On Being a Patient: Living with Life-Altering Illness and Injury

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Abstract

People living with life-altering illnesses and injuries have a unique experience in the world, and there are many factors that influence that experience. Provider-patient relationships, in particular, have significant power to impact the way people living with life-altering illnesses and injuries experience themselves, their bodies, their lives, and their illnesses and injuries. This dissertation is based on a hermeneutic phenomenological analysis of five popular memoirs about living that experience, with a particular focus on the ways in which provider-patient relationships influence the authors' experiences. That analysis is then used to inform an autoethnographic exploration of the realities of living with life-altering illness and injury. It includes an examination of the existential injuries inherent in this experience as well as the role of physicians as doctors versus physicians as doctor-healers, with in-depth investigation of the activities that are part of the doctor-healer role. Those activities include centering patient personhood, fostering hope, and collaborating, each of which is considered in light of personal experiences and existing philosophical and scientific literature. The dissertation concludes with consideration of implications for a variety of audiences, including physicians, patients, healthcare systems, and medical education programs.

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Chapter 1: Introduction

For reasons no doctor has ever been able to satisfactorily explain, sometimes my body just breaks. I'll be strolling around a lake with a friend or hiking with my dog or playing hide-and-seek with kids or doing exercises at physical therapy, and, out of nowhere, I'll feel a snap or a pop accompanied by the searing pain that tells me I've torn a muscle or a ligament or a tendon once again. Sometimes, most times even, the tears heal with time and rest. Other times, a surgeon has to cut me open to put me back together again.

Over the course of the mere 35 years of my life, I've already had a total of 14 surgeries. After one surgery when I was 22, I woke up in the recovery room and immediately plummeted into complete and utter terror, a reaction so intense that the recovery team had to sedate me and try to wake me a second time.

As an adult, I could never understand the intense dread I would feel in every ounce of my being in the days leading up to surgery. I could never make sense of coming out of anesthesia into pure panic.

It wasn't until I was 30 and through 8 surgeries that I realized that in those moments coming out of anesthesia, I wasn't an adult. I was just an 11-year-old kid having her nose pieced back together after a dog bite. I was just a child, suspended in a moment in time, fighting to find purchase; battling for agency; desperately looking for something, anything, to hold onto.

All I hear is darkness; all I feel is silence.

Slowly, like music fading in at the beginning of a movie, I hear beeping and bells.

I float somewhere in this nothingness for what feels like a long time, but then I realize that the beeping and the bells are somehow related to me... my breathing? my heartbeat? something about my tongue? I don't know. I have only a vague memory of what is going on, like a word on the tip of my tongue, just out of reach. There's a tube of some sort in my mouth, and my face is completely covered. I feel like I'm suffocating. I try to open my eyes, but I can’t. I feel so heavy. I try to move my arms to free myself, but the air is thick, too dense to move through. I start to panic, and I struggle to claw my way out of the crushing darkness and find some air.

Then a voice emerges...

“Oh, shit! Hold her still,” the surgeon nearly yells, followed shortly with, “I don’t care. Give her more...”

Then I fade once again into the dark, heavy, silence of nothing.

One year, I was heading toward my third surgery in a span of 15 months, and my second shoulder surgery in a span of 7 months. So, feeling restless and anxious and uneasy, I decided to trek to my favorite place in the world: the mountains.

I venture up the trail, slowly moving deeper and deeper into low, heavy clouds. I stumble one step after another, barely able to see more than a few feet in front of me. My skin feels damp, coated by the clouds, and the scent of wet dirt and soggy, decomposing leaves floods my nostrils. Some boulders grow in my field of vision, and I decide to scramble over them. On the other side, I happen upon a cliff. I take myself right to the edge, and as I stand there, I look out and see only a blanket of white. I am completely lost in the clouds, and I feel the world dissolving around me. It's as if I am standing on the edge of existence itself, and it is terrifying. And yet, in this existential vertigo, I have never felt more alive. I feel whole and at peace.

I come down from the clouds ready to head toward my next surgery, into the unknown.

I find myself wishing that 11-year-old me could find her way to that mountaintop, that the clouds could be a balm to soothe her fractured soul. But it occurs to me now: maybe she already has. Maybe, in fact, she's the one who brought me there.

In that moment of waking up during surgery into the terror of paralysis and seeming suffocation and dissolving into unconsciousness again after the angry surgeon's voice, something changed for the kid I was, something changed for me. That something has stayed with me for decades. It has influenced dramatically how I experience my body, my injuries, and the world of medicine.

That experience, though, isn't the only thing that bears an influence in these areas of my life; there is no doubt a complex network of interconnected elements that contribute to my reality. I wonder: What exactly determines how I relate to my experience as a person living with life-altering illnesses? What are the influences that sway my reaction to my injuries? What are the dynamics that contribute to my mental, physical, and emotional response to medical intervention? What factors play into my relationship with my body, with the ways it breaks, with the ways it heals?

I could spend a lifetime exploring those questions and not be able to answer them entirely. Two things are immediately and abundantly clear to me, however, as I start to ponder those questions. First, I have a unique experience as a person living with life-altering illnesses and injuries, and second, my relationships with my medical providers are an integral part of the sea of factors that influence that experience. I have seen, over my lifetime, the ways in which providers can nudge me toward a new way of experiencing my reality, for my benefit or for my detriment. I know that my interactions with medical providers are essential; they can help me understand my reality or they can obfuscate what little we know.

I know, too, that provider-patient relationships are integral to the way other people experience their lives through the stories I've heard from others living similar experiences and the books I've read. Given this, it is absolutely essential to understand how patients experience their relationships with medical providers and how the experience of those relationships influences the patient's illness, experience of their illness, and relationship to their body. This patient-provider dynamic is a foundational element to understanding what influences the intrapersonal experience of life-altering illness and injury (i.e., the ways a person with life-altering illness or injury experiences themselves, their illness or injury, their bodies, and their lives). This, in turn, influences how we can understand concepts of well-being, wholeness, and thriving in the midst of the realities of life-altering illness and injury.

> "Every project of phenomenological inquiry is driven by a commitment of turning to an abiding concern" (Van Manen, 1990, p. 31).

The need to understand these relationships between providers and patients and processes by which they influence intrapersonal experience is not new. Interpersonal relationships are an essential part of being human, and there are particularities about relationships between patients and their medical providers that set it apart as a unique and powerful relationship. When someone is dealing with life-altering illnesses and injuries, these relationships with medical providers take on an even greater and more central role within that person's life. In those contexts, knowing about these relationships and their sequelae is imperative to understanding individuals' lived experiences.

> "A research method is only a way of investigating certain kinds of questions. The questions themselves and the way one understands the questions are the important starting points, not the methods as such" (Van Manen, 1990, p. 1).

Based upon the need for this type of knowledge, this current project has two main research questions:

1. What does it mean to be a patient living with life-altering illness or injury?
2. How does the patient's experience of the patient-provider relationship influence the patient's experience of themselves, their bodies, their injuries or illnesses, and their lives?

This project will utilize hermeneutic phenomenology, ethnography, and autoethnography to begin to understand some answers to those research questions.

Philosophical Underpinnings

Given the nature of this research, it is important to make explicit the philosophical underpinnings that guide decisions about data sources, methods, and dissemination. These philosophical underpinnings contain decisions and assumptions about ways of knowing (epistemology) and ways of being (ontology) that are integral to the structure and the conduction of this research project. There are two purposes to expounding on my philosophical underpinnings here: (1) to position myself as a social scientist and (2) to demonstrate that there are certain decisions I am making regarding my focus in this project. My foundational philosophical assumptions are complex; therefore, this exploration might not always seem linear or straightforward.

Epistemology

As a researcher, scientist, and person, I do not fall cleanly into any one epistemological system. I acknowledge (and increasingly appreciate) that there are many different ways of knowing and that no one way of knowing is better than the others. The different ways of knowing allow us to understand different aspects of a phenomenon; as such, each way of knowing has its place in a program or system of research.

Regardless of the method by which something is known, all knowing is embodied. Everything I know, regardless of the source or the characteristics of the knowledge, has come to me through my body—through my organs of perception to my brain and my mind. Our brains are shaped by our visceral experience in the world (Doidge, 2007; Schwartz & Begley, 2002). Thus, any knowledge I have is filtered through my past and present experience, quite literally. This filter is also largely invisible to me, much of the time. Some consider the influence of my past on what I perceive and know in the present as a problem for science, but there are several ways to "deal with" this reality (which could also be called the problem of the self of the researcher influencing research outcomes).

The first way to deal with this is to choose methods that are less vulnerable to the influence of the self of the researcher. There are some things we can know with a relative degree of certainty, and there are tools that allow this knowledge a relatively high degree of objectivity. This is an important type of knowledge in that it allows us to act with greater confidence, particularly with regard to interventions. There are ways of knowing whether a certain intervention is effective and for whom it is most effective through the use of well-developed, validated, standardized clinical measures and advanced quantitative methods. These measures and methods have been agreed upon by the majority of the scientific community to be best practices for answering certain research questions. Use of these methods removes as much of the self of the researcher as possible from the process. Using these methods enables researchers and clinicians to provide interventions that are best for different kinds of individuals and families that seek help, services, or supports.

Even within this type of knowing, however, the questions we ask, the outcomes we measure, and the methods we choose are guided by a vast array of influences that we never fully understand. Indirectly, those influences impact the findings and, thus, the knowledge gained. Therefore, even in using methods that mitigate the influence of the self of the research, it is never fully eliminated. Furthermore, ideas about best practices in this type of approach are constantly changing as our knowledge and the development of quantitative methods expand. Therefore, the methods that are agreed upon today as being the least susceptible to influence from the researcher may not be viewed the same way in the future.

A second way of dealing with the influence of the self of the researcher is to rely primarily on the selves of others. This is the approach of many qualitative methods. This way of knowing that comes with less certainty and limited objectivity (though that is not considered a problem in this form of research); this is a knowing that comes from the stories of those around us. In this way of knowing, we recognize that the stories people tell us are not always “accurate” to the facts of what actually happened, but that storytelling captures the truth of how someone has made sense of their experience. As a researcher, being in relationship with a research subject influences the way they tell their stories. However, holding the truth of another person's story grants us knowledge that can enlarge our perspective; it allows us to indirectly experience the world through another's eyes. The story of another not only gives us insight into a certain phenomenon or experience, but it also influences the frame through which we see the world, which gives us a fuller, more textured picture of what it means to be human. These methods, then, focus on developing in-depth descriptions of a phenomenon, rather than judging something as being better or worse than another thing.

> "In autoethnography, 'proximity, not objectivity, becomes an epistemological point of departure and return' (Conquergood, 2002, p. 149)" (Adams et al., 2015, p. 23).

A third way of dealing with the self of the researcher is to embrace it. In this approach, there is no problem to be dealt with here. The self of the researcher becomes the very landscape of exploration and investigation. In this approach, first-hand knowing and experiencing is set forth not as a hinderance or an obstacle but as the very focus of research: the experience of a single individual is valued as an important contribution to science. This allows for a significant amount of depth and richness to the research, as it captures, exactly, the way an individual experiences life and makes sense of their experiences.

Each way of knowing has its place. The first and most important step of a researcher is to decide which type of knowledge is needed to answer a specific research question. In this way, it is possible that all the types of knowing can be used together to answer different types of research questions about a single phenomenon or experience.

Thus, the different ways of knowing are not in tension with each other, but, rather, are working in concert with one another to give a more complete, deeper picture of a phenomenon.

For this current project, I am choosing a combination of the second and third approaches, integrating other people's stories (through their published memoirs) with my personal experience to explore the essence of what it means to be a patient, and, in particular, what it means to be a patient in relationship with medical providers.

Ontology

Given that this autoethnographic hermeneutic phenomenology project aims to understand the essence of an experience, it is necessary to consider ontology and how it might influence these methods. It is important for me to note that it is my personal and academic belief that existence and reality do not have just one nature. I do not, for example, fall into an objectivist camp, nor do I fall into a constructivist camp. I understand that outcomes (i.e., things that happen) have causes that exist independently of our interpretations and that we can use science to understand some of those causes. I also believe, though, that there will always be a myriad of causes for each outcome, and we will never fully understand all of those causes. Further, I understand that the research questions we ask and the way we define and measure constructs (i.e., our operational definitions) are socially constructed (or, put in slightly different language, emerge from a group of people agreeing to certain definitions, meanings, and measures). I also firmly believe that within that socially constructed context there are things that scientists need to measure and observe with as much subjective objectivity as possible (by "subjective objectivity" I mean objectivity that can be evaluated by the agreed upon conventions of judging scientific objectivity).

In sum, the ontological perspective in my philosophical worldview is that there are some aspects of each experience that are objectively true (i.e., they exist outside of a system of social construction) while there are other aspects of each experience that are entirely subjective and socially constructed. In the practice of science and of research, we have to make choices about which aspects of existence are included in the scope of any given project. These choices, then, influence every detail regarding the methodology we need to employ in a given research project or study.

For this particular project, I am making some important choices about the level at which I am studying existence (and, given those choices, it would be more accurate to say, "I am making choices regarding the level at which I am interacting with experience"). I am focusing on the subjective experience of being a patient.

We can understand the experience of deficits in physical health and well-being at two different levels (that align with the two types of aspects of existence I enumerated above). American philosopher Ken Wilber differentiates between these two levels by explaining one as the physical, actual disease process or physical injury. This is the topic of much of medicine and of the "hard" sciences. This is the level of medical tests and measured outcomes and health statistics. Theses aspects fall into the more "objective" part of reality. This is not, however, the part of illness and injury I am choosing to explore in this project. I am choosing to explore the other part of illness and injury which Wilber describes as the meaning (rooted in your sociocultural experience) you and those around you make of your disease process or physical injury (Wilber, 1991).

In this project, I am seeking to better understand the ways we make meaning around illness and injury, and, in particular, the ways in which our experiences of the actions and messages of medical providers influence the ways we understand and experience our illnesses and injuries. This project is focusing on the aspect of reality that focuses on the ontological assumption that human living is a constant act of interpretation. Memory is reconstructive and recalling and telling stories of what we have lived through are active, creative, and generative acts (Freeman, 1993). Due to this project's reliance on memoir, journaling, and storytelling, it is essential to note that "our primary interpretive takeoff point will not be lives as such, but the words used to speak them" (Freeman, 1993, p. 7).

Furthermore, the gap between what actually happened and how people experienced what happened is not a problem for this project. Starting with people's interpretation of what has happened is an even better starting point given the purposes of this project (the emic point of view). There are different types of truth—the actual moment-to-moment unfolding of events and the way we understand the meaning of those events (Freeman, 1993). For this project, I am choosing to focus on the latter. This project does not aim to make claims about causes and effects, nor does it aim to generalize about elements of experiences. The final results will not aid in predicting anything about a patient or a patient's experience. It aims only to give a rich description of what it can mean, look like, and feel like to be a patient.

> "Phenomenological questions are meaning questions. They ask for the meaning and significance of certain phenomena. Meaning questions cannot be solved and done away with (Marcel, 1949). Meaning questions can be better and more deeply understood, so that, on the basis of this understanding I may

be able to act more thoughtfully and more tactfully in certain situations" (Van Manen, 1990, p. 23).

The purpose of this, then, is not to somehow develop a script for how medical providers should act, but, rather, to call attention to the ways in which perceived medical provider actions and non-actions interact with patient's ways of experiencing the world to influence the way they understand their illness or injury. This will demonstrate how some ways in which patients' experience and meaning making in their relationships with medical providers are an essential part of the patient's experience, health, and well-being. Overall, the particular perspective and approach I have chosen for this study is a call for greater care and attention to be placed on patients' experiences with medical providers and within the healthcare system in general.

As this discussion has shown, the choices a researcher makes with regard to ontology will influence the types of knowledge a study generates. The types of knowledge generated then influence the implications of research. My choices about epistemological foci, ontological assumptions, and methodology are tied to what I hope the practical implications of this study to be.

Positionality

I am a person who exists in the world with certain qualities and experiences. These qualities and experiences influence the way I understand and interact with my research questions. Though I will not (and, truly, cannot) give a full and complete account of all of my qualities and positions that may influence my research, it is important to call attention to some of those that are most salient.

> “When we raise questions, gather data, describe a phenomenon, and construct interpretations, we do so as researchers who stand in the world” (Van Manen, 1990, p. 1).

There are so many aspects of where I stand in the world that influence the research questions at the core of this project and the way I view and interpret those questions. I am a well-educated white person who has always had access to medical care when I have needed it. I also spent ten years trying to get a diagnosis and/or treatment for an intense chronic condition that resulted in eight orthopedic surgery and countless episodes of soft-tissue inflammation and tearing. Over the course of those ten years, I gained a lot of skills in navigating the medical system (and the related, though completely different health insurance system). With these skills, I am able to advocate for myself in both of these parallel systems.

This (combined with fantastic health insurance coverage and access to patient assistance programs) has allowed me continual access to medical care within my means. That is, unfortunately, an uncommon experience in this country. Many people do not have the means to afford or access to healthcare, for so many reasons. In a healthcare system that is broken on so many levels, I am an anomaly. My access has allowed me to change doctors whenever I feel a need to, to access a second opinion when I feel it is warranted, and to have options and choices with regard to my medical care and treatment. That means that my experience of the system itself is not typical. However, given this access, I’ve also had exposure to a host of medical providers, and I’ve been able to watch how those experiences have unfolded over time, which affords me a wealth of personal-experience data from which I can explore the topic at hand.

Furthermore, I am a practicing Zen Buddhist, and I have been practicing Buddhism and meditation for more than five years. There are many ways in which this influences my experience of my life; however, the most relevant to this study is the way in which meditation trains a person's ability to observe themselves and their lives. I have practiced, day after day, watching my experience unfold, in sitting meditation, walking meditation, and during ritual. Over time, this ability to observe myself has spilled over into my everyday life—many times, I am able to both be in an experience and be observing what is unfolding and my reactions to it. This allows for a particularly helpful vantage point from which to understand my experience.

Methodology Rationale

This project made use of an ethnographic analysis of five published memoirs about living with life-altering illness and injuries. The themes and understanding that came from that analysis then guided an autoethnographic inquiry. All of this was done within a hermeneutic phenomenological framework.

> "The method one chooses ought to maintain a certain harmony with the deep interest that makes one a [researcher] in the first place" (Van Manen, 1990, p. 2).

The topic for this current research study came directly out of reflection on my own life. I saw the ways in which interpersonal relationships influenced how I relate to my body, my self, and my experience. This was particularly evident for me in the context of my experiences with healthcare. When I started to look around me, I noticed that this was not something that was unique to me—that was something I wanted to know more about and wanted to understand at a deeper level. Getting a rich, deep, and textured understanding of this dynamic is a solid foundation from which to build a program of research that informs how we can better build and deliver healthcare services and supports.

> “Phenomenology describes how one orients to lived experience; hermeneutics describes how one interprets the ‘texts’ of life” (Van Manen, 1990, p. 4).

Hermeneutic Phenomenology

As noted previously, there is a direct link between the philosophical choices a researcher makes and the methods used to answer research questions. The decisions I have made regarding the epistemological and ontological foci of this research lead me directly to work within a hermeneutic phenomenology framework. This framework has at its core the interpreted realities of lived experience, which is precisely what I am interested in better understanding through this research. Hermeneutic phenomenology gives a general process and some specific tools for getting at the essence of what it means to be a patient, and, particularly, what it means to be a patient in relationship with medical providers.

While hermeneutic phenomenology does not have specific, stepwise methods in the way that many more quantitative methods do, it does set forth certain activities in which hermeneutic phenomenological researchers engage. These activities allow the researcher to enter into relationship with their research questions and to emerge with a richer, deeper, more textured understanding of the topic at hand. Van Manen (1990) names the activities of hermeneutic phenomenology as:

1. Turning to a phenomenon which seriously interests us and commits us to the world,
2. Investigating experience as we live it rather than as we conceptualize it,

3. Reflecting on the essential themes which characterize the phenomenon,
4. Describing the phenomenon through the art of writing and rewriting,
5. Maintaining a strong and oriented pedagogical relationship to the phenomenon, and
6. Balancing the research context by considering parts and whole.

These general activities have guided the specific actions I took and decisions I made in my research process.

Autoethnography

Autoethnography is a method and technique that works extremely well within a hermeneutic phenomenological framework. The second activity Van Manen (1990) lists is "investigating experience as we live it rather than as we conceptualize it" (p. 30). The use of autoethnography allows for my personal, lived experience of being a patient to become the central aspect of this research study. This is a matter of researching the experience from the inside out, rather than from the outside in. Using this method allows access to aspects of an experience that are usually hidden from researchers for a variety of reasons (Adams et al., 2015). Moments of crisis, spontaneous interactions, and intense conversations can all inform the research process in a way they are not able to when the researcher is a third-party observer to the phenomenon at hand. Furthermore, the actual feelings of interactions and experiences are directly accessible to me, the researcher, rather than the researcher needing to use methods to draw from participants some description or quantification of those feelings. This has allowed me to develop a richer, more textured, thicker description of the phenomenon at hand than is usually possible in a research context.

> “From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching—questioning—theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. Phenomenology calls this inseparable connection to the world the principle of ‘intentionality.’ In doing research we question the world’s very secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and in us” (Van Manen, 1990, p. 5).

As mentioned, knowledge is embodied, and so communicating knowledge, particularly when attempting to communicate the essence of a lived experience demands that the researcher does more than have a mind-to-mind connection between themselves and their readers. Instead, the researcher must attempt to connect with readers at a heart-to-heart level, eliciting a visceral response from readers that allows them to taste the essence of the lived experience at hand. Autoethnographic researchers “write in a revealing and passionate way because they are seeking connection, desiring to evoke something deep in your guts and your heart that will allow one consciousness to reach another, yours to theirs” (Ellis & Bochner, 2017, p. vii).

> “The goal of autoethnographic projects is to embrace the vulnerability of asking and answering questions about experience so that we as researchers, as well as our participants and readers, might understand these experiences and the emotions they generate” (Adams et al., 2015, p. 39).

In this process of developing a heart-to-heart description of an experience, it is important to note that there is a significant amount of vulnerability inherent in this methodology. I am allowing my life to become the data for my research. Within this, there are choices I have made about what to share and how to share it. While the heart of this process has been conveying lived experience in a way that allows my readers to connect with that experience, there have been other considerations, of both personal and ethical natures. Because of the nature of my research questions, my body and my experience of it are at the heart of this project. My body and my relationship with it are deeply personal and reflect not only my present-moment circumstances, but also a lifetime of experiences from infancy, childhood, adolescence and beyond. Thus, not everything that influences my experience of being a patient in relationship with medical providers has made it into this finished, shared version of this autoethnographic project. Some of it is simply too personal. Some of it is too raw; there are parts of my health and my medical experience that I do not yet understand, that I have not yet made sense of. Some of it has not seemed useful to convey to my readers. Some of it has related to people who are easily identifiable, even if I were to attempt to disguise their identities (e.g., my family); to some extent, this has included even my medical providers. I have engaged in a great deal of reflection and exploration of the ethics of autoethnography throughout this process, and I have made decisions (e.g., not to name my medical providers) in the ways that align best with my current understanding of these ethical issues.

Integration of Autoethnography with Memoir-based Ethnography

While my personal experience has allowed me to develop thick descriptions of what it is to be a patient, this work is different from memoir or autobiography. It is research and social science. "Autoethnographers *intentionally* use personal experience to create *nuanced, complex,* and *comprehensive* accounts of cultural norms, experiences, and practices" (Adams et al., 2015, pp. 32–33). The factors that define autoethnography as science are in linkages to broader sociocultural experiences and grounding in extant scientific literature. For this particular research study, I have linked my personal experiences and my autoethnographic exploration with the experiences of others through the inclusion of an ethnographic and hermeneutic phenomenological analysis of published memoirs about living through life-altering illnesses and injuries. This is always followed by an exploration of connections to the broader scientific and philosophical literature in this field.

> "Thus, phenomenology consists in mediating in a personal way the antimony of particularity (being interested in concreteness, difference and what is unique) and universality (being interested in the essential, in difference that makes a difference)" (Van Manen, 1990, p. 23).

I analyzed the content of the memoirs using a hermeneutic phenomenological framework to identify the defining or essential aspects of the experience of being a patient that are common among the stories of these different people. Those identified aspects were the scaffolding and the landscape of my autoethnographic exploration. In this way, I have worked to link my particular, situated experience with the broader experience of others who have gone through similar things. This is a way of grounding stories of my experiences, which I can actually touch, in a phenomenon as it is more broadly experienced. The memoir analysis determined which stories from my own life I decided to tell.

Potential Challenges and Opportunities

In the preceding text, I have discussed some of the challenges and opportunities of this project. There are some other challenges and opportunities that are important to acknowledge. This project has been a unique combination of methods and data sources; as such, it has the opportunity to bring new understanding to this area, but it has also had unique challenges.

Inability to Generalize

As an autoethnography grounded in an analysis of memoir, as mentioned, the aim is not to be able to generalize results or findings. It is possible, however, that people will want to read the final product and apply the specific findings to other people who experience life-altering illnesses and injuries. This is not the aim. The aims of this project are, however, two-fold: (1) to promote curiosity about what patients are experiencing and (2) to connect to people experiencing life-altering illness and injury, so that they are able to better understand their own experiences and stories (Adams et al., 2015).

Living while Researching

Given that this is an ongoing experience for me, I continued to have experiences of living with life-altering illnesses that are deeply troubling and/or painful during the course of this project. Those experiences have, at times, made it difficult to continue working on this as a research project as the subject matter has become too raw or difficult to work with. While there have been times when I have stepped back from this project to give myself time and space to process these kinds of experiences, I have always returned to it. This project has been about connecting my individual experience with the experience of others in a way that makes people think more deeply about what it means to be a patient. That work, even in the midst of acute difficulties, has reminded me that this is not something I am carrying alone, and it also has given me meaning and agency in the midst of experiences that can feel very helpless. Researching while living the experience has brought greater depth to this project and greater understanding to my own circumstances.

Researching across Time, Place, and Diagnoses

Given my personal experience and the experiences of the authors of the memoirs I am including in this project, I have examined patients' experiences of living with different illnesses and injuries at different times in different places. While there has been an element of challenge to this in that the experiences differ based on each of those contextual elements, this has also strengthened my ability to really get at the essence of the experience. I have been able to examine what is common among the experience that differentiates it from other experiences. The different contexts in which they occur have ultimately given greater depth to that examination.

Background

The physician-patient relationship has been explored over the course of time through a variety of methods and in a wide range of academic fields. To review all literature included in that exploration is beyond the scope of this project. This section, however, will include an overview of some theoretical and philosophical underpinnings of using qualitative methods to study the subjective experience of being a patient in relationship with medical providers as well as an examination of several exemplary empirical publications in this area.

Theoretical and Philosophical Frameworks

There is a rich history of inquiry into the nature of the physician-patient relationship within the field of the philosophy of medicine. This area of philosophical inquiry involves applying different philosophical systems to the physician-patient relationship and exploring the ramifications of those applications.

The basic understanding that runs throughout these philosophical inquiries is that the physician and the patient live in different but overlapping worlds and that these differing worlds result in different points of view which influence the way they perceive and interact with illness or injury (e.g., Pârvan, 2016; Toombs, 1987). Figure 1 is a simplified representation of this idea. It is important to note that the examples of characteristics in this figure are only that, examples. There are physicians and patients alike who do not fit squarely into this model. It is helpful, however, to gain a basic understanding of what is generally thought to differentiate these two worlds. Though there are some areas of overlap between the differing worlds, this difference can be viewed as a vast chasm by which patient and physician are destined to be forever separated (Rudebeck, 2000).

