtig and Stewin, "Effect of Death Education," 32-33.
[451] Hurtig and Stewin, "Effect of Death Education," 33.
[452] Hurtig and Stewin, "Effect of Death Education," 33.
[453] Hurtig and Stewin, "Effect of Death Education," 33.
[454] Hurtig and Stewin, "Effect of Death Education," 33.

jobs well. I think we can do better here and it starts with the teachers and the seasoned professionals to change this stereotype. Possibly are we doing it wrong; maybe we need to be in touch with our emotions, even if that means showing vulnerability, to be better for our patients? This would allow us to not only to be better for our patients and their loved ones, but to be better for ourselves. Perhaps it is important to not only be aware of our emotions/fears toward death but it is necessary for our health. Conceivably if we can confront our death issues we will find a better way to help others do the same. I see this issue very logically. If we as professionals are unable to face difficult situations, we can't be honest advocates for our patients/families. It's hard to teach, support, and direct if you have not taken your own road toward understanding. We are the foundation so it needs to start with us and if we keep hiding behind the fear of being vulnerable, nothing will change.

It has been noted here that end of life conversations come in all shapes and sizes as well as under many different circumstances. As the above examples have implied it is likely that specific communication tools will benefit this field. The examples of a more standardized format or specific method may lend itself more useful when time is not of the absolute essence. It is important to look at the situations that occur within the hospital settings where many of the hopes to create better end of life conversation become much more complex. Fernandez, et al. report in 2012 that "60% of patients that are admitted to the emergency department and die in the hospital, present on a known dying trajectory, meaning their underlying medical condition predicted significant health decline and death due to known medical conditions."[455] This common situation places

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[455] Rosemare Fernandez et al., "Development of a Content Valid Tool for Assessing End of Life

the acute care professionals with the responsibility of both "stabilizing the patient while obtaining the important information regarding medical diagnosis, current treatments, the patient's and family member's understanding of disease, and end of life goals of care."[456] The nature of this situation limits the physician's ability to build a relationship, and when compounded with time constraints, it makes this circumstance challenging. Often the result of this complicated situation is that acute care professionals incorrectly assess the patient's and family's end of life wishes which frequently consists of providing life sustaining care.[457]

This crucial dilemma can often result in providing futile care, escalation of family stress, and the failure to accept the appropriate level of end of life care such as palliative or hospice care.[458] These results and concerns inspired Fernandez et al. to look into creating an instrument to be used to assess "the end of life communication skills of emergency medicine physicians."[459] With the use of eighteen participants with specific expertise in "palliative emergency medicine," the researchers were able to develop a tool they named SILVER with the goal to identify emergency physicians' abilities to provide proper end of life conversation in their hospital based settings.[460]

The SILVER consisted of four sections, **S**eeking **I**nformation, **L**ife **V**alues, **E**ducation/**E**xtends care, and **R**esponds. Each question rated the physician with a 0-4 scale, 0 standing for not at all, 1 for very little, 2 for somewhat, 3 for very good, and 4 for

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Communication in Acute Care Settings." *Journal of Palliative Medicine* 15, no. 4 (2012): 381. doi:10.1089/jpm.2011.0427.

[456] Fernandez et al., "Content Valid Tool," 381.

[457] Fernandez et al., "Content Valid Tool," 381.

[458] Fernandez et al., "Content Valid Tool," 382.

[459] Fernandez et al., "Content Valid Tool," 382.

[460] Fernandez et al., "Content Valid Tool," 382.

excellent.[461] Under the seeking information section, the goal was to understand the physician's ability to obtain "information regarding baseline function, symptoms, behaviors and its impact on family."[462] It also looked to rate the physician's skills in understanding the "current diagnosis, treatment plan, prognosis, and previous end of life conversation."[463] Additionally ranked the physician's ability to identify the patient's support network including friends, family, and other healthcare relationships.[464]

The L and V in SILVER stand for life values; in this section the rating is to distinguish the physician's ability to understand the patient's "activities of daily living, social structure, personality, life approach, and how they may view death and dying and how it applies to his/her diagnosis and treatment."[465] It also strives to understand the communication provided to clarify past decision making experiences toward end of life issues within the family.[466]

