

A Proposed Model to Increase the Number of End of Life Conversations Made
Between Terminally Ill Patients and Their Primary Care Physicians

by
Jason Ryan Duval

A THESIS

submitted to

Oregon State University

University Honors College

in partial fulfillment of
the requirements for the
degree of

Honors Baccalaureate of Science in Biology
(Honors Scholar)

Presented March 2, 2016
Commencement June 2016

AN ABSTRACT OF THE THESIS OF

Jason Ryan Duval for the degree of Honors Baccalaureate of Science in Biology
presented on March 2, 2016. Title: A Proposed Model to Increase the Number of
End of Life Conversations Made Between Terminally Ill Patients and Their
Primary Care Physicians

Abstract approved:

Courtney Campbell

The objective of this paper is to present an alternative model that can be accepted into our current medical care system that outlines protocols for physicians treating terminally ill patients and that will ultimately increase the number of end of life conversations made between them and their patients. The work of two physicians and one organization involved in the direct care of terminally ill patients will be summarized and critically analyzed so as to present the current issues with end of life care with an emphasis on the lack of discussions being conducted between doctors and their patients. The works will also be used to express possible solutions to these issues and will be referred to during the presentation of the alternative model. The model will be conveyed in its entirety and the goals of its implementation will bring the paper to its conclusion.

Key Words: alternative model, end-of-life conversations, medical care protocol, terminally ill, treatment plan

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March 2, 2016
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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Jason Ryan Duval, Author

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Chapter 1 – The Introduction

Increasing life expectancy world-wide has been one of the greatest achievements of the 20th century. Before the year of 1900, most human beings did not live past the age of 50 years old and now there are countries with the average life expectancy as high as 83 years of age (“Living Longer”). There are, of course, exceptions to this rise in survival rates including some countries in Africa where the spread of HIV/AIDS has hindered this progression. In developed countries, however, it is common to have very high rates of survival concentrated in older populations. While better living standards such as more nutritious diets and cleaner drinking water have aided this dramatic improvement, advances in modern science and medicine have made important contributions to this great success. Public health projects during the middle of the 20th century led to the immunization of millions of people against deadly diseases such as smallpox, polio, and measles (“Living Longer”). Once infectious and parasitic diseases were no longer the leading causes of death, the most common mode of human fatality shifted to non-communicable diseases and chronic health conditions.

With chronic health conditions and non-communicable diseases leading the most common causes of death in our modern day society, a number of problems have arisen that did not exist before now. People are living longer, which means that more facilities, more care givers, more healthcare providers, and more treatments must be made available for the increasing older human population in order to maintain high quality standards of health and well-being. This increasing demand for healthcare workers has created a large disparity

between the number of adequately trained healthcare professionals that are needed to provide the best possible care to this elderly population and the number of specifically trained healthcare professionals that are currently available. This disparity has left the increasing elderly population unprepared to deal with the challenges that come as a result of a longer lifespan, including the act of making critical end of life decisions, discussing these critical decisions with their healthcare providers, and ensuring that their decisions are being properly enforced by those surrounding them throughout their treatment plan.

Healthcare professionals are far too often left unaided in their attempts to properly treat their terminally ill patients and as the average age of the population continues to increase, so does the number of patients with life threatening conditions. Treatment plans are not always straight forward, especially when dealing with terminal diseases such as cancer. There is no cure for such conditions and as a result, healthcare professionals are expected to come up with a plan of action. Physicians, particularly, wish to do everything that they can to keep their patients alive, but are they truly listening to their patients when following through with the treatment plan that is ultimately decided upon? Is it really in the best interest of the patient to continue possible life extending treatments at the expense of that person's quality of life during their final days? How can patients who are being cared for by professionals in the hospital, often with limited contact or conversation with family members, have their treatment preferences recognized? Have these patients even had the opportunity to express their end of life wishes with their family, friends, and physicians?

It can be very difficult for some people to talk about the end of their lives. It can be even more difficult for some people to think about their final wishes as they approach the end of their lives. It is the duty of the physician to aid their patients in these discussions and to allow them to effectively express themselves freely and without judgment in order to provide them with the best possible care. When physicians initially assume their role as healer's in today's society, they make a commitment to their patients to follow the ethical principle of beneficence and provide the best possible care for the patient. The modern version of the Hippocratic Oath contains two critical statements that pertain directly to what has been described here: "I will apply, for the benefit of the sick, all measures which are required, avoiding those twin traps of overtreatment and therapeutic nihilism. I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug" ("Hippocratic Oath, Modern Version"). It is the duty of the physician to discuss and deliberate what is in the best interest of their patients in order to effectively plan out the course of action that will fulfill the final wishes of their patients rather than focus exclusively on what can potentially extend their lifespans. It is therefore the responsibility of the physician to sympathize with their patient and to listen to their patient intently in order to understand them as a human being and avoid mechanically turning to an instrument of science to treat them when such measures are not necessary.

Furthermore, there is need for an effective method that healthcare professionals can utilize in order to discover the end of life wishes of their

terminally ill patients. This method need not be perfect nor static, but rather implemented as a general guide that can be followed as well as molded to fit the scenario of any patient faced with terminal illness. It is this guide that will decrease the disparity between the number of adequately prepared healthcare professionals who are needed to properly treat the increasing amount of terminally ill patients and the number of healthcare professionals that are currently ready to effectively treat such patients. It is also this guide, as previously mentioned, that will allow physicians to ultimately decrease the number of people who are unprepared when faced with the uncertainty of death and forced to make quick decisions that they may not have otherwise made in a desperate attempt to lengthen their lifespan and delay that which is inevitable. This will, in turn, allow physicians to be better informed and follow through with a treatment plan better suited to improve the lives of their terminally ill patients before they pass.

This thesis will explore questions in the physician-patient relationship and communication at the end of life. To do this I will examine the writings of two influential physicians who have given thoughtful reflection to these end-of-life issues and who have experienced these issues first hand. First, I will summarize and critically analyze the observations of Dr. Sherwin B. Nuland, especially the writings involved with the end of life care between patients and their physicians and the overall idea of “hope”. After this, I will investigate the literature presented by Dr. Atul Gawande in hopes of discovering similar issues with the end of life treatment process and how discussions play a key role in deciding when to “let go”. I will also investigate several ways in which individuals and organizations

have attempted to resolve these issues in our healthcare system thus far. Upon examination, I will use these avenues of knowledge and experiences to construct the much needed guide that has been previously described in this chapter.

