Agency in the Midst of Illness Uncertainty:
Women and Their Families' Experiences of Living without a Diagnosis

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ABSTRACT

Those living without a diagnosis reside in an invisible margin of health and family research. The purpose of this study was to explore illness uncertainty as experienced by women and their families in the United States. I examined illness uncertainty through a feminist ecological interactionist (FEI) approach with three core constructs: interaction, agency, and context. I conducted narrative-focused, semi-structured interviews with 15 women (aged 25-46) and 11 family members (aged 22 to 62) identified by each woman and completed a constant comparative grounded theory analysis. The findings revealed women's lived experiences with symptoms and social support, interactions with the medical system, and agency in the context of such uncertainty. Findings also model a System of Illness Uncertainty that contends that women's experiences with illness uncertainty is an endless process that changes over time. In the System of Illness Uncertainty, women were Doubters, Resisters, Persisters, or Burnouts; all women experienced a paradigm shift regarding the Western health system as a result of their experiences. This research adds to the knowledge base on individuals who occupy spaces between the legitimized, diagnosable ill and the symptom-free healthy. Implications affect not only individuals and their families, but the politics of Western medical establishments.

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GENERAL AUDIENCE ABSTRACT

Those living without a diagnosis are often outside of health and family research. The purpose of this study was to explore women and their families' experiences of illness uncertainty (i.e., living without a diagnosis) in the United States. I examined illness uncertainty through a feminist ecological interactionist (FEI) approach guided by three core constructs: interaction, agency, and context. I conducted semi-structured interviews with 15 women (aged 25-46) and 11 family members (aged 22 to 62) identified by each woman and completed a constant comparative grounded theory analysis. The findings revealed women's lived experiences with symptoms and social support, interactions with the Western health system, and agency in the context of such uncertainty. I put forward a System of Illness Uncertainty that contends that women's experiences with illness uncertainty is an endless process that changes over time; women were Doubters, Resisters, Persisters, or Burnouts. I argue that all women experienced a shift in thinking about the Western health system as a result of their experiences. This research adds to the knowledge base on individuals who occupy spaces between the legitimized, diagnosable ill and the symptom-free healthy. Implications affect not only individuals and their families, but the politics of Western medical establishments.

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CHAPTER I: INTRODUCTION

I keep playing my life leading up to that day when the symptoms began over and over in my head searching for clues…I have gotten quite good at recounting it all for doctors, nurses, specialists, and physical therapists; all of them looking at me as though they (a) did not believe me, (b) had no idea what to do, or (c) felt sorry for me. Most appointments have left me feeling more unsure and disillusioned …left with more questions than answers. For those appointments in which I feel like progress and understanding have been achieved, I'm only met with contradictory results and medical opinions from new doctors discounting my feelings, others' opinions, and heightening my fears....All the while, I am trying to maintain my relationships, establish my professional career, and figure out my future with no clear view of what my health will allow.

-                    Abbreviated personal narrative

All individuals and families must contend with a degree of uncertainty in their daily lives, some more than others. Declines or changes in health are stressful life events (Boss & Couden, 2002), but when there is long term uncertainty in health, or no determined diagnosis, individuals and families are unable to definitively seek out medical care, have confidence in treatments, or plan for the future. The purpose of this study is to explore illness uncertainty among women aged 25 to 50 and their families. Illness uncertainty is defined as living with prolonged physical symptoms that remain undiagnosed by a medical professional. In short, this research examined women and their families' experiences of when the woman is living without a diagnosis.

Overview of the Chapter

In this chapter I contextualize the problem of illness uncertainty in the United States by discussing health and healthcare in the 21st century and the complicated relationship between illness uncertainty and adult women. Next, I discuss the three theoretical perspectives guiding this study: intersectionality (Collins, 2000; Few-Demo, 2014; McCall, 2005), bioecological (Bronfenbrenner, 2005), and symbolic interactionism (Blumer, 1969; Turner, 2000). Then I illustrate the ways in which I used these three theories in my dialectical feminist ecological interactionist approach. Here I discuss the utility and promise of an approach that allowed for (a)

critical examination of women's lives and context, (b) consideration of objective health

diagnoses, and (c) exploration of women's and families' socially constructed meaning-making

processes in the context of illness uncertainty. Lastly, in this chapter I review my research

questions and conclude with remarks on the study's significance.

