NURTURING THE DISEASE - A GLIMPSE FROM THE OUTSIDE LOOKING IN: AN AUTOETHNOGRAPHIC EXPLORATION OF THE NATURE OF NURTURE AND ITS ROLE IN CHRONIC ILLNESS

by

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THESIS

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DEDICATION

I would like to thank my family and friends for supporting me throughout this trying but rewarding journey. I also want to give a special thanks to my husband for continually standing by my side over the last two years and making it possible for me to obtain my dreams.

ABSTRACT

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This autoethnographic illness narrative explores how my environment (nurture) has impacted my physical health and overall wellbeing. Within this thesis I argue that environmental factors play a significant role in the rise of chronic illnesses. My hope is that this study will allow society and healthcare providers to gain a deeper understanding of the connection between illness and trauma as well as the importance of positive patient-provider relationships. This study also demonstrates the importance of establishing a connection within oneself to create self-awareness and emotional healing. Despite this study being one of the most mentally tasking things I have ever willingly chosen to do in my life, I would do it all over again as the growth I have experienced from writing this paper has forever changed my way of thinking.

APPENDIX A

INTRODUCTION

You inherit your environment just as much as your genes. — Johnny Rich, The Human Script

Debates about the impact of nature versus nurture and which of the two has a more significant influence on a person’s health, development, and behavior have gone on for decades among mental health professionals. To date, the consensus on which is more important has not yet been agreed upon. To appreciate the complexity of this debate, it is vital to establish what nature versus nurture actually means. In psychology, nature refers to the intrinsic aspects of a person, such as genetic inheritance and other biological influences (Eagly & Wood, 2013). In contrast, nurture refers to external forces, such as environmental factors that occur after conception like one’s upbringing, life experiences, and culture (Eagly & Wood, 2013). Although this debate has been around since the mid-1800s, many experts currently acknowledge that “nature” and “nurture” interact in complex ways and that both play integral roles in one’s physical and psychological development (Eagly & Wood, 2013). A prime example of this is when psychologist Donald Hebb responded to a journalist who asked for “his opinion on which contributed more to personality, nature or nurture?” Hebb responded, “that this was akin to asking what contributed more to the area of a rectangle, the length or the width” (Meaney, 2006, p. 2). Ultimately evaluating this debate has led me to consider the following research question: How has my own environment (nurture) impacted my physical health and overall wellbeing?

For this reason, this study aims to specifically explore the impact of “nurture” on chronic illness (CI) and its implications on the person living with the illness as well as society. Over the last few decades, there has been a shift in the type of patients[1]— doctors commonly see in their day-to-day work in the U.S. This is reflected by the reduction in acute illnesses (communicable diseases and injury) and the steady rise in the occurrence of CIs (Holman, 2020). CIs are also considered non-communicable diseases and are characterized by prolonged illness. These are usually incurable conditions comprised of psychological complexities, physical impairments, or disabilities originating from societal interpretations of the illness (Joachim & Acorn, 2000). CNDs or CIs include common conditions such as autoimmune diseases, depression, heart disease, irritable bowel disease (IBD), and arthritis as well as many others. According to the Centers for Disease Control and Prevention (CDC) (2022a), in the U.S., around 60% or just under 200 million adults are living with a single chronic condition, which is projected to grow. Additionally, 40% or more are living with two or more CIs (CDC, 2022a). In fact, CI has become so prevalent that the conditions that fall under the umbrella of CIs now contribute to 90% of healthcare spending and are the leading causes of morbidity and mortality in the U.S., thus, making chronic illness an uncontrolled health crisis in America (CDC, 2022b)

The origins of CIs are something that have long been debated. This debate includes the question of which is the more likely the cause: genetics or environmental factors? Irrespective of there being no apparent consensus on the topic, countless studies solely focus on the impacts of

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[1] The term patient is used throughout this thesis despite my distaste for it and the fact that it goes against social work values due to its pathologizing and subservient root meaning. Despite this, the term was used in this thesis due to the target audience for this thesis, including healthcare providers. A population for which the term patient is often considered the only applicable term, as many doctors do not find the term client appropriate.

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genetics, even though research has demonstrated that differences in environments are a major contributing risk factors for CI (Hindorff et al., 2009; Lichtenstein et al., 2000; Maté, 2003; Willett, 2002). This is because environmental factors play a significant role in how genes are expressed, making it less about the origin in the rise in chronic illness and more about their dual role in increasing the prevalence. According to Maté (2003):

> The activities of cells are defined not simply by the genes in their nuclei but by the requirements of the entire organism — and by the interaction of that organism with the environment in which it must survive. Genes are turned on or off by the environment. For this reason, the greatest influences on human development, health and behaviour are those of the nurturing environment. (p. 317)

Despite this fact, according to Rappaport and Smith (2010), “epidemiologists increasingly use genome-wide association studies (GWAS) to investigate diseases, while relying on questionnaires to characterize ‘environmental exposures.” (p.460). For these reasons, in this study, I will specifically explore the impact of “nurture” on CI using the qualitative research methodology of autoethnography to present a personal narrative about my experience with CI. I am uniquely qualified to speak on this topic as, to date, I have undergone seven surgeries, more than fifteen minimally invasive procedures, and have over thirty-five diagnosed medical conditions and still counting (see Appendix A for medical condition list). The overall intent of this thesis is not only to contribute to the growing academic conversation surrounding those living with CI but also to increase the academic and societal understanding of the lived experiences of those with CI.

METHOD

Autoethnography

Autoethnography is a form of qualitative research. As with all qualitative methodologies, the underlying assumption is that reality and truth originate from and are influenced by the interactions between individuals and their social environments (Yilmaz, 2013). According to Denzin and Lincoln (2005), “qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meaning people bring to them” (p. 3). Despite qualitative methodologies contradicting the positivist viewpoint, which postulates that reality is objective and is separate from the researcher, qualitative research has still been recognized as an important method of research (Yilmaz, 2013).

The term autoethnography was first used by Karl Heider in 1975 and utilizes “personal experience (‘auto’) to describe and interpret (‘graphy’) cultural texts, experiences, beliefs, and practices (‘ethno’)” (Adams, 2017, p.1). This research method emerged in response to scholars becoming disturbed by social science’s philosophical, axiological, and epistemological limitations (Ellis & Bochner, 2000). Additionally, there was a growing need to resist colonialist, sterile, authoritative researchers entering a culture and exploiting them only to thoughtlessly write about the culture for personal financial and professional gain while ignoring personal ties to members of the culture (Ellis, 2007; Heider, 1975).

According to Reed-Danahay (1997), autoethnography “has a double [meaning]—referring either to the ethnography of one’s own group or to autobiographical writing that has ethnographic interest” (p. 2). Thus, calling for the researcher to be able to work at the intersection of ethnography and autobiography. Chang (2008) further goes on to suggest that autoethnography “should be ethnographic in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation" (p. 48). Furthermore, this multi-sense method allows the writer to combine ethnography's social sciences objectivity while permitting them to use the creative aspects of literature to write about one's own experiences for specific academic purposes (Bochner & Ellis, 2006; Cooper & Lilyea, 2022; Reed-Danahay, 1997). In simple terms, autoethnography allows for the systematic immersion and analysis of the researchers own experiences within the context of a particular culture by utilizing "rich descriptions" and multiple layers of consciousness to facilitate an understanding of a culture for both insiders and outsiders (Ellis et al., 2010). These experiences are connected to the larger meanings within culture, including those in social and political contexts. The goal of autoethnographers is to show "people in the process of figuring out what to do, how to live, and the meaning of their struggles" (Bochner & Ellis, 2006, p. 111). For this reason, autoethnography requires the researcher to have reflexivity and political motivation, that can promote personal growth in addition to social change (Adams et al., 2017; Allbon, 2012; Denzin, 2013).

Autoethnography, as with all research methods, has strengths and limitations. One of the strengths of autoethnography is the emphasis on personal experience, aiding in supplementing and filling in the gaps left by traditional research (Adams et al., 2017). Another benefit is that the personal nature alters how the phenomenon is viewed, providing new and distinctive insights into issues often overlooked in society that can contribute to social science. According to Adams et al. (2017), "given the focus on personal experience, autoethnographers speak against, or provide alternatives to, dominant, taken-for-granted, and harmful cultural scripts, stories and stereotypes" (p. 3). Furthermore, proponents of the research method believe that personal experience methods such as autoethnography take into account the "macro and micro linkages; structure, agency, and their intersection...social reproduction; and social change" (Laslett et al., 1999, p. 392). This is because autoethnography aids in illustrating both internal and external experiences (Kleinman, 1988). Per Chang (2008), other advantages of autoethnography are:

> (1) it offers a research method friendly to researchers and readers; (2) it enhances cultural understanding of self and others; and (3) it has a potential to transform self and others to motivate them to work toward cross-cultural coalition building. (p. 52)

Ultimately, this approach allows for reflection on what lessons can be garnered from these experiences, to shed light on how our environment (nurture), including the healthcare system, impacts illness and patient quality of life (QoL).

Despite these facts, opponents of this method view it as narcissistic, introspective, self-indulgent, and personalized (Wall, 2016). Leading opponents to the conclusion that the method is not reflective of the culture being observed, in this case, those living with CI and their viewpoints (Koch, 1998). Although there are numerous strengths to autoethnographic methods, it is not without limitations. According to Chang (2008), some potential pitfalls to avoid are:

> 1) excessive focus on self in isolation from others; (2) overemphasis on narration rather than analysis and cultural interpretation; (3) exclusive reliance on personal memory and recalling as a data source; (4) negligence of ethical standards regarding others in self-narratives; and (5) inappropriate application of the label autoethnography. (p. 54)

Other criticisms about autoethnography include concerns regarding academic rigor and methodological validity. Koch (1998) stated that narrative research methods have been depicted as unscientific, biased methods that lack structure and are susceptible to fabrication as well as lack rigor. Some suggestions she made to improve these issues are adding transcripts to the appendix, leaving an audit trail of data interpretations, and offering adequate descriptions of the original content to ensure conclusions are substantiated in data regarding topics concerning transferability (Koch 1998). James Baldwin once said:

> You write in order to change the world, knowing perfectly well you probably can't but also knowing that…the world changes according to the way people see it, and if you alter, even by a millimeter, the way…people look at reality, then you can change it. (Romano, 1979)

Regardless of how you view this methodology, most can agree that new viewpoints and solutions for complex issues like CI in the U.S. are critical. The biomedical model has failed "to see illness as a matter of the whole person, in that it overlooks the importance of social, lifestyle and psychological factors in the onset of complex and chronic disorders " (Anjum et al., 2020, p. 92). Due to this failure by the biomedical model (our country's primary medical model), CIs continue to be an ever-growing problem in the U.S. (Holman, 2020). This has ultimately led to this population being underserved, marginalized, and struggling to find competent healthcare providers and solutions for their ailments (Holman, 2020). This problem is not simply speculation, as according to a recent Gallup poll, just under 50% of Americans have a negative view of the healthcare system in the U.S. and feel that the system is broken and in need of repair (Gallup,2022; Willcoxon, 2022).

When considering the fit of autoethnography for this thesis, several factors influenced my decision to use the autoethnographic method. The main reason is its ability to use my insider knowledge regarding those living with CI to aid in being a voice for the voiceless. Since autoethnography allows for the researcher to study from the inside, it thus provides a superior representation of those being studied, as it gives the voice of experience and expertise to the subject (Adams et al., 2017). This is particularly problematic for those living with CIs or disabilities as this group is already “Othered” by the general population. According to Richards (2008), this is because:

> The disability movement has been central in reminding us that there is a long history of people living with illness or disability—already Othered by society—being Othered further through the writings and research of outsiders in general, and health professionals in particular. ‘Othering’ means turning a person into an object of some sort, such as a stereotype or even an object of study. (p. 1717)

Furthermore, “[t]he expert on…disability or illness is not the clinician, but the person experiencing disability or illness” (Richards, 2008, p. 1717). Despite this fact, scholars and healthcare professionals often subvert the voices of those with lived experience who are Othered. Another reason I selected autoethnography, is its ability to aid in describing aspects of the everyday lived experiences of someone with a CI, which is unobtainable through more traditional methods and its ability to create and distribute text on important topics that can engage both academic and non-academic audiences (Adams et al., 2017). For these reasons, it is important for those of us who are Othered but have credentials that validate us in the academic and professional fields

Lastly, I opted to use autoethnography as I seek to research this self in hopes of gaining a better understanding of what created this self. According to Frank (2000), when a person shares their story, it aids in repairing the damaged self, and more profoundly, he states that the self is not the cause of the narrative but a product. Consequently, allowing the person living with an illness to tell their story and make sense of their complex health experiences (Hinson & Sword, 2019). For these reasons, I have chosen to employ the use of the illness narratives as these are particularly intimate and often reveal a struggle with adversity, marginalization, stigma, suffering, and acceptance (Bochner 2001, Frank, 2000; Richards 2008). This is because illness narratives assist the person with the lived experience in providing context to their unique struggles and long-term suffering while drawing attention to the social and cultural factors that have influenced their understanding of their illness and symptoms (Kleinman, 1988). Lastly, illness narratives can be placed in the greater picture of autoethnography (Ellis & Bochner, 2000).

Illness Narrative

According to Burchardt (2019), “since the 1970s, illness narratives have acquired the status of both an important methodological approach and a theoretical concept in the sociology of health and illness and in medical anthropology” (p.2). This is because the concept of the illness narrative has been applied to training doctors to improve communication with patients (Brown & Garden, 2017). Illness narrative works by helping the provider understand the different meanings patients give their illnesses, as well as aids patients in changing their narratives to improve their overall outcome (Brown & Garden, 2017). Additionally, listening to illness narratives enables individuals who are not ill to feel empathy for those who and aids in establishing a sense of solidarity by providing reassurance that someone else knows the complexities of living with an illness.

An interesting element of illness narratives is that they can be written by either providers or patients. Moreover, these narratives are unique in the sense that they can be of any length, take on the form of poetry, consist of oral accounts, as well as written ones (Vougioukalou, 2019). According to Vougioukalou (2019), illness narratives can be:

> (a) a short story about a therapeutic event and specific characters such as an encounter between a patients, doctors, nurses or caregivers; (b) an extended story about a significant

> aspect of one’s life such as an illness, a trauma, recovery, or bereavement; or (c) a narrative of one’s entire life from birth to present, – which is often referred to as a life history. (p.1)

Illness narratives include the experiences, interpretations, perceptions, and evaluations of the person living with the illness (Burchardt, 2019). Illness narratives are unique, as despite the subjective nature, they are socially constructed (Frank, 1995). These occur at the intersection of healthcare, biographies, and society. For this reason, a single story tells not only about the individual but just as much about society and the healthcare system they navigate (Riessman, 1993).

Although there are numerous ways to write an illness narrative, I will be using the framework constructed by Frank (1995), a sociologist and a cancer survivor. Due to his unique perspective, he sees the illness narrative as an interactive experience that the person who is ill enters and not simply an externalized construct (Frank, 1995). I choose to use Frank’s approach to illness narrative as upon reading the preface, I felt an instant connection to his way of thinking about illness:

> I hope to shift the dominant cultural conceptions of illness away from passivity — the ill person as ‘victim of’ disease and then recipient of care — towards activity. The ill person who turns illness into a story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability. (Frank, 1995, p. xi)

Core to how Frank views illness narratives is his belief that the stories told about our lives are not precisely the lives as they are lived but that the stories are about the experience of those lives. Ultimately, these stories shape one’s perceptions of their lived experience over time.

Additionally, illness narratives are necessary as telling one's story allows the person who is ill to regain control of their illness, as it empowers them to come to terms with what happened to them and reflect on how their illness has shaped their sense of self (Frank, 1995).

In his book, Frank (1995) categorizes illness narratives as three distinct types, restitution (expectation of recovery), chaos (suffering and loss), and quest (unforeseen positive effect from illness). These classifications are viewed as the framework that the person who is ill uses to understand and explain their illness (Frank, 1995). Nevertheless, Frank points out that in telling an illness narrative, no single story completely fits into any of the three narrative types and ultimately includes elements of all three. According to Frank (1995), "In any illness, *all* three narrative types are told alternatively and repeatedly. At one moment in an illness, one type may guide the *story;* as the illness progresses, the *story* becomes told through other narratives" (p. 76). In this thesis, I will be primarily telling a quest narrative to convey my illness experiences. However, due to the nature of Frank's typologies, elements of the other narrative types will be scattered throughout this thesis and examined in the discussion section.

The Restitution Narrative. Restitution narratives are characterized by unequivocal hope and tells the story of a person plagued with illness being restored to perfect health as though nothing had happened due to the marvels of modern medicine (Frank, 1995). Therefore, this type of narrative is most often associated with those with acute illness and least frequently with those with chronic illness. According to Frank, restitution narratives are what the medical community strives for and are propagated by society, thus are considered the most preferred. These narratives follow the simple story of, "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (p. 77). They indicate a natural desire to get and remain well and are linked to parabolic phrases such as "good as new" (p.77). According to Frank (1995), "In the restitution narrative, memory is not disrupted because the present illness is an aberration, a blip in the otherwise normal passage of time. The ‘normal’ trajectory remains intact” (p. 90).

The Chaos Narrative. In stark contrast to the restitution narrative, chaos narratives are characterized by feelings of vulnerability, helplessness, and bewilderment, thus leading to a loss in agency (Frank, 1995). The chaos narrative describes the unpleasant side of illness and has been deemed by Frank as the hardest to “hear because they are too threatening” as they do not provide happy endings, as restoration to health is not a sure thing. (pp. 97-98). Chaos narratives are the “anti-narrative of time without sequence,” thus difficult to follow as they are always beyond speech because the person with the illness cannot put the chaos into order as it is too chaotic. (p. 98). Therefore, involve the person living with illness to speak without the ability to reflect on their experience. According to Frank (1995):

> To turn the chaos into a verbal story is to have some reflective grasp of it…For a person to gain such a reflective grasp of her own life, distance is a prerequisite. In telling the events of one’s life, events are mediated by the telling. But in the lived chaos there is no mediation, only immediacy…. Lived chaos makes reflection, and consequently storytelling, impossible (p. 98)

Ultimately emphasizing the importance of listening to those amid a chaos story (Frank, 1995).