Chapter 2 – The Problem

The prescribed idea of improving end of life care for patients who are terminally ill must not be taken lightly. Every human being on this earth will eventually come to the end of their life and the means by which they find themselves dying is an area of healthcare that we can continue to improve upon. Some of the most noteworthy observations on end of life care and the overarching idea of hope can be found in Dr. Sherwin B. Nuland's book entitled *How We Die: Reflections on Life's Final Chapter*, originally published in 1994.

Dr. Nuland begins the 11th chapter of his book *How We Die* by talking about how patients tend to base their overall level of hope on their physician's suggestions. Physicians strive to never allow their patients to lose hope, but hope itself can also come from the patient's friends and family. Dr. Nuland presents the definition of hope from Webster's Dictionary, stating that it is the highest degree of well-founded expectation. It is also defined as expectation that is at least in sight. Another definition which seems to be the center of an overarching issue in medicine is "to hope against hope," meaning having hope though it seems to be baseless. Samuel Johnson described hope as being "...itself a species of happiness and perhaps the chief happiness which this world affords" (Nuland 223). Dr. Nuland speaks of hope as often being a future of happiness that one could attain, such as a patient whose suffering and sorrow is vanquished. Doctors often see treatment or remission as the only way to attain this outcome and maintain hope within their patients. This is the baseless hope where we attempt to avoid the fact that Mother Nature always wins. William Bean of the University of Iowa says the

ineffective delaying action of physicians is "...the busy paraphernalia of scientific medicine, keeping a vague shadow of life flickering when all hope is gone. This may lead to the most extravagant and ridiculous maneuvers aimed at keeping extant certain representative traces of life while final and complete death is temporarily frustrated or thwarted" (Nuland 224).

Dr. Nuland goes on to present his readers with the case of his older brother Harvey who was diagnosed with metastatic intestinal cancer at the age of 62 in 1989. He worked in New York at an accounting firm but found happiness at home with his family. Harvey was having bowel problems and his doctor found a mass on the right side of his abdomen. X-rays confirmed a tumor which had spread to the surrounding tissues as well as the liver. Many of the malignant cells were removed during surgery, but several had to be left behind due to their critical locations. Dr. Nuland was left with a very hard decision to make, since the doctors seemed to him to be too self-absorbed to care about his brother's hope. Harvey seemed to return to his adolescence after the operation and turned to his younger brother for guidance.

The action Dr. Nuland took next was one he would later regret. He chose to search for a miracle drug or treatment that could cure his brother's fatal disease. He found an experimental treatment called the 5-fluorouracil-interferon treatment, which had shown to reduce the size of tumors in patients but never cure them completely. The drug had toxic side effects and even caused chemo-induced death in one patient who had taken it. Dr. Nuland could not tell his brother the extent of the metastatic growth nor his inevitable prognosis. He did not want to

take away his “hope” and felt that he had a duty to his brother and his family, including his wife Loretta and their two college-aged children. This sense of duty is much different from that of the duty of the physician described in chapter 1. Here, Dr. Nuland’s sense of duty to his family overcame that of his duty as a physician to his patient. As a family member, one has the responsibility to emotionally support the other members of their family in times of need and Dr. Nuland felt that he would betray this sense of duty if he were to follow through with his responsibility as a physician.

Harvey’s son Seth called one afternoon after the treatment had started to tell him that Harvey had been taken to the emergency room due to increased drug toxicity and periodic states of unconsciousness. When Dr. Nuland arrived he found that the emergency department was so hectic that there were no rooms or beds available, so his brother was placed in a small area with several other patients who were deathly ill. With his wife and two children by his side, Harvey lay on a stretcher in his own diarrhea because the doctors and nurses were too busy with all of the other patients. His younger brother was fortunately able to get him into a room on the nursing floors due to his medical influence. He eventually recovered from his near death episode, but his tumor cells that had originally shrunk 50% due to the treatment were now growing back to their original size and there was no reason to continue chemotherapy. Harvey and his family returned home.

Hospice was called in soon after the episode and Harvey’s house was rearranged so that he could move about more easily. The hospice workers also

taught Seth how to manage his father's pain and nausea with different medications. As Harvey's pain increased and he became more and more weak, his intestines continued to narrow and medicine had to be administered suppositorally. Dr. Nuland visited his brother and they talked about the long past that they shared together. His brother died just a couple days after his last visit in his own bed surrounded by his family. Dr. Nuland reflects upon his regretful decision when he declares: "Thirty years earlier when there was no chemotherapy, Harvey would probably have died at about the same time that he eventually did, of the same cachexia, insufficiency of the liver, and chronic chemical imbalance, but his death would have been without the added devastation of futile treatment and the misguided concept of "hope" that I had been reluctant to deny him and his family, as well as myself" (231).

After reading through the story of Dr. Nuland and his older brother Harvey, many issues relating to end of life experiences can be observed. Perhaps the most apparent issue is that of Dr. Nuland's internal struggle between fulfilling his duty to his family and fulfilling his duty as a physician. Even though Dr. Nuland is not his brother's physician, he still feels a sense of responsibility when it comes to his brother's medical care. As a family member, Nuland does not want to fail his brother and cause him and the rest of his family to lose their sense of hope. Because of this, he chooses to neglect his sense of duty as a physician and avoids having an end of life discussion with Harvey even though he knew how critical his brother's condition appeared to be. This leads one to conclude that it may be better for physicians to remove themselves from any sort of end of life

treatment with their family members to avoid such internal struggle and problematic repercussions, but this is not the primary issue here. The overarching problem in this story is simply the fact that the end-of-life wishes of Harvey were never discussed. Even as a family member, Nuland had a responsibility to talk about these wishes with his brother in order to help him in his time of need as best as possible. If Harvey had been given the chance to express his concerns and discuss how he would wish to spend his final days alive, he may have come to the conclusion that trying experimental treatments is not his desired path and that he would rather die in the comfort of his own home in the presence of his close friends and family.