Background

Health and Healthcare in the 21st Century

The passage of the Affordable Care Act (ACA) in 2010 marked a significant step in

changing individuals' and families' approaches to health, tremendous investment in the

healthcare system, and access to health insurance and healthcare (Department of Health and

Human Services [HHS], 2015). With full coverage for screenings, check-ups, and vaccines,

Americans are reorienting their approach to health from reactive to proactive. With advances in

technology and screening methods, Americans may take advantage of the latest tools in

diagnostic testing, treatment, and health maintenance. As of 2015, over 90% of Americans have

health insurance (Kaiser Family Foundation, 2016) with the ACA granting over 9 million

Americans with health insurance (2.2 million aged 18-34). While an imperfect healthcare

system, the ACA expanded preventative health insurance benefits and provided subsidies to over

8 million marketplace customers (HHS, 2015). Despite efforts to repeal the 2010 ACA

(Goldstein, Bonis, & Snell, 2017) it currently remains a monumental piece of legislation,

improving access to health insurance for Americans in the 21st century.

Interactions with and use of healthcare, however, lie outside issues of access to health

insurance; the *usability* of healthcare relies on the ability to receive diagnoses, referrals, and

treatment plans from medical professionals (Roberts, n.d.; World Health Organization, 2016).

The onset of a health condition in which medical professionals cannot or do not assign a

diagnosis jeopardizes patients' ties to the healthcare system (Nettleton, 2006). Without

diagnostic certainty, patients come to solely rely on the judgment of the medical establishment

rather than the results of a test or screening to determine the next steps for treatment, prognosis,

and prospective recovery. In a system that relies on objective, biomedical certainty, individuals

whose diagnosis (and subsequent tie to the healthcare system) is not ascertained or documented

are in the margins of the healthcare system (Nettleton, 2006).

More recently, some medical professionals have developed numerous and varied labels

for health conditions that have no biomedical markers by which to diagnosis their patients with

certainty (Dumit, 2006). Health conditions or chronic illnesses that cannot be confirmed with a

blood test, X-ray, or exam are labeled *biomedically invisible illnesses* (Japp & Japp, 2005).

Researchers and practitioners also have a whole host of labels including but not limited to

medically unexplainable physical symptoms (MUPS; Kornelsen, Atkins, Brownell, & Woollard,

2016) and idiopathic illnesses or diagnosis of exclusion (Fred, 2013).

Women and the Margins of Healthcare

Women are far more often in the margins of healthcare when it comes to biomedically

invisible, medically unexplainable symptoms, or unknown illnesses; that is, research has far

more documentation on women's experiences with these types of illnesses (Japp & Japp, 2005).

This phenomenon has historical roots dating back to ancient Egypt up through the 20th century

with Sigmund Freud and Joseph Breur's *Studies on Hysteria* (Tasca, Rapetti, Carta, & Fadda,

2012) in which biomedically invisible illnesses were labeled as women's troubles as a result of a

wandering uterus (Werner & Malterud, 2003). Today, the invention of seemingly new

biomedically invisible conditions is a reflection of improvements and advances in medical

screenings and improved medical training (Nettleton, 2006; Swoboda, 2008) as well as a shift

away from this historic framing of possibly un-diagnosable illnesses affecting women.

These illnesses, and the women disproportionately diagnosed with them, are not without controversy (Swoboda, 2008). Biomedically invisible illnesses have gained legitimacy in some medical communities, but some researchers and medical professionals continue to clash over the root cause: psychological or organic (Dumit, 2006; Swoboda, 2008). Furthermore, not only are these illnesses contested in their recognition, but they are characterized by lengthy and tenuous journeys to reaching a diagnosis (Dumit, 2006; Rodham, Rance, & Blake, 2010). Therefore, women's experiences with illness uncertainty is a contested and lengthy process that may never achieve a resolution (i.e., a diagnosis).

The medical backdrop to the issue of illness uncertainty underscores the larger context I considered in this research. This research is located in the midst of changes to how American women access care and how medical professionals conceptualize and treat illnesses with no biomarkers (i.e., no amount of testing could reveal pathology). When the process of seeking out a diagnosis is prolonged, it places women in a vulnerable position to receive care, devise treatment plans, and make plans for the future (Nettleton, 2006). I now turn my attention to the guiding theoretical perspectives to understanding this tiring, arduous, and stressful process.

My Paradigm: Orienting the Reader

I do not present a new theory, but a comprehensive theoretical framework that guided my research questions, methods, and data analysis. Before presenting my guiding theoretical perspectives and feminist ecological interactionism framework, I will situate myself as a family researcher using a dialectical method as inspired by Olson, Fine, and Lloyd (2005) to create my guiding theoretical framework.

