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Outside the Boundaries of Biomedicine: A Culture-Centered Approach to Female Patients Living Undiagnosed and Chronically Ill

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Outside the Boundaries of Biomedicine: A Culture-Centered Approach to Female Patients Living Undiagnosed and Chronically Ill

by

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of the requirements for the degree of
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ABSTRACT

As a community who voices feeling misunderstood, unheard, and uncared for by the medical system, female patients who live undiagnosed and chronically ill and their health narratives lie beyond biomedical boundaries. To examine how chronically ill and undiagnosed female patients narrate their experiences in and with the biomedical system and how these narratives resist biomedical health standards, I employ semi-structured interviews with 20 female patients living undiagnosed and chronically ill as well as engage in critical autoethnography to recount my own health experiences living a part of this community. In utilizing the culture-centered approach to health communication as a theoretical framework and an abductive thematic analysis to explore these health narratives, participants voice being pushed into and seen as outside the biomedical box, the biomedical failures and unmet community health needs, and how the interview itself fostered community. The narrated health journeys from this community not only begin to fill the discursive gaps biomedicine creates, teaches, and reinforces, but also practically aids in a new era of communicative medicine that prioritizes support over diagnosis and care over cure.

CHAPTER ONE:

INTRODUCTION

They each stare at me, eyes open wide as if my body is a joke- a space to be mocked. I can't even fight to be taken seriously as my mouth feels cemented shut and each spoken word takes every piece of energy I have left. Each muscle in my body feels glued to the hospital bed, like a magnet pulling me deeper and deeper into the hard surface… "Bianca, are we thinking this is anxiety? Would you like something to calm you down?" I don't want to be calmed down. I want to be heard. Wouldn't you have anxiety if you woke up one day and could barely walk or talk? I don't understand what I have to do in order to have my pain, my fear, my life be taken seriously. Every test comes back normal, once again, and they decide to check my reflexives. Nothing. Not one inch of movement. His face turns pale, and he slowly steps out the room to make a phone call. Are you going to call me crazy now?

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I have lived as an undiagnosed and chronically ill female patient for four years. Living with these identities has completely altered all aspects of my life and the way in which I move through this world. My illness experience has brought me to this very moment writing this paper as I am inspired to share my story as well as that of the 20 other female patients living undiagnosed and chronically ill, who I interviewed for this project. I begin this paper with a narrative to provide a moment in time living as an undiagnosed and chronically ill female patient. In this moment and in majority of my health experiences, my illness, pain, story, and life were not taken seriously by my medical professionals. Living chronically ill, undiagnosed, and female, I have felt continuously uncared for by the medical system. From a biomedical perspective (Harter et al., 2005), I do not fit the standards of what a "diseased" person should look, act, and feel like. As a female, I am constantly framed in hysteria and told that my symptoms are psychosomatic (Johansson et al., 1996; Werner & Malterud, 2003). Living chronically ill, my body is stigmatized and incurable (Millen & Walker, 2001), therefore difficult to explain where my sickness resides or ends in my body. Without a diagnosis, I do not fit into certain categories or molds of a particular disease, and therefore doubted if I have one (Lillrank, 2003).

I have found living with these identities can be an often lonely and isolating feeling. It is difficult for others to understand these types of experiences unless they live them. Due to this, I began to search for online social support and discovered an entirely new world of individuals who collectively share and empathize with one another's medical experiences as well as the pain, frustration, and isolation that accompanies them. I realized that many individuals did not feel heard in their illness experiences and that this is a community, whose members, just like me, felt misunderstood, uncared for, and left out of biomedical understandings and practices. Similarly, I witnessed a community eager to voice their individual and collective health needs, stories, and identities. It is not that this community does not exist, it is that voices of members of this community have not been heard in ways that matter to the biomedical discourse.

Based on my own experiences as a member of this community and the stories I have heard from other members of the community, in this thesis project, I look to attend to the unique and unheard narratives of female patients living chronically ill and undiagnosed. These narratives lie beyond biomedical structures and normativities and can therefore help in understanding how members of the community interact in and with the biomedical system. By evaluating these experiences and prioritizing the individual and collective health needs of this misunderstood and uncared for community, I hope to begin to fill the discursive gaps biomedicine creates, teaches, and reinforces. To accomplish these goals, I share my own experience utilizing critical autoethnography, and by collecting and analyzing interview narratives from other members in this community of females who are chronically ill and living undiagnosed. In documenting these narratives, I will use a culture-centered approach (CCA) as a theoretical framework, as the CCA has been widely used to document how narratives from the margins have been absent in biomedical discourse (Yehya & Dutta, 2010; Basu, 2011; Basnyat, 2011; Koenig et al., 2012).

This project includes four chapters: the first chapter introduces the undiagnosed and chronically ill female patient experience and the biomedical system while also presenting a literature review of existing academic research and other sources of information such as online communities that are foundational to this project; the second chapter explains the methodological considerations and approaches of the project; the third chapter presents the thematic findings, and the fourth chapter includes the theoretical and practical contributions as well as limitations and future directions.

II. Literature Review

In this section, I introduce existing academic research about undiagnosed and chronically ill female patients and biomedicine as well as address how I seek to fill the gaps in academic literature on these topics. Additionally, I present the culture-centered approach to health communication as a theoretical framework that guides and situates this research project.

A. Undiagnosed and Chronically Ill Female Patients

When searching for social support groups with those located in similar health positions as myself, I discovered many stories of people who face similar unwanted and emotionally intensive experiences in the biomedical system as myself. Specifically, I found a plethora of Facebook groups with individuals who identified as chronically ill and undiagnosed who expressed their frustration with not receiving a medical diagnosis, with unwanted and stigmatizing interactions with medical professionals, and feeling misunderstood and burdensome to their medical professionals. These narrations and lived experiences reflect existing research, yet there appears to be is a lack of academic research that intersects all three of the identities of living undiagnosed, chronically ill, and female.

Undiagnosed and Medically Unexplained Symptoms

Individuals who live undiagnosed and have medically unexplained symptoms have a unique health experience compared to those who are diagnosed. Inhabiting the “medical orphan” status (Aronowitz, 2001), individuals who are undiagnosed may encounter difficult and unwanted health and illness experiences as well as feel abandoned by the medical system. With over thirty million people living undiagnosed in America (Spillmann et al., 2017), 250-280 rare diseases discovered and acknowledged annually internationally (Gainotti et al., 2018), and forty percent of rare diseases diagnosed incorrectly (Shen et al., 2019), undiagnosed patients and rare and unexplained diseases impact many individuals globally.

As undiagnosed and chronically ill patients endure shame, disbelief, and skepticism in their illness endeavors (Lillrank, 2003), they are stigmatized in their experiences and often face unwanted and undesirable responses from peers, family, and even medical professionals (Carnevale, 2007). Goffman (1963/1968) argues how stigma and a “spoiled identity” warrants negative reactions from others, fueling shame and an outsider status. Groopman (2007) contends that clinicians’ medical practices such as listening can be shaped by stigma, potentially causing errors, even a misdiagnosis and/or lack of a diagnosis. Similarly, Spillmann et al., (2017) argue undiagnosed patients often express that having to validate and legitimize their symptoms to healthcare providers are large parts of their health stories. As patients who are undiagnosed and inhabit medically unexplained symptoms often acknowledge the "chaotic" nature and structure of their health stories as well as the concern symptoms may be deemed as psychosomatic in their illness narratives, undiagnosed patients are actively worried about their ongoing medical treatment and support (Nettleton et al., 2004).

LaVecchia (2019) found "undercared-for chronic suffering," or what they coin as the experiences of patients who are chronically ill and experience difficult diagnostic journeys, dictates one's lived experiences inside and outside the doctor's office. They found living undiagnosed affects clinician attitudes towards patients, patient understandings of care and treatment, and even patient perceptions of their own illness experiences. Undiagnosed patients and those with medically unexplained symptoms are often accompanied by uncertainty and complex diagnostic journeys, and this can inspire fear of being believed and questioned in their medical experiences (Rausch, 2021). Due to the uncertain and ambiguous nature of an undiagnosed condition, medical professional communication work can shift, often restricting one's communicative goals (Hintz & Scott, 2021). This can lead to isolation and unwanted health and personal experiences. In their autoethnographic account of living undiagnosed and chronically ill as a nurse, Ricker (2020) explains how living with these identities has affected them in both familial, social, and professional contexts, often feeling isolated in the unknown, loss, and hidden identity of living undiagnosed and chronically ill. Additionally, Ricker (2020) calls for medical professional education on undiagnosed illness and rare diseases. They urge for further research to attend to the lived experiences and cultural contexts of patients who are undiagnosed and chronically ill, and this project seeks to address this call and examine the health stories of female patients living undiagnosed and chronically ill.

Chronic Illness and Female Patients

When examining the social support Facebook groups, many individuals who voiced their experiences identified as female. Those who identified as female, undiagnosed, and chronically ill often discussed their experiences in a biomedical system, including how their medical professionals would not take their symptoms seriously. Many mentioned they were either seen as "crazy" or that their pain was "all in their head". Similarly, a handful of people expressed how exhausted they were in navigating these situations, constantly fighting for their body and well-being. Scholarly conversations that examine chronically ill female patients also reflect these experiences. Kralik et al., (2001) examine female patients who endure chronic illness, and many identify with how memorable and monumental receiving a medical diagnosis was to their illness journey. As female patients with diagnosed chronic illness often feel undermined and minimized in their symptom severity by medical professionals (Koch et al. 1999), they are faced with the burden of immense communicative "work" to be taken seriously, believed, heard, and credible in their chronic pain (Werner & Malterud, 2003).

In health communication studies, Hintz's (2018; 2019; 2020) work is deeply foundational in examining female patients with chronic illness. Similarly, Scott, Hintz, & Harris' (2022) qualitative piece that examines how structures of negative messages that discuss menstruation appear in the health experiences of women with chronic pelvic and genital pain conditions (CPGPCs) is also important to this project. The authors acknowledge CPGP female patients often undergo difficult diagnostic journeys and are untreated, examining similar identities to this study, which is chronically ill, undiagnosed, and female. Findings illuminated how early-life communication limits how CPGP female patients dialogue about their health experiences in adulthood as well as how this communication normalizes women’s pain, further explaining the difficult diagnostic journeys and delays of women a part of this community. Hintz (2020) acknowledges the lack of communication research and theory about pain communication and to address this, provides a detailed agenda with diverse methodologies and theoretical approaches to advance pain communication (PC). To address the lack of literature about pain communication, she suggests methodologies such as the CCA, the theoretical and methodological approach of this study. She explains, “examining PC through a CCA approach would produce understandings of the localized knowledge and marginalized experiences of these populations” (p. 414).

Although there is existing literature on undiagnosed patients and medically unexplained symptoms, unwanted and stigmatizing experiences with medical professionals when living undiagnosed, and female patients and chronic illness, there is a lack of literature on female patients living undiagnosed and chronically ill. It is important to point out the lack of literature for this community as these three variables and identities overlap with one another and influence this population’s position at the margins of the biomedical system. Given this lacuna, I seek to document and understand how members of the community who live at these intersections communicate about the issues they face with biomedicine.

B. Biomedicine

Biomedical teaching, understanding, and practice of health in western contexts constitutes a normative body and *doing* and *being* of health. Harter et al. (2005) contend the western biomedical model of health “reduces disease to a biological mechanism of cause and effect that can be affectively diagnosed and treated through science and technology” (p. 22). Similarly, Spieldenner & Toyosaki (2020) contend the biomedical model has become the dominant "master narrative," perpetuating Othering of communities that do not fit the biomedical health mold and standards (p. 22). Thus, it is productive to examine the central tenants and principles of biomedicine to examine the lived experiences of undiagnosed and chronically ill female patients.