Dr. Nuland goes on to talk about how easy it is for patients, their families, and even their doctors to hope for a cure in this new biomedical era, which often ends in unintentionally worsening the condition of one's life in their final days. He proceeds by presenting his readers with a former patient of his by the name of Robert DeMatteis. Bob had been in a serious automobile accident 14 years prior and was deathly afraid of anything that had to do with medicine or medical treatment. He was a 49 year old man who worked as an attorney and a political leader in the city where he resided. Bob was 5 foot 8 inches tall, weighed close to 320 pounds, and was intimidating to most but was actually very kind and warmhearted. His fear made him particularly difficult to treat effectively, so Dr. Nuland was not exactly excited to hear that he had been admitted into the hospital for passing a large amount of blood rectally 10 years ago.

Bob had also noticed a change in odor in his stool and confessed that he had recently been experiencing abdominal discomfort. X-rays showed superficial erosion of the duodenum and thickening at the ileocecal valve. The colonoscopy revealed that the thickening was actually a tumor and consent for an operation to remove it was eventually given. The operation revealed a much more aggressive form of cancer than was expected and the metastatic cells had already invaded much of the surrounding tissues including 8 of the 17 lymph nodes. Everything was discussed with Bob as he had asked and he did not lash out in hysteria as previous history might suggest. He had accepted that he was going to die. His wife Carolyn, however, wanted to explore every option and had her husband see an oncologist who recommended treatment. They decided to accept his recommendation.

Chemotherapy was delayed at first, as is necessary with all patients with obesity. During this time, Bob met with the oncologist once more and was receptive to the doctor's treatment. Dr. Nuland believes that Bob did this to please his wife and daughter Lisa. He had regained his weight that he had lost from the previous operation and was feeling very well without any negative symptoms before the treatment began. After he was started on chemo, he began to suffer from high fevers, constipation, diarrhea, irritated and eroded skin around the buttocks, and had to use narcotics to control the onset of pain. He could no longer go into his office to work. The metastasis began to grow at an alarming rate, he became jaundiced due to his liver failing, and his legs swelled dramatically due to

the cancer blocking his blood vessels in his pelvis. Bob's daughter Lisa had to stay home to care for him and they grew even closer together as a result.

Christmas was always a time for joy at the DeMatteises household where they would host a huge party for all their friends and family. Bob wanted Christmas to be no different than any other so they held their party as they always had. Dr. Nuland attended early so as to have time to suggest hospice care for Bob. He was very receptive and agreed to follow through with his recommendation for his final days. The Christmas party was just as joyful as always and Bob told his wife that it was the greatest he had ever had. Shortly after starting the hospice care program, he started to develop high fevers and his diarrhea was often uncontrollable. Bob was eventually admitted into the inpatient building of the Connecticut Hospice in Branford. His liver was highly enlarged and his restlessness required frequent use of tranquilizers along with his morphine. He seemed to be weakening by the hour. On the second day, Bob held his wife and daughter very close and asked them to give him permission to die. He fell unconscious shortly after that and died the following day just a few minutes after his wife told him how much his life meant to her.

There was a huge funeral in Bob's honor with the mayor and the honor guard in attendance. Lisa slipped a goodbye letter in his casket before it was lowered into the ground forever. Dr. Nuland speaks of how Bob taught him that "...hope can still exist even when rescue is impossible" (241). He had his favorite words from his favorite writer Charles Dickens inscribed on his grave marker. It

reads: “And it was always said of him that he knew how to keep Christmas well”
(Nuland 241)

The issues that appear here in the story of Dr. Nuland and his patient Robert may not be as apparent as they are in the previous story. It seems as though all worked out as best it could in the end, but at the beginning of the story it is made known that Robert had already accepted the fact he was going to die and yet he went forward with further medical treatment anyway. In this situation, it was not Nuland that disregarded his sense of duty to maintain his patient’s sense of hope. It was actually Robert’s wife Carolyn that chose to let her love for her husband overcome her responsibility to discuss what his own end-of-life wishes were. Robert was not holding on to a baseless sense of hope that Nuland describes at the beginning of his chapter, but his wife Carolyn most definitely was. She wanted to try every possible avenue to cure her husband and extend his life, but in doing so she neglected to have that critical end of life discussion with Robert and find out how he would have wanted to spend his final days from the moment he learned of his terminal diagnosis. It was also the responsibility of the oncologist to have this conversation with his patient to make certain that this was what he truly wanted to move forward with and to allow his patient to make a well informed decision. If this sort of discussion had taken place, Robert may not have chosen to go through with the oncologist’s recommendation for treatment and would have possibly spent more of his last days alive in hospice at home with his family.

Dr. Nuland’s personal experience with his brother Harvey and his more professional experience with Robert both show and express the difficulties that

arise when it comes to the end of a person's life. Our basic instincts often force us to grasp at any form of lasting hope that could lead to the recovery and survival of ourselves and our loved ones. This notion of hope as Nuland has discussed in his book, however, can ironically lead us to miss out on our most valued wishes during our final days.

Chapter 3 – The Problem Continued

Dr. Atul Gawande is another author who writes on his personal experiences with end of life care and who stresses the importance of planning ahead and having critical end of life discussions with patients in order to fulfill their final wishes and provide the best possible care. Gawande's approach in his observations on the subject of end-of-life care differs from that of Dr. Nuland, however. Rather than focusing on the false sense of "hope" that Nuland most notably describes as being the cause for such drastic measures to be taken in order to extend the life of the patient, Gawande focuses more on the difficulty that the patient, physician, and family have when deciding when to "let go" and how ignorance of modern medicine's limits can lead to frustration and misunderstanding when faced with such a decision. The term "letting go" that Dr. Gawande is referring to does not mean simply giving up on the patient, nor does it mean the patient is finished enjoying life, nor does it mean the family members have stopped caring for their loved one. The term letting go refers to the point at which the patient, physician, and family have discussed the terminal condition of the patient and have all accepted the fact that modern medicine will never completely cure the patient. It is at this point that all involved in the process decide to follow through with the patient's final wishes in order to provide the highest level of care.