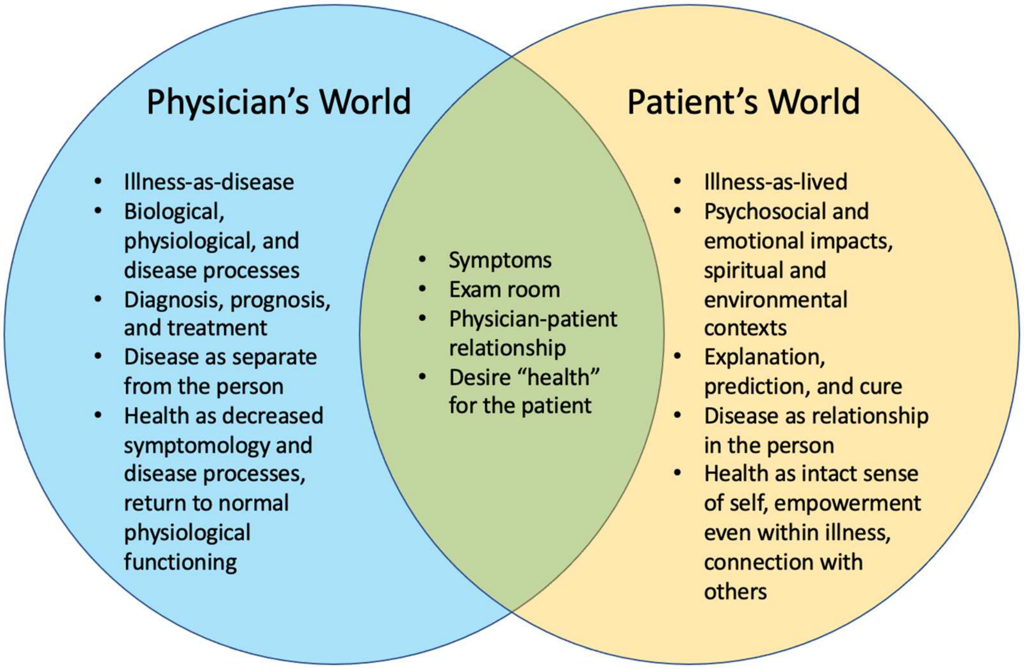

Figure 1. Representation of distinct and overlapping elements of the physician's world versus the patient's world.

Despite these differences, however, it is essential that the physician's understanding of the patient's symptoms aligns with the patient's experience of those symptoms in order to make a proper diagnosis and to evaluate disease trajectory over time (Rudebeck, 2000). Philosophers have proposed different solutions to the seeming contradiction of the impossibility and the absolute necessity of patient and physician coming to a shared understanding of the illness. This shared understanding can be thought of as a shared narrative of the illness, a narrative that contains both a “text” (the sickness) and a “context” (the culture in which the patient experiences the sickness, Coulehan, 1991).

An important distinction all philosophical solutions share is the explicit naming of the illness-as-disease versus the illness-as-lived (though not all philosophers use those exact terms). The illness-as-disease is the physiological process of the illness along with the science-based understanding of the link between disease and symptoms and disease and treatment. The illness-as-lived, however, is the way in which the patient experiences the illness in their day-to-day lives, in their embodied experiences (Toombs, 1987). Given these different perspectives of illness, the physician and the patient often have wildly different goals for their work together. The physician often focuses on the illness-as-disease, seeking diagnosis, prognosis, and treatment; the patient focuses on the illness-as-lived, seeking explanation, prediction, and cure (Toombs, 1987). This can make collaboration and the formation of a positive working relationship between physician and patient incredibly difficult. It is not, however, impossible, and there are so many stories that demonstrate the hope and the power that come from overcoming this particular hurdle.

Literature Review

There is a substantial body of quantitative literature regarding components of the patient-provider relationship. Very broadly, these studies show that positive patient-provider relationships can positively impact disease symptoms, patient adherence to treatment protocols, incidences of medical error, and physician burnout rates (Haverfield et al., 2020). Physician empathy, specifically, is associated with better clinical outcomes for patients in addition to lower patient anxiety and stress (Derksen et al., 2013). Moreover, enhanced provider communication, specifically patient-centered communication, is related to better patient understanding of illness, better emotional health, and fewer ordered tests and procedures (Riedl & Schüßler, 2017). There are multiple factors that are associated with levels of patient-provider trust, including patient characteristics (e.g., race/ethnicity, health status, comorbidities); provider characteristics (e.g., type of physician, age, race/ethnicity, interpersonal skills); and characteristics of the organization/healthcare system (e.g., high medical cost, accessibility, coordinated care Murray & Mccrone, 2015). There is also evidence that intensive interventions aiming to enhance patient involvement can enhance patient outcomes, while interventions targeting physician communication can moderately improve patient satisfaction and quality of life (Auerbach, 2009). Furthermore, interventions that focus on enhancing specific communication techniques can enhance patient health outcomes, including indicators of physical and mental health (Haverfield et al., 2020). Quantitative research demonstrates that the physician-patient relationship matters, and it matters a lot, in many different ways.

There is also a growing body of qualitative literature on this topic. These studies have contributed toward the development conceptual definition of trust in the context of the patient-provider relationship: "*Promoting trust* is a provider demonstration of interpersonal and technical competence, moral comportment, and vigilance to support positive patient outcomes" (Murray & Mccrone, 2015, p. 16). The qualitative literature also gives a sense of some of the elements that contribute to the quality of the patient-provider relationship, such as interpersonal skills, offering competent care, partnering with the patient, knowing and respecting the patient, effort, and continuity and time (Murray & Mccrone, 2015). While the qualitative literature gives a sense of the provider-patient relationship and its elements broadly, the current project aims to give deep and rich exploration of those elements. This project is an effort to provide real, accessible, and potent information about what these elements actually *look like* within provider-patient relationships. This research begins with current understanding gleaned from the qualitative literature, which I have then explored and refined through the analysis of the memoirs. The literature findings, along with the analysis of the memoirs have subsequently determined the direction of my autoethnographic exploration.

Given that the aim of qualitative research in this field is to produce rich descriptions of experience with considerable depth, I also want to give a better understanding of what some of the qualitative literature looks like in this field with a deep dive into five articles that fit within this field of literature: three phenomenological qualitative studies and two autoethnographies. I chose these studies based on their methodological and conceptual proximity to my research project; these exemplars (reviewed in chronological order of publication) share the spirit in which I will conduct my current research. It is important to note that not all of these studies are directly about the patient-provider relationship; however, they all investigate and describe factors related to the difference between the illness-as-disease and the illness-as-lived. As such, all of these studies can inform the patient-provider relationship.

Price, "Qualitative Analysis of the Patient-Provider Interactions: The Patient's Perspective" (1993)

Price posited that there was a difference between patients being able to recall and enumerate symptoms and patients sharing what the symptoms are like for them (in the context of their individual lives). She then used video-recorded sessions between patients living with diabetes and providers (a doctor, a nurse, and a dietician) to analyze and describe the ways in which the providers accessed or failed to access the diabetes-as-lived rather than simply the diabetes-as-disease within their work with patients. She grounded her findings from the analyses of the videos in findings from previous qualitative interviews she had conducted (two two-hour interviews with each of 19 patients). Through the previous qualitative interviews, Price was able to develop a generalized trajectory of learning to manage diabetes, giving a rich view of what it was like for patients to adapt to diabetes. As she analyzed video recordings of patient-provider interactions, she was then able to identify which aspects of that experience providers uncovered for the patients in front of them and times in which they failed to pursue an understanding of the process for the individual with whom they were meeting.

In order to use the videos in this way, Price reviewed patient-provider interactions to identify places in which the patient shared their experience of the illness-as-lived. Part of what she looked at in those moments was what the provider did to elicit patient sharing. She found that there were several things providers did to set the stage for the patient to be able to share the illness-as-lived. For example, for one patient, physical proximity and touch coupled with direct praise and encouragement preceded the patient sharing her lived experience. In another example, the provider recognized the specifics about the patient in front of them and adapted typical prognoses and processes to that specific patient (using language like, “but, from what I know about you…” [p. 146] to preface statements about disease management and prognosis.). This recognition of the patient as an individual also evoked more sharing of the illness-as-lived.

Overall, Price found that the illness-as-lived was a very important factor in patient comfort with and adherence to disease management plans and overall well-being. She also found, however, that providers often did not attempt to understand that illness-as-lived and how it was impacting disease management. For example, in response to a provider asking what one patient thought about a management plan, the patient replied, “Yeah, it’s fine. The only problem is that I won’t do it” (p. 147). Price notes that the provider did not ask follow-up questions about why the patient wouldn’t follow the plan, what issues there were with the plan, what the patient has tried in the past and had difficulty with, or any questions to break down the “I won’t do it,” comment. Similarly, when other patients reported difficulties with certain aspects of management plans (e.g., dietary changes or glucose monitoring), providers did not dig deeper into what might be causing the difficulties or lack of adherence to those parts of the plan.

It is clear from Price’s analyses that there was a gap between what people with diabetes experience in their day-to-day lives and what providers ask patients about. Furthermore, she proposes that it is this gap that is largely responsible for lack of adherence to a disease management plan. Price concludes, “Being able to narrate one’s experience offers an opportunity to examine one’s own process and progression. The provider’s expertise is in soliciting this information, organizing and reflecting it back to the person, and then mutually determining new possibilities” (p. 148).

Lindsey, “Health Within Illness: Experiences of Chronically Ill/Disabled People” (1996)

Lindsey’s interpretive phenomenological qualitative study was centered around the goal of describing what “feeling healthy” meant for people with chronic illness and disability. She pursued this research with the underlying foundational assumption that health and illness are not opposites, but rather they are dialectical constructs that can (and even must) coexist. To support this assumption, she cites both philosophical perspectives about illness and health and empirical research showing that the majority of people with chronic illness and disability feel that they are healthy. In this, she differentiates between “healing” and “curing,” where healing is more about existential concerns and curing is more about physical concerns.

In order to explore this idea of health within illness, Lindsey recruited eight participants with a range of chronic illnesses and disabilities to take part in three separate interviews. She found six themes about what health within illness looked like within these interviews: “(a) honoring the self, (b) seeking and connecting with others, (c) creating opportunities, (d) celebrating life, (e) transcending the self, and (f) acquiring a state of grace” (p. 468). These themes are all about healing; none of them have to do with physical well-being. Rather, they center around other aspects of life (e.g., interpersonal relationships, spirituality). Within these themes, participants spoke of the importance of things like self-respect, empowerment, belonging, learning, growing, feeling vibrant and alive, humor, wholeness, and peace.

This concept and experience of health does not lie within the illness-as-disease but the illness-as-lived. A medical provider who does not attend to illness-as-lived would miss out on this conceptualization of health that is independent of disease process, symptoms, and prognosis. Furthermore, this conceptualization of health implies that providers can be healers even when a disease process cannot be altered. They can do this by including focus on the illness-as-lived while also monitoring the illness-as-disease. This study suggests that one of the ways to do this is to pay attention to and help patients cultivate the qualities listed above.

Neville-Jan, "Encounters in a World of Pain: An Autoethnography" (2003)

Neville-Jan is an occupational therapist, spouse, and mother who lives with chronic pain as the result of spina bifida. She notes that throughout the literature in her field, the voice of the patient (in this case, the voice of the person in pain) is visibly lacking. To fill this gap, she tells her story of unrelenting, debilitating pain that she experienced most of her life, but that became intolerable when she was pregnant for the first time. She miscarried this child at 21 weeks, a result of the amniocentesis the doctors urged her to have, thinking that if she was less worried about her baby, the pain would go away. She speaks of how she views the pain as a "demon" and an enemy that she is fighting in a war, the enemy ready to create immense explosions of pain at any time. She never experienced a break nor relief from this life-altering pain. She also speaks of the numerous medical professionals she has seen, many of whom do not believe she is in as much pain as she says she is. She speaks of how some ignore any talk of pain, using a behavioral strategy to "extinguish" the pain by not reinforcing discussion of its presence. She offers insight into how these types of relationships with providers (characterized by disbelief and avoidance) drive shame and anger to grow in her, making her feel like she is alone in the battle against the unrelenting monster of her pain.

She also speaks of doctors who believed her, who believed her pain, and how they became allies in the war. She speaks of these people as embodying "empathy and respect" (p. 95) toward her. Ultimately, these physicians, willing to believe the world their patient says she inhabits do help her find some relief (for a while through steroid injections, then an antidepressant, and finally a medication intended to decrease nerve pain). Yet, she is always scared to bring up those solutions with new healthcare professionals (particularly the antidepressant) because she fears it will reinforce their idea that the pain is made up, all in her head. She lives her life constantly waiting for the next strike of the pain demon, all while continuing to seek out something that will cure her pain so that she can live her life in freedom.

In this autoethnography, Neville-Jan also writes about different perspectives about pain (from a variety of disciplines) and relates those different conceptualizations to her experience. She speaks clearly of how damaging it is to label someone's pain as "made up," "in their head," or even psychogenic or psychosomatic (which are often used as euphemisms for "made up"). This damages the patient's relationship with the physician, the patient's relationship with and view of themselves, and it can often make the pain worse.

Neville-Jan further explores how the medical systems and establishments made it difficult for her to obtain the treatment and support recommended. For example, her insurance denied coverage of twice-weekly psychiatry visits because she was still working (which they took to mean that she did not need that level of care from psychiatry). She also speaks of how her decision to continue to work (a strategy to target the existential aspects of the illness, to preserve her sense of herself and to distract her from the pain) would make it more likely that physicians and others did not believe her reports of her pain.

In putting forth recommendations for the occupational therapy field, Neville-Jan points out that, regardless of where the pain originates, pain is pain, and it is real. She states that trust is essential for an effective provider-patient relationship, and that, with chronic pain in particular, this trust begins to be built on believing the patient when they say they are in pain. She relates how, in her story, there were two people who engendered trust and hope (both of whom started by believing her pain)—she calls them "partners," reflective of their ability to work together and to share pieces of their lives with one another (p. 95).

Fox and Chesla, "Living with Chronic Illness: A Phenomenological Study of the Health Effects of the Patient-Provider Relationship" (2008)

This qualitative study includes the use of interpretive phenomenology to analyze stories 25 women with chronic health conditions told about their interactions with healthcare providers in group and individual interviews. These authors describe how in most of the literature around patient-provider relationships, "the relationship and interaction have been broken down into its constituent parts, and researchers have attempted to identify elements that predict certain behaviors and responses and inhibit others" (p. 110). They go on to note that while this is important, it lacks a nuanced understanding of the patient-provider relationship; furthermore, this nuanced understanding can only be understood by seeking an in-depth understanding of the patient perspective on the patient-provider relationship. At the time this study was conducted, these authors were unable to find any study that examined the patient-provider relationship from patients' perspectives. This is what they intended to do in this study.

The first thing the authors found was that patient-provider relationships could be characterized by where they fell on a continuum, with disconnection anchoring one end of the continuum and connection anchoring the other. The quality of connection was especially evident in the presence or lack of presence of partnership and personableness in the patient-provider relationship.

The women often described partnership with their providers as a "marriage" in which they shared so much of their lives, the good and the bad, in a deep and open way; these women experienced a high degree of intimacy with their providers. A high degree of partnership resulted in patient trust in the provider and was characterized by mutual responsibility and give-and-take, which allowed patients and providers alike to express their concerns, opinions, and reasoning in open and honest ways. Providers in these relationships show empathy and are attuned to their patients' needs and feeling states. When patients in these types of relationships show resistance to certain disease management plan, the provider is willing to investigate the resistance to see what lies underneath it. They make an effort to understand and address the underlying resistance while still working to help the patient improve their health in order to allow the patient more success with a disease management plan. This often resulted in better health outcomes for patients. Patients reported that relationships with providers that included strong partnerships made them “better physically, emotionally, and spiritually as a result” (p. 112).

The aspect of personableness was reflected in providers understanding and knowing patients as individuals; providers with high personableness were able to share some of their personal selves with patients and to see the patients for who they truly were. This allowed the patients to interact with providers with fewer barriers and more openness and vulnerability. This is essential in a patient-provider relationship because patients who are willing to be more vulnerable with providers are more likely to share symptoms, problems, or concerns that make them feel uncomfortable or ashamed. They also felt more willing to challenge the provider through questioning and disagreements, which allowed both patient and provider to feel like they were on the same page and in agreement whenever they moved forward on something.

On the other end of the spectrum, patients experienced disconnection with their providers when the providers did not individualize their care, but rather were categorized and then treated like every other patient in that category. This disconnection was characterized by significant use of power and control and often resulted in clinical mismanagement. Providers in these relationships tend to be distant, aloof, or downright mean (the paradigm example the authors share included a provider who told a patient with diabetes that most patients with diabetes “don’t care” and are “too stupid” to understand information about how to manage their diabetes [p. 114]).

The patients in this study believed that when they had a connected relationship with their provider, they received competent and accurate care; however, when they had disconnected relationships with their providers, they often experienced clinical mismanagement of their chronic illnesses. These disconnected relationships are characterized by conflicting information given to the patient and interrogating the patient about decisions past (or current other) providers have made, which results in fear, confusion, and feeling alone. This results in a significant lack of trust on the part of the patient. They believe that the provider does not know important information about their past medical history and does not really care about them as a person. When the patients in these types of relationships with providers ask questions or push back against recommendations, these providers write the patients off. The authors include the story of one individual in which the patient had experienced such disconnected relationships because of high staff turnover that she no longer believed anything providers told her, and "she was frightened for her health and her life" (p.115) but unable to do anything about it.

Overall, for the women in this study, connected relationships resulted in trust and stability, which allowed them to more effectively manage their chronic illness. Disconnected relationships, on the other hand, resulted in mistrust and isolation, which prevented the women from managing their chronic illnesses effectively. It is not difficult to make the leap to hypothesize that women with connected patient-provider relationships would, over time, experience better health outcomes than those with disconnected patient-provider relationships.

Barry, "On the 'Flip Side': An Autoethnography Utilizing Professional Reflective Practice Skills to Navigate a Medical Experience as the Patient," (2020)

Barry is a Medical Radiation Science (MRS) practitioner. She shares that she originally perceived herself as a *provider* of care and the patient as a *receiver* of care. In this study, she explores the way this perception changed throughout her personal experience as a patient. She notes that there is little research regarding person-centered care and reflective practice from the patient point of view. She writes about how she had an episode in which she experienced significant dizziness and nausea accompanied by difficulty speaking. Emergency Department (ED) doctors told her she likely had a transient ischemic attack (TIA), and she was directed for further testing. When she had an MRI, she writes, “Somehow, having my colleagues performing these tests, and the fact that I have performed procedures on many anxious patients, seems to only heighten my anxiety” (p. 49).

After the MRI, she relates how she waited for more than four weeks after the test and still had not received results. She did not have another episode during that time, and that, combined with the lack of urgency on the side of providers led her to believe that there must not have been significant findings. At that time, however, she had another episode of dizziness, nausea, and difficulty speaking. At the ED, the doctor delivered the results of the MRI done four weeks earlier, the results that had been sitting somewhere waiting for them to be delivered to the patient. The MRI showed an aggressive brain tumor, which had a median patient survival of one year. Barry then speaks about all the waiting that ensues, waiting for surgery, waiting for admission, waiting for transport, waiting for imaging. All this waiting weighed on her, and she felt immense frustration with her providers, stating, “Do they not know my life could now be measured in weeks, not years?” (p. 50), conveying the sense of wasting what little life she had left waiting for providers to do the next thing.

She writes of how she consulted with a neurosurgeon who showed her “the contents of my skull” (p. 50) and bluntly said that the tumor needed to be removed through surgery, without any discussion of how, why, other options, or weighing of risks and benefits. She shares how the process leading up to her surgery stripped her of her identity. She wore a patient gown with no jewelry, and then has parts of her head shaved in preparation for the surgery, all of which felt as if they are robbing her of who she is.

After the surgery, the surgeon reported seemingly good news from pathology. It appeared that the tumor was not as aggressive as thought based on the MRI. Barry was left to figure out how to reconcile the differing medical findings. Although she states, “I feel hope, like a slither of light has been let in, and I can again see beyond the immediate” (p. 51), she still felt trepidation based on the differing opinions.

As Barry writes about her experience of having another MRI after surgery, she writes, in many ways, like a survivor of trauma might. And, indeed, she is a survivor of trauma, defined as “exposure to actual or threatened death” (American Psychiatric Association, 2013) in the most recent Diagnostic and Statistical Manual of Mental Disorders. Barry describes hypervigilance and reexperiencing of the initial diagnosis when she encounters the MRI machine, room, and sounds once again. This is something none of the providers recognized, acknowledged, or addressed.

Concluding about her experience, Barry writes that this experience shifted the way she perceived the patient-provider relationship. Instead of thinking of the relationship as that of provider and receiver, she noted that when her own relationships with providers were characterized as a partnership, she was best able to connect with them and to move forward with the next necessary step in her response to her illness. She also notes her renewed belief in the importance that providers adopt a model of patient-centered care, which leads to better compliance with treatment plans and better health outcomes.

Conclusion

Together, these exemplars from the literature describe some common themes. Patient-provider relationships tend to be better when there is a connected relationship with recognition of the patient as an individual person. These connected relationships are characterized by trust, openness, honesty, and a sense of caring for the individual. Patients tend to do better overall when they feel heard and listened to and when they experience the patient-provider relationship as a partnership.

My current project differs from quantitative research in that there is not a specific "gap" in the literature to point to as a place where my research bridges between one area and another. Rather, the research I have done comes from a certain perspective at a certain time within a certain context. There are many things about my experience that allow my voice to contribute uniquely to this field of literature: I am a young person who has dealt with significantly more medical difficulties than most people face in their lifetimes, I am watching how my health difficulties and my relationships with providers are impacted by the presence of a deadly global pandemic, and I am integrating perspectives from several other individuals through the use of their memoirs. Ultimately, this study has a sample size of one, which will allow for a rich and deep exploration of how these things come together to create a particular experience from my perspective in this time and in this context.

Chapter 2: Method

Neither autoethnography nor hermeneutic phenomenology have specific methods to follow. Both are more a set of core values and guiding principles that aid in decision-making during the course of a research project. The process itself unfolds over time, as the researcher follows what is arising in their work. Therefore, this section includes a general overview of some of the elements of the methods that will be used for this project, but it must be read with the understanding that there was flexibility and different approaches over the course of this project. This flexibility and the varying approaches are an inherent asset of these types of research processes.

Data sources

Data for this project came from five published memoirs, personal journals and essays, and personal experiences.

Memoirs

I have chosen five memoirs analyze line-by-line for this study. I chose these five memoirs for two primary reasons: (1) they are reasonably well-known and popular and (2) the way they relate their stories resonated with me personally. The first reason is important because their acceptance is an indicator that they speak to something that resonates with people generally. This allows me to ground this project in stories that are likely reflective of broader social experiences. The second reason is important because, as an autoethnography, I need to be able to connect my experience with the experiences of others. These memoirs resonated with me because they discuss, in depth, the ways in which there is a dynamic interplay between interpersonal relationships and intrapersonal relationships. That is what interests me most: knowing that these would memoirs speak to that dynamic allowed me to explore that interplay in their stories and in my own stories.

There were other memoirs that I reviewed, but they did not directly discuss many of the themes I was interested in for this project. For example, they focused on “overcoming” the life-altering illness or injury by completing a significant physical endeavor (e.g., an Ironman, kayaking the Grand Canyon) or some other grand achievement. These memoirs tended not to include discussion of interactions with medical professionals. Furthermore, though they did sometimes include passages about how interpersonal relationships helped them complete their endeavor, they did not tend to explore how those relationships influenced the way they related to themselves and their experiences. In the end, the best way I can describe my choice of memoirs is that I chose stories about transcending life-altering illness and injury rather than stories about overcoming them.

The five memoirs which I analyzed line-by-line were:

1. *When Breath Becomes Air* by Paul Kalanithi (2016). Paul Kalanithi was diagnosed with terminal lung cancer at the age of 36 just as he was finishing his residency and training as a neurosurgeon neuroscientist. He wrote the book between his diagnosis and his death in March 2015.

2. *It’s Not Yet Dark* by Simon Fitzmaurice (2017). At the age of 35, Simon Fitzmaurice, a filmmaker, was diagnosed with Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s disease). He published this book in 2014, six years after his initial diagnosis at which point doctors had told him he would likely die within four years.

3. *Waking: A Memoir of Trauma and Transcendence* by Matthew Sanford (2006). Matthew Sanford was in a car accident with his family when he was 13 years old. His father and sister were killed, and he was left paralyzed from the chest down. This book is about his experience in the aftermath of that tragedy, including an exploration of his eventual adoption of a yoga practice starting at age 25.

4. *We Know How This Ends: Living while Dying* by Bruce Kramer and Cathy Wurzer (2015). Similar to Fitzmaurice, Bruce Kramer was diagnosed with ALS, though he was in his 50s when he received the diagnosis. He cowrote this book with Cathy Wurzer, who engaged in public conversations with Kramer (via public radio) about his ALS for the last four years of his life. This book also chronicles Wurzer's journey alongside her father during and after his diagnosis of Alzheimer's Disease.

5. *The Bright Hour: A Memoir of Living and Dying* by Nina Riggs (2017). Nina Riggs was a poet who was diagnosed with metastatic breast cancer at 37 years old. This book was published the year she died, just a month shy of 40 years old.

I realized early on in this project that most of these memoirs are about not only living with life-altering illness and injury but were also about dying. While that might influence the experiences the authors have within the medical arena, these memoirs contain a great deal of rich information about interactions and relationships with medical providers. The fact that the stakes are higher, that these writers are dying, magnifies those experiences in many ways. I continually evaluated my assumption as I went along, and I do not think that this was problematic for what these memoirs taught me about what it means to be a patient.

When you are a frequent participant in the medical establishment, you come face-to-face with your own mortality on a regular basis, regardless of your diagnosis or prognosis. This happens on many levels and in many ways, and so wrestling with the realities of life and death is not an experience that is unique to those who have a terminal diagnosis. The experience of those with terminal diagnoses, then, can show us some very important aspects of what it means to grapple with the actuality of death in relationship with medical providers.

Personal Journals and Essays

I am a writer. I always have been. It's how I process things. It's how I make meaning; therefore, I have hundreds of thousands of words written about things I have experienced and how I have made meaning throughout those experiences over the years. Much of this writing is about my health problems and medical experiences. For this project, I identified about a hundred pages of journal entries and essays that were most relevant to the exploration of what it means to be a patient. I wrote some of those pieces in the moment of an experience (I'm known to text or email myself while sitting in waiting or exam rooms as a way of processing what is happening at the time) or shortly after something happened, while I wrote other pieces months or even years after the event as I was coming back around to the experience, needing to make sense of it in light of current circumstances. I treated these similar to the way I treated the aforementioned memoirs.

Personal Experiences

My story is far from over. This project is one that I worked on while living the actual experience I am attempting to convey in these pages. Throughout the project, I had a plethora of doctors' appointments to manage several health concerns. I had approximately seven medical providers whom I saw on a regular basis, with others coming and going as new issues arose. My experiences with these providers were also a large part of this project. I made a special effort to write about the experiences as they felt relevant to this project. Indeed, many of the stories contained in these pages are things that occurred over the course of my time writing this dissertation. The experiences I had during this time deepened my understanding of the subject at hand, but writing this dissertation also influenced the way I came to understand and respond to my experiences of being a patient.

Data Collection and Analysis

Given the nature of hermeneutic phenomenological methods, data collection and analysis cannot truly be separated out. They are two sides of the same activity; in this framework, the analytic exercise of the researcher is in writing a description of the phenomenon at hand. This writing evolves over time, but it has to be happening at all times. Therefore, I began writing during data collection, and continued writing throughout the entire process of developing this dissertation.

The raw data for this study was immense and unwieldy as it stands naturally. As such, I used a process to identify the passages that included the most information relevant to the current study. For each data source, I first read through and indicated passages that dealt with the following themes:

1. Interpersonal relationships with medical providers

2. Intrapersonal relationships (e.g., mind-body, person-experience, evolution of self)

3. Epiphanies/realization of general or universal truths

4. The experience, development, and evolution of hope

I arrived upon this list of themes through an iterative process. I began initially by indicating passages that fell into the first two themes: (1) interpersonal relationships with medical providers and (2) intrapersonal relationships. As I started with two memoirs with these two themes, I realized that there were many times when the authors wrote about realizations they had that applied not only to themselves and their situations, but to life as a whole. These realizations were a very specific type of intrapersonal relationship or experience. In autoethnographic and hermeneutic phenomenological research, epiphanies play a particular role because they can be seen as moments of peak understanding or turning points that give a significant amount of information about what life is like for the person having the epiphany. As such, I felt those statements needed to be considered separately from the other intrapersonal relationships/experiences. I also began to indicate passages about hope for a similar reason. As I was coding interpersonal and intrapersonal relationships, I found passages about hope to be difficult to categorize, as these passages were often a combination of interpersonal and intrapersonal relationships as well as a combination of actions, understandings, and emotions. There was no clear way to fit them into any of the categories I had at the time. As such, I added the fourth category to indicate passages dealing with hope. Once I had my four categories, I went back to the beginning of the memoirs to make sure I was indicating passages that dealt with all four themes.

The coding/analysis (of the memoirs and of my personal journals) was limited to passages about the aforementioned themes. I considered each complete thought a “line” for the purpose of “line-by-line” coding. This was typically a sentence or (often) a paragraph that needed to be taken as a whole in order to be meaningful. For each “line,” I first pulled out the phrases or words that struck me as being most notable (phrases or words that spoke to the essence of the experience). I also made note of my thoughts and/or words that I felt characterized the passage best. Throughout the process of analysis, I kept these notes in the book itself (using underlining and utilizing the margins) and in a running memoing document (in which I included the book and page number of the passage about which I was memoing).

