

**PATIENT'S PERCEPTION OF CARE IN THE HOSPITAL SETTING:
EXAMINING PROVIDER INTERACTION AND COMMUNICATION**

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**“The single biggest problem in communication,
is the illusion that it has taken place”**

- George Bernard Shaw

For my parents — for their nurturing love; I live to make you proud

To Paul — for his patience and encouragement; I am humbly grateful for you
and Dr. Gaetana Kopchinsky — for her guidance and mentorship; I value your direction

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Preface

*“The very first requirement in a hospital is that it should do the sick no harm”
- Florence Nightingale*

As a staff nurse on a medical/surgical unit in a non-profit hospital within a recognized healthcare network in New Jersey, I witness first-hand the harm that is inflicted on patients by providers through routine interactions. Far too often I see physicians stand at the foot of the bed methodically running through their standardized list of questions for the patient before swiftly going out the door. Discussions regarding treatment and prognosis are held outside of the room by the healthcare team, as though the patient does not have a voice in the matter. Frequently, the nurse is the professional who the individual client then looks to for further information, guidance, and comfort. When physicians prioritize aggressive diagnosis and treatment over communication and interaction, the value and dignity of the patient are regrettably neglected. While providers have the best interests of the patient at heart, disregarding the importance of compassion in the medical process undermines and negatively affects the individual.

As I witness these occurrences I cannot help but wonder: how can this be? Do the majority of providers recognize the harm being done to their patients? Or, is it simply the juxtaposition of my profession with my Medical Humanities education? How do the patients truly feel? Are they aware of the shallow communication that is occurring? Furthermore, do these seemingly mundane interactions affect patient satisfaction and hospital ratings? What affect does this have on health care overall? These questions have been generated from my personal experiences working on a medical/surgical unit of an acute care hospital while obtaining graduate level education in Medical Humanities. This paper aims to answer the above questions through discussion of published literature, patient narratives, and personal experiences.

Introduction

Medicine, as defined by the Merriam-Webster dictionary, is the “science and art of dealing with the maintenance of health and the prevention, alleviation, or cure of disease”.¹ Reflect on this dichotomy for a moment: both a science and an art, which is focused first and foremost on *the maintenance of health*. Then follows *prevention and alleviation*. Note that *cure of disease* is considered last. Although a common understanding of the function of medicine often aligns with this definition, it is not the reality in modern medical practice in the acute setting. In a hospital environment, the practice of medicine today is aimed at curing disease and eliminating illness, while “maintaining health” is secondary. More importantly, larger concepts surrounding patient experience in suffering, human dignity, and care for the soul are mere afterthoughts.

I witness this reality nearly every shift I work. Physicians are focused on aggressive testing, diagnosis, and treatment while intrinsic patient comforts and humanistic matters are neglected. Reasons for this are complex and have different factors — from hospital protocols, demands of physicians, financial reimbursements with insurance companies; to how the culture of medicine has developed over time and even the history of the doctor-patient relationship. However, medical practice can be examined in its simplest and most basic form: the interactions and relationship between provider and patient. The cornerstone of my research lies in the intrinsic connection providers have with their patients. Does something as simple as the way clinicians communicate with individual clients have a direct correlation to how patients perceive their care?

Minute details in communication such as body language and therapeutic touch deliver a

¹ *The Merriam-Webster.com Dictionary*, s.v. “medicine (n.),” <https://www.merriam-webster.com/dictionary/medicine>.

sense of dignity and respect to the receiving individual. When providers do not take the adequate time to sit with a client, answer their questions in detail, touch them, actively listen to their concerns and values they do an injustice to the unique individual behind the patient. This is especially relevant for doctor-patient interactions in the hospital, where a significant difference in power exists between parties and the individual is acutely sick and vulnerable. I believe that the amount of consideration and care one puts into an action is always apparent. Even if patients are not aware of it, they can sense when you have paid attention to every little detail.

The purpose of this paper is to hold a discussion, to peel apart the reality of medical practice in the acute care institution and examine both “why it is the way it is,” and what can be done to change it. More importantly, since the root of medicine is grounded in caring for the patient, this paper will analyze the individual experience regarding communication and provider interactions. I will examine the patient experience in a hospital setting by presenting patient narratives. Using these unique stories, as well as published research and peer-reviewed journal articles, this thesis will connect the patient experience and perception of care to overall patient satisfaction and hospital ratings. In addition, my firsthand experiences as well as those of my colleagues will act as further support for the provider-patient relationship.

This thesis contains five inter-related chapters: *The Culture of Medicine; The Doctor-Patient Relationship; Communication; Patient Perception and Satisfaction; and Development from Here*. By first looking at the established culture of medicine and the history of the doctor-patient relationship, one can better understand the practice of medical care in the hospital today. Moving on to communication, I will examine what quality communication looks like and what patients say is lacking in this area. This will transition to patients’ perceptions of care and what

they uniquely value in health care. Finally, I will discuss how the above affects hospital ratings and provide overall suggestions for improvement.

My central argument is this: harm is being inflicted on patients by providers through their interactions and communication techniques. Individual values, human dignity, and care for the soul are neglected for the sake of timely diagnostic testing and aggressive treatment. I know this to be true based upon what I have seen and experienced working in the hospital setting, as well as from what I have learned from my readings of the pertinent literature. Health care professionals can — and indeed, and must, — do better for the unique individual within each patient. Simple changes can be made by providers that will promote change within the practice of medicine. Furthermore, by engaging quality communication techniques and an empathetic approach to healing, providers will not only improve healthcare overall, but also reduce their moral distress.

Chapter I. The Culture of Medicine

a) Aim to Cure vs. Care for the Soul

The practice of modern medicine, most specifically in the hospital setting, is concentrated on curing illness and eliminating disease. Humanistic matters such as experience in suffering and caring for the soul are lost. Providers are focused on finding an acute problem and fixing it, but what happens to the unique person suffering through it all? The soul within each patient is neglected in the name of medical practice. If there is an identifiable source for the disease, providers know exactly what to do based upon standardized algorithms and care plans. However, what happens if the problem is not fixable? The fact that medicine does not have sufficient answers to this is troubling, and has caused extraordinary harm for patients at the hands of the provider.² Dr. Atul Gawande (1965-), a renowned surgeon, Harvard professor, and writer for *The New Yorker*, discusses the culture of medicine in depth in his best-selling book *Being Mortal*.

He argues:

The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes life significant. The problem is that they have had almost no view at all. Medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul... we have treated the trial of sickness, aging, and morality as medical concerns... putting our fates in the hands of people valued more for their technical prowess than for their understanding of human needs.³

Dr. Gawande's words are powerful and painfully accurate. Medicine today in the acute care setting has developed a culture that tends to ignore the difficult conversations surrounding complex

² Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Picador, Metropolitan Books, Henry Holt and Company, 2017), p.8

³ Ibid, p.127

human needs, especially when the individual's being is in jeopardy (such as end-of-life cases). Reasons for this are multi-factorial. First, coordinating such challenging discussions is not routine. Care is frequently conducted by multiple physicians and it is often unclear who is responsible for initiating the conversation. Second, the United States medical system does not compensate providers exclusively for psychosocial conversations. A system based on productivity and reimbursement does not account for the immeasurable benefits of sustenance of the patient's soul or quality communication. Third, decreasing contact time and minimal relationships between physicians and patients inhibit the connection needed to discuss these important issues.⁴

I often witness the reality of this scenario working as a nurse in the hospital. When it is evident to medical professionals treatment is no longer effective and nothing more can be done, physicians tend to sheepishly avoid difficult conversations with the patient and family. Often times it is not because of cruel intentions, but because of the time and level of rapport needed to do so. Dr. Gawande highlights,

Given how prolonged some of these conversations have to be, many people argue that the key problem has been the financial incentives: we pay doctors to give chemotherapy and to do surgery but not to take the time required to sort out when to do so is unwise. This certainly is a factor. But the issue isn't merely a matter of financing. It arises from a still *unresolved argument about what the function of medicine really is* — what, in other words, we should and should not be paying doctors to do.⁵

Dr. Gawande's argument challenges the established culture of medicine as he identifies a defining gap in how medicine is understood and practiced. He realizes that negligence of the soul is not simply due to financial gain or technical ability, but also stems from a larger issue of how medicine is defined.

⁴ Dale G. Larson and Daniel R. Tobin, "End-of-Life Conversations: Evolving Practice and Theory," *JAMA* 284, no. 12 (September 27, 2000): pp.1573-1578, <https://doi.org/10.1001/jama.284.12.1573>

⁵ Atul Gawande, p.187

Medical knowledge is based upon scientific and empirical data, tangible facts that can be specifically identified and proven. Human emotions and beliefs do not fit into this category. Moreover, how these affect individuals and their health care decisions becomes immeasurable. Medical journalist, Lynn Payer (1945-2001), describes, “This denial of the soul, or indeed even the less mystical emotions, has taken its toll too... Anything that cannot fit into the machine of the body, or be quantified, is often denied not only quantification but even existence.”⁶ As Dr. Gawande stated, illness and death have been dealt with as medical concerns that can be addressed anatomically. Medicine ignores the emotional and spiritual challenges of sickness and aging because they are not physically present. Patient experience and suffering cannot be quantified by data, so they have largely been overlooked. Suffering is only considered when viewed as pain or another diagnostic entity. The simplistic chart of five facial expressions depicting pain level is an extreme example of this oversimplification of the human experience.

Another problem related to a medical culture that relies entirely on treatment and repair is that it denies the reality of certain situations. Being cured is not always possible. Death, an inevitable fate for all living beings, is largely viewed by the profession as defeat. When focus shifts from curing the patient to minimizing suffering, it is considered (by both provider and patient) to be giving up or failure. Steinhauser et. al. describe, “...a medical culture that has often defined death not as a natural part of life but rather as the negative outcome in the fight against disease. To discuss death, we fear, is to remove hope.”⁷ This idea stems from a larger societal culture that views the subject of death as something that is taboo, particularly in the United

⁶ Lynn Payer, *Medicine and Culture: Varieties of Treatment in the United States, England, West Germany, and France* (New York: Henry Holt and Company, 1996), p.151

⁷ Karen Steinhauser et al., “Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers,” *Journal of Pain and Symptom Management*, 22, no. 3 (September 2001): p.728

States. People generally tend to shy away from discussing the dying process and death in open forums. Furthermore, to discuss this undeniable reality in medical situations is seen as taking away all hope for the patient to have a positive outcome. Dale Larson and Daniel Tobin propose other reasons as to why physicians might avoid end of life conversations:

(1) Fear [of] causing pain and bearing bad news, (2) lack of knowledge of advance directive laws and training in delivering bad news, (3) view death as an enemy to be defeated, (4) anticipate disagreement with the patient or family, (5) have medical-legal concerns, and (6) feel threatened by such discussions.⁸

However, despite “popular cultural notions of death denial,... focus groups and national survey data show an overwhelming preference for an opportunity to prepare for the end of life.”⁹ The truth is, patients want to know when they are reaching the end. Despite the acknowledged difficulty, the importance in caring for the individual’s soul is more prevalent in these circumstances than any other. Positive outcomes can be found when patients understand the gravity of their illness. Open discussions that address reality allow for individuals to come to terms with their fate, to say goodbye to loved ones, and to be at peace with their circumstances. Most often it is in one’s final days that introspective spiritual and psychological discussions are held. To deny someone this opportunity by avoiding in depth conversations and to focus solely on a cure inflicts harm on the patient. The soul, where one’s deepest and most intimate emotions lie, ultimately suffers.

I. b) Verbiage

A critical factor in the culture of medicine today and how it neglects the emotional and spiritual needs of the individual lies in the verbiage that is evident throughout practice. Even the words professionals utilize encourage a fear of death and disease which has extended outside the

⁸ Dale G. Larson and Daniel R. Tobin, p.1574

⁹ Ibid, p.1573

realm of medicine to reach mainstream culture and current events. Consider these common phrases: “Cancer *survivor*,” “*Infected* with,” “*lost the battle*.” Emphasis is placed on the illness and whether or not the patient can be “fixed” anatomically. This distinction separates the body from the emotional and spiritual experiences, as it considers them two distinct matters to be addressed independently from each other. Those common phrases do nothing to examine the entity of the soul that has been affected. One’s body may no longer be infected, one’s cancer may be eliminated from the body, but what lasting effect is left on the individual’s experiencing self? Once the problem is fixed and the patient is considered cured, health care professionals deem their job complete and walk away from the case. Patients are then left to grapple with the emotional, spiritual, psychological transformations they experienced in dealing with their health issues on their own.

Moving deeper, another layer to phrases and verbiage that prioritize the physical body is the fact that they devalue individuals who are unable to be repaired. As Lynn Payer suggests, “The patient who beats cancer is considered superior to the patient who fights but succumbs.”¹⁰ These people are typically heralded as heroes and warriors, while those who did not win are more simply remembered fondly. Payer expresses, “When you refer to one group of people as ‘victors,’ what would you call the others?... The implication [is] ‘that winning’ against cancer is some sort of holy crusade, and that victory is simply a matter of will. What, then, is [implied] about those who fought back but did not ‘conquer’?”¹¹ The patient who is unable to be “fixed” anatomically is considered as someone who “*lost*” or was “*unable to beat*”. As Lynn Payer poses, what is someone called if they are not a victor? How does society view someone who did

¹⁰ Lynn Payer, p.133

¹¹ Ibid.

not win? This frame of thought implies that when a patient does succumb to their illness, they are considered to have “failed” their treatment. The individual can be viewed as the failure, not the treatment plan or medicine as a whole. In turn, this may lead people to experience an even greater sense of doubt surrounding their human value and sense of self.