Dr. Gawande starts his article *Letting Go*, published in *The New Yorker* on August 2nd of 2010, by introducing a patient by the name of Sara Thomas Monopoli. She was 34 years old when she was diagnosed with lung cancer in

June of the previous year after she experienced a collapsed lung and her chest filled with fluid. Sara was 39 weeks pregnant at the time so she had an induced labor and gave birth to a perfectly healthy 7lbs 9ounce baby girl named Vivian. Sara's oncologist, Dr. Marcoux, found that the cancer was very advanced and had metastasized to her lymph nodes and the lining of her chest. He offered to treat her with a new drug called Tarceva which had a 65% improvement rate in female non-smokers. It caused an itchy, acne-like facial rash and a numbing tiredness. Sara also underwent surgery to remove the fluid from her lungs and had a permanent tube placed to remove further fluid build-up.

Three weeks after the surgery, Sara was admitted into the hospital due to a blood clot in one of the arteries in her lungs. The experimental drug was not working, so the oncology team put her on carboplatin and paclitaxel which caused an extreme allergic reaction. After being switched to carboplatin and gemcitabine, she spent most of the summer at home with her husband Rich, daughter Vivian, and parents who had moved in to help take care of her. Sara's October CT scan showed extreme progression of the cancer so she was placed on pemetrexed, which was only intended to prolong her life a couple extra months. Her November CT showed that the cancer had spread to her right chest, liver, lining of the abdomen, and spine indicating that the drugs were again not working. This is a very critical point in the patient's care and is the key question that Dr. Gawande believes needs to be answered: "What do we want Sara and her doctors to do now? Or, another way to put it, if you were the one that had metastatic cancer or,

for that matter, a similarly advanced case of emphysema or congestive heart failure – what would you want your doctors to do?” (Gawande, “Letting Go”)

Dr. Gawande elaborates on this issue of decision making by talking about how patients are having talks with their doctors about end-of-life situations, but do so much too late in the process. They tend to be unprepared to deal with death and often accept forms of treatment that may prolong their life, but not the quality of it. People state that they want to avoid suffering, be with family, have the touch of others, be mentally aware, and to not be a burden on others, but our healthcare system is not set up to achieve these goals. This is the central issue that Gawande has presented his readers with in his observations here. He argues that patients today know what they want for their end of life care, but are not expressing these wishes with their physicians in time. His critique of our current medical system here suggests that discovering a way to make these types of conversations happen between patients and physicians is key to resolving this overarching issue. Dr. Gawande speaks of how death used to be a relatively quick process where people would usually reaffirm their faith, repent their sins, and let go of worldly possessions and desires. Now medical care can extend your life, but at what cost?

Sara Monopoli and her family did not see dying as an option and therefore did not have a discussion about her wishes for the end of her life, nor did she have a discussion about hospice care. As a result, Dr. Marcoux suggested an experimental drug PF0231006 and put her on Navelbine in the meantime even though the chances of success were slim and the chances of experiencing debilitating side effects were extremely high. Dr. Gawande goes on to explain that

doctors often have a difficult time being realistic when a patient like Sara is so optimistic. When she later developed thyroid cancer, Dr. Gawande found it easier to discuss possible experimental drugs that could treat both cancers than it was to talk about end-of-life situations. Sara became steadily sicker as the cancer metastasized further into her liver and spine in December and eventually reached her brain during the first weeks of February. The experimental drugs could not cross the blood-brain barrier and were therefore not going to work. Whole brain radiation treatment was then undergone which only left Sara fatigued and further debilitated. She then confessed she had been experiencing double vision and numbness of the hands for quite some time and was put on yet another experimental drug on the 25th of February. Sara then developed pneumonia and was put on antibiotics but slipped out of consciousness and was put on a ventilator in the hospital so she could breathe.

Dr. Morrison, Sara's primary care physician, met Sara and Rich at the hospital when they were transported to the emergency room at the end of February. He sat down and explained to Rich that this was going to be the end and that they could keep fighting but that the cancer will never be gone. The family finally decided to stop the treatments at the very end as Rich whispered into his wife's ear that it was okay to let go before she slowly stopped breathing and died on the hospital bed.

Again, as with the writings of Dr. Nuland, we see several issues with the care that Sara received during the last few months of her life. The core issue does not lie in the way treatment was carried out in any of the cases discussed thus far,

but rather in the planning stages of that treatment. It is very apparent from Gawande's story that Sara went through a tremendous amount of medical treatments that did not significantly extend or improve the quality of her life, which could have been avoided if she had only partaken in critical end-of-life discussions with her physicians. It is specifically stated in the story, in fact, that she and her family did not see death as an option. This is a grave mistake that I believe Gawande observes in many cases and, as previously stated in this chapter, the key point he is trying to make to his readers. He believes that if we were to find a way to have patients accept the possibility of death and make end of life discussions happen between patients and their physicians, then doctors would be better equipped to follow through with the final wishes of their patients and provide an overall higher level of care. Gawande also stated that he personally found it easier to discuss further experimental treatments with his patients than it was to discuss their end of life wishes when they are particularly optimistic. This only adds further complexity to the primary issue here and increases the difficulty of having end of life discussions between patients and their doctors.

Included in the same article about Sara, Dr. Gawande writes of his experience while going on rounds with a hospice care nurse and how he learned that the goal of hospice care is to cease administering medical treatment that is aimed at curing the patient in order to allow Mother Nature to take its course. It is in fact meant to provide care for terminally ill patients to maintain the highest level of comfort and state of awareness possible, as well as provide patients with time to spend with their families. He visited the homes of both Lee Cox and Dave

Galloway while on rounds, both of whom had very different experiences with their end of life care. Lee had instructed her family to call 911 to attempt to revive her when her heart stopped beating with no success, while Dave accepted the hospice care services and died peacefully surrounded by his family.

Dr. Gawande also writes of a patient by the name of Stephen Jay Gould, probably one of the most famous scientists of the 20th century, who developed cancer in 1985. Gould decided to focus on the long trailing tail end of a graph showing lengths of survival time for past patients with his disease. He ended up living until 2002 when he died of a completely different illness. Dr. Gawande believes that there is nothing wrong with the hope on which Gould was clinging to (the same “hope” that Dr. Nuland wrote about), but that we have unfortunately built our healthcare system around it and it ends up preventing patients from adequately preparing themselves for death.

Dr. Susan Block is a palliative care specialist who spoke with Dr. Gawande about how the doctor-patient end of life discussions should primarily focus on what the patient wants. The goal is to discover what the patient feels is most important to them rather than which treatments they will or will not want to participate in. Dr. Block’s own father developed a cyst on his spine and she had to have this discussion with him which greatly aided in her decision making process during his surgery. Similarly, Dr. Gawande describes a 29 year old patient that had developed a brain tumor and had to decide what to do after he showed no signs of improvement after two rounds of chemotherapy. The patient and his

family ultimately came to the conclusion that they truly wanted to stop treatment after a very long and extensive discussion with their oncologist.