Utilizing the process of hermeneutic phenomenology, as I denoted these passages, I began writing descriptions of the overall phenomenon I am studying (i.e., what it is to be a patient in relationship with medical providers) as well as the most salient components or aspects of that experience that were emerging. For example, when indicating passages that deal with the experience, development, and evolution of hope, I wrote things such as:

- “A type of hope—working for the promise of what will be earned?”
- “Acceptance leading to connection leading to hope (contrasted to the disconnection of avoidance)—acceptance might not be the best word here, but I’ll use it as a placeholder.”
- “There seems to be an emerging connection between meaning and hope.”
- “Hope as standing between night and day and experiencing it as ‘sublime.’”
- “Hope as presence living in the moment, whatever the moment is.”

- “Hope as an active relationship with what is.”
- “Hope as bearing witness.”

In addition to these short writings in the margins, I also developed more thorough descriptions of what is unfolding. One example: “Hope in the midst of illness seems a paradox. There is an embrace of life as it is even as the life you once knew is slipping away. You are experiencing substantial loss, sometimes of things you didn’t even know you could lose. And yet, hope seems like finding a way to stand steadfastly in the midst of all of that.”

Once I finished denoting the aforementioned themes and writing about them as I went, I looked at what I wrote during that time while asking myself, “What is it that constitutes the nature of this lived experience?” (Van Manen, 1990, p. 32). This is the central question to a hermeneutic phenomenological inquiry. From there, I used what I learned about the nature of the lived experience as a foundation and structure (a scaffolding of sorts) for the autoethnographic element of this dissertation. It helped me choose which autoethnographic stories to tell and how to organize them. The elements gleaned from the line-by-line coding that seemed essential to the nature of the lived experience became the themes I explored with my stories. My stories, in essence, are an evocative and indirect reporting of the results of the hermeneutic phenomenological analysis. For a direct and more traditional report of the results of the hermeneutic phenomenological analysis of the five memoirs specifically, see Appendix A. Appendix A is a free-standing manuscript regarding the memoir analysis (as such, note that there is content redundancy between the manuscript and some sections of the body of this dissertation).

Reflexivity

As in any qualitative research (and, truly, any research), reflexivity is an essential activity for the researcher. In this case, reflexivity not only allowed me to see my own thought processes, hypotheses, and biases, but also allowed me to begin to connect my personal experiences to the more general experiences of a group of others. My reflexivity took the form of regular journaling and memoing about the research process, what came up for me, what I was thinking and feeling, and ideas or theories I might have. Some of this later became fodder for autoethnographic exploration; some of it did not and simply remained a part of my memoing document.

Chapter 3: Existential Injuries in Life-Altering Illness and Injury

I sat in the one of the old, ratty chairs lining the wall of the pharmacy, holding back tears. Just an hour earlier, I had left my primary care doctor's office with a sense that maybe relief was on the horizon. I had a combination of issues that had all come around the same time—a latent tuberculosis infection that we needed to treat before I could start the immunosuppressants I needed, a skin infection from the brace I had been wearing for months after a major knee surgery, and a flare to my autoimmune disorder. Each required its own medication, and the combination of medications was ruining me. I had been nauseous and vomiting for days. Seeing my primary care doctor gave me some hope; we were able to identify a medication to treat the nausea that wouldn't trigger my migraines (like other anti-nausea meds do). By the time I got in my car to leave the clinic, though, I had a call from my pharmacy saying that they didn't have the medication in stock.

I ventured to a different pharmacy to see if they could fill the prescription. I got there and found the "drop-off" window closed, so I waited in line for 25 minutes just to check and see whether they had the medication and could transfer the prescription over. I finally got to the front of the line, where they took several minutes to figure out if they had the medication and then gave me a form to fill out. The form made no sense; I couldn't figure out what information to include in it. I waited in line again so that I could ask for some guidance in how to complete the form. When I asked for the help, I was informed that it was actually the wrong form, and I was given another form to fill out. I filled out the second form and was told that it would be at least 30 minutes and up to 2 hours before the medication would be ready.

So, I sat down. I wasn't really sure what else to do. As I sat there, I realized that this was nothing new. This was routine for me. My mind drifted to all the time I've spent waiting: waiting to be called back to an exam room, waiting for the doctor, waiting for the nurse to take me to the lab, waiting for test results, waiting for treatment, waiting for surgeries, waiting for medications, waiting for specialist availability, waiting for x-rays and CTs and MRIs, waiting, waiting, waiting. I realized, sitting there, waiting once again, that I had wasted so much of my life, waiting.

Then I thought back to another day where tears had blurred my vision—while walking my dog, driving my car, running errands—all day that day really. At first, I wasn't really sure why. And then, in an instant, I knew. I woke up sore and in pain that morning. I could feel my knee and my ankle full of fluid, swollen and stiff. I could feel stabbing pain in my lower back. I was exhausted before I even opened my eyes and got out of bed.

I've been on a journey—for decades now—of trying to learn to live in a body that fails, a body that breaks, a body that seems uncooperative and relentlessly hell-bent on holding me back.

There are few medical insights regarding my physical reality. We can see the damage on imaging. We can see the inflammation with bloodwork. We can see the injuries and illnesses as they come up, as they arise. We cannot, however, see why all of this is happening. This leaves us to build a hodge-podge-like treatment plan that often creates its own problems, like the ones that landed me waiting in the pharmacy for an anti-nausea medication.

Usually, this doesn't faze me. Usually, I wake up and get up and power through. Usually, I use everything I have in me to make it look like nothing is wrong. I mask the pain and the fatigue with smiles and productivity. That day, though, when I woke up swollen, stiff, and in pain, I just wanted to hide. That day, so starkly face-to-face with my reality, I stumbled to find my way through, to go about my business as normally as possible, but feeling like I was moving through molasses. I felt raw and exposed. I felt vulnerable and fragile.

That day, the curtain was peeled away, and I couldn't hide from the reality of my illnesses and injuries. That day, I could see so clearly the ways in which my illnesses and injuries influence me at my core. Since that day, I've begun to see it more and more.

I make choices, constantly, every day, in response to my illnesses and injuries. Despite my best efforts, they are, in many ways, the true directors of my life. Living in a broken and breaking body is a constant negotiation. Going for a hike in the morning might mean I'm in intense pain as I try to finish chores that evening. Cleaning my garage might mean it takes massive effort swim or go to the gym for several days if I can do it at all. Pushing through to get work done late in the evening might trigger a migraine that lands me in bed for 24 hours. And, when things are really bad, if I choose even just to take a shower, I might have to forego any other activity that day because the shower will simply and completely wipe me out. But all those things could also mean nothing; I could be just fine. I've torn muscles walking around a lake and playing tag with kids. I've snapped ligaments rock climbing and walking my dog. I've flared inflamed tendons walking through airports. I've torn soft tissue without even knowing it. I've also swam multiple 5Ks (3.1 miles) and hiked more than a dozen miles of Colorado mountains in one day and deadlifted 275 pounds. I never know whether something will hurt me until after I’ve made the choice and done the thing; then I learn the price I will pay (or not).

Everyone who has experienced life-altering illness or injury knows this reality or some version of it. Each person who faces this reality responds differently. Each person who faces this reality builds their life around it in a unique and individual manner. Each person, however, knows that their decisions exist in the frame of their illness or injury. Each person knows that their decisions will impact their illness or injury, and that their illness or injury dramatically impact their possible decisions.

Me? I’ve become an endurer. I’ve made that word up. It’s not real, but it’s the word that describes me best. I have taught myself to push through at all times, relentlessly. I’ve taught myself never to give in, to pain or to exhaustion. I have powered through, ignoring how I feel, ignoring what it might cost.

People often ask me how I choose what activities to do, what activities are safe, what I pursue and what I don’t, in the midst of my physical reality. I tell them, “I’ve torn muscles and ligaments just while walking. If walking isn’t safe, nothing is.”

The real response, though, is that if walking isn’t safe, I refuse to acknowledge the potential danger I face with literally each and every step. But, oh, what that willful ignorance has cost me at times. Thinking about all of this, I realize that I have lost significant portions of my life, to waiting, to being afraid, to not knowing what is coming, to powering through, to ignoring my reality. And all of this comes with a grief I don’t think I knew I had. This is all too common for people living with life-altering illnesses and injuries.

Existential Injury

"I realized that the questions intersecting life, death, and meaning, questions that all people face at some point, usually arise in a medical context. In the actual situation where one encounters these questions, it becomes a necessarily philosophical and biological exercise. Humans are organisms, subject to physical laws, including, alas, the one that says entropy always increases. Diseases are molecules misbehaving; the basic requirement of life is metabolism, and death its cessation" (Kalanithi, 2016).

There has been a philosophical movement among medical scholars to recognize the losses that significant illness entails, described by one such philosopher as a "loss of wholeness, constriction of horizons, loss of certainty, distortion of relationships, loss of freedom, loss of control" (Coulehan, 1991, p. 115).

Another describes it by saying, "Serious illness changes everything: our sense of time and priorities, our experience of space, our felt relations with others, and our sense of self and of the body" (Van Manen, 1998, p. 12).

"I lie on my back in bed, imagining being a sick person. *What do sick people think about? How do you know when you start to be a sick person?*" (Riggs, 2017, p. 14).

Those descriptions encompass exactly what I have experienced over the course of my illnesses and injuries. There are several ways of conceptualizing these losses at a more foundational or core level as well. Sociologist Arthur Frank (1995) discusses how life-altering illness or injury disrupts the stories and the narratives the person has about themselves and their lives, wounding the person's voice. He explains that, because of this, the person experiencing such illness is faced with the task of creating and telling new stories, and that they must do this narrative work through a wounded body. Others discuss this experience to be a biographical disruption, in which the progress of the person's life is held back, forced to change direction, or stopped (Tembo, 2017). These biological and narrative disruptions are also described as a stolen identity, an invasion, which eliminates any sense of psychological ownership of one's life (Karnilowicz, 2011).

Another way of conceiving of the existential damage entailed in life-altering illness and injury is by considering the ways in which these experience narrow the person's existential amplitude (del Giglio, 2020). This is a way of describing how life-altering illness and injury limits what is possible in someone's life. Not only does this occur on a practical level in the sense that the patient's possible activities are limited or their ability to do the tasks of daily living are limited (though this is true). It is also speaking to possibility at an existential level; the ways in which it is possible for people living with life-altering illness and injury are able to exist in the world is limited. This extends beyond the physical realm to the emotional, psychological, and spiritual areas of life as well. There is, throughout identity and existence for people living with life-altering illness and injury, a constriction to all of life, which often leads to a constant sense of claustrophobia in the background of each and every day.

These disruptions, the loss of identity and possibility, and this lack of a feeling of ownership in one's life contribute to the person who is experiencing chronic illness not feeling like they are at home in their own life or their own body (Madeira et al., 2019). There is a tension between experiencing the body as both familiar (since the patient has lived with it their whole life) and alien (since the body no longer functions as expected and has become the object of the patient's life in many ways, where it used to be the subject; Van Manen, 1998). Some of this feeling of the body now being a foreign entity comes from experiencing how what was once private and personal in the patient’s life becomes public and visible (Madeira et al., 2019).

> “At our first of several biweekly appointments, Emma's and my discussion tended from the medical ('How's the rash?') to the more existential. The traditional cancer narrative—that one ought to recede, spend time with family, and settle one's toes in the peat—was one option.
>
> 'Many people, once diagnosed, quit work entirely,' she said. 'Others focus on it heavily. Either way is okay.'
>
> 'I had mapped out this whole forty-year career for myself—the first twenty as a surgeon-scientist, and the last twenty as a writer. But now that I am likely well into my last twenty years, I don't know which career I should be pursuing.'
>
> 'Well, I can't tell you that,' she said. 'I can only say that you can get back to surgery if you want, but you have to figure out what's most important to you.'
>
> 'If I had some sense of how much time I have left, it'd be easier. If I had two years, I'd write. If I had ten, I'd get back to surgery and science.'
>
> 'You know I can't give you a number.'
>
> Yes, I knew. It was up to me, to quote her oft-repeated refrain, to find my values” (Kalanithi, 2016, pp. 136–137).

Some philosophers discuss the existential injury inherent in these losses as a separation of the once-united self and body, which interrupts the person’s ability to be fully in the present moment in the world (e.g., Gadow, 1980; van der Meide et al., 2018). Furthermore, this is a separation through which the body constrains what is possible for the self.

For example, people living with rheumatoid arthritis or multiple sclerosis (MS) experience a limitation of body awareness; instead of general awareness of the body, over time with these chronic conditions, these individuals start to experience body awareness in reaction to pain, discomfort, or flares in the symptoms they experience (Lööf et al., 2014; van der Meide et al., 2018). This type of body awareness is then associated with negative emotions about the body, which further emphasize the separateness of self and body and heighten the tension in the relationship between self and body (Lööf et al., 2014). This can sometimes set a person up for a situation in which they have to sacrifice or risk injuring the body in order to nourish their self (or their soul; van der Meide et al., 2018).

There are also some who point out that this disruption between the body and the self in the face of chronic illness can interfere with patients' abilities to follow through or be compliant with treatment protocols (Pârvan, 2016). In this context, the ways in which illness limits possibility become compounded over time. For example, people with chronic obstructive pulmonary disease (COPD) discuss how their difficulty breathing promotes a sense of hopelessness while it also limits the extent to which they are able to engage in rehabilitative activities (Simonÿ et al., 2019). This then limits likely recovery, which further decreases possibility in the individual's life and increases hopelessness. Altogether, this compounding cycle significantly damages the individual's ability to trust in themselves, their bodies, and their capabilities. Similar findings regarding bodily distrust come up in the lived experiences of people with MS (van der Meide et al., 2018). Furthermore, this bodily distrust is experienced viscerally, in the body, as well as emotionally (Carel, 2016).

There are also significant ways in which chronic illness impacts the ability to live everyday life; instead of being able to just live, people with chronic illness often have to consciously plan quotidian activities that were once ordinary and able to take place without pre-planning (van der Meide et al., 2018). These effects extend to numerous dimensions in the life of the person experiencing chronic illness, including the person's function, their emotion, their social life, and their experience of embodiment (Grīnfelde, 2018). There is, however, also evidence that, despite all of these ways in which life-altering illness injures the existential self, there can also be health within these types of illnesses (Moch, 1998).

> "The rest of the day: scans, waiting, talking to pharmacists, more waiting, and meeting the rest of the team—the radiation oncologist, the surgeon. The surgeon makes me smile when he makes a Freudian slip while referring to the choice between lumpectomy and mastectomy as being 'my incision' instead of 'my decision'" (Riggs, 2017, p. 20).

An Invitation

After years of battling my body, of trying to overcome through sheer will the limitations it placed on me, I read a book: *Waking: A Memoir of Trauma and Transcendence* by Matthew Sanford (2006). He was in a car accident at 13 years old, in which he severed his spinal cord and became paralyzed from the chest down. In the book, Matthew writes movingly about his journey to come back to himself, to integrate the silence of his paralyzed body into his daily existence. He writes about how he has learned to shift from an attempt to "overcome" to a movement toward "transcendence." He says, "The silence within my paralysis is not loss. In fact, it is both awake and alive" (pg. 193).

After reading Matthew's book, I wondered if maybe that had some meaning for me. My illnesses and injuries were so different from Matthew's, but, to me, his story felt so full of hope and life. It made me think that maybe I could connect with this part of me that keeps failing and breaking, that maybe I could find a way to integrate it and embrace it. It felt like maybe I could be more whole if I could stop fighting my body. Maybe I, too, could find a way toward healing through letting go of my need to overcome and embracing transcendence.

It just so happened that Matthew was a yoga teacher in Minnesota, just minutes from where I lived. It took me over a year from finding that out to finally join his class. I walked in that first day, intimidated and scared, unsure of what lay ahead. I was hoping, though, that somehow, in learning yoga from Matthew, I could learn transcendence from him, too. I was hoping I could learn to let go of my fierce need to overcome; I was hoping I could find a new way, a different way of living with my reality.

And so I did. I started to have moments during yoga where the sensation of my being would shift from feeling like I was trying to hold the ground down to feeling like the ground was actually holding me up. Those brief moments were a vastly different reality, where I felt the shift from fighting my life to allowing my life. That didn't change everything, though. I still had flares of inflammation, and I still had soft tissue tears, and I still was headed toward multiple surgeries.

Several months into working with Matthew, I took a moment to talk with him after class. It had been weeks of rough days in which I was facing down physical problem after physical problem and feeling lost and overwhelmed. I said to Matthew, my throat constricted, "I can't do this anymore."

He replied, "Of course you can keep doing this, but it sucks, and you need to keep exploring other ways to live in your body."

I walked away realizing that this was an invitation to allow the way I was engaging with my experience to be transformed. He was inviting exploration, where for years I had been working for subjugation. He was inviting me to bring that sense of allowing, of letting the floor hold me up, into the rest of my life. He was inviting me to bring that sense of allowing even to my broken, failing, seemingly defective body.

That day, Matthew invited me toward existential healing. I had, for so long, felt that me and my body were separate, that we were at war (and, furthermore, that my body was winning, and I was losing). I felt the only way to survive was to batten down the hatches, to double up my strength, and simply to endure. Here, though, was a thought, a hand reaching out into the darkness. Maybe my body and I were not separate. Maybe we were not at war. Maybe, in fact, we were on the same side, wanting the same thing. Maybe unity was more important than winning. Maybe allowing was more important than fighting. Maybe transcending was more important than overcoming.

Though the rest of this dissertation is focused on medical professionals, it was not, actually, medical professionals who introduced me to this concept of healing. It was not initially medical professionals who addressed the existential injury that came along with my physical injuries and illnesses. It was people like Matthew, this teacher, using Iyengar yoga. It was people like Nick, a somatic teacher, using Feldenkrais. It was people like Busshō, a Zen priest, using wisdom and compassion practices. Those were the first people who opened me to the idea of existential healing. They were the first to open my eyes to another way of living with my body, with my illnesses, with my injuries.

Once I started to see this other type of healing, I started to demand it, not just from these non-medical healers, but from my medical providers, too. I started (indirectly) asking my doctors to help me do this existential healing work. I wanted them to be part of the team that was helping me find a way to live in my body, to live in my reality. I wanted them to help me find a way to exist, even within the limitations of my illnesses and injuries.

Then, I got to work. I got to work building a network of medical professionals around me who would acknowledge and address not just my physical self, but my existential self as well. At times, I think I call this forth from them, with the questions I ask and the disclosures I make. At times, someone just can’t give me what I need; they just can’t address the existential pain I experience. That is when I know that person is not a good fit for my medical team, long-term. Over time, I’ve built the team I need, the team who can support me in this shift from subjugation to exploration, from overcoming to transcending. The rest of this dissertation is about how we’ve done that work (and times when it has gone awry).

Chapter 4: Doctors and Doctor-Healers

In 2020, COVID-19 rocked the world in every way imaginable. It influenced every aspect of community life, but the very nature of the situation made this nowhere more apparent than in the healthcare field.

Being a person who manages multiple chronic illnesses, my interactions with the healthcare field are extensive. At the beginning of March of 2020, I visited my primary care physician. I walked in and walked up to the front desk, where the receptionist greeted me with a smile and checked me in. I sat in a chair in a busy waiting room next to another patient. A nurse came out and greeted me, then led me back to the exam room and got my vitals. Shortly after that, my doctor walked in with his typical shirt and tie and, with a pat on the shoulder, asked me how things were going.

COVID-19 shutdowns and stay-at-home orders started two weeks later. For nearly two months after that visit, I could not see this doctor in-person, and we did our monthly check-ins over the phone. In early May, I was able to see him in his clinic again.

I walked in the front door where a security guard wearing a mask and face shield greeted me, checked that I had a mask covering my nose and mouth, and directed me to sanitize my hands. I walked to the front desk that had a barrier three feet in front of it to keep me away from the receptionist. I stood behind the barrier speaking to the woman on the other side of the desk—she may have been smiling, but I don't know because, like me, she was wearing a mask. I sat in the nearly empty waiting room in which individual chairs were strewn about the room, no two chairs less than eight feet apart. I watched as the security guard greeted the next patient who arrived and then told her husband he needed to leave the clinic because only patients were allowed in the building. A nurse, also wearing a mask and face shield called me back to an exam room and took my vitals. When my doctor walked in, I barely recognized him—in place of his shirt and tie were scrubs, covered by a hospital gown (to be changed between each patient encounter), and his face, like most I had seen so far, was hidden behind a mask and face shield. There was no pat on the shoulder, no handshake, no physical contact that wasn't absolutely essential.

This was a dramatic shift to the healthcare system, and more than one of my medical providers told me that things would never be the same again, that this would change the way they provided care forever. As I watched these changes unfold, I wondered what this would mean. In the first eight months of the COVID-19 pandemic in the US, I had over 40 appointments with physicians. About half of those visits were virtual (either telephone or video), with the other half in-person. I found myself with a strong preference for in-person appointments despite a rather low tolerance for risk at that time. I started to explore why that might be the case. I started to ask myself, "What is it about in-person appointments that draws me to them over virtual appointments?"

There are differences that feel like they matter, like they really matter. During virtual visits, there is no small talk, no catching up at the beginning of the appointment. There is no eye contact. If the physician is looking at me, they are not looking at the camera, so it seems as if they are looking away. Many visits have occurred with the physician using multiple devices—one with access to medical records and charting and another with a camera, so they are dividing attention between the two. There are constant technology issues. One physician couldn't see me though I could see him. Another could see me, but I couldn't see him, so I had a full visit talking to a black screen. Another physician had a video chat system that crashed literally every 12 minutes. Yet another had to create his own system where we saw each other on video through computer while we talked on the phone. For a while, the physicians were isolated in their offices or home offices for the calls, so I could at least see their faces, but then there came a point where they had to wear full PPE when in the clinic regardless of being isolated from other staff. At that point, there were two computer screens and a face shield and a mask between us.

All of these things contributed to appointments where I felt disconnected from my physician. These virtual appointments felt like a transaction in which we moved our way through a checklist, no different than taking my car in for an oil change. During the in-person visits, however, I still felt a sense of connection and collaboration that were not there for virtual visits, despite the significant changes even to in-clinic appointments.

The rich history of philosophical and medical exploration of the experience of illness and injury from the previous chapter can help inform an exploration of the felt difference between these virtual and in-person visits. The inclusion of the concept of existential injury inherent in life-altering illnesses and injuries allows us to develop a deeper and more textured understanding of the activities of physicians and their roles in the lives of their patients.

Physicians are, of course, doctors practicing scientific medicine, who work to treat and cure disease. They do this by collecting detailed histories, ordering and interpreting appropriate tests, making diagnoses, and deciding on treatment and care plans. This work is essential.

Physicians are also, however, healers who can touch the patient’s suffering and offer healing for the existential injuries the patient is experiencing (or, at least, they have the opportunity to be such healers). Though this role of doctor-healer can be difficult, and increasingly so given advances in and reliance on technology (Madeira et al., 2019), many physicians embody this role in their patients' lives, and, for many, it can make their work even more fulfilling. One physician shared what this development from doctor to doctor-healer was like for him:

> When I started in practice, the thing that gave me joy was the solving of clinical puzzles, the making of good diagnoses, thus impressing my colleagues. As time went on, I found myself preoccupied more and more with the patients I had come to know. It was their joys and sorrows, their suffering and healing, that moved me. Of course, clinical diagnosis and management did not cease to be crucial: simply that a patient's illness or disability became interwoven with a life story. I came to see medicine as more complex, more context-dependent, more poignant, more a reflection of the human condition (McWhinney, 2000, p. 135).

In an effort to help physicians bridge the often-presumed inherent chasm between disease (or scientific medicine) and suffering (or existential anatomy), philosophers have developed two main conceptualizations of how physicians move from being doctors to being doctor-healers. The first invites physicians to open to exploring suffering while also investigating disease (del Giglio, 2020). These two things are not in opposition to each other, but including both requires a shift from thinking about disease as something that is separate from the person to thinking about illness as a relationship between disease and a person (Pârvan, 2016). When a physician considers illness as something that is separate from the person, their job is simply to eradicate the disease. In this model, suffering is completely neglected, along with the very personhood of the patient. When the physician acts in this way, it can lead the patient to disconnect their body from their personhood, which has deleterious effects socially, existentially, and (often) physically (Pârvan, 2016).

When a physician considers illness as a relationship between a person and a disease, however, the patient's personhood is of central concern to the physician. The physician is responding not to the disease itself (as separate from the person) but to the disease as it presents in the daily life of the individual (Pârvan, 2016). This approach is particularly important in chronic illness, when the disease can't be eradicated or cured. Centering the illness-as-lived allows the physician to collaborate with the patient to develop a treatment plan and self-care protocol that can allow for health and healing even within illness (Lindsey, 1996). In this way, the physician can make adjustments to a given treatment plan or protocol based on what they know about their patient's life; this allows for a plan that the patient can more easily manage and follow through on (Price, 1993).

"During my next visit with Emma, we talked about life and where it was taking me... The scientific questions were settled for now, allowing the existential ones full play, yet both were the doctor's purview." (Kalanithi, 2016, p. 157).

The second proposed solution that aims to help physicians move from being doctors to being doctor-healers is the cultivation of empathy in the physician. Philosophers contend that all interactions between doctor and patient are necessarily interpretive because doctors need to translate what patients are telling them into terms that will help them make medical decisions (Coulehan, 1991; Sorum, 1994). Empathy calls for the physician to enter the patient's world as much as possible during this interpretive act, to truly seek to understand the suffering rather than focusing solely on the disease (Rudebeck, 2000), which can be done by taking a stance in interactions with patients that centers meaning-making (Coulehan, 1991). This is a recommendation that doctors make a concerted effort to understand what is wrong from the perspective of the patient rather than simply attempting to make a diagnosis (Toombs, 1987).

> "A consultant anaesthetist, Silvio Gligor, whom I have got to know over the long days here, comes into the room. He wants to say goodbye as I am going home in two days' time. He stands there, wrestling with his emotions, clearly wanting to say something of meaning to me, not just platitudes and farewells. The silence hangs about him as he tries to work out what it is. It is an emotional moment, rarely found between two men. When he does finally speak, this is what he says: Go home and teach your children many things" (Fitzmaurice, 2017, p. 91).

While the physician's view of the illness is often held as the more accurate view because of the physician's superior knowledge (of biological, physiological, and disease processes), developing empathy encourages the acknowledging and valuing the patient's superior knowledge of the suffering and the existential impact of disease, illness, and injury (Toombs, 1987). This approach requires opening up to hearing the stories and narratives patients have about their illness, its progression, its management, and what they think and feel is possible. Beyond allowing the physician to address (or at least create a space in which they bear witness to) the existential injury, this allows for a better system of monitoring disease progression and treatment effectiveness, which can produce better physical outcomes (Price, 1993). This opening to the patient's story in turn promotes a sense of a connected physician-patient relationship, which increases patient confidence and motivation to engage in the behaviors necessary to manage chronic illness (Fox & Chesla, 2008).

"Last week I bit the bullet and admitted myself into the hospital for the first time since I left in March of last year.

It was St. Vincent's Hospital in Dublin, and the week I spent there changed my mind about consultants. The warm, sincere individuals I encountered treated me with the dignity of being a person, not a disease" (Fitzmaurice, 2017, p. 110).

It is important to note that this tends to work better when the physician takes responsibility for inviting the patient to share their narrative. When the patient brings their narrative and their existential suffering to a physician who is unprepared for it, the patient can feel as if they are overwhelming the physician, which can increase negative feelings, including anxiety or the sense of being a burden on the physician (Barry, 2020). Indeed, this physician task of soliciting patient story or narrative is one of the elements that is brought forth in the call for person-centered medicine (medicine that treats the whole person, rather than just the disease or the physical body; Mezzich et al., 2010).

"With my renewed focus, informed consent—the ritual by which a patient signs a piece of paper, authorizing surgery—became not a juridical exercise in naming all the risks as quickly as possible, like the voiceover in an ad for a new pharmaceutical, but an opportunity to forge a covenant with a suffering compatriot: Here we are together, and here are the ways through—I promise to guide you, as best I can, to the other side" (Kalanithi, 2016, p. 88).

This cultivation of empathy, asking for and entering the patient's story, is recognized as a first step toward existential healing, as it allows the physician to begin to engage with the patient in co-constructing a healing narrative (Coulehan, 1991). This highlights a central goal for healthcare: to help the patient find or create a place where their life is livable once again (Van Manen, 1998). Furthermore, this type of livability is co-constructed between the physician and the patient, and it includes attention to physical and biological processes as well as existential and biographical processes. In the absence of this co-construction, patients are left to try to construct a narrative about what has happened to their bodies and what will happen in the future to those same bodies. These narratives formed in isolation through a wounded body can contain misunderstandings or false "facts" that limit what is possible for the patient (Neville-Jan, 2003). This patient-physician work of co-creation, therefore, is essential in the relationship between patient and doctor-healer.

> "I listened in quiet awe as a pediatric neurosurgeon sat down with the parents of a child with a large brain tumor who had come in that night complaining of headaches. He not only delivered the clinical facts but addressed the human facts as well, acknowledging the tragedy of the situation and providing guidance" (Kalanithi, 2016, p. 69).

These methods of moving from doctor to doctor-healer are complex and demanding, particularly within the broader context of medical care, in which there are documenting and billing demands combined with limited time available to spend with patients (Frank et al., 2020). It is, however, possible. Indeed, I've seen providers do it with care and grace, day in and day out, and I've experienced the difference it has made in my life.

This distinction between disease treated by doctors and suffering alleviated by healers is how I came to understand my preference for in-person medical appointments in the midst of the difficult times that surrounded the COVID-19 pandemic. As mentioned before, I have worked hard to build a medical team in which the doctors are also healers. It's taken me years to do just that, but I've done it for the most part. These physicians, these doctor-healers, bring my personhood into our relationship. They practice these two philosophical solutions. They ask me to share my stories, to share my understanding and my experience of my illnesses and injuries. They have seen who I am outside of my disease. They bring who I am into their treatment of my disease. They have attended to my existential injuries, to my suffering, in addition to my physical injuries or illnesses, to my diseases.

At this point, being in the same physical space with my physicians, making small talk at the beginning of an appointment, and, most importantly, having eye contact, are all healing in and of themselves. When I have direct, in-person, shared-space eye contact with these physicians, I feel our relationship, I feel our connection, and I know that they are with me, a person experiencing illness and injury, rather than just being with a patient. In those moments, I become more than my disease. My existential amplitude, the possibilities for my life, open up once again. I let go of feeling like I am my disease, and I remember that I am a person experiencing disease. I experience that reminder of my personhood as something that is like a balm soothing my suffering, and I will always, always want more to come back for that versus coming back for only a treatment of my disease.

Chapter 5: Centering Patient Personhood

I'm sitting in a small, cold exam room in a clinic I've never been to before with more than 50 inflamed, bright red lesions covering my skin from the bottom of my chin to my shins. I've already seen three doctors about these annoying, vicious little things: two family medicine doctors and one rheumatologist. Not a single one of them knows what these lesions are. At every appointment, I have walked away from perplexed doctors, feeling confused (and very, very itchy). Everyone is flummoxed. The tentative conclusion is that this must be a reaction to the biweekly injections I started a month ago for an autoimmune disease. It's like nothing they've ever seen, but its onset shortly after beginning the injections is too uncanny, and no one can think of any other explanation. I pause the injections (which had just begun to give me relief from unrelenting pain). So, now, I’m incredibly itchy and in near-constant pain.

Since no one knows what it is (even if it is a medication reaction), these doctors want me to see a dermatologist for a consult and biopsy. The itching is so intense I can't do much of anything lately, and the steroid creams I've been prescribed calm it down for mere moments for it to emerge even worse a short time later. I'm also terrified; why is my body reacting so severely? Why doesn't anyone know what's going on? Why is everyone so perplexed? What are the possibilities? Could it be bad? Do I have one of the rare cancers or fungal infections I was warned I could possibly develop because of my injections (which suppress my immune system)?

I spend hours on the phone that afternoon, calling every dermatologist covered by my insurance only to be told over and over again that first-available appointments are weeks or months away. By the end of the day, I am nearly begging everyone I talk with to find *some* way to get me an appointment to be seen within a week. Finally, I find a dermatologist who can work me in for an appointment a couple days later.

Now, here I sit in that dermatologist's office, answering all the typical questions from the nurse as she checks me in. I've taken to bringing a written list of everything I can think to include for appointments with new medical providers—medications, medical conditions, allergies—and just hand them the paper to copy into their system rather than trying to remember it all. The nurse and I make it through the carelessly choreographed dance of charting requirements, and, as she walks out, she pulls out a hospital gown and puts it on the exam table. She tells me to change into the gown, that the doctor will be in to see me shortly.

Inwardly, I groan. Outwardly, my shoulders slump forward, and I start to curl in on myself.

As a patient, there is nothing I hate more than meeting a doctor for the first time wearing a hospital gown (and this is not hyperbole or exaggeration). You see, as soon as I undress and put on that formless, nondescript, generic gown, I lose my self; I give up who I am, and I become, fully, a patient. There is nothing to differentiate me from the patient before me or the patient after me. There is nothing to give a sense of my personality or of who I am. I am stripped of my identity as a human being, and I become just another malfunctioning body. This is to say nothing of the inherent vulnerability of those gowns, barely covering me enough to keep my dignity, opening in all the wrong places if I move the wrong way.

Once, when I was receiving an x-ray guided injection to my shoulder, I entered the room and met the radiologist wearing the dreaded gown. He had me lay on the table, where he promptly covered my chest and face with a sterile sheet. In an attempt to protect against infection, he had literally whittled me down to a damaged, dysfunctional shoulder. That's all that he could see. I felt like I was suffocating, in part, to be sure, because of the deep fragrance and thickness of the plastic over my face, but also, in part, because I felt like I was slowly fading away, like the existence of my very self was slipping through my fingertips as I lay there, exposed and erased.

I don't mind hospital gowns as much when the doctor already knows me, when we've met and gotten a sense of each other. Then, when I change into the gown, I have faith (or, at the very least, hope) that my identity is still in the doctor’s mind. I know they have seen me before seeing this characterless patient. They have at least a whisper of an image in their mind of the young person who came in wearing sports shorts and brightly colored tennis shoes and a mountain-covered hoodie.

But when it is the first time I’m meeting a doctor, the doctor doesn't have that image of me when they come into the room. All they see is a body in a gown on a table, no different than the one before, and no different than the one to come after.

So, sitting in that dermatologist’s exam room, I did as I was told, and I changed from my clothes into the dreaded hospital gown, feeling like I was peeling away my identity as I did so. Then I sat down to wait for the doctor, feeling my sense of self getting folded away like my clothes, to lay on the chair until the exam was complete.

Then, at once, it struck me. "No," I thought, "I am not doing this today. I need this doctor to see me, to see the person I am. I need to remember who I am." I turned to the chair next to me, picked up my hoodie, and put it on over the hospital gown. It wasn’t a perfect solution, but it felt like something, and it actually felt like something really big.

When the doctor walked in, I looked at him in the eye. I introduced myself and said hello. He sat and we talked about this rash, when it started, how it had progressed. I gave him all the information he needed, still feeling at least a bit like myself. Then, and only then, when it was time for the physical exam, I took off my hoodie and moved to the exam table for him to look more closely at my skin.

Though seemingly small, it felt like a victory that day... Just to wear my hoodie when meeting the doctor. That act of what felt like defiance allowed me to keep my dignity, allowed me to meet the doctor as myself. And, not only did this give me some preservation of my identity, but it also gave me a sense of agency. I did something to fight the depersonalization that often comes with being a patient. I took action.

After a biopsy, we found out the rash was actually ringworm—passed on to me by a kitten I had discovered abandoned in a parking lot a few weeks earlier. I had found the feisty kitten a permanent home by the time I visited the dermatologist, but not before lots of snuggles through which she had given me this gift. In the end, it was in fact one of those fungal infections that could be easily exacerbated by my autoimmune disease medication. This is why none of the doctors I saw (dermatologist included) could identify it, as common as ringworm is. Instead of one or two typically presenting spots, it went into overdrive, covering my whole body.

Notably, when I saw my primary care doctor a week after my biopsy, I had just received the results. I hadn't been able to see him initially for the rash because he didn't have any availability, so I saw his colleagues instead. Before telling him the results, I asked him what he thought it was (playfully, just out of curiosity). He immediately told me he thought it was ringworm. I looked at him in disbelief, and I asked him how he possibly knew that, when the four other doctors (including a rheumatologist and dermatologist) had no idea. Like the other doctors, he took into account my recent start on immunosuppressants (my injections), but he considered how those medications gave me what acted as an immature immune system. He told me that this was what ringworm looks like when a six-month-old without a fully developed immune system starts at daycare for the first time; it turns out this was also what it looks like in an adult with a compromised immune system.

Depersonalization

My experience in the dermatologist's office was an experience of an all-too-common occurrence in medical settings: depersonalization (or dehumanization) of the patient. Dr. Paul Kalanithi (2016) described this depersonalization as he moved from being a neurosurgeon to being a patient in the same hospital in which he practiced:

> I received the plastic arm bracelet all patients wear, put on the familiar light blue hospital gown, walked past the nurses I knew by name, and I was check into a room—the same room where I had seen hundreds of patients over the years. In this room, I had sat with patients and explained terminal diagnoses and complex operations; in this room, I had congratulated patients on being cured of a disease and seen their happiness at being returned to their lives; in this room, I had pronounced patients dead. I had sat in the chairs, washed my hands in the sink, scrawled instructions on the marker board, changed the calendar. I had even, in moments of utter exhaustion, longed to lie down in this bed and sleep. Now I lay there, wide awake.
>
> A young nurse, one I hadn't met, poked her head in.

> “The doctor will be in soon.”
>
> And with that, the future I had imagined, the one just about to be realized, the culmination of decades of striving, evaporated (p. 16).

The depersonalization represented in this passage is a stripping of identity, just as I experienced in my visit to the dermatologist. The smallest actions and processes on the part of medical professionals and medical systems contribute to converting the individual seeking medical treatment from a person to a patient.

> "She would likely refuse surgery if I launched into a detached spiel detailing all the risks and possible complications. I could do so, document her refusal in the chart, consider my duty discharged, and move on to the next task. Instead, with her permission, I gathered her family with her, and together we calmly talked through the options. As we talked, I could see the enormousness of the choice she faced dwindle into a difficult but understandable decision. I had met her in a space where she was a person, instead of a problem to be solved. She chose surgery. The operation went smoothly” (Kalanithi, 2016, p. 90).

Interestingly, the vast majority of medical research on depersonalization (aside from depersonalization disorder) is focused on depersonalization as a mark of provider burnout (often described as being parallel to or synonymous with cynicism), rather than on the patient’s experience of being depersonalized. For example, a search in the PubMed database for manuscripts about depersonalization and patient experience resulted in a mere four results, while a search for manuscripts about depersonalization and physician burnout resulted in 1,768 results. Importantly, digging through other databases allows for the discovery of more articles regarding the experience of depersonalization for patients; however, this PubMed discrepancy is interesting in that it implies that depersonalization is a problem for doctors and patients alike. Indeed, physician burnout is thought to not only negatively impact physicians and their overall well-being, but also the outcomes and well-being of their patients (Dyrbye et al., 2017).

Depersonalization, particularly through the relinquishment of personal clothing and changing into hospital gowns and other such “clothing” is associated with patients being less active in their own care (Edvardsson, 2009) and feeling more disempowered and vulnerable (Morton et al., 2020). Furthermore, depersonalization can lead to illnesses or injuries impinging upon patients’ abilities to live their day-to-day lives without the medical provider understanding these disabilities, which results in patients not actually being treated for the symptoms that are impacting their lives the most (Peloquin, 1993). There is also evidence that depersonalization can influence physician treatment decisions, resulting, for example, in undertreatment of post-operative pain (Kopecky et al., 2018). These outcomes start to highlight the danger of the depersonalization of patients.

> "I began to look forward to my meetings with Emma [oncologist]. In her office, I felt like myself, like a self’ (Kalanithi, 2016, p. 141).

Medical philosophy describes several motivations that undergird the depersonalization of patients in medical settings in addition to the aforementioned connection with physician burnout. As scientists, doctors are working to diagnose, treat, and give prognoses in the face of disease (Toombs, 1987). In many circumstances, a result of this is that doctors attempt to distill the patient and their presenting problems down to objective, quantifiable data about biological processes (Pârvan, 2016; Toombs, 1987). They do this in an effort to be able to proficiently analyze the data to answer the questions of diagnosis, treatment, and prognosis as well as being able to track the progression of the illness, injury, or recovery. While these activities may be necessary, they often overtake and negate the personhood of the patient (del Giglio, 2020; Pârvan, 2016).

> "Early November, I finally contacted the neurological practice to which I had been referred a few months earlier. A week later, on a Friday afternoon, I was in the neurologist's office for more than two hours. He wouldn't look at me, but he pushed and pulled and hammered and scratched" (Kramer & Wurzer, 2015, p. 3).

In this process, there can be a significant discrepancy between the perception of the patient and the physician that leads to depersonalization: to the patient (particularly a patient in pain), the body can be excruciating and overwhelming, while for the physician, the body can be an object of examination or a problem to be solved (Gadow, 1980). Indeed, for the physician, the physical presentation of symptoms and observable biological processes can easily become much more immediate in this process than the personhood of the patient (Rudebeck, 2000). In fact, at least at one point in recent history, bringing the lived personhood of the patient into the physician's work was not only neglected, but actually considered "taboo" (McWhinney, 2000).

There are many reasons for this depersonalization on the part of the physician. In addition to burnout and medical culture, physicians may also depersonalize patients as a method of protecting themselves, particularly when their patients are experiencing or facing significant suffering or dealing with a terminal or really difficult illness or injury. Furthermore, physicians often see many patients every single day, back-to-back in 15- or 20-minute appointments. It is difficult to maintain high levels of connection and empathy with that type of schedule and structure.

> “We arrive, check in, and sit for one, maybe two minutes. Names called, we are brought into a room unfamiliar, yet every detail remains hyperclear in my memory: floor-to-ceiling bookcases, backs bowed, shelves groaning, weighted down by the detritus of twenty-year-old neurology journals with pages torn, almost vomited from their binders, green Astroturf-like carpet, tired walls, a diploma, a certificate, attestations of qualification. He vaguely shows me where to sit, dismissing Ev to a far corner. He takes his places so that a huge, dark wooden desk separates us. He faces north, focusing his gaze on a computer screen. My chair faces south, not toward him but toward windows that never open. I have to crane my neck in order to see him. The details of the space begin to blur. I have lost track of Ev in the vastness of this space” (Kramer & Wurzer, 2015, p. 5).

It is, however, possible to bring patient personhood into the provision of medical care and even to center patient personhood in that care. This is beginning to become more valued in medical communities, in which there have been calls to return to holistic patient care, with a greater focus on the patient as a person, including attending to the patient’s physical well-being, illness-as-lived, mental and emotional well-being, spirituality, and culture (Mezzich et al., 2010). This allows not only for the inclusion of personal values in treatment decisions, as is called for in evidence-based medicine (Sackettand & Rosenberg, 1995), but for attention to be paid to all aspects of illnesses and injuries as they show up in the patient’s life, especially the non-physical aspects (del Giglio, 2020). This, in my experience, has made all the difference in the world, not only in my experience as a patient, but also in the outcomes I experience.

> "This is my Christmas present from Dr. McMeken, who insists that I be released from the intensive care unit. 'Too long here makes anyone crazy, especially your family,' he says” (Sanford, 2006, p. 51).

Centering Patient Personhood

One September, I had major reconstructive shoulder surgery to repair a massive labral tear: my labrum (connective tissue that creates a barrier of sorts to hold the bone of the upper arm in place in the shoulder) was completely shredded three-quarters of the way around my shoulder joint, and my rotator cuff tendons were starting to fray from taking on all the work of holding the joint together. It was somewhat of a brutal surgery, with a surgeon I had met two weeks prior, recommended to me because he was one of the top shoulder surgeons in the state. When I asked the referring sports medicine doctor about returning to a different surgeon who had operated on my other shoulder three years earlier and my knee earlier that year, he told me, “Your shoulder is too damaged for that. Your other surgeon is a knee specialist who also works on shoulders. You need a shoulder specialist, and the doctor I’m referring you to is the best.” The new surgeon was indeed brilliant and extremely skilled. After the surgery, nonetheless, I had multiple complications—first an infection in my incisions, then a blood clot scare (likely due to my other chronic conditions and their treatment).

Each time I had an appointment with this surgeon, I remember mentioning to my physical therapist how different my relationship with him felt compared to the surgeon who had repaired my knee and operated on my other shoulder. It was always an aside, though, and I always figured it meant nothing. My new surgeon was one of the top shoulder doctors in the state. Why would it matter that he only spent five minutes in the exam room with me? How was it possibly relevant if he didn't know about my work and school and didn't ask about my research? Was it really that important that he know which overhead sport I was hoping to get back to? Could it possibly make a difference if he didn't know how much I loved the mountains and rock climbing and hiking and scaling waterfalls?

In January of the following year, things were finally improving and heading in a really good direction. I saw my surgeon, and he gave me the go-ahead to return to full activity with my physical therapist's guidance.

I was thrilled.

Three days later, I developed a grinding and creaking sound and sensation in my shoulder. My physical therapist and I watched it for a little while until, one day, while getting out of my car, I felt a very intense grinding and creaking, followed by a pop and dull, diffuse, increasing pain. The pain didn’t subside for days.

That was enough to earn me an MRI. Laying in the small, claustrophobic tube, I couldn't think about what I was possibly facing. It just felt too big, too scary. In my experience as a patient, nowhere do I feel more alone than in the MRI machine. You are literally alone in a room that is always freezing, shoved into a tiny tube with massive noises racketing around you while grainy, black-and-white images of the inside of your body pop up on the computer screen so that a radiologist can look for problems. Maybe the technician's voice will reach through the microphone to tell you how much time each scan will take, but that is the most interaction you get. In that space, I mostly let my mind float away, go wherever it will, not to return until they move me out of the tube, and I can breathe freely again.

The day after this MRI, I received my results. There was a possible re-tear in my labrum, but nothing to be too concerned about, given the extent of my surgery and the difficulty in differentiating damage from healing in post-operative radiological images. There was also a ton of fluid surrounding my biceps tendon. The first surgery was supposed to include moving this tendon, but when the surgeon got inside my shoulder, he decided to leave the tendon in place because it looked okay. Now, that tendon was angry. My surgeon decided it warranted a cortisone injection, which I got a few days later under fluoroscope (a moving x-ray machine). Cortisone injections also often include a numbing agent, so I had almost immediate relief from my intense pain. The effects only lasted a few days, though, and by the next weekend, pain was waking me up multiple times throughout the night again. This wasn’t good; the fact that the injection helped told us that the problem was indeed the biceps tendon. The fact that the help did not last told us it would need more substantial intervention.

I went back to see my surgeon, and when I told him what happened in the aftermath of the injection, his response was, "Well, crap. I wish I had just whacked that tendon while I was in there the first time." We talked about options and next steps, and he laid it out for me: hope physical therapy starts working or have a second surgery to deal with the biceps’ tendon.

I left my appointment feeling frustrated and anxious and upset. I knew physical therapy was not going to work. My therapist is one of the most optimistic physical therapists I've ever met, and he had told me that the odds of physical therapy working here were "very, very low." I didn't want a second surgery, and I didn't feel any peace about the prospect. As those feelings floated around, I found myself wishing that I could just be reassured that this was the right course of action.

As I spent time with that, a solution occurred to me: a second opinion. I have a wonderful relationship with the surgeon who repaired my knee and my other shoulder. I trust him. I know he is extremely conservative (having successfully treated my right knee with an experimental injection protocol rather than slicing it open). Most importantly, I know that he knows me, well. I knew the advice he gave me was going to take into account who I am and what I love, rather than giving me advice that was just about another shoulder that happened to have a human attached to it.

I didn't expect to hear anything different from this second surgeon. I didn't expect to be given new options. So, for a while, I discounted this idea of a second opinion: what was the point? But then I realized that, even if the words or the options weren’t different, the relationship was. And the relationship mattered. The trust mattered. The knowledge that my personhood would be part of the conversation mattered.

I went to see the other surgeon for a second opinion.

I didn't hear anything different. My options were still the same. Toward the end of the appointment, this surgeon said to me, "As far as going forward with the surgery, if you choose to do that, you can choose who will do the surgery. I'm more than happy to just be a second opinion here, and I would probably recommend that, since the other surgeon has been in this shoulder already. However, I've also been in your knee and your other shoulder, and I would be willing to do this surgery if that's what you decide you want."

As our conversation unfolded after that, I saw that he understood that I didn’t actually come to him expecting him to give me different or new options, but that I was looking for reassurance, for a human connection. And that is exactly what he gave me.

I walked away from that appointment feeling sad, but at peace.

The next day, I talked to my physical therapist. Again, he told me that he didn't think physical therapy was going to help. I knew I was headed for surgery if I wanted to deal with this pain, to regain full function of my shoulder, to return to the activities I love the most. As I considered that, I found myself really wanting to have the surgeon who gave the second opinion do the surgery. I argued with myself, though. Why would I not want one of the best shoulder doctors in the state? Just because I liked the other guy better? That seemed ridiculous.

Then, I realized: if I was going to be unconscious and exposed, I wanted to see the guy I like, the guy I trust, holding the scalpel as I breathed in the anesthesia and faded away. I wanted to be able to trust that he would make decisions knowing who I am and what I love. And at that time, I was learning that trusting all of those reasons was just as important (and probably far more important) than incremental differences in surgeon skill or experience.

The second surgeon did the surgery.

This second surgery ended up having three major components: (1) moving my biceps tendon out of the shoulder joint and re-anchoring it to my humerus, (2) shaving off arthritic changes from the end of my clavicle, and (3) evaluating the labrum to see if the last surgery was successful or if there was new damage that needed to be repaired. Importantly, going into this surgery, there really wasn't complete clarity on any of those, given the notorious difficulty of reading the post-op MRI. The surgeon would only do the first two parts of the surgery if it looked like they would help, and there was no telling what he would find during the third part. As I came out of surgery and started to regain consciousness, I really wanted to know what had actually happened in surgery.

The friend my surgeon called after surgery was done to let her know how it went and that it was time to pick me up told me that he did the first two parts of the surgery as intended, but that in the third part of the surgery, he found some damage and that some of the anchors were loose. She said he “took care of it.” I asked her what that meant, and she said she didn’t know anything further than that. It was frustrating, but I decided I would just wait until I saw my surgeon on follow-up to understand better what happened during surgery

Two weeks after surgery, I saw my surgeon to have my sutures removed and to check on my healing. I asked him to talk me through the surgery. He pulled up images from the arthroscope to show me. First, he showed me the clavicle and the arthritic changes there. The changes were not too horrible, but, given my history (having the same thing successfully repaired in my other shoulder—by this surgeon), he went through with shaving off the damaged end of the bone. Then, he showed me the biceps tendon; while the tendon itself looked good, he showed me how the place where the tendon inserted into the labrum in the shoulder joint was fraying and damaged, even pulling away from the bone. He told me that this finding made him hopeful that moving the tendon (with a good recovery) would significantly or even completely relieve my pain.

Last, he took me around the images of my labrum. He showed me where there was new fraying, where there were gaps between the labrum and the bone, where the sutures from the last surgery were so loose he could fit his instrument between the labrum and the suture. This could have been devastating news—the last surgery was a failure. It didn’t work. All that I went through in that surgery and the more than four-month recovery afterward seemed like it was for nothing. I started to panic—would I ever be okay? Was I going to be stuck in a cycle of surgery and damage for the rest of my life? I could feel myself starting to close off, to shut down. But then, what my surgeon said next changed that.

He explained to me how he dealt with what he found. He cleaned up the fraying. He tested to see if the pieces of labrum that were separated from the bone would fall into the joint and cause further problems. If they did, he trimmed them. He took out the loose sutures—they weren't doing anything, and if they continued to rub against other structures within my shoulder, they would actually do more damage. He shaved down the bone a little bit to see if that could promote some healing and maybe allow the labrum to reattach with scar tissue. And then he told me why he chose those solutions as opposed to re-repairing the labrum.

He told me that the damage to the labrum caused problems of instability. He said that he knew that my presenting problem was pain, not instability. He knew that my function and my ability to engage in the activities I love was limited by that pain, not by instability. He knows I have hyper-mobile joints generally. Fixing the labrum would resolve instability. While I do have instability, it wasn't the actual problem for me; it wasn't the barrier to me fully living my life.

So, he decided that it wasn't worth the cost. If he had repaired the labrum, my restrictions would have been more significant and would have lasted longer—it would have meant a lot more time away from the things I love. And because he knew me, he knew what choice to make. He cleaned up the labrum the best he could and then he left it—because, in the context of my life, that was the point of diminishing returns. That was the point where the potential cost was too great, and the possible benefit was too small. But he only knew that because he spent time to get to know me and to know what my greatest concerns were. He knew the context of my life. In the context of someone else's life, the decision might have been different. His decision was not based on the physical findings of the shoulder alone. He brought more of me into the decision. He brought my personhood into the decision. I was unconscious. I couldn’t help him do that. I couldn’t give him any information in the moment he made the decision. However, he was able to bring me into the decision in the operating room because he has invited my personhood into every exam he has done and conversation we have had.

Even though I wasn't aware of it, this was why I made the decision to switch surgeons. I was invited into expansion at each visit with the second surgeon. I got to show up in the exam room as a person and not just as a patient. I trusted this surgeon in a way I didn't trust the other one because I knew this surgeon knows me, and now I've seen how much that matters.

About seven months after my second shoulder surgery, I was in Arizona for a work conference. Since that’s where my family lives and it was almost the holidays, I extended my trip to spend some time with my family. On the last day of my trip, I met my brother and sister-in-law and their daughters at a park across from the girls’ school for a picnic lunch before they headed to pajama day at their afternoon preschool. The girls (who were two and four years old) and I had a wonderful time, running around the playground, chasing each other. It was a time full of laughter and tickles and wrestling and hugs.

As I got on the plane to go home that evening, I was looking through photos of the day on my phone. There was one photo of me with my nieces that took my breath away. We are all clearly laughing, with huge grins on our faces. I’m holding my two-year-old niece with my left arm under her armpits, and I’m holding my four-year-old niece upside-down over my right shoulder—my right shoulder that I had surgery on just seven months before that day, my right shoulder that was non-functional eight months before that day.

Without the second surgery with my preferred surgeon, that moment with my nieces literally wouldn't have been possible. Without that second surgery, I would have spent that picnic lunch worrying about how I was playing with my nieces, concerned about reinjuring my shoulder. Without that second surgery, I would have spent that afternoon in immense pain. My surgeon and his decisions (in which he centered my personhood) made that simple and extraordinary moment possible.

Figure 2. Me with my nieces seven months after my second shoulder surgery.

Chapter 6: Fostering Hope

Once upon a time, in what often feels like a different lifetime, I was a preschool teacher. I taught the tiniest kids at our school, the toddlers, ages 16 months to 3 years old. I loved my job. I loved the excitement of greeting the kids as they came in the classroom in the morning. I loved being able to watch these tiny beings becoming people. I loved witnessing them experiencing life for the first time: I will never forget the time the first snow of the year came between drop-off and our outside time. For most of my kids, it was their first time really experiencing snow, and that morning was magical.

That job meant I spent a lot of time on the floor with my kids: helping with changes of clothes, reading books, singing songs, presenting new work to my students, comforting children, helping the tots fall asleep at naptime. If I wasn't on the floor, I was on a very low chair or stool. With ten toddlers and two adults, this also meant I spent a lot of time getting up and down from the floor, moving from child to child.

In the fall of one year, I developed some really bad knee pain that was significantly exacerbated by all that up and down to and from the floor. It really impacted my ability to do my job, and it started to limit what I could do out of work as well. When that happened, I decided it was time to see a doctor about it, so I got an appointment with a knee specialist at one of the local orthopedic clinics.

I will never forget that consultation. It was one of the most soul-crushing experiences of my life (and I do not say that lightly). The doctor walked in the room and started peppering me with what felt like the most random questions:

"When you walk up a flight of stairs, which foot do you use first?"

"How do you place your foot on the ground when you are getting out of your car?"

"When you get out of bed in the morning, do you place both feet on the ground?"

"When you open a door, which foot is forward?"

Now, I can maybe understand this line of questioning, trying to figure out if there was something I was doing or some kind of repeated stress on my knee that might be causing my symptoms. I did not, however, know many of the answers. The doctor was asking about all of these parts of my day that were automatic actions at this point. They were things I didn't pay all that much attention to (especially not to the details he was asking for). As he asked questions and I failed to answer, I could sense that both of us were getting frustrated. I wasn't giving him the information he wanted, and I didn't feel like he was addressing the real problem and what brought me to him in the first place.

Finally, he sat back and said, "Okay. Look. I'm going to be frank. You need to do less. You need to be less active, and you need to limit your activities to things that don't cause you pain. There's this thing called an 'envelope of function,' which is what you can do without causing issues, without causing symptoms or damage. You, right now, are operating in an envelope this big," he held his hands about a foot apart from one another, "and you need to be operating in an envelope this big," he cut the distance between his hands in half.

I looked at him, almost at a loss for words. I was in my mid-20s. If I was going to limit my activities to the things that didn't cause pain, that would mean quitting my job, stopping most of my working out, and limiting my recreational activities significantly. I mumbled something along the lines of, "But that would mean I could do almost nothing."

Without any change to his facial expression, he replied, “Well. That’s just the way it is. That’s just the way your body is built. That’s just the way it works.”

I didn’t reply. I left the exam room. I went home.

That interaction with that doctor was, as I said, soul-crushing. Not only did he tell me that I would have to give up so much of what I love, but he told me that my body was defective and that there was no hope. Instead of addressing the suffering I was experiencing, instead of responding to my existential injuries that came with the physical issues I was experiencing, he enhanced those existential injuries. It was as if he hit me where I was already hurting. He told me, quite literally, that the way in which my illness and injury limited my life was real and total. He told me that the illness and injury won. He told me I didn’t have a chance, and, in doing so, reinforced my perception that my body was my enemy. He reinforced the shame I had around living with a broken body. He taught me that my body would always hold me back, that there would never be room for me to exist in any other way.

To say I was upset would be an understatement. I didn’t know how to move forward. I didn’t know what to do next.

But the action I took next saved me from this existential black hole. I don’t remember how or why, but I found that the orthopedic clinic through which I saw this doctor had an online form, asking for patient stories or feedback. For the first time in my life, I complained about the care I received. I wrote the story into this faceless form, not knowing where it would go or what would happen. I realize now that doing that was an act of defiance and an act of hope. It was one of my first steps toward demanding that my doctors not just be physician-scientists who addressed my physical reality, but that they actually pay attention to me and consider my soul and my existential nature. The reality, of course, is that *this* particular doctor didn't even address my physical reality.

The action of filling out that patient feedback form ended up having huge consequences in my favor. The very next day, I got a call from a patient experience specialist who asked me, in detail, more about what had happened with the doctor. She conveyed how sorry she was, how unacceptable that was, and she asked if I would be willing to see another knee specialist. I was, and she set me up with the knee specialist she said was the kindest and most empathic they had, and he also happened to be a very talented orthopedic physician.

When I went to see this second doctor, he had been told ahead of time what had happened. He started the appointment apologizing for the first doctor. He told me that in no way should I have to limit my life so much. He told me he was there to help me get back to the things I loved. Then, he asked me to tell him my story and to tell him how my pain was affecting my life. I did just that, and then, together, we came up with a plan, a path, a way forward. This second doctor, incidentally, is the one who gave me the second opinion and did my second shoulder surgery in the previous chapter. He is indeed one of the kindest and most empathic doctors I have met, and he truly works with and for his patients, to help them to live the life they want to live, even in the midst of illness and injury and uncertainty. And that ability to live in the midst of difficulty is exactly what I've come to know hope to be.

Hope in the Midst of Suffering

Finding hope in the midst of suffering and in the midst of life-altering illness and injury is no small feat. Oncologist Dr. Jerome Groopman (2004) defines this type of hope and conveys how essential it is for people living with life-altering illness:

> Hope is one of our central emotions, but we are often at a loss when asked to define it. Many of us confuse hope with optimism, a prevailing attitude that "things turn out for the best." But hope differs from optimism. Hope does not arise from being told to think positively, or from hearing an overly rosy forecast. Hope, unlike optimism, is rooted in unalloyed reality. Although there is no uniform definition of hope, I found one that seemed to capture what my patients had taught me. Hope is the elevating feeling we experience when we see—in the mind's eye—a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion.
>
> Clear-eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them. For all my patients, hope, true hope, has proved as important as any medication I might prescribe or any procedure I might perform. (p. xiv)

This definition is, of course, only one definition of hope in the context of life-altering illness and injury (for another definition, see, for example, Perakyla, 1991). It is, however, the definition that has been most helpful to me as I consider how I have experienced hope in this context as well as how others (e.g., the authors of the memoirs which serve as the foundation for this dissertation) experience hope in their own contexts of life-altering illnesses and injuries.

"He went on to describe the planned operation, the likely outcome and possibilities, what decisions needed to be made now, what decisions they should start thinking about but didn't need to decide on immediately, and what sorts of decisions they should not worry about at all yet. By the end of the conversation, the family was not at ease, but they seemed able to face the future. I had watched the parents' faced—at first wan, dull, almost otherworldly—sharpen and focus" (Kalanithi, 2016, p. 70).

There are, clear in this definition from Groopman, multiple components to hope, many of which are directly in the doctor-healer's purview. Physicians have the opportunity to assist their patients in living with this type of hope. They have the ability to facilitate the construction and maintenance of hope for their patients, regardless of the medical realities their patients are facing.

First, hope is "rooted in unalloyed reality." Physicians can help patients understand the actual, physical reality of their situations. They can help patients understand what is known and what is unknown amidst that reality. They can help patients see what is possible. They can also, however, misuse this role. Instead of helping people to live with hope, these same activities can crush patients' spirits, like the first knee specialist did for me. Dr. Groopman discusses the balance necessary here, in sharing the facts in a way that reflects what is actually known, while also conveying the uncertainty inherent in any medical "fact." A physician participant in a qualitative research study also put this very simply, saying, "It's up to the 'healer' to make it [the cultivation of hope] happen… or to take away hope" (Wolf et al., 2018, p. 997).

"I feared I was losing sight of the singular importance of human relationships, not between patients and their families but between doctor and patient. Technical excellence was not enough. As a resident, my highest ideal was not saving lives—everyone dies eventually—but guiding a patient or family to an understanding of death or illness. When a patient comes in with a fatal head bleed, that first conversation with a neurosurgeon may forever color how the family remembers the death, from a peaceful letting go ('Maybe it was his

> time') to an open sore of regret ('Those doctors didn't listen! They didn't even try to save him!'). When there's no place for the scalpel, words are the surgeon's only tool" (Kalanithi, 2016, pp. 86–87).

A physician sharing truth cannot be separated from helping a patient to process the truth or from attending to the existential injuries such truth might inflict on the patient. A person with a life-altering illness or injury can experience hope even in the midst of a very bleak reality or prognosis (Lannie & Peelo-Kilroe, 2019). People can also experience hope even when there is a significant amount of ambiguity and uncertainty around the reality of their illnesses and injuries, as ambiguity is, in itself, an aspect of reality (Tollow & Ogden, 2018). In these types of cases, being grounded in the reality allows the patient to choose how to respond to that reality and exactly how bleak or ambiguous it is (Groopman, 2004). Physicians can help to facilitate the development of that response.

> "'You have five good years left,' she said.
>
> She pronounced it, but without the authoritative tone of an oracle, without the confidence of a true believe. She said it, instead, like a plea... Like she was not so much speaking to me as pleading, as a mere human, with whatever forces and fates truly control these things. There we were, doctor and patient, in a relationship that sometimes carries a magisterial air and other times, like now, was no more, and no less, than two people huddled together, as one faces the abyss.
>
> Doctors, it turns out, need hope, too" (Kalanithi, 2016, pp. 193–194).

Second, hope is an "elevating feeling." I've often experienced this elevation as a sensation of expansion. Hope, in this sense, is the felt recognition of the presence of possibility. This possibility transcends the existential injuries of illness and gives a sense of space where there was once constriction.

> "I am in the hospital over Christmas. During a snowstorm that stopped Ireland. I have got to know all the nurses. One girl, Bridget, from Cork, is

pure heart. She walks across the road to the pub, buys a pint of Guinness and carries it back without spilling a drop. It's New Year's Eve, I think. I'm not sure. I'm on a lot of morphine. I manage a few sips of the Guinness. Another morning she comes into my room with a lunchbox full of freshly fallen snow. Gently, she lives my hand into the cool iciness" (Fitzmaurice, 2017, p. 85).

Third, hope is rooted in seeing "a path to a better future." This aspect of hope is, in many ways, capturing hope as finding a way to heal the biographical and narrative interruptions and disruptions brought on by life-altering illness and injury. This aspect of hope also aligns with an aspect of the concept of "health within illness" as it is commonly conceptualized, namely the aspect of "creating opportunities" (Lindsey, 1996). One group of researchers investigated the experience of people with MS who participated in a climbing expedition of Machu Picchu after a prolonged training program. The participants who partook in this endeavor described how, in the process, they discovered a new awareness of their body that was no longer rooted only in tracking pain and other symptoms as well as a sense of becoming a new person and forging a new identity (Calsius et al., 2015). This is an example of embarking on a "path to a better future," in that these participants found a new way to live in the bodies they had, even as those bodies were affected by MS.

This "path to a better future" is also inclusive of making progress with treatment for and recovery from the physical injury and illness (Lies & Nowak, 2008). It's important to always keep in mind that, when discussing or attending to existential injury, that never means ignoring the physical illness or injury. Treatment and rehabilitation are, indeed, part of a "path to a better future," especially when they include the whole person.

"An inspirational occupational therapist, Sarah Boyle, organises for a rep from a computer company, Nick Ward, to fly over from England to demonstrate an eye-gaze computer with me. It is extraordinary. A revelation

to me. Freedom. My hands back, with the movement of my eyes"
(Fitzmaurice, 2017, p. 94).

Fourth, hope is "clear-eyed," and gives "courage." In the midst of life-altering illness and injury, people sometimes experience that it is an opportunity to better understand themselves, their bodies, and the world around them (Lindsey, 1995). The deeper understanding they are able to access can impart a sense of self-respect (Lindsey, 1996), which can give them the strength they need to start to take control of and responsibility for their altered lives, creating a sense of agency where there were once feelings of a loss of control (Lindsey, 1995). This ability to take responsibility and find agency is associated with an even greater deepening of hope and the ability to continue to live into a life marked with life-altering illness and injury (Vatne & Nåden, 2018). Physicians, in fact, describe how the cultivation of hope in their patients is often related to the patients developing an ability to adapt to their illnesses and injuries (Wolf et al., 2018).

"The physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence" (Kalanithi, 2016, p. 166).

Hope is multi-faceted, which means that doctor-healers have many entry points into facilitating the cultivation of hope for their patients. No matter what entry point they use, however, this facilitation is about helping the patient learn to live within their reality, whatever that may be.

Inviting and Facilitating Living into the Unknown

I have a wonderful relationship with my primary care doctor. He’s one of the best doctors, one of the best doctor-healers, I’ve ever met. He treats me as a whole person at all times. He knows me, and he cares for me.

I had spent a long time trying to find a good primary care doctor, one who fit what I needed and wanted, and, above all, one who could actually help me. Before I started with my current primary care doctor, I was with another one for multiple years. He was good—he cared, he knew my history, and he wanted to help. As time went on, though, it became apparent that he was woefully unprepared to help me handle the physical reality I was encountering. At one point, in the midst of a major acute problem with my lower back (after several other injuries and problems over the previous month), I asked him what was going on and why my body seemed to be falling apart. His answer: "You're just unlucky." That was the least helpful answer he could have possibly given me. It was also the most hopeless answer he could have given me.

He was the best I had found, though... In an effort to keep him as my primary care doctor, I pushed to have him refer me to someone who could help. He referred me to a rheumatologist in his clinic. That rheumatologist told me he didn’t think I had any one of a bunch of different disorders, including all rheumatological diseases and fibromyalgia, but he also didn’t give me any hints about what he thought *was* going on.

I went back to my primary care doctor at the time, and he told me that I was just a really difficult patient, that he wasn't sure what to do with me. I asked him to refer me to someone with more expertise: to doctors at the university or to doctors at Mayo Clinic. He refused. He said that if he referred me outside of his clinic, he would get in trouble because there were rules about keeping referrals in the system, particularly with the insurance I had.

That, for me, was the straw that broke the camel's back, so to speak. I decided that if he couldn't refer me to another system with better expertise, I would move myself to another system. I started to investigate primary care doctors within the university system. I found the doctor who is now my primary care doctor and has been for several years. He was a Doctor of Osteopathic Medicine (DO) rather than a regular Medical Doctor (MD). DOs have significantly more training in the musculoskeletal system, which seemed like something I needed. This doctor had a long history of practice, had a record of research in many areas within family medicine, and he taught medical students. Ultimately, I decided to see him.

I was very frank with him right off the bat. I told him I was there because I wanted a referral to rheumatologists with more expertise than the community rheumatologists I had seen. He went through my history with me and was willing to make the referral.

One thing I remember from that initial meeting was that I had come with a typed-out list of all of my illnesses and injuries and accidents, going back to childhood. He looked at me at one point, right in the eye, and, referring to that list, he said, "This is great. But, next time, don't spend your time on this. Get some sleep instead."

That moved me. It touched something deep inside of me. He saw me as a person who needed to be cared for, rather than just a set of symptoms and a list of problems and a body that kept breaking down. In fact, he would rather see that person being cared for than see the comprehensive list of symptoms and problems.

He tried to make the referral to rheumatologists at the university. They declined the referral because they weren't taking any new patients who did not have three very specific diagnoses, and I, at the time, was not diagnosed with anything. My new primary care doctor called me to tell me about the decision. He said he had even called one of the rheumatologists he knew personally to see if they would make an exception, but they couldn’t. He prepared everything needed to refer me to the Mayo Clinic. They accepted the referral, and I felt hopeful that, surely, these experts would help us get to the bottom of what was going on with me.

Then, about a week later, I got another phone call from my doctor. He told me that after initially accepting the referral, the rheumatologists at the Mayo Clinic declined to take my case. After they reviewed my files, they didn't think there was anything else they could do for me. I distinctly remember that phone call. I was hiking at a regional park, and I stood, leaning against a tree while my doctor and I talked for about 20 minutes. He wanted to start me on medication that would help with sleep and would likely give me some pain relief. He had brought this up the very first time I saw him, but I was really resistant to it at that point. On our phone call, though, in the absence of other possible ways forward, I agreed to start the medication. He also said that he wanted me to come into the clinic for another appointment to talk about next steps.

When I went in to see him, he put his hand on my shoulder, and he looked me in the eye again, and said, "Thank you for coming in. I just needed to see you. I needed to see you in-person to see how you were doing, how you were handling this news."

Only after that did we talk about the practical next steps. He told me that he knew I had already seen five community rheumatologists, but there was one more he wanted me to see. He had worked with her on several difficult cases, and he really thought she could help me. I told him that I was willing to give it a try.

The rheumatologist he referred me to was, in the end, very thorough, and able to give me a diagnosis, albeit a loose one of undifferentiated spodyloarthropathy. Literally two days after that diagnosis, the care system in which she worked unexpectedly closed the rheumatology clinic. She didn't know where she was headed at the time, so it was on me to find a new rheumatologist who would be willing to work with that diagnosis. I did find one. He didn’t initially agree with the diagnosis, but he said that it was good enough, and he started treating me. It was all trial-and-error, but it was something.

Since about three months into our relationship, I have seen my primary care doctor monthly. He does Osteopathic Manipulation Therapy (OMT), so I get an adjustment, and then we check in on all of my various health issues. Each time, he comes in with an index card. On that card, he has written down everything he wants to be sure we check in about. He remembers things like when I have gone on a trip since the last time I've seen him, when I have big fellowship applications due, and how things are going at work and in school. He invites me, all of me, into that exam room every time we meet, each and every month.

He recognizes the effort I put forth to keep my health, to manage everything going on, and he encourages me to continue, even when it looks like I'm getting nowhere, even when I encounter obstacle after obstacle after obstacle. And he helps me. He does whatever he can to make me hurt less, to make me suffer less, to help me be in this body, to help me live my life. He constantly facilitates my process of building and maintaining hope in the midst of suffering.

I have had six surgeries during my time with him as my primary care doctor. He works pretty limited clinic hours, given his other responsibilities, so I often see one of his colleagues when I need immediate care. For most surgeries, due to this scheduling situation, I have had to have my pre-operative examination with other providers. Before one shoulder surgery, though, I was able to get in with my primary care doctor for the pre-op. When I went in that day, he knew all of the relevant information. I didn't need to go back to the drawing board and explain everything. I wasn't met with skepticism when I explained my current medication regimen or the plan for which meds to stay on through surgery. I didn't need to make decisions about what tests were needed or not needed. With other providers who don’t know me, I often carry the burden during these pre-op appointments. My history is complex, and it would be impossible for someone to learn all of it in 40 minutes. So, I carry the responsibility to make sure all of the relevant information is included in the physical. I have to make the decisions, and then I have to justify myself to the provider who barely knows me. This time, I just had to sit back and let my primary care doctor do it all.

He chose to do an EKG because of my tachycardia, which we were still monitoring and figuring out. He chose not to do bloodwork because I had consistent normal bloodwork through quarterly rheumatology visits. He didn't do a pregnancy test, because he knew they would just redo it the morning of surgery. He did a thorough physical exam, even though I saw him less than a month before. Then, even though not part of the pre-op per se he did an OMT adjustment to get me in the best place possible before surgery.

OMT with him is a whole different level. He can feel exactly where my pain is, exactly where my difficulties are with just the gentlest touch. He knows where to check. And he knows how to make it feel better. He knows me, and he knows my body. He truly is a doctor and a healer.

This relationship is a partnership. In the container of this relationship, I am invited to show up—all of me. Because of this, I've been able to bring things to him that have felt shameful or things that have made me feel needy. He has always responded with openness and warmth, which has invited me to show up even more, to bring even more of myself into the exam room. That has transformed not only my experience of the way I interact with the medical community, but also the way I interact with myself, with my pain, with my illness, and with my physical reality.

There's a statement in the foreword to a book called *You are Not Your Pain*:

> The pain cannot be ignored or wished away. But underneath the clanging noise of the pain, there is a deep wholeness that cannot be damaged by illness and disease, a wholeness that can be reinhabited if, just for a moment, we can willingly approach, precisely sense, and tenderly befriend the body that seems to be letting us down so badly (Burch & Penman, 2013, p. xv).

This is what my relationship with my primary care doctor calls me toward... He calls me to willingly approach my body, that seems to be letting me down so badly. He calls me to find ways to live in my reality, both through changing and treating what we can and finding ways to live with what we can’t change or treat. He calls me toward hope.

Reality as Foundational to Hope, but Whose?

One of the elements of hope within life-altering illness and injury that needs closer examination, especially in a medical context is the foundation of hope in “unalloyed reality” (Groopman, 2004, p. xiv). One particular question that emerges in this context is who defines reality. Over and over again in the literature are stories of people feeling that their physicians do not hear them or that their physicians do not accept or recognize their experience of illness as real (Coulehan, 1991).

In *Waking*, Matthew Sanford (2006) describes an experience of this. When Matthew left the hospital after the accident in which he severed his spinal cord, he went to a rehabilitation facility. One day, while there, he found that he could move his left foot despite his paralysis, and that this movement was not just random spasticity, but he seemed to actually have control over it. Physical therapist (PT) after PT examined him, asking him to move his foot, perplexed when he could do so. They were concerned that something random was happening, and that Matthew would start to have false hope that he would be able to move, feel, or even walk again. They thought that this false hope was dangerous, so they were trying to find a way to squash it before it took hold. Finally, a PT student saw that he was using his neck and his lats at the same time he was "moving his foot." They decided he was cheating, that the ability to move wasn't really real because he was using his upper body to make the movement. He didn't do it their way, so it wasn't real.

The irony is that the hope that Matthew was displaying there was not the false hope the PTs feared. It was actually the hope described by Groopman. He was exploring, finding ways to do something, within his reality. He was not ignoring reality or turning away from it but finding a way to move within it. This, Groopman would likely contend, is true hope.

These things demonstrate that the true hope at stake here is based on a co-constructed picture of reality, one that has to assimilate both the medical and physical reality (or probability) as well as the patient's experienced reality. Neither can be excluded for true hope to take hold. Indeed, being understood by a healthcare professional, in and of itself, leads to the development of hope, even for patients who are suicidal (Vatne & Nåden, 2018). This experience of being understood can be felt as a human-to-human connection which gives people experiencing illness and injury the ability to withstand and endure what they are going through.

> "The definitive test [to diagnose a psychogenic coma] was the simplest: I raised the patient's arm above his face and let go. A patient in a psychogenic coma retains just enough volition to avoid hitting himself. The treatment consists in speaking reassuringly, until your words connect and the patient awakens" (Kalanithi, 2016, p. 91).

Furthermore, when a provider is able to trust the reality of a patient's experience, it empowers the patient to trust their own experience. They are then able to be better in-tune with their bodies, better understanding how their bodies are communicating with them, which starts to diminish the body-self split that is often inherent in the experience of life-altering illness and injury (Wilde, 2003). As the patient is better able to tune into their own body, they are better able to communicate what they are experiencing with physicians, which can help to direct the best course of care. That's exactly what happened for me.

Instilling Doubt versus Building Patient Trust in Their Experience

For years, I struggled with vision problems that led to blinding headaches on a regular basis. I often experienced double-vision. No matter how we adjusted my prescription for my glasses, I couldn't see clearly—close up or far away. Eventually, I had a functional vision assessment that showed that I had several issues with the way my eyes worked together, known as eye-teaming issues. My eyes tended to cross slightly all the time, but it got worse as I became more fatigued throughout the day. This actually wasn't surprising. My older brother had surgery when he was 18 months old for a much more severe presentation of the same issue. To this day, if he is tired or doesn't have his contacts in, I can tell just by looking at his eyes. Furthermore, going cross-eyed was causing double vision. In an effort to maintain as much of a cohesive picture as possible, my visual system adapted. It adapted, however, by suppressing the vision from one of my eyes. This would then exacerbate the issue, morphing, over time, to the vision issues and headaches I had been experiencing.

I was in Denver one summer for in-depth professional development for work, and, being in class eight hours a day with three or four hours of homework, these issues became incredibly intense. I was barely able to make it through my days. I was, however, able to find an optometrist in Denver who specialized in eye-teaming issues and who was able to start me on the treatment: vision therapy. He gave me a host of exercises to do at home. One of them involved balls at different distances along a string. I would tape up one end of the string and hold the other end of the string at the bridge of my nose. I would then practice changing my focus, moving among the beads. Sometimes I would aim to have one bead in focus and have it look like the string was crossing through another bead. It was exhausting and hard work. I also had a computer program that I used with a special pair of glasses, playing video games that required me to relax and engage the muscles that controlled my eyes in different ways and at different times. Over days of working on this diligently, I did start to notice improvements. My headaches lessened. My vision wasn't getting as bad as I got tired. Things were heading in a good direction.

Then I started to notice something. I was still getting double vision, but there was something weird about it. One day, while playing around with some visual tasks and trying to figure out if I could communicate the current issues to my optometrist, I realized that I had double vision even when just looking out of one eye. I was perplexed.

The next time I saw my optometrist, I told him about this single-eye double vision. He told me that it was impossible. He educated me: double vision only comes from a disconnect between the two eyes. It only comes when the images from each eye don't align correctly. There was no way, he said, to have double vision with just one eye. It just wasn't possible.

What he was saying made sense. I trusted him and believed him. Also, though, I had my own experience. If I covered either eye, I still had double vision. This was particularly apparent when it was dark out (playing with covering one eye while looking at streetlamps or stopped at a traffic light) or when there was a high-contrast situation (e.g., black text on a white background). But here was a doctor I trusted telling me that my experience simply wasn't possible. It was so difficult for me to try and reconcile those two things. I doubted myself. Was I making this up? Was it a case of hypochondria? Was I faking myself out? Was I creating a problem that wasn't there?

When I came back home to Minnesota at the end of the summer, I followed up with my local optometrist. I told him about my progress with vision therapy and again mentioned the monocular double vision. Again, I got the educational lecture about the causes of double vision and how it’s not possible to have double vision out of one eye. He prescribed me a new pair of reading glasses that should have helped even more.

I left that appointment confused, again. The reading glasses did help overall, though. This was great, but it also left me doubting this double vision out of one eye. I continued to play around with it, to see if I could trick myself out of it. No matter what I did, it was always there. I thought I was going crazy. I just didn’t understand what was happening. I stopped talking about the double vision and made do with the strategies we had in place.

About a year later, I was babysitting for eight kids one winter evening. We were playing hide-and-seek in the dark of the backyard, and we were having a blast. One of the little girls was standing next to me as we were looking for the other kids. I had my head bent down as I was talking to her. Then, I turned my head and took a step. A tree branch went over the top of my glasses and right into my eye. It was some of the most intense pain in my life. I push through pain, though, and that’s just what I did that night. The kids and I finished playing, and we went inside. I got all eight to sleep, and then I sat in the living room with my right eye just flooding with tears and in searing pain.

I spent some time googling eye injuries, trying to figure out what to do. I found that infection is a pretty significant risk with an eye injury like the one I had, and that it needed immediate care.

When I got to my car after the parents got home, I looked in the mirror and saw a red, swollen eye that was barely open. It was late, and no urgent care clinics were open, so I trekked to the ER. There, they put numbing drops in my eye, which gave me immediate relief. This was followed by the doctor putting some tinted drops in my eye. Then, they turned off the light in the exam room and brought out a black light and a magnifying glass; the dye made injuries to the cornea (the connective tissue that domes over the iris and pupil) glow in the blacklight. As the doctor turned the black light on, he looked at me and said, “Yeah. I don’t even need the magnifying glass. I can see the tear with my bare eyes.”

The branch had ruptured my cornea, giving me what is known as a corneal abrasion. The ER doctor gave me a prescription for an antibiotic ointment (indeed, he said, infection was the biggest risk), and I went on my way.

I woke up the next morning feeling sore and like my eye was swollen, but mostly okay. So, I got in my car and started to drive to my job that day working with a toddler with autism. As soon as I got into the sunlight, my eye started to burn. I drove three whole blocks before the pain was searing so intensely that I couldn’t function. I pulled over and parked on the side of the road. From there, I called my supervisor to tell her what was going on, and then I called a friend to pick me up and drive me to an urgent care clinic.

At the urgent care clinic, I had a repeat of my experience from the ER. Numbing drops (instant relief), tinted drops, black light. The doctor told me that my cornea was still significantly torn and also swelling up. It turns out that the cornea has one of the highest concentrations of sensory nerves of any body part. The tear combined with the swelling was setting these nerves on fire. There wasn’t, however, a whole lot to do other than to use eye drops constantly and an eye ointment at night.

Over the next several days spent mostly laying in a dark room, the pain started to subside. Each day, my eye felt a little better. I was able to start getting back to my normal activities. After about a week, I saw an optometrist to check on the healing. He said that the healing was looking good, that the swelling was going down and the abrasion was closing up. It felt like we were through the woods.

Two days later, I woke up and opened my eyes which resulted in an abrupt return of the searing pain; it felt like there was another tree branch in my eye. I got back in with an optometrist who told me that I had re-torn the corneal abrasion open once again. Apparently, this can happen. Corneal abrasions heal from the bottom layer up. Once the top layers form, they are still soft and not completely adhered to the rest of the cornea. At night, while sleeping, those new, soft cells can get stuck to the eyelid. When you open your eyes in the morning, those cells stay stuck to your eyelids and are ripped off of the cornea. That was what had happened to me.

This sequence of events—heal, feel like I was heading out of the woods, open my eyes in the morning and re-tear the cornea—repeated every few weeks. Eventually, it was clear that this corneal injury was not going to heal on its own. I opted to see an ophthalmologist (an eye surgeon) who was a cornea specialist. He evaluated my cornea and the history. We tried some conservative treatment for several weeks (an ointment and a special eye mask to keep my eyes moist throughout the night in hopes of preventing those healing cells from sticking to my eyelid). When those attempts didn't help, he recommended surgery.

It was an easy surgery, and a simple surgery, too. The ophthalmologist would just go in with a lazer and burn off the top layer of the cornea. It was similar to Lasik surgery (for vision correction), but he would burn off much less of the cornea than he would in a Lasik procedure. This would allow healing to happen across the cornea rather than just the canyon-like abrasion needing to heal. This would allow a better, more stable layer of base cells that would make it less likely that I would re-tear my cornea waking up in the morning. During this whole process, I never even thought to mention the double vision I still had out of one eye because I "knew" it just wasn't possible.

I had the surgery, and everything went as planned. I had a lot of pain for the first week after surgery because I had some swelling, but that diminished relatively quickly over time. After I healed, I did not continue to re-tear my cornea.

About three months after the surgery, I was at a rock-climbing film festival with friends. At the end of the films, there was a bunch of information before the credits that showed up in white text on a black background. I could barely read it because I had horrible double vision looking at it, worse than I had ever had before. Out of curiosity, I covered my right eye (the one on which I had surgery). I still had the double vision, but it wasn't as bad as it had been before I covered my eye. I opened both eyes. The double vision got worse. I covered my left eye, and, when looking just out of my right eye, the double vision was atrocious. In the back of my mind, I heard, "This isn't possible. Monocular double vision doesn't exist."

In the front of my mind, I heard, "But it's happening. It's happening right now. And it's worse in my surgical eye."