The Quest Narrative. According to Frank (1995) in quest stories, the person who is ill “meet[s] suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest” (p. 115). Therefore, the narrator shares what it is like to live with chronic illness and seeks to use their experience of illness in a meaningful way. They share their hopes, fears, and sense about the significance of suffering as well as the possibility of death. The quest story implies that the narrator has been granted insight by their experience, that is to be passed on to others (Frank, 1995). However, the purpose is not to inform others about what is needed to return to their former non-ill state but to bear witness to the experience and share knowledge. This does not mean that the person does not wish to be well, rather, they are simply accepting of where they currently are in their illness (Frank, 1995).

Within the quest narrative there are three facets: memoir, manifesto, and automythology (Frank, 1995). The illness memoir involves the writer telling their illness story and other events in their life. The memoir narrative is noted as the gentlest style of quest narrative. It is considered an "interrupted autobiography" and is not told chronologically but instead is recollected from present circumstances with illness interrupting the telling of their story (p. 120). In contrast, the manifesto narrative is considered the least gentle of the quest narratives and is considered prophetic and political in nature. Therefore, the manifesto narrative carries demands for social action and change, including using their "suffering to move others forward with them" (p.121). Manifestos frequently include situations where society represses a truth regarding illness affliction and the narrative seeks to announce that truth. Lastly, the automythology narrative is based on the Phoenix metaphor, which reinvents "itself from the ashes of the fire of its own body" (p. 122). In automythology the author has not only survived but also has been reborn. Additionally, this narrative emphasizes personal change. According to Frank (1995), "The body of the storyteller becomes a pivot point between microcosm and macrocosm, and human potential 'freedom'…. and "destiny"…. depends on whether the lessons that the storyteller has learned can be accepted and practiced by others" (p. 17). Ultimately, I have chosen to write an autoethnography using illness narrative for two reasons. The first is over the years, numerous studies have demonstrated that utilizing expressive writing about a meaningful life and traumatic experiences has the potential to provide the writer with physical and physiological benefits

(Pennebaker & Beall, 1986; Pennebaker et al., 1987; Pennebaker et al., 1988; Pennebaker & Seagal, 1999; Robinson et al., 2017). For example, in Pennebaker et al. (1988) a study focusing on trauma disclosure and immune function, participants demonstrated improved immune function for up to six weeks after completing their journaling assignments. Therefore, utilizing this method will allow me to use my own experiences as a tool for personal growth (Adams et al., 2017; Denzin, 2013; Richards, 2008). Secondly, this method provides an opportunity for my voice to be heard in the social and larger political conversations regarding CI (Adams et al., 2017; Denzin, 2013; Frank, 1995; Richards, 2008). It will help bring to light the need for reflection and change within the healthcare and mental health fields as well as with the general populace unfamiliar with CI. According to Le et al. (2017), medical narratives not only benefit the person with the illness but can aid in providing clinicians with “insight into the why and how of illness causation and treatment, including how illness processes are linked to the broader social and structural contexts of patients, their communities, and their clinicians” (p. 304). Thus, they can aid in improving patient health outcomes, decrease provider burnout, increase provider empathy, and inspire critical reflection on structural inequities and implicit biases among providers (Charon, 2006; Le et al., 2017; Zaharias, 2018). This study will also examine common themes that emerged from my experiences and their relevance to those living with CIs, the healthcare system, providers, and implications for future research, practice, and policies.

Positionality Statement

Positionality refers to a researcher’s culturally ascribed attributes, such as gender, race, and nationality (Hampton et al., 2021). Additionally, positionality is shaped by more fluid and contextual aspects of the researcher, such as personal life history and experiences, which may affect data collection to varying degrees (Chiseri-Strater, 1996; Hampton et al., 2021). Therefore, in the spirit of autoethnographic self-reflexivity, it is necessary to disclose my positionality to capture the investigative process accurately and honestly. Thus, I offer these findings as only one possible interpretation of what individuals living with chronic illness experience. My perspective has been formed based on my standpoint as an educated, mid-thirties, married, gender-nonconforming, heterosexual, Caucasian female from Illinois who has had everything from a high to low socioeconomic status at different points in my life.

Furthermore, my positionality has been formed from my experiences navigating the U.S. healthcare system for my over 30 chronic medical conditions, for which I have seen over 100 physicians during my medical journey. Additionally, I am an avid participant in numerous medical condition-related online support groups. Based on my personal as well as my career and educational experiences as an interior designer, nursing, and social work student, I have developed a deep passion for women living with chronic illness and other marginalized populations. Ultimately, these characteristics have been the key driver in my current career goals and have laid the foundation for this thesis. Accordingly, I acknowledge that my positionality has influenced this project in one way or another and that although my experiences are similar to many, they do not speak for or represent the entire population of those living with chronic illness.

Data Sources and Collection

Due to the personalized nature of autoethnography, it can encompass many different data modalities. Some examples of possible types of data types in autoethnography include emails, text, medical records, letters, articles, stories, journals, conversation, dance, songs, poetry, music, media, art, role play, history, comics, and other types of literature (Custer, 2014). However, this is not an exhaustive list of possible data sources. Within this autoethnography, the primary sources of data were composed of personal and collective memories, reflections, and artifacts. These artifacts include personal and family journals, medical records, photos, notes, and my baby book, which were utilized to amplify my personal recollection and provide depth and richness to my narrative and support my analysis of my illness experiences. According to Waymer & Logan (2016), artifacts are an essential part of autoethnographic research as the "memory works in tandem with symbolism to help tell and preserve organizational stories and histories, as well as help shape our understanding of our organizational lives" (p. 1460). Additionally, Muncey (2005), states that the use of snapshots ("moments frozen in time") and artifacts are "important [for the legitimation of autoethnography] if memory and its distortions appear to be critical features of the process" (p. 1).

In terms of journals and notes, throughout my life, I have sporadically kept journals and notes since the age of 10, leading up to the present day. During the periods when keeping a journal, my journaling was done on a regular basis. The entries include information pertaining to daily life, my education and career, medical issues and visits, and family. However, due to the vast date ranges and changes in technology over the years, my journals are in various formats, from diaries, notebooks, and planners to digital journals. Additionally, to supplement the gaps in my journals, my mother allowed me to look through sections of her personal notebook based daily journals that pertained to me or specific times in my life that I inquired about.

In contrast, to the journals, my medical records do not go as far back. This is because many of my medical records from childhood were lost in moves growing up, and as a young adult, I was unaware of their importance. Because of this, prior to 2015, I had limited medical records. However, I have been able to supplement these gaps with personal and family journals, photos, my baby book, and other artifacts that have aided in memory recall of these issues.

Ethical Considerations

In an autoethnography, the researcher is responsible for relational ethics "requires researchers to act from [their]…hearts and minds, acknowledge…interpersonal bonds to others, and take responsibility for [their] actions and…consequences" (Ellis, 2007, p. 3). Essentially relational ethics is using thoughtful reflection and taking responsibility for the potential impacts the research may have on others. One ethical predicament that came to light while writing this autoethnography is that I would have to write about others in telling my story. Due to personal and relational ethics, I recognized that I had an obligation to protect the individual identities of those described in my data. Thus, to protect the privacy of individuals discussed in my autoethnography, I have de-identified and redacted names as well as other descriptive identifying information from both the text and medical records that could reveal those discussed identities before sharing this document with others. Likewise, artifacts such as photos and my mother's journal entries were only used to jog personal memory and not shared visually with others to protect their privacy. Additionally, all digital personal journal entries, medical documents, and other artifacts have been stored within an encrypted and password-protected personal cloud storage drive. Ultimately, when writing autoethnography, the researcher must consider the consequences of writing about others while still maintaining the reality they seek to portray (Bochner & Ellis, 2012).

DOWN THE RABBIT HOLE, WE GO – MY AUTOETHNOGRAPHY JOURNEY

You should never view your challenges as a disadvantage. Instead, it's important for you to understand that your experience facing and overcoming adversity is actually one of your biggest advantages. — Michelle Obama

People often view adversity in a negative light. However, after years of facing adversity, I have decided to truly evaluate what these experiences have provided me and look at these from a new perspective. For these reasons, I will start my story with where I am today, then work in reverse. Additionally, the use of autoethnography allows for personal reflection, essential as it enables one to switch their mindset and shift their emphasis to how far they have come rather than how far they must go. Allowing yourself to reflect on the journey that has made you who you are today will assist you in being able to consider the things you have overcome and accomplished as well as serve as a positive motivation for the future (Kleinman, 1988).

An Enlightened View in the Here and Now

> *Take a moment. Close your eyes. Give thanks for how far you've come, how much you've transformed and how much you're still evolving everyday.* — Unknown

As previously stated, I currently have over 35 diagnosed medical conditions, with my primary diagnosis being a condition known as Hypermobile Ehlers Danlos Syndrome (hEDS) or previously EDS Type III (see Appendix A for more condition information). EDS is a compromised, poorly recognized group of hereditary connective tissue disorders that primarily impact females and is comprised of 13 subtypes, with hEDS being the most common type (Malfait et al., 2017). Currently, as a whole, the group of conditions known as EDS is estimated to impact around 1 in 5,000 people worldwide (Pyeritz, 2000; The Ehlers-Danlos Society, 2022b). Despite this condition first being named over 75 years ago, limited research has been conducted on this group of conditions until recently. This is likely because the National Institutes of Health (NIH) Genetic and Rare Diseases (GARD) information center continues to have the group of disorders listed as rare (Genetic and Rare Diseases Information Center [GARD], 2021a). Consequently, these conditions are understudied due to lack of funding since the majority of federal funding agencies give preference to researching conditions that are likely to have a direct impact on more patients (Ehlers-Danlos Syndrome Research Foundation, 2022; Monaco et al., 2022; NIH, 2022; Ozkaynak et al., 2021). Despite this, over the past decade, research on the topic has started to increase due to an uptick in confirmed cases leading one to consider that the NIH's estimate may be incorrect (Demmler et al., 2019; NIH, 2022). According to a recent study by Demmler et al. (2019), the current estimated prevalence of hEDS and hypermobility spectrum disorders (HSD) (a diagnosis for those who have asymptomatic or symptomatic joint hypermobility but do not meet the criteria for hEDS) is closer to 1 in 500 in Whales, making the NIH estimated prevalence egregiously underestimated.

Consequently, this finding demonstrates that hEDS and HSD appear to be reasonably common among the general population and, therefore, not rare, as prevalence is around the same number as those who have died from COVID-19 from January 1, 2020, to December 31, 2021 (World Health Organization [WHO], 2022). Despite the recent increase in research on these conditions, there continues to be a lack of research or literature on the topic leaving the majority of providers with limited to no understanding of the condition, its symptoms, or its associated comorbidities. In the end, this leaves a significant number of patients with chronic illness without a diagnosis or with a misdiagnosis and unmanaged symptoms (The Ehlers Danlos Society, 2022a). Ultimately, this results in patients feeling increasingly more hopeless and distrusting of providers and the healthcare system.

Although no specific condition is the focus of this study, I bring this information to light as, like many other individuals with this condition, it took me years to receive this diagnosis. More specifically, this resulted in numerous misdiagnoses and 13 years of actively searching for answers to my strange and extensive variety of symptoms. Regrettably, according to The Ehlers

Danlos Society, (2022a). my experience is nothing short of common for others living with EDS or HSD, as the average time to receive an EDS or associated diagnosis is between 10 to 12 years. This is despite “[e]arly diagnosis [being] crucial to positive health” (The Ehlers Danlos Society, 2022a, para.1).

It has been just under two years since I received my diagnosis; however, issues with provider and societal disbelief as well as generalized gaslighting regarding my hEDS and other associated comorbidities, continue to plague me. Medical gaslighting is a common issue among those with hEDS and other diagnostically complex medical illnesses and is considered a form of psychological abuse (Fraser, 2021; Thompson & Blake, 2020). In terms of medical conditions, gaslighting occurs when a person or healthcare provider is dismissive of a patient’s concerns or symptoms and incorrectly faults their symptoms or illness as psychological factors or altogether denies the existence of their condition, thus causing the patient cognitive dissonance (Sweet, 2019). Despite the challenges and adversity I have faced in terms of my illness, my journey to get to this point has prepared me to better cope and handle challenging situations by teaching me the importance of self-education, medical record maintenance, and self-advocacy. Additionally, self-advocacy has the potential to lead to intentional non-adherence, a trait that occurs when a patient actively decides (self-determination) not to adhere to treatment (Cea-Calvo et al., 2020; Hermansen-Kobulnicky, 2008; Ramos Salazar, 2018). Self-advocacy skills, including an individual’s ability to effectively communicate and negotiate their desires, needs, and rights, are vital components of a person’s right to self-determination (Cobb et al., 2009; Wehmeyer et al., 2000). Therefore, the traits of self-advocacy and intentional non-adherence are indirectly related.

With that said, numerous times throughout my medical journey, self-advocacy and intentional non-adherence have been my saving grace. One example occurred in late 2020 when

I sought help for bladder issues and pelvic pain from a urogynecologist. Upon our first meeting, I had high hopes that this doctor would be able to help me find the relief I had been searching for since the birth of my daughter when my pelvic issues became greatly exacerbated. Upon meeting her, she appeared to be highly knowledgeable and competently went through all the proper steps a physician should during the first consultation. This included gathering past medical history and conducting a physical that included a pelvic exam due to the nature of the issues I was experiencing. Upon conclusion of the exam, she sat down with me, discussed her assessment of my issues, and provided a treatment plan. This was when she notified me that based on my patient history and her physical exam, I had an overactive bladder, disorder of hymen, dyspareunia, adenomyosis, dysuria, female rectocele without uterine prolapse, and female stress incontinence (information was extracted from medical records).

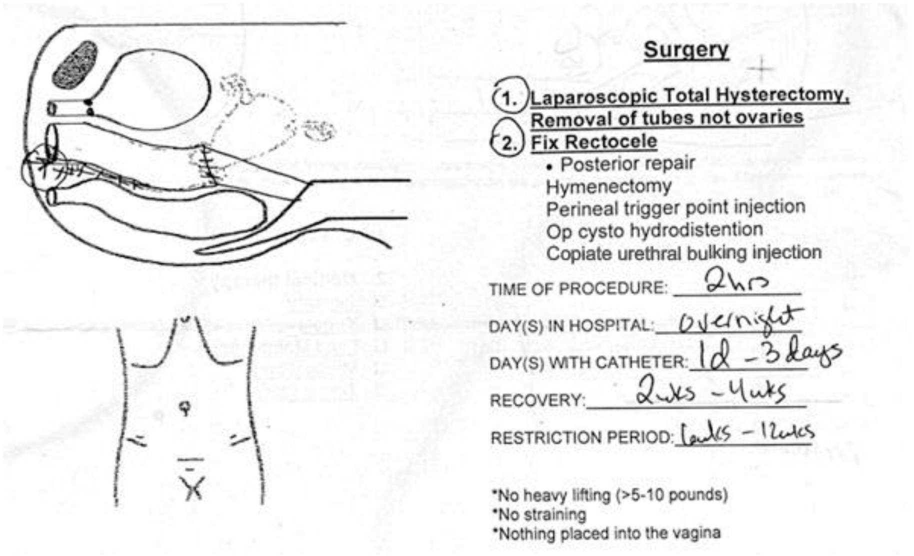
Furthermore, her treatment plan involved a vast number of surgical procedures, all of which seemed valid at the time based on the assessment she conducted, and her findings noted above. At the end of the appointment, she provided me with two prescriptions, Macrobid and Urogesic Blue, in addition to a referral for a pelvic floor physical therapist (PT) to help with symptom management while I awaited our follow-up appointment to discuss the specifics of her surgical plan and decide if I wanted to move forward with surgery. Macrobid is an antibiotic used to treat bladder infections (UTI) and was prescribed as she suspected I might be experiencing a condition known as interstitial cystitis or painful bladder syndrome since all my recent tests had come back as unremarkable. Additionally, oral Urogesic Blue was prescribed to treat my dysuria (pain or burning with urination).

Upon leaving the office, I felt overwhelmed by the sheer amount of information and issues discussed during the visit. At the same time, I also felt a sense of immense joy and relief as I had finally found a women's health specialist who was open to listening and investigating my health concerns. Despite my sense of relief while waiting for my follow-up appointment, I continued to have this uneasy feeling that I could not shake. I ended up chalking it up to stress since I was nearing my first set of finals for my Master of Social Work (MSW) program, that I had entered two months prior in August 2020. During this time, I was also trying to manage my vast array of medical appointments and keep my body from further falling apart, as stress is a major trigger for many, if not all, of my medical conditions (Houman & Stapley, 2013; Liu et al., 2017; Maydych, 2019).

On October 21, 2020, at my next visit with this urogynecologist, she started the appointment by sitting down and thoroughly reviewing her surgical plan that involved multiple procedures. To be specific, in total, there were six procedures she was recommending: a laparoscopic ovary-sparing hysterectomy, a rectocele repair, a hymenectomy, multiple perineal trigger point injections, a coaptite urethral bulking injection, and a cystoscopy with hydrodistension, all of which were to be performed concurrently as seen in Figure 1 below. Although an aggressive approach, after reviewing her surgical plan with her, she assured me that all procedures were necessary and that this was my best chance of symptom reduction, so I decided to move forward and schedule the surgery. I opted to schedule the surgery for December 10, 2020, after my finals to reduce stress and allow for adequate time for recovery before my upcoming spring semester.

Figure 1.

Original Urogynecologist Surgical Plan



Surgery

1. **Laparoscopic Total Hysterectomy, Removal of tubes not ovaries**
2. **Fix Rectocele**
   - Posterior repair

Hymenectomy
Perineal trigger point injection
Op cysto hydrodistention
Copiate urethral bulking injection

TIME OF PROCEDURE: 2hrs
DAY(S) IN HOSPITAL: overnight
DAY(S) WITH CATHETER: 1d - 3days
RECOVERY: 2wks - 4wks
RESTRICTION PERIOD: 6wks - 12wks

*No heavy lifting (>5-10 pounds)
*No straining
*Nothing placed into the vagina

Note. Information has been redacted for privacy purposes.