By individualizing health and discounting communal, cultural, and structural causes of illness, biomedical understandings assume that sickness is solely a physical manifestation that can only be treated in and through physical means (Du Pre, 2005). As noted in the previous section, women who endure difficult diagnostic journeys highlight the moment they finally received a diagnosis. As "classification tools" (Jutel, 2014, p. 4), diagnoses are endorsed through medical standards and comparisons to diseases that already exist within the confines of medicine (Barker, 1998). Therefore, when diagnosing an individual, biomedical understandings fail to recognize the individual holistically and instead, analyze a disease and its symptomology to isolate a "biological cause for the abnormality" (Dean & Street, 2015). Similarly, as diagnoses are legitimized by medical providers and medical providers employ scientific instrumentation to justify these diagnoses (Cox, 2016), when these instruments report inconclusive or ambiguous test results, as is common with individuals who are undiagnosed (Shen et al., 2019), patients must either resist biomedical understandings to legitimize their illness or become discounted and erased from health discourse.

A plethora of the medical and health communication scholarship operates with the assumption that the proposed health interventions of medical systems and providers are inherently effective (Dutta-Bergman, 2005). As biomedicine operates at the individual level, it is assumed one is likely to pursue and fulfill needs that actively improve and fix their bodies (Frank, 2002) and is expected to be financially responsible for these interventions

(Airhihenbuwa, 2007). Through this, we see that health effectiveness is measured on individual levels and biomedical frames continue to disregard structural and cultural contexts of health and illness, and its ability to mitigate the concerns of local communities and their meanings of health (Dutta, 2010).

Another fundamental notion within the biomedical model is paternalism, or what Ellingson & Borofka (2017) refer to as the idea that because healthcare providers have the medical expertise they do, they should be "obeyed by patients, even if the patient disagrees with their treatment recommendations" (p. 96). Similarly, health communication in general has been deemed "top-down," reifying medical paternalism as patients and members of the public are often framed in health communication literature as "pathetic and ignorant, needful of persuasion to change their behavior, resistant to change, obstinate, recalcitrant, lacking self-efficacy, chronically uninformed, and 'hard to reach'" (Lupton, 1994, p. 56). When health provider knowledge is privileged and deemed as superior to patient personal knowledge, history, and emotions (Spieldenner & Toyosaki, 2020), patients are expected to abide by biomedical norms in order to be viewed as cooperative and compliant.

As illness and health narratives act as the "self-telling body" (Charon, 2009, p. 120), they are foundational to one's health and illness experience (Spieldenner & Toyosaki, 2020). By prioritizing biomedical ways of knowing and being rather than embodied ways of feeling and sensing, "the biomedical model discounts narratives that attach personal and cultural significance to the physical experiences of pain, nausea, fatigue, etc." (Spieldenner & Toyosaki, 2020, p. 22). As biomedical standards constitute the "normal" body and the "normal" expression of disease, it also establishes what narrative exists inside and outside the boundaries of health, facilitating "narrative imperialism" (Frank, 2004, p. 212). Health narratives "constitute health by storying (un)healthy bodies and (un)healthy practices" (Spieldenner & Toyosaki, 2020, p. 21). Therefore, if a patient does not fit biomedical standards, their knowledges and expressed performances of illness and health are not prioritized, and their scientific measurements and testing are inconclusive/negative, their narrated experiences of illness and disease are in danger of not being heard or considered as important by medical professionals, when in fact, it is all a patient may have to communicate in a biomedical system. This further pushes communities who do not fit biomedical standards of health and illness stories to the margins.

Just as the biomedical system hurts patients and their health experiences, other medical stakeholders such as medical professionals are negatively affected as well. Chronic stress and burnout continue to rise for both practicing and in training medical professionals (Dyrbye et al., 2014; Dyrbye & Shanafelt). Elder et al. (2020) explore the stressors of medical professionals in emergency medicine and state how they voice a lack of support, inadequate resourcing, incongruent expectations on societal and organizational levels, and overwhelming workloads as key factors to their stress, all leading to an overall feeling of "demoralization in the workforce". As burnout and stress produce extreme amounts of exhaustion, depersonalization, and sentiments of reduced accomplishment, both medical professionals and their patients become negatively impacted (West et al. 2018). As all medical stakeholders navigate a complex and overwhelming biomedical system, West et al. (2018) contend burnout and stress has shown to affect the quality of patient care, such as lower patient satisfaction and increase medical errors. These factors also directly impact how the healthcare system operates, such as increasing medical professional turnover and negatively affecting their safety and well-being. Through this, we recognize biomedical tools and standards produce unfavorable working conditions for medical professionals and inadvertently negatively affect their patients.

Through these central tenants and assumptions, I argue biomedicine is not only a culture, but also a structure. As biomedicine is taught, produced, and reinforced in all aspects of the western medical system and impacts all medical stakeholders, Other and stigmatized ways of knowing, acting, and doing health that do not fit within the specific boundaries and constructions of biomedicine are pushed to the margins of the medical/health discourse. Jensen et al. (2019) discuss Conrad's (2007) theory of medicalization, which contends medicalization is "marked by the construction of a diagnosis, oversight by medical experts, employment of technologies of sight, testing, and treatment, and de-contextualization of experiences" (p. 272). Jensen et al. (2019) argue beyond understandings of *why* medicalization occurs and seek to understand *what* medicalization conveys and *how* it does so. In this project, I extend this conversation by examining the lived experiences of undiagnosed and chronically ill female patients and ask *how* biomedicine interacts with this stigmatized population and what narratives emerge from these interactions.

It is through this understanding that I contend the CCA is a theoretical approach that allows for a clearer understanding as to how biomedicine interacts with this community. Through the CCA, the lived experiences and health needs of this uncared for and misunderstood community can be heard on their accordance. As well, the CCA serves as a lens to understand how and why biomedicine creates unfavorable lived experiences for this population as well as other stigmatized communities.

C. Cultured Centered Approach to Health Communication

The culture-centered approach to health communication interrogates the political and cultural structures of whiteness and western normativities that frame biomedicine. The work of Communication scholars such as Mohan Dutta and Ambar Basu are foundational to the research commitments and engagements of this CCA project (Dutta, 2007, 2008, 2014, 2015, 2018; Basu, 2011; Basu & Dutta, 2008, 2009; Dutta & Basu; 2018). The CCA theorizes methods and frames that highlight community participation and voices at the margins of society in order to co-construct new meanings and knowledge. Through this method, "cultural contexts are placed at the core of meaning-making processes, and meanings are dialogically co-constructed by researchers and cultural participants" (Basu & Dutta, 2009, p. 86). These local meanings -- alternative rationalities -- challenge Eurocentric and western value systems of thought, interaction, and knowledge by critically examining how meanings of health are culturally situated. This approach grants narrative and cultural agency through (counter)storytelling, creating spaces to discuss marginalized communities' individual and collective health needs. The CCA also facilitates the process of communities being able to be heard on their own accordance in their own terms, once again prioritizing the cultural agency of local cultural voice within western systems of thought and practice.

The CCA is used across communication fields such as health, intercultural, and organizational communication to theorize new knowledge at the margins, linking understandings of health, culture, voice, agency, and marginality. This is done through various applications of CCA, such as the examination of African American farmers' lived experiences (Carter & Alexander, 2020), Indian truck drivers' narratives of health (Sastry, 2016a), men in rural Bengal and their health meanings (Dutta & Basu, 2007), Bangladeshi immigrants' health experiences (Dutta & Jamil, 2012), and sex worker voices in India (Basu, 2011). The CCA is also used to advance understandings of community-based participatory lenses for evidence-based health research (Wallerstein et al., 2019), create critical health frameworks such as a health discourse analysis during the COVID-19 pandemic (Sastry & Basu, 2020), and critically examine participatory campaigns such as the Radio Communication Project (RCP) in Nepal (Dutta & Basnyat, 2006). Similarly, CCA has been used to explore the tension between biomedical discourse and cultural and health meanings. For example, CCA was used to discuss Nepalese women living in poverty and their health understandings (Basnyat, 2011), Asian Indians living in the United States and their dietary health meanings (Koenig et al., 2012), and Druze women and their caregiver daughters and their religious and cultural constructions of health (Yehya & Dutta, 2010).

Logically, then, the CCA provides a valid theoretic framework and analytical lens to understand how biomedicine as a larger system marginalizes and Others the voices of undiagnosed and chronically ill female patients. The CCA also allows me to create a space where undiagnosed and chronically ill female patients, their medical stories, and health needs are heard on their own account. Their lived experiences and voices become central to the research and sensemaking process, providing new insights as to how this stigmatized community engages in and with a biomedical system. In this project with undiagnosed and chronically ill female patients, I draw on the CCA's theoretical and methodological commitments to collaboration, solidarity, and alternative modes of thought. It is with these theoretical commitments I formulate two broad research questions that guide this project:

RQ1: How do chronically ill and undiagnosed female patients narrate their experiences in and with the biomedical system?

RQ2: How might these narratives resist biomedical health standards and norms?

CHAPTER TWO:

METHOD

The CCA advocates research methods that foreground unheard and unaccounted for voices on the margins of society to co-create new knowledges. In this study, I use critical autoethnography and interviewing with female patients living undiagnosed and chronically ill to document new meanings and understandings of how this community interacts in and communicates about the biomedical system that appears to marginalize them. In what follows I explain my research methods, starting with data production and then I discuss data analysis.

I. Data Production

A. Critical Autoethnography

I utilize critical autoethnography to tell my own story of living chronically ill, undiagnosed, and female as well as engage in these stories through a postcolonial reflexive lens. As a method that makes sense of the interconnected nature of identity, culture, and relationships, critical autoethnography challenges assumptions of stigmatized identities as well as interrogates privileged ones (Boylorn & Orbe, 2014). Critical autoethnography also administers a space to tell my uncounted story as Berry (2020) argues autoethnographies are untold stories that are often neglected, allowing one to “acknowledge, explore, and advocate a multiplicity of stories (and beings) that exist, are valuable, and merit inclusion and care” (p. 5).

Additionally, critical autoethnography is used within the CCA to further interrupt and decolonize imperial sites of knowledge and privileged identities (Dutta & Basu, 2018). Dutta (2018) contends autoethnography serves as a method where “structures of pain in the subjectivity of the body undo and redo the structures of academic knowledge production and circulation, producing sites of articulation from the colonized margins, and working from the personal to a collective" (p. 94). Through autoethnography, the personal stories and the material body lay on the page, allowing for many possibilities of resistance and counter-storytelling (Dutta, 2018). I look to employ autoethnography, paying specific attention to how my stories resist biomedical and western knowledges of health and illness. Therefore, my reasoning for implementing critical autoethnography in this project is two-fold: I seek to speak *with* this community by sharing my own story in a biomedical system as well as explore my lived experiences and health identities through a postcolonial reflexive lens.

I seek to employ critical autoethnography in this project to explore my lived experiences self-reflexively and "call out positions of privilege and expose moments of vulnerability" (Boylorn & Orbe, 2016, p. 18). I can do this by implementing postcolonial reflexivity, which, as Shome (1996) argues, is a lens that allows one to engage in critical thought that examines academic discourse against larger structures and understandings of western practices. She contends we must ask critical questions that permit us to "recognize the latent ideological structures that inform our scholarship and practices" (p. 46). Postcolonial reflexivity is a research commitment of this project, and it will help form the foundation for my methodological approach. I situate postcolonial reflexivity within the CCA as CCA draws inspiration from postcolonial theory and its philosophies. The two share similar politics of thought and action, both prioritizing knowledge production and meaning making at the margins.