A dialectical approach, used as a methodology, helped me explicitly consider the inherent contradictions and opposing forces embedded within this research (Olson et al., 2005). My

discussion about interactions with the healthcare system contextualize the larger, opposing

influences in illness uncertainty. That is, within this research I recognize that in the context of

illness uncertainty there are theoretical and epistemological "forces that are interdependent and

mutually negating" (Montgomery, 1993, p. 207): (a) objective, organic pathology and certainty

in medicine (Swoboda, 2006; 2008), and the social construction of illness (Conrad & Barker,

2010); (b) the fixed and fluid notions of identity and relationships (Blumer, 1969); and (c) the

realities of inequities of power and the perception of agency (Collins, 2015). I used a dialectical

approach as opposed to a strictly social constructionist (Harding, 1993; Smith, 1987) or

eclectic/pragmatic approach (Greene & Hall, 2010), in order to confront the contradictions and

systems of power embedded within the interactions and context of illness uncertainty.

I chose three theories, feminist intracategorical intersectionality (Few-Demo, Lloyd &

Allen, 2014; McCall, 2005), bioecological (Bronfenbrenner, 2005), and symbolic interactionism

(Blumer, 1969; Turner, 2000), because they provided a coherent and comprehensive dialogue to

handle the opposing ideologies embedded in illness uncertainty. These three theories are

interrelated and complementary due to their cross-cutting concepts, constructs, and themes

(Olson et al., 2005). The synthesis of feminist intersectionality, bioecological, and symbolic

interactionism provided a rich framework through which to understand illness uncertainty

because of the ease with which they fit together, fill in theoretical gaps, and encourage dialogue

among opposing forces (Olson et al., 2005).

Guiding Theoretical Perspectives

Feminist Theory

The first of three theories of my feminist ecological interactionism is feminist theory.

Specifically, I use intracategorical intersectionality as informed by Few-Demo et al., (2014) and

McCall (2005). Feminist theory is an evolving and critical perspective that considers the ways in which our personal relationships reflect and are influenced by larger power structures in society (Allen, 2016).

Feminist theory provided the language, epistemology, framework, and sensitivity to issues of gender, race, class, ableism, ageism, homophobia, and classism (McCall, 2005). White, male, upper-class dominance perpetuates systems of power and inequality oppressing women, people of color, poor or working class individuals, older adults, persons with disabilities, and persons who identify as non-heterosexual, among others (Collins, 2000; Few-Demo, 2014). Throughout its theoretical history, feminist theorists have engaged in internal dialogues to allow for the deconstruction and critique of all categories (e.g., race, class, age, disability, the natural body; Allen & Baber, 1992). The rise of intersectionality is owed to Black feminists like Patricia Hill-Collins (2000) and Kimberle Crenshaw (1993) whose works deconstructed and challenged the ethnocentrism of Western and White second-wave feminism. Feminist critiques of systemic oppression via social class had been a focal point of feminist research through the 1980s (Hartsock, 1983; Hochschild, 1983; 1989). The intersection of class and gender remained an important area of feminist scholarship, but feminism was theoretically enlightened with Black feminists' concept of women's heterogeneous experiences (i.e., there is no single "female" experience; Collins, 2000; no universal "Black" experience; Crenshaw, 1993). Taking a post-modern feminist view, I used intersectionality to examine "the subject of analysis [women seeking out diagnoses] presented in all its details and complexities" (McCall, 2005, p. 1783).

"Intracategorical intersectionality," according to McCall (2005, p. 1773) and Few-Demo (2014), blends together critical feminist approaches that deconstruct and reject all social categories and those that heavily rely on the fixed, universally-experienced social categories. It

problematizes social categories while recognizing social categories remain an important, though

unequal, fixture of society (Few-Demo, 2014; McCall, 2005). Feminist theory provided a critical

examination and methodological approach (Warner & Shields, 2013) to discuss power dynamics

by bringing "the outliers of master social categories [including illness, race, gender, and class] to

the center of analysis" (Few-Demo et al., 2014, p. 89). This approach encourages scholars to

deconstruct those who lie between traditional social categories (e.g., in this proposed study, those

who do not yet have a diagnosis and are labeled as "ill" and those without symptoms who are

defined as "well"; McCall, 2005).

Bioecological Theory

Bioecological theory is a process-oriented human development theory, influenced by

positivist, scientific paradigms like Darwinism, genetics, and ecology as well as subjective,

interpretivist paradigms including human interactions and perceived wellbeing (Bronfenbrenner,

1989; 2005; Bronfenbrenner & Morris, 1998; Bubolz & Sontag, 1993; Tudge, Mokrova,

Hatfield, & Karnik, 2009). I used this theory to consider the multi-level interaction of biological

(e.g., diagnosis, biomarkers, testing, physical health) and social forces (Bronfenbrenner &

Morris, 1998).