The third section named Educates/Extends care, rates how the patient and family were educated on the disease, disease progression, current disease status, and existing treatment options.[467] Here is it important for the professional to explain the roles of the healthcare team and how decisions regarding end of life may influence the treatment. Finally in this subsection a rating goes to the professional's ability to follow through and

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[461] Fernandez et al., "Content Valid Tool," 382.
[462] Fernandez et al., "Content Valid Tool," 382.
[463] Fernandez et al., "Content Valid Tool," 382.
[464] Fernandez et al., "Content Valid Tool," 382.
[465] Fernandez et al., "Content Valid Tool," 382.
[466] Fernandez et al., "Content Valid Tool," 382.
[467] Fernandez et al., "Content Valid Tool," 382.

communicate with other healthcare team members considering the patient and family wishes.[468]

The fourth and final section, named Responds, has one question. It asks for the participant to rate the professional's ability to elicit questions and concerns from the patient and family regarding the disease, process, and treatment options. It also evaluates the physician follow-through and further time and availability given to the patient and family for future questions and concerns. [469]

My reason for including this research and specific tool structure it to emphasize that in the field of end of life care professionals are very aware that we need to have better end of life dialogue with our patients and families. We are also aware that setting an environment can and will affect how we not only provide this level of care but it also affects how we can do it better. By placing a study of this nature within out medical system, we can find how significant issues are and where we fall short. This instrument was constructed for emergency room physicians, for that environment may produce weaknesses and failures that other medical climates may not encounter. However, it is clear that we must start somewhere. Perhaps we should require this tool be utilized in our emergency departments as a way to influence the procedures and education we put forth from here on out. This instrument can likely illustrate where are biggest problems are and only then can we begin to structure ways to rebuild the foundation of communication skills in the field of end of life care. Possibly we start with Fernandez, et al. and the SILVER and then bring in Dr. Ventres and his proposed strategy. I would help develop

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[468] Fernandez et al., "Content Valid Tool," 382.

[469] Fernandez et al., "Content Valid Tool," 382.

the tools needed to remind and educate our medical professionals about how delicate and powerful end of life issues can be. The facts are seen here within these documents that we absolutely have real failures in end of life communication and we need to start somewhere to fix them for the better of our patients, their families, and even, us as professionals.

I propose we even include a study where we ask young healthy individuals about their perception of death and their wishes for their care when the time comes. Yes, their beliefs and thoughts will likely change when death is near but they can have a better internal dialogue if we put the concept in their minds long before it is their time. This way time is no longer such a strong issue. It is my guess that within that study there would be a significant number of participants that wouldn’t mind discussing their end of life wishes; and because death is not near, the impact of the emotional variables won’t place such an immense barrier as it does when death is around the corner.

Conclusion

When I sat to write this paper I reminisced about the courses I took to get here. I reached into my memory box looking deeply for direction, clarity, expertise, knowledge, and academia to formulate my argument and hopefully produce a doctoral worthy document. The strange thing is that I truly struggled to find these, however the one thing that constantly repeated in my mind was one class. Literally, one Thursday evening class on the Joy of Scholarly Writing was what I kept coming back to me even though it was the class I looked least forward to taking throughout my entire program. There were only three of us students and our professor in this particular class. After sharing a piece of my writing, which caused me great anxiety, my classmates began to criticize it constructively. I was scared and had this constant fear of not being smart enough. To my surprise it was not my words that they addressed, it was my passion. One woman stated, "I love your topic. I believe that it is necessary to discuss. After reading your assignment I did think about my life and death and wishes, all things I can't honestly admit I've processed before. But your writing does not even begin to express the passion that I hear from you in this class when you talk about your topic."

As I reflected, I understood what she was saying. I realized when I write, I sometimes hold back, sugar coat and hesitate to be truly honest and open with this subject. I fear that this topic comes with so many stipulations, stereotypes, and fears that when writing for my classes, I attempted to contain my passion with the hopes of avoiding discomfort. So in a sense I was doing exactly what I am saying we, as professionals, need to stop doing in regard to talking about end of life. I wasn't being fair to my topic or to my passion.

So when I sat to write this I vowed to fill it with the passion, honesty, truth, and even the pain it deserves. Death is HARD, it's devastating, it's crushing, it's empty, it's heartbreaking, but it's real! It's something every single one of us cannot run away from. That is the reason we need to talk about it. It is going to be all of these terrible, difficult things when discussion occurs, but maybe those feelings can be minimized. Maybe those fears can be curbed. Maybe, even maybe, we can live life differently because we actually faced and discussed our death long before it arrived. Maybe this conversation will force us to remember how we want to live all the way up to the end!