When I saw my ophthalmologist for a post-op appointment a week later, I mentioned it to him. I told him I had always had this double vision just out of one eye, but it seemed to be a lot worse in my right eye since surgery.

I started to say that I knew it wasn’t possible, but then I saw his face had fallen. The look on his face told me that this was, indeed, actually, a real thing. He asked me to tell him more about it. Then he told me we needed to do an additional test called a corneal topography. With the corneal topography, I put my face in a machine that took a picture of my cornea while flashing a bunch of bright white lights arranged as concentric circles at my eye. The machine was able to get a picture of the reflection of those lights on my cornea, which allowed my ophthalmologist to build a map of my cornea that looked just like a topographical map of a mountain range, showing him the slope of different parts of my cornea. This allowed him to see how my cornea was shaped.

When we got back to the exam room, he picked up the topography and showed it to me, next to what a normal topography should look like. Mine did not look like the normal one. As he was interpreting it for me, he told me that corneas are supposed to be shaped like a hemisphere. The map showed him that mine was shaped more like a cone. It was a condition known as keratoconus. The cone shape of my cornea wasn’t as bad as it could get, especially given my age, so, in my case, it was forme fruste keratoconus.

After explaining this to me, he said, “I always check for keratoconus before Lasik because that type of surgery can make existing keratoconus, which is commonly degenerative, a lot worse. I don’t usually check for it before the surgery you had because that surgery doesn’t involve going nearly as deep with the lazer as Lasik and because keratoconus is so uncommon. But I wish I had known that you had this before I did your surgery. This is why you have double vision out of one eye. When the cornea is shaped like a cone, it acts like a prism, refracting the light coming in through the cornea, creating the double vision you get.”

It was real after all.

Not only was it real; if any of my doctors before that surgery had treated it as real or had believed my experience, we would have known about the keratoconus before going into this eye surgery. If they had believed me, we would have approached things differently. We would have approached things in a way that didn't make this problem worse.

My forme fruste keratoconus doesn't seem to be degenerative, and the worsening after surgery ended up being temporary, though I do have recurring imaging to check on its progression (so far, with no progression). When my ophthalmologist accepted my experience as reality, it allowed us to be more firmly rooted in "unalloyed reality," which gave us a "path to a better future." It allowed me to live into true hope. We've been able to deal with the keratoconus and associated double vision through the use of 3-D printed scleral lenses, which are hard contact lenses that dome over my cornea, making it a hemisphere once again, preventing the refraction through the cone-shaped cornea. Sure enough, with these contacts in, I see better than I ever have before. I have no more monocular double vision. Even more important from my perspective, though, I've learned to trust myself and to keep pushing when I know what's happening and what I'm experiencing. I've learned not to doubt my reality. I've learned that what I experience is real. And I've learned that I cannot move forward into hope without first being rooted in that reality.

Chapter 7: Collaborating

My eighth orthopedic surgery was a pretty gnarly one. It’s incredible with the state of medical technology what physicians and surgeons are able to do today. This eighth surgery involved rebuilding a ligament, implanting new cartilage, opening some tissue, and moving the part of my bone where a ligament inserted. This was all done on a knee in which I had a lot of instability and pain in hopes of resolving my issues for good.

About two and a half years before this eighth surgery, I had been rock climbing. At that point, I had been climbing for about three years, and I decided to join a team in an adult climbing league. On the first climb of our first night, I was climbing one of my favorite types of routes. This is a route that has holds on three walls, named after the shape of the climb: a chimney. I was about 10 feet from the top of the 65-foot wall. I had my left foot on a hold on the wall to my left and my right foot on a hold on the wall to my right. I had my right hand on a hold on the wall to the right of me and my left hand on the wall in front of me. I started to shift my weight to my left leg so that I could reach the next higher hold with my left hand. Suddenly, out of nowhere, I felt and heard a huge pop in my left knee, and I felt my knee bend inward. I fell off of the foot hold and caught myself with my right arm before the rope kicked in to stop my momentum completely.

Once my new climbing partner (whom I had met 10 minutes earlier) realized that I was hurt and not just frustrated, he let me down. I sat in the rubber chips hyperventilating as several people came over to see what was wrong. Luckily, one of my other climbing buddies had been climbing nearby. I couldn’t bear weight on my left leg, so she and a staff member helped me out to her car, where she drove me to the nearby orthopedic urgent care. Once there, they told me I had dislocated my kneecap and that it sounded like the rest of my knee had bent inward, possibly damaging connective tissue (including ligaments). They put me on crutches and in a brace and ordered an MRI, which was scheduled for the next day.

My friend took me back to the climbing gym, where I thanked my climbing partner and the staff who had helped me and got my car to drive home. The next morning, I went in for my MRI, and I was told I would receive the results the following day. When the doctor walked in to tell me about the results, she was super happy, semi-singing, “MCL tear!” This was good news because the MCL (the medial collateral ligament) typically heals on its own and doesn’t need any extra intervention. It takes a while, but it usually does just fine with physical therapy and time.

What the doctor didn’t mention that day was a secondary finding of the MRI, that I had also torn another ligament known as the MPFL (medial patellofemoral ligament), which attaches your kneecap to your femur. When I brought that up with my physical therapist a couple weeks into treatment, asking what we were doing about the MPFL tear and whether it would change things, he did a double take. The doctor hadn’t written about the MPFL tear on the physical therapy referral. I pulled up my MRI results in the online patient portal, and when my physical therapist saw the reference to the MPFL tear, he said that changed a lot of things.

There was a time when the MPFL was thought to be somewhat of a useless structure, not really doing much of anything in the knee. Recent research, though, had shown that the MPFL was actually incredibly important in maintaining kneecap stability. Since a kneecap dislocation was part of my initial injury, this tear would actually make me more susceptible to further dislocations.

Over the course of the following months, my physical therapist and I worked relentlessly at continuing to build strength to try and offset the instability that both preceded and was caused by the injury. Over and over, though, my kneecap would feel like it was sliding out of place (called a subluxation) again, even during the most innocuous activities like getting out of the shower or stepping up a curb, each time accompanied with a stab of intense pain. Four months after my initial injury, my kneecap dislocated completely once again while standing up from a lunge position while playing with my nieces. That was when we decided it was time for a surgical consult. A month later, I had surgery to replace my MPFL using a donor tendon. Overall, recovery went well, and within six months, I was back to all of my activities without the instability I had before surgery.

Two years after the surgery, though, I started to develop pain behind that kneecap, and some of the instability was returning again. At first it was just while doing certain very specific activities, like running uphill. Overtime, though, the pain got worse and started to spill over into more and more activities. Then, it started limiting what I could do. I got an appointment with my surgeon, who ordered an MRI. The MRI showed damage to the cartilage behind the kneecap, though it was a little unclear just how bad that damage was and whether it was just deepening of damage from the dislocations and subluxations before the first surgery or whether those subluxations were still happening and causing further damage.

After discussing it for some time, my surgeon and I decided that he would do a diagnostic arthroscopy, a relatively minor surgery where he would insert a camera in my knee to visualize the damaged cartilage. That would give us better information to make decisions going forward, and he would be able to clean up any rough cartilage edges that might had been causing my pain.

The week before the arthroscopy, I went to Denver to visit some friends. The day before I left Denver to come home, my friend and I went for one of my favorite hikes in the area. At the end of the hike, we left the trail so that we could scale up a waterfall (one of my favorite things to do). We got up the waterfall, and, as I was stepping back onto the trail, my kneecap dislocated completely once again. I stood there for a minute, just not moving, while my friend looked at me quizzically. "I just dislocated my kneecap," I muttered to him as I gingerly put weight on that leg. It hurt, but it was tolerable, and we were less than a mile from the car on mostly flat terrain, so we made our way slowly to the road. As soon as we drove away and got back to a location with a signal for my phone, I called my surgeon and my physical therapist.

My surgery being less than a week away, I wasn't sure how this would change things. I wasn't sure if we would be able to move forward with our plan. When I got home, my physical therapist did a full assessment, in which he noted that my knee was pretty swollen and there was no longer a hard end to how far my kneecap could move to the outside of my knee, which reflected damage to that MPFL structure once again.

My surgeon asked to see me the morning of my surgery in-clinic, right before my surgery that afternoon. He wanted to do some x-rays and a physical exam, and then he also wanted to do a CT scan of my hips, knees, and ankles. He told me that he still wanted to do the arthroscopy that day, but that this other imaging, paired with what he found during the scope, would give us information about how to move forward to keep this instability and these dislocations from happening again.

Once we had all the information, a couple of weeks after my arthroscopy, we made a plan. The imaging showed a few major problems: my kneecap tilted to the outside of my leg and it was too high up inside a groove that was just too shallow to keep it in place the way it was. The scope had also shown significant damage to my cartilage. So, we planned this gnarly eighth orthopedic surgery of mine.

The plan was complex: the surgeon would take out my damaged cartilage and part of the bone to which it was attached, use donor bone and cartilage to fill the area in; rebuild my MPFL, again using a donor tendon; release (i.e., place a cut in to lengthen) the tissue on the outside of my kneecap; and he would saw out the part of my tibia where my patellar tendon inserted and then screw it back into my tibia, but lower (in an effort to bring my kneecap lower and better into the groove). All of this would be in an effort to stop the dislocations for good.

The surgery took about four and a half hours, and when I woke up afterwards around 9pm, I was immediately in immense pain despite having received a nerve block. I knew right away that this was different than my previous seven orthopedic surgeries. The post-op nurses did everything they could to manage my pain. There was a shift change in the midst of my post-op, and, right away, the new nurse knew she was not going to be able to send me home that night. I couldn’t get up to use the restroom, and even rolling over to use a bedpan sent my pain (and concurrently, my pulse and blood pressure) through the roof. She worked with the anesthesiologist to continue to administer some of the strongest pain management medications they could, while monitoring my breathing and other vitals.

Meanwhile, she called the on-call resident to get me admitted to the hospital overnight so that I could continue to have IV pain meds and to have my vitals monitored (since the pain medication at the levels I had received could easily suppress respiratory activity). The nurse came back and told me that the resident wasn't willing to admit me. She told me he wanted to give me some muscle relaxants and oral pain medication to see if that could get me to a place where I would be able to go home. Then the anesthesiologist came over, telling me the resident had asked him to do some testing to see if the nerve block was still in place. Meanwhile, I was in agony.

"Can you tell the resident this is my eighth orthopedic surgery? Can you tell him I've never felt like this after any of the others? Can you tell him I know I can't go home? Can you tell him I live in a second-floor condo with no elevator? Can you tell him I can't even get out of bed to use the restroom?" I pleaded with the nurse, who assured me she was doing the best she could to communicate the situation. She told me she didn't understand what the resident was doing, that she had never had that happen in her 20 years of working post-op.

I was scared, and I was tired, and I just wanted to be able to try to settle in for the night. I needed this doctor to understand what was going on. I needed him to talk to me or come see me (though I've since learned he might not have been in the hospital). I just needed him to understand why we were asking that I be admitted, or, alternatively, for him to explain why he was trying so hard to avoid admitting me, to tell me whether there were risks to staying overnight, to help me understand why he was doing what he was doing.

I told the nurse this (or some tired, medicated, in-pain version of it), and she called the resident again with a similar response; he wanted her to try a few more things before deciding to keep me overnight. Finally, it dawned on me, and I asked, “Is it within my rights to ask to talk to the attending? Can we get another opinion?”

She told me it was, and she called the attending, who assured her he would talk to the resident and encourage the resident to call my surgeon. I felt a wave of relief. I knew as soon as my surgeon was brought into the conversation, I would get admitted. My surgeon and I always made decisions together, and he strongly valued my experience and my opinion.

Several minutes later, the nurse got a call from the resident, upset that she had called the attending, and, according to my nurse, hanging up on her when she was asking him about getting medication orders into the system. Finally, around one o’clock in the morning, my admission and medication orders were in the system and I was being moved to the orthopedic floor, where I spent the night receiving regular IV and oral pain meds. By the next morning, I could get out of bed and move short distances. I was ready to go home.

I made a call the next day to patient relations to explain what had happened, mostly to ensure it didn’t happen to another patient. After discussing it with a patient relations representative, my story was sent to multiple people, including my surgeon. In the end, it sounds like what really happened that night was just bad communication between the nurse and the resident.

Ironically, though, eight weeks after surgery, I had my dog at the dog park, where she could run around, and I could be relatively stationary. I was off crutches at that point, but I was still in a full-length leg brace. My dog was chasing another dog, and she ran directly into my surgical leg at full speed, with enough force to burst the brace open. I was scared and worried that she might have done damage. I knew the bone wasn't all the way healed yet, and I was afraid we were risking a fracture. When we got home, I decided to call my surgeon's answering service (being a weekend evening) to see if I needed to have x-rays done or if there was anything else I needed to watch for.

After the receptionist took my details, she told me that the on-call resident would call me back within 20 minutes and told me his name. I knew, right away on hearing his name, that it was the resident from the night of surgery, the one that seemed to drag his feet on admitting me. I felt a little defeated. When he called, though, he asked me what happened, and, when I finished telling my story, the first thing he said was, "Wow. I'm really sorry that happened. That must have been really scary."

I let out a breath I didn't know I was holding as I said, "It was."

We then proceeded to talk through my symptoms and his concerns and what we should do next. In the end, we decided I didn't need to take any action other than having my physical therapist assess thoroughly the next time I saw him. When I hung up with the resident, I felt relieved; he had seen me and heard me, and we had worked collaboratively to decide how to move forward.

All I could think was, "Man, if he and I had just talked the night of surgery, that would have changed everything."

Collaboration as Healing for Existential Injuries

Collaboration opens up the possibility for the physician to support the patient in the way they make sense of their illness or injury. This creates a working relationship that has depth, which can enhance physicians' potential for bringing forth healing (McWhinney, 2000). Highly collaborative relationships also create a unique balance of power in which both patient and physician have a high level of power, with the power of each individual enhancing rather than diminishing the power of the other (Roter, 2000). Patients who feel this sense of collaboration with their provider in the midst of their illness become more active in their medical care (Alexander et al., 2012), and are more likely to adhere to treatment plans (Arbuthnott & Sharpe, 2009). This collaboration is especially essential for patients with complex illnesses and injuries who work with a variety of providers and specialists, particularly when that collaboration is strong with one physician who can be a central touchpoint to coordinate the milieu of other providers (Noseworthy, 2019).

Through this process of collaboration, physicians can participate in the way patients learn to live into possibility, even in the context of life-altering illness and injury (Wolf et al., 2018). People experiencing life-altering illness and injury who engage in a personal process of making meaning tend to have higher quality of life and higher life satisfaction than those who do not engage in this personal process of meaning-making (Russell et al., 2006). This highlights the value of physicians taking the time and making the space to help patients in this process of making personal meaning in the midst of their illnesses. This is particularly important in the context of life-altering illness and injury, especially as the illness or injury shifts from being an intrusion on the person's life to becoming a way of being in the world (Carel, 2012).

> "Openness to human relationality does not mean revealing grand truths from the apse; it means meeting patients where they are, in the narthex or nave, and bringing them as far as you can" (Kalanithi, 2016, p. 96).

There is a movement within the field of medicine known as “narrative medicine,” which highlights the need for physicians to have “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 calls for physicians not just to identify, understand, and treat patients’ illnesses, but also to walk alongside them through their illnesses (Zaharias, 2018). Narrative medicine sits on the assumption that even the patient’s act of being able to tell their story in a medical context provides existential healing, as it allows the patient to start to put boundaries around the problem and to deidentify themselves from the problem (Charon, 2001).

> “Dr. McMeken does something else for me, though. He gives me wonderful stories about Australia... Do I know what the life ahead of me will be much the same, that going forward I will journey into a strange territory? Not exactly; I am only thirteen. But Dr. McMeken performs an essential healing task. He relights my imagination” (Sanford, 2006, p. 52).

When the physician steps into the patient’s story and into the meaning the patient is already making, they can start to form a therapeutic alliance that will allow them to work with the patient to continue to develop that meaning in a way that allows the meaning to facilitate the patient’s well-being and quality of life (Roter, 2000). Entering the patient’s narrative and building the therapeutic alliance also builds patient trust and openness with the physician, which ensures that the physician receives the whole story from their patient, enabling them to make better decisions about diagnosis and treatment (Charon, 2001). Furthermore, there are skills physicians can learn in order to be able to enter the patient’s story even given time and other practical constraints (Zaharias, 2018).

> “I thought about what Emma had told me. I had gone from being unable to believe I could be a surgeon to being one, a transformation that carried the force of religious conversion. She had always kept this part of my identity in mind, even when I couldn't. She had done what I had challenged myself to do as a doctor years earlier: accepted mortal responsibility for my soul and returned me to a point where I could return to myself... Emma hadn't given me back my old identity. She'd protected my ability to forge a new one” (Kalanithi, 2016, p. 165).

These skills and this process can change the experience and the course of injury and illness progression. Even in cases where there is nothing to be done to physically alter the course of the illness, this collaboration and the physician-patient co-creation of meaning can give a sense of peace and well-being even within difficult circumstances that are unlikely to improve.

Collaborative Decision-Making and Partaking in Patient Meaning-Making

One Sunday night, I woke up suddenly with what I thought was a stomach bug. Over the hours that followed, however, it quickly became clear that things were much worse than I originally expected. As soon as my primary care office opened in the morning, I called and made a video appointment with whomever was available that day. Things had been pretty bad for a while by the time the appointment came around, so I wasn't surprised when the doctor's conclusion was that I needed to head in immediately for a CT scan and lab work. Luckily, I lived minutes from an urgent care with CT capabilities, so I managed to avoid the emergency room. The CT and the lab work were unremarkable, so I was able to go home and wait for another follow-up with my primary care office.

Pretty quickly, they sent me to a gastroenterologist. In many cases, they might have chosen to wait things out for a few days and see what happened. My particular autoimmune disorder, however, is linked with increased likelihood of inflammatory bowel conditions. My symptoms fit those conditions, and they coincided with going off of the immunosuppressants that control my autoimmune condition, so it was crucial that we determine whether I was experiencing an inflammatory bowel disease that was part of my autoimmune disorder.

The gastroenterologist I met was fantastic. It was one of my best initial consults with a specialist ever. He listened to what I had to say—my symptoms, my concerns, my perceptions, my questions. He gave me detailed information. And then he engaged me in the process of deciding how to proceed from there. Together, we decided to pursue better understanding of what was underlying these symptoms. We reasoned that if it was a flare of an inflammatory bowel disease, this was our chance to identify that. It's much harder to identify those diseases when they aren't flared. And treatment for my autoimmune condition would change if I did have an inflammatory bowel disease. So, though it's something no one really wants, I scheduled my first colonoscopy (at 34 years old).

The gastroenterologist of my consult worked at a location 45 minutes away, while I lived five minutes from another location of the same clinic. I opted to have my testing at the clinic near home, so the test was done by a gastroenterologist I had never met. That afternoon, upon our first interaction, I knew things were different with the gastroenterologist doing the scope. Immediately, she questioned our decision to do the scope, telling me it was far more likely that I just had an infection, not even stopping to listen to our reasoning behind the decision. Quickly though, I was fast asleep under sedation and the test commenced.

When I woke up, they were just moving me out of the procedure room. The nurse told me that the doctor would be in shortly to talk about what she found. The doctor came in and brusquely said, "Well, I guess I'm glad we did the scope. You had an area of inflammation and three polyps in different parts of your colon. We biopsied the inflammation and removed the polyps. They'll all be sent to the lab. You'll get a letter in the mail if everything is normal. If the inflammation is abnormal or if the polyps are precancerous, you'll get a phone call. You'll hear from us within a week." Then she walked away.

Suddenly, things seemed much worse and much more frightening than before. Coming from a family with numerous cancers (including colon cancer) on my maternal and paternal sides, just the appearance of the word "cancer" (even within the term pre-cancerous) was enough to send me into a little bit of a panic. There was nothing I could do about it, though, so I went home to wait.

A few days later, I had one of my regularly scheduled appointments with my primary care doctor. We talked through the symptoms I'd been having and the test and what the gastroenterologist said about what she found. My primary care doctor was reassuring in a way that did not convey a lack of concern or a dismissal of my fears. He told me that we would just need to see what came back from the lab. He told me that there were some good things, some things the scope didn't uncover that it could have, some things that would have been much more difficult moving forward. He reminded me that we would make a plan based on what we heard from a lab. He assured me that it was a good thing to have uncovered (and more importantly, removed) these polyps at such a young age; depending on the pathology, they could set us up to make sure we were watching for problems that might have otherwise creeped in outside of our awareness.

We hit a week after the test, and I still hadn't heard anything about the results of the biopsies, so I called the clinic. The nurse pulled up my records and told me that the results were in and a letter was on its way to me. I sighed a huge breath of relief. A letter! That was the good-news-result-delivery method! Then the nurse read the results and summarized them, "The inflammation was due to ischemic colitis, which is when the tissue of the colon doesn't get enough blood. This may or may not be connected to the symptoms you were having. It's unclear. And all three polyps were precancerous. Though the doctor removed all three with clear margins, with that many precancerous polyps at such a young age, you are at very high risk for developing colon cancer, so you'll need another colonoscopy in two years."

My heart plummeted and it felt like my stomach was doing cartwheels inside of me. I wasn't sure how to respond. I latched onto the practical. "The ischemic colitis," I asked, "What causes that? Is it something we need to do anything about? Is it something we need to be worried about?"

The nurse responded that she wasn't sure. She told me that she would need to ask the doctor and get back to me. I thanked her, and not knowing what else to say, not knowing what else to ask, but feeling like the ground had been pulled out from under me, I hung up.

Immediately, I dialed my primary care doctor's office. I spoke to the receptionist, and I said I had a question for my primary care doctor. He was not in the clinic that day, so she asked if I wanted to speak with a nurse or if I wanted to send a message to the rest of the providers to answer my question. I didn't. I wanted to speak with my doctor, the one who had seen my apprehension and anxiety and had reassured me just the week before. I realize now that I didn't need someone to speak to the physical reality of the situation. I needed someone to speak to me, as a person, in the context of my life. I needed someone who knew me rather than just talking to someone who had glanced through my medical record. I needed someone to speak to my fear, to my feeling of having the ground pulled out from under me, not someone who could conjecture about the physiological processes that might be happening in my body.

I told the receptionist that I did not want to talk to a nurse or a different provider. I told her I needed to follow-up about some test results that I had recently received, and that I was okay with waiting for a response from my doctor. She responded that it could be two or three days before I got a response. I didn't really have much of a choice, so I said that was fine.

Then, I laid in my bed, face-down, buried in my pillows and blankets.

Nineteen minutes later, my phone rang. It was a number I didn't recognize, but when I'm waiting for calls from doctors, I always answer. I assumed this was the gastroenterology clinic calling with answers to my questions about results. It wasn't. It was my primary care doctor. He was working at the hospital that day, but he saw my message as it came in, and he wanted to respond right away.

"Oh, hi. How are you?" I asked, almost reflexively, when he told me who it was.

"Well, I was pretty good. And then I got your phone call and looked at the results from the scope. I'm sorry.... How are you doing?"

"I don't know... I just... It's a lot. It's not what I expected. I don't even know what to do here."

"Look," he said, "This is not great news. I'm sure it's incredibly hard. But, really, we kind of knew this was coming. That many polyps at your age are almost always precancerous. And they removed all of them. So, you'll go back in for another colonoscopy in two years, and we will see what things look like then. We can be on top of this now. This type of cancer takes a long time to grow but knowing now that you are at-risk gives us the chance to stay ahead of it."

"Yeah," I responded, still a little hesitant, but feeling seen and starting to settle into this other perspective, "but what about the ischemic colitis?"

"I don't really know about that," was his honest response, "It's not something we usually see in someone as young as you. We almost always see it in older patients. So, make sure you talk to the gastroenterologist about that. But even here, this is most likely good news. The inflammation was pretty localized; it wasn't spread throughout your colon, and there wasn't any evidence of advanced inflammatory bowel disease. While I don't know for sure what to make of the ischemic colitis, those things are good news, too."

After a little more conversation about whether it could be connected to my autoimmune disease and what to do there, he told me, "Hang in there, and let me know if you have any other questions. I'm sorry you have to deal with this on top of everything else." I thanked him and hung up the phone.

I didn't have any more information. I didn't know anything more about what my future might look like. I didn't have any new next steps or actions I could take. What I did have, though, was someone who saw me as a person. I had someone who was willing to acknowledge the uncertainty, willing to sit in the space of not having answers or treatment for me. I had someone who met me in the space of confusion and fear and reassured me. He gave me some perspective without denying or trying to eradicate my uneasiness. He helped me start to process the information, start to make meaning from it, start to recognize the good things that were coming from this bad news. I hung up feeling steadier, calmer, breathing more freely and more deeply.

Hours later, I was glad to have that experience to draw from when I got my next call from the gastroenterologist's office. It was the nurse, calling me back with the doctor's answer about what was causing the ischemic colitis. The answer was that she wasn't sure, but that she also wasn't sure whether it was even an important finding. This, of course, brought forth follow-up questions from me: "Is there anything we need to do about it? Could it be related to my autoimmune disease?"

The nurse seemed annoyed as she told me that she didn't have answers to those questions because she only asked the doctor the question I had asked on our last phone call. Frustrated, I asked whether I should just make a clinic appointment to talk through it and any other questions I had. The nurse replied that she would ask the doctor and get back to me.

Over the next couple of days, I heard back that there was no need for a follow-up and that they didn't have answers to my other questions other than to talk to my rheumatologist about possible connections to my autoimmune disease. A month later, my rheumatologist told me he had never heard of ischemic colitis, and he only knew what it was because he knew what each word meant individually. He told me to talk to my gastroenterologist about any connections to my autoimmune condition. This circular referral experience is incredibly difficult to navigate, and it seems to be more and more common as we move more and more to a model that relies heavily on providers with very specialized areas of practice.

The gastroenterologist was treating physical symptoms and findings without any concern for the person in which they were occurring. She was treating the illness-as-disease. She had no interest, whatsoever, in what that disease meant for me and for my life. She didn't know what to do for the physical disease, and she distanced herself from any interaction with me, the actual patient.

My primary care doctor, however, despite being in the same situation of not knowing what to do for the physical disease, was still able to offer something important, something essential. He worked to help me make meaning of the results I had received, to see them from multiple perspectives. He helped me in the way I was trying to make sense of my physical reality. He offered healing. It was not a physical healing of the illness-as-disease, but, rather, it was healing the illness-as-lived, offering connection and reassurance in the midst of my wholistic experience of the physical disease.

Chapter 8: Conclusion

I had planned on using this concluding chapter to tie a nice bow on this project. I intended to give a summary that I hoped would be elegant and eloquent and pull things together. I foresaw this chapter as a clean and collected end to this project. I intended for this to be an exploration of the simple and foundational aspects of the provider-patient relationship that have run throughout this dissertation.

But I've realized I can't do that.

This dissertation is an attempt to convey a lived experience, that of being a person living with life-altering illness and injury interacting with the world of physicians in healthcare. The problem, the obstacle to my intentions for this chapter, is that the lived experience of being a patient is not clean or collected or elegant. It is never done, and so there can never be a nice, neat bow tying it all together. There is nothing simple about any of this.

Arthur Frank (1995) writes that people who live with serious illness are "wounded storytellers" who must reauthor the narratives of their lives, and who must do so using their broken bodies. When I first read that, I really understood it. It struck me as being so true to my experience.

But then, as I was just finishing my first draft of this dissertation, something happened. This something that happened gave me new insight to just how true the "wounded storyteller" label is. It let me experience, viscerally, what exactly that means.

While at physical therapy rehabbing from a knee surgery, we were finishing out our session with some balance work. It was balance work we'd been doing for a few weeks at that point. On my second rep of the first exercise, I stepped up to balance on an unstable surface, and, as I engaged the muscles of my lower leg, felt and heard a snap accompanied by a rush of pain. I stepped off the ball, doubled over in pain, as my PT started asking me what happened. At first, all I could communicate was that it was my ankle and that I needed to sit down. I hobbled over to his table and sat down. I pulled off my shoe. My PT came over to the table and started poking around; it was exquisitely tender. He looked at me and shook his head. “You sprained it. At the very least. How did that happen?”

I looked at him, trying to convey as much earnest as possible, “I don’t know. I just stepped up, and as soon as I engaged my muscles, it snapped.”

We looked at each other for a few moments, and then I continued, “This is how it is. This is what I’ve been telling you all for years. Every injury I’ve had that you haven’t seen happen, this is how it happens. I do something innocuous and something snaps, something tears.”

