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Thinking About Narrative Medicine:
UMMS Medical Humanities Lab and the Rise of Narrative in Medical Education

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Table of Contents

Abstract

Narrative medicine (NM) emerged as a reaction to the shortcomings of the biomedical model. There is no accepted definition of NM but the central tenet is that narrative is inherently intertwined in human experience of illness. Medical humanities literature can imply a canonical definition of narrative. Investigating perceptions of narrative within the University of Massachusetts Medical School (UMMS) revealed advantages to a more generous definition of narrative. Through rhetorical analysis of medical humanities literature, informal interviews with experts and students, and direct participation in a UMMS Writing Elective, this study provides insight into consistencies and misalignments between NM theorized in the literature and NM in practice.

Introduction

Throughout this past year working as an EMT, I had yet to write my own narrative until I was deep into this project. I have encountered and treated patients with diverse cultures, ethnicities, occupations, and unique stories as to why they have called for an ambulance. Limited time with patients led me to fill in the overwhelming number of checkboxes and lists with hurried efficiency. On the last tab of my electronic patient care report, I always clicked the button labeled "auto-generate" that popped a written narrative on to the screen, awkwardly phrased and containing the bare minimum information to appease the insurance company. It was not because I was lazy or against writing my own narrative; this was how I was trained, and I had never considered not hitting "auto-generate."

This study addresses the importance of the stories that go unnoticed when we click "auto-generate" and take the humanities out of medicine. Narrative medicine has sought to equip physicians to treat people, not only disease, through reintegrating the patient voice and emphasizing listening, reflection, and compassion. The theory of narrative medicine suggests that developing an understanding of narratives can improve doctor-patient communication and lead to better patient care. Medicine has a history of prioritizing the biology over the biography. The term *narrative* has become a buzz word in parts of the medical community but there is little consensus on what comprises a narrative as it relates to narrative medicine.

I sought to understand the perception of narrative in the medical humanities literature and how theory is implemented in practice, specifically at UMass Medical School in Worcester, MA. Chapter 1 of this study explores historical movements that have led to the emergence of narrative medicine. I discuss the biomedicalization of medical education introduced by the Flexner Report, how that morphed into an exclusive focus on scientific advancement, and the development of narrative medicine as a response to the call to rehumanize medicine. I want to point out that this study is not meant to dismiss the history of the biomedical movement. Tremendous advancements arose from Flexnerian ideals that have changed the course of medicine for the better. Nevertheless, the evidence of the research shows that the dominance of this model foregoes other opportunities to improve care.

Chapter 2 a discussion of narrative medicine in its contemporary form. Here I will dive into the question to how different experts define narrative, from philosopher Paul Ricoeur to physician and literary scholar Rita Charon. I will examine how narrative relates to self-

experience, specifically of illness, as well as the nature of narrative medicine as described by the body of medical humanities literature. Finally, I will highlight a more cautionary approach to narrative medicine that stands in stark contrast to much of the literature.

In Chapter 3, UMass Medical School serves as a case study of narrative medicine in practice. In my fieldwork, I worked with Dr. Hugh Silk and Regina Raboin, two of the founders of the UMMS Medical Humanities Lab, as well as several medical students. I was also able to interview Brenton Faber, a paramedic and professor of Writing at WPI. Interviews were set up via email and conducted over Zoom or email after receiving IRB approval. I was graciously allowed to observe and participate in Dr. David Hatem's Writing Elective at UMMS, during which I listened to students' written pieces and engaged in reflective conversation. Throughout this fieldwork, I searched for recurrent themes and challenges to narrative medicine which will be discussed in this section.

Chapter 1: Historical Background

This chapter will explore the historical context that led to the emergence of narrative medicine as we see it in the medical community today. Narrative medicine was developed as a response to inadequacies of previous movements in medicine, therefore it is important to understand how narrative medicine has excelled and where efforts have fallen short. Finally, I do not seek to give a comprehensive history, but one that is meant to selectively examine one possible evolutionary thread.

1.1 The Flexner Report

The evolution of narrative medicine has led to a nuanced approach to healthcare for physicians and students. The movement emerged from multidisciplinary work between medicine, the humanities and arts, and cultural study as a response to Abraham Flexner's 1910 report on Medical Education. Flexner (Lewis & Edu, 2015). Flexner was a teacher in Louisville, Kentucky before earning a master's degree in philosophy from Harvard University. He specialized in education philosophy, specifically the theory of learning through practice and action rather than rote memorization. At the start of the twentieth century, a several well-respected scientists and philosophers coalesced to form a group of "shared thoughts and imagination" which is later known as the Hopkins Circle (Duffy, 2011). Flexner, who had attended Johns Hopkins

University, was an influential member of the Hopkins Circle, leading the efforts to reform medical education. After attaining his MPhil, Flexner traveled to schools all over Europe, particularly in Germany. In 1908, Flexner published his first book, *The American College*, a critique of American education. Flexner's work garnered the attention of Henry Pritchett, head of the Carnegie Foundation, a major philanthropic organization that sought to support the improvement of the American healthcare system at the time. The Carnegie Foundation asked Flexner to survey and suggest improvements to American medical schools for this purpose.

As a teacher and philosopher, Flexner had never attended medical school, nor did he have any medical background. There were several reasons why the Carnegie Foundation chose a non-physician to address the medical education issue. First, the Foundation believed that the way to improve the healthcare system was to fix the education system, a problem requiring an educator, not a doctor. Second, the Foundation predicted resentful responses to the changes that would have to be made in medical schools. Flexner, as a non-physician, could be partially forgiven for overlooking the importance of the doctor-patient relationship (Duffy, 2011).

A strong advocate of the German medical education system, Flexner selected Theodore Billroth's book *Medical Education in the German Universities* as the foundation of his project. German style was firmly based in medicine as an exclusively a scientific discipline with emphasis on objectivity and biomedical advancement. The ideal physician was one who progressed medicinal science through research. Flexner defined the goal of medicine exclusively as the "attempt to fight the battle against disease" and his proposed education model focused solely on the biological sciences. Johns Hopkins was one of the few American medical schools that had already embodied these German ideals and became the gold standard for all medical schools (French, 2020).

Flexner visited and evaluated medical schools across the United States, classifying them into one of three groups. The criteria for classification included admission standards, education by physician scientists, and physical facilities, specifically adequate laboratories. The first tier of schools could compare with Hopkins, the second tier schools were considered below standard but could be remedied with financial aid, and the third tier were "of such poor quality that closure was indicated" (Duffy, 2011). Every medical school now had to be licensed by the state which in turn gave licensing power to the American Medical Association (AMA). One-third of

American medical schools, particularly those that admitted blacks and women or that did not "specialize in orthodox, 'allopathic' medicine," were closed following the release of Flexner's report (French, 2020). The stage was set for medical schools to join the capitalist market as medical schools without funding for high-tech laboratories and investment in rare, exciting diseases were shut down. This allowed the medical schools with the most funding to grow even farther and tuition to become more expensive, perpetuating education inequalities that restrict higher education to the wealthier classes (Trott & Jeremy, 2017). By 1922, the number of American medical schools had been cut in half and, if Flexner's recommendations were followed exactly, twenty states would not have a medical school at all. This one-dimensional approach to health and disease determined medical school curriculum, admission requirements, and even the focus of pre-medical students (Duffy, 2011).