I hope throughout this paper you could feel my passion and it helps you find a passion in whatever you need a passion in. I hope it gives you the ability to think about your death and that of your loved ones, and then in turn forces you to think about life and loving it! Maybe I even hope it scared you. Maybe you open this discussion with your physician next time you see him/her. But ultimately I hope you take something, anything, away from my passion to give you an opportunity to better yourself because that is what this paper did for me.

We need to be better is so many ways when it comes to death. Death is different today than it has been throughout history. As I stated in the beginning of this paper, death is no longer a single event, it is a process. It often comes with a diagnosis, a healthcare team, treatment, enormously heavy decisions, and options that can be paralyzing. Death does not just affect the patient. It affects the loved ones, the individuals who make up the support network, and certainly the professionals that deal with death on a daily basis.

Due to of the medical climate change and the new fragments that come with death we need to change how we handle it since it needs to be handled with care and kid gloves. Only then will peace at the end of life be an option. Death is very much a part of life, technically it's the light at the end of the tunnel of life. That is not meant to be a religious plug, it's just how I see it. It should be on the same level as the goal of graduation, a wedding day, the birth of a child which are all absolutely accomplishments. Why should this accomplishment be different than the rest? Why shouldn't we have a say in how this one pans out? Why should we place it in the hands of others without giving them the direction on how to handle it the way you wish? The answer is, it shouldn't be different. If the changes of medicine have changed the process of death then we should be able to benefit from those changes. Death is often not sudden and that can be a benefit. I know the word benefit doesn't seem to belong in the same sentence with death, but maybe it should.

History has unquestionably influenced the dying process. We now have levels of care and treatment that never existed before. This has changed death since it allows for comfort on new levels. We can assist with both physical and emotional pain in a way that we were not able to do in the past. We have structured standards of care like palliative and hospice that facilitate death with peace and dignity. There are a number of influential individuals who assisted in this voyage as there will likely be more influential figures as we continue to grow. The modern hospice movement continues to demonstrate growth as we recognize the needs of the dying population. I predict that this growth will continue and I am hopeful that end of life conversation will change as we continue to gain experience and knowledge in this field.

The growth of humankind and the melting pot that is the world continue to impact death and dying. We have a greater understanding today than we did in the past regarding values, religion, beliefs, and procedures in the diverse cultures that surround us. We need to use these factors to build our foundation of knowledge and education in regards to death and dying. We must remember as professionals that we don't have, nor do we even know, all the answers. It isn't possible to have clear understanding of all the different perceptions of death, but we must not forget that it is different for everyone, and each individual deserves the same opportunity for peace and dignity.

Next to culture it is necessary to highlight that men and women can and will view the death experience differently. In chapter five, Gender Influence, it is discussed how there are innate differences between men and women. Both their values and fears are often distinct from each other which should inspire us to remember how gender traits can affect the process of death in specific individuals.

Support networks, family, friends, and communities are too a part of the ever growing puzzle of death. We need to include them in our focus, understand that there are times when their role is crucial to patient acceptance of disease and death. However, we can't forget that they too will be in emotional pain and we need to respect their process and struggle as well. A patient with limited support systems will inevitably have a different situation which will subsequently contain its own set of struggles. It's those examples that makes death so complex but also why it needs to be so important, especially in the field of medical humanities. Like life, our human ability to recognize and fear death is our human right. This must be respected.

Education seems to me to be the simplest place to start. Due to the complexity that death comes with, it isn't expected that all individuals, even those entering the medical field, will have the innate tools to discuss death well. But it is part of the world of medicine and the job of being a professional in the field. All medical professionals will likely have some experience with death in their career. This should make it necessary for them to have end of life communication education. I believe that with required education on this topic we may be able to eliminate some of the initial suffering our patients and families endure. Education should in itself allow for a new level of emotional awareness. It needs to include personal awareness as well as awareness of our patient's fears.