Postcolonialism has been used across disciplines to critique and resist normative western and Eurocentric viewpoints as well as to offer new ways of imagining histories (Said, 1978; Guha, 1988; Spivak, 1990, 1999; Chakrabarty, 1992). In theory and practice, postcolonialism is also used in the communication field, highlighting marginalized ways of knowing and thinking to listen to unexplored knowledges (Shome & Hedge, 2002; Beverly, 2004; Munshi, 2005; Chavez, 2009; Basu & Dutta, 2009; Basu, 2011; Pal, 2015; Cruz & Sodeke, 2020). By interrogating dominant, Eurocentric, and western practices and perspectives, postcolonial theory offers new ways of understanding and being in the world by spotlighting “insurgent knowledges that come from the subaltern, the dispossessed, and seek to change the terms and values under which we all live” (Young, 2003, p. 20). Postcolonial theory and reflexivity live in a constant tension with upheld institutionalized knowledge and seeks to “undo and redo the historical structures of knowledge production that are rooted in various histories and geographies of modernity” (Shome & Hedge, 2002, p. 250). Since the framework continuously analyses and questions normative structures, knowledges, and practices, postcolonial theory and postcolonial reflexivity allow for new insights into marginalized and Othered populations’ unique lived experiences and stories of resistance, community, and solidarity. There is so much knowledge that exists on the margins, knowledge that we do not even know exists, and postcolonial theory and reflexivity provides an avenue to listen to the unheard voices that are overlooked in dominant discourse, including the biomedical discourse.

These were all important considerations as I moved through and navigated each step of this project. I used critical autoethnography as a mechanism to again, not only tell my health story living as an undiagnosed and chronically ill female patient, but more importantly, to be reflexive in these critical questions and processes of un- and re-learning. One way I began this process of un- and re-learning through critical autoethnography was to evaluate my researcher positionality. As a critical qualitative researcher, I was committed to looking inward at my author positionality throughout each step of the research process. I strived to be cognizant of the invariable relationship between space and power as acknowledging one's space is a "means and medium of power that is socially constituted through material relations that enable the communication of specific politics" (Shome, 2003, p. 40). I also recognized that my social location as a white, cisgender, and sometimes, depending upon my health state, an able-bodied researcher is not only "epistemically salient," but can potentially be "discursively dangerous" when speaking about and for a group less privileged than myself (Alcoff, 1991, p. 7). As a member of the community being researched, this notion heavily influenced the work I engaged in as it was imperative for me to speak with, rather than for, this community to participate in new thoughts and understandings collaboratively.

Throughout each step of this project, I questioned who is being privileged and who is being silenced? What discourse about this community continues to lie in the margins? How can we listen to the voices of those who are absent in knowledge production spaces? How does my research positionality and privileged identities influence the research process? How do I plan to uphold and prioritize principles of confidentiality, protection, representation, transparency, and healing in this project? What is at stake when I mediate the stories of this community? How do I avoid perpetuating the single story of female patients living undiagnosed and chronically ill? I purposed these questions not to answer them in comprehensive ways, but to allow them to guide each step of the research. They allowed me to be reflexive in my sensemaking processes of author positionality and the power that accompanies it. It also allowed me to establish my critical commitments of prioritizing care, inclusivity, and healing, as well as build relationship and community with my research participants. These sentiments were facilitated in all facets of the research process, including the recruitment of participants, the facilitation of semi-structured interviews, writing my own narrative story, and analyzing the collected data.

B. Interviews

i. Participants and Recruitment

Approved by the University of South Florida's Institutional Review Board, previously or currently undiagnosed, chronically ill, and female patients ages 18 or older were eligible for participation in this study. Undiagnosed, chronically ill, and female are all characteristics that can be self-identified by the participant and do not necessarily need to be considered as such by a medical professional. I recruited participants who meet the inclusion criteria described above. This project used purposeful sampling, or when one "purposefully chooses data that fit the parameters of the project's research questions, goals, and purposes" (Tracy, 2013, p. 134). Following this approach, two recruitment strategies were utilized. First, I recruited participants via social media sites such as Facebook, Twitter, Instagram, and LinkedIn. For example, on Facebook, I posted on private and public support groups I am a part of, where patients living undiagnosed and chronically ill interact. Additionally, I utilized snowball sampling—participant recruitment technique to use when engaging in sensitive subjects where initial field contacts help refer others who are also in the community to participate in the study (Lindlof & Taylor, 2002).

Utilizing these two techniques, over 80 eligible individuals contacted me to participate in this study and share their stories. This overwhelming response demonstrates that this is a community that is not only willing, but eager to voice their health experiences. The first 20 participants who I officially scheduled an interview with were the participants for this project and were compensated for their time. Among the 20 participants, all self-identified as undiagnosed, chronically ill, and female and were over the age of 18. Ages ranged from 19 to 40 ($M = 28$) and years living undiagnosed and chronically ill ranged from 2 to 40 ($M = 10$).

Additionally, all participants have healthcare, and 19 participants live in the United States, while 1 participant lives in the United Kingdom.

ii. Procedures

To ensure extended exposure and persistent exploration with participants (Lincoln & Guba, 1985), interviews totaled approximately 22 hours and lasted between 36 minutes to one hour and 45 minutes ($M = 65.65$ minutes). Each interview was conducted virtually on an online platform such as Microsoft Teams, Zoom, or a phone call. Due to the nature of our world and the pandemic times, to ensure the safety of my participants and myself, we conducted the interviews virtually. Additionally, interview times were scheduled with the participants' convenience and anonymity in mind. Each interview was audio-recorded on a recorder that was purchased utilizing the grant that funded this project and recorded with the permission of the participant.

I utilized semi-structured interviewing, meaning I entered the interview with a set of structured questions but was open to what arose during conversation and allowed for the participant and their story to be the driver of the interview (Langellier, 1989; Lindlof & Taylor, 2017). Each question served as a mere guide rather than a script as I navigated conversations and interactions with my participants. Lune and Berg (2017) contend the flexibility and spontaneity of semi-structured interviews permits a more "textured set of accounts from participants" (p. 70) compared to when only scheduled and scripted questions are asked. Additionally, I provided a detailed research preview, or "describe in detail the research goals and procedure and to discuss with the participant the applications of participating in such a project" to be clear and frank on what the project comprises of (Yassour-Borochowitz, 2014, p. 182). By engaging in transparent dialogue that makes clear the research values, goals, and intentions, a space of discovery and reflexive thought developed. It was important for the research participants to understand each step of this process to ethically consent to participating in it. From there, I received a formal verbal consent to participate and proceeded to engage with the semi-structured interviews. The interview protocol (see Appendix A) consisted of demographic questions for each participant as well as specific questions that attended to the lived experiences of living chronically ill and undiagnosed as a female patient.

In keeping with the critical commitments of this project, I engaged relationally with participants throughout the interview. By sharing similar identities with my participants, it was beneficial to engage in the interview process beyond solely the position of an interviewer. When a participant told a story I could relate to, I would briefly shared with them how I could relate (or not) to those experiences by also living undiagnosed, chronically ill, and female. Each participant was viewed as a co-creator in this project, and utilizing a relational and shared approach to interviewing, especially when I am located in the very same community as participants, was advantageous in navigating the often complex and emotional nature of disclosing vulnerable narratives and lived experiences. This does not mean I was unaware of my position, privilege, and power as a researcher; however, engaging with my participants as a person a part of their community, someone more than just a *researcher,* I accepted part of the emotional labor I asked of participants. Through this, shared thoughts, emotions, and understandings emerged as well as a sense of community and togetherness. This concept is further explored in the findings section of this project.

As this project was funded by the University of South Florida Department of Communication Graduate Student Research Grant, participants were compensated for their time and efforts. I was attentive and reflexive in that compensating my participants invoked a transactional experience and may have inhibited my critical commitments of genuine community building and support. In utilizing a detailed research preview and a relational and shared approach to the interview, I hope for participants to see that I do not see compensating them for their time as a monetary transaction, but instead, a way to acknowledge that the sharing of their vulnerable stories deserves recognition and appreciation. Additionally, as a community that is often absent in research, and especially research and grant funding, I hope that the compensation demonstrates that for this project, the health experiences of undiagnosed and chronically ill female patients are prioritized, recognized, and funded within a research space.

To continue the critical and ethical commitment of fostering community with my participants, I held confidentiality, anonymity, and safety of my research participants as a priority throughout each step of the study, especially during the semi-structured interview process. Gobo (2008) argues we as qualitative researchers have the duty and responsibility to protect our participants from harm and reserve their rights. As noted previously, this project is approved by USF's Institutional Review Board, meaning the study and its proposed procedures and protocols meet all the required guidelines to ensure the anonymity and respect of the research participants. Although these necessary measures are put into place to ethically conduct research involving human participants, there may still be ethical qualms that transpire in the research process. Gobo (2008) contends that even though we have systematic processes in place to help in navigating ethical endeavors, not all situations have "ready-made solutions" (p. 145). As I was asking participants to share emotionally intensive and vulnerable experiences of illness in the biomedical system, I recognize that I must navigate these moments with care and humanity. My work seeks to foster connectiveness, healing, and transformative change and I cannot uphold these commitments if I act in ways that do not value human life over "academic success" or the imperialist "will to know" (Stavig, 2021).

II. Data Analysis

This thesis includes two data sets: semi-structured interviews and my own critical autoethnography. To answer the two research questions, I utilized an abductive thematic approach to analyze the collected data. An abductive approach is a data analysis tool that uses qualitative methods designed for theory building and new and unexplored themes (Timmermans & Tavory, 2012). Timmermans and Tavory (2012) contend this approach "rests on the cultivation of anomalous and surprising empirical findings against a background of multiple existing sociological theories and through systematic methodological analysis" (p. 169). As I enter the data with an abductive lens, I allow for an integrated approach with the objective to discover new and unknown frames in all aspects of the data and the project itself. This project organizes the semi-structured interview data thematically using abductive thematic analysis as well as intersperse that analysis using my own critical reflections and health stories. Dubois and Gadde (2002) contend like grounded theory, abductive approaches to data allow the researcher to discover a "generation of new concepts and development of theoretical models, rather than confirmation of existing theory" (p. 559). By entering the analysis of the data with an abductive lens, new theoretical insights and unanticipated findings allowed for new thought, ideas, relationships, and variables to emerge.

In this abductive thematic process, I began by listening to all 22 hours of the interviews. Then, I re-listened to the interviews and personally transcribed the data, which resulted in 525 double spaced pages of transcriptions. Once the transcripts were de-identified, I studied the interview transcriptions at length and first took notes on how this community voiced their health experiences in a biomedical system and then began to open code to begin the process of finding thematic patterns. After another close read of the transcribed interviews, notes, and open codes, I continued to narrow the thematic analysis, finding larger patterns and themes within the collected data to form three salient, forceful, and persistent themes.

I was transparent in that I sought to un-and re-learn ways of engaging in my own health stories as well as how I engaged in the research process. I approached the data analysis process with an open mind, as an abductive approach allows for a back and forth between my interpretations from the ground up and what knowledge and understandings I believe already exists. As a member a part of this community, this was a productive approach in analyzing the data as I continuously questioned my own assumptions and biases as an insider as I read through and interpreted the data.