The writings and observations of Dr. Gawande accurately depict the core issue being discussed in the story of Sara as well as those presented by Dr. Nuland. Human beings naturally neglect the possibility that there is no cure for their terminal condition and often do not acknowledge the limits of modern medicine. As a result, patients do not have the critical discussions with their healthcare providers about what they want during their final days of living. They more often than not fail to consider alternative methods of care, such as hospice, where they can be comfortable at home with their families rather than reside in a hospital bed under the influence of a multitude of experimental drugs. As a by-product of this issue, medical expenses for the patient and their families dramatically increase. 25% of Medicare spending goes towards terminally ill patients, which makes up roughly 5% of all total patients (Gawande, “Letting Go”). Expense for a patient with breast cancer is usually U-shaped in graph form, showing a dramatic increase in expenditure during the last 6 months of care. This increase can, at least in part, be attributed to last moment efforts to extend the patient’s life through experimental treatments. Having identified the sources of the issue regarding the lack of critical end of life conversations between doctors and their terminally ill patients, it is imperative now to consider ways in which to ensure that these conversations take place.

Chapter 4 – The Solution

With all of the observations and resulting issues relating to end of life care that have already been expressed, possible solutions to relieve these concerns should be constructed. Attempts have been made by physicians and organizations in the past that have been shown to make some noticeable improvement to end of life care and will therefore aid in constructing an overarching model which can serve on the national level. Several of these previous attempts at implementing a solution include those made by Dr. Atul Gawande, the Gunderson Lutheran Hospital in La Crosse, Wisconsin, and the Conversation Project in collaboration with the Institute of Healthcare Improvement.

Dr. Gawande's article entitled *The Best Possible Day*, published in *The New York Times* on October 5th of 2014 and part of his book *Being Mortal*, pp. 243-249, best illustrates his personal attempts at solving this end of life care problem with several different methods. The article begins with him receiving a call from the husband of Peg Bachelder, his daughter Hunter's piano teacher. Peg's husband informs him that Peg is in the hospital. She had been treated with chemotherapy, radiation, and radical surgery when she was diagnosed with a rare pelvic cancer in 2010. Peg was now suffering from a leukemia-like malignancy caused by her treatment. She was sick with fevers and an infection which imaging showed to be caused by a relapse of her original cancer in her hip and liver. Doctors gave her blood transfusions, pain medication, and steroids for her fevers. Being consulted as a family friend, Dr. Gawande now asks himself what the correct route to take from this critical point in time is, much like Sara's

doctors had done in *Letting Go*. Should Peg continue treatment or “give up”? He goes on to talk about how he felt ill equipped to handle these sorts of situations for the previous decade. He often felt unable to help some of his patients facing these tough decisions or his father who was then in his 70’s. To combat this, he had researched managing mortality and how society could improve upon doing so. For three years Dr. Gawande spoke with over 200 people about their experiences with aging, serious illness, and family members. He interviewed and shadowed staff at retirement homes, palliative care specialties, hospice workers, geriatrics, nursing home reformers, pioneers, and contraries. During his years of research, he made two fundamental discoveries: people have priorities other than living longer and the best way to learn these priorities is to ask them.

In addition to these two fundamental discoveries, Dr. Gawande found that the most successful physicians were those who asked four important questions: What is your understanding of your health or condition? What are your goals if your health worsens? What are your fears? What trade-offs are you willing to make or not make? (Gawande, “The Best Possible Day”). The answers that patients give to these questions inevitably change over time and should therefore be asked continuously. They are the questions that Dr. Gawande decided to ask Peg in order to determine what he would advise her to do next. She answered the first by saying there was nothing the doctors could do to save her life and that she was going to die. She answered the second by saying that she had no goals that she could fulfill in the amount of time she had left. She answered the third by saying that she was afraid of experiencing more pain, suffering and humiliation

from losing more bodily control, and being unable to leave the hospital. Because of Peg's answers thus far, Dr. Gawande decided to suggest that she try going on hospice in attempt to achieve one good day that she had not experienced in quite some time. As Dr. Gawande spoke to his Peg, he attempted to express that, "Hospice's aim, at least in theory... is to give people their best possible day, however they might define it under the circumstances" (Gawande, "The Best Possible Day").

Peg decided to take Dr. Gawande's advice and try hospice in an attempt to continue teaching as long as she could. The hospice care specialists first worked with her to set smaller goals such as managing daily difficulties to give her control over her challenges. They did this by moving her bed to the first floor, planning out bathing and dressing, and adjusting her medications to fit her level of desired comfort. Her anxieties lessened dramatically as her sights raised on teaching once again. It was important to her to be able to say goodbye to her friends and to give parting advice to her students.

Peg lived for six weeks after going on hospice, four of which were spent teaching and two final concerts were played. A week after the last concert she fell into delirium and died peacefully in her bed. The last memory Dr. Gawande has of Peg is when she gave his daughter a music book and put her arm around her to tell her that she was special. This was something she never wanted her students to forget.

After Dr. Gawande had recognized the core issue of patients not having these critical discussions about end of life care with their doctors and nurses, he

implemented his own form of a solution. Once he discovered that people have priorities other than simply living longer and that the best way to find out what these priorities are is to ask them, he initiated a discussion with his friend that included asking a specific set of questions that would help guide him in his attempt at suggesting the best possible route of care. This very much resembles the approach of Gunderson Lutheran Hospital in La Crosse, Wisconsin.

The elderly residents of La Crosse, Wisconsin have unusually low end of life costs on average. They spend roughly half as many days in the hospital during their last six months of living than the national average and there is no indication that the doctors there are stopping treatment too early. The resident's life expectancy is also a year longer than the national mean. Dr. Gawande personally visited the hospital in La Crosse to discover what the community was doing different to achieve such results. Dr. Gregory Thompson, a critical-care specialist at the hospital, showed Dr. Gawande his Intensive Care Unit (ICU) and the patients that it cared for. The patients that were admitted were very similar to those in other ICUs that he had seen, but to his surprise: none of the patients were terminally ill.

