THE ETHICAL IMPERATIVE OF NARRATIVE CARE: THE NECESSITY OF APPLYING NARRATIVE SKILLS TO CLINICAL & BIOETHICAL PRACTICE

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ABSTRACT

Medicine and bioethics today are though as fields of pure logic, reasoning, and science, with physicians and ethicists trained to approach patients with an attitude of detatched rationality. In reality, neither medical care nor ethics can be practiced well without an acknowledgement for their deeply emotional, relational, and narrative qualities. Medical care and bioethics must both be practiced through a narrative lense in order to truly meet the humanity of both patients and practitioners. There are practical methods to integrate narrative skills into clinical practice, as well as tangible benefits to doing so. Practially, this is performed through narrative medicine: an approach to medical care that recognizes the stories as a critical component to healthcare; as well as narrative ethics: an awareness of the essential role of narrative in moral understanding. Using narrative as a tool to understanding illness and moral grounds the more abstract and universal aspects of both in practical, individual reality. There are many practical aspects of narratives when applied to bioethics, such as aquiring narrative skills, what happens when stories are shared, recognizing how narratives are built, how they convey knowledge, organize life, and provide meaning. Illness creates an isolation – for both patient and practitioner – and stories allow each to express their experience and be supported though the stories of others. Stories help brigdge the gap in experiences of illness between practioner and patient while helping pracitioners to maintin their empathy in the face of continual suffering. Narrative skills are also useful for practioners to bring awareness to the power dynamics that influence patient stories, such as the power of practitioner as co-creator, whose voice is given credibility, external and internal

influences on a story, who determines the meaning of a story, and how the patient is characterized within the story. Narrative permeates every aspect of human life, including medical and ethical situations, and approaching both through a narrative lens is imperative for the development of true understanding, empathy, and compassion. Cultivating a narrative framework towards illness allows both practioners and patients to be cared for while also caring for the other, thus creating deep, meaningful connections.

DEDICATION

This thesis is dedicated to medical trainees who have been chastised for
spending a few extra minutes listening to a patient.
To spend your time, especially when you don't have much of it,
is the most precious gift you can give another.
To listen is to care.

This thesis is dedicated to medical trainees who have been told
that narrative medicine will make them "soft".
To recognize the suffering in another person and within oneself is an
act of bravery and strength.
To amplify the voice of your patients is your duty.

This thesis is dedicated to Dr. Daniel Schadt,
from whom I received both my love of medicine and of stories.
His example of care, compassion, and dedication to his patients
has been my compass through my training,
which has kept me true to myself and my patients.

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PRELUDE: A SURGERY APPLICANT'S STORY

The interviewer was a woman this time. Not sure why it's important, I guess I just kept getting the comments from male interviewers so I wasn't really expecting it from her. Internalized ideas about women being softer, more talkative, etc. She asked me the question I've gotten in every interview: "I see here on your application that you're involved in "narrative medicine". I'm not familiar with that term, can you tell me what that is exactly?" So I gave her the answer I'd given on every other interview day, at least ten times by now. I start by telling her what narrative medicine was to me in general: the idea that stories are a vital part of medicine, that stories are how we understand our patients, our fellow healthcare workers, and ourselves; that they allow us to form deeper connections, guide clinical decisions, and process what happens in our lives. I talk about the academic kind of narrative medicine, mention Rita Charon and her works, I feel it's important to do this to give some credibility to what i'm saying, to prove to this data-oriented surgeon that half of my CV isn't just let's-sit-around-and-talk-about-our-feelings-kumbaya-hand-waving, but rather a legitimate academic field, built on a foundation of literary analysis, philosophy, anthropology, and ethics. After I've established narrative medicine as something she should take seriously, I begin to talk about my own experience. I tell her that I've always loved stories. When I was a child I thought I would be an author because I liked to read so much that it just made sense to me that I would write books. I tell her that this love of stories came from my grandfather, an internist who inspired me to pursue medicine, who would sit me on his lap on Sunday and we would read together. He taught me that medicine and stories are interconnected,

even though I didn't know that's what I was learning at the time. I tell her how I learned to practice narrative medicine in my preclinicals through electives and workshops. I tell her about the structure of a workshop: reading a piece, the discussion, the writing. I talk about my transitions from participating to leading workshops; how I learned more about the pieces I choose from my peers when we read them together than on my own. I talk about the elective where I sat with patients and listened to their stories; just 30 minutes of a conversation made me realize just how much lies under the surface of our H&Ps. I talk about the impact that close reading skills have had on my conversations with patients in the hospital, how approaching them with a narrative lens helps me see more facets of their experience beyond their medical care and how doing so lets me connect with them deeper and provide better care. I speak about narrative medicine as resilience training; mention how writing helped me process my time in the hospital in the early pandemic. In an effort to seem accomplished and impressive, I quickly regurgitate my resume: mention the conference (organizational and leadership skills), story slam & grand rounds (public speaking skills), minor publications (there's nothing faculty love to see more than publications, right?). Now that I have spent half our time passionately expressing the ethos, pathos, and logos for narrative medicine, I sit there, winded, waiting expectantly for my interviewer's response. "Well I've never even heard of narrative medicine before, but from your description of it I'm surprised that you want to go into surgery, it seems to me that this kind of interest would be better suited for a career in internal medicine. I'm not sure it's applicable to surgery". This is not the first time I have gotten a comment like this during an interview ("Surgical patient encounters don't leave room for this type of

thing", "Maybe you should go into family med or internal med if stories are your passion", "Sounds more like an internal medicine thing to me, but I guess you could make it work in surgery."), so I am ready. Although I'm a bit crushed by yet another surgeon dismissing the importance of narrative care, and in some ways dismissing me and my interest in surgery, I smile and begin to reiterate about how narrative medicine is vital to all fields, especially surgery. I talk about the applicability of close reading skills to patient encounters that are time constricted, how surgery is often a significant plot point in a patient's narrative and as their doctors we have a duty to acknowledge the context our patients exist in so that we can best treat them. I talk about the increasing problem of burnout among surgical residents, attenings, nurses, techs, and how building narrative skills fosters community and resilience. I remind her that each patient comes to us with a unique past, a present, and a future that informs their health and medical decisions, and we must be able to understand these in order to partner with them in their medical care. We are not treating pathology, we're treating people. After this my interviewer is half-convinced, "I understand the importance, but how will you actually do this 'narrative medicine' as a doctor? How will you have the time for it?" I tell her it's less about spending lots of time, and more about mindset, how narrative skills actually save time by helping you read between the lines in a patient encounter and cut to the important things rather than circling around them or missing them completely. I tell her that journaling takes only a few minutes a day and helps monumentally with my mental health and resilience. I am repeating to her the things I said the first time, then again the second time. These things she missed twice because she didn't fully listen to me because

she didn't believe in what I was saying from the outset. To her surgery is technical, stories are not.