All through this process, both in the data production and analysis, I was attentive and reflexive of my privileged position as a researcher who is granted the power to hold my participant's vulnerable stories in my hand (Alcoff, 1991). I acknowledged that although these are their stories, I am transparent in that this project is my own construction and mediation of their stories. As much as I am focused on mitigating this, in all qualitative research, including this project, I bring my own biases, position, and lived experiences to the page and the stories of my participants.

CHAPTER THREE:

FINDINGS

In examining how chronically ill and undiagnosed female patients narrate their experiences in and with the biomedical system and how might these narratives resist biomedical health standards and norms, three new and unexplored themes emerged: (1) the biomedical box, (2) biomedical failures and unmet community health needs, and (3) interview as community.

I. The Biomedical Box

The first theme is the biomedical box. Participants often discussed their experiences on a range of issues within the medical system, from their interactions with medical professionals, to navigating insurance claims, to clinical testing, and much more. Within these narrated experiences, participants persistently discussed not fitting in the constraints and standards of biomedical testing, diagnoses, symptoms, and compliance. Terms such as “box”, “bucket”, and “criteria” were used throughout participant responses to explain this phenomenon. Additionally, as these experiences were narrated, participants also explored the critical implications of not fitting into the confines of biomedicine and how it dictated their health and lived experiences.

I asked Julia, an undiagnosed and chronically ill female patient battling prolonged and unrelenting symptoms for twelve years now, if she felt like she mattered to the healthcare system. She said she did not. When asked why, she replied:

> I think the system is so segmented and has such blinders on for certain illnesses, that there's no real protocol for somebody who falls through the cracks and doesn't fit into boxes. So if you don't nicely fit into a box for a specific diagnosis, then there's no real

> place for you. Everything's so segmented in our healthcare system. So, if you're not actively dying, then the ER is going to kick you out, and if you don't have a rheumatological condition, then you know, rheumatology is going to be like, “bye I can't help you”. You go down the lane amongst other professionals, and if anyone will take you in, good for you. But if you don't fit, then generally, you're kind of working with your primary care provider. And it just… there's no real place for you. I think that's the problem with why you can't matter because there's nowhere to really go.

Julia’s response highlights how if an individual does not fit within the biomedical box, they are continuously seen as outside the system and unable to be helped. Not only are those who do not fit within a specific illness and diagnosis box unable to receive care and are tossed around the system, they feel they “can't matter because there's nowhere to really go”.

Similarly, Brianne, a participant who’s unexplained and disabling symptoms have dictated her life for seven years, explains feeling unheard and uncared for in the system. She explained, “the system makes me feel like I just don't matter, and it makes me feel like it doesn't matter if I wake up or if I wake up paralyzed and I can't move. I just don't feel like I'm a priority to anybody”. Without a place to go to be heard in the medical system, communities who do not fit or resist biomedical standards are left abandoned without the care and help needed to survive and live their life again. These individuals do not feel like they matter to the system, and this has major implications to their health and illness journeys. As a population that continuously defies biomedical principles, undiagnosed and chronically ill female patients are unable to legitimize their experiences in a biomedical model and in turn, are deserted, unheard, and mistreated by the system.

Other participants discussed how when tests results came back negative, and a diagnosis continued to be inconclusive, feelings of not fitting into the medical box became prevalent in their experiences. Callie, a female patient who has been undiagnosed and chronically ill for nine years, voiced negative feelings when her test and lab results did not fit the biomedical criteria of “sick”. As someone who has encountered similar symptoms and health endeavors to Callie, we both discussed our experience in receiving a positive ANA (antinuclear antibodies) test result. A positive ANA result points towards a condition in the autoimmune umbrella but does not isolate a specific autoimmune condition. Although both of us finally had a positive test result, tests that followed this result continued to come back “normal”, causing medical professionals to dismiss our symptoms entirely. Callie narrated how these negative and inconclusive results made her feel:

> It’s frustrating just to hear, again, you're not sick enough on paper. I think nothing upsets me more than that. You can look at me and see how much pain I'm in and you can see that there’s abnormalities in my labs and still, you're disregarding those because it doesn't meet your criteria. It blows my mind. It never will sit right with me. I'm not sure if you've experienced the same thing, but a lot of the time, it's a lot of the same labs. They never try something else and always just stick to the paper of what they think they need to do. Because again, that criteria, so they’re only going to stick to this and never go outside of that. And then everything comes back normal and they discharge me. Okay, so we've given up, right? So if you give up, why shouldn’t I? You're the medical professional…so what hope does that give me?

Callie’s health experience of not being “sick enough on paper” reaffirms how when one does not fit standard biomedical criteria of certain lab and testing results, they are dismissed and seen as unable to receive care. Even with a positive ANA test, when other tests returned normal and no clear diagnosis or cause is presented, Callie's physical symptoms do not hold any weight in a biomedical system. Her expressions of pain and fatigue are continuously dismissed and seen as unimportant to her health experience, because without a test to validate them, they do not exist. Not only are these feelings and symptoms disregarded, but other biomedical instruments such as uncommon or nonstandard medical tests are not an option nor seen as important to Callie and her diagnostic journey.

Like Callie's narrative, Kylie, a nineteen-year-old female patient who has experienced progressive symptoms since she was twelve, discusses how she feels unheard and needs medical professionals who will look beyond the diagnostic constraints and standards of biomedicine. She explained, "I need them to see past illnesses being rare, because not everything that they think is rare is actually rare. They should not be so scared to diagnose people with those rare conditions, because they're not as rare as you actually think". Kylie's experience speaks to how diagnostic tools in biomedicine compare to other standards of diseases that already exist within biomedicine, therefore new and unexplored ideas of disease, symptomology, pathology, and doing and being of health/illness are dismissed. If atypical scientific instrumentation such as uncommon blood tests and rare expressions of disease are seen beyond the boundary of "ordinary" and "standard" biomedicine and in turn, not considered as valid by medical professionals, patients will continue to suffer under the constraints of the system. Just like Callie and Kylie, patients will continue to be unheard, uncared for, and abandoned with nowhere to turn.

Similar to Callie and Kylie's experience, many participants reflected on difficult and unwanted interactions with medical professionals when their tests results and identities did not fit biomedical standards. For example, Anne narrated her difficult health and diagnostic journey and discussed how at the beginning of her story, doctors suspected she had Lyme disease or Epstein Barr virus and therefore, she underwent numerous tests. After all those tests came back negative and no new information was discovered on what is the root cause of her chronic symptoms, a phenomenon that has continued throughout the entirety of her illness journey, she was sent to a neurologist for further testing. She narrated the experience:

> I went to a neurologist, and he was great. He was like, you know, I really understand that there's something wrong here. I want to make everything better. I want to find a solution for you. So then he sent me for an MRI. I came back about a month later, he read the MRI, and he said, "you need to go find a good shrink, because there's nothing wrong with you. I thought it was MS. But it's not so you're just making this all up and you need to find a good shrink." And the whiplash that you get there. I've had other similar experiences, but not quite that bad. And I think this kind of goes to the undiagnosed part of it. If they can't fit you into an easy to find box, they immediately disbelieve everything you're saying. So he cared about me when he thought that I had MS and he could diagnose and treat that, but once he discovered that it was not that, it immediately became a different situation, where essentially, I was no longer valid, my pain was not valid, my thoughts on this process wasn't valid. And I left very defeated. I ended up just screaming in my car for a little while because when the doctors don't believe you and are actively cruel to you, you don't know where to go next, because they're the ones that are supposed to be helping.

Anne’s interaction demonstrates there are real, tangible physical and emotional consequences when one does not fit into biomedical boxes of symptomology, pathology, and diagnosis. When biomedical tools and instruments utilized by medical professionals do not produce results that are seen as valid in biomedical standards, a patient is seen as outside biomedical understandings and cannot be treated. As Anne's MRI scan can back "normal", she did not meet the MS (multiple sclerosis) diagnostic criteria and therefore, according to this medical professional, her illness experiences are no longer valid nor real. Because she did not fit this diagnostic mold, her illness expressions are not only pushed into abnormality but are now seen as psychosomatic. Additionally, her medical professional believes that since Anne did not fit the MS biomedical box, she must fit in another type of biomedical box and therefore, should see a "shrink" to determine the next course of action. Similar to Julia's experience, Anne was unsure where to turn next as her illness experiences were completely discounted and she feels there is nowhere else to go. Her interaction with this neurologist further demonstrates how when a community presents beyond biomedical understandings, they are framed in abnormality and left with nowhere to turn.

As many participants in this study who are undiagnosed and chronically ill voiced their symptoms, test results, and ways of being healthy and ill as outside of biomedical boxes, many participants also felt they were put in biomedical boxes. Participants specifically discussed how when they were placed into a "biomedical box," medical professionals were unable to see them as outside of them. This had critical implications to their health experience, diagnostic journey, and identity. For example, Leonora, a participant who has endured severe chronic and undiagnosed health issues since birth and is now forty years old, had been diagnosed with conversion disorder, also known as functional neurological disorder. This diagnosis, however, does not explain many of her unsolved symptoms that have dictated her entire life and she still considers herself an undiagnosed and chronically ill female patient. Therefore, she discussed how having this diagnosis has given space for doctors to put all her symptoms and health issues into the conversion disorder “bucket” and dismiss all other health possibilities. She elaborated further and says:

> It's kind of a bucket. But that bucket has specific dimensions. And doctors are like, oh, this bucket is the size of the universe. Anything that's ever gone wrong with your person now belongs in this bucket. Conversion disorder doesn't cause everything. It doesn't cause kidney damage. It doesn't cause fevers and throwing up. It doesn't cause an ovarian cyst to burst. It's like, all of these other things that happened in my life and they're like "oh, it’s conversion disorder, it must be you feeling stress, causing *your* body to go wrong." Medical doctors are dismissing everything…but I still have these symptoms. They don't want to deal with me, and it...it means I have to fight twice as hard to be heard. And sometimes I get emotional when I'm in that fight. And then they go, "oh, you're emotional. You're an emotional female. You must be feeling stressed, don't stress out honey, or you're going to have another seizure". When they treat me that way, I'm just ready to blow a gasket. It's like the self-feeding cycle. And that makes it really hard for me to want to continue to engage with the medical community and to keep going back to the doctors.

As Leonora and all her debilitating symptoms are jammed into the conversion disorder “bucket”, her doctors are unable to see beyond biomedical confines and help her receive the care needed to relieve her unrelenting and exhausting symptoms. Forcing Leonora into the biomedical bucket has severe consequences to her health experiences- she’s having to fight twice as hard to be heard, something that is difficult for even a “well” person to do. She is also framed in hysteria and seen as a fragile female who is unable to manage her emotions and stress, prompting her to have to fight more. This “self-feeding cycle” pushes her further in the outskirts of the medical system, so much so that she is unsure if she wants to continue to engage within the medical system at all.

Similarly, another participant, Anastasia, was pushed into a biomedical box. Anastasia has been experiencing undiagnosed and chronic symptoms for seven years now and discusses how medical professionals diagnosed her with PCOS (polycystic ovary syndrome), yet the diagnosis is not getting to the root cause of her unexplained symptoms and she no longer wishes to interact with medical professionals anymore. She explains further:

> I need someone who's going to put together all my symptoms, and not just look at a lab. They just look at these lab values and then they just classify you as normal or abnormal, but you're still having symptoms, so you're obviously not normal if you still have symptoms. Part of the reason I’m still undiagnosed is my own lack of going to more doctors because I see it as not helpful…they just haven't caught up to the way the model needs to be for chronic illnesses. We've just been really operating under this old model that was great for bacterial and viral infections. We need to get to the root cause, but I just think this current model is broken.

Anastasia’s PCOS diagnosis and lab results put her in a biomedical box and classified her as normal or abnormal. She expresses that the biomedical system is broken and does not address the root cause of one’s symptoms and especially needs to change for individuals with chronic illnesses. Due to this, she no longer feels receiving support and guidance from medical professionals is helpful to her diagnostic and health journey. In our interview, Anastasia continues and explains that she now finds means outside of conventional medicine to help relieve her symptoms. Inspired by homeopathic and functional medicine in her own journey, she is now pursuing her master’s degree in functional medicine and is actively working with clients to help them in their own illness experiences.

It is evident throughout the interviews that participants experienced negative interactions in the biomedical system. There were, however, a handful of narrated interactions within the biomedical system that were positive and truly helped a participant begin to live their life again. In these few narrated positive experiences, the medical professional went beyond the biomedical box which in turn, greatly aided the patient’s health and illness journey. For example, Vanessa, a participant who has braved living undiagnosed and chronically ill for twenty-one years, discusses a joyful moment where one of her medical professionals went beyond the standard biomedical box by ordering uncommon tests. This saved her life. She explains:

> My mom was able to find a doctor that didn't practice the standard type of medicine. She was known for doing tests that were a little bit more outside of the box and not doing the standardized, just cookie cutter tasks. I had the normal blood test done three separate times and each time it came back negative, so she chose to do an uncommon test. It was different because she said sometimes those other tests were not always reliable. The test came back positive. So that was eye opening because she was the first person to tell me I wasn't crazy. And at this point in time, I was 20 so it had been about 10 years of being sick all the time. Because of that test result, we know I have celiac, so my quality of life has improved drastically. I was getting close to losing the will to live to now I was a normal part of society, can go about my day, and just continue living.

As Vanessa finds a medical professional that actively acknowledges that the tests she has encountered thus far are not necessarily reliable and in turn, other tests should be explored, she is finally heard and cared for. Vanessa feels believed for the first time in ten years and has a name to her health experiences. Not only did this decision prompt a diagnosis, but it provides a chance to finally live her life again. Like Vanessa, other participants such as Sabrina voiced a positive experience with her medical professionals, which helped her receive a diagnosis after a grueling sixteen years. She explains the experience, “I work in healthcare, so I had access to that knowledge through friends and different doctors that I worked with, but both of my primary care doctors were like, ‘yeah, absolutely, let's do this test and this test. I'll send you home with this, I'll order it right now, you can have the labs done right now.’ My doctors listened to me and I overall had a good experience.”

These positive experiences all include medical professionals actively listening to the patient and believing their stories. Similarly, these interactions demonstrate the need to go beyond the biomedical criteria, because biomedical expressions of illness, symptomology, and tests results are not a one size fits all standard. This community, and other communities with difficult health and diagnostic journeys, are in great need of a system and medical professionals who are willing to make the leap beyond biomedical constraints in order to help individuals continue to survive.

In examining these experiences, it is clear biomedical boxes and buckets continue to dictate medical professional decisions and care, and when one is either seen as outside of them or forced into them, patients and their needs are pushed to exist outside of biomedicine. These narrated lived experiences of navigating the system demonstrate how one is pushed and crammed into a biomedical box, while simultaneously pushed into other boxes that are seen as not biomedical. The moment one is pushed into these boxes and seen as beyond biomedicine, they are no longer deemed relevant and capable of care. This phenomenon not only prohibits female patients who are undiagnosed and chronically ill from receiving the care they need, but it creates an entirely new barrier necessary to defeat in their illness journeys.

Fighting to stay alive against my illness was one obstacle, but also being forced to fight against the biomedical system was a whole other battle. In every facet of my medical experience, I too was seen as outside and simultaneously crammed into biomedical boxes as medical professionals attempted to make sense of my health experiences. Every single test continues to come back normal and inconclusive, yet I am a twenty-year-old female who woke up one day unable to hold my own head up, barely able to walk or talk, and clearly no longer feeling "normal". I sit in my wheelchair at the doctor's office, and I can't stop crying, because there's no way we've ran out of diagnostic tests. There's no way I am going to wheel out of this office without an answer, or a next step, or at least a glimpse of hope. How am I expected to carry on in this state? I no longer want my mother to shower me, or my father to carry me up the stairs, or my friends to clean my room. I am tired of being tossed around like a ping pong ball like I am just another number in a system that could care less if I wake up tomorrow. My life is on the line.

Every single time a test comes back negative, I feel I'm pushed further and further to the outskirts of the system, with less and less places to go and people to rely on. Who do I turn to when every single doctor tells me there's nothing else they can do? Where do I go? Who will listen to my story when they see my piles of negative results? They will automatically think I'm crazy and my pain is all in my head. I fight so hard to hold my tears in at my appointments, so I won't automatically be seen as a hysterical, stressed out, and emotional female. But I am scared…I am scared they missed something. When I tell my doctors I'm upset my test came back negative once again, they look at me funny, because they don't understand how bad I want a diagnosis- a name, a cause, a way to move forward.

II. Biomedical Failures and Unmet Community Health Needs

The second theme is biomedical failures and unmet community health needs. In utilizing the CCA in this project both methodologically and theoretically, it is imperative that I not only attentively listen to the health and lived experiences of undiagnosed and chronically ill female patients, but I also ask the community what their individual and collective health needs are. When asked what participants need, many discussed how the medical system continues to fail them, whether that be because of long wait times, not enough time with and feeling unsupported and uncared for by medical professionals, being shuffled from one doctor to another, and lack of collaboration and coordination between them. In this section, I seek to highlight the health needs of this community, while also contextualizing them in terms of concerns and failures of biomedicine participants bring forward in their narrations.

One of the major health needs voiced by participants that persisted throughout many of the interviews was a plea for more collaboration, time, and support from medical professionals. Interestingly, this conversation often sparked further dialogue about the lack of support medical professionals receive in the biomedical system. Essentially, participants continually discussed how the biomedical system fails them because it also fails their medical professionals. As this community, including myself, have spent countless hours in doctors' offices, hospitals, and in and outpatient clinics, we are able to witness first-hand the many flaws in the biomedical system, and naturally, observe how these flaws influence a patient and a medical professional experience. In her interview, Julia discussed the often-disheartening flaw in the biomedical system- the disconnect and lack of collaboration when medical professionals pass their patients to other specialists and don't follow through. She explains:

> The right hand isn't talking to the left hand. Doctors like to kind of pass you off to someone else. So rather than connecting and trying to brainstorm, they pass you off to the next specialist and then it's just kind of this game of handoff and there's no accountability. There's no compassion to have any accountability or to wonder, oh, I wonder what happened to that patient or how they're doing? Then, there’s no connecting the dots or tying things together, because everyone's going at it alone in their little sub-specialties.

Julia then explains what her health needs are to address this major flaw in the biomedical system:

> I need someone, actually sitting there and taking the time, compassion or empathy for the experiences that have occurred thus far. I think a lot of times you'll get physicians for that initial visit, you know, where they'll kind of work you up, and they'll spend more time with you. But then you’ll get lost in the follow up. If you don't fit in certain boxes, or maybe the first couple medications you try don't work out, then, that's kind of the end of that. So I think that there needs to be a better follow up type system to address your needs, if they don't get addressed in that initial evaluation or with their initial diagnoses or initial treatments that they want to try.

As Julia mentions, when a medical professional continues to hand off their patient to another specialist, and fails to follow through, important connections about the patient and their health story are not explored in the way they need to be. If a patient is unable to meet biomedical boxes of diagnoses, symptoms, and treatment, then they are also more apt to be dismissed and not followed up with. As biomedicine is segmented and many medical professionals only specialize in one category of the body, this community, and other undiagnosed and chronically ill populations, are unable to receive the holistic and integrated approach to health and wellness they seek. Like Julia, Anne also discusses the harm in her care when medical professionals do not collaborate with one another. She explains that because of this lack of communication, she is often faced with the burden of relaying medical information to her physicians, despite not having any formal medical expertise. She elaborates on this phenomenon and how it can be addressed in the medical system:

> I want doctors to communicate with each other. I've been to ten different doctors and it's all on me to be able to communicate to them what each other's findings are and that makes it very difficult to connect any dots, because I don't necessarily know what I'm talking about on the medical side of things. So I wish there was some kind of connective system where that kind of information could be transferred more easily. I can request that they send their documents, but that doesn't necessarily make those connections. What I would love is for doctors to be able to be more aware of everything. But that's, that's not fair to them, they have their limitations, and they are, by and large, doing their best.

Both Julia and Anne explain how the lack of collaboration and coordination between medical professionals are directly hurting their care, and a better follow up and connective system is needed to aid this flaw in the biomedical system. Additionally, as Anne narrates this issue and a potential solution, she also acknowledges that it is unfair to expect medical professionals to be aware of everything due to the limitations they face. Similarly, Allison, a participant who has been fighting for her life and experiencing undiagnosed and chronic symptoms for three years now, speaks to the segmentation in biomedicine and discusses how being passed around the system directly hurts her as a patient. Like Anne, she also examines the medical professional experience in a biomedical system. She says:

> Getting passed around to specialists, you get knocked back to square one. You get disconnected. I mean, it's like being in the most abusive relationship of your entire life. But I'll say hurt people hurt people. I feel like doctors and medical providers are hurt by the industry that they work in, and in turn it causes them to discredit and abuse their patients. I believe they go into medicine because they genuinely want to help people and when they're abused by the insurance companies and limited by what they're allowed to do, they have no choice but to hurt their patients. One of the reasons that I believe my immunology doctor believed me was the fact that he does keep up to date with new research and the new studies that come out. A lot of doctors are so overburdened by the day to day demands that are put on them, like arguing with insurance companies, that they don't have time or energy for that. And I don't blame them. But it also doesn't help me.

Allison explains her experience being passed around from specialist to specialist, while simultaneously acknowledging the abuse and day-to-day struggles medical professionals endure in the biomedical system. Both Allison and Anne acknowledge medical professionals have their limitations and are overburdened by the system, therefore unable to provide the care and support needed to help their patients. This directly impacts the health experiences of undiagnosed and chronically ill female patients, as they are not only pushed in and out of biomedical boxes, but they are also sidelined by the professionals who are positioned to help them. This cyclical pattern of patients not receiving the care they need because medical professionals aren't receiving the support, resources, and training they need, continues to fail all stakeholders in the system.

Similar to Allison who acknowledges how the day-to-day burdens of medical professionals limit their time and energy, Lydia, a twenty-four-year-old participant who has endured extreme and rare symptoms such as premature ovarian failure and does not sleep for days or merely only one hour a day, explains how there is not enough time for doctors to get to the root cause of her unexplained illness(es) and she needs shorter wait times to receive proper care. She explains, “doctors are not able to see the root cause because they're not trained that way. Treating symptoms hasn’t helped me, but there's never enough time or whatever it might be. And I need time.” Like Lydia, Maria, a participant who has struggled with chronic and undiagnosed health issues for ten years now, also explains how medical professionals do not spend adequate time to care and treat their patients and must look deeper into one’s health experiences. She emphasizes how those who are undiagnosed greatly need this time and effort to explore their unsolved illness(es). She elaborates:

> Doctors want to be diagnosticians by nature, but they need to look deeper. They're not looking deep enough into issues that patients are having. They see that they have an appointment for a half an hour, and they think, what can I accomplish in that half an hour? And even if they can't accomplish what they want in a half hour, then alright, times up and instead of devoting any more time to thinking about what is happening to a patient, or opening it up to any other possibility, they don’t, and it ends up hurting patients. There are things out there that need to be tested and explored that takes time and if you’re not going to do that, then why are you a doctor? For undiagnosed patients, that’s the main thing we need…someone to actually look into our illness and figure it out. I need someone to take time naturally to listen to my concerns.

Similarly, Leonora acknowledges how the biomedical system does not allow medical professionals to spend the necessary time and energy with their patients, because doctors are not receiving the support needed to do so. She explains:

> Doctors aren't getting the support that they need to fully be there for their patients. I think if we could fix that, we'd be well on our way to helping patients to have what they need. They're in a system right now where they get to spend so little time with their patients, because they have to rush off and do paperwork. I think if we could change that situation for doctors, to where they could spend more than five minutes with patients, they could talk about more than one symptom at a time.

Lydia, Maria, and Leonora explore how imperative it is to spend adequate time with undiagnosed and chronically ill patients to provide proper care and support. When an undiagnosed and chronically ill patient does not receive sufficient time to explore their interconnected and complex symptoms, health histories, and the potential root causes of these issues, it is impossible for a medical professional to have a clear picture of their patient's symptomology and pathology to begin a holistic and comprehensive diagnostic and treatment plan. Even more so, if a medical professional barely has time to explore more than one symptom, then they are definitely neglecting the patient's emotional, cultural, and social identities - all important for a patient and their health and illness expressions. Biomedical constraints and systemic standards do not allow for patients to spend suitable time and receive proper care, because medical professionals are completely overburdened by the system. Like Leonora points out, medical professionals do not receive the backing and support needed to not only provide needed time and care, but also to move beyond biomedical limitations of supporting and caring for patient needs.

Similar to participants who discussed the harmful effects in not being able to spend adequate time with medical professionals, other participants narrated the difficulty in experiencing long wait times and a lack of urgency from the system as well as medical professionals. Kylie noted how difficult it is to see specialists and when a patient is finally accepted to see a specialist, there is a long wait to be seen. She explains:

> I need to see doctors that actually care, like I need every doctor to care because I could have a diagnosis if every doctor I've seen cared. I need to see changes in getting into specialists, because it's very hard to get in. But when you do get in, there's such a long wait. I kind of understand the wait part, because there's a lot of people but, I just wish they accepted more people in because it took me so long to get into the geneticist. Once I got in, I still have to wait till August and that's going to be forever away, especially when my health is declining.

As a nineteen-year-old female patient with a laundry list of strange and debilitating symptoms such as seizure like episodes, memory loss, feet and hands turning purple, and extreme and sudden fatigue and weakness, Kylie's health is declining and having to wait for so long to even be seen by a medical professional, let alone establish diagnostic tests and treatments, is extremely upsetting. Like Kylie, Jenna, a twenty-seven-year-old participant who has experienced difficult undiagnosed and chronic symptoms for thirteen years now, also explained how long wait times to be seen and treated by specialists, such as rheumatologists, negatively impacts her health experiences and attempts to receive a diagnosis. She states:

> Rheumatologists are so specialized. You really can only get an appointment every couple of months. If I'm having an emergency right now, and I need to talk to my rheumatologist, I'm gonna have to wait at minimum a month, but probably three to four. I don't know why it's like that. I don't know if there's just so many people like us in the world that they just cannot handle it. But I do think that having someone that is reachable

> is important, because I don't know, if we miss something, it does feel like that could be all the difference.

Jenna explains the lack of availability in communicating with her rheumatologist, especially when she is having an emergency that needs immediate attention and care. By having to wait many months just to see one's medical professional, many important details may fall through the cracks. Like Jenna mentions, those missing details could make all the difference in one's health and diagnostic journey. Similar to Jenna, Juliet, a participant who was undiagnosed for six years and continues to live chronically ill, also discusses wait times and sheds light on her experience in navigating flare ups. She explains how necessary it is for medical professionals to be accessible during these grueling moments. She says:

> I need when I'm having a flare up to be able to see my doctor, and not have to go to the ER or the urgent care where people have no idea what's going on, right? I need more immediacy, for my doctors to be to be accessible. And I'm not saying my doctors need to be accessible 24/7, but they need to be accessible enough, so if something does happen, they could quickly prescribe me something to get me through the flare or tell me what I need to do. And because it's not like that now, I've had to over the years learn when a flare up is coming and what I need to do on my own to maintain it, or to get myself out of it which is something I've learned from the illness, but also not ideal.

Kylie, Jenna, and Juliet all explore how they navigate the difficulties in being forced to wait to be accepted and seen by medical professionals. How can this already uncared for and unheard community feel like they matter to a system that pushes their needs at the bottom of a waiting list? In an already uncertain and stressful circumstance due to the lack of answers, undiagnosed and female patients are required to wait to even be considered worthy of care, let alone actually receive the care needed to survive. In a race against time, this community is pleading for shorter wait times as well as a system and medical professionals who truly care and support them.

As the community's health needs were voiced such as a better follow up system, longer time spent with patients, and shorter wait times to address the biomedical failures of lack of support, collaboration, and time, participants also offered the idea of a care advocate or coordinator who can not only help aid the patient, but also medical professionals to alleviate connection, support, and time concerns. Brianne explains:

> I need a care advocate that is dedicated to the people, responds quickly, and keeps things in check. I need somebody there for me and just feeling like somebody cares. But the important thing, I think, is also they are supporting the doctors and the nurses, because the doctors and the nurses should be focused on the nitty gritty of the care, right, but there should be somebody who is backing them up as well. Because generally what I find is the disconnect in everything, especially in the hospitals, it's just the communication, the disconnect of your paperwork, and labs. It seems like it would be seamless because they have these portals that show everything, but constantly, my stuff gets lost, so people skip over stuff when they don't go back to it and I feel like that is definitely one of doctors' biggest problem is that they just don't have the support. They're seeing so many people, and the doctors can't focus on what they should be focusing on. And because they have to deal with all this other stuff, they should really have a support team.

Similar to Brianne's health needs, Grace, a twenty-eight-year-old participant who has been undiagnosed and chronically ill for her entire life, also discusses the need for someone who can help coordinate and collaborate her plan of care. She says:

> At my job, I see this concept of having a caseworker and a social worker that literally coordinates all aspects of your care planning. Why isn’t this a normal part of our healthcare? Just going from doctor to doctor, it's such a pain to have the information shuffle back and forth. Why don't we all work together? Why isn't there just one person that's the maestro of the whole master plan that coordinates everybody?

Brianne and Grace voice their needs for a care advocate to address the concerns of lack of support for medical professionals, lack of support provided to patients, and lack of time spent with patients. As a community who has consistently narrated feeling unheard and uncared for in this study, a care advocate and coordinator can not only provide necessary help in organizing test results, and medications, but also a supportive and caring figure in one’s health journey. Additionally, this can help alleviate the burden and stress many medical professionals experience in having to fill out paperwork, navigate the online health portals, send in prescriptions, and potentially, make space as well as prioritize for more time, energy, and support with their patients and collaboration and connectivity with other medical professionals.

In my experience of navigating my undiagnosed and chronic health issues, even when I was at my worst, when I could barely walk or talk, I too had to wait months and months to be seen by specialists and complete certain tests. When I was at the peak of my illness, every day felt like an agonizing waiting game for appointments and testing. This was physically, emotionally, and financially draining. There is nothing worse than waiting months to see a certain specialist and you walk into their office, head held high, finally able to be heard and begin your health and diagnostic process, and they completely dismiss your symptoms, rush your story, and only spend twenty minutes with you. They tell you the next time they can see you is in six months, but you refuse to give up, so you engage in the entire process all over again. You wait four months to see a new specialist, only to feel even smaller and like your life matters even less. But you’re desperate for some sort of relief, so you take more time, energy, and money to find a new specialist until you discover someone who will at least believe your story. This vicious cycle drained every bit of energy I had left. There comes a point where there is nowhere else to turn, and an individual can no longer suffer through the emotional, physical, and financial damage caused by these experiences.

As I sit and listen to the participants and their stores, I deeply relate to their experiences. I too am frustrated by the lack of connection and collaboration between my medical professionals. Being bounced from one doctor to the next, I am burdened by the heavy lifting of relaying my medical information to my doctors. Since there is such a lack of strategic communication between my medical professionals and this concern greatly impacts my health experiences as well as helped inspire this project. Due to this, I am forced to learn medical terminology to communicate with my specialists more effectively about the diagnostic tests and medications other providers have prescribed. I also find speaking in this way allows me to be taken more seriously as well as understood more clearly as opposed to when I am speaking about my emotions and pain (Werner & Malterud, 2003). Even as I engage in this research, without a medical background, pivotal information often falls through the cracks and so many leads slip through the communicative maze. I often wonder if I would have a diagnosis if my medical professionals were able to collaborate with one another and exchange ideas, hunches, and previous tests administered.

Although there are many flaws in the biomedical system, I continue to seek care from it. I do not have the means to figure this out on my own. I may take long breaks from seeking help from medical professionals, but I find myself continuing to go back because I have nowhere else to turn. Like these participants, I too recognize the system is broken and medical professionals are not taught nor supported in a way that will aid their patients in all facets of care, but I need help and I’m unsure where else to go. I echo and stand behind the many health needs and solutions proposed by my participants. Not only must true and intentional changes be made at the systemic and interpersonal levels of biomedicine to properly diagnose, treat, and care patients, especially those who are female, undiagnosed, and chronically ill, but an entire restructure of teaching, practice, and implementation must occur. All in all, I need a system and medical professionals who practice with care, love, and support at the forefront of all they do. I need a system that sees me as human, and not just another number and dollar sign in the system.

I would like to end this section with a health need voiced by a participant. Andie, a participant who has experienced undiagnosed and chronic health conditions for three years now, beautifully emphasizes what she needs as an undiagnosed and chronically ill female patient from the medical system. I relate very strongly with her words. She explains:

> I think at large, I would say, practicing ethics of care and love, because I think if you really practice that, it will change so many things. Practicing an ethics of care means caring about other people and not about money. So that means everyone having health insurance, or having the ability to go and not pay out of pocket for all of these tests, or take time off of work, or finding someone to watch their children, or having the means to get to a doctor's office. Practicing an ethics of care once you get to a doctor's office, so it's not about how many patients a doctor can see within a day, or how much money I can make. It’s about sitting with a person, listening to them, listening to their needs, understanding that they're people who think something's wrong. They’re human, and scared, anxious, nervous. And this isn’t just about their body, but also about the aftermath

> of illness. It's understanding what it's like taking all the meds I have to take now in the morning or forgetting to take them or pack them and how that's going to affect my life. An ethics of care is thinking about how I'm going to pay for my hospital bills…it's beyond even the fact that I want to get diagnosed with something, but it's all those things afterwards. It's about thinking about how I will navigate my life after that.

III. Interview as Community

The last theme was interview as community. As I mentioned, this project stemmed from my own health journey and feeling immensely alone in the difficulties of living as an undiagnosed and chronically ill female patient. When I sought social support online, I witnessed an entire community who also felt isolated and eager to be heard. Like the stories voiced online, in the interviews, I examined how participants narrated their health experiences in a biomedical system and how these narratives resisted biomedical boundaries. Participants consistently explained feeling unheard, misunderstood, and uncared for. Unlike biomedical spaces that are dismissive and do not prioritize the participant and their narratives, emotions, and feelings, in this project, the interview became a space where participants, their stories, health needs, and identities were welcome, heard, and believed. Similarly, the interview served as a space for vulnerabilities, emotions, experiences, and support to be shared between both the participants and myself. As I listened and spoke with these women about their health experiences, for the first time I no longer felt alone in my health journey and participants voiced feeling heard, validated, and supported in their health experiences through the interview process. Thus, the interview served as a material space of belonging, community, and togetherness and a discursive agent of co-construction of new knowledges and identities.

In the interviews, participants continuously reflected on the beneficial aspects of the interview process such as the self-reflexive nature of the interview and how the interview can serve as a positive moment in one's health journey. For example, in her interview, Serena stated, "I love doing interviews, especially if I'm actually able to do it, because it's also a self-reflexive process for me". Like Serena, Vanessa expressed how the interview process allowed her to examine her entire illness journey from start to finish. She elaborated:

> I think it was good, because I haven't kind of gone back through my journey. It's one of those things where I'm thinking, wow, I really have been through so much, for so long… I really haven't sat down and thought about the whole thing before.

Similarly, Leonora explained that despite the negatives in her health journey, this interview was one of the positives. She said:

> Thank you for taking the time to hear me. There's been so many negatives that have come from my health journey, I want this to be one of the positives and to add a little bit of light into someone's life so I just really appreciate the opportunity to do that with you.

As participants including Serena, Vanessa, and Leonora expressed how the interview served as an affirmative process in their health journey, I began to realize how the interview became much more than a space for reflection and narrations, and more of a pathway for community building, togetherness, support and belonging for female patients living undiagnosed and chronically ill.

One way the interview inspired strong moments of community was the shared exchange of identities and stories. While I prioritized the participants and their narratives, I also felt a strong inclination to share the communal and vulnerable space of the interview with my participants. As a member of this community, I sought to co-construct new and local meanings of knowledge, thought, and understanding. By engaging in the interview in this way, it aided in my critical commitments of walking alongside my participants in this journey and speaking *with* them, rather than *for* them.

Like I discussed in the method section of this project, in the beginning of each interview, I briefly explained that I too am an undiagnosed and chronically ill female patient; however, when conducting the interview, I often voiced agreement when I was able to relate to participants and their health endeavors as well as engage in short stories about my health experiences when participants asked questions. As participants began to understand that I inhabited insider knowledge about these experiences, the lines between researcher and participant began to blur. When participants asked questions about my experiences and would make comments such as, "I'm not sure if this has happened to you, but…" or "maybe you will understand this…", I found myself in a communal and shared conversation with each participant. For example, in her interview, Kylie explained the frightening uncertainties that accompany living undiagnosed and mentioned that I may be able to relate. She explains:

> It's honestly scary, because, like I said, I am losing my memory. That's probably the scariest thing for me, since I'm only 19. This probably sounds crazy, but you might be able to relate, I just feel like, I could just randomly die at some moment, because we don't know what's going on. And what if my chronic illness is something like very serious, it could just take my life at any moment. That feeling is just super overwhelming. Being undiagnosed, I feel like people don't take me seriously. They don't think I'm valid, but I have proof that I have all these symptoms and just because I'm undiagnosed doesn't mean that I'm lying or making this up.

As Kylie explores the overwhelming fears and uncertainties of living undiagnosed, she explains how I might be able to relate to this sentiment, and I told her that I absolutely was able to relate.

As participants were aware of my position both as a member of the community and as a researcher, they began to sense that I could relate and maybe even empathize with the experiences, feelings, and emotions they narrated. In her interview, Jenna, reflected on our exchange of stories and how my participation in this community can potentially influence the interview experiences. She said:

> If someone that doesn't experience it writes this kind of information, I just feel like it doesn't connect. You actually have to experience it in order to understand the words that are coming out of all of these different women. I do think that makes a difference. I think that people are probably just more trustworthy, and I think that since you are sharing like little tidbits of information about yourself, they're more willing to open up because they know that they're not talking to someone that they're either annoying or overwhelming with information. I feel like, as you've heard I'm sure from other people like talking about it, it's really hard to open up because you don't know how people are perceiving it, so having someone that experiences it too is helpful.

As participants began to recognize my position and that I was able to connect with their lived experiences, we often found the many similarities we had with one another, whether this be a shared medication, test result, symptom, emotion, or interaction with a medical professional. These exchanges often led to even more vulnerable conversations where we shared our emotional experiences living undiagnosed and chronically ill. As we explored these similarities, we engaged in communal support and togetherness and actively aided one another in our undiagnosed and chronic health journeys. For example, in our interview, Callie and I found a plethora of similarities in our health journeys, especially our symptoms and inconclusive test results. We compared lab results, recommended blood tests to one another, discussed how frightening certain tests (such as MRIs) can be, and provided tips on how to ask your doctor to order an “uncommon” test. We even compared and explained our pain and once realizing it is similar, discussed the best way to describe this pain to our medical professionals. Below is a small exchange from our interview:

> Callie: I don't know if this is too personal but, what is the pain like for you? Where do you get your pain and how does it feel?
>
> Bianca: I have chronic pain everywhere, especially pain in my back and a lot of the times I have pleurisy…it’s here by my rib cage. I also sometimes get joint pain. Oh, and I always have migraines.
>
> Callie: I literally get migraines every single day and it’s horrible.
>
> Bianca: Right? I can send you some things I use to relieve my migraines if you want. But yes, they’re horrible. And you know what’s frustrating, it’s so hard to describe that pain to my doctors.
>
> Callie: Yes, like I'm in pain. My whole body is in pain, and it's just completely worn down. The fatigue kicks in and, and I can't do anything, but I get really severe pain and it sounds stupid, but the only way I can explain it to them, is I guess I feel it in my bones. It feels like my bones hurt so bad. For me, it's primarily my wrists, my elbows, my knees, and my fingers. Now my fingers are starting to swell and so I've checked out and no arthritis, but they're swelling and I'm getting these bumps on my fingers and I just get this like shooting pain. I don’t know what to do.
>
> Bianca: Does the pain shoot from your joints?
>
> Callie: Yes! And it radiates from here to my wrist. I don't know, I was just curious because I never knew how to explain it and it's hard.

> Bianca: Yeah, in my experience, it’s good to use words like dull, sharp, pulsing and things like that, because doctors actually understand those words when you talk about pain but it’s hard to put it in words. I think you explained it really well!

In this moment, Callie and I were able to communally share our experiences, feel heard, and validate our pain with one another. These small exchanges throughout Callie’s interview as well as many interviews with other participants facilitated a space for community and trust. Similarly, in the interview with Naomi, a participant who has experienced undiagnosed and chronic health issues for two years, we discussed her experience navigating the medical system in the United Kingdom. As the only participant outside of the United States, we found many similarities and differences in how the medical system operates between nations. We both asked questions to one another about our health experiences, insurance, wait times, and how medical professionals functioned in each of our nation’s medical system. Both engaging in the conversation with questions and answers for one another, we formed a common understanding about the many obstacles we each experienced living undiagnosed and chronically ill as female patients. Naomi asked about my own health experiences and the different testing I’ve undergone as well as how insurance operates in the United States. I explained how one of the tests I’ve completed is DNA testing. Below is an excerpt from this portion of our interview:

> Bianca: The DNA test unfortunately came back normal. It was devastating.
>
> Naomi: Where does that money come from? Is it your insurance?
>
> Bianca: I think it was $30,000 before insurance and after insurance, the DNA test was about $5,000. We didn’t know it would cost that much until after and obviously I don’t have that money so my parents had to pay it for me.

> Naomi: It’s disgusting that they think they can charge that much. It’s actually putting a price on people’s lives.
>
> Bianca: Right? It’s horrible. I’m glad you talked about healthcare earlier, too. It’s so interesting to hear how that operates in the UK.
>
> Naomi: Yes, it seems like both places treat us badly, but we may not have to pay as much. But, I mean, the costs here aren’t far off. So, wait, what if you can’t pay that?
>
> Bianca: I don’t think they can arrest you, but I think it messes up your credit and things like that so if you want to buy a car or a house it’s more difficult, but I’m really not sure and I’m too scared to like find out.
>
> Naomi: Wow, it’s like they hold your own healthcare against you.

In some form, this collective and supportive sentiment demonstrated in Callie and Naomi’s interviews resonated throughout all twenty interviews. Participants and I often walked through the interview process together, allowing for new and unexplored knowledges to surface. The interview then allowed us to continue to foster support and togetherness with one another, despite often feeling unheard, unsupported, and under cared for in many other spaces we exist in.

As my research participants and I engaged in togetherness through the interview process, the participants voiced no longer feeling alone. In Andie’s interview, she explored this idea and said:

> Thinking things out loud and sharing it to someone who you know, understands, is so great. I need to find community, you know, because none of us are gaslighting ourselves. When you're surrounded by, I guess able bodied people for lack of a word, you forget that that this life is not the standard. It’s not the normal, but your experiences are still

> valid. This made me angry in a good way, because I want people to listen to us. This made me feel more valid in my experience.

For Andie, the interview was not only a space for healing and support, but it also validated her health experiences. Similarly, other participants discussed how the interview process allowed them to feel heard and not alone in their experiences. In her interview, Grace stated, “I think seeing somebody wanting to give us a voice is always a huge thing, because it's not acknowledged and starting a conversation is important. It’s the little steps.” Like Grace, Anne narrated feeling listened to and as a result, felt less alone in her health and illness experiences. She explained:

> I just kind of like sharing. I feel like I scream into the void and at least this way, I know you are listening and so is your thesis committee, because that's what this is for…to listen to us. Hopefully, if you get this published or something, the people that you read it to or that read it will be listening. I guess it's just another way to feel a little less alone.

Similarly, Tove, a chronically ill and undiagnosed female patient who has endured symptoms for eight years, explained how the interview allowed her to have more control over her illness and in turn, feel less alone. She said:

> This interview helps me have control and how I cope with my illness. I can't control the level of pain I'm going to feel and ultimately, my body is going to determine how sore I'm going to be or how or what I can or can't do that day, but being able to sit back and say, I'm not alone in this…it's just been a lot more manageable.

Andie, Grace, Anne, and Tove all expressed how the interview processes aided in feeling heard and valued in their narrated health experiences.

Just as participants voiced the interview process brought comfort and healing and reduced feelings of loneliness, participants also engaged in comments and questions to ensure I felt the same. For example, when I asked Allison if there was anything else she would like to say before we end the interview she responded, “I think it's important for you to know you're not alone, either”. Additionally, several participants pointed me towards other women who would be interested in participating as well as websites, blogposts, and social media accounts that could showcase our work in this project. It is through these moments where I continued to feel supported by this community and truly felt like all parts of me, including my illnesses, belonged. For the first time, my identities and experiences were heard and even more importantly, believed. One of my goals for this project was to create a space for undiagnosed and chronically ill female patients, their voices, and health needs be heard on their own accordance, but I did not realize my participants would do the same for me. They actively made room for my own health journey and co-created a space for me to belong. As a community that consistently voiced feeling unheard and uncared for, enacting a space where participants as well as myself could speak about our experiences free of judgment or disbelief, opened avenues for true and genuine belonging, community, and solidarity.