Little did I know that another problem was on the horizon. Not long after this visit, I started to experience consistently elevated blood pressures (BP) outside my current typical range. However, this was not uncommon for me as my BP remained elevated since the birth of my daughter in 2018, when I experienced severe preeclampsia (See Appendix A for more condition information). The condition is defined by the new onset of severe hypertension (BP greater than 160/110) with proteinuria (high levels of protein in urine) after 20 gestational weeks of pregnancy (Turbeville & Sasser, 2020). Although the symptoms resolved relatively soon after my daughter was delivered via emergency cesarean section (c-section), my BP never returned to its original baseline. This is likely because women who have experienced preeclampsia have two times greater risk of developing a cardiovascular disease such as hypertension in the future (Paauw et al., 2016; Wu et al., 2017). Additionally, I am also more predisposed to having erratic BP and heart rate (HR) changes due to a condition known as dysautonomia, a condition that causes dysregulation of the autonomic nervous system (ANS) and impacts the sympathetic and parasympathetic elements of the ANS, thus causing BP and HR changes (Choudhury et al., 2019). Although I was not formally diagnosed during this period, I was symptomatic.

However, despite needing to account for these additional medical factors mentioned above, I realized that it was not until after my appointment on October 2, 2020, that my HR and BP once again became dysregulated. Prior to this appointment, even though my vital signs were not always optimal, I had managed to keep them within a reasonably safe range in general prior to that appointment. Furthermore, as time passed, I noticed that I was also becoming increasingly irritable, restless, anxious, and hypervigilant, in addition to having increased loose bowel movements, sweating, temperature regulation issues, and nausea. Despite having similar symptoms from dysautonomia and gastrointestinal (GI) in general, the severity of the symptoms was far outside the typical level I experienced prior to the month of October. The most concerning symptom was my BP which I had started noticing was becoming continually elevated as time went on.

To make matters worse, as it got closer to my surgery date, I continued to feel uneasy and anxious that something was off about the surgery or provider. Because of this concern, two weeks before the surgery, I started extensively researching this provider. Usually, this is something I do with every provider before seeing them; however, I was so overwhelmed and wrapped up with my other health issues, recent hEDS diagnosis, and associated referrals, as well as with school that it fell through the cracks. I started by researching the provider's surgical outcomes outside of what she had stated and checking to see if she had any malpractice suits. Not long after, I discovered her surgical outcomes on SurgeonRatings.org, which were vastly different from what she had stated in my surgical consultation with her. Additionally, I discovered that she was also involved in an ongoing malpractice suit.

Again, since I am aware that providers are not simply doctors but also people, making them prone to mistakes, I decided to ask others about their surgical experiences with her in several of my local online support groups before I decided to cancel my surgery. This was when things started to take a turn for the worse. Although I originally got this provider's name as a recommendation from another member of one of my support groups, the response I received regarding this inquiry was anything but positive. I received ten plus responses from women with similar medical issues suggesting that I avoid this provider at all costs as she was "surgery happy" and often suggested what they deemed to be unnecessary procedures. One woman even shared that due to the botched surgery she was given by this provider, she had to have three reconstructive procedures and quit her job due to the damage she sustained from the surgery.

After hearing these women's stories and discovering this additional information about the provider, I decided to cancel my surgery, and seek a second and third opinion. Additionally, it prompted me to go back and analyze my own medical record from this provider since I was now skeptical about whether her physical assessments of me, recommendations, and surgical plans were even correct or necessary. At this point, everything started to come together as to why I could not shake my uneasiness about the provider prior to the knowledge I had just gained. Before starting my MSW program, I was a nursing student and was in a profession I had a deep passion for, but my body had other plans, which forced me to leave the program due to health reasons. However, it was not all a waste, as my time as a nursing student gave me a deeper and more extensive knowledge base than a typical patient. Therefore, when I sat down and reviewed my medical record, I was dumbfounded at what I had discovered and had missed.

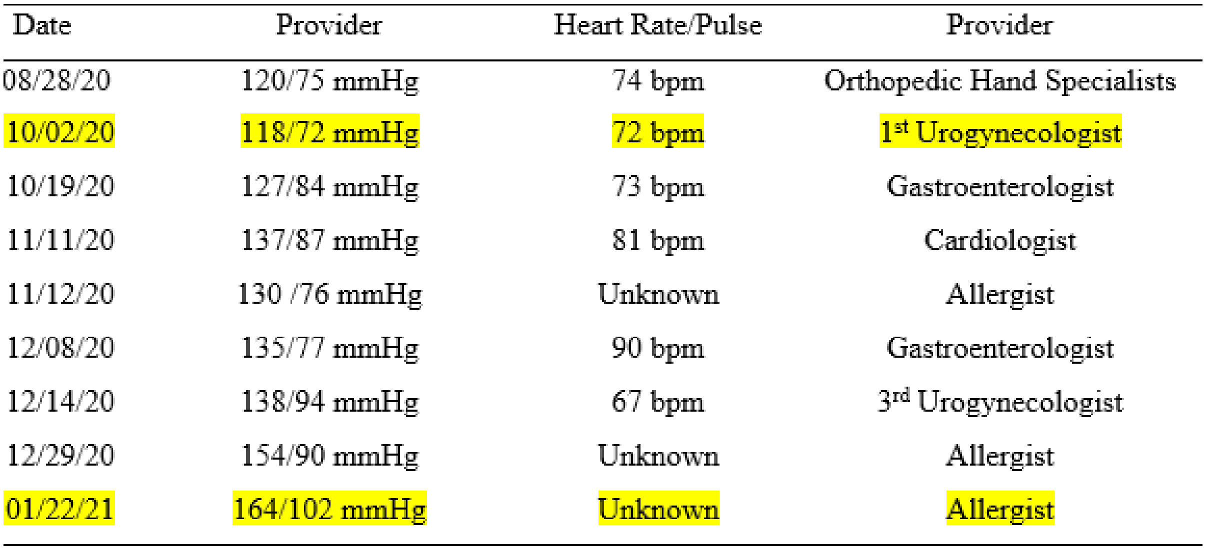
This was the point at which it dawned on me that she had diagnosed me with adenomyosis, a condition where cells from the inner lining of the uterus grow into the uterine muscle wall (Johns Hopkins Medicine, 2022b). According to Chapron et al. (2020) and Johns Hopkins Medicine (2022b), adenomyosis should not be solely diagnosed by a physical examination and patient history as several additional steps should be taken before making this diagnosis. She did, however, complete the first step, which is to review the patient history for associated signs and symptoms and conduct a pelvic exam to determine if the uterus is enlarged and tender, although she did not go any further (Chapron et al., 2020; Johns Hopkins Medicine, 2022b). The second step should have been a uterine ultrasound to aid in ruling out other conditions (Chapron et al., 2020; Johns Hopkins Medicine, 2022b). Finally, the third step would be to order magnetic resonance imaging (MRI) of the uterus and check for thickening of the endometrial-myometrial junction (Chapron et al., 2020; Johns Hopkins Medicine, 2022b). Though, the only way to confirm an adenomyosis diagnosis is to examine the uterus after a hysterectomy (Chapron et al., 2020; Johns Hopkins Medicine, 2022b).

Despite what should have been common knowledge for a provider within the urogynecology field, my provider did not go past the first step. Additionally, upon my second and third opinion by other urogynecologists, I was informed that it is not standard practice for a urogynecologist to diagnose or treat adenomyosis, as it is considered to be outside their scope of work. To add insult to injury, I was also informed by the other urogynecologists that there was no need for any of the procedures that my original urogynecologist suggested and that I did not even have some of the conditions she diagnosed me with. However, despite both my second and third opinions agreeing that my original urogynecologist diagnoses were incorrect, neither of these providers agreed on the origin of these symptoms. Thus, intensifying my skepticism of providers, which was already trending downward.

Nevertheless, by this point, I was beyond thankful that I had decided to cancel my surgery with my original urogynecologist. However, even though I had dodged a bullet in terms of avoiding unnecessary surgery, I still was experiencing all the previous symptoms, in addition to my BP continuing to rise. So, I started trying to look for a pattern and see if I could determine what was causing these symptoms. I knew when the symptoms had started since, I am diligent about keeping my protected health information (PHI) up to date, in addition to the fact that I use a health tracker app to keep track of my vital signs on my mobile phone. Based on this data, I knew the problems had started when I began seeing the urogynecologist back at the beginning of October, which can be seen in Figure 2.

Figure 2.

BP and HR Readings from 10/1/20 to 1/22/21



Date	Provider	Heart Rate/Pulse	Provider
08/28/20	120/75 mmHg	74 bpm	Orthopedic Hand Specialists
10/02/20	118/72 mmHg	72 bpm	1st Urogynecologist
10/19/20	127/84 mmHg	73 bpm	Gastroenterologist
11/11/20	137/87 mmHg	81 bpm	Cardiologist
11/12/20	130 /76 mmHg	Unknown	Allergist
12/08/20	135/77 mmHg	90 bpm	Gastroenterologist
12/14/20	138/94 mmHg	67 bpm	3rd Urogynecologist
12/29/20	154/90 mmHg	Unknown	Allergist
01/22/21	164/102 mmHg	Unknown	Allergist

Note. The first highlighted portion denotes the day the Urogesic Blue medication I was prescribed was started, while the second highlighted portion denotes the day, I decided to stop the medication. This list was compiled based on my own personal PHI that I had access to during this time. However, it is not a comprehensive list of blood pressures or heart rates taken during this time, as I did not always remember to notate them and do not have electronic access to all my medical records during this period.

Although, despite having this information, I still could not pinpoint the cause of the issues I was experiencing. The Urogesic Blue medication for my dysuria was the only thing I was still taking that my original urogynecologist had prescribed and was not known to cause these side effects. It was not until January 22, 2021, when my BP became elevated to the point of nearing a hypertensive crisis, that I decided to check for drug interactions with my other medication and the Urogesic Blue. After reviewing the second medication on my list, it hit me like a rock that all my symptoms were being caused by a drug interaction between the Urogesic Blue and my anti-depressant Wellbutrin (bupropion), as these medications are contraindicated (unsafe therefore not recommended) with each other (Food and Drug Administration [FDA], 2017). This contraindication was due to monoamine oxidase inhibitor (MAOI) properties of the Urogesic Blue and the serotonergic (medications affecting serotonin) properties in Wellbutrin and other anti-depressants (FDA, 2017). When taken together, these medications can potentially cause a severe drug reaction known as serotonin syndrome, a condition which, in severe cases, can lead to seizures and death (FDA, 2017; Gillman, 2010).

To make matters worse, after looking through my personal online calendar between the date of October 2, 2020, to January 22, 2021, I realized that during that time, I had been to 28 doctors' visits with over 20 doctors. These visits included appointments with my psychiatrist and cardiologist; three in-hospital outpatient non-invasive and minimally invasive procedures, upon which multiple providers and nurses were present and had supposedly checked my medication list; and other relevant providers I was seeing during this time, such as my cardiologist, geneticist, as well as others. I was told that it was probably just my dysautonomia or other comorbidities acting up, that they were working to get under control. Thus, creating self-doubt despite me stating that these symptoms were out of the ordinary for my body.

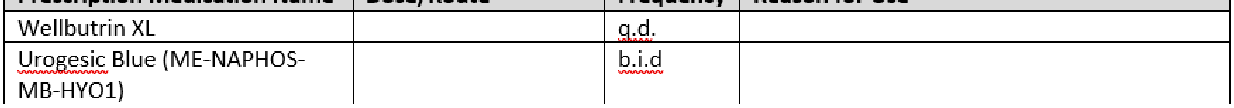
To me, allowing this drug contraindication to go unnoticed was inexcusable since, as a former nursing student and educated patient, I knew that most providers in the U.S. use some form of electronic health record (EHR) system to aid in maintaining electronic patient records

(The Office of the National Coordinator for Health Information Technology, 2022). This technology is not just for patient record keeping as EHR have embedded clinical decision support (CDS), that helps inform decisions about a patient’s care (Tcheng et al., 2017). This tool provides clinical staff, including pharmacy staff, with alerts and reminders to help manage active patient medication lists, check for drug allergies and interactions, and provide other tools and guidelines to increase patient outcomes and safety (Tcheng et al., 2017). According to The Office of the National Coordinator for Health Information Technology (2022), in 2020, when my drug interaction mishap occurred, just under 80% of office-based physicians and over 95% of non-federal hospitals used an EHR.

Furthermore, due to my background, I have an in-depth understanding of the importance and implications of providers and their staff using the EHR to ensure that when new medications are prescribed, there are no drug-to-drug interactions with the patient’s current medications. For this reason, I always ensure I bring a hardcopy list of all my active and as-needed (PRN) medications and other important medical information, as seen in Figure 3 below. I supply this information each time I see a new provider or whenever there are changes in my medication or medical history. I do this because I know firsthand how easy it is to have a medication mishap due to provider errors and a lack of disclosure on the patient’s part.

Figure 3.

Sample of Medication List Given to Providers



Prescription Medication Name	Dose/Route	Frequency	Reason for Use
Wellbutrin XL		q.d.	
Urogesic Blue (ME-NAPHOS-MB-HYO1)		b.i.d	

Note. *This is not a comprehensive list of medications I was taking during this time, as information has been redacted for privacy.*

Ultimately, the combination of all of these factors led me to be intentionally non-adherent with my medication and discontinue the Urogesic Blue without medical supervision. The decision was made to cease using the medication without the guidance of medical professionals due to increased distrust of providers and my extensive research of the medication from reliable sources. Once the medication was discontinued, I quickly saw a reduction in the abnormal symptoms I was experiencing and eventually the return of my baseline BP to the range in which it was prior to taking the medication.

The Aftermath

This type of challenging experience was not one I would wish on anyone. Had I not opted to advocate for myself by doing my own research, gaining second and third opinions, listening to my body, or being intentionally non-compliant, I am not sure where I would be today or if I would even be here at all. However, this is not the first time I have had a provider prescribe me a medication that was contraindicated with an existing medication I was taking, a condition I have, or one that I had listed in my drug allergies. In fact, this problem is all too common for those living with multimorbidity (two or more long-term conditions) or rare illnesses as they are often the most frequently impacted by adverse drug reactions (ADRs) (undesirable medication effects) and misdiagnosis (Dong et al. 2020; FDA, 2018; Navickas et al., 2016; Newman-Toker et al., 2020; Suzuki et al., 2021). According to a systematic review by Arts et al. (2016) studies have shown one of the most prominent reasons for intentional non-compliance is often related to contraindications, therefore supported by valid reasons (Arts et al., 2016). Furthermore, this ordeal was incredibly traumatizing for me as it brought up feelings and memories of similar past situations with misdiagnosis and other preventable provider errors. Additionally, the entire situation made me more avoidant and untrusting of providers moving forward—a common theme among patients with medical trauma and misdiagnosis (Suzuki et al., 2021). Nevertheless, this complex experience also showed me the importance of trusting your instincts.

A View From The Other Side

> *Any great change must expect opposition, because it shakes the very foundation of privilege.* — Lucretia Mott

In contrast to my experiences as a patient, as an MSW student nearing the end of my degree, I frequently get asked, “what do you want to do with your degree?” When I started my MSW journey, this was a question I found daunting. However, as time passed and I completed my internships and continued to contemplate the question, it eventually became clear. The answer is to become a licensed clinical social worker (LCSW) who is certified in integrative mental health. Integrative mental health providers are unique as they take a whole-body person-centered approach to mental health and utilize both conventional mainstream and complementary alternative treatments (Integrative Medicine for Mental Health (IMMH), 2021; University of Arizona Center for Integrative Medicine, 2022). More specifically, I want to provide integrative psychotherapy to women aged sixteen and older with chronic or rare physical and mental health conditions. The response I usually get to my answer is, “what made you interested in that specialty or population?” In response, I explain that it is my passion to serve a unique and underserved population I can relate to. Like many other passions, mine was formed from personal experiences, including my own experiences with CI, my prior educational background as a nursing student, and my interest in mental health.

For years I had only experienced the patient perspective of westernized medicine which is nothing shy of a horror story most of the time. This is because many providers view health in terms of the physical body and physiology of disease (Wade & Halligan, 2004). This non-holistic approach to care, is not only decontextualizing, pathologizing, individualizing but dehumanizing (Rocca & Anjum, 2020). Ultimately, this led me to want a career in nursing, as I wanted to try and change the type of care patients receive and be part of a team that aided in improving patient outcomes. While in my clinical rotations (hands-on, real-world training) during nursing school, I quickly came to realize that the idea of quality patient care which I envisioned, was more of a fantasy than reality. In nursing school, you were taught how to do everything the "right way" per the accepted standards. This included learning how to take the nursing licensing exam and only viewing patient symptoms from the current established "best practices" viewpoint and within the standardized clinical limits. Additionally, we were only briefly taught about certain "uncommon" conditions, as the focus is placed on typical conditions and laboratory reference ranges. Essentially, you were not taught what to do when a patient does not fit within these perfectly defined "clinical check boxes," thus leading to provider and patient frustration and poor patient outcomes (Salisbury, 2020). To further add to the frustration and confusion in my clinical experiences, most of the focus was placed on meeting the set patient goals so they could be discharged, completing documentation, and learning how to maximize efficiency, despite if this meant not fully following "best practice" guidelines and safety. As a student, these experiences led to confusion about what the true objective of nursing is and whether it was to help others or move patients as quickly as possible through the system.