But she is wrong on both accounts. Stories are technical and surgery is not all science and clearly defined guidelines. There is a certain anatomy to narratives: speaker, audience, context, setting, plot, meaning: all of these influence the particulars of a story in such a way that if one changes you have an entirely different narrative. These narrative organs have their own physiology, they interact and influence one another, and as providers we rarely recognize how one aspect affects another, much less even our own impact on a patient's narrative. And to the opposite point, surgery has narrative aspects beyond the Op note. Understanding a patient's narrative helps a surgeon decide how to best care for their patient in the same way it helps an internal medicine doctor: narrative informs us of the unique aspects of a patient's condition and context that allow us to offer them choices and care that fits them specifically. In a medical field mired with ethical complexity, it is imperative for physicians to recognize a patient's unique context, but having examples of other patient narratives can help guide moral and clinical decision making. In surgery, everyone is obsessed with good outcomes. Sure infection, complications, and mortality are fairly standard and technical (although I would still argue that using narrative medicine skills can help us treat patients in ways that will help us reduce these, but that's getting a bit into the weeds), but what are patient satisfaction and quality of life, if not the ending of the story? We can't run a CBC to determine satisfaction like we can an infection, it is the patient who decides. These metrics will be

patient-specific, so in order to achieve them, we must make our care patient-specific. How do we do that? By listening to and understanding a patient's unique narrative.

CHAPTER 1: INTRODUCTION

"Nothing will ease patients's uncertainty in the face of illness, but perhaps their doctors can help them to articulate the uncertainty and thereby live less painfully with it"

- Rita Charon[4]

Part One of Chapter One: Background

Medicine is rooted in science- verified truths about human biology and physiology have become the laws which guide the decisions of physicians. Ethics is rooted in reason-logic and morals, a prescribed way of thinking that is orderly dictates how ethicists draw moral conclusions. In reality, human life is neither lawful nor orderly; rather human lives are composed of a myriad of contradictory stories that are constantly changing, interweaving and clashing with one another. The plots of life stories are not determined by logic or fact alone, but influenced by emotions, circumstances, and factors beyond human control. Sir William Osler, whom many consider the father of modern medical education, promoted an attitude of detachment, in which physicians faced their patients' suffering with an unmovable stoicism, in order to remain objective and clear-minded.[19] This approach has permeated the medical field, with physicians often choosing to view illness as purely pathology, rather than a major event within the unique context of a singular patient's life. Illness at its core is chaos imposed upon a person, and it is a basic

human instinct to attempt to make sense of chaos through stories. People, and whole cultures, for centuries have used narrative to construct their sense of self, communicate with others, and bring meaning to the chaos of life.[2] While medicine often aims at only treating disease, it is at its core, the art of healing people, as the same Sir Osler is credited with the saying "The good physician treats disease; the great physician treats the patient who has the disease"[3]. Medicine is centered on the patient, and is therefore a field of the particular, rather than the general . Physicians cannot truly treat their patients well if they are applying only general scientific knowledge to their situations, in the same way bioethicists cannot truly determine the moral choice if they are relying only on nonspecific, non-contextualized logic. Medicine and ethics must both be practiced with an understanding of the particularity and uniqueness of the person and situation at hand. And how do humans communicate and understand the particularities of their lives with each other? Through stories. The self is constructed through experience, and experience is structured narratively; therefore the identity of a person lies within the continuity of their ever-developing inner narrative.[2] In the context of medicine and bioethics, patients' inner narrative takes the form of an illness narrative, or an account of the personal experience of illness and medical experience.[13] Bioethics must acknowledge the role that both illness narrative and overall inner narrative play in the ethical decision making of patients and healthcare providers alike. This can be done through application of narrative medicine. **Medical care and bioethics must both be practiced through a narrative lense in order to truly meet the humanity of both patients and practitioners. There**

are practical methods to integrate narrative skills into clinical practice, as well as tangible benefits to doing so.

Part Two of Chapter One: Defining Narrative Terms

Narrative medicine is in its most basic form a way of thinking of narratives as a critical component of healthcare.[1] It is the art of practicing medicine with the narrative skills of recognizing, absorbing, interpreting, and being moved by patients' stories of illness.[4] Practically for physicians and ethicists (from this point forward jointly referred to as "practitioners") , it means informing clinical practice through the reading, writing, telling, and receiving stories.[4] There are many aspects of narrative medicine, each rooted in the understanding of the centrality of stories to patient's lives and illnesses. Narrative care is an approach to caregiving that relies on storytelling to promote health through focusing on the unique manifestion of health and sickness in an individuals' life, and roots care within the context of a person's stories, with all their messiness and ambiguity.[2] Narrative care recognizes that the well being of people is shaped not only by the stories they tell about themselves, but also by the stories they are told about themselves by others, and the larger social stories that shape human life and culture.[2] Examples of this in practice, while not explicitly termed "narrative care", are widespread in medicine in the form of support groups and story-based therapy. Narrative medicine and narrative care are based on a foundation of narrative knowledge, which are the skills

used to make sense of stories, which allow us to understand that which is not "fact" but rather a single meaningful event undergone by a unique individual.[4] Engendering narrative knowledge enables a person to understand the plight of another by participating in their story through the complex skills of imagination, recognition, and interpretation.[4] Gaining narrative knowledge allows for an understanding of narrative emplotment, which is the action of the teller sharing their story.[4] The same set of events can be told as many contradictory plots, and narrative emplotment recognizes that a story is colored by the teller's point of view, intentions, stance, and experience.[4] Even though many events are random, unpredictable, and unknowable, narrative emplotment recognizes that a teller seeks to bring meaning through the plot of their story, and that different tellers may find diverging plots and meanings from the same set of events.[4] Thus, an understanding of narrative emplotment makes one less concerned about discovering the "truth" of events, but rather more concerned with understanding the meaning a person derives from a particular set of events within the context of their inner narrative.