CHAPTER FOUR:

DISCUSSION

The goals of this project were to examine the lived experiences of female patients living undiagnosed and chronically ill as well as attend to their individual and collective health needs to understand how this community interacts in and with the biomedical system. Through this, new understandings emerged not only about undiagnosed and chronically ill female patients and their health experiences, but also new knowledges about how biomedicine shapes stigmatized identities and how such identities play out in in medical contexts. In this final chapter, I discuss the theoretical and practical implications of this project, limitations of the study, and potential future directions for health communication scholars and beyond.

I. Theoretical and Practical Implications

As a community that is absent in biomedical standards and normativities, the narrations voiced through this study have begun to fill the discursive gaps of biomedical teaching, reinforcement, and implementation. Theoretically, the voiced health experiences of undiagnosed and chronically ill female patients help explain how biomedical standards and criteria operate. As participants as well as myself described feelings of not fitting and/or being pushed into specific biomedicine boxes, we still all yearned for relief and to be able to live our lives again. Some of us even yearned for a name or a diagnosis to be able to move forward with a concrete plan of care. As we critiqued biomedicine for shoving us into boxes and/or pushing us in them, we also desired to be in *some* sort of box and to be touched by the "magic" of biomedicine that many have experienced. Even through the intense stress, mistrust, and unwanted and stigmatizing experiences in the biomedical system, many participants including myself desired for a box we could fit. This tension further nuances the push and pull of biomedical constraints with undiagnosed and chronically ill female patients, as well as all other populations who operate in biomedical settings. As the dominant “master narrative” (Spieldenner & Toyosaki, 2020), biomedicine becomes so deeply ingrained in our everyday medical experience, it can be difficult to know or imagine beyond it. Even those who have been continuously hurt and let down by biomedicine seek to be touched by it, and this demonstrates the immense complexities present when one is unable to justify their illness utilizing biomedical and scientific instrumentation.

As medical professionals and patients navigate a progressively complex biomedical system, it becomes increasingly necessary for medical professional and patient relationships to be interrogated, disrupted, and finally, convalesced. Throughout the interview process, participants identified immediate individual and collective health needs as well as tangible solutions to potentially aid in combating these biomedical failures. These needs included more support from medical professionals, improved wait times and urgency to see medical professionals, and more collaboration between medical professionals in terms of devising treatment plans. As these health needs were explored, participants also identified how biomedicine continues to fail medical professionals and their needs. Participants recognized the major biomedical obstacles in place that prohibit medical stakeholders from accessing the resources needed for a truly improved patient experience. Therefore, these narrations allow us to practically consider what changes must and can be made in the daily teaching and practice health and illness.

In addressing this question on a practical level, many have found that there are root causes of the disconnect in medical professional and patient relationships that are treatable by other professionals. Lidén et al. (2015) compiles research that finds “psychological issues can be experienced as threatening by both parties” and suggests “counseling could thus be required for healthcare professionals” (p. 8). This may open other doors as well as when the medical professionals themselves are tasked with creating a narrativization of their own journey towards medicine and approach towards their patients. Through this, medical professionals may be able to better access fragmentation and biases that are ingrained in their practice. By asking well-constructed and non-judgmental questions about the illness narrative as a whole (as opposed to investigating an individual symptom) healthcare professionals “…could thus facilitate the cocreation of a more coherent and meaningful story” (Lidén et al., 2015, p. 8). Similarly, in their work with patients with undiagnosed illness and medically unexplained symptoms, Lidén et al. (2015) suggest that “…joint storytelling could involve conversations about how to gain distance to suffering in daily life, how to protect oneself, sources of well-being, and visualizing the future” (p. 8). This, of course, is made much more possible with medical narrativization being incorporated into the medical professional’s training.

In addition to ensuring that providers develop the emotional intelligence and resilience necessary in their medical training to form their own medical narratives and be ready and able to receive stories from those in their care, the results of this thesis project demonstrate that it is also crucial to radically alter the forms that clinical encounters take. The practice of medicine has been framed as one in which the doctor holds not only the most knowledge, but the most power (Ellingson & Borofka, 2017). Within this project, we recognized medical professionals often did not ask questions about what patients need or genuinely fear; simultaneously, they dismissed concerns and placed judgment values on a patient’s emotional responses to their state of illness.

To address this, Stone (2013) finds five main tenets of shifting these encounters; they include “agreeing that the patient is suffering and assuming responsibility for care, tolerating uncertainty and the need for a name and remedy, shifting the focus from curing to coping, and managing the [medical professional’s] need for validation” (p. 3). Each of these points directly relate to the practical changes that participants hoped to see in their clinical encounters, especially in terms of feeling as though they are being placed in a biomedical “criteria”, “box”, or “bucket”. When imagining the ways in which providers may be able to move away from the qualities that currently designate a clinical encounter as “successful,” such as the provision of a concrete diagnosis that fits within the confines of biomedical knowledge and instrumentation, it is crucial to consider how these changes may be practically implemented.

Furthermore, Stone (2013) points out that support may be necessary for medical professionals, both in terms of counseling as discussed above, as well as additional courses in psychotherapy and therapeutic work in medical education. They explain “…the doctors in this study found caring for patients with medically unexplained symptoms a rewarding area of clinical practice” after having been trained to shift the focus from “cure to coping” (p. 7). These results are heartening as they show that some medical professionals have strong core values based in empathy for patients with complex and undiagnosed illnesses, and that education and therapeutic support can be incredibly valuable in terms of ensuring that the nature of clinical encounters could become rapidly and radically improved for undiagnosed and chronically ill patients.

As this project seeks to go beyond the academic paper, I look to continue to co-create new understandings and bring forward the individual and collective health needs of female patients living undiagnosed and chronically ill to the medical community and all medical stakeholders. Utilizing medical forums such as the Undiagnosed Diseases Network as well as online forums that participants of this study have connected me to, I plan to share the health experiences, narrated biomedical failures, and health needs of the community to not only facilitate a space where their stories and voices are heard beyond an academic setting, but also practically aid in addressing their health needs. In the interviews, many participants expressed interest in continuing to walk alongside me in this journey, offering their connections and support in facilitating the stories of this unheard community to the public. Therefore, my participants and I will continue this journey together and voice our stories and health needs as a community.

II. Limitations and Future Directions

This study focused on the narratives of undiagnosed and chronically ill female patients with many identities and within a variety of medical settings. However, other intersecting identities such as race, class, sexuality, gender, socioeconomic status, and the medical setting itself (i.e., private practice vs. large hospital) was not examined. Similarly, all participants had some form of health insurance as well as exist in western health spaces. It is likely these identities and factors play significant roles in the manner and quality of care that is provided to this community. As such, this study was limited in terms of the specificity with which it approached each of these individual qualifiers, and future research should aspire to gain more specific information about the existence of undiagnosed and chronically ill patients at various sociopolitical intersections.

Second, although this research examined how the identities of living undiagnosed, chronically ill, and female intersected in a biomedical system, it did not explore in depth the female experience in a biomedical system. Future research should investigate how the roles of gender complexity and sexuality play in the ways in which patients are perceived by their medical professionals, and how these identities may further complicate relationships that are already defined and hindered by identity politics and biases. For instance, further research may focus on these biases and on the ways in which neoliberal feminism has shifted the biomedical system without necessarily creating tangible change for female patients who are undiagnosed, medically complex, chronically ill, and experiencing distress. Through this work, new and unexplored understandings about this community as well as other stigmatized communities in the biomedical system can be heard.

Additionally, as this study looked to the lived and health experiences of female patients living undiagnosed and chronically ill in a biomedical system, there is much work to be done to continue to examine stigmatized populations and their interactions in a biomedical system. Interrogating and disrupting biomedical systems that are deeply rooted in immovable structures such as colonialism, misogyny, and white supremacy are actions that require dynamic and interdisciplinary scholarship to provide a true foundation for future research. Here, health communication research that builds off scholarship in these subject areas is especially crucial. Thus, it is important that future research continues to identify the gaps or fault lines in these systems, allowing us to sense the most malleable parts of them and understand where change can and may be implemented. We must continue to implement critical methods and theories, such as the CCA and postcolonial reflexivity, that call for an "alternative discourse" that looks to the "politics of the people" (Guha, 1988, p. 40). With this, we can continue to ask who is missing in biomedical histories, teachings, and practices and why they are missing in the first place?

To further investigate biomedical structures, we must listen to the lived experiences and health needs of other communities who exist within these structures. As participants in this study pointed to the cathartic and self-reflexive nature of the interview process itself, noting that they were gaining clearer understandings of the difficulties that they had faced in clinical encounters as a result of reflecting upon them, future research may focus on participating in the interview process with medical professionals in the hopes that they may be able to identify the areas in which they feel ill-equipped to deal with certain types of medically complex patients, such as undiagnosed and chronically ill female patients and other stigmatized communities. This may provide a guide for what types of educational and curricular changes are necessary as well as how counseling may be provided for medical professionals to stipulate them with better skillsets to approach patients with and reframe standard biomedical narratives, practices, and implementations. Similarly, health communication scholars and beyond who are also a part of a stigmatized health community can continue to engage in this work, as it clear in this project, my positionality as an insider in the community as well as a researcher allowed a unique research space filled with community building, new and unexplored understandings, and vulnerabilities.

Conclusion

All in all, it remains clear that there is much work left to be done in the health communication field and beyond to examine the health experiences of undiagnosed and chronically ill patients as well as other stigmatized and unheard communities in the biomedical system. The narratives of undiagnosed and chronically ill female patients provide new and unexplored understandings, histories, identities, and health needs, allowing for nuanced understandings of how biomedicine acts in and through this community. Similarly, the narrations and health needs of this population begins to fill the discursive and material gaps that biomedicine creates, teaches, and reinforces for all medical stakeholders. By providing a space for their unaccounted voices to be listened to and asking the simple question of “what do you need?”, a plethora of new knowledges about this community and about biomedical structures emerged. As I urge for future scholarship to work collectively towards uprooting the current biomedical paradigm, I hope we can begin to usher in a new era of communicative medicine that prioritizes support over diagnosis and care over cure. I hope we can continue to listen to the stories of those who continue to go unseen and unheard to foster the necessary transformation of biomedicine undiagnosed and chronically ill female patients need to survive.

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APPENDICES

Appendix A: Interview Guide

1. Demographic Questions:
    a. Preferred Name
    b. Preferred pseudonym
    c. Age
    d. What age began experiencing health issues
    e. Highest level of education
    f. Sexual orientation
    g. Occupation
    h. Race/ethnicity
    i. Healthcare
2. This answer can be as long or as little as you'd like and you can start this answer wherever you please. What is your health story?
3. What health issues are you experiencing and when did you first encounter them?
    a. Has it changed over time?
    b. Who is involved in this story?
    c. How does this experience make you feel?
4. Does the healthcare system play a role in your health experience? If so, how?
5. How does identifying as undiagnosed influence your health story?
6. How does identifying as chronically ill influence your health story?
7. How does identifying as chronically ill influence your health story?
8. How has your health experiences influenced your identity and who you are?
9. Do you interact with medical professionals? If so, what are your interactions with them like?
10. Do you feel like you matter in the healthcare system?
11. How does health insurance play a role in your health experiences?
12. What do you need to have a better health experience?

13. What would you like others, including medical professionals, to know about what it is like to live as an undiagnosed and chronically ill female patient?
14. What would you like to see change in the healthcare system, if anything?
15. Have you learned anything new from this interview?
16. What advice would you give to other women living chronically ill and diagnosed?
17. Is there anything I didn’t ask that you would like to share, or think is important for me to know?
18. What questions do you have for me? Feel free to ask anything about me, this research, how we will be using the interview, or anything else that may come to your mind