

Illness Memoirs: Implementing and Expanding Narrative Medicine

as Part of the Medical School Education Curriculum

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## Introduction

The varying difference of definition and value of a body between a physician and patient has been a rising discussion within healthcare. The overarching issue is that physicians have lost their “empathetic” or caring touch as they diagnose, treat, and cure their patients (Rothman, 1991). Having to manage physicians’ schedules, their calendars are filled with back-to-back, and sometimes overscheduling, appointments, for there is pressure from the medical institutions asking the physicians to see more patients. This shortening of time typically results in reduction of time of interaction with patients and not getting to know the patients’ true ailments and illness experiences for improved, effective quality care or cure. However, I hypothesize that with proper education and practice of effective listening, discerning, and developing a proper treatment plan for each experience of an illness, then this disruption between the physician and patient will reduce. My proposed solution is found within the context of narrative medicine: reading illness memoirs.

There has been a general push for more STEM education and research, disregarding the humanities and its importance, especially within the medical profession. The Flexner Report is the foundational documentation that set the course for dismissal of the humanities within medical education. While the Flexner Report streamlined and revitalized the medical school education curriculum, resulting in medical research technological advancements and curing a variety of complex diseases, it reduced the emphasis on the humanities and in turn reduced compassion, empathy, and effective communication between the physician and patient. The Flexner Report’s infrastructure on the medical school education system needed to be combated with a revolutionized literary studies program and Rita Charon thus championed narrative medicine. Narrative medicine has since attempted to “[offer] the hope that our health care system, now broken in many ways, can become more effective than it has been in treating disease by

recognizing and respecting those afflicted with it and in nourishing those who care for the sick” (Charon, 2006, p. 4). Literature that tells the embodiment experience of illness has the capability to achieve this hope.

However, narrative medicine still lacks the inclusion of the patient within the two-way communication relationship it solely focuses on the physicians acquiring narrative knowledge, but I argue for the patients should acquire narrative knowledge too. Communication is a two-way street in a relationship, so within the physician-patient relationship, the patient must be included and gain narrative knowledge. However, patients need a literary genre that is not as complicated and complex as journal articles and research papers that might compose narrative medicine tactics. They need lay literature. They need a simple yet direct health narrative literature explaining to them the illness experience in order to adequately convey to their own ailments of to their physicians. Though they might not experience the illness exactly like the authors, they can still find something that is relatable to them, communicate it to their physician and allow the physician to apply their narrative knowledge and create an effective treatment plan against the illness. I argue illness memoir is the literary genre that can satisfy all these issues.

Because narrative medicine encompasses a wide range of literature, my project aims to establish illness memoirs as an accessible but academic literary genre within narrative medicine that can be used as a tool to clarify any misunderstandings of diagnoses between the doctor and patient (Baena, 2017; Charon 2001a, 2001b, 2006). Illness memoirs are available in the local bookstore and library for the general public, typically written in lay language, and, most importantly, they fill the gap of understanding the empathy and background patient information surrounding a medical diagnosis narrative medicine strives for.

I analyze two illness memoirs in this thesis, Roxanne Gay’s *Hunger* and Porochista Khakpour’s *Sick*. Gay’s and Khakpour’s in-depth illness experience of obesity and Lyme

disease, respectively, provide more health information than the disease knowledge memorized from a biomedical textbook. Both authors' illness memoirs represent methods to regain one's voice on, or autonomy of, an expressive illness, a non-linear path towards a cure, and allot the literary space to reconcile the *truth* of what an illness embodies.

## Methods

A qualitative literary analysis was the methodology of my thesis. Because the reconstruction of the medical school education curriculum based on the publication of the Flexner Report—a documentation or a literary piece—further literature needed to be consulted, analyzed, and critiqued to formulate my argument. The lack of emphasis on the study the humanities and narratives—particularly illness narratives—within the Flexner Report suggests that literature or humanities studies could be a remedy to the contemporary disturbance of the physician-patient relationship and understanding the illness experience (Altschuler, 2018). Narrative medicine has recently been a humanity focused study attempting to reinstall the value of narrative and its power to reshape how an illness is treated, so that the highest quality of healthcare can be achieved (Charon 2006; Columbia, 2018).

Narrative medicine has expanded as a practice in medicine so that the physicians can better attune to their patients' stories of their illnesses through various means of literature. Arthur Kleinman redefines the concept of "illness" as "the innately human experience of symptoms and suffering" and "the lived experience of monitoring bodily processes" (Kleinman, 1998, p. 4). He contrasts his illness definition with his definition of disease as "what practitioners have been trained to see through the theoretical lenses of their particular form of practice. That is to say, the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems" (Kleinman, 1998, p. 5). The stark contrast of definitions—the detailed story versus the strict facts, respectively—explains why the physician-patient relationship is distant. And the physicians narrow, factual mindset derives from their training. Thus, directs the necessity of literary narratives—and in this case illness narratives—to be the tool to communicate the "lived experiences".

Therefore, narrative medicine, advocated by Rita Charon in her book *Narrative Medicine: Honoring the Stories of Illness* (2006) and her graduate curriculum at Columbia University, trains physicians “to recognize, absorb, interpret, and be moved by stories of illness” (vii). Narrative medicine advocates for narrative knowledge and competency because the practices associated with illness narratives are humanistic values that are lost in the biomedical text books medical students study. However, while narrative medicine addresses the need for narrative competency for *physicians* there has not been an advocacy for narrative medicine to be taught to *patients*. There needs to be a literary genre that contains the valuable narrative knowledge information, but also resonate with all readers despite their education background. Therefore, illness memoir is the literary genre that compliments both qualities.

Illness memoirs fulfill the characteristics of narrative medicine, particularly the illness experience *and* communicate it with “lay” language. Memoirs focus on a specific interest in the author’s life, and thus, illness memoirs focus on the illness and how it affects the body and life of the author. It is as though the body itself is writing about its story with the illness because it is the focus of the author’s memoir. Thus, the author communicates the experience of their body’s typically in relatable contexts more so than what medical textbooks cover, providing more arguably valuable health information pertaining to that illness.

This study examines two illness memoirs—Roxane Gay’s *Hunger A Memoir of (My) Body* and Porochista Khakpour’s *Sick: A Memoir*—that articulate both the body’s corporeality and the experience of living in that body as the authors reveal their interactions with their illness or disease. My analysis is limited to two memoirs because it granted a more in-depth analysis of how the authors communicate the lived experience of their illnesses. Both memoirs were chosen because they share “the subjective experience of the ill and dying body,” teaching physicians and patients new, valuable health information about the authors’ respective illnesses (Diedrich, 2007,

p. 8; Levine, 2007). Writing about her lifelong fluctuations in weight, Gay challenges cultural assumptions about obesity by describing the destruction, trauma, beauty, fluctuations, and confusions of her body as she reveals her body's experience of rape and weight gain. Gay's central focus of her body and its space in society forces her readers to reconsider how they look at other obese bodies. Khakpour chronicles her diagnosis of Lyme disease, which is incredibly difficult to diagnose, revealing the tribulations she experienced with her own body and the medical community. The memoir challenges readers to live through her tribulations of her diagnosis so that future Lyme disease patients can relate and clearly communicate similar feelings and emotions associated with their own diagnosis to their physicians and show physicians how patients with Lyme disease truly feel. Both memoirs emphasize the particularity and uncertainty of their individual experience that counters the illusion of clear-cut answers that biomedical training promotes.



## **Background & Literature Review**

Every institution has a systemic foundation in order to get started and expand upon as the institution populates. Medical schools and the education curriculum for doctors in training are a prime example. The Flexner Report—researched and standardized by Abraham Flexner in 1910 established what Geoffrey Bowker and Susan Starr’s call the medical education “infrastructure,” or the classification and standardization of an established system. The Flexner Report became the standard rule-book that dictates how medical schools educate, train, and certify future physicians, so that every physician will be qualified to diagnose and treat the human body. However, the new classification and standardization of the medical education system the medicalization of the body minimized the importance of humanistic aspects of medical training and care. The effects of the Flexner Report are still felt today; the American Medical Association continues to set the standards of medical care and ethics based on Flexner’s writing (AMA, 2019; Rothman, 1991). The dehumanizing effects of the medicalization of the body require a new approach to practicing medicine that disrupts this seemingly untouchable medical education infrastructure. Narrative medicine, a humanistic approach to medical training founded by Rita Charon, has become a disruption of modern medicine, restoring the study of humanities—not solely STEM information—and empathy in the practice of medicine. While narrative medicine includes a variety of literary texts and genres in medical education to teach narrative competency of illness, illness memoirs directly immerse readers into the experience of illness thereby granting access for both physicians and patients to acquire narrative competency. Hence, I argue that illness memoirs—within the narrative medicine field—can return emotion and sensation to the diagnosis and treatment of the medicalized body.

### *The Defining Illness and Disease Era*

Tracing the historical timeline of the ways in which illness affects the body reveals the transition from curing the illness for the “sick person” to scientifically objectifying the body that the Flexner Report deemed society to seek care from a medically trained expert. Beginning in the Middle Ages, the two most prevalent epidemic diseases were leprosy and the plague. With doctors lacking modern healthcare knowledge, those who had these diseases—particularly the plague—were automatically subjected to isolation and death (Herzlich & Pierret, 1984, p.4). These bodies were deemed exotic, unruly, disgusting, and feared, building the foundation of categorizing and selecting worthy and redeemable bodies within society. With the lack of knowledge about health, illness and disease, sin was the only explanation and their contraction of the deathly and unwanted illnesses were the individuals’ punishment (Herzlich & Pierret, 1984). From the religious idea of sin, this further alienated the ill person because no one wanted to surround themselves with sinful bodies, manipulating their own purity and holiness. Remarkably, the physicians advocated for these ill bodies to not be discarded, but rather be treated and cared for and attempt to discover preventative health regulations (Herzlich & Pierret, 1984; Hurd, 2018). As more epidemics such as cholera, tuberculosis, and syphilis arose, medicalized terminology began to arise, such as contagion and microbes (Herzlich & Pierret, 1984). Though they were not as trained, the physicians and health prevention administrators pursued the sick body, attempting to discover cures and remedies so that future illnesses do not become epidemics (Cooke, Irby, & O’Brien, 2010; Hurd, 2018).

Ultimately, physicians’ knowledge overpowered the religious explanations of disease. Instead of succumbing to fate and destiny or relying on God as the ultimate healer, it became society’s instinct and obligation to seek medical care once contracting an illness (Herzlich & Pierret 1984; Lupton, *The Lay Perspective*, 2012; Lupton, *The Social Construction*, 2003).

Alongside the specialization of medical knowledge, three separate medical professions emerged: physicians, surgeons, and apothecaries, listed in their respected social hierarchy (Cooke et. al., 2010). Their respected education was as follows: university education, apprenticeship in the hospital and dual-barber, and apprenticeships sometimes in the hospital (Cooke et. al., 2010). Needless to say, the trainings and seriousness of education was neither regulated nor consistent. Nevertheless, during the 18<sup>th</sup> and 19<sup>th</sup> centuries, society's perception of illness shifted so that if one became ill it became that individual's obligation and duty to seek medical care (Herzlich & Pierret, 1984, p. 52; Lupton, *The Lay Perspective*, 2012; Lupton, *The Social Construction*, 2003).

### *Professionalization of Medicine*

Physicians, surgeons, and pharmacists were neither established nor esteemed professions before professionalization of medicine through the creation of the American Medical Association and the Flexner Report (Herzlich & Pierret, 1984; Hurd, 2018; Lupton, *The Social Construction*, 1999). Prior to the turn of the century, medical training was not regulated or standardized across the nations, for students learned the medical trade through an apprenticeship system. Two key events, the founding of the American Medical Association (AMA) and the publication of the Flexner Report, marked a shift toward professionalization that has shaped modern medical practice.

On May 5, 1894, the AMA formed so that regulations and medical issues that arose could be addressed and shared amongst the medical community (Hurd, 2018; AMA History, 2019). The AMA reinvented the “medical educational standards for MDs, including “[a] liberal education in the arts and sciences, a [certification of] apprenticeship before entering the medical college, [and] an MD degree that covered 3years of study, including two 6-month lecture

sessions, 3 months devoted to dissection, and a minimum of one 6-month session of hospital attendance” (Hurd 2018, para. 11). In 1852, more requirements were added to the curriculum and education system such that students took a “16-week course of instruction that included anatomy, medicine, surgery, midwifery, and chemistry...[g]raduates had to be at least 21 years of age, [and] finally, [s]tudents had to complete a minimum of 3 years of study, 2 years of which were under an acceptable practitioner” (Hurd, 2018, para. 12). The rigor to memorize the immense scientific knowledge drastically changed from the tradition of caring, diagnosing, and treating the body through one’s immediate knowledge (Cooke et. al., 2010, p. 14; Herzlich & Pierret, 1984). However, the medical schools were still not as advanced as the European—specifically German—medical schools that were invested in research laboratories and advancing medical care within their curriculum (Cooke et. al., 2010).

When the AMA collectively decided to standardize the medical school education system, they asked Abraham Flexner to observe 155 medical schools across the country and even in Germany, to establish a new standard in medical school curricula (Bailey, 2017; Duffy, 2011; Ludmerer, 2010). Inspired to reshape medical education by his own immersions in the German medical education system that trained students in laboratory research to advance scientific knowledge of illness and disease, Abraham Flexner concluded that there needed to be a restructuring or recategorizing of the United States’ and Canada’s “relatively informal and unfettered [medical educational] affair” (Cooke et. al., 2010, p. 11; Duffy, 2011; Ludmerer, 2010). The newly founded John Hopkins University School of Medicine, which opened in 1893 as the first medical school in America of “genuine university-type, with adequate endowment, well-equipped laboratories, modern teachers devoted to medical investigation and instruction, and its own hospital in which the training of physicians and healing of sick persons combined to the optimal advantage of both,” had the potential to serve as a model for a new United States

medical education system (Hurd, 2018, para. 16). Therefore, Flexner compared all of his 150-155 medical schools to the esteemed Johns Hopkins Hospital, composing “the most notable theoretical discussion of medical education ever written” in a 1910 report (Duffy, 2011; Ludmerer, 2010). The major components of change to medical education include medical positivism, rigorous entrance requirements, the scientific method, learning by doing, and conducting original research (Ludmerer, 2010). His report defined the standard medical school curriculum, the resources each school should provide students, and the people who were qualified to become physicians.

In 1910, the Flexner Report reshaped the entire infrastructure of the medical world and profession. Almost immediately after its publication, its recommendations were implemented by [AMA]. A large number of medical schools were closed because they did not meet the standards as a medicalized research institution connected with a qualified university (Bailey, 2017; Duffy, 2011; Ludmerer, 2010). In addition, many students were denied access to medical schools because of their lack of qualifications in education, wealth, gender, and skin color (Bailey, 2017, Ludmerer, 2010). In effect, the Flexner Report reinvented the medical school education curriculum itself—making it more rigorous, streamlined, extensive, biologically grounded, and laboratory research-based.

### *The Infrastructure Established by the Flexner Report*

The Flexner Report aligns with Bowker and Star’s definition of infrastructure, setting the standard of medical education and the production of doctors and their treatments of the body (Bailey, 2017; Duffy, 2011; Ludmerer, 2010). Geoffrey Bowker and Susan Starr defined what an infrastructure within our society in their book *Sorting Things Out: Classification and Its Consequences* (1999). The Flexner Report aligns with a majority, if not all, of the nine

characteristics: *embeddedness, transparency, reach or scope, learned as part of membership, links with conventions of practice, embodiment of standards, built on an installed base, becomes visible upon breakdown, and is fixed in modular increments, not all at once or globally* (35).

After the publication of the Flexner Report, it was automatically *embedded*—“sunk into, inside of, other structures, social arrangements and technologies”—and *transparent*—“[did] not have to be reinvented each time or assembled for each task, but invisibility support[ed] those tasks”—into society, such that the AMA adopted the report as the model of medical education and curriculum without hesitation (Bailey, 2017; Bowker & Starr, 1999, p. 35; Duffy, 2011; Ludmerer, 2010). The funding for the medical institutions, the education curriculum, the advanced technology and tools for the research labs, the level of professorship, and the qualifications of students attending medical schools (Altschuler, 2018; Bailey 2017; Duffy, 2011; Ludmerer, 2010; Lupton, *The Lay Perspective*, 2003; Lupton, *The Social Construction*, 2003). The Flexner Report became the *embodiment of standards* for medical schools and its curriculum meaning that it cannot easily be challenged; the medical studies and demanding research labs students must endure are constricting. These constrictions are thus set by the Flexner Report, which has been fully established as the “magnificent edifice that is American medicine” (Duffy, 2011, para. 18).

The Flexner Report *reaches or scopes* not just the medical education, but the quality of technologies available for medical research, the socialization of the medical professorship, the students that are accepted into these institutions, and, by extension, the patients that are treated by the doctors that graduate from these medical schools (Bowker & Starr, 1999, p. 35). The advocacy for the highest quality of care:

transformed the profession's effort to reform medical education into a broad social movement similar to other reform movements of Progressive Era America. There

is little doubt that the extraordinary development of medical education that occurred in the years immediately following the report would have occurred without this catalyst. (Ludmerer, 2010, para. 19)

The Flexner Report publicized the medical school education system as an institution and a model to regulate the medical school institution (Ludmerer, 2010). Thus, the institution produced future physicians as their own selected, familiar cohort establishing a *learned membership* status (Bowker & Starr, 1999, p. 35). College students endure the STEM courses required by medical school applications, take the MCAT and excel within their extracurriculars that pertain to the medical or basic science research fields. Receiving the white coat upon entrance into medical school signals to society that those individuals will have access to advanced research technology, labs, knowledge of the medical world, and eventually be licensed to treat patients and practice medicine (Bailey, 2017; Duffy, 2011; Ludmerer, 2010). Understanding that the Flexner Report is an infrastructure allows scholars to see the bigger picture of the report and its impact on the medical school curriculum. After recognizing its impact, steps can be taken to resist and manipulate the Flexner Report's undoing of the physician-patient relationship, specifically the lack of studying the humanities of medicine.

### *Change to Care*

With the implementation and rigidity of the new, refined medical education infrastructure, the Flexner Report inadvertently changed the production of doctors' knowledge on treatment and care for their patients and research subjects. The Flexner Report's infrastructure of the medical education system drastically modernized and equalized the physicians' care to patients. The Flexner Report established standards each physician must adhere to and mandated the quality of knowledge gained during their time at medical school. This quality of medical

knowledge guarantees that all physicians are equipped with the same training to diagnose and prescribe proper medications and treatment plans for every patient they see.

The reinvention of the medical curriculum produced physicians knowledgeable of medical practice and elevated the profession in the social hierarchy (Herlich & Pierret, 1984; Ludmerer, 2010). This newfound authority, established in part by the infrastructure of the Flexner Report (Bowker & Star 1999), established the physician as the professional one should seek when ill, examine the ill body, and adhere recommendations of treatment (Herlich & Pierret, 1984; Ludmerer, 2010; Lupton, *The Lay Perspective*, 2012; Lupton, *The Social Construction*, 2003). This form of authority created a power differential in the doctor-patient relationship that resulted in a reduction of actual, relationship care between a physician and patient.

The new medical education curriculum also demanded that the students adopt the learning-by-doing, self-education strategy, in which “through laboratories and clinical clerkships, students were to be active participants in their learning, rather than passive observers” (Ludmerer, 2010). Even after the Flexner Report publication, “Sir William Osler, a Canadian [recognized as] one of the greatest professors of medicine in modern history...established the first residency training and was the first to bring students to the patient's bedside” (Hurd, 2018, para. 17). The bedside implementation offered the physicians to finally interact with the body and put their knowledge in action. However, the body is the object that the physicians were interacting with, not the human themselves. This new academic curriculum of actively participating with the body in the labs and persistence of advancing medical research disturbed “the primary role of physicians as beneficent healers; the delicate balance of patient care and research could have been pursued with mutual benefits for both sides” (Duffy, 2011, para. 16). Instead, the doctors objectify the body. While medical students, in the new curriculum, were



trained to study and treat human bodies, they were not trained to treat the human as a whole person. Sari Altschuler (2018) has argued this is part the result of the Flexner Report removing the study of humanities and empathy from the healthcare setting, suggesting that humanistic ways of knowing are essential to effective medical care.

The strong emphasis on research and biomedical studies and lack of the humanities in medical school education has impeded empathetic medical care and effective communication between the physician and patient. The Flexner Report re-institutionalized the medical education curriculum, in order to streamline medical research, discovery, and implementation. It set up physicians' exclusive access to study, research and privilege to save lives, cure diseases, and dictate how to live longer with a healthy lifestyle. This exclusivity of knowledge guarantees physicians' power over the care of the human body and subject the body to the orders of the physicians' discretion. In addition, physicians have an upper authoritative role over their fellow healthcare associates (Starr 5). Since the American Medical Association purpose establishes and maintains the high qualitative standards of medical school infrastructure patients and hospital colleagues willingly submit their autonomy to the physicians and rely on the physicians' discretion in regard to medical decision making (AMA, 2019). The result of the physician authority over the body is the loss of personal, empathetic, humanistic communication, for the physician's minds have lost the "[employment of] their imaginations and literary form in the service of human health" (Altschuler, 2018, p. 202). Instead of the localized physician within a designated town or neighborhood, a majority of physicians collect at a central and/or major hospital and are ideally strangers to patients—further losing that personal connection and desire to get to know patients, especially if the hospital is located in a major city such as Nashville, TN (Starr 18). Even though medical students study a multitude of specialties within a designated teaching hospital, the curriculum lost the empathetic connection and humanistic care of a

person's body that can only be taught through medical humanities or literature (Altschuler, 2018, p. 199). Hence, there is a dire need to reinstall the value of the human body, not just the biomedical mechanics of the body.

### *Empathy and Literature*

The Flexner Report's advocacy for science and research-based information disrupts the humanistic understanding of the human body. Biomedical studies became the norm, meaning people must seek medical care for any irregular functioning of their body (Herzlich & Pierret, 1984; Lupton, *The Lay Perspective*, 2003; Lupton, *The Social Construction*, 1999). Then, with the implementation of specialization of physician professions, each specialty was scientifically trained to view, analyze, and treat the body through their own medical lens. As Annemarie Mol demonstrates in her ethnography, *The Body Multiple* (2002), one disease cannot be singularly defined but rather consists of multiple definitions depending on the *enactment* of objects within a hospital's practice. For example, atherosclerosis pluralizes to *atheroscleroses* because of the multiple practices of the disease being diagnosed, treated, observed, communicated, contradicted, measured, felt and understood by the patient, and associated amongst various hospital settings. The epidemiologists, physiologist, internists, surgeons, general practitioners, radiologists, and pathologists vary their observation and action of treatment of atherosclerosis enacting on the body. Furthermore, the objectification of the body becomes multilayered and subjected to further scrutiny of the advancing technology within each medical specialty despite the fact it is one disease. The multiplicity of analyzing an illness effects the coherency of the illness between the physicians enacting on that illness

Due to the reformation of the medical education system, an infrastructure, as defined by Bowker and Star, has emerged from the Flexner Report. The required characteristics that the new

medical educational systems must adhere to thus changed the doctors that were attending, learning the medical profession, and graduating into the world to practice medicine. However, because of this power that the Flexner Report's infrastructure required as advancing medical research and health sciences, these doctors have lost that communication and empathy between them and their patients. Luckily, there has been a new mode of literature emerging in society known as narrative medicine, which challenges the infrastructure of the Flexner Report by attempting to bring back the humanities to medical education. Rita Charon argues that training physicians in Narrative Medicine could reestablish the lost trust and empathy between the physician and patient. Training in narrative medicine in conjunction with the biological sciences can bring back, the empathetic characteristics of doctors.

### *Narrative Medicine*

Narrative medicine has been an intervention within medical education, disrupting its current infrastructure that emphasizes scientific competency. In response to the reduction of studying medical humanities, Rita Charon developed a field titled "narrative medicine" to train physicians in narrative competency. In her book, *Narrative Medicine: Honoring the Stories of Illness* (2006), she defines narrative medicine as "medicine practiced with narrative competence to recognize absorb, interpret, and be moved by the stories of illness" (vii). She continues by claiming what "medicine lacks today—in singularity, humility, accountability, empathy—can in part be provided through intensive narrative training" (viii). Charon established a graduate program at Columbia University that offers multidisciplinary courses "including core courses in narrative understanding, the illness experience, the tools of close reading and writing; focused courses on narrative in fields like genetics, social justice advocacy, and palliative care; electives in a discipline of the student's choosing; and fieldwork" (Columbia, 2018). The program

immerses the students in learning, analyzing, testing, and practicing narrative medicine in the medical setting. While acquiring narrative competence may sound daunting, it is the progressive step towards improving the quality of compassionate medical care. Gaining narrative competence can “[open] up practice...its implications reach to the...health professions training programs for professionalism and humanism in healthcare...as well as the structural routine aspects of routine medical practice” which positively interferes with the current medical education infrastructure (Charon, 2006, p. x).

Rita Charon’s narrative medicine exemplifies the literary resistance against the lack of humanistic quality care founded within medical institutions and education. Because of the restructuring of medical and anatomical knowledge within a designated teaching hospital, there is a division between acquiring this bio-scientific knowledge and humanistic knowledge that attends to “the ordinary human experiences that surround pain, suffering and dying” (Charon 7). By disrupting the authoritative lack of empathy produced by the medicalization of the human body, narrative medicine encourages physicians to consider the entirety of their patient’s story to understand the body in the context of individual lived experience. Narrative medicine recognizes the value of telling the lived illness experience and advocates for a different knowledge for physicians and society alike: narrative knowledge.

Narrative knowledge resists the physician’s objectification of the human body because this knowledge can be gained by the general population. It is through narrative medicine that narrative knowledge can be achieved. Charon argues that physicians need to “enter the world of their patients if only imaginatively, and to see and interpret these worlds [of illness and disease] from the patient’s point of view” (9). To do so, physicians need to *listen* to their patients and understands each patient’s individual circumstances. Narrative knowledge, which includes an ability to listen carefully to patient stories, “enables...the individual to understand particular

events befalling another individual, not as an instance of something that is universally true but as a singular and meaningful situation” (9). Understandably, mastering the listening and interpreting skills necessary to imagine someone else’s experience is challenging. Throughout physicians’ rigorous course memorization and intense research lab hours, the training of perspective and phenomenology has ceased. However, authors such as Altschuler advocate for humanistic competency—“which include narrative, attention, observation, historical perspective, ethics, judgment, performance, and creativity”—to reclaim the vital necessity of the medical humanities (Altschuler, 2018, p. 200). Instead of dismissing imaginative creativity, Charon uses narrative medicine to teach physicians to listen before treating. Just as literature has the power to equalize interactions between the reader and the story, narrative medicine can also equalize the relationship between the physician and patient, creating a more collaborative relationship that understands the many ways that the illness affects a person’s life, not just their body.

Narrative medicine employs literary works to teach narrative knowledge aimed to compliment the scientific knowledge that is central to medical schools’ curriculum. Listening to and imagining the patient’s situation is challenging because it requires the physician to relinquish some of their authoritative power to the patient. However, submitting oneself to another’s situation fosters a trusting relationship, resulting in effective and high-quality care. It is important to emphasize that the medical knowledge taught in medical schools should not lighten because practicing medicine is the physician’s occupation, so they should have substantial knowledge and understanding of the body to care for the body. However, administering that knowledge and the perspectives of viewing patient bodies need to be reestablished. Literature is the best teaching tool medical students can use to master the art of narrative knowledge, for Charon upholds the uses of autobiographies to divulge the imagination of the reader. Charon explains:

This growing narrative sophistication has provided medicine with new and useful ways in which to consider patient-physician relationships, diagnostic reasoning, medical ethics, and professional training. Medicine can, as a result, better understand the experiences of sick people, the journeys of individual physicians, and the duties incurred by physicians toward individual patients and by the profession of medicine toward its wider culture. (2001a, para. 11)

Arguably, memoirs, particularly illness memoirs, offer more because not only do they reveal the experience of illness, but, more importantly, they are accessible to a wide population, not just physicians.

While narrative medicine particularly targets physicians by training them in empathetic communication with their patients, narrative medicine and knowledge can benefit patients as well. Communication is undoubtedly bi-directional in every relationship, including the physician-patient relationship. Through practice, the physician will learn to holistically listen to their patients' lives and influences, effecting their treatment, diagnosis, and plan for curing their patients. Additionally, the patient needs to trust their physician enough to clearly express their emotions, feelings, and body's functions. If the patient cannot communicate their body's experiences properly, then the physician cannot effectively utilize their narrative knowledge and care for that patient. Despite continuous practice and expression of narrative knowledge towards a patient, if the patient does not communicate their ailments, the physician becomes frustrated and will most likely give up on that patient, continuing the disconnect of the physician-patient relationship (Kripalani, Yao, & Haynes, 2007). Hence, the patient needs to acquire narrative knowledge too.

In order for patients to acquire narrative knowledge, narrative medicine needs to include literature that is accessible to the lay-patient. The National Center for Education Statistics

(NCES) concluded the 2003 National Assessment of Adult Literacy (NAAL) conclude in the 2003 NAAL study that 14.5% of adults lack Basic Prose Literacy Skills (Kutner, Greenberg, Jin, & Paulsen, 2006; Korelitz & Sommers, 1975; State, 2003). This is equivalent to 1 in 7 Americans aged 16 and older cannot “read anything more challenging than a children’s picture book or understand a medication’s side effects listed on a pill bottle” (Kutner et. al., 2006; Toppo, 2009, para. 1). Typically, the patients that need the most care are the ones that are uneducated (Graham & Brookey, 2008) because they cannot comprehend the health information presented to them particularly the highly academic, complicated terminology within the medical field. If patients cannot read and understand their medical diagnosis and treatment plan, they will not follow through the physicians’ orders—reducing their chances of being cured but increasing their chances of physicians will give up on them (Kripalani et. al., 2007).

In addition, illiterate patients have difficulty communicating their ailments to their physicians (Graham & Brookey, 2008; Kripalani et. al., 2007). If patients cannot effectively explain their varied feelings, pains and overall differences of their everyday functioning of their bodies to their physicians, it results in misdiagnosis and an endless cycle of medical tests producing negative results, frustrating the physicians and dismissing the patients. Therefore, narrative medicine and its implementation of narrative knowledge should include a literary genre that effectively provides that academic, intimate, personal, direct health explanation of illnesses that is accessible for physicians and patients of the lower literacy caliber. Illness memoirs are the literary genres that fulfill these requirements.

## Illness Memoirs Overview, Hunger and Sick

### *Defining Illness Memoirs*

Illness memoirs are a literary genre that fulfills and expands the goals of narrative medicine as mediums to communicate the experience of illness that medical schools and their scholarly formulated texts ignore. More broadly, memoirs focus on a specific event or occurrence in the author's life. In fact, memoirs are “not only well-researched accounts of real-events or experiences but also artful narratives...[employing] literary techniques...including distinguishable first-person voice, posing questions, and often injecting uncertainties and ruminations into their factual texts” (Kirby & Kirby, 2010, p. 22). Caroline Levine's *Forms: Whole, Rhythm, Hierarchy, Network* (2015), informs how critics should analyze these affordances—voice recollecting the illness, the setting, chapter titles, etc.—of an illness memoir. As Lisa Diedrich explains in her book, *Treatments: language, politics, and the culture of illness* (2007), illness memoirs are impactful because they tell “the subjective experience of the ill and dying body” (Diedrich, 2007, p. 8). Memoirs are an effective genre for writing about illness because they are, literarily accessible, entertaining, and insightful—leaving the reader with narrative knowledge about the experience of illness.

Scholars of illness narratives and the experience of illness provide qualitative explanations of how vital writing and reading illness narratives impact perspectives, and how illness memoirs structurally allow authors to express their experience of illness. Arthur Kleinman distinguishes between illness and disease in *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988). He argues that illness is “the innately human experience of symptoms and suffering” and “the lived experience of monitoring bodily processes” whereas disease is the practitioners' theoretical lens they have learned in medical school to diagnose, treat, and hopefully cure the present body (4). Disease is technical and objectifying, while illness is the



living experience through a body. This distinction importantly differentiates individual and biomedical understandings of illness and disease. Kleinman's definition of illness as lived experience explains why Arthur Frank insists that illness needs to be told in a literary fashion. Illness itself is a call for stories, Frank argues, because narratives help to create meaning out of the experience. Illnesses need a story-like form so that the bodies explaining that experience have the freedom to reveal the multilayered complexities of the "wounded body" (Frank, 2013).

Lenore Manderson explains it better stating that illness narratives "offers [readers—whether physicians, patients, and the general public--] access to the physical, emotional and social dimensions of disability" or the disability of the "normal" body (39). The authors have that choice to voice their daily livings of their illnesses in a way that might not follow the typical, happy-ending of cure or restitution. Rather, illness narratives can tell anything *but* the literary cannon of illness, where the stories told *through* the "wounded body...[which] sets in motion the need for new stories when its disease disrupts the old stories" of illness as described in biomedical textbooks (Frank, 1995, p. 2). Furthermore, illness memoirs begin the conversation of discerning the differences between the language of disease that is taught in medical schools and the experience of illness that is communicated in illness memoirs. Frank perfectly concludes the necessity of illness memoirs as he argues for

the *need* of ill people to tell their illness stories, in order to construct new maps and new perceptions of their relationship with the world...the *embodiment* of these stories: how they are told not just about the body but through it...[and finally] the times that the stories are told in: how social contexts affect which stories get told and how they are told. (3, emphasis in original)

Because the lived experience of illness is both social and individual, illness narratives can serve to facilitate understanding of that experience in ways that biomedicine cannot.

Both Gay's and Khakpour's illness memoirs demonstrate the multiple layers encompassing an illness that are typically left out of medical school research and biology studies. Memoirs give authors, like Gay and Khakpour, the freedom and affordance—a term that Caroline Levine borrows from design theory “to describe the potential uses or actions latent in materials and designs,” pushing authors and readers alike to incorporate “both particular constraints and possibilities that different forms afford, and the facts that those patterns and arrangements carry their affordances with them as they move across time and space”(6) –“to create empathetic bonds between [the authors] themselves and their listeners” (Frank, 1995, p. xii). The author and reader can take a literary text and focus on the specificities of techniques and how they add to the product of the text itself and its benefits with literary and social spaces. In addition, the design of the text proposes its own affordances, or qualities, that bolster the understanding of the text. The reader can examine how one literary technique has its own history of usage, how it is used in a text, the explicit interpretation of the technique, and how it benefits the text as a whole to advance the text beyond its own historical, social, and political contexts. Gay and Khakpour both experiment with the form of the illness memoir to not only expand the narrative medicine practice to physicians but also relay their illnesses to the everyday readers or potential patients.

Memoirs—at their foundation—disclose an author's personal segmentation of their life, and Gay and Khakpour apply this ideal by highlighting their illnesses and their lived experience in an unruly body that defies traditional narrative structures. Khakpour details her experience of Lyme affecting her body and life as a continuous search of the unknown, just like the disease itself. From the first page of her illness memoir she states, “[t]he hardest part of living with Lyme disease for me has always been lack of concrete ‘knowns’ and how much they tend to morph and blur over the years, with the medical community and public perception and even

within my own body. To pinpoint this disease, to define it, in and of itself is something of a labor already” (1). By putting her at the forefront of her illness memoir, she welcomes readers into her story but cautions them about the journey because of the tribulations that lie ahead. At the same time, Khakpour is claiming her Lyme disease as *her* disease, noting to her readers that she alone has the authority to tell *her* story. Her opening suggests that it will not be a tidy story, but one lacking “concrete ‘knowns’” and resolution.

Gay’s memoir similarity establishes Gay as the authority in her own experience. Her first chapter is a two-sentence ringer that states, “Every body has a story and a history. Here I offer mine with a memoir of my body and my hunger” (3). Bluntly, Gay’s memoir announces itself as an illness memoir by directing the reader’s full attention to her body and her hunger. Gay’s second chapter emphasizes that the “story of her body is not a story of triumph...[her story] is simply, a true story” and it is her true story of her “super morbidly obese, according to your body mass index, BMI,” body (4, 11). Like Khakpour, Gay authorizes her story of her “super morbidly obese” body claiming it as true and *hers*, informing her readers her reliability as the author.

Both authors claim their stories as their own, granting them the literary to tell their stories as they see fit, challenge the “facts” of medical school education. Their authority as the authors of their own stories promotes Charon’s initiative of narrative medicine—medicine and health is not the same experience for everyone like you see in a textbook. Their experiences are their own, but they provide valuable information for their readers, whether they are a patient or a physician. These two illness memoirs give voice to illness experiences that resist the objectification and simplification of biomedicine. Written in a non-linear and complex form these illness memoirs tell a version of illness that defies tidy narratives structures and allocates space for bodies deemed unruly by biomedical fields of healthcare. These stories of illnesses cannot be fully embodied in biomedical textbooks and lab research that the Flexner Report promotes. Rather

they can be found in illness memoirs such as Roxanne Gay's *Hunger* and Porochista Khakpour's *Sick*.

*Illness Memoirs Reestablishing the Author's Illnesses Voices and Perspectives*

As Arthur Frank explains in his book *The Wounded Storyteller*, "Illness [is] not just the topic of [an illness narrative author's] story; it [is] the condition of [the author] telling that story...through a wounded body" (2). By telling the story through their "wounded body" the author gains control and authority of that body, making them a reliable source or author of their illness narrative. Furthermore, this authority translates crucial information for physicians and patients to comprehend because it is through sickness that bodies may be deemed as "lesser" or inadequate, reducing the body and coincidentally the person inhabiting that body, to that illness. Thus, the person is lesser or inadequate raising issues of blame and social health constructions of curing that body. These are issues that are textually exposed in Gay and Khakpour's memoirs.

Early in her illness memoir, Gay quickly establishes the authority of her wounded body:

To tell you the story of my body, do I tell you how much I weighed at my heaviest? Do I tell you that number, the shameful truth of it always strangling me? Do I tell you I know I should not consider the truth of my body shameful? Or do I just tell you the truth while holding my breath and awaiting your judgement? (6)

Gay contemplates these questions because she knows the social implications and the horrid images that will appear in readers minds when they read her weight of 577 pounds (6). Obesity has that social stigmatization—especially in the United States—as an ugly illness for which the individual is to blame. Popular narratives portray it is the person's fault that they are obese because they aren't exercising or eating correctly, becoming recognized as lazy, out of control, and worthless. Through her illness memoir, Gay can express that she *knows* how she should feel about her obese body, but she authorizes that it is not how she *actually* embodies her obesity.

Through the illness memoir, Gay reclaims her body's voice by revealing her trauma of being raped by her boyfriend and his friends at only twelve years old (14). With this reveal, Gay's obesity is seen from a different point of view that probably never would have been recognized if she did not share her rape trauma. In fact, throughout her memoir, whenever she encounters or interacts with a physician, she does not disclose her rape and its trauma. She does not even tell her family of the violation of her body because she feels like she has to maintain the "good girl" image (46). But because Gay reveals, that she

splayed out in front of [her boyfriend, Christopher, and] his friends...[becoming] a thing, flesh and girl bones with which they could amuse themselves...[with Christopher] just unzip[ing] his jeans and [kneeling] between [her] legs and [shoving] himself inside of [her]...[and then] [a]ll those boys raped [her]. (42-43)

readers can come to understand her experience and her sheer desire to hide herself with food causing her obesity. An experience leading to obesity that would not be discussed in a biomedical textbook.

Readers are captivated by Gay's direct and impactful word choice as she reveals her struggling relationship with food and weight as an obese black woman. Her readers sympathize with her confessions of knowing food and its ability to "become more solid, stronger, safer...[be] undesirable [so she] could keep more hurt away" (15). This new piece of information triggers her uncontrollable desire for food and the beginning of her body's story—the non-linear, non-successful, and incredibly complex story of an obese body.

As she divulges the numerous contexts of obesity in her illness memoir, Gay gains her voice and authority over her body, providing her and her readers a newfound narrative with which to understand obesity. Narrative medicine encourages "getting inside the patients' mind" or "seeing the illness through a patient's mind" so that physicians who treat obesity can be more

aware of an obese patient's situation and ultimately invent a treatment plan that aligns with the necessary treatments each particular obese patient needs (Charon, *Narrative Medicine: Honoring*, 2006). Furthermore, through Gay's voice, obese patients and the general audience will comprehend that there is not a simple solution to weight loss and that maybe there are other factors affecting their own weight gain. Gay concludes within the last pages of her illness memoirs "I am using my voice, not just for myself but for people whose lives demand being seen and heard" because this story will not be found in the biomedical textbooks, but in Gay's illness memoir (303).

Porochista Khakpour gives voice to her own bodily experience, demonstrating a foundation of narrative medicine practice: that no illness narrative is truly the same. Khakpour understands that Lyme disease is a diagnosis that's extremely difficult to test for as she experiences throughout her countless physician visits. Having an un-diagnosable illness as an Iranian woman growing up in an increasingly Islamophobic United States after the attacks on 9/11, her body is repeatedly disregarded or made "lesser" than. In one of her early encounters with a physician and nurse during one of her Lyme relapses, the physician and his nurse did not take her illness symptoms seriously (22). Rather, upon the physician's refusal to test Khakpour with an MRI to detect her Lyme disease he offered "his half smile" and it was followed by "[Khakpour's] rage" (22). Because no one took her and her Lyme diagnosis seriously, she was routinely dismissed. Her body was rejected from treatment because the physicians lacked understanding of toll that Lyme disease takes on the body and the person. This lack of understanding on the part of biomedicine results in a frustrating, draining process in which Khakpour is dismissed as an "unruly" body. Thus, Khakpour resorts to other means to live her life to ease her suffering: cigarettes and drugs.

Khakpour wanted something positive to cling onto in her life because all she ever has been and known is being sick. Therefore, the second she moved away from her life in California across to country to Sarah Lawrence University in New York for college, she bought her first package of Marlboro Reds and quickly became addicted (44-45). Soon she began consuming drugs such as heroin, cocaine, marijuana, and ecstasy “[enjoying] it more than [she] thought [she] would--it was like coffee but the high was very positive for [her] then, no anxiety at all in the mix...” (47). Khakpour is desperate to find herself and her body that has always been unknown to her and drugs just became her solution. However, physicians did not see her consuming illegal drugs the same as she did. Rather, they instructed her to stop because their reasoning is that her illnesses and emergency room recurrences are because of her addiction (44). Therefore, Khakpour’s illness memoir allows her to reveal this information to us and explain that because she did not know her body or how to properly care for it, she resorted to means that gave her a sense of authorship.

Writing her illness memoir has effectively given Khakpour’s voice and authorship of herself and her body back. This memoir routinely hints that Khakpour knows her illness more than her physicians and the family and friends she interacts with. Her ability to distinctly detail her routine insomnia and other body failings like “a dark blanket of smoke, unchanging, unbreathable, thick, immovable: depression” (107). Her weight rapidly drops “in five-pound chunks due to chronic diarrhea, [and her] hands would shake so hard [she] could barely hold a glass of water,” yet physicians would prescribe her the same medication such as Nurotonin and Klonopin—benzodiazepines—which did not combat her body’s failings (107). Physicians, family, friends, and therapists would see her body continuously fail and Khakpour would quite distinctly email her body’s reactions and emotions “[writing] them as a person who could not be

helped, who knew this, and could live with just being heard, a sign of still being alive somehow,” yet they all would not understand why Khakpour is still sick (175-177).

This illness memoir exposes the powerful utilization of language and its ability to convey the body’s illness—in this case Lyme—effectively while showcasing the lack of true care and understanding by physicians and patients or the general population. Essentially, Khakpour voices the reasons why narrative knowledge is needed within the medical field, especially illness memoirs because they expose the details of illnesses so that better diagnoses and treatment plans can be made. Since Lyme disease is particularly difficult to diagnose via biomedical tools, illness memoirs provide the authorship of those with Lyme disease like Khakpour to discuss their body’s doings and feelings so that it can be better recognized and treated.

#### *Illness Memoirs Afford the Non-linear Narrative*

Illness memoirs reveal that illnesses and the bodies that they affect are varied and complex, which strays from the biomedical textbooks physicians and patients initially read. Rather than standardize, illness narratives particularize. Furthermore, since every author tells a different narrative of an illness, it becomes more vital for illness memoirs to be read in order to comprehend the vast range of experiences a body endures with an illness. Instead of telling an illness narrative with a clear beginning, middle and end—like most stories do—or follow a well-researched, disease curing result, these illness memoirs transcribe the detours, the mishaps, the interfering people and physicians that affect their deemed “perfect medialized solution.”

In *Hunger*, Roxanne Gay structures her illness memoir as a kind of stream of consciousness, constantly diverting from the current conversation—even as she discusses her own personal retellings of her illness—exemplifying the non-linearity of an illness experience. Because it is *Gay’s wounded body* retelling its “truth”, it’s only fitting that she forms her memoir with interruptions of the social contexts of obesity or explain a different event relating to the one



she currently retells just like how a body's mind would recollect its story (303). When Gay does this, she forefronts the idea that there is no correct way to write about a body experiencing an illness. Thus, she is illustrating to physicians and patients that no two stories of the same illness can possibly be the same. Gay further indicates that physicians and patients need to read a broadened collection of illness memoirs of the same illness within their specialty to completely master narrative knowledge of that illness. Confirming this notion, Gay affirms, “[m]y body and the experience of moving through the world in this body has...expanded my empathy for other people and the truths of their bodies,” which is the central problem of the physician-patient relationship (297). Nevertheless, at the start of *Hunger*, she contemplates where to begin her story of her obesity because she does not know how her readers will react (3). She does not know if they will be repulsed, threatened, heartbroken, concerned, eager, anything, she can only trust that her wounded, obese body will tell the story as needed to fully encapsulate the obese illness experience.

Therefore, she starts at the center of the problem: misunderstanding of the physician and patient illness. She recalls the brief story of a previous consideration of surgery that will have her “anatomy drastically altered to lose weight...75% of [the] excess weight within the first year” would be lost and all she would have to do is “fall asleep for a few hours” (7-8). Weighing at 577 pounds the surgery does not seem like the worst idea. If anything, her readers might even be rooting for her to undergo the surgery so she can lose weight, be happy, and anticipate the happy ending. However, Gay diverts from the conversation and abruptly, in two sentences, sneaks in the comment that she was raped before continuing how she feels about her body but does not provide full detail of the traumatizing event all at once (14). Rather she provides bits and pieces throughout the chapter all the while explaining how she experiences her obese body.

In essence her memoir is her mind, which is the control center of *her* body and how *she* opts to describe it, because minds do not always focus on one “thing” at a time. It is interrupted by another stimulus or thought before coming back to its original thought. Gay writes intermittently throughout her illness memoir. Readers are told bits and pieces of her personal experiences of her obese before she interrupts her experience with societal understandings of obesity. For example, in section III of her illness memoir, she begins to illustrate how “[during her] twenties, [her] personal life was an unending disaster” as she gains hundreds of pounds throughout her twenties (115-116). Gay explains how her friends and family would attempt to help her and motivate her to lose the weight; however, by the next chapter she diverts her personal narrative of her overweight body to societal recognition “is constantly and prominently put on display...[and] the subject of discourse” (120). Then, in the next chapter, she begins discussion on the obesity epidemic--what it is, how it arose, and what are people doing to cease the epidemic, etc.—before interrupting with the discussion of televised obese people like *The Biggest Loser* (122-126). This non-linear example of her body exemplifies that her illness memoir “provides different points of access to the cultural elaboration and interrogation of corporeality” (Manderson, 2011, p. 40). Again, Charon argues for the practice of narrative medicine because it teaches physicians to get inside the patient’s mind and Gay obviously does so, emphasizing the value of illness memoirs to be within the narrative medicine genre or literature readings. The non-linearity of obesity—how it occurs, why the treatments do not work, why Gay’s weight continuously fluctuates—told by Gay disturbs the formulated medical treatment equation taught in medical schools and assumed by patients for an immediate cure.

Poroehista Khakpour’s *Sick* has a similar approach of expressing her illness of Lyme disease through her illness memoir, but it is evident that it is not the same, indicating that no illness memoirs can afford being told within the same confinements or structures as the rest.

Each author has to recollect their bodies' story through their own interpretation so that physicians and patients can completely comprehend the multivariable expressions of an illness and react accordingly. Khakpour first opens her illnesses memoir with a predicament. She contrasts between her "seek medical advice" page versus her "Author's Note." Her "seek medical advice" page states,

This book contains my personal story. I am not a medical professional, and, therefore, the inadvertent advice and information I share throughout this book is in no way intended to be construed as medical advice. If you know or suspect that you have a health problem, it is recommended that you seek the advice of your physician or other professional advisor before embarking on any medical program or treatment. (no page number listed)

Despite her giving professional authority of medicine, specifically Lyme disease, to authors, she opts to detail the specifics of Lyme disease in her "Author's Note." She lists factual, biomedical information regarding Lyme disease including that "the disease is caused by a spiral-shaped bacteria (spirochete) called *Borrelia burgdorferi*...[causing] infection of multiple organs and produce a wide range of symptoms" (1). The language might be deemed too elaborate and foreign just like how her next chapter reveals her unknowingness or foreignness of her body *before* beginning her story of where she was last, the latest car crash caused by a Lyme relapse.

Within her elaboration of her illness in her memoir, she also interrupts her illness story by providing historical contexts or personal anecdotes to her situation, such as the cultural issue of islamophobia and her numerous relationships. For example, in her prologue, she recalls the psychiatric experience of her

"first sign of Lyme relapse...[f]irst a thick burnt fog, of melancholy that [creeps] slowly—mornings when [she cannot] quite get out of bed, sticky inability to

express [her] thoughts, hot pangs of fear and cold dread at unpredictable times, a foundation of anxiety, and panic—that fluorescent spiked thing, all energy gone bad, attacking like clockwork around noon daily—all unified toward that endless evil white, insomnia” (8).

And right after, she explains her role as a professor and comforter to her students at Bard College. Because of the “Paris attacks and the new wave of Islamophobia” in 2015, she remained in her office late one Friday night to talk to students (8). Khakpour then backtracks and discloses her extensive email to her friends about her increasing sense of losing control of her Lyme and body—which no one responded—before providing the Lyme disease standard list of prescribed supplements she received from her doctor’s visit (9-12). These interruptions to her story illustrate the situations and people that interfere with her ability to cope with her Lyme disease affecting her body. There is more to being ill with Lyme disease than what is available in biomedical textbooks, and Khakpour reveals these through narrative knowledge.

Even at the end of her illness memoir she diverts from her personal experience of Lyme disease as she challenges her readers to just reconsider the care for those with Lyme disease. Even by titling her last section “On Being a Bad Sick Person” and her first sentence stating “I’ve never been good at being sick” directs attention to how her illness memoir is not like the typical illness narrative that strings perfect events of success of treatments, remaining strong throughout the process, and ending with a cure (Khakpour, 2018, p. 227; Manderson, 2011). Rather, Khakpour’s illness memoir reveals the unruliness of the daily hindrances and failures of the body, her depressions and thoughts of suicides, the fractured relationships she creates, and the challenge for her body to be a “good sick person” or patient within the hospital setting. Khakpour’s memoir affords her to tell the non-linear narrative of her disease, in order for physicians and patients to get a broader sense of Lyme disease through the patient’s mind as the

body endures the illness. A perspective that typically is not disclosed in medical school textbooks. By doing so, physicians and patients expand their narrative knowledge of tactics to diagnose, treat, and build a relationship within the hospital setting.

### *Illness Memoirs Provide the Space for Experiencing Illness*

Quite literally, bodies take up physical space, and for physicians and patients, a body that is ill needs to take up physical and psychological space to best diagnose, treat, and interact with that body as narrative medicine prompts. Illness memoirs allow Gay and Khakpour to emphasize their utilization of space because the experience of illness is all about embodiment and the experience of living in an unruly body. Illness memoirs afford Gay and Khakpour to talk about both physical and figurative space to describe their illness experience, redirecting the body's focus from the textbook facts to the configuration of a body itself.

For Gay, her setting is influenced by her perception of space and how her body particularly takes up that space. Living in an obese body, she cannot *not* be noticed by society. In fact, she takes up so much space that she impedes others, as they have to navigate around her “rolls of brown flesh, arms and thighs and belly” (16). The people moving around her probably don't sympathize with her and her weight. They definitely take notice of her and rather than sympathize, they disgustingly judge. They see her struggling to transfer from one location to the next, they see the perspiration exuding from her forehead, breasts, between her thighs, further highlighting her weight and increasing the disgust and judgment of her body (19).

Gay expresses how she “feels every extra pound [she is] carrying...[and] More often than not, [she] is in some kind of physical pain” (18). This indicates that not only is society recognizing her presence in various spaces, but she does as well because it is her body that she lives in. Her recognition of society judging her body and herself judging her body because of the

large space she occupies, resonates with readers. By printing her highest weight, readers actively picture, or at least attempt to, fathom how large she is. The biophysical marker of weight presents an image for readers, forcing her body and her trauma into her reader's mind and space. Gay is an obese woman to be recognized and take up space physically and psychically, so that she can have the literary space to reveal her rape incident to reshape the current obese illness narratives and improve narrative knowledge to both physicians and patients.

Gay understands her obese illness is not culturally ideal, confessing that "I hate how people treat and perceive me. I hate how I am extraordinarily visible but invisible"—however, by forcing herself to be recognized within her illness memoir setting, she rewrites the obese narrative, expanding the narrative knowledge of obesity (154). For physicians, a typical response is to exercise, eat better foods, and take the appropriate medicine. While physicians have the medical knowledge that losing weight takes time and consistent commitment to the weight loss plan, if the desired results are not seen the physician might refer them to another physician to handle their weight or recommend surgery. Physicians tend to not apply narrative knowledge skills and listen to the whole story about the patient's weight gain and connect with other physicians to manage the root of the weight. Because while it takes time to lose weight, it also takes time to gain weight, especially to a weight of 577 pounds. There has to be an underlying reason to the weight gain. Gay's memoir affords her literary expertise to discuss at length the drowning sensation of being overweight within the cultural context of the world today. Importantly, she reveals her need for food as a comfort for her rape trauma so that her body may ideally be hidden. Reasonably, Gay probably needs to reconcile with her past trauma before attempting to manage her weight loss. This is a message to physicians because Gay's treatment plan cannot simply require a weight loss plan, but also include some therapeutic counseling. All

the while, her doctors should be in communication with each other and with Gay ensuring she is accountable for her specific designed regimen.

Gay does not want to live in a cage anymore and be trapped inside a body that has been victimized. She does not want to feel afraid of her own body because she does not like the body she has. Rather she hungers for a new one and “tastes the idea of being free of the realities of living in an overweight body. [Gay] tastes the idea of being free” (157). *Hunger* allows Gay to at least attempt to free herself from her because she understands the cultural ugliness of her obese body. Gay provides that narrative knowledge for physicians and patients to comprehend the process of gaining weight and losing it.

Khakpour uses setting as a mechanism for her readers and herself to locate and recognize her chronically ill body. Every chapter is titled with a specific city or location and each place tells a different story of her Lyme relapse. These places range from Iran, to Los Angeles, to New York, Maryland, Illinois, back to Los Angeles and New York, to Santa Fe, to Leipzig, Germany, and then back to Los Angeles and New York. I argue that this tactic actually outlines her presence in these locations and spaces. For throughout Khakpour’s memoir, her body is not obstructive to peoples’ transportation paths. Rather, she’s a ghost or she shrivels away as she is “losing weight in five-pound chunks due to chronic diarrhea” (5, 107). Her hands and body shakes but not enough to direct people’s attention to her. If anything, people might even be envious of Khakpour’s slimness, which is the complete opposite of Gay. Thus, Khakpour opts to title her title all of her chapters as actual locations where she endures her Lyme disease. By titling her chapters as places, readers envision her placement in those locations, so that they can see her. All the while, Khakpour can identify her body in these locations and “find a home in [her] body...[going] much deeper than [she] thought, under the epidermis and into the blood cells” (6). In a way, it is as though she actually becomes a Lyme disease herself. She’s

unpredictable, uncomfortable, and leeches on people, if given the chance, to have around in her life so “they can tell you I was real. Sometimes too real” (239).

Khakpour exhausts all of her resources when trying to identify her body in various settings. Everywhere she went, she finds a new physician to consult her symptoms or meets at a new emergency room. However, no matter whom she visited, her test results were inconclusive. As Khakpour’s story continues in a variety of settings, she begins to claim more authority of her ill body, for she routinely asks her physicians to test for Lyme disease. The physicians’ reactions are demoralizing--they laugh, prescribe her the same medications that don’t help her, and they give up on her. Even her boyfriends and mother try to console her and help, but they can only help so much before giving up on her too. Khakpour has no choice but to find other means of identity and self, and she successfully achieves that by locating and defining her presence in various locations throughout her memoir. Khakpour monologues,

And the deal with so many chronic illnesses is that most people won’t want to believe you. They will tell you that you look great, that it might be in your head only, that it is likely stress, that everything will be okay. None of these are the right things to say to someone whose entire existence is a fairly consistent torture of the body and mind (82).

This gets to the heart of what Rita Charon praises about narrative knowledge and the study of narrative medicine. Physicians and patients do not fully grasp the concept of illness until it happens to them. Which is why illness memoirs should be studied within the context of narrative medicine. Authors such as Gay and Khakpour centralize their wounded bodies and the illnesses causing them and how they associate themselves with society as “lesser” and “undesirable.” Illness memoirs afford their authorship to rebuild their identities by giving them the proper literary form to do so.



## Conclusion

Illness memoirs render the experience of living in an ill body transparent so that physicians *and* patients can grasp the deeper contexts of the author's specific illness and realize that the process of illnesses affecting the body is not uniform. Rather, the process is more convoluted, complex, and enduring than expected. Illness memoirs convey the story or beyond-the-biomedical-text-books of *embodying* a specific illness. This literary genre allows the author to convey the brutal failures of their bodies and the loss of identity they feel when their body does not function as a "normal" body. They explain just how unruly their bodies are compared to their societal counterparts, such that there is not uphold the biomedical formula that a cure is possible. The voices the authors provide are truthful to their body's experiences so that physicians, patients, and the general public can try to *understand* and *empathize* with the ill body, and humanize the medical care process, rebuilding the physician-patient relationship.

Roxanne Gay and Porochista Khakpour's books are only two examples of illness memoir that have the potential to teach physicians *and* patients about the experience of living in an unruly body, and thus, provide clearer understandings of that illness while also contributing to narrative knowledge and practice of medicine holistically. By reclaiming their voices, illustrating the non-linearity of the illness experience, and then disturbing the physical and psychosocial spaces of their readers minds, they force their illness experience to be reckoned with. Gay and Khakpour refuse their illnesses to be subjected to the disease story medical schools drill. Thus, they express their illness through an illness memoir and further expand the literary scope of narrative medicine.

Future research can be conducted to continue promoting physicians, patients, other medical administration, and the general public to read illness memoirs. It would be particularly imperative to compare two or more illness memoirs of the same illness. This qualitative literary

analysis will reveal how each memoir expands the narrative beyond the biomedical texts of the specific illness. This study would also advocate for more illness memoirs to be read so that complete narrative competency is a necessity, for each structure and story between illness memoirs will be the same. In addition, this particular comparison between similar illness memoir topics could reveal the genre's limitations.

Scholars discuss “[t]he [p]roblem(s) [w]ith [n]arrative [m]edicine” and its structural limitations of true expression of an illness experience or exclusions of particular individuals based on race, class, gender, access to healthcare services, etc. (Ensign, 2014). Literature has specified formation rules, and the narrative, and illness memoirs are literature, so there are potential truths that cannot be composed within the space of a page, but rather through other means of expression. Gay and Khakpour even push the limitations of illness memoirs because of their ability to represent new insights of obesity and Lyme disease, respectively, which suggests that there could be other forms of expression that could showcase their illnesses better. Narrative medicine currently focuses on literary narratives of health and medicine, but scholars and my two authors imply that physicians, specialists, health administrators, patients, and the general public should look beyond literature. Other modes of art, music, dance, theatre, etc. could be modes of illness experience representation. A comparison between two illness memoirs of the same illness with a non-literary form of expression of that same illness is another analysis that can be studied.

In conclusion, the advocacy to study literature, or the possibility of other modes of expression, within the medical sphere should expand. Literary advocacy should continue to oppose the infrastructure of the Flexner Report that perpetrates miscommunication, inefficiency and discord between the physician and patient. Resulting in effective, true, and complete humanistic-medical care.

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