Part Three of Chapter One: Narrative Bioethics

Bioethics is concerned with resolving moral issues in the areas of medicine and health-related research. While many reduce its purview to merely biomedicine, it also comprises aspects concerning human dignity, rights, and vulnerability, as well as social

responsibility.[2] The inherently humanistic and cultural nature of bioethics implicitly places narrative in a central role, although it is often not explicitly recognized in classical bioethical practice. Narrative bioethics is a division of narrative ethics related to medicine. Narrative ethics is the idea that narrative in itself is a way of ethical understanding which provides moral education, engenders empathy and moral sensitivity, extends the range of ethical experience, and allows for exploration of different approaches to dealing with a particular ethical situation.[2] Drawing from narrative ethics as well as classical bioethics, narrative bioethics is an ethics practiced from a narrative dimension that extends beyond the usual limits of clinical bioethics to connect biomedicine with medical humanities, philosophy, literature, and ethics.[15] Narrative bioethics takes a hermeneutical approach, which posits interpretation as an ethical activity and means of moral evaluation, creating a more context-sensitive description of moral situations.[15] Classically, bioethics is performed by interpretation of cases, which are tangible stories.[5] The exploration of cases is a learning of stories, which are then re-awakened in clinical ethical practice, and in this way the practice of bioethics proceeds through stories.[5] When cases are approached from a narrative lens, it becomes possible to examine plot, context, intentions, and ethical principles embedded within the story, revealing a more true understanding of both the person(s) involved in the case as well as the imperative ethical issues at play.[2] In this way, stories ground bioethics in practical reality and bring a concreteness to ethical decision making, which is helpful not only to ethicists, but especially to physicians, who are often less comfortable with bioethical principles.[15] This accessibility and pracitcalty givses narrative bioethics an advantage

over more theoretical and abstract bioethical frameworks. Consequentialism focuses only on the outcomes of an action, while ignoring the morality of other aspects of a narrative, such as meaning, values, tensions, hopes, desires, and intentions.[2] Deontology reasons through only abstract duties without acknowledging that in the true flux of experience there are a myriad of competing obligations.[2] Principlism, the manner of ethical thought most central to medicine, dose not consider the narrative trajectory of an ethical situation, and gives no provision for paradox the uniqueness of a communal experience,[2] but rather tries to simply apply principles in a standard manner to citations which are anything but standard. Each of these approaches to bioethics has a usefulness, but only when applied through a narrative lens that appreciates that any form of ethical reasoning on its own cannot adequately address a singular contextualized moral narrative.

CHAPTER 2

PRACTICAL ASPECTS OF NARRATIVE AS APPLIED TO BIOETHICS

"Storytelling is less a work of reporting, and more a process of discovery"

-Arthur Frank, *The Wounded Storyteller*[7]

Part One of Chapter Two: Aquiring Narrative Skills

Through the close reading and analysis of stories as well as through processing and writing personal or patient stories, narrative medicine teaches skills that are imperative to medicine and bioethics but often seem intangible to attain. These skills include: the ability to systematically adopt the perspective of another; the ability to recognize the particular alongside the universal; the identification and interpretation of an individual's words, silences, and behaviors; the creation of an authentic relationship between a listener and teller; and the ability to respond to one's own thoughts to achieve certain behaviors.[4] Narrative curriculums seek to foster these narrative competencies in order to create individuals who are able to co-create narratives with patients by being both adept listeners and story-tellers.[8] This brings practitioners from a level of recognizing disease to recognizing *illness* - a more individualized suffering that contains a narrative arc with a search for personal meaning.[13] Narrative skills then provide the basis for the core competencies of narrative bioethics, which are: contextualization,

search for meaning, emphasis on moral sensitivity and subjective experience, and a focus on a patient's own story and its relations.[15] Narrative bioethics achieve these competencies through the use of analytical tools from hermeneutics and literary theory, coupled with the classical bioethical tools of abstract ethical theories and principles.[15] All of these competencies and skills - of both narrative medicine as well as narrative bioethics - rely on having a thorough working understanding of narrative knowledge and the ability to apply that knowledge to clinical and ethical scenarios. Narrative knowledge consists of the skills used to make sense of narratives which allow one to understand a singular meaningful experience of another person, rather than merely an event that is "true".[4] The following sections detail the 5 aspects of narrative knowledge specifically in their relation to narrative medicine and narrative bioethics.

Part Two of Chapter Two: What Narratives Are, and How They Are Built

A narrative by definition is a story with a teller, a listener, a time course, a plot, and a meaning.[4] This narrative structure allows the teller to recount events and suggest their causes, depict characters, represent the passage of time, and use metaphors to convey otherwise elusive meaning. When a teller seeks to confer a set of events with originality, significance, and irreproducibility, it is the commonality of the narrative structure that allows it to be communicated and understood by others who have not experienced the same set of events.[4] There are 3 common narrative structures that stories

may take: restitution, chaos, or quest.[4] These three narratives are experienced by all persons in various ways, and thus provide a common framework from which particularity can be effectively conveyed and understood. The components of a narrative are timeline, character, narrator, plot, context, and relation between listener and teller.[4] These features correspond quite well with narrative features within medicine such as temporality, intersubjectivity, singularity, causality, contingency, and morality.[4] For example, the plot of a narrative is not merely a set of separate events, but rather the meaningful causal relationship between those events.[4] In this way the plot is a manifestation of the basic human urge to make sense of why things happen by imagining or creating connections between events. Sicknesses manifest themselves over time and are often described in terms of their temporality.[2] Various characters and narrators bring a multifaceted intersubjectivity to a single set of events, and in the realm of medicine these players can include not only patients, families, and providers, but imaging, documentation, labs, and procedures which can all tell a slightly different story of the same patient or illness. Likewise, specific motives, contexts, and stakes of both teller and listener can impact how a story is told and received, and the meaning derived from it.[4] It is precisely in this narrative emplotment that a specific tension is created between listener and teller, and the extent to which the vulnerability of the teller is met with respect by the listener creates a unique story with every telling. A story is not simply the words spoken or written, but rather a story is created in the receiving of those words, thus in order to allow patients to create and own their narratives, clinicians and ethicists must learn how to listen, interpret,

and join in creating those narratives. In this way, storytelling is not so much a work of reporting, but rather a process of communal discovery.[7]