Verbiage that affects medical care and the value of the unique individual is also seen when clinicians often define the client by their disease. For example, phrases used in clinical settings include “the *diabetic patient*” or “*he’s a sickle cell-er*” which identify individuals based upon their illness. Assumptions are placed on these people simply from what they are exhibiting physically, while ignoring what the patient is experiencing more intimately. What ramifications does this mentality have on patient care and health care overall? Furthermore, negative attributes are commonly associated with these illnesses that are discussed in conversation amongst medical staff. Patients who have sickle cell disease and are in an acute crisis experience tremendous pain and are looked down upon as “*pain med-ers*” or “*drug seeking*” by providers who are supposed to be caring for them. Patients with uncontrolled diabetes that are admitted for acute issues like foot infections or too high of a blood glucose level are viewed as “*non-compliant,*” or “*deviant*”. Terms such as these are used in medical practice every day. I witness this reality in my own professional environment as I have heard both physicians and nurses describe patients in this manner. Human value is negatively affected by a profession that emphasizes anatomical disease. Priority is placed on the illness and subsequent behavior, not on the individual experiencing or suffering that may cause said behavior. Words professionals choose to employ speak volumes on the culture of medicine as humanistic matters of the soul are neglected and ignored.

I. c) Aggressive Treatment above Symptom Management and Quality of Life

In relation to verbiage and the aim to cure, there is a focus on aggressive diagnostic testing and treatment by medical professionals. The culture of medical practice is to prioritize these actions above symptom management and quality of the patient's life. Physicians are trained to maintain health and fight illness, but typically receive little guidance on how to minimize suffering. This is particularly true of the United States hospital setting where more diagnostic imaging and extensive surgeries are performed than other developed countries.¹² Lynn Payer, in her book, *Medicine and Culture*, compares at length the status of medicine in the United States to that in Europe. She notes, "American medicine is aggressive. From birth — which is more likely to be by cesarean than anywhere in Europe — to death in hospital, from invasive examination to prophylactic surgery, American doctors want to *do* something, preferably as much as possible."¹³ She goes on to give alarming examples:

American doctors perform more diagnostic tests than doctors in France, Germany, or England. They often eschew drug treatment in favor of more aggressive surgery, but if they do use drugs they are likely to use higher doses and more aggressive drugs... recommendations as to dose are often higher than those given in other countries... Surgery, too, besides being performed more often, is likely to be more aggressive when it is performed... An American woman has two to three times the chance of having a hysterectomy as her counterpart in England, France or Germany... Prostate surgery also will be performed more often than in Europe, and will be performed on both younger and older men.¹⁴

Payer's research demonstrates a culture of medicine in the United States that is focused much more on diagnosis and aggressive treatment than its European counterparts. This reality should bring into question the priority and actions of American health care providers.

Again, as with the notion of death discussed in the previous section, this nature stems from a larger societal culture in America that values action and a 'can-do' approach. Generally

¹² Lynn Payer, p.124

¹³ Ibid.

¹⁴ Ibid, p.125-126

speaking, people in the United States desire a diagnosis or medical term for their symptoms because it provides a justification for their experiences and behaviors. American society as a whole is aggressive, busy, and product-driven. Patients bring this attitude into medicine as well. Lynn Payer admits, “But we should not altogether blame doctors... they are often merely responding to the perceived or real demands of their patients. American medicine is aggressive partly because... many patients equate aggressive with better.”¹⁵ She claims that if people were not so eager for a quick fix, doctors will eventually shift away from that mentality. This point is significant and holds weight in the argument for the negative impact of medical culture. Medicine in the United States is a product of the larger culture of society. This translates into a fear of giving up, removing hope, and death that both provider and patient share.

The priority of aggressive management coupled with the fears just mentioned has created a reality where human needs for symptom management and quality of life are considered less important in the acute hospital setting. I frequently experience this in my day to day nursing tasks. Doctors quickly round on their patients, focused on their biomedical needs while the nurse is the one caring for the patients’ overall well-being and comfort. One unique example that comes to mind is when a surgical resident walked out of a patient’s room who was quite obviously confused and experiencing delirium. He said to me in passing (as I happened to be the individual standing near the door), “That patient is getting out of bed, can you check on them?” I then looked into the patient’s room to see someone who is laying sideways in the bed, limbs hanging out of the side railings, screaming. I look back at the resident as he walks down the hall. Clearly that individual’s quality of life and overall well-being was deemed beneath the expertise of the resident who walked away and left them in that precarious position. The actions of that

¹⁵ Lynn Payer, p.155

doctor demonstrated that if a patient issue is not a quantifiable piece within the mechanics of the body, it is not important for him to address.

Another example of this is seen in connection to the specialty of Palliative Care. Palliative Care “Focuses on the relief of suffering for patients with serious and complex illness and tries to ensure the best possible quality of life for them and their family members. It is delivered at the same time as other appropriate curative and life-prolonging treatments and it is not limited to the terminally ill.”¹⁶ First and foremost, the fact that there is a need for a specialty that focuses on relief of suffering should be concerning for health care professionals. Medical care that is provided to patients should always aim to maintain and improve quality of life, it should not rely on a small number of specialty clinicians to provide that level of humanistic care. Furthermore, the culture of medicine is widely understood to have two mutually exclusive goals: either to cure disease and prolong life *or* to provide comfort care. Consequently, the decision to focus on reducing suffering is typically made only after life-prolonging treatment has been ineffective and death is imminent.¹⁷ I know this to be true based upon my every day interactions with providers.

Very often I am advocating for the patient by recommending to the doctor that they should consult Palliative Care for reasons such as pain management, crippling nausea, or the inability to adequately care for and maintain one’s health independently. It is not uncommon for my request to be met with hesitation and even resentment from the provider who falls into the belief system that aggressive treatment is more important than symptom management and quality of life. I have heard more than once from physicians, “We are not there yet,” demonstrating

¹⁶ Diane E. Meier, Stephen L. Isaacs, and Robert G. Hughes, *Palliative Care: Transforming the Care of Serious Illness* (Jossey Bass Inc, 2014), p.4

¹⁷ Ibid, p.23

where their focus in health care lies. Quite often, I must deal with moral distress at work because I believe the decided treatment plan is inflicting more harm on my patient as it is ignoring humanistic factors of quality of life and suffering.

I have also seen patients lie in a hospital bed waiting in limbo between the dichotomy of prolonging life or comfort care, while plan of care is discussed privately amongst hospital staff. A ninety-year-old patient with dementia who was minimally interactive was admitted to my unit for a malfunctioning feeding tube due to a growth in the abdomen. It was decided that surgery was not a viable option due to the patient's age and overall health status. She was provided an alternative intravenous nutrition that is not a long-term solution, and stayed on the floor for nearly a month. Finally, after weeks of debating, the doctor consulted palliative care who quickly involved the hospice team and addressed the appropriate next steps in care towards alleviating suffering and prioritizing comfort. Time and resources were spent on that patient which could have been mitigated if the appropriate actions took place as soon as the surgical team said repair was not possible. The patient experienced unnecessary harm, pain, and poor quality of life at the hands of providers who did not address these needs soon enough.

Doctor Gawande argues an alternate role of a physician while commenting on the culture of medicine. He eloquently notes,

The job of any doctor... is to support quality of life, [which means] two things: as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world. Most doctors treat disease and figure that the rest will take care of itself. And if it doesn't — if a patient is becoming infirm and heading toward a nursing home — well, that isn't really a medical problem, is it?¹⁸

Dr. Gawande words articulate this chapter's discussion on the culture of modern medicine in the hospital setting: one that is focused on diagnostic testing and aggressive treatment while ignoring

¹⁸ Atul Gawande, p.41

the human need for quality of life and care for the soul. I have demonstrated that this belief is rooted in the culture of larger society as well. In the coming chapter, I will discuss how the culture of medicine developed as a result of history and biotechnological advances, and how medical culture of the hospital inhibits quality doctor-patient relationships today.

Chapter II. The Doctor-Patient Relationship

a) Historical Paternalism

The doctor-patient relationship is central to the practice of healthcare. A sound partnership is essential for the delivery of high-quality care in the treatment of the individual. Both parties meet with a mutual ultimate goal: health and wellness of the patient. It is a common understanding that the patient arrives with an ailment that needs to be relieved, and that the doctor has the necessary expertise and resources to accomplish this. The term relationship encompasses two distinct parties working cohesively in mutual partnership. To further explain:

... The term ‘relationship’ refers to neither structure nor function but rather an abstraction encompassing the activities of two interacting systems or persons. The apparent, intrinsic quality of this unique doctor-patient relationship allows two people, previously unknown to each other, to feel at ease with variable degree of intimacy. This relationship, in time, may develop to allow the patient to convey highly personal and private matters in a safe and constructive environment.¹⁹

The core of the relationship depends on respect, communication, and trust between two mutually participating parties or individuals. Inherently, a working doctor-patient relationship founded on these principles will foster enhanced accuracy of diagnosis, an increase in the patient’s knowledge and ability to care for themselves, and an ultimate relief of the patient’s symptoms and suffering. Conversely, when the relationship is poor — lacks understanding, communication, and shared values — the physician’s ability to make a complete assessment is compromised.

¹⁹ R. Kaba and P. Sooriakumaran, “The Evolution of the Doctor-Patient Relationship,” *International Journal of Surgery* 5, no. 1 (2007): p.58, <https://doi.org/10.1016/j.ijssu.2006.01.005>

In this case, the patient is more likely to distrust not only the diagnosis and proposed treatment plan, but also the physician and larger institution he/she works for. In turn, this leads to a decrease in compliance to medical advice and an overall unhealthy outcome for the individual. Due to the nature of this relationship, the physician's primary obligations are to the patient he/she cares for. As American physician and bioethicist Ezekiel Emmanuel (1957-) describes, "Because the subject of medicine is an individual, the primary ends of medicine are restoring health and relieving suffering of individuals... The success or failure of the physician is evaluated... by the restoration of the patient's health or relief of the patient's suffering."²⁰ Patients' health and wellbeing are enhanced by a quality working relationship between doctor and individual. Unfortunately, this dynamic is challenged by the culture of medicine as discussed in Chapter One. I argue that by prioritizing aggressive testing and elimination of disease over innate human comforts and dignity, common understanding and a sharing of values between the two parties may be threatened. Focusing on a physical cure while ignoring humanistic needs of the soul may inhibit the relationship between provider and patient. Moreover, the incorporation of paternalism — a system under which people in positions of authority regulate the freedom and conduct of the individuals subordinate to them²¹ — by the provider over his/her patient, I believe, further inhibits the development of a relationship based on communication and trust.

The doctor-patient relationship in its historical context has changed with the medical situation and social milieu of the time. The medical situation is the presenting condition of the pa-

²⁰ Ezekiel J. Emanuel, *The Ends of Human Life: Medical Ethics in a Liberal Polity* (Cambridge: Harvard University Press, 1991), p.16

²¹ *The Merriam-Webster.com Dictionary*, s.v. "paternalism (n.)," <https://www.merriam-webster.com/dictionary/paternalism>.

tient and the available means to address it; included are both the physicians' and patient's capacity for self-reflection and communication, as well as their technical skills. The social milieu refers to the socio-political and the intellectual-scientific climate of the time.²² The dynamic between the two parties has evolved and changed throughout history in conjunction with societal culture. However, a significant point in time stands out as a catalyst for the modern doctor-patient relationship and medical culture of today, beginning in the 1800s. During the Industrial Revolution, science and medicine underwent mass growth and development in terms of knowledge and technology. The new science of biomedicine brought problems as well as benefits to clinical care. By the 1850s, physicians measured health in terms of statistical norms rather than in terms of the patient's 'natural' state of health as voiced by the individual. Anatomist and pathologist Xavier Bichat (1771-1802) refined pathology by demonstrating that diseases affected localized tissues rather than organs as a whole. His discovery drastically and permanently changed the course of medicine. Once there was a scientific source for diseases the patient's narrative was no longer as important. To elaborate:

Once Bichat's tissue pathology established an oncological foundation for observing and defining disease, a patient's experience could be dismissed as secondary. If diseases could be located in tissues or cells, there was no reason to attend to a patient's subjective description of symptoms. Bichat's contributions also paved the way for a new form of medicine — known as clinical or hospital medicine — that displaced the more individualistic... medicine of the eighteenth century.²³

Rapid growth of microbiological knowledge and surgical skills developed a medicine not based on the symptom and the individual's experience, but rather on forming an accurate diagnosis and pathology. This advancement began the shift in focus to be on treatment and disease rather than

²² R. Kaba and P. Sooriakumaran, p.58

²³ Thomas R. Cole, Nathan Carlin, and Ronald A. Carson, *Medical Humanities: an Introduction* (New York, NY: Cambridge University Press, 2015), p.49

the care of the person. Physicians increasingly used manual diagnostic techniques and technology during this time period that would ultimately discount and replace the patient story.

The first tool to be routinely used in evaluating patient's illness was the stethoscope which allowed the provider to hear much more distinct sound compared to the traditional practice of placing their ear against the patient's chest.²⁴ The information the stethoscope gave doctors about the condition of the client's heart and lungs by listening to the sounds they made were so compelling, doctors began to pay more attention to the sounds of the body than the words and thoughts of the individual.²⁵ Cole et. al explain, "Technological achievements anticipated the empirical method of modern medicine that would privilege the specialized opinion of the doctor over the subjective and unreliable accounts of the patients."²⁶ For the first time in history, there was a literal separation between doctor and patient. In place of a doctor's warm hands and therapeutic touch, there was a cold hard piece of technology. This is the beginning of modern medical culture as the practice of incorporating technology and the physician's diagnosis begin to take precedence over patient experience.²⁷ Individual thought becomes secondary to statistical data.

By the turn of the century, major advancements in technology and medicine began to remove the provider from the patient's home and place them both into clinical settings. The number of hospitals increased dramatically from 1860-1920.²⁸ Traditionally, relationships between doctors and their clients were based in local communities, developed over time, and relied on mutual respect. Providers likely cared for multiple generations within one household. Interactions were face to face, entailed a thorough personal examination, and occurred in the comfort

²⁴ Thomas R. Cole, Nathan Carlin, and Ronald A. Carson, p.78

²⁵ Ibid, p.77

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid, p.35

and privacy of an individual's home.²⁹ Patients expected to be cared for and comforted. As biomedical technology advanced, the familial dynamic between provider and client slowly dissipated in the clinical environment.