The Persistent Patient

Our greatest weakness lies in giving up. The most certain way to succeed is always to try just one more time. — Thomas Edison

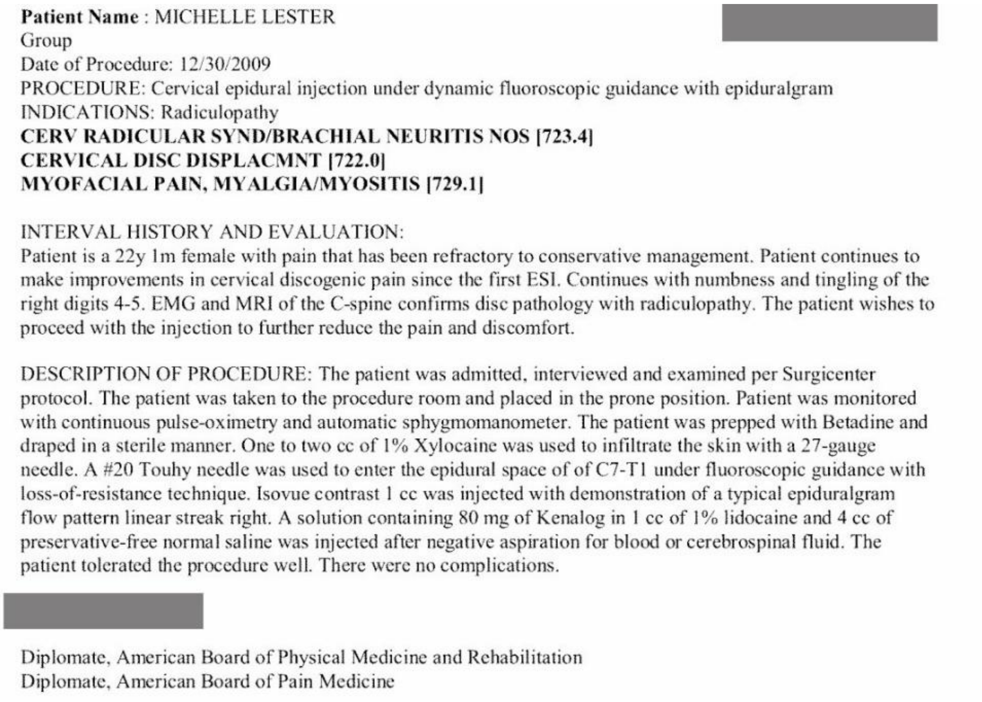
In 2009, at the age of 21, not long after graduating with my first undergraduate degree, my medical issues reared their ugly head. The problems all started one random morning as I woke up, a morning which I remember clear as day. I had been out drinking the night before with some friends, so when I randomly woke up feeling dehydrated, dizzy, unable to move my neck, and dealing with a severe migraine, I just chalked it up to a bad hangover. Unfortunately for me, this was just the beginning of my new nightmare. Over the next few days, my headache started dissipating; nevertheless, the severe neck tension and pain, dizziness, and inability to move my neck continued to persist. I began by seeing a chiropractor, who determined my cervical spine was severely out of alignment from a car accident I had been in when I was sixteen. The chiropractor started by treating my spinal alignment issue, he thought was the culprit of my pain; though, this was not the case. During the three months I was with his practice, he utilized multiple therapeutic modalities to treat my neck pain and stiffness; however, I saw little to no reduction in pain or stiffness despite him fixing my spinal alignment. The chiropractor was running out of ideas, so he decided to refer me to the staff PT and their therapeutic masseuse to offer any relief or suggestions. However, like with the chiropractor, I got little to no relief, leaving them both equally perplexed. This was when he told me I needed to see an internist and look for other potential causes, as he had run out of ideas and suggested that pain could be psychogenic in nature and caused by depression. At the time, I did not feel depressed, just stiff and in pain. A pain that was continually starting to spread throughout the muscles in my body and began to cause pins, needles, and numbness in my right arm.

To make matters worse, I was unemployed and had no insurance since I had just graduated with my bachelor’s in interior design at the end of an 18-month economic downfall we now call the Great Recession. Although I did not agree with the chiropractor, nor did I have the financial means to see another doctor, I decided to see an internist since my pain had continued to increase to the point of being unbearable. Similarly, like many doctors, there was a significant wait to see the internist. By the time I did get into see the internist, my symptoms had progressed to include GI issues, widespread muscle pain and weakness, numbness and tingling in my right arm, dizziness, severe fatigue, and malaise. However, meeting this doctor was not the experience I had hoped for, leading to only seeing her for two visits as the internist was equally dismissive as the chiropractor to my growing number of unexplained symptoms. Essentially, she just conducted a basic physical exam on the first visit and ordered several blood tests. After a few weeks, I returned for my second visit, where she reviewed my labs and informed me of the results. During this appointment, she explained that my lab results had come back unremarkable. Thus, leading her to conclude that my symptoms were psychogenic in nature and solely caused by the anxiety and depression she diagnosed me with. At this point in the appointment, I started to sob uncontrollably as I was overwhelmed, and I knew something was physically wrong and that it was not simply all in my head. Unfortunately, my justified emotional outburst to her only confirmed that she was correct in her diagnosis. After a few minutes, I pulled myself together and composed myself. Shortly after, she informed me that she was only willing to prescribe me anti-depressants and assured me this would help my mood and the irritable bowel syndrome (IBS) that she had also diagnosed me with (see Appendix A for medical condition list). She also informed me that she was providing me with a referral for a therapist who could help me manage my psychogenic symptoms. After leaving the office and getting into my car, I broke down again, as I was left feeling more confused, defeated, and drained than I previously had been.

Despite feeling deflated and defeated by the last provider, I was determined to get rid of the pain and growing array of symptoms, so I decided to reach out to a pain management specialist. Regrettably, after a few visits, the provider had his own health emergency, which led to me being transferred to a different physician within the practice. However, before being switched, this provider placed orders for me to be seen by their in-house PT on a biweekly basis which I continued for twenty-four visits. Fortunately, this PT proved more helpful than the last in managing my pain and stiffness while the new doctor tried to establish a diagnosis. The second provider I saw in this practice was also male, relatively young, and overconfident. I only saw him for three visits since he was highly dismissive and quick to throw in the towel when trying to determine the root cause of my physical issues. On my third visit with him, like the internist, he stated, that there was nothing he could find physically wrong with me, and that the problem was "all in my head." At this point, I started to wonder if all the issues were truly just in my head or if there was a physiological reason for my pain. However, my third pain doctor at this clinic did not give up so easily. He went all out when trying to unravel the root cause of my ever-expanding symptoms. He sent me for electromyography (EMG) and magnetic resonance imaging (MRI) while having me continue PT to help with symptom management. These tests revealed I had cervical radiculopathy (pinched nerve in neck) in my C8, causing nerve damage in my right pinky, ring finger, and arm. This led to me being diagnosed with brachial neuritis, cervical disc displacement, and unspecified myalgia and myositis, that were then treated with three rounds of cervical epidural injections under dynamic fluoroscopic guidance with epidurogram seen in Figure 4 below. Although the nerve pain in my neck and arm decreased a little after the injections, my widespread muscle pain remained, as noted in Figure 5 below.

Figure 4.

Cervical Epidural Injections Notes



Patient Name : MICHELLE LESTER [redacted]
Group
Date of Procedure: 12/30/2009
PROCEDURE: Cervical epidural injection under dynamic fluoroscopic guidance with epiduralgram
INDICATIONS: Radiculopathy
CERV RADICULAR SYND/BRACHIAL NEURITIS NOS [723.4]
CERVICAL DISC DISPLACMNT [722.0]
MYOFACIAL PAIN, MYALGIA/MYOSITIS [729.1]

INTERVAL HISTORY AND EVALUATION:
Patient is a 22y 1m female with pain that has been refractory to conservative management. Patient continues to make improvements in cervical discogenic pain since the first ESI. Continues with numbness and tingling of the right digits 4-5. EMG and MRI of the C-spine confirms disc pathology with radiculopathy. The patient wishes to proceed with the injection to further reduce the pain and discomfort.

DESCRIPTION OF PROCEDURE: The patient was admitted, interviewed and examined per Surgicenter protocol. The patient was taken to the procedure room and placed in the prone position. Patient was monitored with continuous pulse-oximetry and automatic sphygmomanometer. The patient was prepped with Betadine and draped in a sterile manner. One to two cc of 1% Xylocaine was used to infiltrate the skin with a 27-gauge needle. A #20 Touhy needle was used to enter the epidural space of of C7-T1 under fluoroscopic guidance with loss-of-resistance technique. Isovue contrast 1 cc was injected with demonstration of a typical epiduralgram flow pattern linear streak right. A solution containing 80 mg of Kenalog in 1 cc of 1% lidocaine and 4 cc of preservative-free normal saline was injected after negative aspiration for blood or cerebrospinal fluid. The patient tolerated the procedure well. There were no complications.

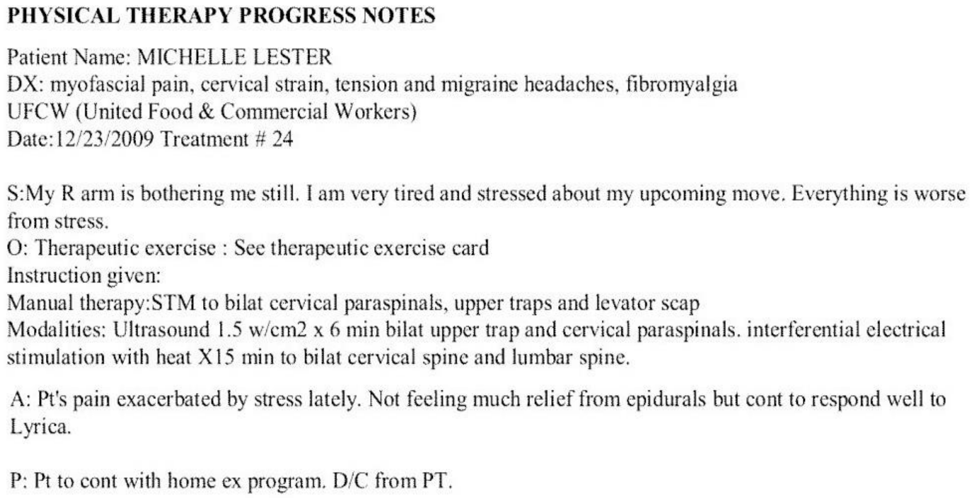
[redacted]

Diplomate, American Board of Physical Medicine and Rehabilitation
Diplomate, American Board of Pain Medicine

Note. Information has been redacted for privacy for of the providers.

Figure 5.

Physical Therapy Progress Notes



PHYSICAL THERAPY PROGRESS NOTES

Patient Name: MICHELLE LESTER
DX: myofascial pain, cervical strain, tension and migraine headaches, fibromyalgia
UFCW (United Food & Commercial Workers)
Date:12/23/2009 Treatment # 24

S:My R arm is bothering me still. I am very tired and stressed about my upcoming move. Everything is worse from stress.
O: Therapeutic exercise : See therapeutic exercise card
Instruction given:
Manual therapy:STM to bilat cervical paraspinals, upper traps and levator scap
Modalities: Ultrasound 1.5 w/cm2 x 6 min bilat upper trap and cervical paraspinals. interferential electrical stimulation with heat X15 min to bilat cervical spine and lumbar spine.

A: Pt's pain exacerbated by stress lately. Not feeling much relief from epidurals but cont to respond well to Lyrica.

P: Pt to cont with home ex program. D/C from PT.

Note. Information has been redacted for privacy for of the providers.

Eventually, this led the doctor and the PT to diagnosing me with fibromyalgia as my primary condition, a functional condition causing widespread pain with numerous comorbidities as my primary condition (See Appendix A for more condition information). Although I was grateful to finally have a name for the pain and symptoms that had been plaguing me, it was also overwhelming, as I was set to move to the Middle East for a job in less than a month. Consequently, leaving me with no aftercare other than taking my prescribed antiepileptic medication to help with nerve pain since there were few to no doctors who dealt with this condition at the time in the area in which I was moving to. However, at no point in time, despite the numerous pain management doctors and my ongoing concerns over the debilitating and unmanaged (despite other treatments listed above) pain, was I ever offered any narcotics (pain relief medication) or medical cannabis (legal in California where I lived). Even before my fibromyalgia diagnosis, two of the three pain specialists were aware of the extensive soft tissue damage (found on MRI) I had from a previous car accident and that the PT explained to the providers that pain was unmanaged despite treatment. This is despite fibromyalgia first being mentioned in clinical studies in 1981 and being said to cause chronic and debilitating pain for which pain medication (narcotic and cannabis) can aid in improving, particularly complementary alternative medications (CAMs) such as cannabis (Berger et al., 2020; Fiz et al., 2011; Habib & Artul, 2018; Inanici & Yunus, 2004; Rocha et al., 2019; Russo, 2004).

A New Toll and Take

Upon receiving this diagnosis, I knew the road ahead of me would be a difficult one. However, I was blissfully unaware of what struggles I was about to face in terms of dealing with the healthcare system. At the time I received this diagnosis, I was only 22 years old and naïve about the systemic issues that plague the U.S. healthcare system, although I was soon about to get a crash course (Agaronnik et al., 2019; Chew-Graham et al., 2017; Gille et al., 2021; Guerra-Farfan et al., 2022; Iannone et al., 2016; Jadhakhan et al., 2019; Ostropolets et al., 2020; Suzuki et al., 2021; Tawfik et al., 2018; World Health Organization (WHO), 2019). I was under the assumption that now that I had a formal diagnosis, doctors would take my ever-growing number of symptoms more seriously and that the gaslighting would stop. I soon found out I could not have been more wrong. I instead was faced with more gaslighting from providers. This included being told my condition was not real and is a "junk diagnosis" or was just psychological in nature. Along the same lines, I was frequently told that "I do not look sick," suggesting I was not physically disabled enough and that "I am too young to have these issues," as if all diseases are ageist and discriminate. Although some may argue that diseases do discriminate and are agist, which in some cases is true. Nevertheless, if chronic diseases indeed do discriminate, it is improbable that this category of diseases would impact over 60% of the U.S. population. With that said, CI "risk factors are largely determined by the social, physical and economic environment" and therefore disproportionately impact marginalized groups" (Erving & Frazier, 2021; Pan American Health Organization (PAHO), 2015, para. 6).

Another common theme was being told my weight was the cause of my symptoms and if I would just lose weight and exercise, my pain would go away. This was said despite being a size six to eight at the time and having exercise intolerance (a common issue among those with fibromyalgia, among other conditions, in addition to being a hallmark sign of dysautonomia) (Ambrus et al., 2020; McManimen et al., 2019; Ruiz Maya et al., 2021). The other most common issue I ran into regarding being gaslit by providers was anytime they could not determine the cause of a new symptom or issue I was experiencing; they would simply default to blaming my fibromyalgia for the issue with minimal or no further investigation into the problem. This was regardless of if the issue was even a symptom associated with fibromyalgia. Over the years, this took a hefty toll on both my physical and mental health; however, it fueled my determination to be my own advocate and try to become well-versed on every condition I was diagnosed with. I started scouring the internet for any information I could get from a reliable source as well as joining online support groups. This is where I learned my experience with the health system was anything but unique and that others with chronic conditions were also victims of medical gaslighting leading to trauma (Au et al., 2022; Fraser, 2021; Sebring, 2021; Sweet, 2019).

Infancy to Adolescence

Peripartum and Infancy: The Importance of a Proper Foundation

A house built on a shaky foundation will eventually collapse — Toni Payne

Looking back, I wish my childhood had been filled with happy memories and joy. However, this was not the case for me or a large percentage of the population. Instead, my childhood was filled with trauma that started shortly after conception, as my mother's pregnancy with me and my early childhood was full of immense stressors and adversity. While pregnant, my mother experienced extreme trauma and stress, starting when she was three months pregnant with me, as my father was mugged by six men with bats and nearly lost his life. Unfortunately, this was not the end of their traumatizing experiences. When my mother was in the middle of her third trimester, my parents became victims of arson when someone burned down the new house they were building, which they also happened to be living in. However, thankfully no one was injured, but my parents were left without a home. Sadly, this was a theme for my parents throughout the remainder of my mother's pregnancy with me. Based on both my mother's and other family members' accounts of the situation, the combination of these events led to my mother experiencing what appears to be undiagnosed postpartum depression (PPD) and post-traumatic stress disorder per the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR).

Although my parents' lives were full of immense stressors during the time of my birth, this did not prevent my mother from doing the best she could to be a loving and supportive parent. In contrast, even though he tried his best, parenting did not come naturally for my father, leading to him being remarkably absent throughout my childhood. This issue was further compounded by the fact that my father desperately wanted a boy and is what could be considered a misogynist. Nearly all the burden of raising a child was left up to my mother. Regardless of these facts, since I was my parents' firstborn as well as the first grandchild on both sides, I was naturally very spoiled, loved, and doted over by the family in general. However, despite all the love and affection I received, I was a difficult infant to care for, as I had my nights and days mixed up and would only eat at night and sleep during the daytime. Additionally, I was also a very colicky baby with high anxiety. This was likely an unfortunate side-effect of all the trauma and stresses my mother experienced while I was in utero.

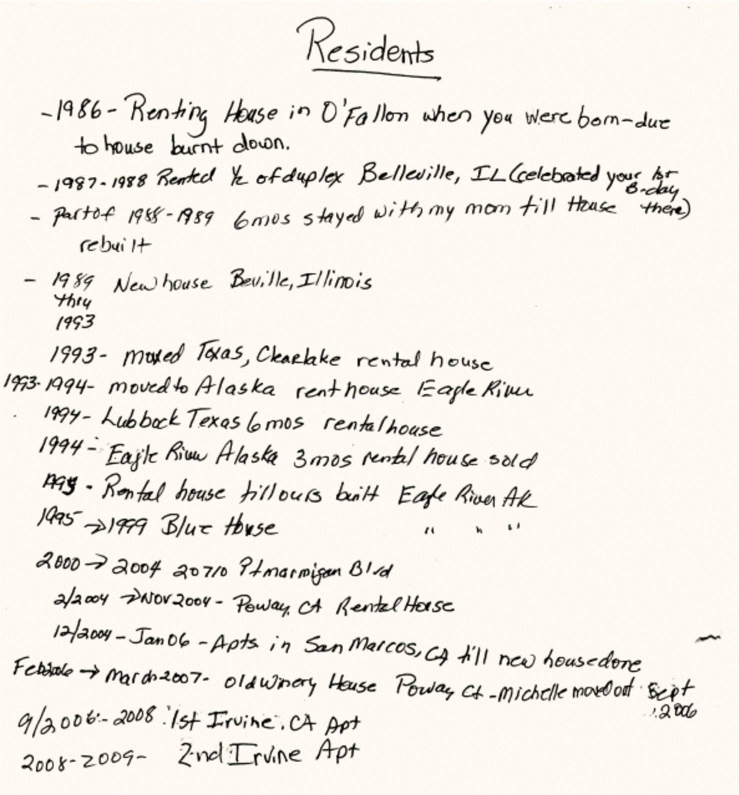
Childhood and Adolescence

Unfortunately, the life stressors and adversity I faced in utero and in infancy laid the foundation for what was to become an ongoing theme throughout my childhood and adolescent years. Growing up, I was raised in what seemed like a typical family, comprised of one biological brother (Mark), who is eighteen months younger than me, and two older adopted brothers (Jonah and Daniel). However, my family was anything but typical. Growing up, my parents were self-employed, as my father owned his own construction and land development company. Since he was self-employed, there were many highs and lows our family experienced financially, that led to my father frequently moving our family around, as we would go where the work was. This pattern started from the year I was born and continued till the age of eighteen when I moved out to go to college, as seen in Figure 6. During my upbringing, we lived in various parts of the U.S., including numerous parts of Illinois, Texas, Southern California, and Alaska—where I grew up from age five to age sixteen. Additionally, the financial ebb and flow also impacted the conditions I lived in growing up. Due to this, I have lived in everything from a Chevrolet Suburban with five people to multimillion-dollar homes. Thus, it allowed me to have the unique experience of knowing what it is like to live in the polar extremes of our society both below the federal poverty line and in the top 1% of earners.