He continued to look at my foot in disbelief. “I’m so sorry this happened,” he murmured as we tried to figure out if I needed to go straight to urgent care. In the end, we came up with a list of possible diagnoses: a sprain of a ligament, a strain of a tendon, a subluxation (dislocation) of a tendon, or some combination of the three. We decided I would go home for the night, try using one of the braces I already had, and go into the sports medicine walk-in clinic the next morning if I needed to.

All night, my tendon felt like it was about to slip out of place again, and I had really painful snapping. It seemed like the subluxation was almost definitely a part of what happened. I did some research that night. Tendon subluxations in the ankle are no joke. They are hard to treat conservatively, with at least 50-74% ending in surgery. There was one study, though, that showed that casting in the foot in a certain position for six weeks could resolve the issue without surgery. It was a study using an incredibly small sample size, and the more I read, the more I realized it was a pretty controversial finding. To me, though, if there was a chance to avoid surgery by casting for six weeks, I wanted to take it.

I trekked to the walk-in clinic the next day. I saw a doctor I had seen before for a stress fracture in this same foot. He immediately said it was a sprain and put me in a more rigid brace than the one I had. I kept pushing, telling him it felt different than other sprains, asking about the subluxation, asking about the snapping I was having, asking about the instability I was having. He kept brushing my questions aside. I didn't know how to bring up the studies I had read without being "that patient" (you know, the one who has their MD from Google University). So, I didn't bring it up. Instead, I asked, "Is there anything else, *any*thing else, we can do for this?"

"Nope. Just wear the brace. It'll heal."

I walked out of the clinic, my tendon still painfully snapping every so often. He hadn't heard me. He hadn't seen me. I was worried and scared.

I knew I needed to find a way to bring up what I had read, the research I had done. I knew I needed to advocate for myself here, but I didn't know how. Eventually, after considering several different paths forward, I tried calling my primary care doctor. He knows me, I reasoned, so he would know I'm not trying to be Dr. Google. He was out of the clinic, though, working at the hospital for the week. He called me back, but I missed it while on a work meeting. I ended up sending him a message through the electronic system. I told him I was worried given that this wasn't an isolated incident. I told him that this didn’t feel like any of my other (frequent) ankle sprains. I told him about the research I read, and I asked him if it were worth casting.

In what was paradoxically a very comforting response, he told me he didn’t know enough to know whether casting would be helpful here and told me I should go into the primary care clinic and see the sports medicine fellow. His willingness to admit that he didn’t know was comforting because it told me that he saw me, he heard me, and he was willing to consider what I had to say. He was also willing to admit the edges of his knowledge and ability.

A couple of days later, I went in to see the sports medicine fellow who, within minutes, was fixated on it being a sprain. I tried to tell him I hadn’t rolled or twisted my ankle. I tried to tell him this was different than all my other sprains. I tried to tell him that I was worried because this was a pattern of dislocations and tears (sprains and strains). I tried to tell him that I didn’t understand how physical therapy could have caused this. He just kept reiterating back that it was an acute sprain and we needed to give it time to heal before worrying about the tendon. I asked him about casting, and he brushed it away like a mosquito on a summer day. Eventually, he decided he would put me in a walking boot for two weeks. If, after that, I was still having trouble, he told me, we could do an MRI.

I went home. The walking boot relieved the vast majority of my snapping and instability. I thought maybe it would work. As soon as I took it off for bed, though, the snapping returned. I couldn’t understand why no one was hearing me, why no one cared about this snapping, why no one was remotely concerned about the probable subluxation, why everyone was stuck on the potential sprain.

When I went back to physical therapy the next week, my PT asked how things were going. “No one is frickin’ listening to me,” I said.

He asked me about my experiences and reiterated that he agreed that it was a subluxation and that the continued instability was an issue. I asked him what I should do. Immediately after I finished physical therapy, I was headed to see my knee surgeon for my three-month post-op appointment. My PT encouraged me to ask my surgeon about my ankle. I know that this surgeon feels out of his league when it comes to feet and ankles; he has told me as much before. But he knows me. This surgeon has operated on me five times: three times on my knee and once on each shoulder. (He was the second opinion doc in my story about two of my shoulder surgeries.) I didn’t think he would have much to say about my ankle, but maybe, just maybe, he would at least hear what I had to say.

As my surgeon walked into the exam room that afternoon, he looked at my walking boot and said, “Geeze. Stop getting hurt, would you?”

I looked at him intensely and seriously and said, “If you can tell me how to do that, I’ll do it. This happened during physical therapy.”

His eyes widened, “While rehabbing your knee?”

I nodded.

“I didn’t realize that. What happened?”

I told him the story of stepping on the unstable surface. I told him that my ankle stayed straight and upright and how, as soon as I engaged my muscles, I felt the snap and the pain. I told him of the continued snapping and instability. And then I told him, “But no one is listening to me. They all think it was a sprain. They all think I rolled or twisted it. But I didn’t, and it doesn’t feel like my other sprains. It doesn’t hurt in the right place. It hurts in a different place.”

He asked me to show him where it hurt. I did. He asked more about the ongoing instability and symptoms. Then he suggested I see his colleague who is a foot and ankle specialist. He told me it sure sounded like a subluxation, and that those were not something to mess with, that they often required surgery as soon as possible to heal properly. He told me that it needed to be looked at as soon as possible because continued subluxations can be risky. He said he would put in the referral.

Then, we had a discussion about these repeated injuries and surgeries, these dislocations and soft-tissue tears. He didn’t have any great insight other than to tell me that it’s clear my body’s connective tissue works differently than most. We talked about physical therapy, about strengthening and muscle coordination and proprioception (all things we are working on, and, in fact, how I injured the ankle in the first place). He suggested pursuing genetic testing (which I had already started with my rheumatologist). Then he told me that, even if we knew what was causing it, there’s not really any good treatment. He told me it just might be a matter of doing everything we can to prevent injuries and then dealing with them when they come. I told him how discouraged I was because this had happened during *physical therapy*, while trying to do exactly this prevention work. He told me he understood and that he wished he had a better answer. He told me we just have to keep trying, keep doing everything we know and learning as best we can as we go along.

He ended by saying, “You know… I know these injuries and surgeries tend to set you back. But you live a really active life generally. And we will keep doing what we need to in order to get you back to that active life. We will do it every time. I know surgery is no fun, but you actually respond and recover really well. You get to keep living that active life, even if there are setbacks."

As I have been considering telling this story in this conclusion chapter, I find myself thinking that I need to wait to see it through so that I can offer the full story, so that I can share with my readers how it ends. It occurred to me today, though, that I don't need to wait, and, really, I don't want to wait.

Right now, I have an appointment with a foot and ankle surgeon in a couple of weeks. I'll get an MRI before then. I also have an appointment with a medical geneticist who specializes in connective tissue disorders in a couple of months. Where will any of this head? Will I need surgeries? Will we find any answers? I don't know.

As I've written before, this dissertation is about conveying a lived experience, a lived experience that has no tidy bow or neat endings. So, here it is. This is my life, living as a patient with chronic illness and numerous injuries. This uncertainty, this doubt and unpredictability, this uneasiness and anxiety, this struggling to be seen and heard, this is it. This is all of it. This space of not knowing is where I live.

Chapter 9: Discussion

It is incredibly important to remember the co-occurring and intersecting realities of illnesses-as-diseases and illnesses-as-lived. The lived experience of the patient, including the existential injuries they encounter, are an fundamental to the essence of life-altering illness and injury. Patients need to tell their stories of the illness-as-lived, and they need this as much as they need any other medical tests or interventions. Not only is this essential for getting a full picture of what is going on for and with the patient, it is also healing in and of itself. It creates a patient-provider working relationship that has depth and allows for healing (McWhinney, 2000) while leveling out the inherent power differential in the relationship (Roter, 2000). It allows the patient to trust themselves and their experience, to find hope in the midst of difficulty and uncertainty (Wolf et al., 2018), and to become active participants in their own care (Alexander et al., 2012). These things are healing at an existential level, and it's important to remember that existential healing can happen even if there is no possibility for physical treatment or healing. In fact, physical treatment and existential healing are two separate things. One does not entail the other. They are separate things that must each be intentionally attended to. This attention can come through the cultivation of a space in which patient personhood is central in (and outside) the exam room; where everyone works together, listens to each other, and make decisions as a team; where hope is fostered in a way that allows the patient to live forward into unknown circumstances. This allows for better understanding of patient issues, leading to better diagnosis and treatment plans (Charon, 2001) and increased patient adherence to treatment plans (Arbuthnott & Sharpe, 2009).

There are places where this is already starting to happen in systematic ways, in narrative medicine (Zaharias, 2018) and person-centered medicine (Mezzich et al., 2010). Both of these approaches take a wholistic approach to patient care. They strive to center patient personhood and patient story in a way that allows physicians to engage in healing during the course of treating patients. While these movements are present and gaining momentum, there is so much more that can be done. These things (or other methods that center patient personhood and pay attention to existential injury) also need to move from being research and theoretical movements to being practiced in all exam rooms at all times. There are doctor-healers who do this already, and many of them are faculty in medical schools. There is hope that this will become more engrained over time. And yet, still, it is lacking so much of the time. So much of provider-patient relationships are focused only on physical presentation and the results of tests without any attendance to patient personhood or illness-as-lived. This can have disastrous effects for patients and their physical, emotional, and wholistic well-being.

> "A moment of kindness to a panicked, terrified patient, to the most vulnerable of people, allows the part of me that feels like every part to take a breath" (Fitzmaurice, 2017, p. 90).

This project is written fully from a patient perspective. I cannot pretend to know what these experiences have been like for the physicians providing my care. Throughout this project, I have often wondered how my physicians would tell these same stories. What was happening in their minds? What was happening in the rest of their day? How were they feeling about the interaction? What do I do that influences how they do their jobs? I can't answer those questions. I do know that physicians operate in systems of complex requirements (from insurances and healthcare systems and clinics) that place a lot of boundaries on what they are able to do and how they can do it. This all occurs in a country with significant challenges to healthcare delivery (which is probably an understatement). These challenges push continued increases in productivity and efficiency, which can directly interfere with physicians being able to spend quality and effective time with their patients.

There are books written on all of these challenges and how they might influence patient care; however, I know that even within this context, physicians have agency. I know this because I've experienced distinct differences between providers operating in the same systems. Furthermore, some of my best experiences with physicians have been with one-time 20-minute consults. Acknowledging the existential nature of life-altering illness and injury can be done in even very small ways. In my experience, this has been as simple as a resident acknowledging the potential for fear or a specialist proposing two different plans and asking what I thought about them. These small actions, taking seconds to minutes, are small acts of healing. Long-term relationships with physicians allow for deeper and more thorough attending to existential injuries, but it's important to note that those are not the only types of relationships in which this type of healing can occur.

> "My brother gives me a red-lighted, hand-controlled electronic football game, and I play it well into the night. Sometimes a night nurse named Ray plays it with me. Those nights are less painful" (Sanford, 2006, p. 57).

This project has focused on physicians. Physicians, however, are only one player in the midst of a host of providers. Nurses are often acknowledged as some of the people who bring the most existential healing to patients, attending to their personhood, working with the illness-as-lived, being *with* the patients day-in and day-out. This really can't be overlooked, though in-depth exploration would be beyond the scope of this project.

One of my orthopedic surgeons had an athletic trainer who acted in the way nurses act in many clinics. He was wonderful. I knew I could call him any time a concern came up and that he would listen to me and find answers. After one of my surgeries, he checked me into the exam room, and we chatted about how my recovery was going, what was going well and where my struggles were, and then about my schoolwork and his kids, and then he left to go get the surgeon. About a minute later, he came back in the room. He had forgotten that he was supposed to remove my sutures before the surgeon saw me. "I forget we aren't just friends," he told me. Six weeks later, when I went in for another follow-up, I found that he wasn't there. I asked if he was on vacation and found out he unexpectedly had to move out-of-state. I was surprised that day at the grief I felt at the loss of someone who had quietly but consistently been a healing presence in my life over the course of several surgeries and many years.

Another group of people who cannot be overlooked in this arena are therapists: physical, occupational, speech, etc. I have worked with my current physical therapist for over three and a half years, and he, more than anyone else, has helped me to develop my intuition about my body and trust in myself and my experience. He asks me what I'm thinking, what I'm feeling. We make each and every decision as a team. He reminds me, over and over, of times when I instinctively felt something about my body and was right. He told me recently, "Well, there's protocol and then there's Amy protocol. I trust your thoughts and your intuition, and we adapt the general protocol to include those things." The healing power of this relationship has been profound.

There are so many others who matter, more than I can mention here. Medical schedulers, phlebotomists, imaging technicians, nursing assistants, receptionists… The list could go on and on. All of these people play a role in treating illness and injury, and all of these people can contribute to existential healing.

Grounded Autoethnography as a Process

I'm choosing to think about and label my research strategy in this dissertation "grounded autoethnography." This is not to somehow suggest that other autoethnographic projects are groundless; rather, it is meant to highlight the intentional nature of the inclusion of grounding practices in my process. This dissertation began with in-depth analysis of multiple memoirs about living (and dying) with life-altering illness and injury. That analysis illuminated certain aspects of that experience; it showed me some of the more universal aspects of the lived experience of facing life-altering illness and injury, and, in particular, doing so in relationship with medical professionals. Those aspects then became the structure, the scaffolding, on which I built my autoethnographic process. My stories are meant to be the manner through which I am sharing the results of my analysis of the memoirs. These stories are meant to evoke visceral, emotional, and cognitive responses from my readers. Those felt responses are the closest I can get to sharing the actual lived experience. My stories stand on their own, but I chose them and told them the ways that I did for a very specific reason: to share these universal aspects of living with life-altering illness and injury. My autoethnography, therefore, was grounded in qualitative analysis of the stories of others.

Furthermore, after exploring and telling my stories, I returned to grounding, this time in existing empirical and theoretical literature. bell hooks writes about theory as a potential space for healing (hooks, 1991), and that is what the process of engaging with theory and existing research to understand and explain my own experience ended up becoming for me. It allowed me to start with a more universal experience (from the memoir analysis), move to my personal experience, and then widen my view again to the more universal. The theory and the existing literature was something like a response to the call of my autoethnographic storytelling. The storytelling often felt vulnerable and exposing (though I developed firm boundaries about what I was willing and unwilling to share), and exploring the theoretical and empirical literature was like hearing, “But you are not alone. This is not only yours to live with and to carry.” That allowed me to continue to have faith that the process of autoethnographic inquiry in general, and my autoethnographic inquiry specifically, had merit and power as a research methodology.

This project was a dramatic departure from my (mostly quantitative) research career to date. It was a stretch for me to allow for and engage in this process as a form of research. It was something I had to re-understand and come to terms with again and again throughout the course of this project. One of the things I realized throughout the process was the power of story. Numbers and statistical analyses are powerful in their own way and are essential to the way we understand the human condition and social life; they give us information that just hearing one voice, or a small handful of voices will never give us. They can answer intricate questions about associations and relationships and causes and effects. Stories, though, are also extremely powerful, and they convey an experience in a way that numbers and statistics never can. I came to learn, to experience, and to acknowledge that power of stories throughout the course of this project. It has been a joy to interact with the work of other autoethnographic researchers as I have engaged in this process myself.

In preparation for an interview once, I read all of the research articles I could get my hands on about a specific intervention. Every single article I read had a unique structure. It started with a rigorous, quantitative evaluation of the impact of this intervention on a variety of important outcomes. Then, in each article, at least one story was included about a specific program participant, illustrating one (or more) of the outcomes demonstrated in the quantitative analyses. The group of researchers investigating this intervention managed to harness the power of numbers and the power of stories. It made a convincing and impactful case for the intervention in a way that either by themselves would not have been able to do.

One of the questions I had to answer for myself early on in this project was how I was going to present my stories. This is research about a vulnerable and often marginalized community of individuals. The exploration of interactions between these individuals and the medical community are filled with power dynamics; issues of race, ethnicity, sexuality, and gender; discrimination based upon body size or socioeconomic status; inequities in access to and the delivery of life-altering or life-saving treatments, services, and supports; and a myriad of other critical issues. I decided not to take on those issues head-on, but rather to allow them to run throughout my stories as they appeared. I did this for several reasons. One is that some of those issues lie outside of the boundaries I set for what I was willing to share in this very public project. The second is that I am a person who has a great deal of privilege in this setting. While there are certainly ways in which these dynamics impact my care, they are minimal compared to what many people in oppressed communities (and particularly those with multiple oppressed identities) face. This project was autoethnography; I cannot speak to experiences I have not had. I am well-educated, well-spoken, and I have resources. I know how to push back against the system when it seems to be limiting my access or giving me care that is inappropriate or not enough. I have learned how to navigate around gatekeepers in the medical community. I have my insurance customer service number programmed into my phone, and I know more than one of the representatives by name. All of this is both a result of privilege (along with effort) and a cause of greater access to better healthcare.

With all of that said, there are still significant power dynamics that are evident throughout my stories. I have decided, though, to let those dynamics speak for themselves. I have focused on the impact those dynamics (and the actions of those in power) have had on me as an individual. I have focused on the ways in which these interpersonal relationships with medical providers have affected my intrapersonal relationships (with myself, my illness, my body, and my experience). Those effects are real and tangible. Also, those effects are just the tip of the iceberg (so to speak) for people living with life-altering illnesses and injuries who are marginalized and oppressed for other reasons.

Implications/Take-Aways

The implications of autoethnographic research are not necessarily the same as the implications of other research. In my experience, autoethnographic research seems to produce more questions than it answers (and, indeed, that is one of the reasons it is so powerful). The exploration of implications here is really a review of what I hope the impact of this project will be.

For Qualitative Researchers.

This project demonstrates the power of deeply told stories. Qualitative research exists on the foundation of the stories of people's lives; and yet, so often, it is distilled into a recitation of themes and subthemes with some pithy quotes from participants. Often, this is helpful and necessary, but there is so much more qualitative research can do. I am walking away from this project with a profound appreciation for thick descriptions in conveying lived experience.

This project also centers around the knowledge that people experiencing life-altering illness and injuries experience injury to their existential natures; the possibilities for their lives are limited and constrained by the life-altering illnesses and injuries. Qualitative research regarding life-altering illness and injury is uniquely situated with the ability to be healing for participants who take part in the research. When people experiencing life-altering illness and injuries are able to tell their stories, to truly be seen and heard, and to allow their stories to contribute to research knowledge and to refining the practice of medicine, they can experience existential healing in a way not available otherwise. Bringing that perspective to research in this area will allow the research to have significant depth and will enhance the power of the research.

For Quantitative Researchers.

Numbers have power. Never forget, though, the stories that the numbers represent. Medical research is about bodies and physiology and biology and the interventions we use when things go awry. There is another aspect of illness and injury, though, namely the illness-as-lived. This includes the ways in which the illness or injury impact the individual's life, well-being, existential nature, and possibilities. When considering outcomes in medical literature, I would challenge quantitative researchers to consider ways to incorporate illness-as-lived and existential injury/well-being as a central outcome. I would encourage quantitative researchers to find ways to measure and examine healing of existential injuries in addition to physical treatment outcomes. This type of healing is always important to consider, regardless of the topic of study at hand. If a treatment increases physical well-being but also increases existential injury, that is important information. If, on the other hand, a treatment does not impact physical well-being but demonstrates existential healing properties, that is also important information. One is not necessarily better or more important than the other, but it is important not to ignore one in favor of hyper-focus on the others.

For Physicians.

Taking a time to really listen to a patient's story, to ask them what is most concerning to them, is time never wasted. This will almost always influence your diagnostic and treatment decisions. Even if it does not, the very act of listening and attending to concerns can be healing. People experiencing illness and injury need healing beyond just the physical. They need help learning how to live into the future, even if (and especially when) that future is unknown or uncertain. Patient interactions with you influence their experience of themselves, their illnesses and injuries, their bodies, and their possibilities. You can help patients live into hope even in the most difficult situations. You can help patients learn to trust their own experience, to live in the bodies they have. And this, then, influences patient well-being on every level.

For Medical Educators.

There have been movements in medical education toward including teaching medical students the "soft skills" of learning to relate well with patients, to build rapport that establishes positive relationships. That is a positive movement. It could be taken one step further, though. Teach students about the parallel realities of illness-as-disease and illness-as-lived. Introduce students to the idea of existential injury in the midst of life-altering illness and injury. Teach students about their opportunity to be healers in addition to their work as doctors. This could be accomplished in many ways, but one of the easiest is to integrate patient stories into training. Allow patients to tell students their stories or expose students to memoirs or other books written by patients or written to include patient stories. Constantly bring forth the ideas of centering patient personhood, fostering patient hope, and working collaboratively with patients. Help students learn how to educate patients in order to empower them to be active members of their care in order to balance out the power differential inherent in the patient-provider relationship.

For Healthcare Systems.

There are a million factors that go into the structure and the policies in healthcare systems. Patient experience is immensely important. Having systems and processes that enhance and empower patient ability to make choices about their care and changes to their care team when they feel it is needed is absolutely essential. These can be things like patient feedback forms that are immediately followed up on or patient advisory councils on which patients can share their stories with decision-makers so that patient stories inform policy and procedure. It would also be immensely helpful for patients to have an easy, or at least a low-barrier, way to find a doctor who will potentially be a good fit for what they need most from their providers. I can't tell you how many hours I have spent over the years pouring over provider profiles. When half of the profiles are empty, it becomes and extraordinarily frustrating experience. Connecting patients with the providers that will be best able to help them, rather than connecting them with the first available appointment, allows for more effective and efficient healthcare delivery and reception. These things don't require drastic overhauls to medical systems, but they do require the development, testing, and continual improvement of tools that help patients be active participants in their own care.

For Patients.

Dear patients experiencing life-altering illness and injuries, you are not alone. Your experience is real. The way in which you feel like your illnesses and injuries are stealing your lives are also real. Your lived experience matters. Furthermore, your relationships with your doctors and other providers matter, and you have the ability and the right to demand a team that listens to you, remembers you, and pays attention to your personhood. It is hard when you are dealing with illness and injury that takes up a great deal of time and effort and energy in and of itself to fight for the medical care you deserve. I am here to tell you, though, that it is worth it. It is a valuable thing, to fight for yourself, to find the medical team who puts your personhood at the center of all they do.

There are many reasons this is true. When you find a team who keeps you at the center, they will listen to you and hear you. This has the power to change the course of your treatment and your outcomes. This type of team will teach you what you need to know to understand yourself and your illness or injury so that you can be an active participant in your own care. Beyond helping you feel a sense of agency and power in a situation that is often characterized by helplessness, it also enables you to advocate for yourself and what you think or know to be best. Often it is difficult, especially early on, to feel confident in your intuitions as a patient. When you have a team that keeps your personhood at the center, they can help you build that intuition and build your trust in it. This makes all the difference in the experience of living with life-altering illness and injury.

Limitations

This type of research doesn't have limitations in the way most research does. Limitations generally speak to the ways in which results of research cannot be generalized to certain populations. Generalization, however, is not the goal of this research. It is meant to give one unique perspective. By grounding the autoethnography in memoir analysis and existing empirical and theoretical literature, there is some ability to generalize, but it is still limited. What is clear is that the high-level themes and the feelings inherent throughout my stories seem to be universal while the specifics of the stories shared are highly individual. Existential injuries in the midst of life-altering illness and injury, the possibility for doctors to become doctor-healers, the importance of centering patient personhood, the essential nature of collaboration, and the need for cultivating hope in the midst of life-altering illness and injury are all universal or nearly universal aspects of the reality of living with a life-altering illness or injury. How those things show up, what is needed to help cultivate these things, how to enhance the qualities of the provider-patient relationship that help the most, those are all more individual. They will look different for each provider and each patient, and indeed for each provider-patient relationship. This project has only captured those specifics for one patient in a variety of provider-patient relationships.

Future Directions

It seems as though each section of this dissertation could generate a lifetime of quantitative and qualitative research questions. There are so many questions about how these dynamics work and show up generally, across patients and providers. There are questions about cause and effect, and how provider-patient relationships influence the patients experience of themselves, their bodies, and their illnesses and injuries. There are further questions about how the patient experience of themselves, their bodies, and their illnesses and injuries influence the provider-patient relationship. There is almost certainly a bi-directional relationship that would need much more investigation and exploration to understand.

There are also many questions about how these things influence disease progression, treatment plan adherence, and physical and non-physical outcomes for patients. How does the patient-provider relationship influence those things? Are there other factors that are equally as important that might influence both the provider-patient relationship and the outcomes? There is more work to be done around understanding hope, patient agency and playing an active role in their care, and the importance of collaborative patient-provider relationships. There is so much investigation warranted into the mechanisms through which these things matter as much as they seem to matter. All of these explorations need to be investigated using quantitative and qualitative methods. There is so much more to be learned.

Conclusion

The exploration throughout this project has given an in-depth understanding of the importance of story as well as the experience of living with life-altering illness and injury. It has highlighted the experience of existential injury and the power physicians have to be doctor-healers when they address those existential injuries. It has demonstrated how doctor-healers do this work through centering patient personhood, fostering hope (especially in the midst of unknown or uncertain futures), and building collaborative relationships. It has also demonstrated some of the impacts when physicians are just doctors and do not engage with patients as healers. What is abundantly clear is that the provider-patient relationship dramatically influences the patient experience of themselves, their experiences, their lives, their bodies, and their illnesses and injuries.

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Appendix A: Memoir Analysis

The Influence of Provider-Patient Relationships on Patients' Experience of Themselves, Their Illnesses, and Their Injuries

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Abstract

Provider-patient relationships are a key component of the diagnosis and treatment of injuries and illnesses. This is well-known throughout quantitative and qualitative research. These relationships, however, can also influence the way patients' experience themselves, their bodies, their injuries or illnesses, and their lives. This is discussed less often in the literature. There is, however, a rich history in the philosophy of medicine exploring illness-as-disease versus illness-as-lived, which can inform discussions of how provider-patient relationships contribute uniquely to each. Based upon that philosophical foundation, this article presents in-depth analysis of five popular memoirs about living with life-altering illness or injury. Results explore the realities of existential injuries in the midst of life-altering illnesses and injuries as well as the ideas of how medical providers provide treatment versus how medical providers facilitate healing for patients (even in the midst of untreatable and/or uncurable injuries and illnesses).

Keywords: provider-patient relationships; patient experience; healing; existential injury; illness-as-lived

The Influence of Provider-Patient Relationships on Patients' Experience of Themselves, Their Illnesses, and Their Injuries

Provider-patient relationships matter. They significantly impact disease symptoms, patient adherence to treatment protocols, incidences of medical error, and physician burnout rates (Haverfield et al., 2020). There is a rich history in medical philosophy exploring the phenomenon of the physician-patient relationship specifically and the different factors that underlie the relationship. The philosophical literature in this area posits that physicians and patients live in separate (but overlapping) worlds, and that the differences between those worlds contributes to a chasm between how each perceives, experiences, and relates to illness and injury (Pârvan, 2016; Toombs, 1987).

One of the simplest ways to understand this disconnect is through consideration of physician and patient goals for the physician-patient relationship. The physician focuses on illness-as-disease, seeking diagnosis, prognosis, and treatment, while the patient focuses on illness-as-lived, seeking explanation, prediction, and cure (Toombs, 1987). These differing goals can contribute to situations in which physician-patient communication is compromised and frustration runs high, both for physician and patient.

In the midst of this reality, there is a significant need for physicians to be able to accurately understand what a patient is experiencing, in order to understand how a disease is unfolding over time (Rudebeck, 2000). This requires that the physician pay attention to and really attempt to understand the illness-as-lived, which gives access to a shared narrative of the illness, a narrative that contains both a "text" (the sickness) and a "context" (the culture in which the patient experiences the sickness, Coulehan, 1991).

There is a growing body of qualitative research that is seeking to understand the physician-patient relationship and how it is influenced by differences between illness-as-disease and illness-as-lived. Qualitative studies have contributed toward the development conceptual definition of trust in the context of the patient-provider relationship: "*Promoting trust* is a provider demonstration of interpersonal and technical competence, moral comportment, and vigilance to support positive patient outcomes" (Murray & Mccrone, 2015, p. 16). The qualitative literature also gives a sense of some of the elements that contribute to the quality of the patient-provider relationship, such as interpersonal skills, offering competent care, partnering with the patient, knowing and respecting the patient, effort, and continuity and time (Murray & Mccrone, 2015).

There is a movement within medicine in response to this type of exploration and thinking known as "narrative medicine," which calls for the physician to not only work to truly understand the patient's narrative, that is, how the patient is experiencing the illness-as-lived, but also to walk alongside the patient as that narrative continues to unfold (Zaharias, 2018). In this movement, it is recognized that the very act of a patient being able to tell their story and have it heard and understood can be healing in and of itself (Charon, 2001).