Part Three of Chapter Two: How Narratives Convey Knowledge About the World

Narratives provide a common framework from which people can convey knowledge and experience with each other. In the medical field it is often implied that "knowledge" is composed of truths that are universally understood. However this impulse of medicine towards universality has stifled the acknowledgement of the singularity and creativity in acts of observation and description.[4] For example, a physician may describe a rash using medical terminology that they believe to be universally true and understood, while an artist might look at the same rash and describe it in a completely different manner. The rash is the same, but people may create multiple different stories of it. Thus, one's interpretation of "facts" is influenced by experiences and methods of description and interpretation. The interaction between patient and clinician is influenced by personal experience, as well as socioeconomic and cultural factors, oftentimes these are not shared between the two parties. Narrative can be used to share knowledge of these different factors in such a way that each can understand the other without having the same lived experience.[17] The illness narrative that patients share becomes a window for the clinician into the patient experience.[13] In ethical cases, where the ethicist may find themselves removed from the interactions and events, narratives allow moral claims to be seen in

action, conveying context so that an event can be understood. Likewise, narrative works can be used to convey moral knowledge about the world through implicitly raising and answering moral questions.[5] In this way ethicists, clinicians, and patients can share and receive knowledge that help each to understand one other, themselves, and the situations they experience.

Part Four of Chapter Two: What Happens When Stories Are Told and Listened To

In the modern age of widespread availability of information, it is no longer the task of the clinician to simply possess medical knowledge, rather the task of the modern clinician lies in knowing how to adapt and apply that knowledge in the unique context of a particular patient's situation. Thus, what needs to be learned through medical training is a set of tools that allow clinicians to engage compassionately in the lives and stories of patients.[1] This begins with basic clinical curiosity, the striving to understand a patient in order to discover the underlying medical condition, but if you stop at clinical curiosity, then a medical condition may be determined without ever acknowledging or addressing the patient's true suffering. Narrative knowledge equips clinicians and ethicists with the complex skills needed to participate in a patient's illness narrative and thus more fully understand and address their needs. Clinicians and ethicists are not merely witnesses to patient stories, but actors within those stories, and it is imperative that they are invested in understanding and co-creating a patient's narrative if they are to make decisions that

are moral within a specific illness narrative. Practitioners must recognize that the character they project onto a patient affects the patient's quality of life, and therefore every aspect of their behavior, even how they receive a patient's story, has ethical significance. The ability of practitioners to actively listen and engage with patients will directly influence the rightness of their actions and responses.[4] There is an inherent divide between patient and practitioner because practitioners are not themselves experiencing the suffering that the patient is. To bridge this divide requires that the practitioner have compassion, or the ability to suffer with their patient. In order to have compassion, practitioners must cultivate empathy, which is the ability to see and feel from the perspective of another.[17] Empathy requires that the practitioner be attuned to the patient's perspective and how their illness is interwoven into this particular person's life; compassion is the ability to convey this empathy to the patient.[17] There are many additional requirements for compassion: the ability to simply perceive suffering, the ability to interpret what is perceived, the ability to view events of illness from multiple viewpoints, the ability to envision the outcomes of illness, and finally to be moved to action by what is perceived and envisioned.[4] All of these skills are learned and strengthened through narrative reflection and practice. In each patient encounter practitioners have the opportunity to engender empathy through taking a patient's illness narrative seriously, being sincerely interested in knowing who the patient is and what their life is, being curious about their process of becoming ill, and learning of their resources for dealing with the illness.[4] To do this in every patient interaction requires either much time, skill, or both, so it is imperative that practitioners be able to practice

and refine the skills required for compassion and empathy, and this can be accomplished through the reading or listening of stories. Stories allow practitioners to engage with another's illness narrative in "living through" it, rather than just possessing knowledge of it.[4] In close literary analysis, the reader develops the capacity for perception, discrimination, confrontation of mystery and freedom, skills which can then be applied to the illness narratives of their patients.[4] By engaging with stories, practitioners can learn how to be touched by their patient's narratives. Stories also teach imagination, which is a necessity to understanding the situation and point of view of another, and thus is a cornerstone of empathy.[4] Imagination allows practitioners to actively enter into the narrative of a patient and anticipate a patient's needs or struggles and act accordingly. This forms the basis of narrative care: to not only recognize the plight of another, but share in it with them.[5] This recognition, whether it be as simple a gesture as a nod or a gentle touch, can help to free a patient from the isolation they may feel from their illness.

Part Five of Chapter Two: How Narratives Organize Life

Each individual's life is organized by one's own inner narrative- the stringing together of events in a manner which gives meanings and provides identity. But storytelling is central to the human experience beyond the individual. Narrative knowledge is how people have communicated their own inner narrative as well as whole community narratives for centuries, making stories a major source of both personal and

community identity.[4] Narratives are inherently relational- a story requires both teller and listener- and each story is shaped not only by its author, but its audience as well.[2] Stories are also relational within themselves in the ways in which they characterize the players within them; this is a particular area which practitioners must pay close ethical attention to, as the way one is characterized within an illness narrative can impact the manner of care they recieve and they way in which they feel about their care. Oftentimes, mischaracterizations occur due to the differences in the way in which medical narratives and illness narratives are organized. Practitioners often view the context of illness as a biological disease requiring intervention, while patients view illness within the scope of their entire life and how it impacts their inner narrative.[4] In order to effectively address illness and provide true care, practitioners and patients must be able to understand each other's perspective on the organization of an illness narrative. The responsibility here falls mostly on the practitioner, as they are the ones with access to both the medical and human perspectives. Somewhere along medical and/or bioethical training the vernacular and organization of medicine becomes second nature, and it can be difficult for practitioners to remember that they are approaching illness with an entire language and set of views that the patient is not even aware of. This is where cultivating the narrative skill of imagination becomes imperative, as it is required of the practitioner to enter into the patient's perspective and recognize where the gaps in knowledge and communication lie so that they may be bridged. Practitioners must remember that even something as simple as a diagnosis is really only a construct, a term ascribed to a set of symptoms,[4] and that if they only pay attention to the medical organization that dictates the discovery of a

diagnosis, they may run the risk of losing sight on the objective of relieving suffering within the patient's illness narrative. Practitioners must recognize how narratives structure both individual and community life, and be aware of the multiple ways narratives organize life in order to avoid focusing only on one.