More specifically, I used the *process-person-context-time* model (Bronfenbrenner, 2005).

Bioecological theory posits that individuals and their surrounding environments engage in

bidirectional interactions (Shehan & Kaestle, 2009; Tudge et al., 2009). These interactions or

processes can occur on more local or personal levels, such as proximal processes; or occur on

more indirect, systematic levels such as distal processes (Bronfenbrenner & Morris, 1998; Tudge

et al., 2009). The bioecological theory also argues that *persons* have differing and meaningful

characteristics or resources that influence their interactions with others and their surrounding

environments (Bronfenbrenner 2005; Tudge et al., 2009). For example, women have material

resources (i.e., characteristics) through their socioeconomic status and access to social support

and emotional resources through past experience, emotional regulation, and intelligence.

Bioecological theory is most well-known for its conceptualization of individuals'

multidimensional *context* (Bronfenbrenner, 1989; Tudge et al., 2009) consisting of (a) a

microsystem, the immediate context that includes the individual, their personal attributes (e.g.,

race, class, gender, age, health) and their family; (b) the mesosystem, the close system often

made up of family members, also known as the "system of microsystems"; (c) the exosystem, the

context that indirectly impacts the individual (e.g., laws and policies), and (d) the macrosystem,

the larger systemic values, ideologies, and the culture (Bronfenbrenner 2005; Bronfenbrenner &

Morris, 1998; Bubolz & Sontag, 1993). The last element of bioecological theory, as influenced

by Elder's (1978) life course perspective, includes a fifth system, the chronosystem, or *time*

(Bronfenbrenner, 1989). This includes both ontogenetic, the time in individuals' lives (i.e., late

twenties to fifties), and the larger sociohistoric time (i.e., 21st century) (Bronfenbrenner, 2005).

Symbolic Interactionism

I used symbolic interactionism, and its interpretative paradigm (i.e., how humans

perceive and experience the world is a subjective truth) to assert that women's interactions with

others produce meaning (Blumer, 1969), shape their roles and relationships (LaRossa & Reitzes,

1993), and influence their idea of "self" (Blumer, 1969; Cooley, 1928 as discussed in LaRossa &

Reitzes, 1993). Symbolic interactionism asserts that humans' interactions are sites of meaning-

making (Blumer, 1969), self-awareness (LaRossa & Reitzes 1993), and agency (Stryker, 2001;

Turner, 2000). *Meaning-making* is the individual's subjective perception of an experience or

interaction, and it occurs in the midst of and as a result of interaction with others (Blumer, 1969).

Because humans are social creatures, Blumer argues, they seek out interactions with others in order to gain meaning and identities. For example, in the midst of seeking out a diagnosis, women engage in interactions with others (e.g., doctors, loved ones, friends, online chat rooms, anyone that will listen) as part of the meaning-making process.

Out of this meaning-making process, symbolic interactionists argue, individuals locate their *sense of self* (Blumer, 1969), and according to the Chicago School of Thought, they can enact agency through role-making (Turner, 2000). The Chicago School of Thought, a promoter of qualitative research, posited that individuals make meaning through interactions and meanings can be transformed (rather than be set and pre-determined; Burr, Leigh, Day, & Constantine, 1979). Furthermore, individuals are self-aware - able to consider how they appear or come across through the eyes of others (Blumer, 1969). From this sense of self and other meaningful interactions with the medical community, loved ones, and others, they can establish their roles (i.e., prescribed set of behavior and expectations) and responsibilities in relation to others (LaRossa & Reitzes, 1993). Symbolic interactionism allows for the consideration of illness uncertainty by positing that when women did not have clear roles or identities (i.e., were living without a diagnosis) they could experience role strain or ambiguity (Burr et al., 1979; Stryker, 2001). However, following the Chicago School of Thought, symbolic interactionism also theorizes that individuals (i.e., women) engage in the agentic process of *role-making,* where they can be innovative and negotiate new rules and roles for themselves using what is available to them (LaRossa & Reitzes, 1993; Turner, 2000). The context of illness uncertainty and the opposing forces at play will influence one's engagement in meaning-making, and therefore I posit that women's sense of self, enactment of roles, and search for meaning is not predetermined (Blumer, 1969).