The focus on patient story within the field of narrative medicine provides foundation for the current study. This study utilizes patient story (in the form of published memoirs of living with life-altering illness and injury) to explore and better understand the association between interpersonal relationships with medical providers and intrapersonal relationships within the patient. Namely, this study seeks to understand the ways in which interactions and relationships with medical providers influences patients' experience of themselves, their bodies, their injuries or illnesses, and their lives.

Method

This study is grounded in a hermeneutic phenomenology framework, intending to convey a lived experience. These analyses intend to convey how people (namely, the authors of analyzed memoirs) made sense of their experiences of being in relationship with medical professionals and of living with life-altering illnesses and injuries. There is, as such, a focus on the way the authors interpreted their relationships with medical providers rather than on the actual events as they unfolded. Though this is generally the case when utilizing qualitative methods that ask people to report about their experiences, it is especially true when working with memoirs as data sources. Memoirs are works that have been deliberately formed to convey a storyline in a compelling way. Memory is always reconstructive, and the act of telling (or writing) stories of our lives and what we have experienced is necessarily active, creative, and generative acts (Freeman, 1993). This potential gap between what the authors actually experienced and what they reported in their memoirs, however, is not a problem for these analyses. The aim of this study is to give a rich description of what it can mean, look like, and feel like to be a patient living with life-altering illnesses and injuries in relationship with medical professionals. As such, the way people interpret and remember those relationships are of the utmost importance.

Hermeneutic phenomenology does not have specific research methods per se. However, there are a set of activities in which hermeneutic phenomenological researchers engage, namely:

1. Turning to a phenomenon with seriously interests us and commits us to the world,
2. Investigating experience as we live it rather than as we conceptualize it,
3. Reflecting on the essential themes which characterize the phenomenon,
4. Describing the phenomenon through the art of writing and rewriting,
5. Maintaining a strong and oriented pedagogical relationship to the phenomenon, and
6. Balancing the research context by considering parts and whole.

These activities and the general ideas that underlie them have guided the specific decisions I made throughout this project as well as the actions I took along the way as I moved from the memoirs through analysis and to writing this article.

Data Sources

Data for these analyses came from five popular, published memoirs. I chose these five memoirs for two main reasons: (1) they are reasonably well-known and popular, indicating that they speak to something that tends to resonate with people generally (and are, therefore, likely reflective of broader social experiences) and (2) they discuss the ways in which there is a dynamic interplay between interpersonal relationships (with medical providers, friends, families) and intrapersonal relationships (with themselves, their experience, their bodies, their lives, and their injuries or illnesses). Memoirs that were considered but not included in analyses tended to focus on overcoming life-altering illness or injury. These memoirs often did not include much discussion regarding interactions or relationships with medical professionals; therefore, it was unlikely that they would contribute significantly to the topic at hand.

The five memoirs included in this study are:

1. When Breath Becomes Air by Paul Kalanithi (2016). Paul Kalanithi was diagnosed with terminal lung cancer at the age of 36 just as he was finishing his residency and training as a neurosurgeon neuroscientist. He wrote the book between his diagnosis and his death in March 2015.

2. It’s Not Yet Dark by Simon Fitzmaurice (2017). At the age of 35, Simon Fitzmaurice, a filmmaker, was diagnosed with Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s disease). He published this book in 2014, six years after his initial diagnosis at which point doctors had told him he would likely die within four years.

3. Waking: A Memoir of Trauma and Transcendence by Matthew Sanford (2006). Matthew Sanford was in a car accident with his family when he was 13 years old. His father and sister were killed, and he was left paralyzed from the chest down. This book is about his experience in the aftermath of that tragedy, including an exploration of his eventual adoption of a yoga practice starting at age 25.

4. We Know How This Ends: Living while Dying by Bruce Kramer and Cathy Wurzer (2015). Similar to Fitzmaurice, Bruce Kramer was diagnosed with ALS, though he was in his 50s when he received the diagnosis. He cowrote this book with Cathy Wurzer, who engaged in public conversations with Kramer (via public radio) about his ALS for the last four years of his life. This book also chronicles Wurzer’s journey alongside her father during and after his diagnosis of Alzheimer’s Disease.

5. The Bright Hour: A Memoir of Living and Dying by Nina Riggs (2017). Nina Riggs was a poet who was diagnosed with metastatic breast cancer at 37 years old. This book was published the year she died, just a month shy of 40 years old.

Data Analysis

Given the nature of hermeneutic phenomenological methods, data collection and analysis cannot truly be separated out. They are two sides of the same activity; in this framework, the analytic exercise of the researcher is in writing a description of the phenomenon at hand. This writing evolves over time, but it has to be happening at all times. Therefore, I began writing during data collection, and continued writing throughout the entire process of developing this dissertation.

The raw data for this study was immense and unwieldy as it stands naturally. As such, I used a process to identify the passages that included the most information relevant to the current study. For each data source, I first read through and indicated passages that dealt with the following themes:

1. Interpersonal relationships with medical providers
2. Intrapersonal relationships (e.g., mind-body, person-experience, evolution of self)
3. Epiphanies/realization of general or universal truths
4. The experience, development, and evolution of hope

I arrived upon this list of themes through an iterative process. I began initially by indicating passages that fell into the first two themes: (1) interpersonal relationships with medical providers and (2) intrapersonal relationships. As I started with two memoirs with these two themes, I realized that there were many times when the authors wrote about realizations they had that applied not only to themselves and their situations, but to life as a whole. These realizations were a very specific type of intrapersonal relationship or experience. In hermeneutic phenomenological research, epiphanies play a particular role because they can be seen as moments of peak understanding or turning points that give a significant amount of information about what life is like for the person having the epiphany. As such, I felt those statements needed to be considered separately from the other intrapersonal relationships/experiences. I also began to indicate passages about hope for a similar reason. As I was coding interpersonal and intrapersonal relationships, I found passages about hope to be difficult to categorize, as these passages were often a combination of interpersonal and intrapersonal relationships as well as a combination of actions, understandings, and emotions. There was no clear way to fit them into any of the categories I had at the time. As such, I added the fourth category to indicate passages dealing with hope. Once I had my four categories, I went back to the beginning of the memoirs to make sure I was indicating passages that dealt with all four themes.

Utilizing the process of hermeneutic phenomenology, as I denoted these passages, I began writing descriptions of the overall phenomenon I am studying (i.e., what it is to be a patient in relationship with medical providers) as well as the most salient components or aspects of that experience that were emerging. For example, when indicating passages that deal with the experience, development, and evolution of hope, I wrote things such as:

- "A type of hope—working for the promise of what will be earned?"
- "Acceptance leading to connection leading to hope (contrasted to the disconnection of avoidance)—acceptance might not be the best word here, but I'll use it as a placeholder."
- "There seems to be an emerging connection between meaning and hope."
- "Hope as standing between night and day and experiencing it as 'sublime.'"
- "Hope as presence living in the moment, whatever the moment is."

- “Hope as an active relationship with what is.”
- “Hope as bearing witness.”

In addition to these short writings in the margins, I also developed more thorough descriptions of what is unfolding. One example: “Hope in the midst of illness seems a paradox. There is an embrace of life as it is even as the life you once knew is slipping away. You are experiencing substantial loss, sometimes of things you didn’t even know you could lose. And yet, hope seems like finding a way to stand steadfastly in the midst of all of that.”

Once I finished denoting the aforementioned themes and writing about them as I went, I looked at what I wrote during that time while asking myself, “What is it that constitutes the nature of this lived experience?” (Van Manen, 1990, p. 32). This is the central question to a hermeneutic phenomenological inquiry. From there, I used what I learned about the nature of the lived experience as a foundation for developing themes that could be used to structure writing to convey the lived experience.

Positionality

The person I am and how I exist in the word deeply influences this research; as such, it is important to call out at least some of the ways in which that occurs. First, philosophically, I am approaching this research from the ontological assumption that human living is a constant act of interpretation, and, as such, there is no static truth to a situation, but only the meaning that is being made at a particular point in time. Second, I am a person who lives with multiple chronic illnesses that are associated with a significant number of acute injuries over the course of my life. Within that experience, I am also a significantly educated white person who has always had access to medical care when I have needed it. I worked for over ten years to get a diagnosis for my main chronic illness, and during that time gained a great number of skills for how to navigate and negotiate the healthcare and health insurance systems. Those skills, combined with access to very good insurance coverage and patient assistance programs has allowed me continual access to medical care within my means. My experience is, unfortunately, all to uncommon today, particularly in the United States. Many people do not have access to care at all, much less the care they need the most. In a healthcare system that is challenged on many levels, I am an anomaly. However, this also means that I have substantial experience through which to understand and interpret what the memoirists are discussing and sharing through their stories. I have not tried to set aside my experience as a patient in the course of this research. Rather, I have used it as a strength that puts me in a unique position to be able to convey the lived experience portrayed in the five memoirs I analyzed.

Reflexivity

Given my significant personal relationship to the topic at hand, I continually kept track of my personal reactions to what I was reading and writing and the personal interactions I had with medical professionals as the project was unfolding. I particularly paid attention to the ways in which my experience influenced my interpretations of the memoirs, space where my experience confirmed what I was already conceptualizing from the memoir analysis, and space where my experience felt different than what I was finding through the memoir analysis. All of those things were taken as information while I worked on answering that main hermeneutic phenomenological question of, “What is it that constitutes the nature of this lived experience?” (Van Manen, 1990, p. 32).

Results

The process of interacting with the memoirs through analysis resulted in six main elements of what it means to live as a person with life-altering illness and injury in relationship with medical providers: (1) existential injuries in life-altering illness and injury, (2) doctors versus doctor-healers, (3) centering patient personhood, (4) fostering hope, (5) instilling patient trust in their experience, and (6) collaborating.

Existential Injury

These memoirs echo what has been long discussed in medical philosophy. Injury and illness have effects that are not limited to the body or even the body and the mind. Injury and illness also come with what has been called existential injury. Existential injury refers to the ways in which illness and injury influence the patient's ability to exist, their ability to be. This is also a substantial change to the person's perception of their own existence and being, captured in when Riggs (2017) tells of a time after her initial breast cancer diagnosis, saying, "I lie on my back in bed, imagining a sick person. *What do sick people think about? How do you know when you start to be a sick person?*"(p. 14). This captures the ways in which being a "healthy person" and being a "sick person" are experienced as completely different realities and completely different ways of being.

One philosopher discusses this experience of existential injury as a "narrowing of existential amplitude" (del Giglio, 2020). This philosopher points out how illness and injury limit what is possible for someone's life and for their ability to exist in the world. Their possibilities of being become smaller. This existential narrowing exists on many levels: the practical ways in which patients experiencing illness and injury can be in the world are limited, but so are their emotional, psychological, and spiritual possibilities (especially early on in and without support). This is reflected in a passage that captures a conversation between Kalanithi (2016) and his oncologist, Emma:

> At our first of several biweekly appointments, Emma's and my discussion tended from the medical ('How's the rash?') to the more existential. The traditional cancer narrative—that one ought to recede, spend time with family, and settle one's toes in the peat—was one option.
>
> "Many people, once diagnosed, quit work entirely," she said. "Others focus on it heavily. Either way is okay."
>
> "I had mapped out this whole forty-year career for myself—the first twenty as a surgeon-scientist, and the last twenty as a writer. But now that I am likely well into my last twenty years, I don't know which career I should be pursuing."
>
> "Well, I can't tell you that," she said. "I can only say that you can get back to surgery if you want, but you have to figure out what's most important to you."
>
> "If I had some sense of how much time I have left, it'd be easier. If I had two years, I'd write. If I had ten, I'd get back to surgery and science."
>
> "You know I can't give you a number."
>
> Yes, I knew. It was up to me, to quote her oft-repeated refrain, to find my values. (pp. 136-137)

Suddenly, with the arrival of a diagnosis with a specific prognosis out of reach, everything Kalanithi had planned and was working for was upended, and he needed to figure out what that meant for his ability to exist in the world and what, exactly, that now meant.

Not only is this true in a philosophical and metaphysical sense, but there is also a very real way in which illness and injury impact a patient's day-to-day life. They are now managing a variety of appointments: with physicians, therapists, diagnostic imaging, procedures, laboratory testing, and the like. A significant amount of their time is taken up simply through the practical aspects of managing their illness and injury. Riggs (2017) comments on one such day, overtaken by waiting and appointments, stating, "The rest of the day: scans, waiting, talking to pharmacists, more waiting, and meeting the rest of the team—the radiation oncologist, the surgeon. The surgeon makes me smile when he makes a Freudian slip while referring to the choice between lumpectomy and mastectomy as being 'my incision' instead of 'my decision'" (p. 20). When you add all of these practical considerations to the reduced energy and wherewithal patients dealing with life-altering illnesses and injuries have, what used to be normal daily activities become things that need to be carefully scheduled and monitored and constantly evaluated and modified because of the illness or injury. The cascading effects of illness and injury on a person's ability to be in their lives, to exist in the world, cannot be understated.

Doctors versus Doctor-Healers

There is an opportunity within the medical profession to attend to these existential injuries in addition to attending to the physiological disease or injury. A simple way to differentiate this work from the other work of physicians is to talk about doctors (who treat biological and physiological disease, which is absolutely essential) and doctor-healers (who do the additional work of including existential injury in the discussion and addressing it to the extent possible). In medical philosophy, there are calls to do this work through including attention to the patient's suffering while gathering information about the physical symptoms and medical tests (del Giglio, 2020), to view the disease not as something separate from the patient, but as something in relationship with the patient (Pârvan, 2016), and to cultivate deep empathy for the patient by centering patient meaning-making (Coulehan, 1991; Rudebeck, 2000). Many of these processes can be summed up in making a concerted effort to understand what is wrong from the patient's perspectives, including how the problems influence the patient's life and overall well-being (Toombs, 1987).

Kramer (2015) writes about the tension inherent in being a person working with doctors who pay no attention to healing, saying:

> The greatest challenge of this experience has always been to remain whole, in spite of the systems that medicine imposes, reducing me to a series of measurements and symptoms that are indicative of diseases' control and prognosis in an unending and inevitable religious celebration of the power of science. (p. 119)

In this passage, Kramer is speaking to the way that the medical establishment often not only overlooks existential injury, but actually exacerbates it when attention is not paid to the ability of doctors to be doctor-healers. Kalanithi (2016) writes directly to the possibility of the medical establishment including consideration of existential injury: "During my next visit with Emma, we talked about life and where it was taking me... The scientific questions were settled for now, allowing the existential ones full play, yet both were the doctor's purview" (p. 157).

In the memoirs, there were many examples of doctors doing this work of being doctor-healers. Fitzmaurice (2017) shares about an interaction with a physician as he is leaving a long hospitalization stint:

> A consultant anaesthetist [sic], Silvio Gligor, whom I have got to know over the long days here, comes into the room. He wants to say goodbye as I am going home in two days' time. He stands there, wrestling with his emotions, clearly wanting to say something of meaning to me, not just platitudes and farewells. The silence hangs about him as he tries to work out what it is. It is an emotional moment, rarely found between two men. When he does finally speak, this is what he says: Go home and teach your children many things. (p. 91)

This is a moment in which a physician is engaging in the work of facilitating patient meaning making. It is particularly compelling because to this point, this particular consultant had suggested to Fitzmaurice that it was time for him to stop fighting and to die. As the consultant watched this patient, whom he had counseled to die, prepare to go home to his children, he begins to connect to the existential aspects of Fitzmaurice's experiences.

Kalanithi (2016), with his unique perspective from both the physician side and the patient side of the relationship offers several reflections on the possibility of doctor-healers, two of which are particularly powerful. In the first, he is writing about a physician he worked with and observed during his medical training:

> I listened in quiet awe as a pediatric neurosurgeon sat down with the parents of a child with a large brain tumor who had come in that night complaining of headaches. He not only delivered the clinical facts but addressed the human facts

> as well, acknowledging the tragedy of the situation and providing guidance. (p. 69)

In the second, he reflects on how his experience witnessing these types of interactions influenced his personal development as a physician. The idea of being a doctor-healer infiltrated all he did, including, even, the process of informed consent:

> With my renewed focus, informed consent—the ritual by which a patient signs a piece of paper, authorizing surgery—became not a juridical exercise in naming all the risks as quickly as possible, like the voiceover in an ad for a new pharmaceutical, but an opportunity to forge a covenant with a suffering compatriot: Here we are together, and here are the ways through—I promise to guide you, as best I can, to the other side. (p. 88)

In the memoirs, there were clear behaviors and attitudes that doctor-healers embodied, particularly when compared to doctors who did not act as healers. These included the remaining identified themes: (1) centering patient personhood, (2) fostering hope, (3) instilling patient trust in their experience, and (4) collaborating. It is important to note that these four themes are not independent of one another. In fact, they build upon and influence one another. As such, all are essential elements of provider-patient relationships in which healing can occur.

Centering Patient Personhood

Centering patient personhood was an absolutely essential element of a physician-patient relationship characterized by healing, as the quotes above begin to suggest. Depersonalization or dehumanization of patients is an all-too-common occurrence in medical settings, and it negatively impacts the well-being of physicians and patients alike

(Dyrbye et al., 2017). Kalanithi (2016) describes his stark experience of this when he is admitted to the same hospital in which he was a practicing neurosurgical resident:

> I received the plastic arm bracelet all patients wear, put on the familiar light blue hospital gown, walked past the nurses I knew by name, and I was check into a room—the same room where I had seen hundreds of patients over the years. In this room, I had sat with patients and explained terminal diagnoses and complex operations; in this room, I had congratulated patients on being cured of a disease and seen their happiness at being returned to their lives; in this room, I had pronounced patients dead. I had sat in the chairs, washed my hands in the sink, scrawled instructions on the marker board, changed the calendar. I had even, in moments of utter exhaustion, longed to lie down in this bed and sleep. Now I lay there, wide awake.
>
> A young nurse, one I hadn't met, poked her head in.
>
> "The doctor will be in soon."
>
> And with that, the future I had imagined, the one just about to be realized, the culmination of decades of striving, evaporated. (p. 16)

Kramer (2015) also describes what this experience was like for him:

> Early November, I finally contacted the neurological practice to which I had been referred a few months earlier. A week later, on a Friday afternoon, I was in the neurologist's office for more than two hours. He wouldn't look at me, but he pushed and pulled and hammered and scratched. (p.3)

Both of these passages speak to behaviors and processes ubiquitous in medical settings that contribute to the denial of patient personhood.

Fitzmaurice (2017), however, offers an exploration of the impact of centering patient personhood rather than patient disease:

> Last week I bit the bullet and admitted myself into the hospital for the first time since I left in March of last year.
>
> It was St. Vincent's Hospital in Dublin, and the week I spent there changed my mind about consultants. The warm, sincere individuals I encountered treated me with the dignity of being a person, not a disease. (p.110)

He points in this passage to the “dignity” afforded to him through physicians who treated him like a fellow human being. For him, this influences not only his experience in the hospital, but also his trust in the medical establishment. This attention to his personhood actually begins to increase and restore trust between him, as a patient, and his physicians.

Kramer (2015) explains how this attention to patient personhood (or lack thereof) is particularly influential in the delivery of a life-altering (or, in his case, terminal) diagnosis:

> He vaguely shows me where to sit, dismissing Ev to a far corner. He takes his places so that a huge, dark wooden desk separates us. He faces north, focusing his gaze on a computer screen. My chair faces south, not toward him but toward windows that never open. I have to crane my neck in order to see him. The details of the space begin to blur. I have lost track of Ev in the vastness of this space. (p.5)

He actually goes on to explain that three years after that event, he was able to recognize that he had a post-traumatic stress response to the diagnosis, and, for him, it had far more to do with how the diagnosis was delivered rather than the diagnosis itself. When he realized this, Kramer actually returned to the diagnosing neurologist, to confront him about the way he delivered the ALS diagnosis:

> I met with him to make the case in every way I knew for a more humane, a more sensitive, a more holy and human act than what I had experienced. I met with him to say what I regretted not saying: that how one reads the script might be more important than the script. I met with him to help him see that great privilege, granted in a life-changing moment, requires far more creativity and imagination than is available in a strict reading of a perceived protocol. (p. 63)

Here, Kramer shares his perception of the relationship between patient and physician as a sacred space in which healing can occur even when cure is not possible. It is essential to note, as well, that this neurologist was in Kramer's life for a very short time. He assessed Kramer's condition and delivered the diagnosis and then referred Kramer on to other specialists. The power of this relationship, despite its brevity is clear, as is the opportunity contained within.

Fostering Hope

The importance of hope was abundantly clear in these memoirs, as was the role physicians can play in fostering the development and maintenance of hope. The type of hope addressed in the memoirs aligns most closely with oncologist Dr. Jerome Groopman's (2004) definition of hope: "Hope is the elevating feeling we experience when we see—in the mind's eye—a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path" (p. xiv).

Kalanithi (2016) describes witnessing the aforementioned pediatric neurosurgeon assisting a family of a child with a brain tumor in cultivating this type of hope:

> He went on to describe the planned operation, the likely outcome and possibilities, what decisions needed to be made now, what decisions they should start thinking about but didn't need to decide on immediately, and what sorts of decisions they should not worry about at all yet. By the end of the conversation, the family was not at ease, but they seemed able to face the future. I had watched the parents' faced—at first wan, dull, almost otherworldly—sharpen and focus. (p. 70)

Riggs (2017) describes the development of this type of hope, rooted in a firm acknowledgement and thorough understanding of the reality of a situation as a shift in perception, "Not the world ending, but the ground shifting" (p. 68). In this shift in perception, the ground shifting becomes something that she and her husband can respond to versus the impossibility that was inherent in the world ending. That is the type of hope physicians can assist patients in developing.

Hope in these memoirs also included learning to live within the difficult and often uncertain reality. Fitzmaurice (2017) writes about this in two passages, one in which hope shows up as finding ways to live life despite limitations and the other in which hope shows up as expanded possibility for existing and acting in the world:

> I am in the hospital over Christmas. During a snowstorm that stopped Ireland. I have got to know all the nurses. One girl, Bridget, from Cork, is pure heart. She walks across the road to the pub, buys a pint of Guinness and carries it back without spilling a drop. It's New Year's Eve, I think. I'm not sure. I'm on a lot of morphine. I manage a few sips of the Guinness. Another morning she comes into

> my room with a lunchbox full of freshly fallen snow. Gently, she lives my hand into the cool iciness. (p.85)
>
> and
>
> An inspirational occupational therapist, Sarah Boyle, organizes [sic] for a rep from a computer company, Nick Ward, to fly over from England to demonstrate an eye-gaze computer with me. It is extraordinary. A revelation to me. Freedom. My hands back, with the movement of my eyes. (p.94)

This type of hope, in all five memoirs, is about learning to live in the midst of life-altering illnesses and injuries or, in many cases, continuing to live even while dying.

Instilling Patient Trust in Their Experience

There were many examples in the memoirs of physicians or other medical providers not believing the patient's experience, and, in turn, instilling doubt within the patient regarding their own experience. Sanford (2006) describes an experience of this. When Sanford left the hospital after the accident in which he severed his spinal cord, he went to a rehabilitation facility. One day, while there, he found that he could move his left foot despite his paralysis, and that this movement was not just random spasticity, but he seemed to actually have control over it. Physical therapist (PT) after PT examined him, asking him to move his foot, perplexed when he could do so. They were concerned that something random was happening, and that Matthew would start to have false hope that he would be able to move, feel, or even walk again. They thought that this false hope was dangerous, so they were trying to find a way to squash it before it took hold. Finally, a PT student saw that he was using his neck and his lats at the same time he was "moving his foot." They decided he was cheating, that the ability to move wasn't really real because he was using his upper body to make the movement. He didn't do it their way, so it wasn't considered real. He describes his response to this interaction, “I feel humiliated, silly that I even attempted to move my foot. I remember my forgotten phantom feelings. Once again, I feel oddly ashamed” (p.106). He shares how this felt as if it forced him to reject a significant portion of his experience of his body, which made him feel as if he was moving forward “with a body that is barely mine” (p. 107).

The ability to trust in one’s experience leads to greater attunement between the patient and their body, which can diminish a mind-body split that often occurs with life-altering illness and injury (Wilde, 2003). None of these memoirs had compelling examples of how medical providers bolstered patient trust in their own experience, but similar to Sanford, they all contained exploration of circumstances in which the opposite happened and its aftermath.

Collaborating

Collaboration came out as an important element of physician-patient relationships that contributed to healing. Kalanithi (2016) describes what this type of collaboration looks like from the physician side of the relationship, saying “Openness to human relationality does not mean revealing grand truths from the apse; it means meeting patients where they are, in the narthex or nave, and bringing them as far as you can” (p.96). These collaborative relationships are ones in which the personhood of the physician and the personhood of the patient are both in the room. In these circumstances, collaboration assists patients in their process of making meaning within their shifting life. Sanford (2006) describes one way such a thing happens:

> Dr. McMeken does something else for me, though. He gives me wonderful stories about Australia... Do I know what the life ahead of me will be much the same, that going forward I will journey into a strange territory? Not exactly; I am only thirteen. But Dr. McMeken performs an essential healing task. He relights my imagination. (p. 52)

For Sanford, the igniting of his imagination represents the beginning of learning to live with his new reality and his altered body. Kalanithi (2016) reports a similar effect of collaboration with his oncologist:

> I thought about what Emma had told me. I had gone from being unable to believe I could be a surgeon to being one, a transformation that carried the force of religious conversion. She had always kept this part of my identity in mind, even when I couldn't. She had done what I had challenged myself to do as a doctor years earlier: accepted mortal responsibility for my soul and returned me to a point where I could return to myself... Emma hadn't given me back my old identity. She'd protected my ability to forge a new one. (p. 165)

For him, too, collaboration results in being able to move forward into his future.

Collaboration, as stated above, is about opening to both the patient’s and the physician’s personhood. This often results in the development of bonds which deepen the relationship. This can enhance the physician’s ability to facilitate existential healing (McWhinney, 2000) while creating a unique balance of power, in which patient power enhances physician power and physician power enhances patient power (Roter, 2000). This is what allows patients living with life-altering illness and injury to feel active in their lives, facilitating hope as described above.

Discussion

Analysis of these five memoirs about living with life-altering illness and injury highlights the presence of existential injury in the experience of these types of illnesses and injuries. Patients in these cases experiencing a narrowing of the possibilities for their lives, and they lose much of their time, energy, and capacity to dealing with their illness or injury. Yet, this analysis also demonstrates that within this reality, physicians (and other medical providers) are uniquely situated to facilitate existential healing in addition to treating diseases. The memoirs showed that this healing occurred when providers center patient personhood, facilitate hope, foster patient trust in their own experience, and collaborate with patients. They also highlighted the consequences when providers do not do those things; namely, the provider-patient relationship tends to exacerbate the existential injuries.

There is evidence in existing literature for these themes, even from the other side of the provider-patient relationship. One physician shared what this development from doctor to doctor-healer was like for him:

> When I started in practice, the thing that gave me joy was the solving of clinical puzzles, the making of good diagnoses, thus impressing my colleagues. As time went on, I found myself preoccupied more and more with the patients I had come to know. It was their joys and sorrows, their suffering and healing, that moved me. Of course, clinical diagnosis and management did not cease to be crucial: simply that a patient's illness or disability became interwoven with a life story. I came to see medicine as more complex, more context-dependent, more poignant, more a reflection of the human condition (McWhinney, 2000, p. 135).

Limitations

While in-depth, this analysis included stories from only five people experiencing life-altering illnesses and injuries. Furthermore, these stories were cultivated to be published and shared with the public, which likely influenced the ways in which the stories were told. These results are not necessarily generalizable, though that is not the goal of this research. From this research, one can only consider the ways in which these dynamics might be present in provider-patient relationships and what might happen if there is an increased focus on existential healing within those relationships. This research also lays foundation for a host of other research questions and possible future studies.

Future Directions

Much of this article focused on physicians and patients. There are two places where this exploration could further be expanded. The first is to consider non-physician providers (some of this is addressed here, but there is significant opportunity to delve deeply into this area). In several of the memoirs, nurses and therapists played central roles in existential healing. The second is to consider caregivers. These memoirs also included discussion of the ways in which physicians and other providers contributed to or alleviated the pain and suffering of the patient’s family. The phenomenon of existential injury and, associated, its healing, in caregivers is an essential area to understand better. This is particularly true as more and more people are becoming caregivers to family members.

This research could also be approached from the opposite direction: what is it like for physicians or other providers when provider-patient relationships are healing? What is it like when healing is not present? Furthermore, exploration of factors that contribute to or inhibit a physician's ability to facilitate healing would allow for an expansion of knowledge regarding these processes.

Relatedly, much more research is needed regarding how to influence the presence of healing in physician-patient relationships. This research could investigate what types of training or support is necessary to allow physicians to develop the capacity to facilitate existential healing. It could also evaluate different approaches to interventions at both the physician and patient levels to determine the ways in which interventions might influence this relationship.

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