As if my parents did not have enough going on in addition to being self-employed, both of my parents were also ordained, youth ministers. As ministers, my parents frequently encountered troubled youth with problematic home lives. My parents felt it was part of their calling to help this underserved community, leading them to informally fostering several of these teens. I use the term informal as my parents were not formal foster parents of the state and did not receive a stipend or other financial assistance from state agencies. Often these teens were close to or at the age where they could become legally emancipated from their parents, a process which my parents would assist them with while they were staying with us. My parents would then help them get set up in their own place and help provide them with necessities until they got on their feet. Although most of the "foster kids" in general were relatively transient, this was not always the case. When I was thirteen, my parents fostered a 14-year-old boy named Jonah, who they eventually adopted. However, neither my brother Mark (18 months younger) nor I got along with Jonah, as my father favored and coddled him. This was infuriating to Mark and I as, growing up, my father rarely spent any quality time with us. Looking back, I can now see Jonah was incredibly triggering for me since he came into our life at the same age with a similar background to my other adopted brother Daniel, whom I will discuss shortly.

Figure 6.

List of Number of Times Moved



Residents

-1986 - Renting House in O'Fallon when you were born - due
to house burnt down.
- 1987 - 1988 Rented ½ of duplex Belleville, IL (celebrated your 1st B-day there)
- part of 1988 - 1989 6 mos stayed with my mom till House
rebuilt
- 1989 thru 1993 New house Beville, Illinois
1993 - moved Texas, Clearlake rental house
1993 - 1994 - moved to Alaska rent house Eagle River
1994 - Lubbock Texas 6 mos rental house
1994 - Eagle River Alaska 3 mos rental house sold
1995 - Rental house till ours built Eagle River AK
1995 → 1999 Blue House " " "
2000 → 2004 20710 Ptarmigan Blvd
2/2004 → Nov 2004 - Poway, CA Rental House
12/2004 - Jan 06 - Apts in San Marcos, CA till new house done
Feb 2006 → March 2007 - old Winery House Poway CA - Michelle moved out Sept 1, 2006
9/2006 - 2008 1st Irvine, CA Apt
2008 - 2009 - 2nd Irvine Apt

Note. *List was on a loose sheet of paper that my mom created years ago and put in my baby book. Timeline is from birth to age eighteen.*

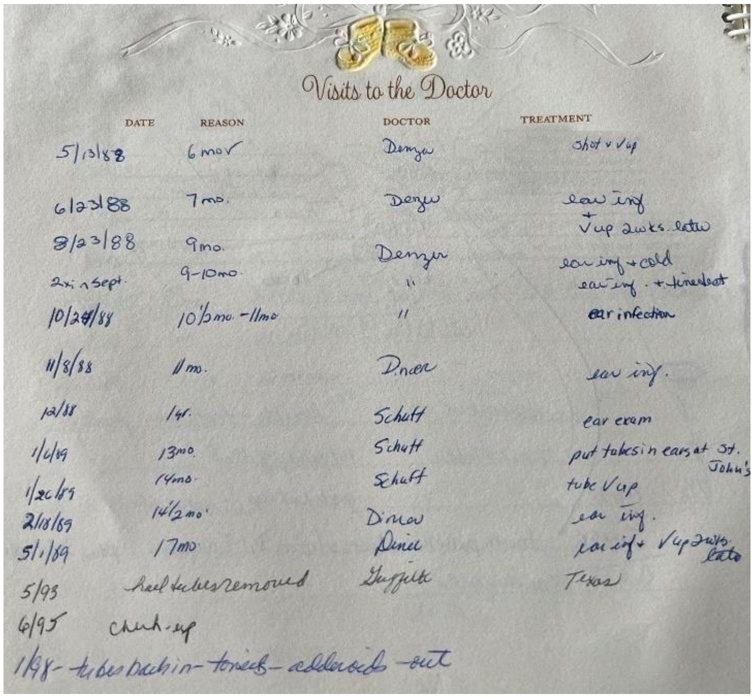
Childhood Health Issues

Unfortunately, the immense life stressors I faced throughout my upbringing were not the only adverse experiences I encountered in my childhood and as a teen, as I also endured complex medical issues. As a child, my first health issue involved dealing with continual infections, including chronic ear infections. These chronic ear infections started when I was seven months old and continued to be a significant issue until the age of eighteen. It is important to note that when referencing chronic ear infections, these were neither typical nor mild infections in nature and often occurred without any reasons as to their frequency. Looking back at my baby book, my mother's old journals, and using her memory recall, she estimated that I had around 200 ear infections before age 18. An example from my baby book can be seen in Figure 7 below. My chronic ear infections were severe enough that I needed seven sets of ear tubes (small hollow cylinders that are surgically placed in the eardrum to relieve pressure and allow fluid to drain fluid from behind the eardrum). These chronic ear infections also caused my eardrums to rupture (a hole in the eardrum) 11 times between both of my ears (ruptures occurred in different ear drums at different times). Although various things seemed to cause the ear infection, the continual sinus, bacterial, and viral infection I suffered from only served to exacerbate my chronic ear issues.

In conjunction with these persistent infections, as I got older and reached my teenage years, the mild eczema I had experienced in my childhood became wildly exacerbated. From the age of thirteen to twenty, my eczema symptoms became exceedingly flared and uncontrolled. This is because the treatments provided by my dermatologist only offered temporary relief and would eventually end up exacerbating the problem. By the age of 18, my eczema symptoms had peaked and were completely out of control, resembling 2nd and 3rd degree burns over 75% of my skin from my torso up, including my face as well as parts of my legs. To add to the problems during my childhood and adolescence, my family did not have medical insurance since my parents were self-employed. Although private insurance was an option for some self-employed during this time, my parents could not obtain it for me since I had pre-existing conditions and the Affordable Care Act (ACA) had not yet been established. This ultimately placed financial strain on the family since my parents spent thousands of dollars annually on doctors' visits and medication for my health issues. However, this was not the worst of my or my family's problems.

Figure 7.

Baby Book



Visits to the Doctor

DATE	REASON	DOCTOR	TREATMENT
5/13/88	6 mo ✓	Denzer	shot + ✓up
6/23/88	7 mo.	Denzer	ear inf + ✓up 2wks. later
8/23/88	9 mo.	Denzer	ear inf + cold
2x in Sept.	9-10 mo.	"	ear inf. + [illegible]
10/24/88	10½ mo. - 11 mo	"	ear infection
11/8/88	11 mo.	Dincer	ear inf.
12/88	1 yr.	Schutt	ear exam
1/6/89	13 mo.	Schutt	put tubes in ears at St. John's
1/26/89	14 mo.	Schutt	tube ✓up
2/18/89	14½ mo.	Dincer	ear inf.
5/1/89	17 mo.	Dincer	ear inf + ✓up 2wks. later
5/93	had tubes removed	[illegible]	Texas
6/95	check-up		

1/98 - tubes back in - tonsils - adenoids - out

Note. This is not a comprehensive list of ear infections during this time period as not all were noted in my baby book and due to the nature of the other artifacts (my mother's old journals) not be my own and containing her personal information the images of these artifacts were not included.

Although these issues started in childhood, they continue to plague me today. Until this point in my life, no doctor has been able to determine the root cause of my immune system dysfunction and inflammation issues. This is because my blood work provides little to no indication as to why my immune system is so susceptible to infections and inflammation, thus leading me to look at alternative reasons, such as environmental causes, including toxic stress and trauma. As previously mentioned, our social environment plays a significant role in our behavior as well as our physical and mental well-being (Conti, 2021; Gendle, 2016; Hindorff et al., 2009; Lichtenstein et al., 2000; Maté, 2003; Willett, 2002).

The Awaking of a New Horror

As previously mentioned, I grew up with two adoptive brothers, Jonah and Daniel, who both came into our family when they were 14. Not only did they come into our lives at the same age, but they shared equally traumatic experiences with their birth families. However, Daniel came to live with us when I was two and a half years old, and my younger brother Mark was around one. Daniel, like Jonah, was quite troubled as his birth mother struggled with substance misuse and was physically, sexually, and emotionally abusing him. In addition to Daniel's history of abuse and neglect, he also dealt with behavioral and emotional regulation issues. My parents tried to get Daniel's mother help while they fostered him. However, she ultimately decided to relinquish her parental rights to my parents. Despite the challenges associated with fostering a teen with behavioral and emotional regulation issues, my parents wanted to give Daniel a better life. This is because they feared what would happen to him if he went into the foster care system. Although it took a few years, my parents eventually formally adopted Daniel. Despite not yet being officially adopted, my parents always raised and treated Daniel as their own. After Daniel had been in the family for a few years, my parents began to trust him and started to allow Daniel to babysit Mark and I since he was 12 years older. However, after a few years, some of Daniel's demons began to surface as he would molest me during these times. It was a horror that continued for years to come. Although the abuse continued for years, due to my age and the trauma I experienced, my memory of what age the abuse started as well as its frequency, is hazy. However, I vividly remember the first time he abused me at age five. Additionally, while I am not sure of the exact frequency, I know it was relatively frequent and that the abuse continued until the age of 11 when Daniel was 24 and married.

The reason for my fragmented memory is thought to result from a lack of elaboration of memory due to elevated emotions and dissociation during a traumatic experience (van der Kolk, 2003). Dissociation (involuntary detachment) is a common trauma response among abuse survivors (Conti, 2021; van der Kolk, 2000). It is our body's protective coping mechanisms used to aid in distancing oneself from trauma that would otherwise be psychologically unbearable (Conti, 2021). According to van der Kolk (2000), dissociation is a significant predictor involved in the development of post-traumatic stress disorder (PTSD). A mental health condition triggered by a traumatic event which causes the memory of the traumatic event to monopolize the survivor's conscious and unconscious, thus diminishing their meaning of life (van der Kolk, 2000). Additionally, van der Kolk (2000) also states that "[t]he longer the traumatic experience lasts, the more likely the victim is to react with dissociation" (p. 7).

Even though the abuse stopped, the guilt, shame, self-blame, anxiety, repression, denial, dissociative patterns, and interpersonal relationship problems continue to plague my life—all of which are common problems among those who have experienced adverse childhood experiences (ACEs), an ever-growing problem that includes all types of abuse and neglect (Finkelhor, 2020; Trask et al., 2011; van der Kolk et al., 1996; Wilson et al., 2006). Due to the guilt, shame, and repression, it was not until the age of 16 that I told anyone about the abuse. Furthermore, it took me till the age of 21 before I was able to disclose the abuse to my father and biological brother.

Although this is not a comprehensive list of the trauma or stressors I experienced as a child or in my youth, it paints an overall picture of some of the adversity I faced in my childhood and youth. Due to the traumatic and chaotic lifestyle I had as a child, my adulthood has been anything but easy. The combination of these experiences has led to unwanted and hazardous ways of thinking, that have ever changed my life trajectory. Despite this fact, working through these issues has allowed for positive personal growth, that without these experiences, would have never been possible. This positive personal growth includes creating a greater awareness of my individual strengths, improving my compassion towards others, increasing inner strength and resiliency, enhancing my gratitude for my close and supportive relationships, a greater appreciation for life despite its challenges, and inspiring spiritual growth. Additionally, I feel these adverse experiences have aided me in finding my purpose in life by fueling my passion for helping others and my sense of social justice. Without these experiences, these traits may not have become elements of my personality or part of my personal values, thus leading me down an incredibly different path in my life and career.

DISCUSSION

The overall goal of this thesis was to answer the research question: How has my own environment (nurture) impacted my physical health and overall well-being? The answer is complex as, like all human beings, both nature and nurture have played vital roles in impacting my overall health, physical health, and well-being. With that said, this thesis has demonstrated that nurture has played a significant and dominating role in influencing vital elements of this self. The complex and challenging experiences I have endured throughout my life have played a vital role in creating a breeding ground for 30 plus chronic illnesses I currently have.

This thesis has come about during a time when research and our understanding of how nurture impacts our overall well-being is changing. As such, the conclusions gathered from this thesis are in line with what recent and ongoing research has demonstrated. This includes the fact that one’s environment and other external factors play a crucial role in gene expression and can create long-lasting changes to one’s biology (nature) (Castori, 2021; National Health Service (NHS), 2022b; Talotta et al., 2017; Tung & Gilad, 2013). For example, although my primary condition of hEDS is considered a genetic condition (nature), research is starting to draw a correlation between the expression of genetic conditions like hEDS and one's social environment. Research has shown that despite hEDS being a hereditary condition, it involves complex phenotypes (observable characteristics in an individual, stemming from the expression of genes, which are commonly modulated by environmental influences) resulting "from the cooperation of multiple internal and external forces, including genetic, developmental, functional and environmental factors" (Castori, 2021, p. 2543; National Human Genome Research Institute, 2022). Comparably, research by Tung & Gilad (2013), where the principal motivation for the study was to gain deeper insight into the "relationship between social effects on gene regulation, health, and disease," determined the following:

> First, social conditions often affect the regulation of genes of known importance in disease risk or progression...Second, in keeping with their role in health and disease susceptibility, social environmental exposures impact the response to external stressors, in part through affecting gene regulation…Finally, social conditions also predict gene expression patterns in tissues already affected by disease—thus providing a window into social environmental effects on disease progression as well as disease susceptibility. (p. 4332)

Furthermore, this section will discuss the major findings of the study. These findings include examining the impacts of conducting my illness narrative and Frank's typologies (look back for another word). The impacts of the illness narrative will be followed by a discussion of the three major themes identified within this study. Following the discussion of the findings, I will explore the research and policy implications and end with the study's conclusion.

My Illness Narrative

As mentioned in the method section, Frank suggests that there are three types of illness narratives: restitution, chaos, and quest (Frank, 1995). As with all illness narratives, my story did not solely fit into one type (Frank, 1995). However, Frank's restitution typology is less evident in my illness narrative, mainly because most of the illnesses I have experienced in my life are chronic in nature. Additionally, the acute illnesses I have experienced were not generally discussed within this thesis. My experiences with diagnosed and undiagnosed chronic illness are unlike a restitution narrative which follow a linear pattern, as my story is more circular in character as it alternates between periods of chaos and quest.

Like many others, my narrative illness journey started as a confusing compilation of overwhelming illness-related experiences in my early childhood, which followed me well into adulthood. This brings me to the chaotic elements of my narrative, which can be seen throughout this thesis through my detailed struggles with new and worsening symptoms and my frustration with obtaining a proper diagnosis for my various conditions. Chaos narratives often demonstrate a lack of control in one's life and a story that lacks coherence and structure (Frank, 1995). These stories also demonstrate vulnerability, senselessness, and powerlessness. For example, until 2020, when I was diagnosed with hEDS, I had no explanation for the chronic ear issues I have experienced throughout my life. However, since receiving this diagnosis, I have now been able to link the issues with my defective eustachian tubes and flabby eardrums caused by this connective tissue disease.

Furthermore, chaos can be seen throughout this study in areas where I have described my increasing emotional distress and sense of self-doubt due to the disbelief and gaslighting by providers regarding my medically unexplained signs and symptoms. A chaos narrative was particularly prominent before receiving my fibromyalgia diagnosis, as I was in chaos during my attempt to find answers for the physical symptoms that disrupted my social and professional life. Additionally, although my illness narrative has elements of chaos that occurred prior to receiving my primary diagnosis for hEDS, this time was also reflective of a quest story due to my continual investigation and research into different illnesses in my pursuit for a correct diagnosis.

Nevertheless, despite the chaos narrative elements of my illness journey, the quest typology was the most prominent and representative type of narrative demonstrated throughout my illness journey in this thesis. This is because this autoethnographic illness narrative is about my quest to find understanding, meaning, healing, and wellness amid my compilation of chronic illnesses. For this reason, Arthur Frank’s (1995) quest narrative lent me a narrative structure to make sense of my illness. As such, my narrative serves as a first-hand account of my experiences living with multiple complex chronic diseases, thus acting as a map of one route through this collection of conditions. According to Frank (n.d.), “in quest narratives, illness and suffering become sources of insight that the ill person understands the world as needing. The quest is to tell the healthy world truths that can be learned only through illness (p. 86).

There are some primary reasons that people choose to share their illness narratives. First is their desire to bring previously suppressed or unknown information to the forefront of society (Denshire, 2010). The second is to develop a sense of belonging through shared experiences (Spieldenner, 2014). Finally, illness narratives enable those living with illness to take control of their lives, as well as achieve healing and transformation through the use of therapeutic storytelling (Gingras, 2012; Jones, 2012).

First, autoethnographic illness narratives have grown to cover a vast array of perspectives and topics (Burchardt, 2019; Charon, 2006; Ellis & Bochner, 2000; Frank, 1995;

Hinson & Sword, 2019; Kleinman, 1988). Even then, I initially found it difficult to find familiar voices among the piles of published literature. This may be due to the sheer number of complex and “uncommon” illnesses that I have, my age, or the debilitating nature of my primary condition, hEDS. In my experience, many people with a collection of illnesses as expansive as mine are often older than their mid-thirties, except for those living with highly complex and systemic conditions. When attending my specialty doctors’ appointments, I am often the youngest person in the waiting room, apart from certain more common specialties such as gynecology, internal medicine, etc. Additionally, I have met a few people who have experienced similar upbringings to mine. While I may not have come across others with comparable experiences to mine. Based on the body research I uncovered to support the claims made in this study, it would be wildly inaccurate to assert that it is uncommon for others to experience complex or traumatic childhoods (Bethell et al., 2014; Bucci et al., 2016; CDC, 2021; Farrant & Watson, 2004; Felitti et al., 2019; Finkelhor, 2020; Hughes et al., 2017; Kerker et al., 2015). Therefore, I can confidently say that in my experience, I have not come across others with parents and family with a similar family structure and level of dysfunction that I grew up with, which includes: (a) a father who consistently relocates their family but is not military; (b) having self-employed parents; (c) being part of a family that has experienced every level of social class at one point or another; (d) living with parents who were youth ministers; (e) having an absentee father; (f) experiencing having two adopted siblings; (g) having to share your home with countless unofficial fosters kids (unsure of exact number for over 15); and (h) enduring sexual abuse by an adopted sibling for an extensive number of years. Furthermore, in my experience, it is a rarity for someone with the sheer number of physically and mentally debilitating conditions to be able to hold a job or even complete general activities of daily living without assistance.

Much less have the physical or mental capability to write extensively about it, thus making my story one that has been relatively untold. My hope is that telling my story will shine a light on what, to my knowledge, is a unique and previously unheard voice in the field of autoethnographic illness narratives.

Second, my illness narrative details my initiation into what Arthur Frank (1995) describes as an invitation into the world of illness. In navigating that frontier and answering the call of illness, I found myself in a mysterious world that nearly everyone will inhabit at some point in their life. Through telling my story and subsequent analysis, I have improved my compacity to be more open and share the details of the adversity I have faced, consequently allowing me to grow closer to other members of the chronic illness community. In writing my illness narrative, I also enhanced my understanding of my own conditions and life journey, as well as allowed me to gain new insight into the perspectives of others living with complex and medically unexplained chronic illnesses. Ultimately my hope is that my illness narrative act as a basic map for others struggling with complex, uncommon, or unexplained conditions and allows them to realize they are not alone.

Finally, a quest narrative’s last stage includes returning to the world of the living. Frank (1995) describes the quest narrative as an exploration one goes on to discover what kind of journey one has been on, which is precisely what this autoethnographic illness narrative has shown me. I started this thesis to tell my story in hopes of improving the lives of others living with complex chronic illnesses and informing how the medical system provides care to this underserved population. However, through continual reflective analysis, a desire to heal, and sheer determination, I emerged like a phoenix from the other side as a changed person with enhanced compassion toward others, improved appreciation for my close and supportive relationships, and a superior appreciation for life despite its complex challenges. In the end, I feel that I have succeeded in what I set out to do as I have shared my illness journey in the hope of aiding those who find themselves lost in the chaos of their illness and initiating systemic change. Telling my story has allowed me to better understand myself and my journey on a fundamental level and in a way that I would otherwise not have been able to do.

The Study's Key Themes

The findings within this study were compared across all data sources. The analysis led to three identified themes that characterize my journey in determining how my environment (nurture) has impacted my overall physical and mental well-being, including my collection of complex chronic illnesses. As previously mentioned, the three themes are (a) the importance of intuition, self-awareness, and self-efficacy; (b) the harms of non-holistic care; and (e) trauma as a foundational driver of il

The Importance of Intuition, Self-Awareness, and Self-Efficacy in Chronic Illness

The theme "the importance of intuition, self-awareness, and self-efficacy in chronic illness" is evident in the facets of my medical journey. Although these traits differ from one another they are indirectly related and have played a vital role in creating my sense of autonomy, confidence, and resiliency.

According to the Encyclopedia Britannica, Inc. (2022), intuition is defined as the "[n]atural ability or power that makes it possible to know something without any proof or evidence: a feeling that guides a person to act a certain way without fully understanding why" (para 1). Therefore, intuition aids in helping you learn to trust the wisdom of your body and, in turn, better understand and trust yourself, thus creating self-awareness. Increasing one's awareness of themselves can help strengthen intuition and aid one in making decisions that align with their values, thus allowing one to be more present (Delmonte, 1988; Klussman et al., 2022). Self-awareness is defined as "knowing one's internal states, preferences, resources, and intuitions" (Klussman et al., 2022, p. 121). Therefore, having self-awareness aids individuals in increasing one's understanding and interpretation of their own body. One study found "that regular awareness practice makes information about the biopsychosocial self-available to meditators in a way that enables them to make choices in support of the organism's natural ability to heal and/or resist disease" (Delmonte, 1988). Increased self-awareness has also been found to lead to be able to improve one's perspective and understanding of their existence. Additionally, self-awareness and self-efficacy complement each other as self-awareness has been shown to increase self-efficacy and elements of personal autonomy (Engin & Cam, 2009).

Lastly, self-efficacy refers "to an individual's self-perceived ability to act effectively in a variety of situations" (Chan 2021, p.1). As a result, self-efficacy includes a person's confidence in themselves to control their behaviors and is associated with increased effort, superior persistence, and advanced goal achievement. (Ebrahimi Belil et al., 2018; Chan, 2021). Therefore, it is an essential trait in increasing one's ability to self-manage symptoms of chronic diseases (Ebrahimi Belil et al., 2018). Additionally, the process of establishing and employing self-efficacy beliefs has been shown to be an intuitive practice (Ebrahimi Belil et al., 2018; Chan, 2021).

Utilizing my intuition has helped me learn to trust my body's insight and develop self-understanding and trust myself. Numerous times in my illness journey, intuition has been my saving grace, acting as a cautionary voice and has aided me in making complex decisions in unfamiliar situations both quickly and effectively. This is because intuition can allow you to determine something nearly instantly without having to reason your way through it, since it goes beyond logic or learned behaviors and has a way of revealing who we are and the knowledge we have gained from our experiences. Along the same lines, my self-awareness has aided me in my medical journey by enhancing my ability to manage my chronic illness and allowing me to be attuned to my body. Additionally, this trait has also enabled me to appropriately convey and prioritize my needs based on my body's capacity in the moment. Thus, self-awareness has assisted me in being able to anticipate and, in some cases, prevent an impending health crisis. Lastly, self-awareness has also aided in increasing my determination and perseverance to overcome the physical and mental obstacles I am faced with. All of which are essential elements in managing chronic illness. In terms of self-efficacy, this trait has assisted me in asserting control over my environment, improved my adaptability, made me more confident in my intuitive decision-making capabilities, and helped me be more motivated while pursuing my goals. Therefore, this trait has been a crucial factor in influencing my ability to self-manage the symptoms of my various conditions.

With all of this said, these traits have played various roles in my narrative, as without these traits, it is likely I would still be without a primary diagnosis. Some examples in my narrative where one can clearly see I utilized these traits would be prior to my fibromyalgia diagnosis and in 2020, when I was told I needed six surgeries and was prescribed a contraindicated medication. During these times, I followed my gut instincts and kept pushing for answers to my signs and symptoms. I did not simply accept multiple providers telling me that my symptoms were all in my head or allowing them to blame them on one of my existing conditions without investigation. Instead of becoming defeated, I chose to utilize my intuition and self-awareness, which was telling me something was physically wrong with my body, and the issue was not just in my head. I also utilized my self-efficacy to stay motivated in my pursuit of answers until one was found.

I am also a firm believer that the combination of these characteristics has aided me in being able to reduce the physical burden and impact of my primary condition and the complex array of other chronic and debilitating illnesses I have. Had I not started honing these traits in my 20s, I firmly believe that I would be far more debilitated than I currently am, similar to others with similar conditions to mine. Therefore, I would not be capable of writing this thesis which is why it is crucial to shed light on this theme for others living with chronic illness.

Harms of Non-Holistic Care

The second theme of "harms of non-holistic care" was also prevalent throughout my entire thesis. Had any of my providers bothered to utilize holistic care in childhood and adulthood, it is highly likely my outcomes would have been different. This is because holistic care is "an approach to wellness that simultaneously addresses the physical, mental, emotional, social, and spiritual components of health" (St. Catherine University, 2022). Therefore, holistic doctors account for the complex relationship between mind and body to provide comprehensive treatment plans for their patients. Holistic care has been associated with significant improvements in outcomes and overall quality of life for those living with chronic illness (Savage et al., 2015).

In contrast to the holistic care model, most physicians are currently taught the traditional medical model (aka the biomedical model), which focuses on treating physical problems with scientifically based physical solutions leaving no time, or reason, to consider anything else (Jennings et al., 2009). These concepts have been drilled into physicians throughout their training, career experience, and in the medical literature. Thus, reducing the complexity of how the "power/knowledge discourse" interacts to subjectify individuals, establish providers as experts, and allow them the ability to proceed as having "true knowledge" (Foucault, 1980; Foucault & Rabinow, 1984). According to Foucault, power and knowledge are not seen as separate entities but are indistinguishably related (Foucault, 1980; Foucault & Rabinow, 1984). Furthermore, this discourse indicates that power is characterized through recognized forms of knowledge, scientific discernment, and "truth" (Foucault & Rabinow, 1984).

Although providers often have more scientific knowledge than the average patient, those living with CI are the experts on their bodies and needs (Chen et al., 2017; Hinson & Sword, 2019; Kennedy, 2003; Lefkowitz et al., 2022). This is because, across the span of their chronic illness, individuals learn how to adapt to their illness's profound effects on them (Gignac et al., 2000; Livneh et al., 2018). Some of the manners in which this occurs are patients becoming more attuned to their bodies, the signals it provides, and their reaction to these signals (Chen, 2016; Chen et al., 2017). Consequently, this leads to greater awareness of pain, physical limitations, and overall bodily functioning (Chen, 2016; Chen et al., 2017; Livneh et al., 2018).

Furthermore, the scientific non-holistic manner of thinking has also taught providers for patients to have optimal outcomes, they must maintain therapeutic compliance to reduce the societal disease burden (Brown & Sinsky, 2015; Cea-Calvo et al., 2020; Hagan & Medberry, 2015; Kleinsinger, 2018; Scialli et al., 2021; Walsh et al., 2019). This approach leaves no room for the psychosocial spiritual elements of the patient. However, research has shown that patients with CIs like myself, who are seasoned and well into their health journey, are often well-versed in their conditions and how the healthcare system operates (Anjum et al., 2020; Lefkowitz et al., 2022). It is important for providers to understand that the patients have an intimate knowledge of their own bodies and an innate sense of what works best for them, making *them* the expert of their bodies, *not* the provider (Chen et al., 2017; Hinson & Sword, 2019; Kennedy, 2003; Lefkowitz et al., 2022; Richards, 2008). Thus, this intuition and self-awareness leads to those with chronic illness being more comfortable with self-advocacy since they have a more extensive knowledge base than the general population (Anjum et al., 2020; Hagan & Medberry, 2015; Kennedy, 2003; Lefkowitz et al., 2022).

Regardless of these facts, not all physicians support self-advocacy. In my experience, the characteristic of self-advocacy is often viewed as a negative trait by providers since it has the potential to leave the patient with opposing viewpoints with their provider (Ha & Longnecker, 2010; Hermansen-Kobulnicky, 2008; Ramos Salazar, 2018). This is problematic for physicians due to their utilization of the biomedical model, which places them in the role of the knowledgeable professional who knows what to do and the patient in the role of the recipient of their knowledge and the one who is to do as instructed (Jennings et al., 2009; Rocca & Anjum, 2020). Another potential reason that not all providers favor self-advocacy is that it has the potential to lead to intentional non-adherence, a trait that occurs when a patient actively decides (self-determination) not to adhere to treatment (Cea-Calvo et al., 2020; Hermansen-Kobulnicky, 2008; Ramos Salazar, 2018). Some may be contemplating how self-advocacy and intentional non-adherence correspond to one another. This is because self-advocacy and self-determination often go hand in hand. As self-advocacy skills, including an individual’s ability to effectively communicate and negotiate their desires, needs, and rights, are vital components of a person’s right to self-determination (Cobb et al., 2009; Wehmeyer et al., 2000). Therefore, the traits of self-advocacy and intentional non-adherence are indirectly related. Thus, at times leaving providers at odds with self-advocacy since intentional non-adherence has negative implications among healthcare and mental health professionals. Additionally, patients who utilize self-advocacy have the potential to be viewed by some providers as challenging to work with or a nuisance and have the potential to frustrate physicians. This is because self-advocacy often equates to them having to spend more time answering questions and dealing with the patient's concerns (Ha & Longnecker, 2010; Hagan & Medberry, 2015; Hagan et al., 2017).

Despite these facts, providers should take a more holistic approach to care and view self-advocacy as a positive trait since respecting one's personal health is a vital boundary needed to maintain a healthy patient-provider relationship (Danielson et al., 2019; Hagan & Medberry, 2015; Scialli et al., 2021;). Additionally, providers are human and, like all humans, are prone to errors at some point. Although providers are trained to have a negative association with intentional non-adherence, it does have benefits in particular circumstances. However, it is not something to be taken lightly and should only be utilized through informed decisions.

Another issue with the biomedical model is that it has been unsuccessful in managing chronic conditions. According to Rocca & Anjum (2020), this is because this model views illness is viewed as "a condition of the whole person" where physicians are taught to treat patient's biological and psychological problems separately there for they "alleviate some symptoms without solving the source of the problem" (p.78). Another issue is that doctors are not trained to be out-of-the-box diagnosticians and are encouraged to focus on the issues of the masses (Salisbury, 2020). In nursing school, my professors, when discussing diagnosis, would recite the adage taught to new doctors, "when you hear hoofs, think horses, not zebras," meaning you should be looking for a more "probable" diagnosis than a rare one. Thus, this has led to marginalized populations becoming even more marginalized and discriminated against. For example, according to Holman (2020), despite the ever-growing prevalence of CIs in the U.S., our clinical research, critiques, and literature have remained unchanged and continue to be focused on acute illnesses. Consequently, turning a blind eye to the continual rise of CIs and best practices for treating this growing and underserved population (Boehmer et al., 2019; Holman, 2020; McManimen et al., 2019). Nevertheless, since there has been limited research or literature on many CIs, most providers are unaware of how to properly deliver care to those with chronic illness, particularly those living with chronic pain (Berger et al., 2020; Boehmer et al., 2019; McManimen et al., 2019; Ozkaynak et al., 2021; Williamson et al., 2021). This leaves many patients living with chronic illness without a diagnosis or misdiagnosed as well as with unmanaged symptoms and feeling more hopeless, thus more likely to become avoidant of providers and the healthcare system (Chew-Graham et al., 2017; Ha & Longnecker, 2010; McManimen et al., 2019; Ozkaynak et al., 2021).

Thus, this demonstrates the importance of provers utilizing a holistic care approach. If providers applied this approach in their daily practice, those with similar multi-systemic issues to mine would probably have a better chance at avoiding countless misdiagnose over their lifetime. Thus, they would be able to aid in achieving their goal of reducing the societal burden of chronic illness (Rocca & Anjum, 2020; Scialli et al., 2021; Walsh et al., 2019). However, the chronically ill population is not without hope. Dr. Peter Attia believes we are moving into the 3rd iteration of medicine, although we are not yet there (Attia, 2022). He notes that the 1st iteration was pre-germ theory prior to society utilizing a scientific way of thinking. While the 2nd iteration, which we are currently in, involves post-germ theory, which focuses on acute illness and advancing emergency and lifesaving medical care via technological advancements. Though, he believes that this 3rd iteration of medicine will aim to serve the needs of those living with chronic illnesses, which are vastly different than those with acute issues. He believes this change cannot be conducted from evidence-based practice guidelines but evidence-informed practice guidelines since we do not yet know everything we need to know.

Trauma as a Foundational Driver of Illness

The final theme of "trauma as a foundational driver of illness" was identified in my autoethnography. Although trauma has been prevalent in various ways throughout my life, the most severe traumas were prominent in my childhood. These traumas can be seen in countless ways in this thesis and be linked to my vast array of illnesses. This is because, despite the western medical community treating mental and physical health as two entirely separate entities, they are bidirectional and have an immense impact on each other (Gendle, 2016; Maté, 2003). For example, trauma has been shown to cause increased inflammation, consequently impacting our immune system—our primary source of scathing off external and internal infections (Conti, 2021). According to Conti (2021):

> Inflammation creates a cascade of dysfunction that triggers the immune system, confuses it, and can cause it to turn its weapons against us. And when immune system turns against the body and brain it's designed to protect, it can lead to low-level symptoms such as fatigue, nausea, increased pain, rashes, and hair loss, or it can result in more impactful and large-scale autoimmune disorders (p. 232).

Therefore, illustrating a direct correlation between trauma and disease and establishing a potential cause for my chronic immune system dysfunction and inflammation.

In terms of childhood trauma, family dysfunction and ACEs have been shown to cause extensive long-term issues that impact one's overall physical and mental well-being even in adulthood (Finkelhor, 2020; Hughes et al., 2017). This is because toxic stress from things like ACEs can change the manner in which the brain develops and affects how the body responds to stress (Conti, 2021). As previously noted, our social environment plays a significant role in our behavior and physical and mental well-being. Furthermore, it demonstrates the importance of reducing ACEs and household dysfunction that occur in childhood to aid in diminishing the current rise in disease burden (Conti, 2021; Felitti et al., 2019; Kerker et al., 2015; Maté, 2011; Tolleson & Zeligman, 2019).

According to Makris et al. (2022), “early life stress (ELS) describes a broad spectrum of adverse and stressful prenatal events, namely, prenatal maternal stress (PMS), or early postnatal events, which can have detrimental long-term influences on the physiology, cognition, and behavior of an individual” (p.1). In light of this information, one can draw a correlation between several of the signs and symptoms I faced in childhood and all the trauma and stresses my mother experienced while I was in utero. For example, until age five, I had my nights and days mixed up, likely due to my narcolepsy, which was not discovered until I was 33. Narcolepsy research has indicated that immune reactions and traumatic life events may be to blame, thus suggesting the disease is likely caused by environmental exposures prior to the age of onset in the genetically vulnerable (Longstreth et al., 2007). This could explain why my sleep cycles were off as an infant and child. Although narcolepsy is generally viewed as excessive daytime sleepiness, it can also cause irregular and disrupted sleep, where one frequently awakes during the night (National Institute of Neurological Disorders and Stroke [NINDS], 2022). In conclusion, despite the western medical community treating mental and physical health as two entirely separate entities, it is clear they are bidirectional and have an immense impact on each other (Conti, 2021; Gendle, 2016).

RESEARCH AND PRACTICE IMPLICATIONS

Although the experiences I have went through over the years were challenging, to say the least, they do shed light on some of the medical system's significant flaws in terms of patient care, including: provider knowledge gaps, medication errors, diagnostic errors, ethical concerns, bias, and medical gaslighting. However, do not be mistaken; these issues are not solely provider problems. These are top-down systemic issues within the U.S. healthcare system, that include provider burnout due to physician shortages and increased chronic disease burden, inadequate or improper training, generalized knowledge gaps of specific topics due to gaps in research, and poorly constructed and overly generalized clinical guidelines (Agaronnik et al., 2019; Beliveau et al., 2014; Chew-Graham et al., 2017; Grace et al., 2014; Gille et al., 2021; Guerra-Farfan et al., 2022; Iannone et al., 2016; Jadhakhan et al., 2019; Okumura et al., 2010; Ostropolets et al., 2020; Suzuki et al., 2021; Swaine, 2011; Tawfik et al., 2018; Woolf et al., 1999; World Health Organization (WHO), 2019).

Knowledge Gaps

In terms of health care issues, knowledge gaps are one of the most significant issues we face. While there is not a single source for the gaps, various contributors exist. A major source of knowledge gaps can be tied back to research (Zielinski, 2019). Research is vital as it is the foundation of science and informs healthcare training, guidelines, monitoring systems, and how healthcare providers deliver care (Institute of Medicine et al., 2009). Additionally, research informs societal understanding of health since it provides essential information about diseases, risk factors, outcomes, the standard of care, healthcare expenditures, as well as proactive and preventive lifestyles (Institute of Medicine et al., 2009).

For this reason, deficits in research lead to systemic issues within our healthcare system. These systemic issues include-misdiagnosis, over-investigation, excessive and unnecessary treatment, medical gaslighting, various forms of bias, lack of resources and support, patient and physician frustration, and poor patient QoL (Hamberg, 2008; Ostropolets et al., 2020; Struthers, 2020). These issues become further compounded for those with medically unexplained symptoms (MUS), rare diseases, multiple comorbidities, young patients, the elderly, and with individuals taking multiple medications (polypharmacy) due to research deficits (Chew-Graham et al., 2017Farrant & Watson, 2004; Gille et al., 2021; Ostropolets et al., 2020; van Bruchem-Visser et al., 2020).

Additionally, although advances in research have considerably improved in terms of the prevention and treatment of diseases, these advances have been disproportionately distributed among marginalized groups (Havranek et al., 2015). These social determinants of health (SDH) are disproportionately distributed across class, gender, sexual orientation, race, socioeconomic and minority groups, leaving these vulnerable groups disproportionately burdened with CIs (Havranek et al., 2015). With the prevalence of chronic diseases continuing in an upward trend, it is now more critical than ever to improve our research methods, subjects being studied, and funding provided to a more diverse range of potential treatment options. This will allow us to reduce healthcare and patient knowledge deficits regarding the understanding, management, and prevention of CIs to improve overall QoL and the health of society.

Medical Errors

According to Carver et al. (2022), medical errors (ME) are defined as:

> a preventable adverse effect of medical care, whether or not it is evident or harmful to the patients…. [and include] adverse drug events and improper transfusions, misdiagnosis, under and overtreatment, surgical injuries and wrong-site surgery, suicides, restraint-

> related injuries or death, falls, burns, pressure ulcers, and mistaken patient identities. (p. 1)

Globally ME represents one of the foremost sources of patient morbidity and mortality (Makray, 2016). Makray (2016) also stated that medical errors are the third major cause of death in the U.S., following heart disease and cancer, respectively ranked first and second. These types of preventable errors result from systemic issues or basic human error and have the potential to cause severe injury and potential death to patients (Atanasov et al., 2020). Additionally, these lead to severe psychological, emotional, and financial stress for the patient, physician, and healthcare system (Atanasov et al., 2020; Detsky et al., 2013). Thus, placing an extensive amount of preventable undue burden on the healthcare system and society.

As previously mentioned, knowledge and training deficits are a substantial problem within the U.S. healthcare system, leading to diagnostic errors that have harmed patients and cost countless individuals their lives (Newman-Toker et al., 2020; Sonderegger-lseli et al.,2000). Even though there are significant determinantal implications of diagnostic errors in America, currently there is a lack of formal and consistent means of tracking these types of errors. The National Academy of Medicine (NAM) (2015) has noted that there are information gaps and stated, “the available research estimates [are] not adequate to extrapolate a specific estimate or range of the incidence of diagnostic errors in clinical practice today” (p. 97). Thus, leaving overall real-world diagnostic error rates unknown and serious harm rates even less certain (National Academies of Sciences, Engineering, and Medicine, 2015). NAM also stated that “most people will experience at least one diagnostic error in their lifetime, sometimes with devastating consequences” (National Academies of Sciences, Engineering, and Medicine, 2015, p. 1). Despite a lack of consensus on the genuine rate of occurrence for diagnosis errors, a study by Dong et al. (2020) revealed that patients with rare diseases were twice to five times more likely to be misdiagnosed that people with common conditions. Although the statics are not consistent, according to Graber (2013), the most frequently cited estimate of misdiagnosis based on expert opinion is between 10–15% of all diagnoses. According to Sonderegger-lseli et al. (2000), in the U.S., misdiagnosis contributes to 40,000-80,000 deaths a year. Based on these findings, one can conclude that many of the diagnostic errors associated with deaths are of those with complex medical conditions and rare diseases. Thus, further impacting already marginalized and underserved populations (Dong et al. (2020).

Although diagnostic errors are problematic and concerning, medication errors have been shown to be among one of the most common types of medical error (Atanasov et al., 2020). According to The National Coordinating Council for Medication Error Reporting and Prevention (NCCMERP) (2015), medication errors are defined as “any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of the healthcare professional, patient, or consumer” (para 1). In the U.S., medication errors are said to be one of the costliest types of errors, amounting to over $40 billion dollars and causing between 7,000 to 9,000 deaths annually (Tariq et al., 2018). Medical errors include adverse drug events (ADEs), wherein an injury occurs due to a medication (CDC, 2017). ADEs are said to impact over seven million people annually and cause over a million emergency room visits yearly, with over 26% of those patients requiring further hospitalization (CDC, 2017). However, similarly to diagnostic errors, the exact number of ADEs is unknown due to ambiguous operational factors, even though the government and healthcare system understand that this issue is a substantial and preventable public health issue (FDA, 2018). Furthermore, many patients do not report their adverse drug reactions (ADRs) or other medication-related complications (Tariq et al., 2018).

Additionally, under the umbrella of ADEs are drug-drug interactions (DDIs), a problem that occurs when two or more drugs react with one another (FDA), 2013). According to a recent systematic review by de Oliveira et al (2020) of 34 studies involving 9,577 patients, the prevalence of DDIs has greatly varied from just under 10% to 100%, of which similar results were also rendered by Sánchez-Fidalgo et al. (2017). Thus, denoting clear and prevalent data discrepancies that need to be addressed to understand the severity of these issues.

Physician Ethical Concerns

In healthcare, ethically challenging situations are common (Cho et al., 2020). However, professional ethics are commonly discussed in literature from the healthcare professional's perspective, whereas in contrast, the patient's perspective of physician ethics is seldom discussed. One of the rare publications that does take the patient's perspective into account is a study by Cho et al. (2020), which surveyed 196 participants (patients and their families) from three hospitals using open-ended questions regarding their most memorable healthcare experience that involved ethical issues or concerns. The themes extracted from the study's data included: patient-physician relationship and treatment plan disputes, patient decision-making capacity, end-of-life care, healthcare access, reproductive decisions, genetic testing, and clinical trials. Ultimately, the study emphasized, "the need to improve patient physician relationships, communication, and navigation of uncertainty during patient provider encounters" (Cho et al., 2020, p. 17)

Despite healthcare and physician ethics being debated publicly, there are significant discrepancies between what is "technically correct or appropriate" and what occurs in practice (Detsky et al., 2013). For instance, reluctance continues to exist when it comes to the disclosure of errors to patients, often disregarding the significant amounts of research published indicating that there is often no increase in legal action or economic consequence when disclosure occurs (Kachalia et al., 2010). Additionally, despite the serious nature of a physician's job, it appears they are held to a lesser standard than other healthcare-related fields whose licenses are more restrictive in terms of their allowable scope of practice. For example, professions such as social work, require providers to practice within the realm of which they have received extensive training and adequate education, in order to ensure ethical practice within the field. The National Association of Social Workers (NASW, 2022) provides ethical standards that promote social workers' growth and protect patients. Within the NASW's Code of Ethics, competency is emphasized as an ethical standard for social workers, requiring them only to provide services that they are proficient in (NASW, 2022). According to the American Board of Physician Specialties (2020), while physicians are encouraged to be board certified in a specialty, they are allowed to provide services outside of their specialty as long as they are licensed to practice medicine in the state, they are operating. Although there are ethical concerns regarding healthcare professionals, the American Medical Association (AMA) has curated medical ethics principles that remind physicians to behave appropriately by providing medical care and competent medical services for all (AMA, 2001; Riddick, 2003).

Another ethical concern within the medical field is the implicit bias by physicians. Bias has been described as negative associations placed upon an individual within a group compared to members of a different group (FitzGerald & Hurst, 2017). Similarly, implicit bias is described as judgments that are produced unconsciously and unintentionally, influencing an individual's decisions and behaviors toward others (FitzGerald & Hurst, 2017). A study by FitzGerald and Hurst, (2017) found that physicians produce implicit biases that are comparable to the general population, including biases regarding gender, race, disabilities, age, and socioeconomic status.

These implicit biases were also found to impact the quality of care patients received from physicians (FitzGerald & Hurst, 2017). Although women are more likely to experience symptoms of chronic pain than men, women are often diagnosed with psychological diagnoses before they are diagnosed with a physical one, as physicians' implicit bias views them as hysterical or dramatic (Samulowitz et al., 2018). These biases produce negative experiences for people that are part of marginalized groups and make it difficult for them to receive the care they need.

Trauma

Trauma is a unique experience in that it impacts each person differently, regardless of if the event they experienced occurs once or repeatedly over time (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). According to Knipscheer et al. (2020), the lifetime prevalence of potentially traumatic events and other life events was just over 70%, with most people reposting experiencing one potentially traumatic event at some point in their life. Regardless of this, only a subsector of the population develops PTSD. According to the U.S. Department of Veterans Affairs (2022), PTSD is a multifaceted condition that negatively impacts around 12 million people in the U.S. each year. Additionally, studies have shown that PTSD disproportionately affects women compared to their male counterparts (Adams et al., 2021; Olff, 2017). According to Conti (2021), PTSD causes a wide array of symptoms, the most common being avoidance of trauma triggers, reliving traumatic events, inadequate sleep and nightmares, hyperarousal, and behavior changes. While other well documented symptoms include impaired cognitive function, loss of productivity, intrusive thoughts, significant social and personal problems, diminished quality of life, and elevated levels of CI compared to the general population (Alonzo, 2000; Sareen et al., in press).

As previously mentioned, trauma is also associated with chronic disease. This is because extreme emotional stress is a catalyst for various physical changes within our body (Conti, 2021; Maté, 2003; Salleh, 2008). According to Conti (2021), this is because “Our brains don’t work without our bodies, and our bodies don’t work without our brains.” (p. 226). Research has suggested that trauma is likely caused by dysregulation of the immune system, that acts as the biological mediator (Conti, 2021). This is due to the toxic stress caused by trauma leading to inflammation that negatively affects the structure of the brain, and the systematic organ system dysfunction, which, in combination with gene methylation leads to epigenetic changes, resulting in chronic diseases (Bucci et al., 2016).

Additionally, toxic stress and CIs appear to have a robust link between ACEs that have been associated with a broad range of adverse outcomes persisting well into adulthood (Poole et al., 2017). According to the CDC (2021), ACEs are involved in at least five of the top ten leading causes of death. Additionally, just over 60% of adults have experienced one ACE, with just over 15% of adults in the U.S. experiencing four or more ACEs (CDC, 2021). Furthermore, marginalized groups are at an elevated risk for experiencing four or more ACEs (CDC, 2021). One important note is that people with ACEs who have established some form of resilience have better health outcomes as children and adults (Bethell et al., 2014; Poole et al., 2017). According to a systematic review by Purewal Boparai et al. (2018), child adversity intervention programs have demonstrated improvements in brain development, cortisol levels, and epigenetic regulation. Despite this being one of the biggest problems we face, many do not realize that exposure to ACEs is an associated health risk both in adolescence and adulthood, thus making ACEs a healthcare emergency.

Limitations

The study’s primary limitation is that it exclusively draws on the experiences of a single person, who is both the researcher and the participant. As such, the study is not generalizable, although it can be transferable as long as it provides data that makes transferable judgments possible to others (Barnes et al., 2005). However, the limitation of the study having only one research participant ultimately generated a deeper analysis of an illness experience. Additionally, possible biases include gender bias as I am a woman, potential bias as a social worker, and other influences from my personal and professional experiences.

CONCLUSION

The key themes demonstrated in this study relate to the impacts of ACEs, trauma, and the U.S. healthcare system's impact on individuals’ physical health and overall well-being. In terms of the healthcare system, this includes vast and concerning gaps in research leading to provider knowledge training deficits, poorly structured, and overly generalized clinical guidelines. This study demonstrates the importance of reflexivity methods inherent to autoethnographic and illness narrative studies and how these are valuable tools for capturing the hidden meaning behind the experience of those living with chronic illness, thus allowing providers and the healthcare system to gain an understanding of how patients experience their illness and shed light on the systemic issues within the healthcare system and society that inadvertently negatively impact disease prevalence and those living with illness. Shedding light on these issues will allow for meaningful change within our society, consequently reducing the disease burden and improving the quality of life for those living with chronic and complex illnesses.

The process of writing this paper has been nothing like I thought it would be. I started with the preconceived notion that it would be easy to write about my own experiences within the context of the chronically ill culture, despite what others had said. However, applying autoethnography in combination with the illness narrative method allowed me to look at my experience in a unique and unbridled way. Conducting this study has allowed me to open my mind and expand on what I unconsciously knew about myself and brought it to my conscious level. Doing this has allowed me to see how far I have come despite the immense adversity I have faced and to better understand my growth and inner strength, that has allowed me to advocate for myself all these years. My hope is that this study will allow society and healthcare providers to gain a deeper understanding of the connection between illness and trauma as well as the importance of positive patient-provider relationships. This study also demonstrates the importance of establishing a connection within oneself to create self-awareness and emotional healing. Despite this study being one of the most mentally tasking things I have ever willingly chosen to do in my life, I would do it all over again as the growth I have experienced from writing this paper has forever changed my way of thinking.

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APPENDIX A

Medical Condition List

Diagnosis and Definition	Personal Experience
Asthma A condition where your airways become inflamed, swell, narrow, and generate excess mucus, making breathing difficult (Cleveland Clinic, 2022a).	For me, asthma causes shortness of breath, chest tightness, a dry cough, and wheezing. These symptoms become intensified at nighttime, when I am ill, or exercising.
Bilateral Femoroacetabular Impingement (Hip Impingement) Involves abnormally shaped hip joint leading to friction and damage to the joint (Johns Hopkins Medicine, 2022a).	Hip impingement is a common issue that is considered benign for many. However, in my case, it causes clicking in the hip joint, stiffness, limping, and sporadic sharp stabbing with occasional dull achy pain in the groin area.
Bursitis A condition characterized by inflammation of the bursa, small fluid-filled sacs that act as cushioning and helps decrease friction between bones, tendons, and muscles near your joints. Often this condition is caused by an injury, overuse, or infection (Mayo Clinic, 2020b).	This condition causes me extreme localized pain and tenderness, limited range of motion (ROM), severe swelling, and tenderness. My most recent episode lasted 1 month.
Cervical (neck) and Lumbar (low back) Bulging and Herniated disc Bulging disc is condition that occurs when the inner part of the intervertebral disc between the bones in the spine gets compressed and begins to protrude through the outer wall but remains intact. Whereas with a herniated disc, the outer wall	For me, my cervical herniated disc causes neck and shoulder pain, radiating sharp and burning arm pain, numbness and/or tingling in the arms and hands. Alternatively, my bulging lumbar disc causes me severe low back pain, sciatica, bilateral leg pain, pins and needles, as well as burning in low back, legs, and feet.

of the intervertebral disc partial or completely ruptures, placings pressure on the spinal cord or nerves (Mayo Clinic, 2022a).	
Chronic Sinusitis A condition that arises from long-term sinus infections and inflammation lasting longer than three months. It occurs when the sinus cavities become blocked and filled with fluid (Mayo Clinic, 2021d).	For me, this condition came out in full force about ten years ago. Some of the symptoms I experience with this condition are nasal congestion and inflammation, a runny nose, postnasal drip, and pain and swelling in the face around the cheekbones, eyes, nose, and forehead. Additionally, intermittently, it causes a reduction in my ability to taste and smell, ear pain, achy pain in my jaw and teeth, coughing, sore throat, and fatigue.
Complex Post-Traumatic Stress Disorder (C-PTSD) A condition where an individual has been exposed to multiple traumatic events through personal experiences or witnessing them (NHS, 2022a)	Unfortunately, I have experienced numerous traumatic events throughout my life, including numerous adverse childhood experiences (ACEs), several near-death experiences, and medical trauma, among other things. This compilation of adverse experiences has left me with C-PTSD. Due to this, some of the symptoms I experience are avoidant behavior, flashbacks, hyperarousal, difficulty with emotional regulation, dissociative symptoms, negative self-perception, altered perception in my belief system, distrust, and interpersonal relationship difficulty.
Dermatitis Involves skin inflammation which causes the skin to become dry, itchy, rash, blisters, ooze, and/or flake off (Mayo Clinic, 2021f).	Unfortunately, I have multiple types of dermatitis, including atopic (eczema), perioral (rash around mouth), contact (rash due to allergy), and seborrheic dermatitis (scalp). Some of the symptoms I have experienced due to these conditions are extreme skin sensitivity, dry and severely itchy skin, which is worse at night, as well as swelling of the affected area. It also causes embarrassing, painful, and raw feeling, bright red to brown patches of skin on hands, feet, ankles, wrists, neck, upper chest, eyelids, the inner aspect of the elbows and knees, face, and scalp. Specifically, on my hands, I get tiny, raised bumps that look like pimples but, when scratched, ooze and crust over.
Deviated Septum A condition where the nasal septum displaces from the nose’s center line, leading to difficulty breathing (Mayo Clinic, 2021e).	My deviated septum can make breathing challenging due to the obstruction and causes snoring, facial pain, as well as intensifies my chronic sinusitis.