Dr. Thompson explained the history to Dr. Gawande. He explained how local medical leaders in 1991 headed a systemic campaign to have patients and physicians discuss end of life wishes. In the years following, it was normal to have patients fill out a multiple-choice form containing four vital questions when being admitted to any hospital, nursing home, or assisted living facility within the city. The four questions included: 1. Do you want to be resuscitated if your heart

stops? 2. Do you want aggressive treatments such as intubation and mechanical ventilation? 3. Do you want antibiotics? 4. Do you want tube or intravenous feeding if you can't eat on your own? (Gawande, "The Best Possible Day"). Dr. Thompson expressed how eighty-five percent of the city's residents had written advanced directives for their healthcare providers by 1996. Prior to this, only about fifty percent of the residents there had completed such instructions.

Dr. Thompson specifically expresses how this standard set of questions is not what makes his job easier, rather they open up an opportunity for further discussions. The answers to the four multiple-choice questions are ever changing for patients, which means they must continuously discuss their wishes with their healthcare providers. The discussions taking place, in Thompson's professional opinion, lead to patients and physicians becoming more prepared for the future. They also increase the likelihood of patients expressing their wishes before they and their families are taken by surprise and forced into making difficult decisions under immense pressure and unimaginable stress. It is these conversations, not the list of questions themselves, that help prevent this stress from ever occurring and what Dr. Thompson attributes to La Crosse's end of life costs being just over half of the national average.

The idea of providing a greater opportunity for these end-of-life discussions to take place in La Crosse actually began with a local medical ethicist by the name of Dr. Bernard Hammes who was working at the Gunderson Health System during the mid-1980's (Joffe-Walt). He was specifically working with patients who had suffered a stroke, gone into a coma, or placed on machines

where their family members were faced with very critical life altering decisions. He began to notice that he was having the same sort of conversations with his patients where they would express that they had never had any form of end-of-life discussions with their family or friends. Dr. Hammes recognized this problem and began training nurses to ask patients if they would like to fill out an advance directive. After a while, it became common for nurses and other healthcare professionals at the Gunderson hospital to ask patients questions such as, “If you reach a point where treatments will extend your life by a few months and side effects are pretty serious, would you want doctors to stop, or continue to do all that could be done?” (Joffe-Walt). Many of the patients would say that they would want their doctors to stop treatment in these sorts of scenarios. As a result of these findings, Dr. Hammes, the Gunderson Health Network, and other leaders of the major health organizations in La Crosse began their systemic campaign, now called *Respecting Choices: Advance Care Planning* in an attempt to get patients to have conversations about their wishes for the end of their lives.

The philosophy behind the methods found within both those of Dr. Gawande and Dr. Hammes resemble that of the Conversation Project, which is currently in collaboration with the Institute of Healthcare Improvement. The Institute of Healthcare Improvement is a not-for-profit organization that is a leader in health and health care improvement worldwide. If you were to go to the website of the Conversation Project, you would immediately observe statements such as: “The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care”, “When it comes to end-of-life care, one conversation

can make all the difference”, and “We’ve had the conversation. Have you?” (“The Conversation Project”). These statements not only capture the goal of the project, but also bring attention to the core issue that has been previously discussed.

The Conversation Project’s website also presents several facts that continuously alternate in succession and scroll across the screen. These include: “90% of people say talking with their loved ones about end-of-life care is important, but 27% have actually done so”; “60% of people say that making sure their family is not burdened by tough decisions is extremely important, but 56% have not communicated their end-of-life wishes”; “80% of people say that if seriously ill they would want to talk to their doctor about end-of-life care, but 7% report having had an end-of-life conversation with their doctor”; and “82% of people say that it is important to put their wishes in writing, but 23% have actually done it” (“The Conversation Project”). These facts are not only meant to leave a lasting impression on the project’s participants, but they are also meant to educate the general public on the major problems with end of life care. This project aims to raise the second percentage stated in each of the facts listed above by utilizing a variety of methods. These methods include compiling true stories of individuals being provided with end of life care, exhibiting factual information and statistics to its participants to make well informed decisions, and constructing a Conversation Starter Kit with a variety of questions that get patients to make decisions about their end of life wishes and have personal discussions about these wishes with their doctors as well as their loved ones.

The Conversation Starter Kit is fairly lengthy, but it guides its user in a step by step process that aims to actively engage its user and help patients determine what they want for their end of life care and discuss these things with their family, friends, and caregivers. The steps include: Step 1 – Get Ready, Step 2 – Get Set, Step 3 – Go, and Step 4 – Keep Going.

Step 1 – Get Ready is the first step in the process and involves educating the patient on the importance of discussing end of life care and provides statistical information including that which has already been presented above. This is to help prepare the patient for what is to come and to motivate them to think about important decisions that need to be made. It also has the patient answer both of the following questions: What do you need to think about or do before you feel ready to have the conversation? Do you have any particular concerns that you want to be sure to talk about? (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

Step 2 – Get Set is the second step in the starter kit process and involves a series of questions, the answers of which are set on a scale from 1 to 5 and attempt to help the patient determine what is most important to them. They are also aimed at helping the patient determine what role they want their doctors, family, and self to play when it comes to making end of life decisions.

Step 3 – Go is the third step of the starter kit and involves a series of multiple choice questions aimed at helping the patient decide who they want to discuss their end of life wishes with, when they would like to have these discussions, and where they would like to be when they have them. This step also

helps to guide the patient in sorting out what to say during their discussions as well as how to initiate them to begin with.

Step 4 – Keep Going is the fourth and final step of the starter kit and involves educating the user about legal and medical documents that may be of use. These include Advance Care Planning (ACP), Advance Directive (AD), Health Care Proxy (HCP), and a Living Will. This last step is also meant to encourage the patient to continue having these critical conversations about their end of life wishes and to reflect on past discussions to discover how to improve upon them in the future.