Part Six of Chapter Two: How Narratives Allow Us to Recognize What Life Means

Narratives help individuals to bring meaning to seemingly random and chaotic life experiences. Illness narratives are constructed by a complicated process of consolidating and reconciling memories, intentions, and language in order to find some form of meaning or order within the context of a chaotic set of illness events.[13] Narratives themselves, however are fundamentally unstable as well, as they are able to be re-written with different meanings, contexts, intentions, language, and trajectories.[2] As people are in a constant process of changing and becoming, there can never be a "final" narrative for a person, nor can one narrative exhaust what can be known of a single person.[2] Practitioners must keep this in mind particularly as they re-engage with the same patient over multiple points in time, and remember that what was true of a patient or their illness narrative at one point does not necessarily have to remain true as their narrative progresses through time, and can even contradict earlier version of an particular illness narrative. A core task of practitioners is to absorb patients' multiple and often contradictory stories of illness[4] without attempting to reduce or distort them in

order to fit into a singular version of "truth". As difficult as it may be to do so, practitioners must remember that truth is in reality multiple and moldable, as a multitude of plots and meanings can be derived from the same set of events. It can be difficult for anyone to recognize the narrative structure informing meaning into life if it is not consciously sought out.[5] This is often why patients feel as though practitioners fail to absorb the meaning of what is being said - because practitioners are not trained to actively seek out the narrative structure and meaning of a patient's words. But through the practice of close examination of literature and other narrative mediums, practitioners can deepen their capacity to truly hear, recognize, and interpret illness narratives in what their patient's tell them.[4] The effort that practitioners put into creating a narrative along with a patient invites practitioners to invest deeply in their patients, to truly understand their viewpoint, and therefore allows them to give the best guidance for each individual patient. The practice of engaging with stories also allows practitioners to avoid anchoring onto one single illness narrative through witnessing the way in which meaning and narrative changes throughout various stories. This is achieved by seeking contradictory and evolving details within stories, allowing for multiple tellings of the same story with more than one meaning, drawing attention to those aspects that are in the background, and identifying what is "unsaid" in order to reveal further meaning and possibility.[4] This allows practitioners to keep an open narrative future for their patients and avoid imposing totalizing frameworks or narrative foreclosure.[4]

CHAPTER 3

STORIES, INTERCONNECTIVITY, AND RELATIONSHIPS IN MEDICINE AND ETHICS

"I needed to gather around me voices that had shared what I had been through."

-Arthur Frank

Part One of Chapter Three: The Inherently Narrative Nature of Human Relationships, Communication, and Cultures

Humans are not only a social species, but an inherently narrative species, as people define themselves in relation to those events that take place in their lives, as well as in relation to those around them. [5] Stories allow people not just to process life events, but the creating and sharing of stories helps each person in the form their personal identity while forging connection with others[4] Narrative structure is how people communicate themselves to the world, and thus narrative knowledge forms the basis for both identity as well as community. Stories are themselves relational: it is the act sharing and receiving that creates a story and gives it unique meaning.[9] For centuries, communities have been built through narrative; within a culture life is not composed of mere abstract forces, but by the narratives that help structure those forces into creating communal meaning.[5] Narrative structure is fundamental to communication and decision

making[2], so it should be of no surprise that it is imperative for practitioners to possess narrative awareness and skills in order to communicate effectively with patients and join with them in their decision-making process.

Part Two of Chapter Three: The Inherently Narrative Nature of Ethics

Traditional ethical schools of thought such as deontology and utilitarianism rely solely on reason and logic to draw moral conclusions. These approaches to ethics to moral reasoning are lacking because human life is not composed of only reason and logic, but instead of random events, emotions, desires, relationships, and context. Moral reflection cannot be reduced merely to a cognitive practice, instead it must be recognized that morality is also a matter of the human heart, which is by nature relational.[15] Thomas Levinas defines ethics as the responsibility of one person towards another.[4] Ethics is the intersubjectivity of human responsibility; where intersubjectivity refers to a situation in which two authentic selves meet.[4] Since narrative meaning is created by the meeting of the listener and teller, it follows that narratives are an ethical act in that they build relationships through conveying information, emotions, needs, and context.[4] This is plainly seen in the way ethics is classically practiced, through cases. Although traditional ethics attempts to reduce cases into forces of reason and logic, cases are essentially narratives to which ethical principles are applied. Ethics is practiced through cases

because it is understood that ethical principles and reasoning change with different context and situations, simply put, ethics is not possible without narrative.

Part Three of Chapter Three: The Inherently Narrative Nature of Illness

Illness is a significant disruption into a person's life, bringing on chaos, uncertainty, isolation, and even tensions within one's identity. This creates a need for ill people to find meaning out of their illness, and to create new communities to combat the way in which illness sets them apart from their previously held communities. Stories allow those experiencing illness to unite as an act of self-healing; hearing the stories of others allows a patient to process and then share their own story,[7] helping to reconcile one's illness narrative with one's greater inner narrative. When illness is spoken into story, the ill person transforms the disease that sets their body apart from others into a common band of suffering, which creates shared vulnerability.[7] The task of the patient to tell their story in any setting is made difficult by the challenge of expressing pain, uncertainty, and anguish, along with fear that they may still go misunderstood. This is why it is vital for patients to share their stories: in hearing the shared vulnerability of another, a patient may find the strength to prioritize their reality through the expression of their own experience,[1] and find freedom from uncertainty and isolation in the process.