Eosinophilic Esophagitis (EOE) A chronic allergy-induced condition where the walls of the esophagus become overwhelmed with white blood cells called eosinophils, triggering immune-mediated inflammation of the esophagus (Mayo Clinic, 2020d).	This condition is very temperamental, as it causes my throat to swell, leading to food getting stuck in my esophagus and choking. To prevent this, I often have to vomit whatever food I have eaten back up to keep from completely blocking my airway. The times when I have not been able to remove the blockage by vomiting, I have had to receive the Heimlich maneuver. Additionally, this condition causes chest and abdominal pain as well as heartburn.
Fibromyalgia An idiopathic (unknown cause) chronic condition characterized by widespread musculoskeletal pain, amplified pain sensations, and fatigue (Cleveland Clinic, 2022b)	Fibromyalgia causes me systemic muscle pain, extreme fatigue, cognitive and memory impairment, sensitivity to touch, sleep disturbance, exercise intolerance, mood disturbance, abdominal pain, headaches, nausea, sensitivity to light, muscle twitching, vision issues, and difficulty maintaining weight.
Gastroesophageal reflux disease (GERD) A condition where the stomach contents (food or liquid) leaks backward from the stomach into the esophagus. These corrosive fluids irritate the esophageal tissue and limit its ability to clear the esophagus (Mayo Clinic, 2022g).	In my experience, GERD causes heartburn pain, regurgitation, nausea, at times, difficulty breathing, difficulty swallowing, and the sensation of a lump in your throat. When I am lying down and not elevated, these symptoms become aggravated.
Gastritis Inflammation of the stomach lining, resulting from irritation of gastric mucosa (Mayo Clinic, 2022d).	Although this condition is currently inactive, it is not uncommon for those with EDS to have occasional random bouts of gastritis. When this condition is active, I experience bloating, nausea and vomiting, loss of appetite, unintended weight loss, and upper abdominal pain.
Generalized Anxiety Disorder (GAD) Characterized by persistent worry and tension about numerous things, both justified	In my case, my anxiety is a bit complex due to being both an anxious person from early childhood and having physiological conditions that exacerbate the issue. Some symptoms I experience with this condition are irrational fears and thoughts, feeling tense and nervous, difficulty concentrating, irritability, restlessness, stomach upset,

and unjustified (Johns Hopkins Medicine, 2021b).	heart palpitations, excessive sweating, muscle tension, fatigue, headaches, and in rare cases, panic attacks.
Goiter A condition characterized by abnormal enlargement of the thyroid gland (Mayo Clinic, 2021g).	The reason I have goiter is I am likely in the beginning stages of Hashimoto’s disease (an autoimmune thyroid condition) that alters thyroid function. Currently, I go through phases with my thyroid being within what is considered normal range to randomly being elevated, thus causing symptoms. When my symptoms are active, I experience hair loss, weight gain, brittle nails, fatigue, facial swelling, increased sensitivity to the cold, dry skin, constipation, muscle tenderness, and stiffness, and increased joint pain.
Hypermobile Ehlers Danlos Syndrome (hEDS) A genetic connective tissue condition caused by faulty genes that leads to collagen defects and dysfunction (Genetic and Rare Diseases Information Center (GARD), 2021b).	hEDS is my primary medical condition and is the cause of many of my secondary conditions (comorbidities). This condition is also the primary condition in what is referred to as the EDS trifecta. The trifecta also includes postural orthostatic tachycardia syndrome (POTS) and mast cell activation syndrome (MCAS), which are commonly co-occurring disorders. The condition is systemic in nature, as connective tissues are in nearly every part of the body. This condition primarily causes systemic joint hypermobility, loose and unstable joints that easily dislocate, persistent widespread pain, extreme fatigue, poor wound healing, fragile skin that easily bruises, severely dry eyes and mouth, vision issues, blood pressure regulation issues, and other cardiac issues, dental issues, digestive issues, bladder issues, and frequent headaches.
Inguinal Neuralgia A condition caused by compression of the ilioinguinal nerve as it passes through the lumbar (lower) spinal region, triggering nerve pain in the groin or pelvis (London Pain Clinic, 2017).	My experience with this condition is that it causes abdominal and pelvic pain, as well as radiating burning and numbness that occurs from the lower abdomen to the genitalia and inner thighs.
Intestinal Malrotation (Congenital) A condition where the intestine does not form or rotate correctly (Cleveland Clinic, 2022c).	Although I just recently discovered that I have this condition in the last three years, my doctors believe it is something I was born with and have decided to leave it uncorrected for the time being. Some of the symptoms I believe which are associated with this for me are intermittent abdominal pain and bloating in the midsection

	of my abdomen, malabsorption, and exacerbation of my alternating constipation and diarrhea.
Kidney Stones A condition where small, hard deposits of salts and minerals form inside your kidneys (Mayo Clinic, 2022f).	Luckily, I have only had one kidney stone so far which occurred the year I had my daughter. Although I only had one, the one I did have was large enough to get stuck in my ureter that it needed to be surgically removed. The symptoms experienced when this condition was active were excessive nausea, vomiting, and sharp pain in my back and lower abdomen. Other symptoms included fever, chills, and burning with urination. I can, without a doubt, say kidney stones were one of the worst pains I have ever experienced in my life.
Major Depressive Disorder A mood disorder characterized by one or more major depressive episodes (Mayo Clinic, 2018a).	Due to chronic illnesses, I experience depression for both psychological and physiological reasons. With that said, some symptoms I experience are depressed mood, loss of motivation, hopelessness, restlessness, irritability, lethargy, changes in appetite and weight, self-criticism, and withdrawal from others.
Mast Cell Activation Syndrome (MCAS) A condition that causes mast cells, a type of blood cell involved in mediating immediate allergic reactions. In MCAS, mast cells malfunction leading them to respond to environmental factors and things in the body they deem dangerous despite being nonproblematic and safe for much of the population. When this happens, mast cells mistakenly release excessive chemical agents (mediators) into the body, leaving the person (host) feeling less than optimal. Additionally, due to the high prevalence, sensitivity, and constant and random release of mast cells in body tissues, MCAS has the potential to cause a vast assortment of symptoms across	MCAS is a highly unusual condition since you can have various levels of allergic reactions, including idiopathic (unknown) anaphylaxis. MCAS is very difficult to keep under control. This is because MCAS causes mast cells to react to things you are not even allergic to. Thus, making it highly difficult to predict and protect yourself from flares, especially since mast cells are found in tissues throughout the body and are closely involved in normal bodily functions. Due to the systemic nature of MCAS, it causes a host of symptoms, including: • Neuropsychiatric symptoms: Brain fog, difficulty concentrating, insomnia, excessive daytime sleepiness, anxiety, depression, widespread weakness, headaches, tremors, numbness, pins and needles, auditory processing issues, hearing loss, and sensory processing issues. • Skin symptoms: Itching, flushing, rashes, hives, and swelling under the skin (angioedema). • Gastrointestinal (GI) symptoms: Diarrhea, constipation, nausea, vomiting, gut motility issues, GI tract swelling, abdominal pain, bloating, excessive salivation, dry mouth, and difficulty swallowing.

multiple systems (American Academy of Allergy, Asthma, and Immunology (AAAAI), 2022).	- Cardiovascular symptoms: Elevated and/or low blood pressure, high and/or low heart rate, poor circulation, and irregular heartbeat. - Urinary and Reproductive symptoms: Painful and burning urination, pain with intimacy bladder pain, excessive or insufficient urination, and painful or irregular menstrual cycle (periods). - Respiratory symptoms: Excessive phlegm, runny nose, sinus congestion, sneezing, swelling of the airway, wheezing, and cough. - General symptoms: Reduced endurance, exercise intolerance, itchy, bruising easily, and dry and itchy eyes. During flares, MCAS also causes hypermobility of the joints, thus further exacerbating my EDS, making the joint pain nearly unbearable and dislocations highly likely.
Meralgia Paresthetica A condition involving nerve entrapment on the outer aspect of the thigh which causes neuropathic pain (Mayo Clinic, 2022b).	This condition causes me to experience burning, tingling, numbness, and increased sensitivity to pain on the outer upper aspect of my legs.
Migraines A chronic condition characterized by moderate to severe throbbing pain on one side of the head, usually generally associated with nausea and vision changes (Mayo Clinic, 2021c).	Besides the symptoms caused by the EDS trifecta, I would have to say this is one of my more frustrating conditions. This is likely because my migraines also aggravate my other conditions leading to intensified symptoms. With my migraines, I often experience aura, which causes temporary vision changes about an hour before the head pain begins. Other symptoms I experience include intense throbbing head pain, extreme sensitivity to smells and light, nausea, vomiting, and occasionally difficulty speaking and facial numbness.
Narcolepsy Type 2 (w/o cataplexy) A chronic neurological disorder that affects the nervous system leading to sleep disruption and excessive daytime sleepiness (Mayo Clinic, 2020e).	My narcolepsy impacts my wake and sleep cycles leading to extreme uncontrollable daytime sleepiness and sleep attacks (bouts of falling asleep at inappropriate times), which last for a few seconds or mins in my case. During sleep attacks, I am often unaware of their occurrence as my body continues to function on autopilot. This condition also causes me to have poor rapid eye movement (REM) sleep, sleep paralysis (temporary loss of the ability to move

	when falling asleep), difficulty maintaining sleep, hypnagogic hallucinations (hallucinations when falling asleep or waking), and at times restless leg syndrome.
Osteoarthritis (OA) A condition that causes chronic inflammation leading to gradual deterioration and loss of joint cartilage, leading to loss of normal joint structure and function (Mayo Clinic, 2021b).	Although I am sure I have OA in numerous joints, currently it mainly impacts my right ankle and finger joints. OA causes my joints to be painful, feel tender and stiff, as well as crack and swell.
Pelvic Floor Dysfunction A condition where the pelvic floor muscles have difficulty tightening and relaxing properly (Cleveland Clinic, 2022d).	This condition has caused me severe pain and discomfort with sexual intimacy due to increased pain during sexual penetration. This condition also causes heaviness, fullness, pressure, pulling, and aching in the vagina area that worsen as the day goes on or with bowel movements. Additional symptoms include pelvic pain, stress urinary incontinence, bowel movement dysfunction, and pain during urination.
Post-partum Depression (PPD) A type of depression that occurs after childbirth (Mayo Clinic, 2022e).	My experience with PPD was not entirely typical. However, I did have mild to moderate symptoms after my daughter was born, which was to be expected due to the traumatic nature of her premature birth and having multiple risk factors. With that said, my symptoms did not become severe until I stopped breastfeeding at ten months post-partum. Some of the symptoms I experienced include intense sadness and guilt, difficulty bonding with my daughter, suicidal ideation, feeling like a bad mother, feeling continually depressed, severe mood swings, changes in sleeping habits and patterns, difficulty concentrating, excessive bouts of crying, having thoughts of harming my daughter, and feeling withdrawn from others.
Postural Orthostatic Tachycardia Syndrome (POTS) Is considered a form of dysautonomia. This condition causes dysfunction of the autonomic nervous system (ANS), which controls the body’s involuntary automatic functions such as blood pressure,	POTS generally causes systemic issues since it impacts the ANS and causes a host of symptoms. For this reason, it is easier to break down the symptoms I experience by systems: • Generalized Symptoms: Impaired vision (blurred vision and floaters), sensitivity to light and sound, temperature regulation issues, issues with fluid production (dry eyes, dry mouth, difficulty swallowing, dry skin),

heart rate, temperature regulation, pupil response, and digestion, to name a few. In POTS, the ANS dysfunction leads to both decreased and overactivity of the sympathetic and parasympathetic nervous systems causing exaggerated alterations in blood flow when sitting and standing (Cleveland Clinic, 2022e).	weakness, exercise intolerance, muscle pain, and tremors. • Orthostatic Intolerance Symptoms: Balance issues (difficulty standing still), fatigue, dizziness (near fainting), and pallor (turning pale). All of which are increased by upright posture. • Neuropsychiatric Symptoms: Depression, anxiety, and hypervigilance which are frequently misdiagnosed as bipolar disorder despite these symptoms are caused by physiological response not a psychological issue. Additional symptoms consist of brain fog, headaches/migraines, neuropathic pain, and cognitive impairment. • Pulmonary Symptoms: Shortness of breath and rapid breathing • Cardiovascular Symptoms: Chest pain, uncontrolled high or low heart rate, abnormal blood pressure functioning (high or low blood pressure), and blood pooling. • Urinary System: Complications with urine retention and excretion. • Gastrointestinal (GI) Symptoms: Nausea, vomiting, diarrhea, constipation, abdominal pain and cramping, acid reflux, and impaired gut motility.
Pudendal Neuralgia A condition that occurs when the pudendal nerve is injured, irritated, or compressed, causing nerve pain in the pelvis and genitals (NHS, 2021).	Pudendal neuralgia is an excruciatingly painful condition that causes me increased pain sensitivity, numbness, pins-and-needles sensation, and sharp and burning pain in the genitals, urethra, perineum, and anus. This condition has also caused me to experience occasional full sensation in the genital region, as well as swelling, raw, and electrical shock sensations. Often these symptoms are exacerbated by sitting as well as at night and cause pain and other issues during intimacy.
Raynaud's Syndrome This condition occurs when the blood vessels in your hands and feet temporarily constrict and limit blood flow due to an overreaction to low temperatures or stress (Mayo Clinic, 2020f).	Raynaud's causes my hands and feet, particularly my fingers and toes, to be highly sensitive to temperature changes. For example, my fingers and toes will turn pale or blue and become numb, as well as triggers a pins and needles sensation in these areas when exposed to cold temperatures. This reaction also occurs in response to stress and emotional distress. In contrast, when my hands are warm or in hot temperatures, my fingers and toes will turn red and can become swollen and painful.

Recurrent Acute Otitis Media (ear infection) This condition occurs due to inflammation or infection in the middle ear, the air-filled space behind the eardrum when the eustachian tube continually remains blocked due to repeat infections, allergies, swelling of the adenoids, or ear trauma (Penn Medicine, 2022).	To date, I have had over 200 ear infections, as I started having ear infections as soon as I began cutting teeth as an infant. This pattern of continual infections persisted till the age of 18 when they randomly dramatically decreased. However, these infections occasionally still occur. In addition, my ear infections have also caused each of my ear drums to rupture multiple times over the years, one of which occurred this year. Some of the symptoms I experience due to this condition are hearing loss, continuous drainage and pressure in ears, severe ear pain, loss of balance, and irritability when an infection is active.
Sciatic Neuritis A condition characterized by spinal nerve compression in the lower back leading to pain, inflammation, and irritation in the back, hips, and out aspect of the leg (Mayo Clinic, 2020c).	Sciatica is an excruciatingly painful condition. However, the plus side is that this condition is intermittent, not constant. Some symptoms I experience when I have a flare are severe pain in the lower back, buttocks, hip, and legs that worsens when sitting. Other symptoms include burning and tingling sensation, weakness, numbness, and shooting pain in the legs and feet, making it difficult to walk or stand.
Severe Preeclampsia A condition that occurs during pregnancy and is diagnosed after 20 gestational weeks. Severe preeclampsia causes maternal hypertension (above 160/110), swelling, and high levels of protein (3+ or greater) in urine that indicate kidney or other organ damage. Severe preeclampsia is considered a medical emergency and, if left untreated, can lead to severe or even fatal complications for both the mother and baby (The Society for Maternal-Fetal Medicine (SMFM), 2013).	Prior to becoming pregnant, I had always had normal blood pressure. However, as soon as I hit my third trimester, I began to experience preeclampsia symptoms. These symptoms included severely elevated blood pressure (175/110, which later rose to 210/150), severe headaches, sudden severe facial and body edema, shortness of breath, abrupt vision alternations, right upper abdominal pain, severe nausea and vomiting, and restricted fetal growth. Due to this condition, I had severely decreased kidney and liver function to the point where I was becoming close to having what is considered kidney and liver failure. Because of this, I had to deliver my daughter at 28 weeks and 1-day gestational age via emergency cesarean. Since she was three months early at 2 pounds 1 ounce, she had to spend 89 days in the neonatal intensive care unit (NICU). This condition also led me to spend 6 days in the hospital to get my blood pressure under control and improve my kidney and liver function.
Tinnitus, Unspecified Laterality A condition characterized by ringing or buzzing noise in one or both ears that can be constant	In my case, tinnitus causes me to hear random sounds such as ringing, clicking, buzzing, and hissing in one or both of my ears at various pitches and volumes.

or come and go and is often associated with hearing loss (Mayo Clinic, 2021a).	
Temporomandibular Joint Dysfunction (TMJD) A condition that causes the TM joint is that joint that connects your jawbone to your skull and aid in facilitating movements like chewing and speaking. TMDJ is where the joints become inflamed due to trauma, teeth grinding, and leading to severe pain (Mayo Clinic, 2018b).	For me, TMJD causes severe muscle tension and pain in the jaw leading to migraines, facial swelling, difficulty chewing, dull and achy pain in and around the ear on the affected side and clicking and locking of the jaw.
Venous Insufficiency This condition arises when the vein walls are weakened and valves are damaged, leading to venous blood refluxing in the vein, thus causing edema in the leg (Johns Hopkins Medicine, 2021a).	This condition causes me severe swelling in the legs and ankles after prolonged periods of standing, results in varicose veins, and dull achy pain in legs.
Vulvodynia A condition that causes chronic pain, stinging, and burning in the vulvar area lasting more than three months and does not have a discernible cause (Mayo Clinic, 2020a).	This condition causes tenderness when localized pressure is placed within the vulvar vestibule. This condition causes pain and tenderness provoked by touch or pressure, such as sexual intercourse, inserting a tampon, or prolonged sitting. The vulvodynia condition is not only painful but significantly impacts a women’s sexual function and quality of life.