The similarities between the strategies used by Dr. Gawande, Gunderson Lutheran Hospital in La Crosse, and the Conversation Project to get patients to have end of life discussions with their family and healthcare providers are very apparent. All three use a set of predetermined questions to open up opportunities for discussion. They realized the overwhelming disparity between the number of people believing that having these end of life conversations is important and the number of people who actually have them. The questions themselves can be beneficial to the patients by helping them to decide what matters most in their lives and beneficial to the caregivers by giving them instructions for future care, but the ultimate goal of these questions is to provide opportunity for discussion. Talking about the wishes of a terminally ill patient is the key to providing the best possible care. This is not just a one-time discussion that should be taking place, but a series of discussions over time. The wishes of the patient are always changing and the more they talk about what means most to them and what they

want for their end of life care, the better prepared all those involved will be when the hard times come. Tough decisions should not be made during times of stress and disorder, but rather when the patient is in a clear state of mind with no pressure or time restraint.

Chapter 5 - My Solution

Based on the prescribed information, I propose a three tiered model that will allow for greater opportunity of end of life discussions and shorten the disparity between the number of those who believe these discussions are important and the number of those who actively participate in them. This model will be able to be implemented in any health care facility, but will be stated here as being a part of regular hospital procedure for simplification purposes. This model will also have the ability to adapt to the needs of any region nationwide and is not meant to remain static. In addition, it is by no means believed to be a quick and easy solution to the over-arching issue discussed here. It is a slow and delicate process that takes years for a patient to completely navigate through. The process starts with the very first doctor-patient interaction and only finishes with the end of life. The intent of this model is in the best interest of the patient as well as the healthcare providers of the terminally ill.

The first tier of this model involves the first interaction any patient has with the hospital. From the very first encounter, the patient will be asked to fill out a small questionnaire. It will include four yes or no questions including: 1. Do you want to be resuscitated if your heart stops? 2. Do you want aggressive treatments such as intubation and mechanical ventilation? 3. Do you want antibiotics? 4. Do you want tube or intravenous feeding if you can't eat on your own? This is the same set of questions that the Gunderson Lutheran Hospital in La Crosse gives to all of its patients. This is to, as Dr. Thompson stated, increase the likelihood of patients participating in these sorts of discussions with their

doctors and nurses. This information also more directly aids in providing better instruction to the healthcare workers on how to treat their patients well in advance of any sort of life threatening emergency. Since these questions may be considered fairly off-putting for a first time admittance into a hospital, the questionnaire is completely optional and the answers to these questions will be made available only to those providing care to the patient. The responsibility of recording this information for later reference would furthermore be placed on the healthcare provider(s) directly providing care to the patient. While the campaign known as *Respecting Choices* more directly focuses on increasing the number of people who fill out advance directives in order to increase the likelihood of patients expressing their final wishes, this first tier of the model is primarily meant to get patients to think about these sorts of critical scenarios even if they choose not to fill out the questionnaire.

The second tier of this model involves a series of questions that are only asked by the primary care physician of the patient under the following conditions:

1. The patient has been definitively found to be terminally ill.
2. The patient has been informed of their current health condition.
3. The patient has agreed to further care after receiving knowledge of their illness.

These questions include: What is your understanding of your health or condition? What are your goals if your health worsens? What are your fears? What trade-offs are you willing to make or not make? These questions are the same four questions that Dr. Gawande found to be asked by the most successful physicians during his search for providing better care to his terminally ill patients. This is to provide a second

structured opportunity for discussion between patients and their doctors. These questions should also give the physician a better idea of the patient's prior knowledge of the life threatening condition, feelings towards end of life care, and wishes for the future. The responsibility of recording the information discussed during this conversation for later reference is placed on the physician directly providing the care to the patient.

The third tier of this model involves providing terminally ill patients with the Conversation Starter Kit. This is the same four-step starter kit that is available on the Conversation Project's webpage and previously discussed in further detail above. The kit is meant to provide information in order for the patient to make well-informed decisions and help patients make tough decisions at their own pace. This should also effectively help prepare patients for the future and provide yet another opportunity for patients to have important conversations about their end of life wishes with their healthcare providers. Having these conversations with their family is also a critical part of this process and would be more likely to take place after this tier of the model is reached. The responsibility of providing the Conversation Starter Kit to the patient is placed on the physician directly providing care to the patient, just as it is for initiating the conversation involving the questions presented during the second tier.

Logistically, this model can be made financially feasible when considering some of the current medical care reform over the past year. According to Pam Belluck of *The New York Times* in her article published in July of 2015, the federal program that insures 55 million older and disabled Americans known as

Medicare announced that it will be reimbursing physicians for having conversations with their patients about whether and how they would like to be kept alive if they were to become too sick to make any such decisions for themselves. Belluck is paraphrasing the words of Dr. Patrick Conway, the chief medical officer for the Centers for Medicare and Medicaid, when she states that, “The plan would allow qualified professionals like nurse practitioners and physician assistants, as well as doctors, to be reimbursed for face-to-face meetings with a patient and any relatives or caregivers the patient wants to include. Dr. Conway said the proposal did not limit the number of conversations reimbursed” (Belluck). I believe that a reimbursement system such as this will only help increase the number of times these critical end of life discussions occur between doctors and their patients and that it would also aid in the overall process of inserting my proposed model into current medical care facility protocols. Furthermore, physicians would not have to sacrifice any form of payment by setting aside personal time to have these conversations with their terminally ill patients and the medical care facility would not have to lose money if my model were to be put into place.

The goal of this model is to provide an increased number of possibilities of critical end of life discussions taking place and to make the final journey of one’s life much more enjoyable. As healers, physicians must do everything they can to provide the best care possible to their patients. Once they have exhausted all of their options with modern science and medical knowledge and there is no sure way to cure their patient, they must listen to their patient’s wishes in order to

provide this high level care. Only the patient knows what is truly important to them and only they know how they wish to spend the end of their lives. It is the duty of the physician to encourage discussion and discover what these wishes are so that they can fulfill their mission as best as possible. This model is meant to aid in the success of that mission.

Chapter 6 – The Conclusion

With the ever growing human population and increased survival rates in older individuals, problems in medicine arise that could not have been foreseen. As infectious and parasitic diseases are continuously beaten by advances in modern medicine, more and more people are living longer and ultimately facing non-communicable diseases and chronic health conditions. As a result of this major shift in the primary cause of death, there is a definite need for a structured model which physicians can follow and adapt to their individual scenarios when treating terminally ill patients. When physicians are ill equipped to handle such scenarios, they often attempt to do everything they can to extend the life of their patient without listening to their patient's wishes and considering what is truly best for them as they reach the end of their life. Dr. Gawande speaks on this matter in one of his articles covering this critical dilemma: "Medicine has forgotten how vital such matters are to people as they approach life's end. People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world. These moments are among life's most important, for the dying and those left behind. And the way we in medicine deny people these moments, out of obtuseness and neglect, should be cause for our unending shame" (Gawande, "The Best Possible Day"). It is therefore the duty of the physician to listen, respect, and do everything in their power to fulfill the wishes of their patients to ensure that their patient's final days are spent doing what is most important to them.