Cole et. al go on further to say, "Despite its undeniable benefits, the 'new' scientific medicine of testing and diagnostic precision stood in tension with the 'old' medicine of compassion and care".³⁰ In the hospital, physicians were less likely to know the patient's story and their family prior to the visit. The setting is sterile and plain with white walls and uncomfortable cots. Here, the physician's authority reigns supreme. Technology attenuated the relationship between patient and doctor, and diagnostic testing took over the individual's experiences. The expectation to be comforted and cared for also disappeared as doctors began to further separate themselves from the individual. American physician and Harvard professor Francis Peabody (1881-1927) warned that laboratory-based methods of diagnosis threatened the personal bond between doctor and patient:

In prophetic comments, he noted that patients in... hospitals were sometimes passed from one specialist to another, submitted to multiple tests, and treated for unimportant conditions. Tests and technology were no substitute for personal relationships... In his most memorable phrase, Peabody went to the core of the issue: 'One of the essential qualities of the clinician is interest in humanity, for the secret of care of the patient is in caring the patient'.³¹

Sadly, his fears have become realized. It astonishes me that Peabody wrote this at the turn of the century; I see this reality today in the clinical setting nearly one hundred years later. Advancing biomedical focus threatens the care for the individual person within the patient. Patients are passed to different specialists and aggressive diagnostic testing is the norm. There is no personal

²⁹ Ibid, p.34

³⁰ Thomas R. Cole, Nathan Carlin, and Ronald A. Carson, p.35

³¹ Ibid, 36.

relationship between provider and patient in the hospital. Humanism and patient values are lost. This sense of paternalism and control providers have on patients is evident to me every day. The doctor enters the room, says something along the lines of ‘We think you have (A), so we are going to do (x, y, z) to confirm’ and they are gone. The individual then lays in the hospital bed nervously waiting for tests they do not fully understand, and anxiously waiting for results they do not completely comprehend.

II. b) Inherent Inequalities

A critical factor in this dynamic of paternalism and the doctor-patient relationship are the inherent inequalities within it. Consider this: a doctor walks into the room holding all of the knowledge and expertise, dressed professionally in an esteemed white coat, standing over the bed where the patient lies, tethered to lines and machines, in an impersonal hospital gown. The patient is acutely ill, unsure of what is happening to his/her body, feeling scared and vulnerable. Furthermore, in order for an accurate diagnosis to be possible the individual must reveal personal truths about themselves that under most other circumstances a stranger would not typically share. An uneven power structure inherently exists between doctor and patient in the hospital setting. The individual is at the mercy of the physician and institution, and has no choice but to rely on the provider to be knowledgeable, trustworthy, and that the provider will act in their best interest.

Ezekiel Emmanuel emphasizes:

This relationship is marked by three types of inequality: inequalities of need, knowledge, and vulnerability. A person comes to the physician, his existence or his integrity threatened by illness. He comes in need of knowing what he suffers from, its significance and prognosis. He also needs emotional support in this time of fear and fragility. He comes to the physician because the latter has knowledge of and expertise on his illness. Hence the patient must accept much of the physician’s advice on trust. For a diagnosis to be made and treatment rendered, the patient will have to expose both his body and intimate factual details to the physician.³²

³² Ezekiel J. Emanuel, *The Ends of Human Life: Medical Ethics in a Liberal Polity*, p.17

The magnitude of inequality inherently built into the relationship is undeniable. This perpetuates paternalism as power hierarchies cause imbalances of privilege and influence, which prevent patients from being adequately heard.³³

However, acknowledging this reality is vital to maintaining the patient's dignity. It is easy for any clinician to overlook when he/she is going through their everyday routine, busy with numerous patients and tasks, functioning without being mindful and fully present. Providers are simply doing their job and often are not cognizant of these underlying factors. Fortunately, this behavior can be easily changed by those who are willing to do so. Howard Brody (1949-), American physician, bioethicist and professor, specifically outlines the duties a practitioner has for his client that help to alleviate inequalities in the working environment. He details:

The physician should be alert to the sense of powerlessness often accompanying illness and be prepared to respond to it in several ways: (a) by sharing knowledge; (b) by identifying specific psychological sequelae of illness and including their management in the treatment plan, as part of her exercise of... power; (c) by illicitly reminding the patient of the power [they] still possess and how essential that power is for treatment; (d) by reassuring the patient that [the provider's] ...power are employed to secure for [the patient] a positive therapeutic outcome.³⁴

Brody's suggestions for behavior help providers to reduce the inherent imbalance between providers and their patients. By simply being aware of one's actions and the environment they are in, while being receptive to others' circumstances and needs, one can make adjustments in behavior and communication techniques that will reduce inequalities.

The clinical environment also has an effect on the patient's control and vulnerability as all aspects of their day become regulated by the institution. Sleep and rest, arguably what one

³³ Rita Charon et al., *The Principles and Practice of Narrative Medicine* (New York, NY: Oxford University Press, 2017)

³⁴ Howard Brody, *Healers Power* (Yale University Press, 1992), p.65

needs most while sick and fighting infection or disease, becomes limited as staff are making rounds throughout the day and night. Doctors come to patient rooms based on their own personal schedules. Staff are required to check vital signs at certain hours. Laboratory work is commonly ordered for early morning so patients are stuck for blood before they eat breakfast every day. Medications are ordered at specific times, regardless of when a patient may normally take it while home. Patients may even be woken up in order to take a medication in the middle of the night. Visitor restrictions are put into place that limit the number of people allowed into the room and how long they are able to stay for. Staff enforce protocols that restrict when patients can ambulate on their own and limit where the individual can go. Even something as basic as using the toilet can be determined by staff or because the individual is attached to equipment, sometimes forcing patients to use a pan or urinal while in bed. This greatly demeans the patient's basic autonomy and human dignity.

My hospital requires the doctor to give approval for all patients who want to take a shower. Some institutions require patients to share hospital rooms and bathrooms with another patient giving the individuals little to no privacy during their stay. My hospital does not have a shower in every room so if a patient is able to, they must walk in their hospital gown (which is open in the back) to a communal shower room in the hallway of the unit. Hospitals can require patients to pay for basic utilities like telephone and television, particularly affecting lower income individuals who are unable to afford such amenities. Currently, my hospital charges \$8/day for telephone use. All of these barriers, while seemingly trivial, consistently control the patient and reduce the power they have in the acute care setting.

Furthermore, power hierarchies are more greatly defined when patients are marginalized in some form. The inherent inequalities between doctor and patient and the institutional regulations are more apparent for certain populations including, but not limited to, physical and mental ability, gender identity, race, religion, ethnicity, and educational level. Rita Charon (1949-), physician and expert in narrative medicine, spells out this reality:

Healthcare professionals can overlook the challenges faced by patients in being heard at all — speaking a language other than the dominant one, not being fluent in the diction of bureaucracy, holding nontraditional beliefs about health and life style. Patients... can be too easily silenced if they ask too many questions, want too much evidence, or challenged medical opinion.³⁵

As difficult as it is for a coherent, able bodied patient to be stripped of their clothes and forced to follow institutional protocols, it is significantly more so for those individuals who do not speak the same language, cannot ambulate on their own, have cognitive or learning deficits, or have nontraditional beliefs and values. These circumstances work to make the individual even more vulnerable, and leave them at a greater risk of control from the provider and institution. I witness the struggles both patients and providers have when they require basic necessities in order to communicate affectively or when a patient has varying cultural views that affect their acceptance of the standardized plan of care, which will go on to affect their compliance with post-discharge instructions.

For example, Jehovah's Witness is a religion that does not allow for the transfusion of any blood products to a patient and I have seen physicians non-discreetly push that option on individuals who do not believe it is appropriate. In one particular case, not only did the doctor repeatedly recommend a blood transfusion as the next appropriate step in care, despite the patient's denial related to religious values, he became frustrated and said, "If you want to die that's your

³⁵ Rita Charon et al., *The Principles and Practice of Narrative Medicine*, p.195

choice” before abruptly walking out of the room. He left the patient and his wife stunned by his actions and scared for his well-being while under the care of that provider and in that institution. This interaction highlights the paternalistic approach of medicine and the inequalities that individuals face in the hospital. He demonstrated that his authority as physician was more important than the individual’s religious beliefs, which were entirely undermined by the words and actions of that provider. The doctor-patient relationship was ruined and the innate human dignity of the patient was compromised. Clearly patients who fear or reject the doctor’s imposition of a treatment protocol are at greater risk for ignoring recommendations post-discharge, affecting overall health and wellness of the individual.

II. c) Patient Centered Care

Admittedly, the profession of medicine and the institutions they work for are not naive in the matter of quality doctor-patient relationships and paternalism in medical practice. To combat these norms, initiatives have gained prominence that challenge professionals to do better for their patients. Patient-Centered Care (PCC) is one of these movements that was developed to bring the focus in medicine back to the individual person. In 2001, the Institute of Medicine released its seminal report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which identified six aims for improvement in the health care system within the United States. This included that care must be: safe, effective, *patient-centered*, timely, efficient, and equitable.³⁶ The Institute of Medicine also endorsed six key dimensions of PCC that requires care to: 1) be respectful to patients’ preferences, values, and needs; 2) be coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide

³⁶ Barbara Cliff, “The Evolution of Patient-Centered Care,” *Journal of Healthcare Management* 57, no. 2 (April 2012): pp. 86-88, <https://doi.org/10.1097/00115514-201203000-00003>)

emotional support; 6) involve family and friends.³⁷ Patient-Centered Care is one that is respectful of and responsive to individual patient values and needs, and ensures that patient preferences ultimately guide all clinical decisions. It requires patients to become partners with their providers, challenging traditional paternalism by changing their role from passive pawns that follow orders to an active member of the health care team. PCC requires dialogue, open and honest communication between provider and individuals and their families concentrated on the individual's comfort and wellbeing. Benefits from the patient-centered approach have been shown in multiple areas, such as: "improved satisfaction scores among patients and their families, enhanced reputation of providers among health care consumers, better morale and productivity among clinicians and ancillary staff, improved resource allocation, reduced expenses and increased financial margins through the continuum of care."³⁸

It is important to stress that Patient-Centered Care goes deeper than simply communicating well and incorporating the patient in decision-making. It also requires clinicians to treat patients in all facets, including (but not limited to) their emotional, mental, spiritual, and social well-being. Providers must be willing to become involved in a full range of problems patients may present, not simply their biomedical needs. PCC looks at the individual's whole picture, understanding multiple aspects of the patient's life and how they affect overall health care decisions.

³⁷ Flora Tzelepis et al., "Measuring the Quality of Patient-Centered Care: Why Patient-Reported Measures Are Critical to Reliable Assessment," *Patient Preference and Adherence*, June 24, 2015, pp. 831-835, <https://doi.org/10.2147/ppa.s81975>)

³⁸ NEJM Catalyst, "NEJM Catalyst," *NEJM Catalyst* (NEJM Catalyst, January 1, 2017), <https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559>)

Dale Larson (1949-), professor of counseling and psychology, sees PCC as “broadening the biomedical view to one that ‘sees through the patient’s eyes’ and appreciates the web of relationships and contexts within which a patient suffers.”³⁹ Furthermore, patients experience and react to similar illnesses differently, and individual suffering may vary from it. In order to create a complete understanding of the patient’s presenting signs and symptoms and develop an adequate plan of care, providers need to understand the patient as a unique personality within his or her own background. Larson et. al. summates this idea simply: “At the heart of the patient-centered approach is the need to understand the *meaning of the illness* for the patient...”⁴⁰ In this way, PCC implies that the patient is not simply an entity with an illness or disease, but rather that the patient is an individual experiencing and suffering from their illness or disease. Kaba and Sooriakumaran explain further:

Attending to ‘*the patient’s story of illness*’ involves exploring both the presenting symptoms and the broader life setting in which they occur, by eliciting each patient’s expectations, feelings and fears about the illness. The goal... is to understand the complaints offered by the patient, and the symptoms and signs found by the doctor, not only in terms of illnesses, but also as expressions of the patient’s unique individuality, his conflicts, and problems.⁴¹

This way of thinking and medical practice challenges the provider to develop a relationship with their patient that resembles something of the past when the physician traveled to and entered their home. Patient-Centered Care demands that physicians take the time to get to know their patients and their families, to understand what illness and suffering means to them, and how it affects their day to day activities. Providers who truly abide by the PCC approach see the pa-

³⁹ Dale G. Larson and Daniel R. Tobin, p.1575

⁴⁰ Dale G. Larson and Daniel R. Tobin, p.1575

⁴¹ R. Kaba and P. Sooriakumaran, p.61

tient as an individual experiencing an illness that threatens their personal identity. They understand that the patient has a myriad of factors (environment, relationships and support network, education and employment status, religion and culture, emotional status and coping ability) that all work in varying degrees to affect the individual's health and wellness. Most importantly, clinicians who are patient centered employ communication techniques that draw out all of this information and incorporate it into their care regimen.

While Patient Centered Care has been adopted by the medical profession throughout a majority of health care networks, criticism circulates regarding the authenticity of certain claims that providers and institutions make in terms of truly incorporating a patient-first practice. Hospitals continue to operate as a business, pushing protocols and demands that burden physicians with productivity-driven medicine.

A nurse practitioner told me while on the job that she often has eighty-hour work weeks, with caseloads that limit the amount of time and energy she can spend with each client. It is not that providers do not want to take adequate time with each patient, it is simply not feasible. However, clinical behaviors can still be effectively patient-centered even in a limited time frame. A common example of this is when clinicians ask their patients, "Any questions?" after relaying a large amount of information. Patients are likely to passively reply, "no," often overwhelmed with all they just heard and unsure of where to begin. Patient-Centered Care requires a more active approach from the provider, inviting the patient to participate by asking, "Can you tell me what you understand from what I have just told you?" or "I want to clarify everything for you so

you better understand your illness”.⁴² Even the words health care professionals use alter the experience patients have and make a significant difference in the approach of care.

Also seen by hospitals are “superficial changes” that might make the environment look and function better but do not in fact equate to PCC. Epstein and Street describe: “In the name of patient-centeredness, hospitals have been adopting models used by boutique hotels with greet-ers, greenery, and gadgetry. Although such amenities might enhance the patient’s experience, they do not necessarily achieve the goals of patient-centered care. Calls for patient-centered care have often emphasized the implementation of infrastructural changes.”⁴³ I also witness these changes in my work environment. My hospital recently completed a major construction project that built an entirely new central lobby with floor to ceiling windows and a piano designed to play automatically, providing an initially pleasing aesthetic. Meanwhile, my unit still admits two patients to a room without a shower.

Despite ongoing upgrades in design and technology, hospitals still lack specific resources which further inhibit authentic patient-centered care. One specific patient example I recall is a case where the patient’s wife and power of attorney had concerns about her husband going for a colonoscopy that he would have to be sedated for due to his compromised respiratory status. She delayed the procedure for days because she was so reluctant to put her husband at such a risk. The wife wanted her concerns heard and to discuss the case with an unbiased medical professional before she signed the consent form, so she asked to speak with a patient advocate. Unfortunately, I had to tell the wife that we did not employ one in the hospital. As a result, I as the

⁴² R. M. Epstein and R. L. Street, “The Values and Value of Patient-Centered Care,” *The Annals of Family Medicine* 9, no. 2 (April 2011): p.100-103, <https://doi.org/10.1370/afm.1239>

⁴³ R. M. Epstein and R. L. Street, p.100-103

nurse spent time with the patient and his wife tending to their needs and addressing their emotional, mental, and spiritual perspectives. The reality was that she feared her husband would not be able to fully recover from the sedation and was extremely apprehensive about his overall prognosis. She, as the primary care giver and decision maker for her husband, needed a clinician to witness her suffering. She needed someone to understand her unique perspective and appreciate the web of reality they existed in, as she saw it. This is authentic Patient-Centered Care (PCC). Eventually, she signed the consent forms for the procedure and the patient recovered afterwards without any issues. This particular patient and family experience highlight what patient-centered care can provide for the individual, and where it falls short in medical practice.

II. d) Personhood and Patient Autonomy

Connected to Patient-Centered Care is the concept of personhood and patient autonomy. These topics have been discussed by biomedical ethicists long before the popularity of PCC, questioning what they truly look like within a practice of medicine that is rooted in paternalism. Personhood relates to the discussion above as it recognizes that each patient is their own unique individual and should be viewed as such when developing a plan of care. Patient autonomy establishes the right for an individual to make his or her own health care decisions without the overt influence from their provider.⁴⁴

A research study which examines patients' perception of care was conducted through interviews and discussions with numerous groups of patients regarding their experience while being in the hospital. Results demonstrated individuals value the maintenance of their dignity in

⁴⁴ Carolyn A. Bernstein, "Take Control of Your Health Care (Exert Your Patient Autonomy)," Harvard Health Blog (Harvard Health Publishing, May 6, 2018), <https://www.health.harvard.edu/blog/take-control-of-your-health-care-exert-your-patient-autonomy-2018050713784>

medical care. For example, “In every group, multiple participants stressed attention to personhood, defined in the literature as the belief that each person... has inherent value, and is worthy of respect and honor regardless of disease or disability. Patients and families repeatedly noted the importance of clinicians ‘treating the patient as a person’.”⁴⁵ Based on patient discussions, the researchers defined high-quality care for the patient as “encompassing two key components: assurance of comfort and attention to dignity and personhood.”⁴⁶ These patients voiced what they value in being cared for. Patients want to feel comfortable at the hands of clinicians, and they want to be treated as a unique experiencing individual. Reluctance from the medical profession to honestly examine the patient experience in illness and dying in the acute setting denies the dignity and basic comforts patients both want and inherently deserve. In turn, I believe this increases the harm providers inflict on people who they are supposed to be caring for.

One-way providers may be able to maintain personhood and patient dignity is by remembering that each person in the hospital is their own person — a son or daughter, a brother or sister, possibly someone’s mother or father — who exists in their own web of relationships and realities. It is easy for clinicians working with hospital protocols and demanding caseloads to begin looking at patients as just another number or statistic with a standardized course of treatment. However, as Peabody stated, patient care means *caring* for the patient and the individual human life lying in the hospital bed. One participant in the study mentioned above stated:

My mother had a team of doctors.... some were good, and I thought some had a blank face, looking at my mother as just a number, number 35.... I said, my mother is not just an old lady, my mother had a life, of course now she’s hooked up to a million cables...

⁴⁵ Judith Nelson et al., “In Their Own Words: Patients and Families Define High-Quality Palliative Care in the Intensive Care Unit,” *Critical Care Medicine* 38, no. 3 (March 2010): pp. 808-818)

⁴⁶ Ibid, p.808-818

It's not just a piece of meat that is sitting in that hospital bed. It's a life. That is 100% important.⁴⁷

These words underline the importance of maintaining dignity and care for the individual while in the hospital. Personhood relies on valuing humanism in medical practice. It challenges physicians to remember that each patient they see is not only unique, but to be appreciated as an individual deserving of care that maintains innate human value. Illness and disease threaten patient dignity and integrity, the very essence of how individuals see themselves is in jeopardy as they become vulnerable. The institutions and professionals that society turn to during these difficult periods should not make it worse.⁴⁸

A large factor in the threat to patient dignity while in the acute care setting is the sudden loss of independence patients may experience while acutely ill and fighting disease. Clients may have to rely on staff for even the simplest of tasks, like going to the bathroom, feeding or bathing oneself. This sudden loss in ability and control challenges the individual's sense of self. Maintaining personhood and patient autonomy during these tasks are critical for the clinician in order to provide care that is patient-centered. Another excerpt from the research study touches on this when a patient explains:

What really made it different was [the clinician] treated me with respect and dignity, and the dignity was what made it above and beyond. There were certain things that... I was not able to physically do, that were humiliating, that she had to do for me... But [the clinician] treated me with respect and dignity and I thanked her profusely... You really make the difference... And that really contributed to my healing, and getting better...⁴⁹

I experience this truth in my day to day routine at work. In the hospital, patients are often unable to care for themselves in the way that they could prior to being ill. I routinely have to assist people, young and old, to the bathroom, to get dressed, even to simply sit in a chair. Myself and the

⁴⁷ Judith Nelson et al, p.808-818

⁴⁸ Atul Gawande, p.173

⁴⁹ Judith Nelson et al. p.808-818

patient very quickly reach a level of intimacy most strangers normally would never get to. For instance, one time as I was first meeting my patient for the day at the very beginning of the shift, my patient asked to be assisted to use the bathroom. I pleasantly agreed, applied gloves, and helped the elderly woman stand and pivot towards a bedside commode (a toilet-height bucket with standing handles). Her open hospital gown fell forward, exposing her entire back side and bare chest as I bent closer to pull her underwear down and assist her down onto the seat. I specifically recall thinking to myself, “I just met this woman less than five minutes ago and here we are!” Providers are in a unique position of proximity and intimacy that can threaten the dignity of the person within the patient.

The attitude and behaviors of the professional have a direct impact on the experience the patient has and the value that they feel. Using Patient-Centered techniques will help to maintain the client’s personhood. In my experience just mentioned, after getting the woman onto the commode, I simply smiled at her and offered her a roll of paper towels, allowing her to take the time she needed and to wipe herself. During these tasks, clinicians should promote patient autonomy by giving choices and asking questions. For example, while feeding a patient, a clinician may say, “You have eggs, toast and potatoes. Which would you like? How do you take your coffee/tea? Would you like some now?” The clinician should also motivate the individual to participate as much as possible, maintaining whatever independence they may still have while fostering more. Providers need to take their time while performing tasks of everyday life, by going slowly and explaining what they are going to do before they do it.

Dr. Atul Gawande eloquently summarizes this notion, “This is what it means to have autonomy — you may not control life’s circumstances, but getting to be the author of your life means

getting to control what you do with them.”⁵⁰ By providing patients the opportunity to do so, clinicians not only maintain patient autonomy and personhood but also develop a quality relationship that cultivates trust in the provider and institution. This will lead to greater patient satisfaction and perception of care. In turn, this promotes adherence to medical advice and will generate better patient outcomes, as well as overall health and wellness of the individual. Dr. Gawande articulates the human need for autonomy in situations where individual integrity is threatened.

He writes,

Whatever the limits and travails we face, we want to retain the autonomy — the freedom — to be the authors of our lives. This is the very marrow of being human... All we ask is to be allowed to remain the writers of our own story... we want to retain the freedom to shape our lives in ways consistent with our character and loyalties.⁵¹

Dr. Gawande has more than a good point.

⁵⁰ Atul Gawande, p.210

⁵¹ Atul Gawande, p.140

Chapter III. Communication

a) What is Lacking?

Thus far, this paper has examined the culture of medicine and the doctor-patient relationship — specifically how each has developed over time, and how the two are interwoven and connected within society. I have demonstrated what quality relationships look like through the presentation of Patient Centered Care and how those behaviors have a direct effect on patient care in the hospital environment. This paper will now turn to focus more specifically on provider communication.

Throughout Chapters One and Two, there is strong evidence (from both peer-reviewed journals and personal experiences) to support the argument that effective physician communication skills are lacking. Health care professionals in the United States are challenged not only in initiating crucial conversations regarding life-threatening illnesses, but also in the most basic aspects of communication techniques that provide the receiving individual with a sense of respect and value. The way providers communicate with their patients has a direct impact on the way

patients perceive the care they receive. Moreover, provider communication affects the individual's overall health and well-being, especially so in the acute setting where critical health care decisions are made based upon the information that has been communicated and the manner in which it was delivered. Larson and Tobin reinforce this claim when they write,

For patients and families facing advanced illness, the medical interventions and quality of life that lie ahead are largely determined through a series of conversations they have with their physicians and other healthcare providers... When these often difficult conversations are avoided or are managed poorly, the quality of remaining life for patients can be seriously jeopardized.⁵²

Individual choices can only be as effective as the knowledge used to make their decision. Therefore, adequate communication is integral to the patient's ability to make an informed decision that is in their best interest and most aligned with their unique values and beliefs. There is an overwhelming amount of information and evidence to identify what is lacking in the area of provider communication and how it may affect individuals. Aside from published research and documented studies, I deal with this matter regularly in my professional environment.

In recent work experience, two separate patients on one shift confessed to me their concerns regarding this topic. One patient shared with me her dislike for an attending physician in charge of her case. After probing into her reasoning for not liking this doctor, we came to the understanding that my patient did not like the communication and behavior of this provider. The individual did not feel ready to be discharged from the hospital even though the doctor was suggesting that it would be happening within a day or two. While explaining this to me, the patient stated, "She told me that we (referring to her team of physicians) had other patients to take care of." Whether or not this physician actually spoke those words is less important than the fact that

⁵² Dale G. Larson and Daniel R. Tobin, p.1573

this is what the patient perceived and understood through their interaction. “We have other patients to care for” became the salient aspect of the message.

This individual felt as though her concerns for not feeling entirely well were being dismissed, and therefore was left with a sense of being unimportant and not worthy of the physician’s time or effort. The provider’s communication completely neglected the humanistic value of the individual. This led to a distinct dislike for the provider; which in turn may cause the patient to distrust the institution, ignore post-discharge instructions, not follow up with the provider, and possibly have a negative effect on the patient’s overall health.

The second scenario was when I entered an elderly patient’s room to find the individual visibly distraught and teary-eyed. She explained to me that the doctor said they wanted the patient out of here as soon as possible as she risked becoming more sick and weaker from staying in the hospital longer than she needed to be. She was overwhelmed by the process of being discharged and getting back to her assisted living, and was worried about how this all would happen so suddenly on a weekend. I then sat with the patient and simply explained the process and how it works — that all physicians involved in her case needed to clear her for discharge first, not just this specific one; that a social worker would discuss her options of assisted living versus rehabilitation unit; and that transportation will be set up for her when in fact she was ready. As I patiently answered all of her questions, I could visibly see a sense of relief wash over her face. The patient said to me, in her slight Southern drawl, “That’s the thing, not everybody takes the *time*.”

This individual was put at ease from the information and time that I gave her. This patient had greater emotional and psychological concerns which were ignored by a provider who only addressed the patient’s biomedical needs. The communication techniques employed by that

physician clearly left the patient experiencing more distress and anxiety than she had experienced prior to their meeting, demonstrating the harm that can be done to individuals through ineffective provider interactions.

These two separate patients in one shift demonstrate how prevalent the issue is related to the lack of provider communication skills. Both patients identify insufficient communication regarding the plan of care and preparation for discharge. Both patients were left feeling dissatisfied in their care and unsure of their stay in the hospital. Furthermore, the basic humanistic needs of understanding, respect, and value were ignored by providers who are responsible for caring for these two persons. These individuals' experiences were negatively impacted simply from the way their physicians communicated to them. In turn, their perceptions of care and possibly their follow-up post hospitalization were also threatened based upon their interactions with professionals.

Further evidence for lack of quality communication can be found in a plethora of journal articles and published research. One specific example is Marian Krawczyk and Romaine Gallagher's work, in which they declare:

From the quantitative results of our study, slightly more than 50% of family members felt very satisfied with the quality of communication about the patient's illness and likely outcomes of care. Less than half (43%) reported that they were always kept informed about the patient's condition, and close to half (45%) reported wanting more information...⁵³

Fifty percent satisfaction rating from patients on provider communication regarding patient illness and outcomes is poor. Less than half of participants felt they were kept informed. These results demonstrate a severe need for improvement. Further, their research identified multiple

⁵³ Marian Krawczyk and Romaine Gallagher, "Communicating Prognostic Uncertainty in Potential End-of-Life Contexts: Experiences of Family Members," *BMC Palliative Care* 15, no. 1 (December 2016), <https://doi.org/10.1186/s12904-016-0133-4>, p.3

themes related to patients' and family members' reports of communication.⁵⁴ Krawczyk and Gallagher go on to give some specific participant quotes from their study, some of which are especially pertinent to this paper:

"The doctor knew it wasn't going to be positive. Instead of being straight up he wasn't; I never thought she was dying."

"My brother asked about palliative care and the doctor said 'oh no, we haven't given up on your mother.'"

"I didn't know why he was breathing so heavily [a natural symptom commonly close to death] because nobody talked to me about it. It was like they thought I knew... but I did not. Was his death natural?"

"If you're doing a study about this, tell them that [the patients] need to know about the medicine and about death. Nobody wants to talk about it, but it's there..."⁵⁵

The above four quotes from separate individuals indicate patients and families' dissatisfaction related to communication with providers, particularly when the individual is acutely ill or near the end of life. Specifically, these quotes depict areas of communication that are lacking in the following: transparency in prognosis, ability to discuss comfort measures and goals of care, explanation of presenting symptoms and subsequent health outcomes, possible side effects of medications and procedures, and even the inevitable reality of death and dying. All of these facets are crucial for quality patient care, especially in the hospital setting. Furthermore, the lack of communication and knowledge left the patients and their families questioning their healthcare decisions and outcomes.

Krawczyk and Gallagher also provide inappropriate communication techniques and behaviors employed by providers that were identified by the participants in their study, including:

⁵⁴ Ibid.

⁵⁵ Marian Krawczyk and Romaine Gallagher, p.4-5

“Information being cloaked in confusing euphemisms, providing unwanted false hope, and incongruence between message and the aggressive level of care being provided. In extreme cases, these techniques left a legacy of uncertainty and suspicion.”⁵⁶ Physicians reluctant to communicate the critical level of the patient’s state or the imminence of the patient’s death can leave the family members shocked, unprepared and angry. These examples highlight just how much patient’s and family members’ experiences are impacted by the communication skills of the provider.

I can only imagine the guilt, frustration and fear one must experience when they question if their loved one’s death was natural, or caused by something that could have been prevented. Providers must not be responsible for causing or being a part of this anguish. The research results are alarming and should be concerning for all health care professionals. Patients continuously express the need for better communication, providers have a duty to their patients to listen to their concerns and improve the care they provide.

The truth of this matter is that while physicians are trained to fight illness bio-medically, they typically receive little formal education on how to effectively communicate with patients and their families. Mary Isaacson and Mary Minto stress this reality when they write the following:

A recent study of physicians specific to [End-of-Life] discussions and advanced care planning with patients and families revealed that 46% of physicians are uncertain what to say when initiating these conversations and *only 29% indicated receiving formal training specific to [communication]*.⁵⁷

⁵⁶ Ibid, p.5

⁵⁷ Mary J. Isaacson and Mary E. Minton, “End-of-Life Communication,” *Advances in Nursing Science* 41, no. 1 (March 2018): pp. 2-17, <https://doi.org/10.1097/ans.0000000000000186>

If physicians are not taught how to adequately communicate with their clients, how can we expect them to perform well?

Recall Chapter One's discussion surrounding a culture of medicine which is focused on aggressive diagnostic testing and eliminating disease. Quality communication techniques are viewed as less important to clinicians and the overall profession. As Dr. Gawande poses, "...the mistake clinicians make in these situations is that they see their task as just supplying cognitive information — hard, cold facts and descriptions. They want to be 'Dr. Informative'. But it's the meaning behind the information that people are looking for more than the facts."⁵⁸ Hospital patients, in acutely vulnerable circumstances, are searching for more from health professionals. Patients do not understand what the facts imply, only the professionals do; therefore, providers must be able to relay information in a fashion in which patients have a full understanding. Individuals need more than quick, factual interactions. They need deep and meaningful discussions.

Thinking back to my own education and training in nursing, the curriculum for a bachelor's degree in science also had a biomedical focus. I cannot recall learning about communication styles or humanistic approaches in my undergraduate degree. It is expected that these aspects of care are to be learned on the job, demonstrated from other colleagues who have experience interacting and building relationships with patients. But if no-one is being properly trained or educated, how can medicine be sure that what is being passed on is anything of quality? It was not until my graduate training in Medical Humanities that deeper concerns for personhood and human dignity were explored.

III. b) What Quality Communication Looks Like

⁵⁸Atul Gawande, p.206

Quality communication may look different for different patients and their unique relationships with physicians. As Patient-Centered Care emphasizes, it is important to understand health issues from the individual's perspective within their own context. Therefore, communication styles and behaviors may vary based upon specific patient needs. Certain defining factors such as culture and religion, country of birth, how one was raised will all affect a person's preference in communication style and their ability to build relationships.⁵⁹ For instance, I have taken care of patients and families where the men cannot look women in the eye due to religious and cultural beliefs. I have also taken care of patients who are not accustomed to meaningful, introspective conversations because they grew up in a household that did not discuss emotional and spiritual well-being. Health care professionals must be able to identify these scenarios and adapt their communication techniques accordingly as this, too, will affect patient care. For the purpose and length of this paper, I mean to discuss quality communication for the average American in the state of New Jersey with no obvious cultural or religious barriers.

Communication, when done properly, will elicit trust and respect from the receiving individual while empowering them to make difficult decisions. More importantly, quality communication can alleviate pain and suffering. While doing my own research, I asked for the experience of a family friend who suddenly lost her husband due to a heart attack. Fortunately, she had a positive experience and her words epitomize what quality communication looks like in the hospital environment in an acute emergency. She wrote to me the following:

“...my husband had a severe heart attack at home... When he arrived [at the hospital]... his care was taken over by a young ER doctor who immediately began to assess my husband's vitals and symptoms. This young doctor started treatment and then explained to me what was happening and what he was doing... His manner was gentle, relating the

⁵⁹ Jessica Anne Viveka Hemberg and Susann Vilander, “Cultural and Communicative Competence in the Caring Relationship with Patients from Another Culture,” *Scandinavian Journal of Caring Sciences* 31, no. 4 (December 2017): p.822-829

damage that occurred... as I was sitting, he knelt in front of me explaining... the damage to both [his] heart and brain was becoming extensive... he held my hand explaining [his recommendations]... his level of caring and compassion tempered my grief and state of mind so I was able to say goodbye to my husband... when I was ready, he hugged me and offered his condolences. His treatment of my husband as well his empathy are exemplary of a... doctor's skill set."

This is what quality communication looks like and what it can provide for the individual patient or family. The pain the woman was experiencing in the moment of losing her husband is unimaginable, but she noted that it was relieved by the actions of the physician. Importantly, because of the communication the doctor provided, she was able to grasp what was physically happening to her husband and the level of damage that was occurring to his body. Her understanding led her to be able to make healthcare decisions in which she was confident, prevented any doubt from developing afterwards, and consoled her in the level of care her husband received.

Published research also supports this woman's experience and the claim that communication can alleviate suffering. Dr. Richard Balaban, in his article published in the *Journal of Internal Medicine*, wrote, "Good communication can help allay fears, minimize pain and suffering, and enable patients and their families to experience a 'peaceful death'. Poor communication can result in suboptimal care, and patients and their families may be subjected to undue mental or physical anguish."⁶⁰ Krawczyk and Gallagher also identified similar results in their study which was just previously mentioned: "Family members who reported discussion of prognostic uncertainty also reported high levels of effective communication and satisfaction with care. They also reported long-term benefits of knowing the patient was sick enough to die, including a sense of peace and lack of regret..."⁶¹

⁶⁰ Richard B. Balaban, "A Physician's Guide to Talking about End-of-Life Care," *Journal of General Internal Medicine* 15, no. 3 (2000): pp. 195-200, <https://doi.org/10.1046/j.1525-1497.2000.07228.x>, p.195

⁶¹ Marian Krawczyk and Romaine Gallagher, p.5

Besides the emotional and psycho-social benefits in quality communication from providers, biomedical improvement has been seen as well. Dr. Jodi Halpern notes, “Engaged communication has been linked to decreasing patient anxiety, and, for a variety of illnesses, decreasing anxiety has been linked to physiologic effects and improved outcomes.”⁶² The above excerpts from journal articles all demonstrate that communication is capable of providing a sense of relief and comfort when done appropriately and effectively, as well as improving biomedical outcomes.

As mentioned, what quality communication specifically looks like will vary with each unique case. However, broad generalized standards can be established by professionals that are then adapted and implemented into individual patient scenarios. First and foremost, communication must be patient-centered and concentrated on the individual’s health and wellbeing. Quality communication techniques help build the partnership between provider and patient, which allow the provider to be able to connect with the individual on their level and in their own context. In order to do this, the provider must be able to employ non-verbal behaviors that reach the patient and establish a healing relationship.

Specific examples of this include the following: a) sitting with and next to the patient by pulling up a chair adjacent to the hospital bed or even sitting on the edge of the bed if it is appropriate to do so; b) reducing distractions by silencing the provider’s cell phone, closing the door to the patient’s room, drawing the curtain closed, or asking if it is okay to turn down the television; c) establishing and maintaining comfortable eye contact between all parties present; d) display-

⁶² Jodi Halpern, “What Is Clinical Empathy?,” *Journal of General Internal Medicine* 18, no. 8 (August 2003): pp. 670-674, <https://doi.org/10.1046/j.1525-1497.2003.21017.x>)

ing body language that is open, professional, and focused towards the patient; e) using therapeutic touch by grasping a hand, or pressing a shoulder that conveys comfort and presence; f) actively listening to the words and stories of the individual while asking clarifying questions to ensure understanding; and g) having a calming, gentle approach that soothes the individual before any words are even exchanged.⁶³

Non-verbal communication techniques are vital to establishing a sense of dignity and human value to the receiving individual. When providers incorporate these fundamental behaviors into their practice, patients are not only comforted by reduced fear and anxiety, they are also empowered to make difficult decisions because they feel supported by professionals. My family friend's experience reinforces this as she explicitly stated the doctor "had a gentle manner," "knelt down" to her level, "held her hand". This person felt compassion and a true sense of caring from the doctor, even during the death of her husband, simply from the way he behaved.

Other aspects of quality communication include specific styles that draw out the patient narrative and unique story of the individual. Doctors must be willing to take the time to step back and ask their patients meaningful questions regarding preferences and values, and what these may look like in their treatment and overall plan of care. This will help to understand illness and suffering from the patient's perspective. Providers must ask and understand matters like, "What are your biggest fears and concerns? What goals are most important to you? What trade-offs might you be willing to make, and which ones are you not?"⁶⁴ Physicians must also be

⁶³ Deepika Phutella, "The Importance of Non-Verbal Communication," *IUP Journal of Soft Skills* 9 (December 2015): pp. 43-49, <http://eds.a.ebsco-host.com/eds/pdfviewer/pdfviewer?vid=25&sid=2b6cd493-ae40-42d2-bf15-8ce23396090b@sidc-v-sessmgr01>)

⁶⁴ Atul Gawande, p.201

willing to re-examine these questions as illness progresses and plans change. For example, a father might initially prioritize in his plan of care being home with his son on Sundays to watch football, cook, and eat together. As disease advances, this father may come to desire specifically being able to watch football with his son if he is no longer able to cook or eat food. Even further, the father may come to value simply being home after losing all other capabilities. The importance lies in what the patient holds most dear to their being and determining how that affects health care decisions. Health care professionals must be willing to elicit this information not only through non-verbal communication techniques that place the patient at ease and relieve suffering, but also through engaged conversations where the provider asks purposeful questions, clarifies meaning, and becomes involved in the unique web in which that patient lives in.

It is important to note here that specific styles of communication are also vital in engaging conversations. Basic aspects of conversing such as word choice, complexity of language and grammar, speed, volume, and appropriate pauses between separate points all play a significant role in the discussion between provider and patient, and will affect the understanding and perception of care of the individual.⁶⁵ For example, I have taken care of patients who are nearly deaf and wear a hearing aid in only one ear. My communication techniques for these patients were particularly slow, speaking directly towards the one ear with the hearing aid, making sure to enunciate, and speaking especially more clearly than I normally would.

All providers must be acutely aware of their client's specific needs and alter their communication styles appropriately. Generally speaking, providers should employ communication styles that exhibit patience, avoid colloquial terms so that non-medical personnel can understand,

⁶⁵ Veronica Peterson, *Clinical Companion for Potter and Perry Fundamentals of Nursing*, 7th ed. (St. Louis, MO: Mosby/Elsevier, 2009), p.208

and allow for pauses or breaks in their speaking. These pauses enable the patient to both absorb the information, and ask clarifying questions. More importantly, communication should be delivered with meaning — that is, what the information and facts that are being delivered imply for the patient’s outcome, what the individual and family can expect, and the impact everything will have on the patient’s life and well-being.

Dr. Gawande discusses how he communicates difficult news to his patients, and provides a technique that he employs to both help ensure understanding, and allow the patient to ask clarifying questions. To ensure the patient and family understands the gravity of what he is sharing, he says, “I am worried”. Not only does that deliver a sense of meaning, it allows the patient to feel supported and comforted by the provider through their interaction. Further, he uses an “ask, tell, ask” approach to ensure the patient is appropriately understanding all of the information being provided. He writes,

They were such simple words, [I am worried], but it wasn't hard to sense how much they communicated. I had given her the facts. But by including the fact that I was worried, I'd not only told her about the seriousness of the situation, I'd told her that I was on her side — I was pulling for her... I let her and her family take in what I'd said... I asked her what she wanted to know. This was another practiced and deliberate question on my part. I felt foolish to still be learning how to talk to people at my stage of my career. But [a colleague] had recommended a strategy... physicians use when they have to talk about bad news with people — they “ask, tell, ask”. They ask what [the patient] wants to hear, then they tell [the patient], and then they ask what [the patient] understood.⁶⁶

Both of these communication techniques help to deliver clarity, understanding, meaning, and value for the individual in their unique circumstance.

Another meaningful characteristic of quality communication is shared decision making (SDM), incorporating family or loved ones into the conversations between patient and doctor so

⁶⁶ Atul Gawande, p.206-207

that the provider may guide a meaningful discussion that leads to an adequate plan and strong decisions. It is important to note that patients are commonly not single persons living independent lives, but rather are parts to a larger family unit with varying economic and social statuses.

Therefore, health care decisions are often affected by this reality. Choices that patients decide on are not simply medical decisions, but also are emotional and financial ones. Physician and bio-ethicist Ezekiel Emanuel discusses in depth the importance and value in shared decision making.

In an article published for the peer-reviewed medical journal, *The Lancet*, he writes:

In caring for dying patients, clinicians need to remember that [illness and death] affects a wide social network. The families of patients experience significant caregiving and economic burdens; they are also preparing for loss and must cope... clinicians must not just care for their... patients but minister to the patients' families and friends. This entails inquiring whether families understand the patient's clinical situation, and preparing the family for what to expect. It requires bringing families into the process of advance-care planning and discussing future care... It can require more substantial involvement such as inquiring about families' burdens and what additional assistance they might require.⁶⁷

Moreover, by incorporating family into discussions in the hospital environment, this opens the doors for communication at home among family members, as well as invites further discussions between family members and the provider as illness advances and needs change.

True shared decision making equates to shared power among all parties — physician, patient, and family. In this frame, professionals act more as a guide and mediator for the patient and family to come to the best possible health care decision for them based upon their unique preferences and values. A three-step method for shared decision making in clinical practice has been offered in an article published in the *Journal of General Internal Medicine*. The authors write,

We describe three key steps of SDM for clinical practice, namely: *choice talk*, *option talk* and *decision talk*, where the clinician supports deliberation throughout the process.

⁶⁷ Ezekiel J Emanuel and Linda L Emanuel, "The Promise of a Good Death," *The Lancet* 351 (May 1998), [https://doi.org/10.1016/s0140-6736\(98\)90329-4](https://doi.org/10.1016/s0140-6736(98)90329-4) p.121-129

Choice talk refers to the step of making sure that patients know that reasonable options are available. *Option talk* refers to providing more detailed information about options and *decision talk* refers to supporting the work of considering preferences and deciding what is best.⁶⁸

This three-step guide is an approach of communication that invites and involves both patient and family to form decisions through in-depth discussions concentrated on personal preferences. The provider, being the professional and holding the knowledge and expertise, first details all of the choices the patient has — from doing nothing to radical surgery if appropriate. Next, discussions occur that further detail what these options particularly involve and might mean for subsequent decisions and well-being. Finally, decisions will be made based on which best aligns with the patient and family preferences and what is ultimately best for their unique circumstance. Providers need to communicate information in an honest, but gentle manner; provide professional recommendations based upon statistics or research; and then guide the patient to come to the best choice for their individual situation.

III. c) Empathy

Arguably the most important aspect to quality provider communication is empathy. Empathy is the visceral experience of another person's thoughts and feelings from their point of view, rather than from one's own.⁶⁹ Empathy facilitates healing behaviors that come from within so that one may behave in a more compassionate manner. To expand, "It is the ability to step into the shoes of another, aiming to understand their perspective and experience, and to use that

⁶⁸ Glyn Elwyn et al., "Shared Decision Making: A Model for Clinical Practice," *Journal of General Internal Medicine* 27, no. 10 (October 2012): pp. 1361-1367, <https://doi.org/10.1007/s11606-012-2077-6>

⁶⁹ "Empathy," *Psychology Today* (Sussex Publishers), accessed February 20, 2020, <https://www.psychologytoday.com/us/basics/empathy>

understanding to guide our actions.”⁷⁰ An emphasis on empathy relates back to the argument for patient centered care, sound doctor-patient relationships, and care for the individual’s soul. None of which are possible without an empathetic nature. Elaine Wittenberg-Lyles et. al. argues this idea in their article published in *Patient Education and Counseling*. They write:

Patient centered communication remains at the forefront of national efforts in the United States for improving and emphasizing health communication in clinical settings. One feature of patient-centered care is the provider’s ability to express empathy. Physician empathy has been defined as an understanding of the patient’s situation and feelings, the ability to communicate understanding and check for accuracy, and acting on the understanding to help the patient... Communication may be adversely affected if the provider fails to recognize an empathic opportunity, interprets emotion incorrectly, or neglects to respond. The physician’s lack of an appropriate empathic expression can result in poor interactions and unmet expectations that increase anxiety for patients.⁷¹

These words are powerfully relevant to this paper’s discussion on communication and patient’s perception of care. Empathy is an intrinsic component to quality communication and patient-centered care. Professionals ignore empathic opportunities by discussing the patient amongst themselves, remaining silent during moments of emotional expression, and by verbally ending the conversation when the patient signals that they are not ready. The patient’s perception of care and experience in the hospital may be negatively affected by the physician’s inability to incorporate such qualities into their practice. More importantly, negative effects on psychological and physical well-being are seen as well when providers do not communicate empathetically.

⁷⁰ Roman Krznaric, “Six Habits of Highly Empathic People,” *Greater Good*, November 27, 2012, https://greatergood.berkeley.edu/article/item/six_habits_of_highly_empathic_people1)

⁷¹ Elaine Wittenberg-Lyles et al., “Conveying Empathy to Hospice Family Caregivers: Team Responses to Caregiver Empathic Communication,” *Patient Education and Counseling* 89, no. 1 (May 2012): pp. 31-37, <https://doi.org/10.1016/j.pec.2012.04.004>)

Further, an empathic nature and approach aids the provider in eliciting the patient's trust and their ability to share their symptoms and illness, which in turn enhances the accuracy of diagnoses and adherence to the prescribed treatment plan. Again, this can be aided by the non-verbal communication techniques mentioned in the previous section. Appropriate facial expressions and active listening both display a sense of empathy to the receiving individual. As Jodi Halpern notes,

A... related contribution of empathy is that it facilitates patient trust and disclosure. Physician's express empathy not only by grasping the personal meanings of patients' words, but also by (authentically) matching patients' nonverbal style... When doctors attune to patients nonverbally, patients feel more comfortable to give fuller histories.⁷²

In other words, health care professionals must be skilled at 'reading between the lines', that is interpreting what the patient may be feeling and thinking without actually speaking it. Halpern goes on to give a specific example of this awareness of patient's nonverbal cues:

If a patient says that she has stopped taking her medication, empathy involves taking cues from her tone. This patient may be angry about sexual side effects, or she may be upbeat, and see the medication as unnecessary because she doesn't feel sick, or she may see the medication as useless because she feels hopeless about getting well. In each case, addressing the patient more or less appropriately depends upon attuning to the patient's emotions.⁷³

This aspect of empathy circles back to patient-centered care and addressing more than simply the superficial biomedical needs. True empathy and PCC require the provider to become involved in the patient's emotional and psychological well-being, in order to understand illness and the presenting symptoms in relation to the patient's experience and everyday life. It is not enough for a health care professional to accept that the patient has stopped taking the medication prescribed in the treatment plan, or to simply reinforce the need for taking it.

⁷² Jodi Halpern, p. 670-674

⁷³ Jodi Halpern, p.670-674

Physicians must be willing to take the time to understand why the patient has stopped taking their medications and come to the root of the problem. For example, providers can ask probing questions like, “I hear some anger in your tone of voice when talking about this medication, is there something particularly bothering you about this treatment?” Or, “Are you experiencing any unwanted side effects?” One question such as this can open discussion and help build a relationship between provider and patient that aids mutual understanding, patient experience, and improves the patient’s overall health and wellness.

I often witness negative actions from providers in my hospital regarding communication and empathy. When patients are frequently re-admitted for the same issue, doctors are not often willing to communicate with patients on a deeper level in order to find the heart of the issue and alter treatment plans accordingly. Rather, professionals follow the associated algorithm to restore health and then send the patients on their way again once they are close enough to baseline, knowing that they will probably see the patient admitted again soon. Physicians must be willing to uncover deeper reasoning and work with the patient to develop solutions to which the individual will adhere. Using empathy as a communication tool, providers are not only better able to grasp the meaning of illness as the patient experiences it, but also are motivated to act on behalf of the individual. This calls for professionals to incorporate different therapeutics or regimens that may work best for the unique person.

Research further supports my experiences. Rita Charon writes, “Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illness... physicians sometimes lack the capacities to recognize the plights of their patients, to extend empathy towards those who suffer, and to join honestly and courageously

with patients in their illnesses.”⁷⁴ This accompaniment means witnessing the individual’s suffering and sharing their experience. Accompaniment challenges providers to partner with their patients and truly work with the individual and their family in order to create the best possible plan of care for them as a unique person within their own web of life.

Chapter IV. Patient Perception and Satisfaction

a) What Do Patients Value and Why?

Since the purpose of medicine is intrinsically for the benefit of the patient, it is crucial for this paper to examine the patient’s perception of care in the hospital and what specifically they value. How do the patient’s feel about communication and provider interactions in the acute setting? What do they value while in the hospital? Does this affect patient satisfaction ratings? I have incorporated the patient’s voice throughout my discussion thus far — from first hand experiences with individuals, and from published research that specifically outline their findings with participants and patient responses.

⁷⁴ Rita Charon, “Narrative Medicine,” *JAMA* 286, no. 15 (October 17, 2001): pp. 1897-1902, <https://doi.org/10.1001/jama.286.15.1897>, p.1897

All examples provided in this paper suggest that patient's value individualized, compassionate care that preserves dignity and enhances well-being. Furthermore, the examples given (particularly my first-person experiences) demonstrate that patients are in fact cognizant of physician's communication styles. Recall the cases of the Jehovah's Witness patient refusing blood products where the physician walked out on him; the wife looking to speak with a patient advocate because she was concerned about her husband's prognosis and needed someone to speak openly with; the patient who was visibly distressed from anxiety after being told by her physician she has to be discharged as soon as possible; and the family friend who was comforted in the midst of her husband's death because of the interaction with the Emergency Room doctor. In every one of these examples both the behavior and communication techniques of providers have had direct impact on the patient's experience and overall perception of care.

Research also supports my central argument. One study specifically identifies the following: "Patients and families in our focus groups identified four aspects of ... care that were most important to them: communication by clinicians about the patient's condition, treatment, and prognosis; patient-focused medical decision-making; clinical care of the patient to maintain comfort, dignity, personhood, and privacy; and care of the family."⁷⁵ The participants of this research include forty-eight subjects (both individual patients and families) from three different hospitals in Oklahoma, urban California, and a "northeastern city."⁷⁶ The diversity demonstrates how prevalent issues are: various people across the country collectively value and emphasize in their care quality provider communication, patient-focused shared-decision making, and care that promotes human dignity and personhood. The researchers even highlight the importance of the

⁷⁵ Judith Nelson et al., pp. 808-818

⁷⁶ Ibid.

interaction between patient and provider when they write, “According to one patient, the top priority was clinician ‘communication, with compassion... because, being in the dark is like being in oil’.”⁷⁷ Individuals value compassionate and clear communication, because without it, their experience in the hospital is like being in oil.

To further understand the patient’s perception and what they value most in the acute care setting, one must employ the technique of empathy. Health care providers should try to put themselves in the position of the patient and family and ask themselves: what might be important to them in this circumstance? In acute medical emergencies, what patients often value most is whatever they still have control over. Because they cannot control their illness or body in that moment, patients may look at details that seem unimportant to a hurried health care provider. A research study examined nurses and patients from forty different medical-surgical units across seven hospitals in the southeastern United States, in order to determine if providers know what patients think is important for their care. The results found that:

Nurses appear to underestimate the value that patients place on a variety of elements..., including those that involve the physical environment. Things like a comfortable bed, good lighting, low noise level, and a comfortable temperature in the room may not be things that are usually mentioned under the heading ‘quality of care,’ but patients feel very strong about these things and appear to take them into consideration when evaluating the quality of the nursing care they received.⁷⁸

While the physical environment is not often considered by providers in caring for their patients, there is evidence to show that patients value these matters in the hospital. Attention to detail makes a difference for patients who cannot control much else. When one is acutely sick

⁷⁷ Ibid.

⁷⁸ Mary R. Lynn and Bradley J. McMillen, “Do Nurses Know What Patients Think Is Important in Nursing Care?,” *Journal of Nursing Care Quality* 13, no. 5 (June 1999): pp. 65-74, <https://doi.org/10.1097/00001786-199906000-00008>, p.71

and vulnerable, a comfortable bed and adequate lighting comes to be valued even more. Although physicians and nurses are not trained to take these matters into account, perception of care is influenced by the environment. Providers should ask their patients before leaving the room, “Are you comfortable?” “Would you like me to turn off the lights, or close your window shades?” Professionals may not be able to control the bed mattress or temperature of the room, but small acts can be done to demonstrate to the patient a sense of compassion, understanding, and care for the soul. For example, providers can quickly grab an extra pillow or blanket for the patient who is uncomfortable in bed, or offer to adjust the thermostat in the room. These seemingly minute gestures have a direct impact on patients’ perceptions of care they receive in the hospital environment. These actions make the individual feel valued.

Another aspect that is important to patients is certain behavior characteristics like being talkative and friendly, being honest, and using humor. The research study mentioned above goes on to note,

The importance to patients of many of the more psychological elements of... interactions also appears to be underrated by nurses, including aspects of... behavior like being talkative and friendly with patients as well as using humor... many of these behavioral characteristics also do not fall within the traditional definitions of quality of care. In fact, some of these behaviors are those that nurses were traditionally taught not to do.⁷⁹

The value individuals have in personality characteristics relates back to communication techniques and the provider-patient relationship. Patients want providers who approachable and congenial. Using humor and being friendly are not traditionally taught in medical education; providers are instructed to be professional and act confident. However, patients value behaviors that are more human and natural. People want to be taken care of by professionals who are friendly

⁷⁹ Mary R. Lynn and Bradley J. Mcmillen, p.72

and honest. Again, providers should place themselves in the position of their clients and be motivated to act on their behalf. How would they want their doctor or nurse to interact with them? When health care professionals are talkative, friendly, and use humor, patients perceive their care to be more compassionate and person-focused. This will automatically put the patient at ease by reducing anxiety and relieving suffering.

Published journal articles and my own professional experiences illustrate the fact that patients value compassionate person-focused care, quality communication that is clear and understandable, promotion of patient autonomy and personhood, the incorporation of family in care and decision making, and behaviors that make the patient feel more comfortable. This is quite the contrary to the culture of medicine that values timely diagnostic testing, aggressive treatment, eliminating illness, and surviving disease. Patients value more comfort measures in the hospital environment where they are acutely vulnerable, and research has demonstrated that humanism — not the tests — have an impact on how patients understand the care they receive. Physicians can follow protocols for specific diagnostics and management while still prioritizing communication and care for the individual's soul. When providers incorporate defining characteristics and approach that focus on what patients truly value, the individual perception of care and overall experience will be enhanced.

Moving deeper, people with serious illnesses that are nearing the end of life have values that differ even more from the values of medical culture. Dr. Gawande brings to light,

People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden to others, and achieving a sense of that their life is complete.⁸⁰

⁸⁰ Atul Gawande, p.155

Patients who are near death prioritize more intimate and human affairs. When individuals are aware that the end of their life is near, people become more introspective and seek the validation from loved ones or religious entities that all needs are met. These values allow the individual to be at peace, and feel ‘ready to go.’ However, as discussed throughout Chapter One the practice of health care today opposes the matters that patients value most when near death. Dr. Gawande continues on to write, “Our system of technological medical care has utterly failed to meet these needs. The question therefore... is how we can build a health care system that will actually help people achieve what’s most important to them...”⁸¹

Being sharply aware of what patients value and why is an enormous opportunity for providers to improve not only the outcome of the patient in the acute setting, but also the health and wellness of the individual overall. By developing quality relationships through adequate communication, empathy, and understanding patient perception, the individual will be more likely to continue their learned behaviors after discharge and attend follow-up appointments. This in turn will decrease the risk for hospital readmissions and greater health issues. The writers of the previously mentioned research study begin their conclusion for their article by summing this argument:

Care providers need to fully understand the expectations that patients have for their care, and subsequently provide care consistent with those expectations. If this can be achieved, it should result in more positive perceptions on the part of patients, which might influence their future attitudes and encounters with the hospital, as well as their compliance with their care regimen after discharge.⁸²

Health care professionals need to understand the patient’s perception of the care being provided. They need to realize what patients expect and value. As Dr. Gawande challenges, providers and

⁸¹ Ibid.

⁸² Mary R. Lynn and Bradley J. Mcmillen, p.72

the practice of medicine need to address what is most important to patients while in the hospital environment. When providers address the values associated with humanistic care, patients have a more fulfilling experience.

IV. b) Patient Satisfaction and HCAHP's

Patient satisfaction is closely linked to perception of care because how the individual views and feels about the care they received, will directly affect their satisfaction with the hospital and staff post discharge. This satisfaction will influence their willingness to seek further medical attention from the institution moving forward. Recall from Chapter Three the patient who told me she did not like her attending physician as a result of their conversation and what was exchanged. Towards the end of my shift as she was thanking me for taking care of her, she said, "Why do you think I keep coming back to [this hospital]? It is because of the care I get." The same individual who felt unimportant after an interaction with her physician, came to feel valued and especially well taken care of. Had that patient left the hospital still feeling dismissed and under-appreciated, she most likely would not have been compliant with her care regimen and her satisfaction of the hospital would have been poor. However, because of my behavior, communication style, and the relationship that we built, this individual came to be satisfied with her care once again.

Another patient example of satisfaction I managed is a person who was being discharged with a newly placed feeding tube in their stomach. The man was elderly and although he was alert, oriented, and able to function mostly independently, he was having difficulty swallowing after a stroke. Since he was being discharged on my shift, I needed to ensure that the patient and his family understood how to use the feeding tube and could demonstrate the proper technique back to me. In order to properly educate the individual and his daughter I waited for her to come

in after work, which was near the end of my shift, and had education material printed out and ready to provide them that specifically outlined the process of using a feeding tube and caring for it. I then sat in front of the two of them and performed the process of feeding the patient through the tube while simultaneously discussing it with them. I worked slowly and made sure they each understood every step. I then allowed them to “teach-back” to me the process to ensure accuracy. I patiently answered all of their questions and gave the recommendations for feeding based on the nutritionist’s input.

I very easily could have simply given them the printed hand out and let them walk out, especially since this was the last hour of my shift. However, this likely would have resulted in a malfunction of the feeding tube, an increase chance for infection, or poor nutritional intake. All of such possibilities would have negative effects on the overall health and well-being of the individual, which in turn would impact their satisfaction with treatment. Instead, the patient was able to leave the hospital feeling educated and empowered. Ultimately, I know that that patient and his daughter felt pleased with the level of care he received simply from the time and effort I gave them. This satisfaction in care enhances their perception of the hospital and will ensure follow-up post discharge. More importantly, I demonstrated that the provider-patient relationship and communication technique are integral to the patient experience. By being mindful of what individuals value and incorporating patient-centered care and empathy, I influenced the perception of care and overall satisfaction.

Healthcare systems and individual institutions analyze patient satisfaction primarily through the implementation of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. The Hospital Quality Alliance (HQA) program was created by federal policy makers and private organizations (including the Centers for Medicare and Medicaid

Services) to collect and publicly report data on the quality of the health care Americans receive. The HQA program incorporated HCAHPS into its battery of measurements. HCAHPS data allow researchers and medical professionals to gain insight into the experiences of patients in the hospital and how these experiences relate to aspects of care. The survey asks patients fourteen questions which are summarized by the Centers for Medicare and Medicaid Services and reported in six domains: communication with physicians, communication with nurses, communication about medications, quality of nursing services, adequacy of planning for discharge, and pain management.⁸³ Hospitals heavily rely on these results because reimbursement from Medicare and Medicaid Services are affected by it.

One particular study analyzed the public data available from July 2006 through June 2007. The findings include the following:

On average, 63% of patients gave their care a high global rating (9 or 10), and an additional 26% rated their care as 7 or 8, whereas only 11% gave a rating of 6 or less. Sixty-seven percent of the patients said that they would definitely recommend the hospital in which they had received care.⁸⁴

These results prove interesting for the discussion of this paper. As stated, 63% of patients gave their care a high rating, and only 67% say that they would definitely recommend the hospital in which they received care. Sixty-three percent leaves much room for improvement for institutions that desire high ratings in patient satisfaction. Further, over thirty percent of individuals would not recommend their hospital, and therefore are also less likely to seek medical care from

⁸³ Ashish K. Jha et al., "Patients Perception of Hospital Care in the United States," *New England Journal of Medicine* 359, no. 18 (October 30, 2008): pp. 1921-1931, <https://doi.org/10.1056/nejmsa0804116>, p.1922

⁸⁴ Ashish K. Jha et al., p.1924

the institution again. While only eleven percent of respondents gave a poor rating⁸⁵, this data illustrates a fairly large percentage of dissatisfaction.

The article goes on to mention, “The proportion of patients who reported satisfaction with their care in specific domains varied substantially: on average, 79% of patients reported that doctors always communicated well whereas only 54% of patients reported that their room was always quiet.”⁸⁶ Nearly 80% satisfaction with doctor communication is better than anticipated, but makes me wonder if the general public has become complacent in their expectations from doctors. As discussed in Chapter One, societal culture and medical culture are inter-connected; a society that expects fast-paced quick fixes, might not expect intimate and introspective discussions from doctors.

The key, however, is that only half of patients reported that their room was quiet. This statistic circles back to what patients truly value in the hospital setting and further supports previous evidence and my argument. As stated, patients value the little things whenever everything is out of control. When one is acutely sick and vulnerable, small things like comfort and lighting truly help to make the individual feel better. Seemingly minute details, such as a quiet room and comfortable bed, actually have an effect on overall satisfaction as they are taken into account by patients when evaluating the care they receive.

The researchers go on to expand on their results:

... although these ratings suggest that only a small percentage of patients were seriously dissatisfied, very few hospitals received the highest ratings from 90% or more of their patients... More important, HCAHPS highlights specific areas for improvement, such as nursing care, communication about medications, pain control, and provision of clear discharge instructions.⁸⁷

⁸⁵ Ibid.

⁸⁶ Ibid.

⁸⁷ Ashish K. Jha et al., p.1926.

While only 11% of patients would rate their hospital at a six or less⁸⁸ (taken from the quote on the previous page), very few hospitals are receiving high ratings from the majority of respondents. This illustrates that there is a broad range of satisfaction amongst patients who are receiving care within the same institution.

If all care is to be delivered with compassion and a unique patient-focus for every person, why is there such diverse ratings? One can infer from this information that true individualized Patient-Centered Care is, in fact, lacking. Institutions force standardized algorithms into all patient cases, therefore satisfying a certain population of patients. Hospitals and providers need to consider the unique circumstance of each patient case and adapt their methods accordingly. True patient-centered care means understanding the illness from the patient's perspective and acting in alliance with what the individual specifically values and prefers. When hospitals receive a high satisfaction rating from only a small group of individuals, both institutions and providers should consider bending the plan of care and approach to more adequately cater to varying patient needs.

Chapter V. Development From Here

Before moving forward, let's reconnect with the central argument and discussion questions for this paper. Harm is being inflicted on patients by providers through their interactions and ineffective communication techniques. Furthermore, do the majority of providers recognize their behaviors as being inadequate for maintaining their patient's intrinsic value? How do the patients feel about the doctor-patient relationship today and the approach of their provider? Do these interactions affect patient satisfaction and health care overall? In Chapter One, I focus on the medical culture of today and argue that human dignity and care for the soul are neglected for

⁸⁸ Ibid, 1924.

the sake of timely diagnostic testing and aggressive treatment. Throughout Chapter Two, I discuss in-depth the doctor-patient relationship and how it impacts the patient experience through Patient-Centered Care and the motif of personhood. Chapter Three looks specifically at communication techniques and the interactions providers have with their patients.

By providing mounting examples from published literature, peer-reviewed journal articles, and personal experiences I demonstrate how the way clinicians communicate with individual clients has a direct correlation to both how patients perceive their care and their health outcomes. Chapter Four looks deeper into patient perception and the way it is connected to satisfaction of care and hospital ratings. By discussing personal examples and the HCAHPS scores, I demonstrate that patients' understanding of the care they receive reflects in their satisfaction ratings of providers and the hospital in which they are treated. In this final Chapter, I will first examine the role of the nurse more closely in caring for and then conclude with suggestions for improvement.

a) Role of the Nurse

Throughout this paper, I frame the nurse as a provider who has a more intimate and personal working relationship with the individual which subsequently shapes the patient experience. Nurses are in a unique position to directly care for people who are vulnerable, and who seek support and comfort from professionals. In the hospital environment, the nurse spends an entire twelve to thirteen-hour shift with a set group of clients in which they dive head first into the struggles, challenges, successes, and personal truths of complete strangers. The nurse, with help

from nursing assistants and other ancillary staff, have numerous responsibilities in caring for their patients that go far deeper than traditional working relationships.

Nurses will deliver medications and are responsible for educating patients on what is being given while ensuring the patient understands why he/she is taking the medication. Nurses will assist patients to the bathroom and with other routine daily living activities; they are responsible for making sure their patients are clean and well-kept. Nurses monitor vital signs and laboratory values and are responsible for notifying physicians when levels begin to deviate from standards. Nurses send patients to procedures or tests and are responsible for making sure the patient knows what they are going for and determining if it is safe for the patient to go. Nurses consistently reassess their patients throughout the shift and are responsible for communicating to physicians any concerning signs or acute changes in mental or physical status.

Nurses are advocates for their patients. They are responsible for addressing and helping to control pain and physical discomfort. They are required to speak up for patient safety and patient concerns. Nurses must communicate and collaborate with various members of the health care team to ensure all patient needs are met (for example, Social Workers, Physical Therapists, Case Managers, Speech Pathologists, and Respiratory Therapists). Nurses also facilitate discharge from the hospital, and are responsible for educating patients on follow-up instructions left by the doctor.

Moreover, nurses are the “first line of defense” on a hospital unit. Not only are they responsible for closely monitoring patients and communicating with doctors to prevent negative outcomes, but they are also the first to arrive and assess in cases of emergencies. Nurses are also the professional who is physically present on the floor, and who patients and families look to for

information and guidance. When families arrive, they first ask for the nurse in charge of the individual that day to inquire how the patient is doing and what the plan is. Any issues ancillary staff may have — such as dietary personnel, phlebotomists, engineering, and housekeeping — are directed towards the nurse to manage. The duties for a nurse are dynamic, and are intrinsically vital to the day to day patient experience.

All of the above stands in contrast to the doctor or nurse practitioner who sees the patient for five to ten minutes before leaving the floor. Providers state, “I am going to order X, and we will do A, B, C” and then place their orders. However, who is the one carrying out these orders and tests? The nurse is most often the professional collecting blood samples or specimens for analysis. The nurse is the one delivering the newly prescribed medication. The nurse is the one preparing the individual for tests. Often times, the nurse is the professional who must explain further what these tests, medications, and procedures really mean for the individual.

One specific example of this occurred during a recent shift I worked. A colleague of mine had a patient whose nurse practitioner ordered for the patient to undergo a colonoscopy, along with the necessary bowel regiment beforehand, and changed their diet to liquids in preparation for this procedure. When a liquid lunch was delivered by the dietary staff, the patient refused his tray and questioned where solid foods were. The dietary worker reported to the nurse what happened, who then had to explain to the patient why his diet was changed. The patient refused the colonoscopy, stating he had received one a few months prior. The nurse was now responsible for notifying the practitioner that the patient was refusing the procedure and associated preparations. After attempting to reach the practitioner for hours, the nurse was finally able to communicate the patient’s concerns and needs over the telephone. The practitioner explained to the nurse that the patient needed the colonoscopy due to a suspected mass in the lower portion of

the colon and that the team wanted to perform a biopsy. Now, the nurse was responsible for going back to the patient and educating him on what the procedure was specifically for and its importance. Imagine the questions the individual had and the emotions he was experiencing after being told he had a mass that needed to be biopsied.

This patient example reinforces the various roles of the nurse — “first line of defense” for the dietary personnel to approach after the patient refused their tray, educator for the patient as to both why his diet was changed and why he needed the colonoscopy, patient advocate when the individual refused the colonoscopy, and also a source of comfort when the patient understood he had a mass that needed to be biopsied. The example demonstrates the stark difference between the nurse and the practitioner in caring for individual patients — a working relationship built on continued interactions and exchanging of dialogue, compared to a quick examination without meaningful discussion. This further supports my argument that quality provider communication is lacking. That Nurse Practitioner should have adequately explained to the patient what tests they were ordering, what the patient could expect beforehand, and the reasoning behind it. A colonoscopy and the necessary diet change should not have been a surprise to the individual.

Moving inward, nurses play a fundamental role in caring for those who suffer. They are present with their patients when they receive negative results or “bad news”. They comfort their patients who grapple with a loss of independence or sense of self. Amidst the many hours of a shift, nurses intimately connect and build relationships with patients and their families or friends that reach much deeper than average relationships between strangers. Meier et. al. expands on this idea:

The relief of suffering is at the core of nurses work as a profession committed to the human response to illness or injury. Nurses also are dedicated to serving the most poor or vulnerable. Nurses are intimately involved in whole-person care and are, apart from

families, the witnesses most often present as people struggle with fundamental ethical concerns and spirituality in illness.⁸⁹

Nurses are in unique positions that privilege them to witness and accompany patients through periods of introspective spiritual, emotional, and psychological discussions. In the patient example given above, the nurse ended her shift in a very specific role that required her to a) comfort the individual while he absorbed the reality of a biopsy, b) witness his introspective thoughts as he explored what these results could possibly mean for him moving forward, and c) ease the patient's suffering and anxiety related to fear of unknown outcomes for his health and wellness.

Furthermore, first-hand patient experiences that I have given throughout this paper highlight the role of the nurse and the unique opportunities they have to shape client experience and perception of care. The elderly woman whose anxiety was relieved by my explanation of the discharge process, the patient who transitioned from disliking her physician to recognizing the quality care she received, and the father who was educated and empowered to care for himself and his newly placed feeding tube, are all examples of how influential the role of the nurse can be. Every single one of these individuals had a significant experience that was shaped by communications styles of their nurse which improved their overall health outcomes.

Nurses need to recognize their specific place in the health care team and the importance they have on direct patient care. Nurses will most often be the professional who establishes healing relationships, addresses psycho-social and emotional wellbeing, and enhances human dignity and value. They should be empowered by their responsibilities and motivate themselves to be the best they can be for the individuals who look to them for care and comfort when they are

⁸⁹ Diane E. Meier, Stephen L. Isaacs, and Robert G. Hughes, p.147

most vulnerable. Furthermore, nurses must employ empathetic behaviors that work to give the patient the best possible perception of care and outcome.

V. b) Suggestions for Improvement

To complete this paper, I will now dictate suggestions for improvement related to patient's perception of care, provider communication styles, and satisfaction ratings. First and foremost, all provider's need to be aware of what patient's truly value while in the hospital and not blindly follow protocols and standardized algorithms. I have demonstrated throughout my discussions that this includes the following: individualized, compassionate care that preserves dignity and enhances well-being; quality communication that is clear and empowering; non-verbal behaviors that emphasizes empathy and support from the health care team while comforting the individual and placing them at ease; incorporation of family and loved ones in the decision-making process; and attention to detail and the environment. Without the knowledge of what patients view as important, appropriate changes that address these topics cannot be made.

As the cornerstone of this paper, communication and behavior during patient interactions needs to be improved by all physicians and providers. Physicians must begin to take the adequate time needed to ensure quality communication is being performed and to ensure patient understanding. I have provided detailed examples of what quality communication techniques and styles look like in Chapter Three — enunciating, speaking slowly, allowing for pauses, using plain language, for example. Verbal communication needs to be honest, clear, and delivered with meaning. Patients need to understand their illness and be able to speak to prognosis and expected outcomes. Odgers et. al. provide a detailed list for suggested changes regarding communication:

Clinicians should be sensitive, use plain language and avoid euphemisms, with follow up to ensure the [patient and] family understands. Secondly, there is potential for ambiguity

and uncertainty at the end-of-life. Clinicians should explain the prognosis and that the dying process varies between individuals. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers.⁹⁰

Non-verbal communication techniques should also be developed — eye contact, therapeutic touch, active listening, appropriate body language — because these deliver a sense of value to the receiving individual, and make the patient feel comforted and cared for. Furthermore, physicians must work on the ability to initiate and maintain discussions surrounding complex human needs and end-of-life cases. While both patient and physician acknowledge the difficulty discussing these topics, it is the physician's responsibility to open conversations and to encourage patients and their families to face certain realities.

It is pertinent to acknowledge that the established culture of medicine, as discussed throughout Chapter One, make it difficult for physicians to make the necessary changes. First, physicians need adequate training and support from their employers and educators. This identifies an overwhelming gap that needs to be addressed. Medical schools and advanced training need to shift their focus to incorporate adequate communication training in their education. As Dr. Ezekiel Emanuel argues:

Clinicians must receive training in communication, not general communication skills but skills specific to the concerns of dying patients. Clinicians must be as comfortable in talking to patients about the dying experience as they are taking history of angina. This training must include structured approaches... for clinicians to use in common aspects... such as delivering bad news, advance-care planning, addressing spiritual concerns, and giving condolences.⁹¹

Even though Emanuel's article was published in 1998, this still rings true today over twenty years later. A fellow nurse on my floor who is completing her education towards becoming a

⁹⁰ Jade Odgers et al., "No One Said He Was Dying: Families' Experiences of End-of-Life Care in an Acute Setting," *Australian Journal of Advanced Nursing* 35, no. 3 (n.d.): pp.21-31, p.29

⁹¹ Ezekiel J Emanuel and Linda L Emanuel, "The Promise of a Good Death," p.121-129

nurse practitioner admitted to me that she did not receive any training in communication, let alone in speaking about the dying process. Even though she is graduating this semester and will be placed in a nurse practitioner role in a matter of months, she is “so scared” to talk to patients about dying and delivering bad news. She exclaimed to me, “How am I supposed to tell someone they have been diagnosed with Cancer?!” Again, if no-one is being appropriately trained how can we possibly expect physicians and practitioners to be able to perform properly?

Future development must include a change in the education system for health care professionals that enables and empowers clinicians to feel confident in communication. Miller et. al. make a powerful claim for the importance of teaching communication skills to residents while on the job. They write:

There needs to be a cultural shift surrounding the education of medical residents... communication must be treated with the same emphasis, precision, and importance as placing a central venous catheter.... We propose that high-stakes communications between physicians and patients... must be viewed as a medical procedure that can be taught, assessed, and quality controlled. Medical residents require training, observation, and feedback in specific communication skill sets with the goal of achieving mastery.⁹²

⁹² David C. Miller et al., “Improving Resident Communication in the Intensive Care Unit. The Proceduralization of Physician Communication with Patients and Their Surrogates,” *Annals of the American Thoracic Society* 13, no. 9 (September 2016): pp. 1624-1628, <https://doi.org/10.1513/annalsats.201601-029ps>, p.1624

The authors argue that communication skills should be taught and assessed just as any other skill that residents learn. If medical schools are not capable of educating doctors-to-be on how to effectively communicate with patients and families, it should be required during residency to be observed as part of the physician's ability to finish their program.

If communication was viewed by professionals as a medical procedure, there would be a vastly different approach to patient care that would ultimately generate greater health outcomes and perception of care. Another possibility for educating physicians is to incorporate these standards into requirements surrounding maintenance of licensure. All providers are mandated to obtain education hours that ensures their license to practice is upheld. Medical boards and other such authorities can establish policies that requires communication styles, especially those regarding end-of-life and the dying process, be learned in this manner.

A second factor affecting physician communication is institutional settings that make it difficult for providers to have in-depth, meaningful conversations. As mentioned in Chapter One, hospital protocols and patient caseloads inhibit physician time and energy to give adequate attention to each individual. Emanuel continues in his article, "For well-trained clinicians with good intentions, the delivery of the best care requires institutional settings that facilitate the provision of good care to dying patients and proper reimbursement arrangements."⁹³ Hospitals and insurance companies continue to run as businesses that emphasizes aggressive treatment, productivity, and quantifiable results. This diminishes the importance of quality communication for providers and discourages physicians to incorporate the necessary techniques.

Hospital management need to determine whether or not their institution complies with Patient Centered Care initiatives. Are changes that are being made superficial, structural designs

⁹³ Ezekiel J Emanuel and Linda L Emanuel, "The Promise of a Good Death," p.121-129

that give an illusion to be more patient focused? Or, are they working to empower individuals to become involved in the plan of care and make sure their personal values are prioritized? Institutions should also analyze HCAHP ratings more closely to determine if their standards align with patient values and satisfaction results. Recall that very few hospitals received top ratings for a majority of respondents. This illustrates an area that needs to be explored further and may possibly affect medical culture in the future.

It is most important, however, that clinicians must not wait for culture and society to change. Change must come from within the profession. Health care professionals must challenge themselves to be better and to do better for the individual. Clinicians need to be more cognizant of the harm that can be inflicted through their interactions with clients. I do not think the doctor who left the patient anxious over the discharge process was aware of just how much he/she negatively affected the individual. I also do not think the physician verbally said, “We have other patients to take care of” to the patient who disliked her attending doctor. Despite good intentions, these were the realities for those two patients. This is how they felt and perceived their care after interacting with doctors. Physicians must push themselves and their colleagues to be more present in seemingly routine interactions and be more attune to what the patient understands and perceives. Furthermore, physicians should place themselves in the patient’s position and ask themselves what they would want and expect from a doctor if they were the ones feeling sick and vulnerable. Would they want to be comforted? Would they want their own values and preservation of dignity to lead the plan of care?

A physicians’ job is to provide care within their scope of practice. Improvement can be made if clinicians become more aware of their own capabilities and be less reluctant to consult other colleagues. When a patient’s clinical status no longer is in accordance with their expertise,

physicians must be willing to coordinate care with other specialties, especially Palliative Care. Providers must also accept that death is a natural, inevitable reality that cannot always be avoided. The reluctance of the medical profession to accept death and provide comfort in end-of-life inflicts harm on the individual and generates unnecessary patient suffering.

Moreover, recent studies have found that Palliative Care actually reduces hospital stay and cuts costs for institutions. *U.S. News and World Report* published an article in 2018 that stated the following:

A meta-analysis published... in the journal *JAMA Internal Medicine* examined 130,00 patients from six previously conducted studies on palliative care... The study, ‘Economics of Palliative Care for Hospitalized Adults With Serious Illness’, found when palliative care was added to a patient’s treatment, hospitals saved an average of \$3,237 per patient over the course of a hospital stay compared to patients who did not receive palliative care. Additionally, for cancer patients, hospitals saved an average of \$4,251 per stay.⁹⁴

This should especially be pertinent for all institutions aiming to lower costs in expenditure. Expanding palliative care capacities will reduce costs in acute care settings and significantly improve overall health and wellness for patients.

The study recommends palliative care consultations occur within three days of hospital admission.⁹⁵ Arguably, any patient admitted with uncontrolled pain or other symptoms and multiple co-morbidities should be seen by Palliative Care to discuss long-term management goals. Currently, this is not what I witness in my professional experience as Palliative Care is often delayed and looked down upon. Future development should expand palliative care programs and emphasize consultations as it has the potential to reduce suffering for patients while maintaining

⁹⁴ Alexa Lardier, “Study: Palliative Care Reduces Hospital Stay, Cost of Sickest Patients,” *U.S. News & World Report* (U.S. News & World Report, April 30, 2018), <https://www.us-news.com/news/health-care-news/articles/2018-04-30/study-palliative-care-reduces-hospital-stay-cost-of-sickest-patients>)

⁹⁵ Alexa Lardier, (U.S. News & World Report, April 30, 2018).

a financial bottom line for institutions. Institution can create triggers that automatically prompt a Palliative Care consult. For example, during the admission interview the provider has with their client, if certain criteria are met the computer system will populate a recommendation for palliative care to see that individual.

Physicians also need to have a greater focus on true Patient-Centered Care and building doctor-patient relationships while steering away from strict algorithms and standardized plans of care. A truly skilled physician can take their knowledge and expertise obtained through training, and adapt it to work accordingly with each unique patient case. Physicians must focus on patient narrative and experience while understanding what illness means for the patient as an individual. Rita Charon challenges, “A scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering. Along with scientific ability, physicians need the ability to listen to the narratives of the patient, grab and honor their meanings, and be moved to act on the patient’s behalf”.⁹⁶ By understanding the illness from the patient’s perspective and developing a relationship that fosters trust and independence, providers will ultimately see greater health outcomes for their patients.

⁹⁶ Rita Charon, “Narrative Medicine”, p.1897

Conclusion

This paper is the culmination of my studies in Medical Humanities while working as a nurse on a medical/surgical unit of a hospital in New Jersey. My research questions and argument have been generated by the juxtaposition of what I have witnessed in the acute setting against what I learned in the graduate level classroom. I firmly believe that harm is inflicted on patients in today's hospital environment by health care professionals who continue to prioritize timely diagnostic testing and aggressive management above the individual's experience and innate human dignity. A plethora of information has been given to support my claim through peer-reviewed journal articles, published research, books, first-hand experiences, and patient narratives.

The art of medical practice requires providers to work towards developing therapeutic relationships with their clients that extend far beyond their biomedical needs. My work demonstrates that patients value compassionate, individualized care that empowers the unique person to make health care decisions which are in line with their emotional and spiritual values. Unfortunately, this is not the reality of doctor-patient interactions in the hospital environment today. Medicine is rooted in providing care for the individual's well-being, all providers and institutions must challenge themselves to practice true patient-centered care. It is their duty.

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