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Literature and Medicine

Companionship and Mortality: Bridging the Gap in Medical Practice

46-year-old patient admitted due to chest pain. Pneumonia detected. Conditions continue to worsen—needs further investigation. Biopsy ordered on lung. Malignant mass detected in the lungs—further testing results small-cell lung cancer. Inform patient of cancer. At this stage of a doctor's investigation, the delivery of the harsh mortality of this 46-year-old patient must be done with care. Besides the science of this cancer, a physician must learn the role of companionship and empathy in the appropriate use of language. Medical humanities can facilitate this discussion. Companionship and empathy are vital ways in revealing one's vulnerability and mortality. The medical humanities allow the exploration into one's own mortality by connecting literary expressions to scientific reasoning.

The Epic of Gilgamesh encompasses the concepts that *The Hippocrates Writings* and *Aristotle's Poetics* establish by chronicling medicine, developing ideas of immortality, and demonstrating the use of literature as a "mode of imitation" (Aristotle Section I Part I). Gilgamesh's search for immortality as a response to grief reveals striking similarities to the goals of medicine. As Gilgamesh starts his journey, he proclaims "I will make a lasting name for myself, I will stamp my fame on man's minds forever" (Mitchell 95). Gilgamesh, the typical hero character, strives not only to be the best, strongest, and most accomplished—he wants all to know that he is capable of defeating the unbeatable returning to his city as he "carried Humbaba's head" (Mitchell 129). This seemingly impossible goal of traveling to the "Cedar Forest where the fierce monster Humbaba lives" as well as defeating him, and later in the text, a search for immortality "to overcome death" parallels medicine's goal of defeating inevitable death and prolonging life (Mitchell 94,161). Medicine, like Gilgamesh, battles monsters of illness that may seem impossible, yet medicine accomplishes the impossible and its feats are made to be known. This similarity between Gilgamesh and Medicine is allowed to be created because human experiences such as illness can

be imitated through the text—in which Aristotle himself argued. The conceptualization of medicine being immortal is mentioned within *The Hippocratic Writings*, when *The Oath* establishes physician's goals to earn "good repute among all men for all of time" (*Hippocratic Writings* 67). *The Epic of Gilgamesh* develops the meaning of immortality more by Gilgamesh's literal search for it. When immortality is inevitably unreachable and Gilgamesh is told "you will never find the eternal life you seek…humans are born, they live, and they die" immortality changes (Mitchell 168). Instead, immortality is "a lasting name" or the legacy one can leave on the world that continues to live on (Mitchell 95). Doctors can perform healing practices that prolong the life of a human, maybe even prolong the process of dying itself—yet doctors cannot defy death completely--all humans will die inevitably. Medicine, however, is immortal itself. Healing and medicine have always played an important role in human's lives, even if it presents in different forms, and that story is imitated through Gilgamesh's character.

Gawande's observations and contributions provide real potential in developing end of life care with the understanding of what the end-of-life entails. By introducing different viewpoints of patients and their own stories, he is able to articulate a common theme of what many people wish to receive in their last days and evaluate the extent in which our current healthcare system understands these concerns. Gawande utilizes stories of the shortcomings of nursing homes to make the point that they fail to achieve individual's autonomies:

> The only way death is not meaningless is to see yourself as part of something greater: a family, a community, a society. If you don't mortality is only a horror. But if you do, it is not… As our time winds down, we all seek comfort in simple pleasures—companionship, everyday routines, the taste of good food, the warmth of sunlight on our faces. (Gawande 127)

Nursing homes fail to allow "comfort in simple pleasures", familiar "companionship" of one's families is replaced with strangers and "everyday routines" such as getting dressed is handed over to "staff [that] ends up dressing people like they're rag dolls" (Gawande 105, 127). While this situation is complex, Gawande provides the insight into what really matters to those nearing their end and provides examples at a smaller scale to fix the larger problem. Gawande achieves this by providing examples that have

improved patient's experience, such as providing residents of Chase Memorial Nursing Home with animals and children, a "real opportunity for them to grab on to something beyond mere existence" (Gawande 127). Besides providing examples of how to improve end of life care, Gawande simply pushes the importance of education in improving palliative care for individuals.