Feminist Ecological Interactionism: A Dialectical Approach to Illness Uncertainty

A dialectical approach encourages the examination of the opposing forces that underlie the experience of illness uncertainty (Olson et al., 2005). Women in the midst of a prolonged search for a diagnosis occupy a contested space that requires consideration of the ways positivist views and medical models interact with subjective, lived experiences. These tensions are captured in the integrative Feminist Ecological Interactionism (FEI) perspective and the core constructs guiding my research: *interaction*, *agency*, and *context.*

FEI is a "flexible architecture" (Olson et al., 2005, p. 316) that allowed me to focus on the social (i.e., interaction), agentic, and contextual components of illness uncertainty. These essential components to help my exploration and understanding of illness uncertainty. Each theory alone explains an aspect of illness uncertainty, but together the FEI approach provides a more in-depth explanation as to why women living without a diagnosis occupy a contested space and how their personal and systemic interactions (and subsequent meaning-making) play into shaping their politicized status and relationships with others.

Interaction

Intersectionality suggests that interaction regarding is influenced by systems of patriarchal power and oppression (Few-Demo, 2014); interaction is the site of agency and outcomes of interaction determine women's legitimacy in seeking out a diagnosis. Similarly, the bioecological perspective posits that interaction in illness uncertainty is a bidirectional process that occurs at the direct (personal or local) level and indirect (distal, systemic) level (Bronfenbrenner & Morris, 1998; Tudge, et al., 2009). Interaction in illness uncertainty, according to symbolic interactionism is the socially constructed site of meaning-making that informs our sense of selves and our roles (Blumer, 1969). Taken together, the feminist ecological

interactionist perspective considers *interaction* to be:

- at its most basic level, the way individuals come to make sense of themselves, interpret

  their experiences, and formulate their roles,

- shaped by patriarchal systems of power and oppression that can disempower women, and

- occurring on interdependent personal (proximal) and systemic (distal) levels.

In all, feminist ecological interactionism allows for a conceptualization of interaction that

includes the systemic and experiential components of interaction.

Agency

Agency in illness uncertainty, from the perspective of intersectionality, is shaped by

women's social location and varies based on their intersecting positions of privilege and

disadvantage (McCall, 2005). The bioecological perspective considers agency in illness

uncertainty to be embedded in women's resources (e.g., material, emotional, social), and their

intention to use those resources to fulfill their needs (Bronfenbrenner, 2005). Symbolic

interactionism suggests that agency is in the form of role-making or women's ability to engage in

innovation and creativity as a woman shapes or reformulates her role (Turner, 2000). My FEI

approach considers agency as:

- embedded in the context of intersecting systems of power and oppression,

- determined by access to resources, and

- how individuals can be creative and innovative.

FEI shows how women and families can engage innovative, agentic processes based on positions

of privilege and disadvantage.

Context

An feminist perspective suggests that context consists of systems of patriarchal control

that act as powerful shaping forces that can (de)legitimize women's experiences (Few-Demo et al., 2014; McCall, 2005; Shehan & Kaestle, 2009). The bioecological perspective posits that context is multilevel and value laden (Tudge et al., 2009), where women must simultaneously contend with positivist norms and medical practices and personal and familial experiences. Symbolic interactionism views context as the situation, and using the Chicago School of Thought, context is limited in its determination of individual and family lives (Blumer, 1969). Therefore, FEI considers how the *context*:

- devalues women's experiences and perceptions so that they face challenges to asserting themselves in the process of seeking out a diagnosis,

- situates women's experiences in different systems of knowledge (medical/positivist, interpretative/relational) that cannot be separated, and

- is limited in how much it dictate one's meaning-making abilities because individuals can take part in creative role-making.

In summary, the FEI perspective encourages ripe discussion on how context is an inevitable source of conflict for women, but that the circumstances and context can only determine so much of how women respond and make meaning of their experiences.

Figure 1 demonstrates the integrative framework that guided my research questions, data, and analysis. Each circle represents individual theory's concepts and processes; these are the unique concepts in each of theory. I also included areas of overlap to show how different theories account for different concepts and processes in similar and overlapping ways. In this section, I articulated how interaction, agency, and context are conceptualized by each theory and can be understood together. This visualization showcases the conceptual overlap that allowed for a comprehensive, integrated framework rather than a piecemeal combination of theories.

Theoretical Visualization of *Feminist Ecological Interactionist* Approach

Bioecological
- Interdependency
- Biological-Social Model
- Process-Person-Context-Time

Symbolic Interactionism
- Roles
- Role-taking, -making
- Meaning-making
- Self Concept

- Adaptation

- **Interaction**
- **Agency**
- **Context**

- Objective & Subjective Exp.
- Proximal & Distal Factors

- