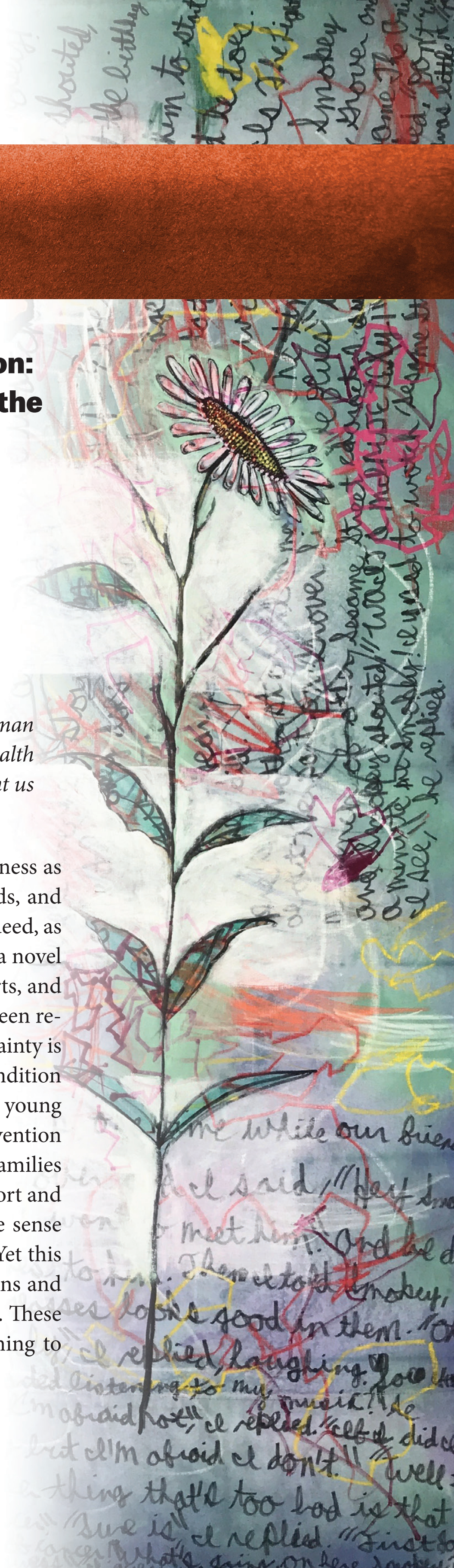


CHAPTER 7

Stories as Clinical Knowledge in Medical Education: Improving Future Physicians' Ability to Thrive in the Midst of Uncertainty

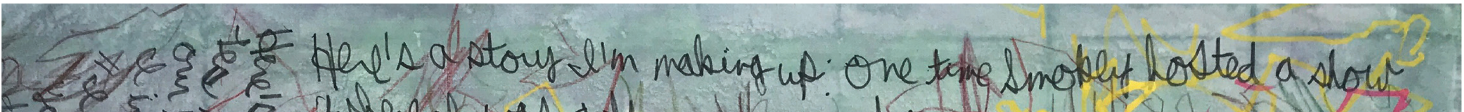
Anna M. Kerr

> *Communication in health and illness constitutes one of the most vital human experiences. Few other human phenomena are more elemental than health and illness: few connect us more viscerally with our aspirations, or confront us more palpably with our limitations.* (Brashers & Babrow, 1996, p. 243)

Humans are confronted daily with the uncertainty of health and illness as they pertain to our own lives and the lives of our families, friends, and communities. Some illness uncertainty is universal and public. Indeed, as I am writing this chapter, our nation is grappling with the uncertainties of a novel virus that has tested the medical community, politicized public health efforts, and exposed long-standing racial health disparities. We are living in what has been repeatedly referred to as a time of "unprecedented uncertainty." Other uncertainty is experienced more privately—by the parent of a child with a rare chronic condition in search of information about their child's future (Kerr & Haas, 2014) or a young adult male with increased BRCA-related cancer risk who faces unclear prevention and treatment options (Rauscher et al., 2019). When patients and their families experience illness uncertainty, they turn to the health care system for support and information. They are seeking medical explanations that help them make sense of their illness experiences and make decisions in the face of uncertainty. Yet this sensemaking work is often unsuccessful for individuals with rare conditions and those experiencing medically unexplained symptoms (O'Leary, 2018, p. 7). These individuals struggle to find traditional medical narratives that give meaning to their experiences, while also finding that their personal illness narrative is not considered legitimate in the medical community (Japp & Japp, 2005).

In this chapter, I focus on the importance of storytelling in situations of uncertainty. This chapter represents a meaningful intersection of my research on illness uncertainty and my teaching in medical education. Indeed, stories are a valuable resource for individuals faced with illness uncertainty and their families (Banerjee et al., 2018) and stories are a valuable resource for teaching medical students to manage medical uncertainty (Ofri, 2017). *Illness uncertainty* refers to "the inability to determine the meaning of illness related events" (Mishel, 1988, p. 225) and stems from ambiguous symptoms, complex treatment options or health care systems, unclear illness severity, and unpredictable prognoses. Individuals diagnosed with chronic illnesses also face uncertainty about the long-term medical, personal, and social effects of their illness. For example, young breast cancer survivors face uncertainty about fertility and future romantic relationships (Miller, 2015). Under these conditions, uncertainty is especially enduring when the information needed to assign meaning, predict outcomes, navigate complex health care systems, and discern possible options is unavailable or inconsistent (Babrow et al., 1998). Through my own research, I have explored the complex uncertainty parents of children with rare vascular anomalies face when information about their child's condition is unknown to them and to the medical community (Kerr et al., 2019; Kerr & Haas, 2014; Kerr, Harrington, et al., 2020). These same parents face uncertainty when their child is stigmatized by insensitive comments from others who are unfamiliar with their child's rare, yet visible, condition (Kerr, Thompson, et al., 2020).

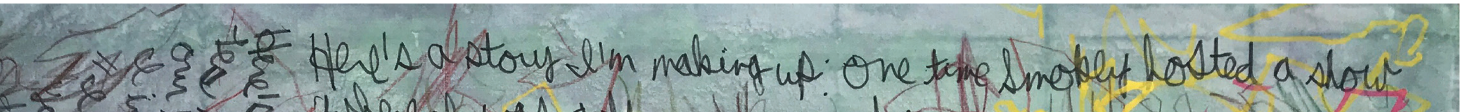
Physicians also experience uncertainty. Physicians experience diagnostic uncertainty when they are unable to accurately diagnose a patient's symptoms (Bhise et al., 2018). Yet physicians' medical uncertainty also includes technical uncertainty stemming from a lack of medical knowledge or skills, conceptual uncertainty resulting from an inability to apply universal medical knowledge to unique patient situations, and personal uncertainty due to a lack of understanding of the patient's goals (Beresford, 1991). A physician's tolerance of this medical uncertainty is represented by their cognitive, affective, and behavioral responses (Hillen et al., 2017). Physicians who are more tolerant of uncertainty respond more positively in ways such as accepting uncertainty (cognitive), remaining calm and hopeful (emotional), and using the uncertainty to facilitate shared decision making (behavioral). However, despite the prevalence of uncertainty in medicine, many physicians feel threatened by uncertainty, responding with anxiety, avoidance, or deferring decision making (Gerrity et al., 1990; Hillen et al., 2017). This intolerance of uncertainty can lead to increased costs and excessive intervention if physicians manage uncertainty by ordering excessive tests, providing more referrals to specialists, and overusing high-technology medicine (Santhosh et al., 2019). Physicians are also



frequently reluctant to disclose their medical uncertainty to patients, their families, and other physicians due to the fear of seeming incompetent (Farnan et al., 2008). This fear stems from both a personal and public expectation that physicians are infallible and that there is no room for uncertainty or error in medicine (Wu, 2000). In some cases, physicians may even suppress uncertainty or create an illusion of certainty in an attempt to preserve trust or prevent face-threatening situations (Katz, 1984). This is problematic given that conversations about uncertainty are central to patient-centered care and shared decision making (Politi et al., 2007).

In her influential text on uncertainty, Fox (1957) described the feelings of stress and anxiety medical students experience when faced with the limits of their own knowledge or the limits of medical knowledge in general. This anxiety is due in part to the quest for certainty (i.e., factual knowledge) that occurs during medical education. Traditional medical education is rooted in the assumption that if students learn enough medical knowledge they will be able to solve every clinical problem (Guenter et al., 2011). When medical education prioritizes factual knowledge as a "badge of honor," it overlooks the importance of teaching students to anticipate and tolerate uncertainty inherent in medicine (Campbell, 2014) and much less to thrive in situations of uncertainty or view uncertainty as a *surmountable* challenge that fosters curiosity and creativity that leads to better patient care (Simpkin & Schwartzstein, 2016). The prioritization of certainty in medical education is problematic given that the actual care students will provide throughout their career is "steeped in uncertainty" (Ofri, 2017, p. 1) and even the most skilled physicians make decisions "in the face of incomplete knowledge, diagnostic uncertainty, and unpredictable individual responses to therapies" (Simpkin et al., 2018, p. 699). Indeed, physicians often struggle to apply seemingly universal facts to the singular patient experience (Montgomery, 2006). Thus, while medical education may help address technical uncertainty by increasing factual knowledge, it does less to adequately prepare future physicians to manage conceptual and personal uncertainty (Beresford, 1991).

Embracing storytelling as clinical knowledge in medical education is one way to improve physicians' ability to not only tolerate uncertainty that stems from the limits of medical knowledge, but to thrive in situations of uncertainty stemming from unique patient circumstances (Montgomery, 2006). Indeed, storytelling in clinical medicine is not a novel concept, stories are pervasive in the practice of medicine. However, there is often a great chasm between *illness* narratives and *medical* narratives. Medical narratives are the biomedical stories of disease that feature clinical and pathological evidence, observable symptoms, and causal explanations (Boyd, 2000). Illness narratives, on the other hand, are the stories of patients' experiences with ill health that feature traditional storytelling elements: characters, motives, scenes, and plots that include medical, personal, social, cul-



tural, and emotional experiences (Sharf & Vanderford, 2003). Illness narratives can exist even when no disease can be found (Boyd, 2000). In the following sections, I review the traditional narratives of medical education and demonstrate how conventional medical narratives often perpetuate narrative surrender and an illusion of certainty. I conclude the chapter by encouraging medical education to use narrative to foster brave spaces for vulnerable illness narratives that serve as training for uncertainty.

Stories in Medicine

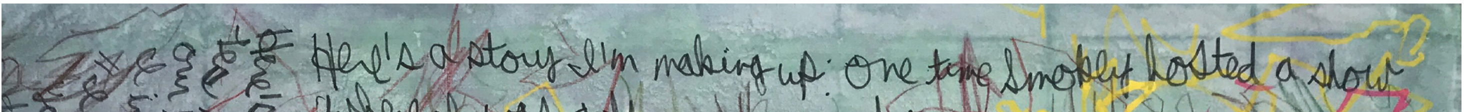
Medicine is fundamentally narrative. (Hunter, 1991, p. 5)

Stories are a central feature in the practice of medicine (Hunter, 1991; Montgomery, 2006). Clinical reasoning involves the construction, interpretation, and dissemination of histories of disease, diagnostic plots, medical mysteries, treatment successes and failures, and even causes of death. In fact, a resident physician's shift in a hospital or clinic is largely organized by storytelling—from the patient's opening statement to the case presentation to the patient chart.

The Opening Statement

"What brings you in today?"

The opening story a patient tells their physician is arguably one of the most important stories in medicine (Hunter, 1991). This is due, in part, to the long-standing recognition of the patient's history as one of the most useful tools for diagnosis (Peterson et al., 1992). By the end of their first year of training, nearly all medical students receive the advice of Sir William Osler, a pioneer of modern medicine and advocate for humanism and compassion in patient care: "Listen to the patient, he is telling you the diagnosis" (Silverman et al., 2008, p. 98). This long-standing belief is the reason that physicians-in-training are taught to open the medical encounter with the question, "What brings you in today?" This question is designed to elicit the patient's story through an opening statement. Inherently, this question is an examination of cause: identifying the patient's reason for scheduling a visit (Montgomery, 2006). The patient's response typically reveals the symptoms that are most troubling, how those symptoms have interrupted their daily routine, and what outcomes they hope to achieve with the help of medical advice or intervention. Essentially, this question allows patients to use their own words to establish what is known in medicine as the "chief complaint." The physician is looking for a detailed and chronological story of the most concerning symptoms. Medical students and new physicians often follow a conventional structure to obtain a patient



history—relying on mnemonic devices to help remember each section of the history that they will need to enter in the chart (Podder & Lew, 2020). Some of the most skilled physicians can masterfully obtain a highly accurate patient history by allowing the patient time to tell their story rather than relying on a series of clinically focused questions (Haidet & Paterniti, 2003).

The Case Presentation

The patient is a 14-year-old girl presenting with a two-year history of chronic, constant, knife-like periumbilical pain, without associated medical signs or symptoms. Formerly an A-student, she had not attended school for six months. She reported difficulty falling asleep "because of the pain," but slept through the night. She denied stressful life events, emotional distress or a history of physical or sexual abuse. Multiple physical examinations, complete blood count, liver function tests, erythrocyte sedimentation rate, C-reactive protein, urinalysis, abdominal computed tomography scan, and colonoscopy yielded normal values. Results of her gastroenterological, urological, and gynecological consultations were also normal. The patient and her parents believed that the pain stemmed from an underlying organic cause, despite reassurance that organic factors had been ruled out. The patient was referred to an interdisciplinary medical psychiatry team for evaluation.[1]

Case presentations as medical narratives are considered the primary means of thinking and knowing in medicine (Montgomery, 2006). As an undisputable narrative act, the case presentation is a result of the physician engaging in narrative emplotment—organizing the patient's response to the opening question and the findings of the physical examination into a coherent plot, while connecting these therapeutic events to the broader context of the patient's life (Mattingly, 1991). Case presentations are constructed to help physicians organize, record, and share medical information.

An effective case presentation starts with the individual patient and synthesizes patient and physician stories from the visit into one biopsychosocial story (Fortin et al., 2012). The plot of these stories serves as the justification for the diagnostic hypotheses, known as the differential diagnosis, and treatment recommendations presented. When the details of the case presentation are consistent with existing illness scripts (i.e., known disease symptoms and patterns) physicians are able to confidently rule in (or out) certain diagnoses and make treatment recommendations based on the known course of the illness (Charlin et al., 2007). Developing a case presentation requires a narrative-based approach to medical interviewing that incorporates both the biomedical perspective and the patient's perspective (Haidet & Paterniti, 2003). Therefore, the effective case narration requires "the

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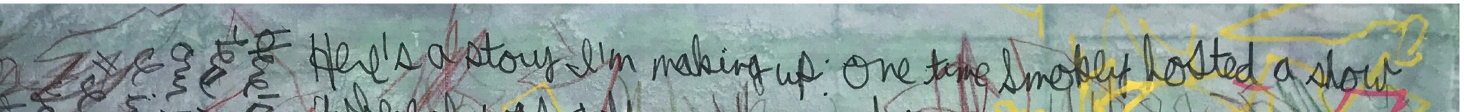
[1] Case presentation from Geist, Weinstein, Walker, & Campo (2008)



elicitation of useful information from the patient, the performance of a good physical examination, a focused and parsimonious use of tests, the prescription of efficacious therapy with minimal harm to the patient, and attention to the psychological, moral, and social problems that may arise in connection with the illness and its treatment" (Montgomery, 2006, p. 50). In essence, when done well, the result is a case presentation that moves effortlessly between "chart talk," during which the disease is the main character, and storytelling, which refocuses the clinical problem in light of the patient's unique experience with the disease (Mattingly, 1991).

The Patient Chart

`PATIENT:` `Doe, Jane M.`

`DOB:` `Apr 09, 2006` `Age: 14`

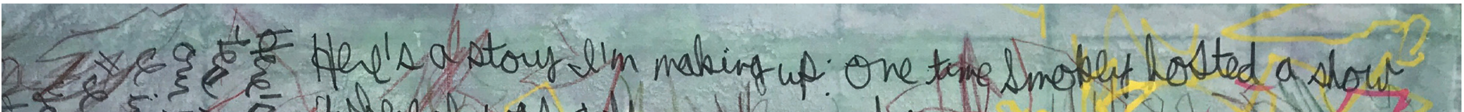
`MRN:` `0123456789`

`CC:` `abdominal pain`

`HPI:` `Constant knife-like periumbilical pain started 2 years ago. Multiple physical examinations, complete blood count, liver function tests, erythrocyte sedimentation rate, C-reactive protein, urinalysis, abdominal computed tomography scan, and colonoscopy yielded normal values. Results of her gastroenterological, urological, and gynecological consultations were also normal.`

The case presentation is an oral presentation of the progress notes that make up the patient's chart, which becomes the official story of the patient's illness (Frank, 1995). Alongside the patient's chief complaint, history of present illness, results of laboratory testing, orders for prescription medications, and the patient's medical, personal, and family history, the physician adds notes in the medical chart about their most recent visit with the patient. The note is the physician's opportunity to tell the patient's story from their own perspective and in their own voice (Fins, 2008). Dr. Joseph Fins recalls,

> Although we had all been trained in the architecture of the medical note and the progression from Chief Complaint (CC) to History of Present Illness (HPI) on down to Assessment and Plan (A/P), each of us did it a bit differently. Each of us had our own voice. I recall marveling at the charting styles of my colleagues and professors: the long,



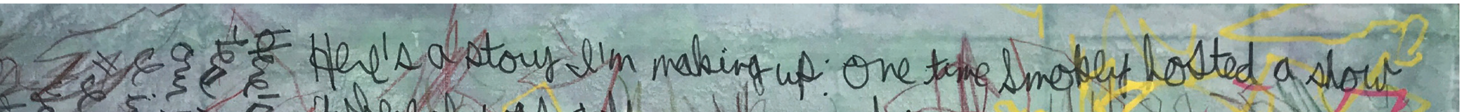
> obsessively complete note of the intern versus the almost aphoristic musings of the attending—the former chock full of unorganized information, and the latter synthetic in its encapsulation of the problem and plan of action. And in that transition, through our writings in the medical record, we all learned how to think as doctors. (p. 37)

These progress notes can help the physician "to discover thoughts, feelings, perceptions" related to the patient's illness (Charon, 2005), to prepare for patient visits by reminding them of previous visits (Koopman et al., 2015), and to facilitate conversation about the patient with other medical professionals (Moros, 2017).

Medical Education and Narrative Competence

During their first two years of medical school, students learn the form and content of these medical narratives as effective history taking, case presentation, and medical documentation are all required competencies of graduating medical students (Hammoud et al., 2012). Their education includes the structure of a traditional progress note, or SOAP note, which organizes the patient presentation into four categories: subjective (patient's complaints), objective (vital signs, physical exam findings), assessment (synthesis and possible diagnoses), and plan (treatment plan including medications, referrals, education) (Podder & Lew, 2020). These note-writing skills prepare students to deliver an oral patient case presentation while on clinical rotations—a narrative activity they are required to do multiple times per day. This practice helps students learn how to organize their thoughts, how to discern what information is clinically relevant, and how to narrow the information down to a problem list that will inform that plan of care (Holmes & Ponte, 2011). As a narrative genre, case presentations have a conventional structure and language that is widely accepted in the medical community (Hunter, 1991). Over time, students learn the linguistic and narrative skills needed to deliver a case presentation; their mastery of the required structure, inclusions, exclusions, and interpretations needed to engage in effective clinical reasoning is what helps them transition from student to future physician (Holmes & Ponte, 2011).

The narrative act of case presentation is central to students' ability to learn clinical reasoning, or the process by which physicians connect symptom patterns with possible diagnostic hypotheses that they test to reach a final diagnosis (Eva, 2005). Clinical reasoning is often likened to solving a mystery. Hunter (1991) compared the physician's clinical reasoning to Sherlock Holmes' process of organizing clues of a crime scene into a hypothetical narrative explanation. Holmes masterfully connects microscopic details with environmental and personal factors to construct a story that makes sense of the crime scene, reveals probable motives, and

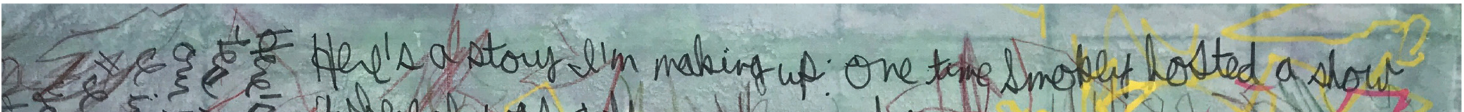


identifies possible suspects. Much like Holmes, physicians should use an interpretive clinical reasoning process to determine a medical diagnosis that incorporates the patient's story with the illness scripts. However, medical students are commonly taught to rely on analytical and algorithmic (rather than interpretive and creative) models of clinical reasoning (Eva, 2005). They are taught to only include the elements of the patient's story that support the hypothesized diagnosis and minimize any details that are not directly associated (Holmes & Ponte, 2011). This linear process assumes that patient's symptoms will fit neatly into the illness script of a known disease process and that diagnosis solely requires the physician to have an a priori understanding and ability to identify the characteristic features of each disease process.

This approach to clinical reasoning does not adequately prepare students to handle the situations where the patient's symptoms do not match an illness script. In their analysis of student case presentations, Lingard et al. (2003) found that medical students avoid expressing uncertainty or go to great lengths to disguise it. Students' reluctance often stems from the fact that they view uncertainty as a shortcoming of their own medical knowledge and do not acknowledge that uncertainty stems from external factors such as limits of clinical evidence, limits of professional agreement, and limits of scientific knowledge altogether (Fox, 1957). However, their reluctance to disclose uncertainty is also a result of how they were trained to deliver case presentations: distill the uncertainties of the patient's experience, the physical exam findings, and the complex medical history down to a recognizable illness script. Thus, rather than being an interpretive or creative narrative act that incorporates the voice of the patient with the voice of medicine, the case presentation becomes a persuasive narrative act that provides evidence for the most convincing diagnosis (Holmes & Ponte, 2011). This approach to medical education primes students to look narrowly for clinically relevant facts in the patient's story that serve to confirm or discard their hypotheses. This narrow medical gaze results in what Arthur Frank (1995) described as narrative surrender and contributes to an illusion of certainty.

Narrative Surrender in Medical Narratives

The opening statement, case presentation, and patient chart represent common medical narratives, yet their form and function often stray far from true storytelling (Hunter, 1991). Despite the prevalence of stories in medicine, narrative has often been deemed "the antithesis of all that is believed to be scientific" (Montgomery, 2006). Medical students are taught the importance of the case presentation, while also being cautioned against anecdotal evidence. In many ways, the exclusion of the anecdote is an attempt to restrain the narrative features of medical stories—purposefully excluding the irrelevant, emotional, or unclear. For example,

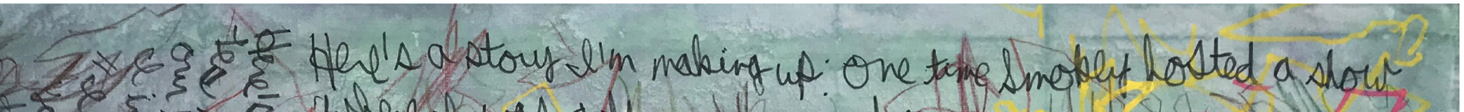


the patient's opening statement typically does not sound like the rich and complex illness stories that they share with friends, family, and even strangers outside of the medical encounter about a confusing symptom, missed diagnosis, or miraculous recovery. Instead, the patient's opening stories are sterilized accounts of events that the patient considers relevant to their current complaint or illness (Hunter, 1991), based on the cues they receive from physicians about what type of information they should share (Sanders, 2009). In turn, the physician becomes the "spokesperson" for the patient's story (Frank, 1995, p. 6), which then "pulled and shaped in its medical retelling into a flattened, only distantly recognizable version" (Hunter, 1991, p. 6). This prioritization of medical narratives over personal illness narratives by both patients and physicians is known as narrative surrender (Frank, 1995). The suppression of the personal illness story can lead to an *illusion of certainty* in medical narratives when it involves imposing biomedical structure onto complex patient narratives. This serves to prioritize stories that fit into a predetermined clinical framework and excludes patient stories that are chaotic or those told by an "unreliable" narrator.

Narrative Types and the Illusion of Certainty

Narrative provides a way to make sense of experience. Stories provide particularly important ways of understanding when unexpected, unpleasant, ambiguous, or uncertain bodily experiences challenge what had previously been taken for granted or when we experience our body in significant new ways. (Babrow et al., 2005, p. 45)

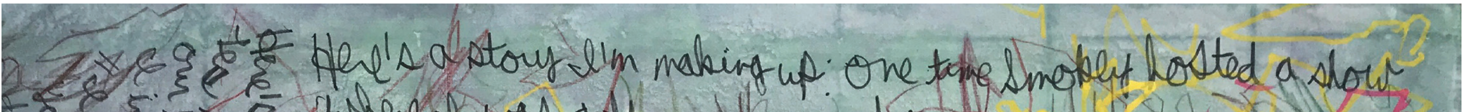
Frank described three forms of illness narratives told by the wounded storyteller: restitution, quest, and chaos (1995). The *restitution* narrative is the predominant storyline in medicine. The story begins with a healthy person who became ill and, with the help of modern medicine, regained their health. The stories typically highlight test results, anticipated outcomes, competent physicians, and innovative treatments. Ultimately, in these stories, medicine is the hero because it intervened in a known disease story, a predictable chain of cause and effect based on the patient's symptoms, to shorten the illness story and give it a happy ending (Montgomery, 2006). As the most prevalent narrative in medicine, the restitution narrative has become the accepted structure for illness narratives (Frank, 1995). In everything from hospital brochures to direct-to-consumer prescription drug commercials we are exposed to narratives about medical intervention helping patients get back to work full-time, back to playing with the kids, and back out on the tennis court. They all return "back to normal." When the restitution narrative is the prevalent illness narrative in medical education, students may be more likely to pursue unnecessary tests and procedures when they enter practice in an attempt to fix every clinical problem. For example, medical narratives often frame disability in a way that teaches students that disabilities are something to be fixed to help the



patient return to "normal" functioning (Goering, 2015). While most patients enter into medicine with the hope that medicine will be able to intervene and alter the outcome, the restitution narrative does not resemble those narratives told by individuals living with complex chronic illnesses for whom "total recovery" or "back to normal" are virtually impossible, or for those whose "normal" was part of the ensuing health challenges (e.g., those addicted to opioids). These patients and their families often hope for just a handful "good days" in the midst of ongoing pain and suffering (Titus & de Souza, 2011). Therefore, "the restitution narrative limits sensemaking for patients whose illnesses are chronic and enduring—providing no narrative framework for them to rely on" (Frank, 1995, p. 94).

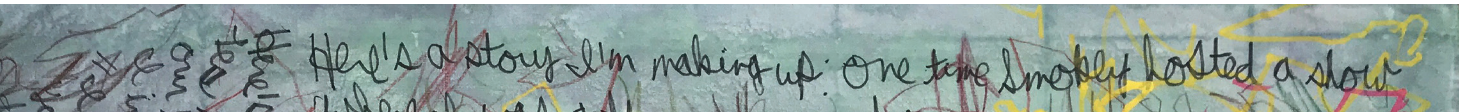
The *quest* narrative represents the story of the chronically ill person (Frank, 1995). Chronic illness acts as a biographical disruption in a person's life (Bury, 1982; Corbin & Strauss, 1987). After the diagnosis, patients must find ways to manage this disruption and effects it has on their identity, roles, relationships, and future. Illness narratives enable young adult cancer survivors, for example, to engage in biographical reconstruction by allowing them to engage in sensemaking, create order and regain agency, (re)establish identity, build community and awareness, and warrant decisions (Iannarino, 2018). When these chronic illness narratives take the shape of a quest narrative, the disruption of chronic illness is "reframed as a challenge" (Frank, 1995, p. 128) during which the patient engages in self-discovery, overcomes obstacles, and offers support and wisdom to others who may be on the same journey. It is no surprise that quest narratives are the dominant voice of illness memoirs; rather than representing the triumph of medicine, they represent the triumph of the patient. They also fill the space of many online advocacy groups. For example, the "pink ribbon discourse" of breast cancer advocacy groups focus on women who overcome the odds with courage, gratitude, hope, and strength (Hochstetler, 2016). Patients often share stories referring to their diagnosis as a gift and in an effort to offer inspiration to other survivors. In the context of pediatric cancer, this type of narrative can help some parents come to recognize their own strength as a caregiver and maintain hope for their child's future (Bally et al., 2014). However, Barbara Ehrenreich (2001) suggests that this type of "brightsiding" can actually marginalize the harsh realities of cancer and cancer treatment. When medical education overemphasizes quest narratives, it can silence, and even shame, the voices of individuals who do not identify as "fighters"—those who are faced with enduring uncertainty, pain, and suffering as a result of their illness (Hochstetler, 2016).

Finally, the *chaos* narrative is the story of the person suffering and struggling to imagine life getting any better (Frank, 1995). For example, parents of children receiving cancer treatment express chaos narratives when they feel a loss of control that results in doubt, fear, and uncertainty about their child's future (Bally et al.,



2014). This chaos narrative often emerges when the child transitions to a new, unfamiliar treatment. Unlike the teller of the restitution narrative who praises medicine for giving them a happy ending, the teller of the chaos narrative is cautious of medical intervention, concerned that the institution of medicine is denying their suffering and going to great lengths to give the illusion of certainty and control (Frank, 1995). Chaos narratives are also the plot of stories from individuals who receive no medical explanations for their symptoms, report inadequate care from health care providers, or lack support from family, friends, and their community (Zheng et al., 2013). The chaos narrative lacks sequence and causality; it is the antinarrative (Frank, 1995). The stream-of-consciousness of the plot (e.g., "and then, and then, and then") means that chaos narrative is susceptible to interruption—both by the teller who interrupts in an effort to tell the story and the listener who interrupts due to the lack of narrative order. Physicians may be averse to the chaos narrative because it challenges many of the conventions of modern evidence-based medicine. As a result, they try to impose structure and direct the patient's narrative to a plot more similar to a restitution narrative, focusing on interventions and outcomes, or a quest narrative, reminding the patient to be a fighter and to stay positive. This push to "move on" minimizes the experiences of the patient and can further intensify the chaos and suffering (Frank, 1995). Chaos narratives are rarely used in medical education, and their exclusion silences the experiences of individuals with medically unexplained symptoms (Rausch, 2020) and discredits patients whose stories are disordered or tumultuous due to the vulnerability of suffering.

Medicine's prioritization of clinically relevant stories that resemble restitution narratives can result in students considering the teller of the chaos narrative to be an unreliable narrator. An unreliable narrator is a literary term used to describe a character who "is biased, makes mistakes, lacks self-awareness, tells lies not of substance but of form" (Craig, 2020, p. 93). An unreliable narrator may be untrustworthy—judged with skepticism by an audience forced to make sense of discrepancies in the story (Olson, 2003). On the other hand, the narrator may simply be fallible—prone to mistakes and holes in their stories. The fallible narrator is more likely to be forgiven by an audience. In film, literature, and theater, an unreliable narrator is a tool used to alter the believability of the narrative and require audiences to consider alternate points of view (Craig, 2020). A well-known unreliable narrator in cinema is Edward Norton's character in David Fincher's film *Fight Club* who tells us a story that turns out to be untrue (Anderson, 2010). In medicine, however, the unreliable narrator trope refers to the patient whose symptoms do not align with clinical indicators or whose reports of pain or other symptoms are inconsistent or even contradictory (Craig, 2020). Physicians may label these patients as "poor historians" by documenting their inconsistencies in the medical chart. This label, like the label "noncompliant," makes a judgment about the patient based on how well their experiences and behaviors align with medical nar-



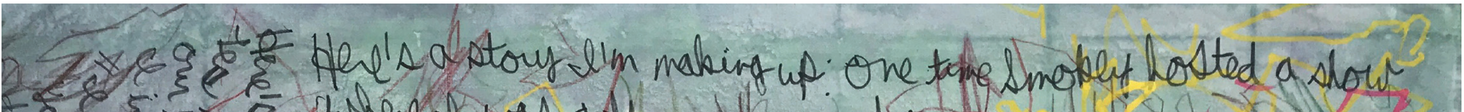
ratives and ignores the possibility that their unreliability is actually a result of the "vulnerable spaces that arise from narrating suffering" (Craig, 2020, p. 93). Thus, we do not give the fallible narrator the same grace in the exam room that we do in the pages of a novel. Chaos narratives are often overlooked in research (Beck et al., 2005), and even more so in the health care system. But these are narratives of real people whose stories are often ignored because they lack resolution.

Embracing Vulnerable Narratives in Medical Education

"*The need to honor chaos stories is both moral and clinical.*" Arthur Frank (1995, p. 109)

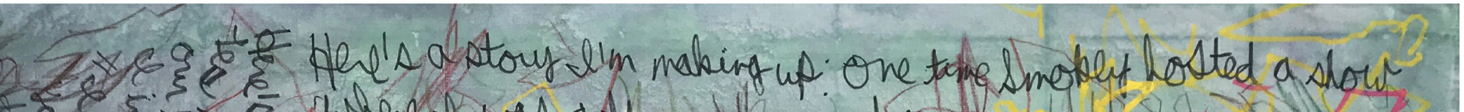
Narrative pedagogies in medical education can help future physicians engage in brave space-making during the medical encounter that honors brave and vulnerable patient stories; to deny these stories is to deny the experiences of the individuals faced with great chaos and uncertainty (Frank, 1995). Storytelling is the primary way for individuals with medically unexplained symptoms to make sense of the uncertainty of illness, yet their story is repeatedly rejected by institutionalized medicine (Rausch, 2020). While these patients may receive medical services and treatment, they are robbed of the benefits of an empathic therapeutic relationship with their physicians (Frank, 1995). While our students are trained to diagnose and treat patients, diagnosing and treating can only address a small portion of patient suffering (Epstein & Back, 2015). Students must learn to recognize that suffering is not only physical, but emotional, social, spiritual, existential, and financial and it is conveyed through more than just the expression of emotion; patient suffering often manifests in inconsistent illness narratives or difficulty finding the words. Patients living in the midst of chaos and uncertainty may not know how to tell their story, how to ask for help, or even how to accept help (Frank, 1995). When medical students are not taught to tolerate this chaos and uncertainty they may be paralyzed in the face of it (Fox, 1957). They may dismiss the suffering or assign a psychological diagnosis that allows them to suggest a course of treatment in an attempt to regain control of the narrative (Frank, 1995). Instead, if medical students truly want to help their most vulnerable patients, they must learn to be humble witnesses to the chaos story; accepting chaos as a part of the illness story. This requires students to learn narrative skills that extend beyond the content and structure of a SOAP note and case presentation.

The rapidly expanding field of narrative medicine aims to improve medical students' narrative competence, or "the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf" (Charon, 2001, p. 1897). This approach to medicine acknowledges that "scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering" (p. 1897). Physicians who study literary texts, in addition to scientific texts, deepen their abilities to absorb, interpret, and re-



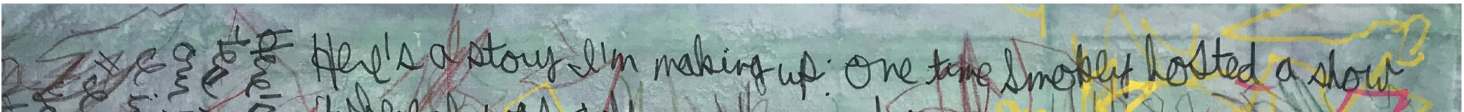
spond to the stories of others. These literary ways of thinking help individuals adopt contradictory points of view, embrace the metaphorical as well as the factual, and be moved by what they hear (Charon, 2001, 2006). Indeed, narrative medicine does not involve simply listening *to* patient stories, it requires obtaining the narrative knowledge needed to listen *for* patient stories (Charon, 2006). When medical students are taught to listen *to* patient stories, they learn to look for clinically relevant pieces of the story that confirm or refute a diagnosis. When physicians listen *for* patient stories, they draw from their narrative understanding of plots, characters, setting, tone, and point of view to understand each patient's unique experience. Rather than minimizing uncertainty and inconsistencies, they highlight the ambiguity and complexities that characterize the singular experience (Charon et al., 2016). The field of narrative medicine has shown the value of narrative pedagogy in medical education (Charon, 2017). Relying on chaos narratives is particularly valuable because "conceiving suffering as pedagogy, agency is restored in ill people" (Frank, 1995, p. 145). By equipping students with the knowledge of chaos narratives, they are better prepared to listen *for* chaos narratives and to understand the meaning illness has for the suffering patient.

As a faculty member at the Ohio University Heritage College of Osteopathic Medicine, I teach medical students about eliciting a patient's story and writing an effective SOAP note, but I have also had the opportunity to be involved in educational programs rooted in storytelling and aimed at improving students' narrative competence for witnessing stories of chaos, uncertainty, and suffering. Since 2008, students at Ohio University have participated in the *Confessions of a Reluctant Caregiver* Palliative Educational Program, a drama-based educational experience created by Merri Biechler, an award-winning playwright and Dr. Tracy Shaub, a palliative care physician. The program includes a staged reading of Biechler's play *Confessions of a Reluctant Caregiver*, which is inspired by Biechler's real-life experiences as a caregiver and addresses many of the complex palliative care principles Shaub found difficult to teach students in traditional educational formats. Students watch as the main character, Mae, who previously lost her mother to cancer, navigates caring for her dying father. The play incorporates themes such as caregiver stress, end-of-life care options, the paradox of a "good" death, physician stress, the language of disease and treatment, and navigating the health care system (see Kerr, Biechler, et al., 2020). At times, the story shifts into a chaos narrative—both the main character and her father are overwhelmed by their situation, frustrated with the futility of medical treatments, and angered by the disruption cancer has caused to their lives and identities. After the staged reading, the students participate in a facilitated discussion with the actors, palliative care physician, and playwright. This discussion provides an important opportunity for reflection, which is an important aspect of palliative care education and helps students grapple with the more humanistic aspects of care (Borgstrom et al., 2016).



The evaluation surveys confirm that students and practicing physicians considered the program to be more valuable than traditional didactic approaches in medical education (Kerr, Biechler, et al., 2020; Kerr et al., 2021). Participating was an emotional, albeit positive, experience for participants, and they reported more comfort discussing end-of-life issues and more confidence in their understanding of end-of-life care after participating. Drama-based learning opportunities, like *Confessions of a Reluctant Caregiver*, improve students' narrative competence through a process of narrative transportation, or total immersion into a story and the experiences of the characters (Busselle & Bilandzic, 2008; Green, 2004; Green & Brock, 2000). Highly transported individuals experience sympathy for the characters, and when those individuals' emotions mirror the emotions of the characters, their capacity for empathy increases (Bal & Veltkamp, 2013; Busselle & Bilandzic, 2008; Oatley, 2002). Even fictional stories, like the one presented in *Confessions of a Reluctant Caregiver*, allow students to engage with characters and be influenced by their experiences and behaviors (Busselle & Bilandzic, 2008). Thus, fictional stories representing chaos narratives can help increase students' ability to honor patients' stories characterized by suffering, vulnerability, and uncertainty.

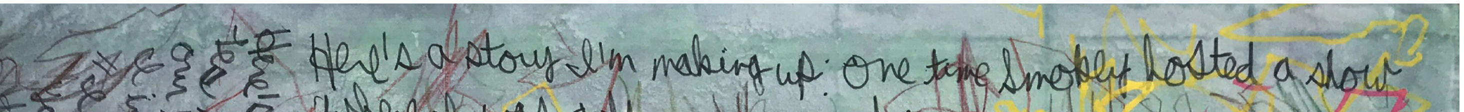
Ohio University's medical students are also given the opportunity to participate in an elective known as The Open Book Project (OBP): A Narrative Medicine Program for Social Justice and Inclusion (Casapulla et al., 2020; Harter, 2019; Harter, 2020). The OBP curriculum teaches students the narrative medicine skills of close reading, radical listening, and reflective writing (Charon, 2017) through examinations of art, literature, poetry, scripts, and even a patient's scrapbooks. The weekly sessions cover topics ranging from cultural roots, pain metaphors, dismissal, passing, and the disruptions of chronic illness (Casapulla et al., 2020). These sessions provide students and facilitators a space to share their own stories and listen to the stories of others—increasing their capacity for empathy and perspective taking. In one session, students pair up and engage in a radical listening activity during which the teller verbally responds to a prompt for five minutes while the listener listens with the goal of retelling the story. During those five minutes, the listener does not take notes or listen for specific information; the listener suspends their own assumptions and biases and listens with the intent of absorbing, interpreting, and honoring the teller's story (Charon, 2005). The listener then retells the story, writing what they heard using the teller's own words, structure, and tone—including complexities, contradictions, and ambiguities. This radical listening activity introduces students to one of their most powerful clinical interventions: "silent witnessing of a patient's suffering" (p. 100). The skill of radical listening teaches students to embrace a patient's chaos narrative rather than interrupting it or attempting to direct it into a restitution narrative. The skill of radical listening ultimately helps students foster an affiliation with patients, which increases their investment in their patients' well-being (Charon, 2015). As narrative pedagogy,



the OBP "positions narrative competence as integral to the process of attending to and joining with another who suffers" (Casapulla et al., 2020, p. 3).

Narrative pedagogies also increase medical students' affiliation with their peers and strengthens the strong bonds they will develop with their physician colleagues (Charon, 2005). In fact, students often crave the connection that is fostered through the collective witnessing of stories. Two students at Ohio University's medical school acted on this desire for connection by harnessing the power of the stories of their peers and creating an annual event titled *Behind the White Coat (BTWC): A Night of Storytelling* (Polakampalli & Nandyal, 2019). The event was inspired by *The Moth*, a nonprofit organization that hosts storytelling events to create a space where people can share and be heard. The founders of *The Moth* advocate that listening to stories can strengthen a community when its members realize what they have in common. During the BTWC event, students share stories that extend beyond the scope of medical school and reveal significant moments—big or small—about loss, growth, love, family, tragedy, and regret with their peers. These are stories students are rarely given an opportunity to share within the traditional structure of medical education where conversations center on preparing for board exams and sharing high-yield study resources. Yet they are stories that can help them connect with their peers while confronting the harsh realities of illness and death, coping with the stressors of medical school, and creating their professional identities (Charon, 2001). At some institutions, students are given opportunities to reflect on issues related to patient care or professional ethical conflicts, but are rarely afforded opportunities to share personal tragedies or triumphs (Torppa et al., 2008). This student-created storytelling event makes space honors the stories of medical students, which prepares them to honor the stories of their patients.

In addition to these cocurricular programs, storytelling can be integrated in medical education by assigning more qualitative research articles and incorporating patient and caregiver panels. The prioritization of quantitative research in medical education means that physicians are often unfamiliar with qualitative research methods and struggle to evaluate qualitative evidence and integrate it into their own practice (Kuper et al., 2008). Integrating qualitative research articles into medical education can help students understand how patient stories can inform clinical reasoning and patient care (Braun & Clarke, 2019). For example, when students learn about the Down syndrome, they benefit from reading the practice guidelines for communicating a Down syndrome diagnosis established by the National Society of Genetic Counselors (Sheets et al., 2011). However, when students read mothers' stories of receiving their children's Down syndrome diagnosis (Lalvani & Taylor, 2008), they begin to grasp the importance of their communication in framing the meaning of the diagnosis and the meaning of disability for the patient. Yet students can learn the most when they are able to hear from patients and

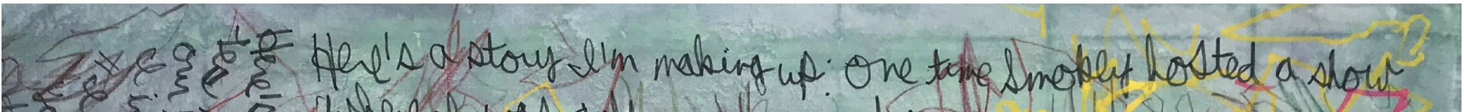


caregivers themselves through patient and caregiver panel presentations. These educational opportunities that involve real patients and caregivers can help students understand what it is like to live with a chronic condition (Moreau & Eady, 2017), and also learn to accept there is no one-size-fits-all illness narrative that represents the patient experience.

Stories as Training for Uncertainty

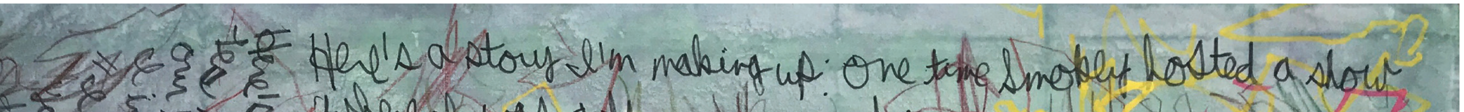
The goal of this chapter was to highlight the pervasiveness of uncertainty in patients' experiences of illness and the practice of medicine, while revealing how common medical narratives ignore this uncertainty in an effort to maintain control and predictability. Indeed, much of medical education involves drawing boundaries within broad topic areas and reducing complex medical knowledge down to high-yield facts (Slinn, 2019). This pedagogical strategy is useful for helping students learn the sheer volume of information needed to practice medicine. Yet, when the same approach is taken with patients' stories, the stories are reduced down to familiar medical narratives that would be virtually unrecognizable to the person whose story it tells (Hunter, 1991). Medicine's desire for coherence and certainty ignores the fact that all human stories are "partial and indeterminate" (Harter et al., 2005). A patient's illness story does not begin when they enter the medical encounter—it is situated in the middle of an ongoing life story (Hunter, 1991). Likewise, stories are not seamless; they are told to create meaning of out of disparate events and, therefore, are inherently characterized by seams, gaps, weaknesses, and unraveling threads that are used to weave new stories (Babrow et al., 2005). Integrating narrative pedagogies can teach students to embrace, rather than resist, these imperfect and unraveling stories and to resist imposing structure that burdens patients by focusing narrowly on unattainable recovery and problematic conceptualizations of normalcy (i.e., restitution narratives) or perpetuates discourses that place unrealistic expectations on patients to be perpetually strong and optimistic (i.e., quest narratives). These narrative pedagogies can also help minimize the burden of certainty that medicine imposes on young physicians—allowing them to (re)learn the interpretive and creative clinical reasoning skills needed to thrive (and help their patients thrive) in situations of uncertainty.

Learning medical knowledge does help medical students learn to cope with uncertainty because they start to gain "a more complete picture of medicine and a better understanding of how the different disciplines relate to each other" (Fox, 1957, p. 218). The knowledge helps them understand the language and the common disease pictures of clinical medicine and the terminology needed to deliver an effective case presentation. But as they enter patient care they will be faced with the enduring uncertainty that arises when they must apply these solid-seeming facts to individual patients (Hunter, 1991). This chapter suggests that the ideal resolution



for this gap is personal illness narratives as pedagogy; as narrative "bridges the gap between rule and case" (p. 46). Most importantly, to truly improve students' ability to embrace the possibilities of uncertainty in patient care, chaos narratives must be incorporated into medical education as they represent the experiences of those patients who are excluded and marginalized by the health care system. When chaos stories are appreciated as a way of knowing in medicine, students will learn that uncertainty is inevitable and legitimate (Fox, 1957), and their most suffering patients will be afforded the benefits of a truly empathic therapeutic relationship (Frank, 1995).

As faculty in a medical school, I have navigated this tension between the voice of medicine and the voice of the "lifeworld" in medical education (Mishler, 1984). The influence of the hidden curriculum on students' attitudes about patients is evident at times (Hafferty, 1998), and the students' desire for high-yield board-relevant content is clear. Yet my students have also expressed their frustration with one-size-fits-all approaches to patient communication that they feel is too rigid and reductionist in situations that are highly emotional and uncertain. I am repeatedly reminded of my students' capacity for witnessing human suffering, grappling with uncertainty, and embracing vulnerability. I have witnessed firsthand how the power of stories can foster connection between the medical student and patient, medical student and faculty member, and between medical students. What is most important is that I am in position where I can make space for brave and vulnerable stories that can prepare my students to care for suffering patients. Integrating patient stories into medical education does not teach students to disregard the medical knowledge they have obtained; instead, students learn the skills to respond to suffering, to make decisions in the face of uncertainty, and to learn from their patients stories (Frank, 1995). This comprehensive understanding of medicine as more than just a science can help medical students *to know* and *to treat* the patient.



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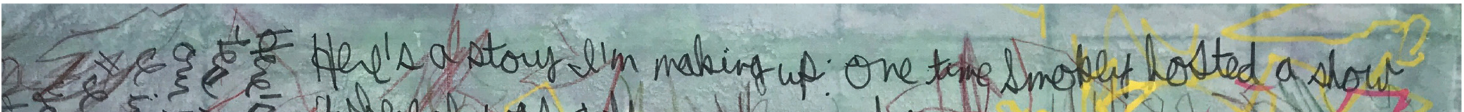

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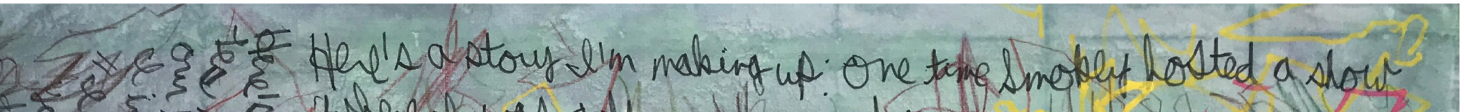

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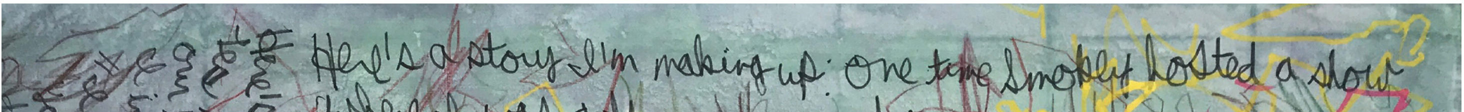

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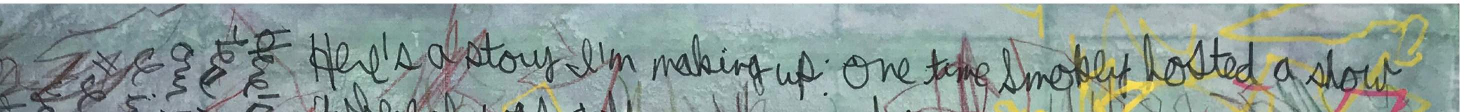

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Supplemental Classroom Resources

The Open Book Project: A Narrative Medicine Program for Social Justice and Inclusion

1. *Defining Moments* (Season 1, Episode 10): Inclusive Healthcare and Social Justice: Disrupting Racial Inequalities Through Narrative Medicine with Tracy Shaub, DO.
2. *Defining Moments* (Season 2, Episode 2): Physician Shortages in Medically Underserved Areas: Fostering Inclusive Healthcare Through the Rural and Urban Scholars Pathways Programs with Sharon Casapulla, EdD and Alyssa Gerth, DO.

Behind the White Coat: Medical Student Storytelling Event:

1. Behind the White Coat Website
2. Behind the White Coat YouTube Library