Companionship and vulnerability expose one's own fragile mortality in which the medical humanities are able to chronicle. In the classical literary text of *The Epic of Gilgamesh*, Gilgamesh and Enkidu's friendship explicitly reveal just that: "Enkidu, my brother, whom I loved so dearly, who accompanied me through every danger—the fate of mankind has overwhelmed him" (Gilgamesh 174). Gilgamesh loses his closest friend in which he references as "my brother", and "[roams] the wilderness in his [grief]" (Gilgamesh 174). The loss of someone present in one's everyday life, brings the death of oneself much closer to reality. Gilgamesh becomes hyperaware of his own mortality, when he cries out "My beloved friend has turned into clay—my beloved Enkidu has turned into clay. And won't I too lie down in the dirt like him, and never arise again" (Gilgamesh 175). In *Being Mortal,* Gawande further develops this concept through the realization his father will die:

> The scan revealed a tumor growing inside his spinal cord. That was the moment when we stepped through the looking glass. Nothing about my father's life and expectations for it would remain the same. Our family was embarking on its own confrontation with the reality of mortality. (Gawande 194)

Gawande's companionship, different from Enkidu's, is a father and son relationship. As parent's become older, or become sick, it is a harsh reality to imagine life without your parent in it. Gawande, and his family, are forced to look death directly in the face and begin their own "conformation with the reality of mortality" (Gawande 194). In contrast to Enkidu's quick death, Gawande experiences his father's decline in health as his father "lost more weight. He was so weak his speech sometimes slurred…He's become old before my eyes" (Gawande 222). In this situation, mortality is seen even before death, taking life away from Gawande's father. The illness or death of a loved one, which is explored in both of these texts and medical humanities as a whole, illustrates these vulnerabilities in normal life such as needing "help

standing from sitting" (Gawande 222). This can be not only hard for the companion, like we see in Gilgamesh's intense grief, but it can also make friends fearful of the sick loved one. Bailey in a patient's telling narrative, highlights the uncomfortable confrontations with a friend's illnesses:

> But halfway through a visit, they would notice how little I moved, the stillness of my body and an odd quietness would come over them. They would worry about wearing me out, but I could also see that I was a reminder of all they feared: chance, uncertainty, loss, and the sharp edge of mortality. Those of us with illnesses are the holders of the silent fears of those with good health. (Bailey 40)

The closeness of death reminded Bailey's friends "of all they feared: chance, uncertainty, loss, and the sharp edge of mortality" (Bailey 40). "The sharp edge of mortality" shines when the mortality hits close to home. People die every day; death is inevitable, and most people realize this. However, when it's your best friend like Enkidu, your father like Gawande's, or simply your companion like Bailey's—the fragility of mortality is exposed more emotionally. Medical humanities represent these realities through the exposure in different mediums and situation.

Companionship is vital in providing healing and acceptance of impending mortality. End of life care is often a delicate balance between allowing one to live their days out the way they wish, while also making sure they receive the proper care and safety that concerns many families of elderly that too often falls short: "Medical professionals concentrate on repair of health, not sustenance of soul…For more than half a century now, we have treated the trials of sickness, aging, and mortality as medial concerns" (Gawande 128). With the concentration "on repair of health" and concerns of safety, many elderly populations are placed into nursing homes. In the nursing home settings, there is a removal from one's previous life and autonomy and can often lack companionship. Chase Memorial Nursing Home recognized this lack of connection between it's residences and purpose in life, and implemented a program that "included one hundred parakeets, four dogs, two cats, plus a colony of rabbits and a flock of lying hens" in combination with "on-site child care for the staff and a new after-school program" that promoted interactions between the elderly and children (Gawande 123). By providing so much more

interactions with different living things, provided residents "with reasons to live, period" (Gawande 125). This coincided with a "theory about what living things provide. In a place of boredom, they offer spontaneity. In a place of loneliness, they offer companionship. In a place of helplessness, they offer a chance to take care of another being" (Gawande 125). In this case, these living things provided a sense of life, and a "chance to take care of another being" while also offering companionship (Gawande 125). In a broader sense, this companionship provided a way of healing. Mortality is not just about the act of dying. It is instead an awareness that one will die, morality shows that one's life is not limitless, yet we can find solace in this vulnerability and fear that death can bring through our own companionships.

The positive impact of companionship addresses the vulnerability's that come with the impending understanding of one's own mortality. These companions do not have to be human. Instead, Tova Bailey finds companionship in a snail, "whereas the energy of [her] human visitors wore [her] out, the snail inspired me" (Bailey 41). While Bailey may be isolated from the rest of the world due to her disease, she is able to find companionship and connection to the rest of the world and celestial world through the companionship with this creature:

> My bed was an island within the desolate sea of my room. Yet I knew that there were other people homebound from illness or injury, scattered here and there throughout rural towns and cities around the world. And as I lay there, I felt a connection to all of them. We, too, were a colony of hermits. (Bailey 84)

As Bailey is isolated in her bed, "an island within the desolate sea of her room", she finds comfort in the "connection" to all the other people similar to here (Bailey 84). This connection and solace are brought about by her own connection to her snail: "The original snail had been the best of companions; it never asked me questions I couldn't answer, nor did it have expectations I couldn't fulfill...leading me through a dark time into a world beyond that of my own species. The snail had been a true mentor; its tiny existence had sustained me (Bailey 160). Companionship to Bailey meant that she did not have to fulfill "expectations" or be "asked questions [she] couldn't answer" (Bailey 160). Instead of answering to those who did not understand her condition, this companionship she finds solace in is one with common

experience, with “a colony of hermits” (Bailey 84). Companionship for Bailey provided peace in “a dark time” and “sustained” her through her illness (Bailey 160). Companionship, for Bailey and many others, depends on providing the appropriate level of comfort and understanding throughout a period of time such as an illness where a patient can be exhausted by their own vulnerabilities.

Physicians play a vital role in providing the proper companionship in order to correctly communicate with one’s patient, and medical literature reinforces the value of this specific communication. A physician’s role in a patient’s life is to not only diagnose and treat a patient’s illness, but to communicate directly to the patient information on how to proceed with a care plan. In *The Immortal Life of Henrietta Lacks,* we see the effects when doctors fail to communicate scientific understanding with Henrietta Lacks and her family:

> “Now I don’t know for sure if a spirit got Henrietta or a doctor did it,” Cootie said, “but I do know that her cancer wasn’t no regular cancer, cause cancer don’t keep growing after a person die.” (Skloot 82)

Since Hopkins doctors failed to communicate the cause of Henrietta Lack’s cancer, her family went on unsure what cancer was, or if this personally effected themselves. For instance, Lacks’s daughter Deborah “heard many times she’d inherited some of the DNA inside those cells from her mother. She didn’t want to hear that her’s mother cancer was in that DNA too.” (Skloot 265). The lack of communication of inheritance, the fact that “children don’t inherit those kinds of changes in DNA from their parents”, was never communicated to Henrietta herself or her daughter. This lack of communication caused misinformation between Lacks’s family that never knew “if a spirit got Henrietta or a doctor” caused her cells to continue to live, or if they themselves were at risk for diseases (Skloot 82). Communication as the basis of understanding is vital in preventing lasting effects as in the case of Henrietta Lacks.

Communication in the form of companionship of a physician can greatly improve patient care and facilitating these discussions can stem from the abilities of medical humanities. Statistically, end of life discussions between families and patients as well as their palliative care doctors are actually able to increase life expectancies:

> The result: those who saw a palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives—*and they lived 25 percent longer.* In other words, our decision making in medicine has so failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality. If end-of-life discussions were an experimental drug, the FDA would approve it. (Gawande 177)

On paper, these patients that lived "25 percent longer" are just numbers, and until you place a face or experience to these numbers it may be hard to implement these practices in order to improve patient care. In other words, we need to be able to see these discussions and learn how to facilitate them as physicians, "Physicians who lack a passion for language or who fail to see beauty will be at a loss to translate these wonders in the most meaningful terms for their lay patients and into the larger society around us" (Campo, "Why Should Medical Students Be Writing Poems"). Medical humanities can serve to bridge the gap between this scientific knowledge and actual human interactions. Gawande demonstrates what productive patient to physician conversations look like, by highlighting the importance in companionship and personality as a central quality to a physician:

> Patients tend to be optimists, even if that makes them prefer doctors who are more likely to be wrong. Only time will tell which surgeon would be right. Nonetheless, Benzel has made an effort to understand what my father cared about most, and to my father that counted for a lot. Even before the visit was halfway over, he decided Benzel would be the one he would trust. (Gawande 199)

Gawande emphasizes physicians who "made an effort to understand what my father cared about most" would be the one who the patient, Gawande's father, "would trust" (Gawande 199). Physicians who make an effort to get to know the patient and effectively communicate serve in some way as a companion instead of a cold, distant medical provider, and bridge the gap between diagnoses and language.

The acceptance of anecdotes plays a role in the role of companionship in understanding mortality and subsequent treatments. Patients are the ones who are suffering from some ailment. While physicians

undergo years of training and education of what may be occurring within the patient, in a treatment setting, patients have to communicate their own pain levels to their healthcare provider. As a healthcare provider myself, working primarily with patients undergoing withdraw or severely confused dementia patients, communication may not always be trustworthy or clear. However, "if we can recognize a breakdown in our communication with a suffering patient, we can begin the crucial process of repair" or simply recognize there is a change in a person's mental status. At a late-night shift at the hospital, my patient was severely confused and unable to tell us where he was located. Lost in communication from dayshift to night-shift, was the fact that our confused patient kept asking for alcohol. In this case, one may just glaze over and see an alcoholic, similar to an addict "exaggerating her pain to obtain more narcotics" (Campo "Anecdotal Evidence"). Yet, through this patient's communication, doctors failed to miss that this patient was a severe alcoholic, drinking a bottle of whiskey every day. As alcohol withdraw is extremely serious and can be fatal if a patient's body responds to the withdraw with a stroke, the patient who was talking to me about fishing, noted in a disconnected rambling way, went silent. Minutes later, the patient was tachycardic, and his oxygen levels falling below 90 for a significant amount of time. An hour later, he was transported to the ICU. If the patient was properly listened to, and "ground rules of empathetic mutual trust which exchange of language" was established, this entire interaction mostly likely would have been avoided. These experiences are not unusual, and through simply listening to patients' word can save lives.

Literature chronicling patient narratives are vital in providing insight to these communicative experiences, that allows actual change to be initiated within the medical field. While the physician's experience is important in completely understanding their role in healthcare, a patient's narrative is arguably more significant in assuring the goal of medicine—healing—is provided. As companionship and empathy are vital in understanding one's own mortality, insight from Manguso reveals too much empathy can be counterintuitive in medicine:

> I refused to let him in my hospital room again, and my parents and I re-enrolled in our health plan with a different doctor. I felt no antipathy, just a certainty that his pity would accrue to me, and

> would grow in me like a sea of antibodies with which I was already invisibly killing myself, and I couldn't take in any additional poison. (Manguso 84)

Manguso presents an opinion that is not often heard within patient narratives—which is highlighted when she discusses her doctor's "pity [that] would accrue me" that would ultimately lead to her "invisibly killing" herself (84 Manguso). Manguso feels as a patient she is reduced to her illness, and the subsequent suffering which the primary care doctor "said [she] already endured something much worse than most people". In this communication between patient and physician, Manguso's identity is lost and is instead replaced with the physician's emotions based on *his* understanding of suffering. In another instance, miscommunication between Manguso's "neurologist seemed to believe that plasma replacement would make [her] disease go away" (Manguso 87). However, the inhabitant of her own body, she felt no effects from this course of treatment and did not improve her condition. In turn, "tired of being told by a twenty-one-year-old girl that he was wrong" that "neurologist recommended [her] to a doctor at another hospital" (Manguso 87). Again, we see the patient and physician relationship, without companionship and without communication that ends in Manguso being passed to "another doctor at another hospital" (Manguso 87). This exact instance is why a patient narrative's in text or in practice must be heard in order for physicians to be able to take a step away from the textbooks and actually listen to the patient. Without this, a doctor can fail to connect with the patient and create an overall respectful balance between their knowledge and the patient's understanding of their own body. But, with Manguso's ability to express this through texts, doctors are more readily available to understand how their words affect the relationship and emotions of their patients. Campo, a physician himself, advocates for this understanding as he argues "our patient's stories too, if only we could listen to them less critically and cynically might similarly inspire us to the more practically important discoveries of what truly ails them" (Campo, "Anecdotal Evidence"). The nuances of anecdotal evidence aside, patients are exactly the patients. They experience the pain and the misfortunes of diseases. The ability for physicians to communicate across this chasm of disconnection and understand what is really occurring in someone else's body, requires learning. This learning, while not about the renal system or the different between systolic pressure versus diastolic, is just as important

and informative. The patient's narrative through medical humanities allows for this learning and establishes medicine as a comprehensive field of language and science, not just the latter.

In order to provide care, physicians must know when to stop treatment, apply appropriate empathy, and the limitations of this mortality is explored in classical literature. In Gilgamesh's grief-stricken search for immortality, he is met by a tavern keeper that provides harsher advice:

> Shiduri said, "Gilgamesh, where are you roaming? / You will never find the enteral life/ that you seek. / When the gods created mankind, / they also created death, and they held back/ eternal life for themselves alone. / Humans are born, they live, then they die, / this is the order that the gods have decreed." (Gilgamesh 168)

This external reinforcement of Gilgamesh's mortality parallels that of a physician. Shiduri explains to Gilgamesh that he "will never find the enteral life" in which he seeks, the fatigue Gilgamesh puts him through in this search is not worth the outcome. Utnapishtim echo's the concerns of Shirduri by questioning Gilgamesh on why he has "worn [himself] out through ceaseless striving" where he has "filled [his] muscles with pain and anguish" (Gilgamesh 177). Gilgamesh pushes himself through this grief and journey that can symbolically represent the treatment of a disease, only to prolong this grief and pain to ultimately fail at reaching immortality. It is the job of physicians and external influences, such as Shirduri and Utnapishtim, to question the limits of their patient's physical and mental body.

Gawande explores the limitations of medicine and recognition of mortality, as well as the appropriate levels of empathy through his own experiences as a physician. It is hard to grapple with the death or illness of a young person, as in our society we often believe mortality is something that only comes to us in old age. Gawande's patient Sarah, is a strong representation of young patients with terminal illnesses that are in the healthcare system to fight their disease, and not to remain comfortable and pass away:

> "Sara did not seem discouraged by the discovery of a second cancer. She seemed determined. She'd read about the good outcomes from thyroid cancer treatment. So she was geared up, eager to discuss when to operate. And I found myself swept along with her optimism. Suppose I was

> wrong, I wondered, and she proved to be that miracle patient who survived metastatic lung cancer?" (Gawande 168).

Through Gawande's internal monologue, he reveals how we struggle between "optimism" and the fact that as a physician he needs to explain the diagnosis while also "confronting the mortality of her lung cancer" (Gawande 168). My father, a young lung-cancer patient just like Sara, most likely sat through the same conversation with his own doctor. His doctors chose the same path as Gawande, and attempted to fight his small-cell, non-operatable metastatic lung cancer through "whole brain radiation to try to reduce the metastases" as well as "different experimental drug" through different clinical trials (Gawande 170). And just like Sara, as each option tried and failed, the acceptance of mortality was postponed. Should my father's doctors put him through two separate spinal surgeries in the last two weeks of his life, in order to attempt to remove the cancer knowing full well he was going to in fact die? Should younger cancer patients be designated as fighters, and "to die with chemo in our veins or a tube in our throats" or in my own father's case, radiation in his brain, chemo in his veins, and staples in his spine? Scientific studies will tell us that patients who "have discussions [of end-of-life care are] far less likely to undergo cardiopulmonary resuscitation or be put on a ventilator or end up in an intensive care unit. Most of them enrolled in hospice. They suffered less, were physically more capable, and were better able, for a longer period, to interact with others" (Gawande 177). This is where the disconnect from science and actual experiences of patients and doctors through literary humanities come in. Simply, most people, like my father and like Sara, do not want to accept failure in the face of the enemy. "Death is the ultimate enemy" (Gwande 171). So, while studies may show patients "suffered less" when they were placed on hospice, I know the acceptance of death for my father would have caused more suffering over time if he had been placed in hospice for longer than a week. So, should we listen to the science or should we listen to the experiences? There is no right answer, it is in human nature to not recognize "we may be shortening or worsening the time we have left" with our loved ones until doctors "tell us there is nothing more they can do" (Gawande 173). However, medical literature is able to chronicle these very experiences, to question if it is right to go against medical facts of survivorship curves, and to recognize that a physician's

"optimism" can overlook the this and instead see a patient with a young family, with two young daughters, and incorrectly see a father would survive an un-survivable cancer.

Mortality, while inevitable as it is often a concept most people attempt to ignore in their lives out of the fear of the unknown. Gilgamesh is a perfect example of someone who is undeniably attempting to escape the cycle of life, and he becomes more fearful as the one's around him, Endiku face mortality themselves. This companionship not only makes one more aware of their ultimate fate in life, but it plays an important role in healthcare treatment as well. Physicians must navigate how to care for a patient in the proper balance of empathy and distance in order to respect and understand patient's experiences. We are able to understand these experiences through patient narratives and learn from literature what makes life worth living. Through each of these lessons, physicians can become better physicians that are able to understand and communicate difficult topics. As an individual that arguably have been exposed to the reality of mortality at a younger age with the death of my father as a teenager, the exploration of this topic is comforting. Listening to other stories that share the same raw emotions and reactions to death that I may have experienced in my grief validated these emotions, but it is the awareness and research that is applied to these stories that serve a larger purpose. In a larger sense, these texts exemplify how to treat patients such as my father, or my grandfather, or any others loved one with these concepts in mind. All of these understandings and education encompass what medicine's role is in mortality and show a larger healing that encompasses those surrounding the patient as well as the patient themselves. Medical humanities bridge the disconnect of medical science and the act of healing through this education and understanding. Perhaps, language is just as important to medicine as the devices and science behind it.

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