Part Four of Chapter Three: The Inherently Narrative Nature of the Practioner-Patient Relationship

Medicine is not merely a task of treating disease, rather it is the process of understanding illness and relieving suffering. The relationship between patient and provider is at its core a human one, full of emotions and context,[17] that relies on a foundation of listening, communication, and open dialogue. In today's medical field, there has been a breakdown of this relationship, with increasing specialized and procedural care, decreased time available for visits, and barriers to access. There are many external and internal factors that have led to a lack of communication and empathy from providers, in addition to the internal attitude of detachment practitioners are encouraged to adopt. A shift towards narrative care can begin to remedy this breakdown of relationships, as stories invite practitioners to involve themselves emotionally in the illness narrative instead of acting solely as detacthe bystanders.[15] Medicine practiced through narrative care recognizes that that one of the greatest miseries of sickness is solitude, and in order to relieve suffering a practitioners must not only recognize their patient's plight, but also share it with them.[5] Sharing in a patient's suffering can be frightening for practitioners, and there is even a belief that emotions cloud a practitioner's judgment, but it is impossible to encounter suffering without having some form of emotional response, and in ignoring emotions practitioners run the risk of allowing themselves to be controlled by the very emotions they claim not to have.[17]

There are many such forces that impact the practitioner-patient relationship which narrative skills can help bring awareness to. Firstly, if practitioners do not recognize that

illness is structured narratively, they may not listen with a narrative curiosity to the patient, and may fail to absorb what the patient is actually trying to communicate.[5] Narrative care recognizes the uniqueness of each patient's illness narrative, without which practitioners may approach patient suffering with an attitude of universality and reproducibility that misses the possibility for singularity and creativity in their care plan.[4] Another of these forces that can go unrecognized is the ever-changing nature of people, and by extension, their illness narratives. No narrative can truly encompass what can be known of a person, and it is important for practitioners not treat patients as they exist at a singular moment within their illness narrative, but instead to constantly be in dialogue with a patient about the wide and varied ways in which their story changes and evolves.[2] Guilt is a large, often unrecognized, force at play for both patients and practitioners. Patients often feel the need to "blame" their illness on something, and practitioners often feel a high sense of accountability which can motivate their thoughts and behavior.[4] Feelings of blame and guilt can cause patients and practitioners to seek to hide in some way from each other, and leads to a breakdown of trust. Similarly, fear can create a chasm, and requires vulnerability and courage to be allowed to be actively acknowledged, rather than denied. Finally, cultural, financial, and socioeconomic factors can influence a patient's illness,[17] and narrative curiosity can help practitioners not only elucidate these factors, but understand contexts that differ from their own experience. All of these narrative skills help uncover forces that affect the ability to cultivate empathy, allowing practitioners to understand how illness is woven specifically into a patient's narrative and also be aware of the forces they are bringing to the interaction as well.

CHAPTER FOUR

THE IMPORTANCE OF NARRATIVE AWARENESS FOR PRACTIONERS

"Self-contained grief is self-destructive"

- Grace Dorelene Seabold[14]

Part One of Chapter Four: Narrative Awareness of Emotions

Despite an attempt by practitioners to remain detached from emotions, both their own and those of their patients, medicine is an inherently emotional act. Though many practitioners feel that emotions will negatively affect their ability to perform their duties, emotions in themselves are neither good nor bad, it is rather how they are managed that determines their impact.[17] Emotions have the power to affect patterns of thought and behavior, especially when no awareness is brought to them doing so. By denying the role emotions play in actions, practitioners run the risk of allowing themselves to be controlled by emotional forces, making mistakes they are not even aware they are committing.[17] Practitioners must acknowledge that they do not practice in a bubble- each has their own contexts, emotions, and internal/external forces to grapple with- all of which affect how well they are able to engage with their patients. To be truly and fully available to sick patients as a therapeutic source demands risky self-knowledge and personal awareness on the part of the practitioner.[4] When practitioners are isolated from

authemic engagement with their emotions they are less equipped to recognize others emotions and perspectives, thereby having a greater difficulty developing empathy.[4] Stories invite practitioners to involve themselves emotionally in the illness narratives of their patients[15] and help them understand the meaning of what they witness for both themselves and their patients.

Part Two of Chapter Four: The (Not So) Inevitable Decline of Empathy

It is a well-documented phenomenon that medical students' innate empathy, respect for the suffering of others, and ethical discernment diminishes throughout medical school.[11] The sharpest decline is seen during students' third year or study, or first year of clinical practice.[11] To some extent students learn this behavior through watching their residents and attending detach from patient suffering. When suffering becomes commonplace, it can be both difficult to be moved by it once the novelty has worn off, and at the same time can take an emotional toll to continually re-engage with the trauma of suffering day in and day out. One medical student writes in an essay published in a collection of student reflections:

> "Maybe becoming desensitized, at least partially so, is necessary- to carry the weight of all of our patients suffering would be too consuming. Or maybe I am wrong- maybe I will come home and cry often, not just for deaths but for unfortunate diagnoses or mistakes I have made. It's difficult to decide which outcome I'd prefer- to feel more professional, more balanced, or to feel more like most other people, those who are deeply struck by the fragility of life and death." [1]

This student is clearly grappling with how to handle their emotions between the only two options they believes they have: to ignore them or be overwhelmed by them. Medical education does not equip trainees with the tools they need to manage the difficult emotions are are faced with daily. In a study at the Robert Wood Johnson Medical School in New Jersey, students took course in a Humanism and Professionalism throughout their third year, in which they participated in peer discussions about patient care and difficult situations, read stories from patients and practitioners, and write blog posts about their own experiences[17]. The students took the Jefferson Scale of Empathy, a standard means of measuring empathy based on responses to 20 statements, at the beginning and end of their third year.[8] Unlike other classes that showed a distinct decline in empathy scores over the span of the year, the class that took the Humanism and Professionalism course showed no decline in empathy scores.[8] This study shows that a decline in empathy is not an inevitable part of medical training, but rather an unfortunate consequence of neglecting to teach students to engage with and manage their own emotions and those of their patients.

Part Three of Chapter Four: Narrative Willingness to Share in Suffering

While patient suffering is at the heart of medicine, practitioners suffer through their patients, in this way the two are suffering in parallel, but separate from the other.[7] What practitioners need is the capacity to share in, and therefore lessen, the suffering of

their patients. But to share in suffering is not without consequences for practitioners. Oftentimes practitioners attempt not to empathize with their patients due to the terrifying nature of their patients' situations, in which having empathy might mean facing their own mortality.[17] Faced with this fear, practitioners will seek to keep distance from their patients for their own protections. However it is precisely this fear that is isolating and paralyzing for patients, and what they need is for their practitioners to vulnerably join them in their fear. As Amanda Dorman writes in her poem "Good Grief":

…
Grief commands its own grammar,
Structured by intimacy and imagination.
We often say:
We are besides ourself with grief.
We can't even imagine.
This means anguish calls us to envision
More than what we believed was carriable
Or even survivable.
This is to say, there does exist
A good grief
…

The act of taking grief and anguish onto onesself to imagine the suffering of other towards the end of relieving it is no small task. This is where stories can be of great help, as they can be a sort of "training wheels" for practitioners to engage with difficult emotions and fear in a less real and personal manner. By getting comfortable with vulnerability and fear through reading and listening to stories, practitioners expand their capacity to engage with difficult situations and learn to recognize and manage the emotions that arise within them. Being able to recognize one's own suffering in the face of another's suffering allows practitioners to imagine their patients' needs while at the

same time being able to articulate their own needs.[4] Practitioners must be able to recognize how their own singularity is important to their patients- they are not simply impartial, reproducible actors, but they each bring their own narratives to each patient encounter and have their own unique impacts, especially emotionally. Whether these impacts are positive or negative depends on the practitioner's ability to recognize and manage their emotions and response to their patients' suffering.

Part Four of Chapter Four: The Practioner's Need to Cope

Finally, practitioners must be able to cope with the trauma of suffering they encounter for their own mental and physical well-being. The phenomenon of burnout has been widespread in the medical field, in large part due to the emotional toll that witnessing death, anguish, and pain on a daily basis has on practitioners. For a long time, it was the attitude in medicine that attending to one's personal needs and emotions was selfish in the face of patient suffering, but this isn't so. To deal with one's own emotional turmoil is a responsible action that is necessary to practitioners to have the emotional capacity to truly engage with and provide the best possible care to their patients. For practitioners, it is not necessarily grief or pain in itself which is the problem, but instead that the grief remain unacknowledged and unprocessed.[17] Just as patients seek companionship in their suffering, so do practitioners. Stories can provide an outlet for practitioners to share their grief and emotions, to connect with others, and combat the

isolation they may feel in the face of suffering. Even the act of simply writing out one's emotions or describing a situation may help relieve a practitioner of some of their emotional burden or allow them to gain some awareness and perspective on their feelings and tensions. Writing is an act of self-discovery, and cultivating the habit of self-expression allows practitioners to be aware of what is happening within them beneath their cognitive surface. In sharing stories, practitioners give each other the freedom and power to moved by suffering, and be vulnerable and honest about the impact it carries. Sharing and receiving stories of struggles allows practitioners the permission to recognize and grapple with their own emotions in the face of suffering.[17]

CHAPTER FIVE

NARRATIVE AWARENESS OF POWER DYNAMICS

"Care more particularly for the individual than for the especial features of the disease"

-Sir William Osler[18]

Part One of Chapter Five: The Power of Practioner as Both Audience and Co-Creator

Narrative ethics and care is concerned not only with the stated content of stories but also with the storying telling process itself and the factors that influence it.[2] This demands that close attention be paid to the construction and co-construction of narratives, with special awareness of how different players and forces shape an indivual's personal illness narrative.[2] Practioners like to think of themselves of abstract impartial forces, but in reality their actions influences patients' feeling and actions; therefore part of the ethical question central to all medical interactions is about how the character projected by a practioner affects the life of a patient.[5] So often patients modify the stories they tell of their illness narrative to practioners with concern to how they will respond,[4] and so before a practitioner even acts or speaks they have already exerted power in shaping a patient's story. Therefore, it is imperative that practitioners are cognicent of the impact

that they have on a narrative simple as an audience, and even more so as a con-constructor.[2] Storytelling is inherently vulnerable, it opens up the teller to the risk of exploitation,and a listener must acknowledge this with respect and a desire to build trust. If rather, a listener creates a dynamic of holding power over the teller, they can easily take possesion of a teller's narrative to direct it to fulfill their own purposes.[4] There will always be tensions that exist in what the teller and listen take away from a story, but narratives skills can help practitioners mitigate and work within those tensions so that they can interpret and jointly creat meaning in their patient's narrative, rather than attempting to control them. What is learned through narrative practice is how to be a trustworthy receiver of stories, one that can co-construct narratives while remaining aware of the power dynamics at play. There are a number of factors that practitioners need to actively consider as they attempt to interpret the story they are co-creating with a patient.

Part Two of Chapter Five: Who is (Really) Telling the Story

When engaging with a patient story, practioners should be aware of who the true teller of the story is. It may seem obvious that the teller of a patient's illness story is the patient themselves, however it is possible for patients to have their stories possessed, and for their illness narrative to be told from a medical or ethical perspective that is not their own.[1] Practitioners must ask themselves, while pricing together a patient's story, whose

voices heard, and whose it not. Is the patient's view muted by a pathology report, or a note from a consultant? Are the words a patient expresses their own, or what another has said to them? When the different voices of an illness narrative contradict one another, practitioners must be aware of which voice they inherently assign credibility to: the patients', or the medical perspective.[13] Within cultures, there are certain "master narratives" that act to silence other narratives by being the background against which other narratives are evaluated.[2] Often, practitioners make the medical narrative master over the patient's illness narrative because it is the perspective of the medical narrative that aligns with their perspective, and therefore is the one they assign credibility to. To avoid this, practitioners can try to listen to patient's stories in the voice of the patient as teller, rather than in the voice of a healthcare professional.[13] Practitioners must realize that stories are constructed both by one's self, and others; whose voices can converge to form a coherent narrative, or diverge into conflicting ones. When practioners as seek to co-create through the singular voice of the patient narratives converge and the patient becomes the center of their own narrative. But when voices compete for acceptance as the "dominant" story, the narrative diverges, displacing the patient from the center, and their personhood becomes vulnerable.[2] Practitioners must be wary of the extent to which their own voice is present within a patient's narrative, as well as how much they prioritize other voices over the patient's. They must become a tool for which to amplify a patient's voice, for in truly sharing their story, patients are able to gain authority over their illness, and re-establishsubjectivity and singularity in the face of objectifying and generalizing treatment.[4] Patients are able to prioritize their reality and voice when they are given the

freedom to share their true story without attempts to be silenced or changed by outerforces for co-creators.[1]

Part Three of Chapter Five: How a Story is Told

The same set of events can give rise to multiple differing narratives, and stories can be told in different ways that give rise to multiple different meanings. Through narrative emplotment, the act of telling a story colors a narrative with a particular point of view, intentions, and stance.[4] Practioners must ask themselves as they receive a patient's story about the effects that motives, contexts, and stakes have on the narrative being told.[13] It is vital that practitioners be aware of the outer and inner forces shaping the way a patient frames their narrative, in order to be aware of the multiplicity of meanings a particular story might have, and recognize the particular meaning a patient is trying to convey. Narratives are fundamentally unstable- their meaning can be changed by something as simple as different word choice or voice inflection. Practitioners must be active listeners and observers to read between the lines of what their patients actually say to critically exmaine how they are telling a story, what language are they using, what body language they adopt, where their eyes wander, and what goes unsaid. There must be an acknowledgement that patients are not entirely transparent with their stories, coupled with an active curiostiy to uncover the questions and forces that they keep beneath the surface. This should not be done with the intention to uncover the "truth" from a patient

or an attitude of distrustful suspicion, but rather from a desire to understand a patient to the fullest extent, and invite them into a process of open dialouge in which patient and practioner bring to light the hidden aspects of a story together.

Part Four of Chapter Five: Who Determines the Meaning of a Story

In medicine, there is typically a belief that a patient's story is either "true" or "false". When what a patient describes in their illness narrative does not align with what practioners know to be possible or plausible, there is a tendency for them to dismiss the patient as being intentionally untruthful or not actually knowing what it is they experience. In this way, the meaning of a story for practitioners often is found in how much of it they believe to be "true", and then they will only act on the aspects of it that meet their criteria for truth. But truth for practitioners and patients are different; practioners derive truth from the generalizable facts of a disease that are the same over time, while patients derive truth from particular experience within the context of their life.[4] In the context of illness narratives in general, there is a difference in basic meaning derived by the practioner and the patients. For practioners, the meaning of an illness narrative is the uncovering of a biological or ethical phenomenon requiring intervention. For patients, the meaning of an illness narrative is the expression of illness and search for relief within the scope of their entire lives. Practioners must avoid projecting their perspective of meaning of an illness narrative onto a patient, for doing so silence's the

patient's meaning. While one meaning may appear obvious to a practioner, it is important to rember that events in and of themselves have no inherent meaning, rather it is people who ascribe causality, and therefore meaning, to a set of events. Meaning never just exists on its own, it must be created and assigned by a person or group. Often in medicine, meaning is ascribed to a patient's particular story by conforming that story to fit into a metanarrative, which is a general narrative that forms the standard for what is "normal".[4] Metanarratives act to silence singular meaning, consequently taking the voice away from individuals or smaller groups, and exerting power of morals, self-agency, and social resources. Practitioners should ask themselves if the meaning they are taking from a story is actually that of the patient's, or rather that of either their own, or a metanarrative's.

Part Five of Chapter Five: Characterization of a Patient within a Story

The way in which a patient is framed in the context of a narrative, whether their own or that of a practioner, is a ethical issue because it has the power to influence the care they recieve.[2] This charactization can happen subtly, such as when practitioners use words such as "non-compliant" or "poor historian", effectively placing blame on patients through descriptors. The subtly is where the true power and danger of this characterization lie, because it colors the listener's view of the patient without explicitly stating that is what is being done, and so negative chracterizations are taken as objective

ones. It takes narrative skill to be able to develop imagination to see beyond descriptors to ask why a patient is being described in such a way, and question whether the descriptor is accurate. It is important to do this even when a patient is characterizing themselves, as they may be doing so based on a master narrative that they have been told to be true about themself. An example of this can be seen very starkly in the narratives surrounding victims of gun shot wounds. Practioners, and society in general, tend to hold the view that victims of shootings are in some part responsible, that they were only in a situation where they could be shot through some intentional action and poor decision making. "*What were you doing that got you shot?" "Don't go jumping in front of bullets anymore."* This master narrative is so pervasive that victims adopt it towards themselves. "*I don't know what I did to deserve this." "I thought I was a good person, but I guess not."* The characterization of patients within both their own illness narrative and their medical narrative impacts how they are viewed and treated not only by those in their healthcare teams, but by themselves as well. Therefore, it is imperative that practitioners be cautious with the language they use to describe patients, and be aware of the characterizations implicit in what they say to and about a patient.

Part Six of Chapter Five: The Impact of a A Particular Story

Stories do not exist in a vaccum, but instead are shared within the context of other stories which are woven together to form narrative webs.[2] The point in telling a story is to have an impact, to have an affect on others which has the power to sway the trajectory of subsequent stories. Therefore, as practitioners co-construct stories with their patients, they must remain cognicent of the impact that the story they are creating will have on both the patient's illness narrative as well as other adjcent narratives. Practioners should keep an open mind towards potential narrative futures, and avoid creating totaliznig frameworks that prevent the divergence of certain plots or meanings.[4] This is important not only within the context of the impact on a singular's patient's life, but the impact of inidivual stories can affect broader social structures and narratives as well. When medical stories become rigid, they are less able to engaage creatively in dialouge about health equity, the limits of medical power, and the ideals of healthcare.[4] While each illness narrative exists within a unique context, it should be remebered that stories have impacts that rippe out and affect others beyond the singular individual.

CHAPTER SIX: CONCLUSION

In summary, narrative is present in every illness, every patient-practioner interaction, even every moment of life, regardless of whether it is recognized or not. Thus it is necessary to practice medicine and ethics with not only awareness of the illness narrative, but a thorough working knowledge of narrative skills. Practioners much train themselves in these skills to develop them to a point that they are able to apply them to patients' illness narratives, and be aware of the impact they themselves, as well as other forces, can exert on their patients' illness narratives. Medicine and bioethics must move away from an attitude of detachment and finally recognize that there is no separation of emotion and reason. Narrative care must be embraced, with all of it's ambiguity, vulnerability, and specificity, which is no small feat for a field that prioritizes precision, hardness, and generalizability. It is imperative to begin teaching narrative skills early in clinical and ethical education so that they become a integral part of a practioner's framework for practice. Hopefully, through engendering narrative care, medicine and bioethics can bridge the ever-widening gap between patients and practitioners, and ground care and moral decisions in narrative reality.

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