Financial contributions from the Rockefeller and Carnegie Foundations were a key reason The Flexner Report succeeded in changing the American medical education system. The lives of physicians in academic medicine were also drastically changed by the influx of philanthropic gifts. Professors in medicine were no longer required to practice in a clinical setting, instead encouraged to focus on research and teaching. This led to a chasm forming between medical educators and the clinical world they were supposed to be instructing students about. Implementation of what became known as the "full-time system" narrowed physicians' focus and "removed them from the realities and messy details of their patients' lives" according to critics such as William Osler and Harvey Cushing (Duffy, 2011). The voices of critics were rare however, and often overwhelmed by the sheer river of money flowing into the remodeled medical training.

The amazing discoveries and advancements made by the medical community in the past century make it impossible to deny the positive impacts the Flexner Report has had on society. That should not shield Flexnerian Medicine from criticism and change. Flexner and the Hopkins Circle set medicine on a track to blindly pursue science, research, and education in the biomedical areas while ignoring the humanistic aspects of the field. Bioethicists point out that "the profession appears to be losing its soul at the same time its body is clothed in a luminous garment of scientific knowledge" (Duffy, 2011). Looking back at medical care in the past century shows that trust and respect have dramatically declined. Patients were pieces of the

education system, tools for the academic purposes of medical professors. Flexner and the Hopkins Circle failed to acknowledge patient beneficence and the role of physicians as healers. Their philosophy can be traced to the major tragedies of medicine's history including the Tuskegee experiments and the disaster of the Henrietta Lacks tissue culture. All are examples of science being prioritized over the well-being of the patient, stemming from the Flexnerian paradigm implemented in American medical schools.

The late 1900s saw surges in technology use, medications, and hospital expenses that raised healthcare costs and limited accessibility to the public. Corporations became increasingly involved in privatized medicine and direct-to-consumer advertising of pharmaceuticals and medical devices. The American healthcare system developed incongruently while being pulled in different directions because the nation has never decided whether "healthcare is a right, a product to be bought and sold, or an essential government service" (Frank & Mayberry, 2017). An emphasis on scientific advancement and research led to overspecialization, ignorance of sociocultural or personal values, poor communication, inequalities, high potential economic gain, and little emphasis on preventative medicine. These are still relevant problems today indicating that Flexnerian medicine is deeply rooted in the healthcare system and American physicians. I want to emphasize that I am not dismissing the benefits of this model but showing that it needs improvement.

1.2 Engel's Biopsychosocial Model

By the 1970s, a novel approach to medicine was forming, grounded in George Engel's biopsychosocial model. Engel opposed the narrow perspective of medicine shaped by Flexner and proposed the biopsychosocial model as an attempt to rehumanize medicine. This framework sought to expand the goals of medicine to "fighting disease and reducing human suffering" (Borell-Carrió et al., 2004). Compared to Flexner's biomedical model, Engel was proposing a more holistic perspective focused on understanding and responding to patient suffering. The biopsychosocial model itself was centered on the idea that there is circular and structural causality in a disease process. There is a complex web of independent and inter-dependent factors contributing to illness that are biological, psychological, and social in nature. New emphasis on the psychological and social aspects of illness shifted power to the doctor-patient relationship because an illness could no longer be reduced to solely biological, tangible

phenomena. The biopsychosocial model also called for the expansion of a physician's skillset to recognize and treat the psychosocial aspects of disease. A physician became likened to a musical instrument that required constant tuning and calibration to best perform (Borell-Carrió et al., 2004).

The biopsychosocial model can be understood two-fold. There is a philosophical aspect that seeks to understand how suffering, illness, and disease are affected by numerous factors and at various levels whether it be molecular, societal, or psychological. The framework can also be used as a practical guide to understand a patient's subjective experience. The idea that a patient's illness was more than objective and biological was revolutionary in medicine. Separation of body and mind, as Flexnerian medicine stressed, was rejected by Engler. Instead, the mind and body were in a mutual, dynamic interplay (Borell-Carrió et al., 2004). A patient's own attitude and knowledge of their illness, revealed through doctor-patient dialogue, became a key piece in diagnosis, outcomes, and care.

1.3 Medical Phenomenology

Around the same time as the biopsychosocial model was advancing, another movement was forming in opposition to Flexnerian medicine. Phenomenology was first introduced as a branch of philosophy by German philosopher Edmund Husserl in the early twentieth century. Husserl attempted to find a scientific method to study the phenomena of experiences, meaning the "world of apparent, visible, and perceptible things" (Carel & Carel, 2010). Rather than rely on presuppositions about the world, phenomenology focused on one's consciousness and perception of experiences as they are lived and the meaning of those experiences. It meant recognizing a person's subjective perception as their reality as opposed to one universal reality shared by everyone.

Phenomenology found applications in medicine as scholars and practitioners rebelled against the objectivism of Flexnerian medicine. Like the biopsychosocial model's recognition of the subjective patient experience, medical phenomenology acknowledged the importance of perception in illness. There is a distinction between the objective body, a material thing, and the body as lived and experienced by a person. According to medical phenomenology, these two exist in harmony when a person is healthy, but illness disrupts that alignment. This is because illness changes the way the body performs, reacts, and experiences. Illness is a transformative

experience that causes not only physical sickness, but social difficulties, challenges to identity, frustration of intention, altered sense of space or time, alienation, and disruption of daily life (Carel & Carel, 2010). In contrast to Flexner's attention to the physical body alone, phenomenology acknowledges that a patient experiences illness in all aspects of life.

The goal of phenomenology in medicine was to bring multiple perspectives into the doctor-patient relationship. The physician has their objective evaluation that contributes to, but is not equal to, the patient's own experience. This allows the construction of a collective understanding of a patient's illness, increasing trust and compliance, as well as helping develop meaningful and impactful interventions. Phenomenological methods have been applied in conditions like phantom limb or anorexia nervosa, in which the object body and a person's subjective experience are misaligned (Carel & Carel, 2010).

1.4 Healing vs. Curing

In his 2001 article, Edmund Pellegrino, an esteemed bioethicist at Georgetown, defined the goals of medicine slightly different (Pellegrino, 2001). Pellegrino understood the responsibilities of a physician to be two-fold. A physician must promote the physical well-being of the patient, but also the well-being of the whole person. This includes respect for personal values and self-determination. In his description, Pellegrino also uses the word "healing," suggesting a compassionate and inclusive approach, rather than "curing," which focuses purely on treating disease. In psychology, healing is defined as "a process in the service of the evolution of the whole person towards ever greater and more complex wholeness" (Egnew, 2005). Pellegrino was one of the first to introduce the holistic role of a physician as a shift away from the Flexnerian role as a "curer of disease" (Pellegrino, 2001).

Healing considers a patient's experience of being sick, including the social, economic, and cultural factors. The healing process, while not fully agreed upon among experts, typically includes several common elements: 1) active engagement of the patient, 2) multidimensional in the sense that social, cultural, and psychological factors are considered, 3) creativity and meaning making, 4) restoration of balance between mind and body, and 5) neither the healed nor the healer can be an individual or involve multiple people (Szawarska, 2015). The engagement aspect of healing is in stark contrast to the philosophy of the Flexner Report, in which science was being done to patients as subjects of study. Connotation implies that a disease is cured, and

an illness is healed. Illness implies a person's subjective experience to being sick, formed by their culture, social status, and circumstances. A disease is the organic, biological cause of illness. It is even questionable whether humans ever experience disease as the definition describes. Simply the state of knowing one is sick is a component of the personal, emotional, and cognitive experience. Western medicine is built on the concept that a physical disease causes the body to malfunction and curing this disease consequently heals the patient (Szawarska, 2015). This can be true and there are certainly scenarios where defining the dichotomy between curing and healing is unnecessary. There are many instances, however, like mental health or sexually transmitted diseases, where a physician must go beyond an organic curing process because the problem can involve social, cultural, and personal factors in addition to biological. This implies, as Pellegrino suggested, that the dichotomy between the two processes is worthy of deeper understanding.

1.5 Medical Neoliberalism

I previously described the growing role of the capitalist market in American healthcare during the late 1990s. Branching from free-market capitalism, focused exclusively on commercializing healthcare, was the rise of medical neoliberalism. As a derivation of the liberal political philosophy, neoliberalism promotes deregulation of the private sector, cutbacks in social goods, and privatization of services. Medical neoliberalism turned patients into consumers and healthcare into a thing to be purchased rather than an intrinsic right. The rhetoric of neoliberalism is that society benefits most from a booming healthcare industry.

As consumers, individual patients shoulder the responsibility for the healthcare decisions they do, or do not, make. Individuals are seen as having the obligation to utilize goods and services in healthcare. Any problems are consequently interpreted as problems of choice instead of problems with the healthcare system (Ratna, 2020). The increase in autonomy and accountability for patients and physicians has also led to an eruption of malpractice suits. Patients were more easily allowed to claim that their care was inadequate, just as one would return a defective purchase at a store. Consequently, a greater proportion of physicians' time and attention must be spent on documentation and preventing liability. This can deter physicians from spending more quality time per patient understanding their story and non-biological influences (Fisher, 2007).

Tremendous advancements in science and research, stemming from Flexner's paradigm, led to an increase in costs, customized products, biopharmaceutical industries, and private health insurance. These products were often aimed at specific problems that could be fixed by a "targeted magic bullet" (Fisher, 2007). Another hallmark of medical neoliberalism was the beginning of "direct-to-consumer" advertising. With this method, pharmaceutical companies advertised their products to the patients, shifting power away from the doctor-patient relationship. Patients were presented with a discourse that framed illness in reductionist terms, just as Flexner had done. For instance, psychiatric illnesses specifically have been portrayed in a way that overlooked psychosocial factors and context of a person's life. Instead, psychiatric illnesses have been viewed exclusively as an imbalance of chemicals in the brain, easily fixed by a single drug (Fisher, 2007). At the same time as the biopsychosocial model and phenomenology were attempting to rehumanize medicine, medical neoliberalism was pushing backwards towards Flexner's paradigm.

A historical perspective of medicine provides us with the context for the introduction of narrative medicine. The Flexner Report is viewed as a turning point in medical education that led to immense benefits in scientific advancement while falling short of developing complete, well-rounded physicians. The biopsychosocial model, medical phenomenology, and shifts toward "healing" as opposed to "curing" have sought to regain a humanistic foothold in the medical community. There is pressure on these movements to conform to commercialized, business side of medicine as healthcare costs are driven sky-high. In the following chapter, I will describe how narrative medicine evolved into its form.

Chapter 2: Contemporary Narrative Medicine

This chapter will examine the emergence of narrative medicine in the historical context of Chapter 1. I will look in depth at how narrative is defined in medical humanities literature and what is necessary to constitute a narrative. The nature of narrative requires an understanding of self-experience and meaning making, specifically in the context of illness. I will seek to understand how narrative medicine is put into practice in contrast to theoretical frameworks.

Finally, I will highlight warnings and criticisms of contemporary narrative medicine that lack a significant presence in medical humanities literature.

2.1 The Birth of Narrative Medicine

Narrative medicine is one domain of the medical humanities. There have been substantial systemic efforts to humanize the medical profession in recent years. Narrative medicine emerged from interdisciplinary work with medicine, the arts, cultural studies, and the humanities as a way to enhance, not displace, the biomedical model in use at the time (Chu et al., 2020). In her 2005 landmark paper, a physician and literary scholar from Columbia University named Rita Charon coined the term "narrative medicine" and became widely acknowledged as the founder of the field. Charon called for the development of "narrative competency" as a necessary skill for being able to listen and understand "alien perspectives, following the thread of a story of another, being curious of other people's motives and experiences, and tolerating the uncertainty of stories" (Lewis & Edu, 2015). Rather than narrative competency being an elective skill, Charon proposes that it be a crucial, main area of education. The biomedical model of Flexner's era has made such incredible technological advancements in medicine that society perceives medicine as primarily a science. Medicine, through its work with human beings and suffering, is also a humanistic practice. George Zaharias, a medical educator who has published extensively on narrative medicine, states that narrative medicine is the "means by which the art of medicine can be practiced" (Zaharias et al., 2018b).

2.2 Humans as meaning making beings

Flexner emphasized the natural science of the body, stating that "the human body belongs to the animal world" (Duffy, 2011). The effects reverberated throughout medicine as students were shaped to think objectively about healthcare. Medicine became a biological field in which the human body was an object of study for pathological processes. Flexnerian medicine failed to acknowledge the meaning making aspect of human beings. Disease is woven into an individual's web of meanings. Humans have complex relationships with their bodies that are molded by cultural, emotional, and historical ideals. Illness narratives can illustrate how the illness process relates to the context of the patient and their community, "interpreting people as they are interpreting themselves" rather than as data and findings in a detached scientific inquiry (Kaplan-Myrth, 2007).

The idea that narrative medicine can help physicians understand patients as meaning-making beings is based on the claim that storytelling is universal. Few experts seem to contradict the claim that humans are born into community narratives and continue to experience and understand their lives in a narrative, temporal form. It is widely agreed upon that language development lends itself to a narrative self-experience and that narratives are a "reservoir for meanings, expression, and comprehension" (Holloway, 2001). When people encounter adversity, they adjust their narratives to save their sense of identity. Disease, which threatens the symbiotic relations between the mind, body, and daily life, leads patients to reconstruct their narratives. It is at this point that physicians, if able to recognize and understand the unique facets of an illness narrative, can co-construct illness narratives with their patients, weaving together the knowledge and context of both the physician and patient (Holloway, 2001).

2.3 What is a narrative?

Literature reveals a lack of consensus regarding the definition of narrative medicine (NM). Different experts declare it a form of communication, a therapeutic method, or simply a frame of mind. Depending on the field, NM can take on many different forms of genres. Narratives can fall into categories such as illness narratives, physicians' stories, physician-patient encounters, or metanarratives (Kalitzkus & Matthiessen, 2009). Metanarratives consist of overarching themes that unite and give context and meaning to smaller stories. Religious worldviews such as Buddhism and Christianity are examples of metanarratives because these have the power to meaningfully explain other events. NM is difficult to articulate because it is a fluid, interdisciplinary field that cannot be neatly defined. Zaharias points to this as a problem because challenges arise in defining skill sets, implementing and evaluating programs, and establishing goals (Zaharias et al., 2018a).

Jerome Bruner asked, "Do we really need a book about anything as obvious as narrative?" (Bruner, 1991). As several experts, Bruner included, who have addressed this question agree that a narrative requires a better explanation because it is so ubiquitous. Without a deep dive into the literature, a comprehensive definition of narrative medicine is difficult to come by. A phrase so commonly promoted loses traction without a true understanding of its meaning. The medical community also likely lacks the training and time to give consideration to narrative medicine's growing body of literature. An understanding of narrative medicine needs to

be made more accessible to the medical community if proponents hope to permanently interweave narrativity into medical practice.

The dictionary definition of a narrative is an account of connected events occurring over time (Bruner, 1991). A narrative is often associated with a story, a sequence of clauses and sentences that guide a reader through events. In this section, however, I will demonstrate that narrative as it is used in narrative medicine is an umbrella term that encompasses more than the spoken or written word. There are current assumptions that people know what a narrative is, that narratives are essential to healing, but lack of guidance challenges attempts to put narrative medicine into practice.

One assumption occurs when narrative is identified as a story with the traditional components: beginning, middle, and end. The temporal aspect is accepted as a necessary and universal component of narrative. This does not necessarily imply a beginning, middle, and end. As a method of gathering meaningful events from the dull routine of daily life, a narrative necessitates the distinction between *kairos*, periods of significance, and *chronos*, the uninterrupted flow of time. A narrative differentiates *kairos* from *chronos* by connecting various events and communicating intention, desire, goals, and pain in a way that a chronology does not (Shimazono, n.d.).

In my own research, I found that even the advocates for a broad narrative definition often maintained a brief list of necessary components. For instance, Yosuke Shimazono's analysis of narrative in medical anthropology, shows the multiplicity of narratives, but still acknowledges three essential components: 1) an actor trying to achieve a goal, 2) eventfulness (synonymous for *kairos*), and 3) plot configuration (Shimazono, n.d.). The second and third components are contiguous with the concept of narratives in that there are interconnected, meaningful events. The first component, however, contradicts the inclusion of fragmented, incomplete narratives such as poems, photography, or music. Many forms of art that express connected, noteworthy events can be brief and broken, lacking a clear actor pursuing a goal. Instead, I argue that any forms of expression that convey meaning and connected events fall under the umbrella of narrative.

A second assumption is that individuals need narratives to restore their sense of self that has been skewed by the "biological disruption" of illness (Shimazono, n.d.). Gareth Williams, a medical sociologist, coined this process as "narrative reconstruction." This approach aims to repair and realign fractures between the body, self, and world by linking and interpreting them through narrative. Williams' philosophy is, however, predicated on the presumption that a person's life was aligned and coherent before illness. Paul Ricoeur contends that there are more complex forces at work that minimize the possibility of a person's life being unified prior to illness. To view the role of illness as an isolated event is an oversimplification of a person's life. Instead, Ricoeur uses the term "narrative incompleteness" to point out the inherent limits of narrative. The argument against narrative reconstruction is grounded in the idea that a narrative is incapable of fully grasping life in its entirety. Indeed, there is not a distinct beginning, middle, and end of our lives (Shimazono, n.d., Ricoeur, 1992). Moreover, not all aspects of experience are translatable or able to be clearly articulated to an audience. Narrative is an attempt at translation and expression that is always going to fall slightly short of the experience itself.

The dichotomy of narrative is that there is the desire to form a complete storyline while simultaneously trying to encapsulate the complex and intimate moments of experience. These two goals are at odds with each other. The natural tendency within the medical community to impose standardized structure tilts the scale towards the neat and tidy, yet lacking, approach to narrative. Paul Atkinson points out that narrative studies gravitate toward a "confessional discourse" with the expectation that patients or providers reveal their personal feelings and intimate experiences. Atkinson asks if we must "implicitly ask of every sick or disabled person that they produce for us floridly constructed and highly personalized accounts of their troubles? (Atkinson, 2009). He makes a critical point that other experts fail to acknowledge. Current attempts at narrative medicine resemble a trojan horse in that there is the appearance of a person-centered, empathetic approach but the underlying goal is an epistemological effort to gather data, categorize, and analyze. Narrative should not seek to recreate an individual's authentic experience; there are too many untranslatable aspects of human experience. Instead, it seems that we need to learn to be comfortable with ambiguity, with the acceptance that, despite empathic listening and attention to narratives, we still cannot fully understand the nuances and fragments of another's experience. Rather than searching for the answer to how someone "really thinks and

feels", narrative is a window into how experience is influenced by cultural and social structures, how individuals construct stories, and how this relates to experience (Atkinson, 1997).

Cheryl Mattingly, in her book *Narrative and the Cultural Construction of Illness and Healing*, brings up an interesting point that should be adopted into the narrative medicine movement. Mattingly challenges the traditional construction of narrative with "emergent narratives" that are acted, danced, embodied, and drawn rather than strictly written. These are often riddled with fractures and incongruities because we are "creating a transient plot" as we continuously interpret, reinterpret, and anticipate events (Shimazono, n.d., Mattingly, 2000). As I will examine later, Mattingly's ideas resonate in the humanistic efforts of UMMS. Narrative medicine is employed in a vast range of devices, many of which lack any established structure resembling a story as most people understand it. It appears the current understanding of narrative medicine, in which a narrative is approached as a unified whole with plot and structure, would not encompass these efforts. I hope to emphasize and expand on the words of critics in that a strict sense of narrativity severely limits the potential of narrative medicine. Expansion of scope and understanding could facilitate more diverse humanistic efforts and effects.

2.4 The Illness Narrative

Illness is inherently intertwined with the temporal nature of human experience and can therefore easily adopt a narrative framework (Shimazono, n.d., Ricoeur, 1984). We perceive events in temporal relation to each other, as part of the past, present, or future (Le Poidevin, n.d.). Similarly, illness has a temporal dimension in the timing of disease onset, symptoms duration, recovery time, and effect on daily life (Le et al., 2017b). William's idea of narrative reconstruction and narrative as a necessary component of healing is simplistic, but narrative, temporal experience, and illness are undoubtedly intimately connected. In the clinical setting, the story-telling voice of the patient often clashes with the medical voice of the physician. The "medical voice", by design, is depersonalized, passive, treats medical technology as the agent, and clearly distinguishes the subjective patient account with key words such as "states", "reports", or "denies" (Shimazono, n.d., Mattingly, 1998). Charon suggests "four divides" that contribute to the disconnect between doctors and patients in the clinical setting (Zaharias et al., 2018a). These are:

1. **Relation to mortality:** doctors have training and experience with death (doctors are regularly confronted with mortality) that gives them a difference perspective than patients.
2. **Context of illness:** Patients view illness in the context of their entire lives because it often affects multiple facets of their life. For doctors, illness is primarily biological.
3. **Belief about disease causality:** The medical knowledge of doctors typically exceeds that of patients and can result in different beliefs regarding the source of disease.
4. **Shame, blame, and fear:** Patients and doctors can feel embarrassment when dealing with the intimate aspects of illness. Patients can blame themselves, a situation, or the doctor for their illness. Doctors can blame patients for noncompliance while also fearing lawsuits.

Attending to these four divides, Charon insists, can lead to better patient care. Clinical exchanges that give attention to the story-telling voice of the patient and co-construct illness narratives are now seen as an important part of healing. Previously silenced by the biomedical surge, illness narratives are garnering considerable attention as more effort is given to understanding the context of illness and patient experience.

Classification of illness narratives is as speculative and undetermined as the definition of narrative medicine. Arthur Frank indicates three major types of illness narratives: 1) restitution narrative in which the patient restores their health, triumphing over disease; 2) chaos narrative in which there is no coherent sequence and life does not improve; and 3) quest narratives that paint that patient as the hero/heroine on a journey to find different ways of living with illness (Shimazono, n.d., Frank, 1984). Mike Bury describes a different categorization of narratives as stable, progressive, or regressive (Holloway, 2001). While there is value in narrative analysis, it seems like too much focus is placed on categorization and standardization. One concern is that the cultural contexts of narratives can be diminished to a set of stereotypical attributes memorized alongside anatomy and pathology. Once again, the scientific, didactic methods of knowing that is so familiar to doctors and medical students can unintentionally overtake the approach to illness narratives. A reductionist or pedagogical framework of illness narratives can ultimately lead to inadequate care. Preventing this necessitates an authentic approach that is attentive to the cultural, social, and structural contexts of illness and a mindset that is flexible and

comfortable with ambiguity. Illness narratives have the potential to highlight the context of disease in a patient's life, foster empathy, and stimulate reflection on bias and inequities (Le et al., 2017a).

2.5 Narrative Medicine in Practice

Narrative medicine was first implemented by Charon in the medical school curriculum at Columbia University in New York with the goal of developing "narrative competency." Charon's approach to narrative medicine emphasizes close reading, prompted writing, and dialogue. A narrative medicine workshop could include reading and discussing a short text, the syntax, tone, nuances, and implications. The group would then receive a brief writing prompt to integrate themes from the close reading discussion with personal experiences and perspectives. Group members would be allowed to share their writing and give feedback. Education in narrative medicine seeks to embody a broad range of perspectives, therefore it is most effective with a diverse group and leader who serves as more of a guide or facilitator than an instructor (Spencer, 2017). The reason for and process by which we respond to experiences, our thoughts and behaviors, is important to analyze. Through holding multiple viewpoints simaeultaneously, the practice of narrative medicine increases awareness of individual presumptions, stereotypes, and projections.

Zaharias, while indicating the power of narrative medicine, concludes that the scientific evidence indicating the benefits of narrative medicine is feeble. Absence of a clear definition additionally challenges researchers seeking to define required skill sets and outcomes (Zaharias et al., 2018a). Scarcity of empirical research is a conclusion shared by several experts in narrative medicine. Megan Milota, a lecturer in medical humanities at UMC Utrecht, conducted a narrative review of 36 articles with three research questions in mind: 1) Is there a model for NM in education? 2) Is there evidence that NM education has measurable outcomes? 3) What is the quality and nature of reported outcomes? Milota found a consistent, pedagogic approach involving a 3-step read-reflect-respond model as well as a measurable effect on students' attitudes, perceptions, or skills. The long-term impact of NM programs is still unclear, however. Without longitudinal studies, experts cannot conclude if NM interventions will have impacts on patients and patient care (Milota et al., 2019). A different review study of 31 articles by Wieżel et al. argued that no replicable model of NM exists in education (Wieżel et al., 2017). After my

field work in the reflective writing programs at UMass Medical School and my own textual research, I am inclined to acknowledge the common structure of NM in education as Milota does. Milota's review was conducted two years later than Wieżel et al.'s and, with the rise in NM awareness in recent years, could have captured the evolved and accurate approach to NM in education.

Milota recognizes four measurable outcomes for assessing NM interventions: physicians' "awareness of themselves, their ability to reflect meaningfully upon their emotions and actions, their relationships with their colleagues, and their interactions with patients" (Milota et al., 2019). Milota and Wieżel et al. agree on the potential of NM to enhance the first two outcomes, a conclusion supported by the majority of literature on NM. Both sources also acknowledge that, at this point, there is insufficient data showing NM interventions ultimately lead to more effective physicians and a improved patient care – the latter two outcomes. Self-awareness and the ability to reflect meaningfully could be considered short-term outcomes in which individuals are able to quickly recognize the change in themselves. The latter two outcomes are inherently dependent on the former two outcomes, and involve other people, therefore any change could be developing more slowly or be harder to recognize.

Since its introduction in the early 2000s, the field of NM has grown. We have seen the emergence of undergraduate majors, masters degrees, and certification programs in medical humanities. Medical schools are accepting a greater percentage of applicants who are humanities majors as well (Charon et al., 2020). Charon's own work indicates that NM has indeed been proven to improve self-awareness, knowledge of patient situations, affiliation with peers and patients, satisfaction with work, and sense of wellness, while decreasing physician burnout. In one of her recent articles, Charon acknowledges these proven benefits but when discussing effects on patient care, relies heavily on theory (Charon et al., 2020). The abundance of theoretical articles paint an idealized image of NM as a significant force that will rehumanize patient care and the doctor-patient relationship. The theory of NM has been soaked up with enthusiasm in the medical field, but little progress in evidence-based research has slowed the movement. From Charon's groundbreaking article in 2001 until now, the effect of NM in medical practice is still primarily theoretical. More research is needed into how the idealized vision of NM differs from NM in practice. This will show what values and qualities are most

effective in a medical setting and allow educators to modify their programs accordingly (Milota et al., 2019).

2.6 Precautions and warnings

There is some opposition to the narrative medicine movement that deserves a louder voice. Two of narrative medicine's most recognized critics are Galen Strawson, a distinguished professor of philosophy from the Univsersity of Oxford, and Angela Woods, a medical humanities researcher at Durham University in the United Kingdom. While both acknowledge the potential of narrative medicine, Strawson and Woods argue that Charon makes a blanket statement with too many assumptions and not enough skepticism. Both make the case that "this debate has passed unattended by several of those engaged in understanding narrativity and medicine" by challenging the assumptions narrative medicine researchers have made (Ahlzén, 2019).

In *Health, Illness and Disease: Philosophical Essays*, Woods questions the assumed benefits of narratives by pointing out that narratives are limited by the constraints of language. Non-verbal forms of expression are downplayed, doing a disservice to those who are not narratively-inclined (Woods, 2012). Strawson goes into greater detail, stating that narrative medicine makes the assumption that all persons search for meaning and understanding in their lives through narratives and that narratives are *essential* to lead a good life. Failure to construct narratives leads to greater suffering (Strawson, 2004). The case for narrative medicine relies on the generalization of humans and takes for granted fundamental differences in individual personality and outlook on life. Strawson differentiates between self-experience as Diachronic or Episodic. The former experiences themselves in a long-term continiuum of time and likely has a narrative outlook on life by thinking in terms of a story with a past, present, and future. Diachronic individuals view themselves as the protagonist of one, consistent storyline (RonBC, 2012). The Episodic person tends not to experience themselves in a narrative outlook because their temporal style does not lend itself to a typical storyline. In other words, Episodic persons have little sense of past, present, future and therefore do not align self-experience with narrative. A blog post from "Notes from Aboveground" explains the Episodic self-experience as follows:

Episodic people, on the other hand, remember the sequence of events similarly to the way that Diachronic people do, but they don't see themselves as a single unchanging protagonist. For

the Episodic self, the "I" that I was when I won the high school track meet at sixteen is not the same person who now has four grandchildren. Of course there is a single life history for the episodic self, but the "I" then is not the same "I" as the "I" now, or the "I" that will be ten years from now (RonBC, 2012).

In a blog post in *Hpotheses* in October of 2021, Tabea Cornel, a professor of medical humanities at New College of Florida, muses over the related concept of neurodiversity. Cornel suggests that empathy and compassion training for medical professionals is neuro-discriminatory because they way in which some people experience or portray those qualities looks different than the way society expects (Cornel, 2021). Cornel's article is not expansive enough to consider dismissing empathy training; similar to Woods and Strawson, the benefits of these trainings and narrative medicine outweigh the concerns. Their arguments, however, should be interwoven into the narrative medicine movement more emphatically to gain a clear understanding.

Critics like Woods and Strawson make important arguments in the case against narrative medicine that have been glossed over in the majority of the field's literature. I agree that, while narratives play a role in the life of all humans to some extent, it is unreasonable to assume that everyone benefits from narratives as universally as Charon claims. Narrative medicine has many characteristics of an "intellectual fashion that comes and goes" (Ahlzén, 2019). Proponents make sweeping declarations that lack empirical evidence showing the effect of NM on patient care. Much of the literature presents theory with fervent devotion and little skepticism. The voices of Woods, Strawson, and other critics need to be emphasized to foster debate and provide greater understanding. The current movement makes the leap from suggesting the potential benefit of narratives in the doctor-patient relationship, clearly true, to presuming that all doctors and patients require narratives to understand their experiences. I do not believe, however, that Strawson's arguments against narrativity, such as the dangers of the narratives, are supported enough to outweight the proven advantages of NM. Strawson's point of view is crucial to consider, if only to think critically and appreciate all sides of the NM movement, but should not hinder NM and the potential positive impact it could have in medicine.

Chapter 3: UMMS Fieldwork

The University of Massachusetts Medical School (UMMS) is one of the many North American medical schools that are in the process of integrating narrative medicine into the curriculum and community. I examined various NM-related efforts by using UMMS as a case study. I conducted informal interviews with physicians and students at UMMS, as well as professors of medical humanities at Worcester Polytechnic Institute (WPI). Additionally, I had the incredible opportunity to attend and participate in an UMMS Writing Elective taught by Dr. David Hatem. The following chapter will analyze recurrent themes that emerged during my fieldwork at UMMS. Common themes included a liberal definition of narrative, multiplicity of forums, expanding the horizons of science-minded individuals, and a read-reflect-respond format. I was also interested in how the language used to describe narrative medicine influenced perception, specifically Charon's use of *narrative competence*. Finally, the misalignment of the theory of narrative medicine and real-life implementation led me to investigate challenges to implementation at UMMS.

3.1 UMMS Medical Humanities Lab

Founded in 2002, the Medical Humanities Lab serves as an informal platform for the UMMS community to combine the arts and humanities with medicine. The project website is led by Dr. David Hatem, Dr. Hugh Silk, Dr. Regina Raboin, and a committee of fourteen members across various departments. The most consistent recurring theme among the UMMS community is the multiplicity of opportunities to "get your feet wet" in the narrative world, likely a consequence of holding a generous definition of narrative. The Medical Humanities Lab is the embodiment of this theme.

The Lab is a collection of forums and efforts to cultivate humanistic perspectives in the medical community. Examples include 2020 Hindsight, a compilation of pictures, essays, and recordings reflecting on the tumultuous experiences of the pandemic; Med Moth, a forum based on The Moth radio show that allows students and faculty to share and reflect on their experiences through storytelling; Streams of Consciousness, an online journal of literary and visual arts; Family Medicine Moments, a list-serve where one can share meaningful moments and photos in medicine; Dramatherapy, where those with mental health or substance abuse challenges can express their experiences; and Creative Writing in the Elderly, a project focused on engaging

nursing home communities in writing and understanding the effects on depression and socialization.

While a multitude of options to participate in narrative medicine should be able to reach the most diverse range of people, several community members noted that UMMS efforts were only reaching a narrow subset of people. In my observation of the Writing Elective, all the students had a background in the humanities. This would align with the suggestion that current UMMS efforts are attracting those with a pre-existing tendency toward narrative medicine and neglecting the large portion of the community that lacks a humanities background. Despite medical schools admitting more students majoring in humanities, these matriculants still comprise only 3.5% of the nation's medical student body (*2021 FACTS: Applicants and Matriculants Data | AAMC*, n.d.). Some students in with science majors will have minors or considerable experience in the humanities, but the majority likely enter medical school lacking the full range of humanistic perspectives that coursework and experience offers. This is likely the section of the community in which narrative medicine may have the most potential to enhance skill set.

One facet of the Lab is the Interstitium, a multimedia, online space for the UMMS community to reflect on their experiences in medicine. It was started by UMMS student Marya Pulaski as her capstone project under the advisement of Dr. Silk. As Dr. Silk explained and as stated on the site, the name is rooted in the word interstice, a gap or break in something continuous, and the biological interstitium, a fluid-filled space that function as shock absorption from daily function and as a communication network. The flexibility and accessibility of this forum stood out. Reflections take the form of haikus, stories, or poems. Anyone can leave a comment on another's piece. In Dr. Silk's own blog post in 2019 on the Interstitium, he reflects on the "expediency of medicine,", emphasis on billing, and the electronic medical record as compromising a physician's ability to experience a relationship with their patient (Silk MD, MPH & Pulaski, 2019). The grandmother of a medical student left a comment on his post, expressing her gratitude for "sharing [his] humanity with honesty and devotion to [his] profession" (Silk MD, MPH & Pulaski, 2019).

3.2 How UMMS defines narrative

As I discussed earlier, there is no clear consensus on the definition of a narrative as it relates to narrative medicine, but one that is flexible will be the most effective in practice. In an interview with Brenton Faber, a professor of writing of WPI, he observed that, during his career in medical humanities and as a paramedic, the "notion of narrative has changed from the very structural plot, character, theme, setting because we've realized that that was overly prescriptive" (B. Faber, personal communication, March 9, 2022). UMMS employs a progressive idea of narrative, arguably one of the most important factors in the success of narrative medicine efforts, which is perpetuated through an informal, open-minded environment. This is immediately noticeable by the circular arrangement of chairs in Dr. David Hatem's Writing Elective course. The course focuses on the written form of narrative, but this is simply a starting point for discussion and demonstrates the loosely structured approach UMMS has toward narrative.

Various forms of narrative at UMMS are evident in the Medical Humanities Lab, which includes opportunities for expression in the form of art, photography, music, and poems. The goal of the Lab, and therefore that of the forums encompassed by it, aligns with that of narrative medicine: to foster humanism and connection in medicine by merging science with the humanities. By accepting that narrative is any form of expression of self-experience, the Medical Humanities Lab doesn't limit the experiences that can be expressed to only those that can be written.

Traditionally, narrative is thought of as expression of a story that is limited by language in the same way that writing is limited. If we were to limit narrative strictly to coherent, canonical stories, much of the content of the Medical Humanities Lab would be discounted as narrative medicine. Meg Hansen, a UMMS student and active participant in the Medical Humanities Lab, asserts that we experience in narrative fashion when we have "taken the information, processed it, and created something out of it, whether that is something physical or as a guide for our actions" (M. Hansen, personal communication, Feb. 8, 2022). If we believe that human beings experience life through narratives, wouldn't we also be limiting self-experience to that which can be expressed by words? Self- experience is complex, unique, and sometimes untranslatable. Shouldn't narrative, in the context of narrative medicine, also be complex, unique, and sometimes untranslatable if the goal of narrative medicine is to facilitate expression of a patient's self-experience?

Observation of the UMMS Writing Elective provided further insight into the nature of narrative. This course was designed to give students the opportunity to write in response to a prompt provided ahead of time then read, discuss, and reflect on their pieces in a group setting. Dr. Hatem perpetuated an informal and open-minded environment, evident in a circular arrangement of chairs, in which he served more as a guide than an instructor. Once a student read their piece aloud, the group shared their thoughts or advice. As implied by the title of the Writing Elective, I expected the focus of the class to be on the written piece of medical humanities. Most students, however, commented that their piece was incomplete or had to elaborate on the details of their story to clarify for the class. Long pauses of silent reflection were frequent and comfortable. The expectation of the course was not to produce a polished written narrative. Instead, we listened attentively to partial narratives, asked questions, and experienced the ambiguity or enlightenment of a foreign perspective.

One student wrote of an encounter with a patient who arrived from a prison and the inner conflict between the physician's duty to treat all patients equally and the knowledge that this patient had committed a crime. The story concluded abruptly and ambiguously, without the narrator reaching a decision or achieving a goal. First, this calls into question Shimazono's qualification that narratives require an actor working towards a goal (Shimazono, n.d.). The prisoner story is an excellent example of a narrative, a series of connected and significant events, yet the narrator does not reach a distinct conclusion or conduct as last act. Second, the lack of a succinct conclusion is exactly what makes the narrative so powerful. Resisting the desire for a neat conclusion becomes important in medicine because of the abundance of grey areas. The ability to hold multiple perspectives and opinions simultaneously, eloquently illustrated by the student's prisoner narrative, is also a critical skill in medicine.

As has been identified as a problem in cultural competency training of physicians, a reductionist approach to narratives could make narrative medicine inaccessible to parts of the community. Culture is acknowledged as a fluid, obscure concept that cannot be neatly defined. Inadequate patient care occurs when culture is reduced to checklists and common concepts (Bhavnit & Bhatia, n.d.). It seems that narrative medicine will have to follow a similar pattern of thought to succeed. A generous definition of narrative as any form of expression of self-

experience has facilitated the success of narrative medicine efforts at UMMS so far. Consequently, this is how I will define narrative for the remainder of this discussion.

3.3 Self-selecting bias

While the Flexner and biomedical era of medicine championed scientific advancement more than anything else, narrative medicine seeks to balance science with humanities. Important in this process is for medical professionals to have experience in both fields and understand how the overlap between the two can lead to better patient care. Like many facets of their programs, this is fostered at UMMS by maintaining a flexible idea of what makes something narrative. As Hansen stated, programs like the Medical Humanities Lab that include diverse forms of expression allow "people who view themselves as 'science people' to push themselves to be more creative, more well-rounded" (M. Hansen, personal communication, Feb. 8, 2022). The ability of these programs to expand the horizons of medical students and faculty is echoed as a top advantage of narrative medicine, in the literature and within the UMMS community. As several experts have noted, however, there is little empirical evidence showing that, by expanding physicians' horizons, narrative medicine can directly improve patient care[1].

In recent years, medical schools have tried to balance experience with scientific ability. The admissions process has been transformed by the idea of "holistic review" that balances academics with experience and attributes. There is greater recognition of the value in a humanities background specifically. In an interview for the American Medical Association (AMA), John D. Schriner, PhD, associate dean of admissions at Ohio University Heritage College of Osteopathic Medicine, stated that coming into medical school with a humanities perspective "gives students an opportunity to assess the human condition through a different lens, and to realize that folks are more than just the symptoms they present" (Murphy, 2021). A 2018 study in the Journal of Medical Education indicated that medical students with humanities backgrounds could be more effective at patient communication as well (Murphy, 2021). In my observation of the UMMS Writing Elective, the background of the students in the class were representative of this phenomenon. One had been an English major in college, and another had been a Biology major with an English minor. Responses written by students were well-

[1] See section 2.5 Narrative Medicine in Practice which specifically examines the nature of impact on physicians and patient care.

formulated, utilizing diverse literary techniques. The ease with which they spoke of complex, difficult clinical experiences were impressive. This was only a subset of the UMMS student body, certainly biased by the fact that those with a humanities background are more likely to take a humanities elective. Rather than simply being aware, courses in narrative medicine gives students the ability to communicate and speak about diverse ideas and perspectives. It is possible that simply by being able to express difficult concepts eloquently, medical students with training in the humanities can provide better patient care because they can communicate with greater compassion and empathy.

3.4 Read-reflect-respond format

Milota et al. (2019) observed a consistent three-step read-reflect-respond model in narrative education. First, there is reflective interaction with a narrative or text. Second, an exercise in writing or reflection on that narrative. The third step involves sharing responses with a group. Keeping in mind the pedagogical approach of read-reflect-respond, I was curious if these efforts by UMMS followed a similar pattern (Milota et al., 2019). In the Interstitium I found read-reflect-respond approach but adapted to reach more members of the community. While I believe when Milota speaks of the read-reflect-respond approach it is in a traditional class setting, the Interstitium is a nuanced attempt to expand narrative medicine efforts. There are approximately fifty blog posts as of January 2022. There is no prompt, other than a brief message indicating it as a space for "pausing and processing amidst the grind of long study days or the buzz of a busy clinic" (Silk & Pulaski, 2019).

The drawback of the Interstitium as opposed to the Writing Elective is that there is no way to ensure commitment of community members to participating, which is indicated as important to the development of narrative medicine values. It is still a valuable aspect of narrative medicine at UMMS that should be considered at other hospitals because it allows the entire community to see and participate in humanistic efforts.

The Writing Elective course followed a similar three-piece structure. The class begins by Dr. Hatem rearranging the chairs into a circle. As the students trickle in, the atmosphere is informal and comfortable. The students were given the opportunity to share their responses to the following prompt which had been given the week prior:

*"Theme: **A Memorable Patient or A Memorable Patient from the patient's perspective***

There are certainly times when there is something we don't understand from the patient encounter that trying to write from the perspective of the patient unlocks an avenue of inquiry or an insight we had not previously thought of."

Purposefully open-ended, the prompt was meant to be an imaginative exercise of writing from the patient's view or to stimulate reflection on one's own actions. Dr. Hatem read the prompt aloud and asked if anyone wanted to share their piece. A pause followed, but less than a minute passed before someone volunteered. There was an air of expectation that everyone would eventually share, a reasonable expectation given the elective nature of this course, but there was clearly no rush.

The first student spoke about an internal conflict when treating a prisoner. There was a conglomeration of emotions: sympathy for the prisoner's pain, guilt for that sympathy, curiosity, resentment, and the commitment to treating him the same as any other patient. A second student personified an eating disorder as "Ed" and illustrated the challenges an eating disorder imposes on daily life. The third student compared the "normal" of a patient with an autoimmune disorder to the accepted "normal" of society. After each reading, there was a pause for us to consider the reading and formulate our own reactions. The silences were often drawn out as everyone processed the information, but it was a thoughtful, comfortable silence. Dr. Hatem asked the student what they thought of their own writing before allowing each listener to reflect on their reactions and give feedback. Students frequently asked each other to elaborate on specific or confusing aspects of their writing. The ease with which this humility was expressed was striking because it allowed students to express themselves ambiguously or to the best of their ability. There was no obligation to express ideas in ways that would be clearly understood by the group because students were comfortable asking questions.

Reflective exercises, in a supportive environment, have been directly linked to improvement in clinical reasoning by teaching students to examine a "wide range of information, including their own experiences and sources of bias" (Milota et al., 2019). There are varying opinions on the presence of a narrative medicine methodology: Wieżel et al. concludes there is no structured narrative medicine approach while Milota et al. finds a consistent read-reflect-respond methodology (Milota et al., 2019; Wieżel et al., 2017) across institutions. The structure of efforts at UMMS support Milota's review and findings.

3.5 Narrative humility

Charon coined the term *narrative competency* to encompass the skills which enable a physician to practice narrative medicine. *Narrative competency* parallels the term *cultural competency*, a skill widely accepted by the medical community as being necessary for physicians to care for diverse populations. As noted earlier, one concern regarding cultural competency is a didactic approach to memorizing lists of stereotypical cultural attributes that fail to address the fluidity and nuance of culture (Kleinman & Benson, 2006). One possible factor is the discourse surrounding the word *competence*. *Cultural competence* implies that one can become fully competent in other cultures and communities, that "culture can be reduced to a technical skill" (Kleinman & Benson, 2006; Tervalon & Murray-García, 1998).

The same can be suggested by *narrative competence*. Sayantani DasGupta, MD, MPH, from Columbia University's Narrative Medicine Program, proposes the alternative concept of narrative humility, that is, one can engage with stories and perspectives while acknowledging the existence of a unique, incomprehensible element (DasGupta, 2014). Charon suggests narrative *competency* but utilizing the term narrative *humility* instead better aligns with the notion that narratives are only an attempt to express an experience. As previously discussed, narrative always falls short of the exact experience because it is incapable of capturing the subjective nuances of self-experience. This shows the incredible power of language to change the discourse around an idea. To accept that patients will come with ambiguous stories and one can never attain full competency in their narratives, we must first accept that there is an untranslatable element of self-experience.

Dr. Hugh Silk supports that the idea that narrative, like culture, is too dynamic to fully master. In one of our interviews, Silk pointed out that the humility aspect comes from "learning how to ask questions [and], even if you learn culture not to put everyone into the same category" (H. Silk MD, personal communication, March 21, 2022). The ability to recognize that we can never be fully competent is what gives us humility. Silk also stresses the importance of acknowledging one has a lot to learn and therefore simply asking the patient, facilitating a more open dialogue.

While language is critical for developing an appropriate discourse, it seems like concern over the presence of overly didactic approach to narrative medicine is premature. In practice,

narrative medicine has not had time to catch up to this theory. There are simply not enough people who routinely practice narrative medicine to unintentionally abuse it as has happened in the case of cultural competency (B. Faber, personal communication, March 9, 2022). The problem with the language of culture competency that Kleinman & Benson (2006) describe should serve as a harbinger for the future of narrative medicine, given the similarities between narrative and culture. While the discourse is not currently overly prescriptive, it is important to consider the language we use to talk about narrative medicine as the field is still in the early stages of development.

3.6 Challenges

The greatest challenge in narrative medicine has been finding the most effective method of implementation. Voluntary workshops, such as the UMMS Writing Elective, are the traditional education style. In a study on narrative medicine workshops implemented in obstetrics and gynecology residency programs, researchers found that approximately one quarter of residents reported difficulty sharing personal reflections (Winkel, 2016). This is an underappreciated obstacle to engagement in narrative medicine. Atkinson is one of the few experts to acknowledge the tendency to expect a confessional aspect in any narrative (Atkinson, 2009). In other words, there is an unspoken expectation that narratives, especially illness narratives, reveal something hidden or personal about the narrator. This is an intimidating barrier that could discourage people from participating in narrative medicine interventions because they wish to maintain their privacy. The significant benefit of the curriculum, as Winkel (2016) notes, is its impact on the community, therefore sharing personal reflections is necessary. However, in our conversations, Dr. Silk explained the importance of emphasizing that students will not be asked to share if they aren't comfortable due to unpredictable triggers, and not only with emotional topics (H. Silk MD, personal communication, March 21, 2022). I argue that developing a certain comfort level discussing difficult topics is a necessary element of medicine, but this does not require a student to share their own experiences.

Ultimately, the goal of narrative medicine is to improve patient care. To do this, physicians need to be competent in discussing difficult, emotional, and personal topics. This does not necessarily mean physicians need to be competent discussing their own personal or difficult experiences. An intrinsic right to privacy exists for physicians and medical students as well as

patients. In a clinical setting, competent physicians seek to illicit a background story behind the disease, to co-construct an illness narrative with the patient, but the patient might not want to share their story. When training medical students in narrative medicine, having a variety of expressive medias could stimulate reflection for those who are uncomfortable putting their individual experiences into such a clear, obvious medium as writing.

A second challenge is time. Medical students already have immense educational expectations and packed schedules. How can narrative medicine be incorporated in a way that does not overburden students and faculty? Winkel suggests that workshops be scheduled during the routine workday to maximize participation. Even students with a predisposition to the humanities are less likely to participate outside of school (Winkel, 2016). It is possible that students and faculty might simply tire of the hospital or educational environment, making them less likely to participate outside of the allotted time for work. This circles back to the question of how to squeeze more training into the full schedules of students and physicians. Since narrative medicine is meant to enhance current medical practice, Dr. Silk suggests that incorporating aspects of medical humanities into the current curriculum is most effective rather than piling on more requirements. One of his current projects with his family medicine residency program is to incorporate some aspect of the humanities, whether it is a photo, poem, or essay, into each health topic to discuss with students (H. Silk MD, personal communication, March 21, 2022). Current research supports this model, as opposed to isolated, elective courses, because it embodies the holistic approach to modern medicine (Daryazadeh et al., 2021).

Third, the emergence of the electronic medical record (EMR) has created the ability for artificial intelligence to generate a narrative based on checkboxes and drop-down menus. The EMR provides easy access to data, aggregation and monitoring of data, and better communication while also being shown to decrease physician error. Despite these benefits, the EMR has been shown to have negative effects on establishing rapport and patient-doctor communication . The rigid uniformity of the EMR erases a physician's voice in the story through its emphasis on checkboxes and lists (Balhara, 2019). One perception is that the "only story produced by the EMR is the same story repeatedly" (Balhara, 2019). The relationship between narrative medicine and the EMR is important because narrative medicine has the potential to remedy negative effects of the EMR. By handing narratives over to a computer, there is little

chance for physicians to reflect on their own story or that of their patient. As Brenton Faber, a professor of writing at WPI, explains, “by divorcing narrative from the patient encounter, you are also divorcing self-reflection” (B. Faber, personal communication, March 9, 2022). Dr. Silk stated similarly that the EMR “has kind of robbed us” of listening to and writing the story. To eliminate the EMR would be ludicrous because of the significant advantages of computerized data. The EMR is simultaneously an obstacle to the practice of narrative medicine and a problem begging for a solution.

Conclusion

In this project, I have observed a progressive idea of narrative, as opposed to the canonical definition, that I conclude plays a critical role in the success of narrative medicine efforts. Through my fieldwork at UMMS and interviews with students and professionals, it appears that developing a generous and liberal notion of narrative is important in laying the groundwork for putting narrative medicine into practice. This stands in opposition to much of the literature that describes narrative as requiring the elements of a traditional story. As it relates to medicine, narrative should not be rigidly confined but any form of expression in which someone has “taken the information, processed it, and created something out of it”, as Ruddy states (M. Ruddy, personal communication, Feb. 13, 2022).

UMMS served as an informative case study for analyzing community perspective on narrative and I found that, predictably, the majority of UMMS members whom I interviewed share this notion of narrative. There is no doubt that students and faculty can benefit from narratives that can be written and read coherently. However, acknowledging the untranslatable aspects of narrative and the limitations imposed by language could expand accessibility to narrative.

Since I have taken a deep dive into my Professional Writing major at WPI and, specifically, narrative medicine, I have questioned why this education was not required for pre-medical students at the undergraduate level. The theme of “broadening the horizons of science-minded individuals” appeared frequently during my research. Students are entering medical school either as a science-minded individual or with a predisposition to the humanities. Greater emphasis on training in the concepts of narrative medicine, especially at the undergraduate level,

could serve to help incoming medical students to cultivate an appreciation of narrative. In a small study of medical interns training in narrative medicine, one participant commented that "[their] foliage has now formed, and we have become a tree. We could have been formed sooner than this when we were a seedling", while another stated that "internship is too late for teaching NM" (Daryazadeh et al., 2021). Veno et al. (2016) point to frequency of practice as a possible factor in accessing the benefits of narrative, therefore I propose that emphasizing practice at the pre-medical level could be advantageous.

On the other hand, Faber suggests that requirement might lessen appreciation for narrative. Faber likens current programs with the Darwin effect in that those that take advantage opportunities to educate themselves in narrative medicine will be more successful and effective physicians and, over time, will become the majority (B. Faber, personal communication, March 9, 2022). Whether narrative medicine training is required of students or an elective addition to the curriculum, there is enough evidence showing its positive relationship with communication, empathy, and compassion to warrant serious consideration for pre-medical students at the undergraduate level.

There are several limitations to this study. Some interviews were conducted over email rather than Zoom, limiting the depth of response and continuity of follow-up questions. I also spoke with individuals who were involved in medical humanities, whether it be as a professor, physician, or student. There is likely inherent bias towards the positive aspects of narrative medicine. While UMMS provided great insight into narrative medicine efforts, it is also only a single case study. A more thorough evaluation of medical schools across the country is necessary to draw stronger conclusions.

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