In the last chapter I discussed the importance of this personal awareness. Often I fear, as medical professionals, we are pushed to evaluate the patient's understanding, competency, awareness, values, and fears regarding death. Though this is a great starting point, I feel it necessary that we do our own soul searching about our emotions, personal experiences, and our very own fears regarding death. As a social worker, we are taught to always be aware of the possibility of transference entering our work. Often we are encouraged to have our own therapist to process our emotions that arise while doing our job. This is important because without this awareness and understanding we can inflict avoidable harm on our patients. Yes, this part of education can be difficult and likely emotionally draining to the professional. But it isn't fair to place any of our fears or un-confronted concerns about death onto our patients and families. Sometimes I wonder if that mistake is harder to fix than just the patient/family issues alone.

We also must educate ourselves on how we can do our jobs better. Maybe before we implement required training or certification programs, we research where the biggest problems in end of life communication are. Some of the issues we have may be deeper than others and some may cause a different level of suffering, while some may have a simple fix. It's hard to fix a colossal deficit if we aren't aware of the facets that create the problem.

Once we figure out our failures and breakdowns only then can we start to build the foundation of education and develop the tools necessary to resolve our critical problems. In chapter six, I discussed some of the proposed tools that can both be used to find our faults as well as fix them. I hypothesized coming up with a template for an end of life procedure or policy that influences the professional's skills, and for the importance of factors that influence end of life communication. Future research is required in this part of the field. As I had written earlier, we may even want to study healthy individuals and their perspective on death including their wishes for when the time comes for the conversation to be had. This idea allows for the conversation to start, however, it does not need to be concluded with answers or a concrete death plan because that is unrealistic. One's end of life values and wishes will absolutely grow and change as they live their lives and also as death becomes a reality. The proposal of this kind of study would be to find out feelings about death in a population who may not feel threated with the idea of death, as well as serve as an early intervention. It will allow for an inner dialogue long before it is needed with the hopes that peace can be gained quicker when the end is near.

Therefore the main points are: death is real, it is different than long ago, and as medical professionals we need to facilitate conversations better and earlier. We need to understand patient/family awareness, culture, and fears as well as our own. We need better education so that we can do our job better. Also, we need to find where we are ineffective and put tools in place to avoid this ineffectiveness. Finally, we need to look for an inner and outer peace for our patients and families. We need to take an innately terrifying time and attempt to make it beautiful and easier.

I leave with the following because I promised to be true to my passion. I recently read this and I believe it is the perfect way to end this heavy, emotional paper.

To Remember Me by Robert N. Test

> The day will come when my body will lie upon a white sheet neatly tucked under four corners of a mattress located in a hospital; busily occupied with the living and the dying. At a certain moment a doctor will determine that my brain has ceased to function and that, for all intent and purposes, my life has stopped.
>
> When that happens, do not attempt to instill artificial life into my body by the use of a machine. And don't call this my deathbed. Let it be called the bed of life, and let my body be taken from it to help others lead fuller lives.
>
> Give my sight to the man who has never seen a sunrise, a baby's face or the love in the eyes of a woman. Give my heart to a person whose own heart has caused nothing but endless days of pain.
>
> Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchildren play. Give my kidneys to the one who depends on a machine to exist. Take my bones, every muscle, every fiber and nerve in my body and find a way to make a crippled child walk.
>
> Explore every corner of my brain. Take my cells, if necessary, and let them grow so that, someday a speechless boy will shout at the crack of a bat and a deaf girl will hear the sound of rain against the window.

> Burn what is left of me and scatter the ashes to the winds to help flowers grow.
>
> If you bury something, let it be my faults, my weaknesses, and all prejudice against fellow man.
>
> If, by chance, you wish to remember me, do it with a kind deed or word to someone who needs you. If you do all I have asked, I will live forever.

I know that this composition brings up so many other issues and I'm well aware that it appears to be from a man who is brain dead which may not feel like the ideal fit here. However, let me explain what I hear when I read this and why I feel it is a very appropriate piece to end this paper. The words of this man emulate peace. This individual is not fearful of death or saddened by the end of his ability to live. He has reached a place of comfort and peace, where life is so much more than the death that comes at the end of it. This is the peace I wish for every patient and family I work with, the peace I hope we see as our goal in end of life care. This is the peace that I believe proper end of life education and conversation can and will create. It is a peace that we as humans all deserve when we reach the end of our tunnel.[470]

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[470] Robert N.Test, *To Remember Me.* December 2016. http://www.funeralplan.com/funeralplan/alternative/rememberme.html.

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