The three tiered model based on the observations made by Dr. Nuland, Dr. Gawande, Dr. Thompson, Dr. Hammes, and the Conversation Project is meant to aid healthcare workers in their attempts at discovering what is most important to their patients as they reach the end of their lives. It does so by providing healthcare workers with several opportunities for initiating critical end of life discussions throughout the lives of those admitted to any hospital setting around the world. It cannot only be the responsibility of the patient to come to their doctors and nurses to discuss their end of life wishes. People often find it difficult to discuss such matters and commonly try to avoid discussions such as these to pretend that everything is fine. This avoidance often leaves patients unprepared to face their illness and prevents them from making well informed decisions about the end of their lives, which ultimately causes them to cling to Dr. Nuland's idea of false hope. Dr. Gawande states: "...our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw upon. They need doctors and nurses who are willing to have the discussions and say what they have seen, who will help people prepare for what is to come – and to escape a warehouse of oblivion that few really want" (Gawande, "Letting Go"). With this model in effect, individuals will have the opportunity to express their end of life wishes with their healthcare providers from the first time they are admitted into the hospital up until they are faced with the final days of their lives. In this way, the wishes of the patient can be fulfilled and they can die under the best possible circumstances given their unfortunate illness.

More information on this subject can be gathered and further research into this area of healthcare can and should be continuously conducted. The average life expectancy of individuals continues to rise today and healthcare providers need to be prepared to successfully treat patients with non-communicable diseases and chronic health conditions. Thus, it is critical for conversations between these patients and their healthcare providers to take place in order to allow for proper communication of the patient's wishes and effectively enable healthcare providers to provide successful treatment plans. These treatment plans do not necessarily need to include the "surgeon's knife or the chemist's drug," but must always include what is best for the patient and follow their dying wishes. Only in this manner can a patient find themselves pleased with their medical care and come to terms with their terminal illness. Furthermore, there are several methods of researching this subject that can be carried out in order to improve upon this area of healthcare as well as this proposed model in particular.

One method of researching this subject to improve end of life care for terminally ill patients is to personally speak with several healthcare workers that treat these patients first hand, much like Dr. Gawande had done over the course of several years. Researching books and articles written by physicians who have faced the challenges of treating terminally ill patients has been extremely effective at discovering the issues in this field of healthcare today and has aided in providing several methods of resolving these issues. However, personally speaking with physicians directly and asking questions about this area of care would undoubtedly prove beneficial to making further improvements. These

discussions could involve questions covering the methods of the physicians when treating their patients, the discussions they have had with their patients about end of life wishes, the opportunities they provide for their patients to express these wishes, the success they have had with treating their patients, and the methods they would suggest for improving upon this area of healthcare.

Another method of researching ways to improve end of life care would be to directly interact with, observe, and possibly question terminally ill patients that would be willing to participate. First hand stories and experiences of end of life care from the other side of the doctor-patient relationship could prove extremely beneficial to discovering ways to improve care. These sorts of discussions would hopefully occur with my proposed three tiered model in place, however, specific questions could be asked with the intent of discovering new ways to improve the system already in place. Patients and family members who have experienced this process themselves would have the unique perspective to inform researchers on the effectiveness of the three levels of opportunity for discussion provided to them by this model. They would also be able to provide vital information on what changes they would want made to the structure, organization, and quality of care the patients received.

With this three tiered model of care designed to increase the likelihood of patients expressing their end of life wishes in place and further research being conducted in this area of healthcare, physicians and other healthcare providers will be more adequately prepared to treat their terminally ill patients. Patients, in turn, will have made critical end of life decisions well in advance of any

emergency and will have expressed these decisions with their friends, family, and physicians. The people supporting these patients will, as a result, not be burdened with making quick misinformed decisions in a final attempt to extend the patient's life that may end in debilitation without the ability to fulfill their final wishes.

References

- Belluck, Pam. "Medicare Plans to Pay Doctors for Counseling on End of Life." *The New York Times*. The New York Times, 8 July 2015. Web. 19 Jan. 2016. <http://www.nytimes.com/2015/07/09/health/medicare-proposes-paying-doctors-for-end-of-life-counseling.html?emc=eta1&_r=0>.
- Gawande, Atul. "Letting Go: What Should Medicine Do When It Can't Save You?" *The New Yorker*. 2 Aug. 2010. Web. July 2015. <<http://www.newyorker.com/magazine/2010/08/02/letting-go-2>>.
- Gawande, Atul. "The Best Possible Day." *The New York Times*. The New York Times, 4 Oct. 2014. Web. July 2015. <http://www.nytimes.com/2014/10/05/opinion/sunday/the-best-possible-day.html?_r=0>.
- Hatkoff, Craig, Rabbi Kula, and Zach Levine. "How To Die In America: Welcome To La Crosse, Wisconsin." *Forbes*. Forbes Magazine, 23 Sept. 2014. Web. 16 July 2015. <<http://www.forbes.com/sites/offwhitepapers/2014/09/23/how-to-die-in-america-welcome-to-la-crosse/>>.
- "Hippocratic Oath, Modern Version." *Bioethics*. Johns Hopkins. Web. July 2015. <<http://guides.library.jhu.edu/c.php?g=202502&p=1335759>>.
- Joffe-Walt, Chana. "The Town Where Everyone Talks About Death." NPR, 5 Mar. 2014. Web. 16 July 2015. <<http://www.npr.org/sections/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>>.
- "Living Longer." *Global Health and Aging*. National Institute on Aging, 22 Jan. 2015. Web. July 2015. <<https://www.nia.nih.gov/research/publication/global-health-and-aging/living-longer>>.
- Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter*. New York: A.A. Knopf, 1994. Print.
- "The Conversation Project." - *Have You Had The Conversation?* Web. July 2015. <<http://theconversationproject.org/>>.

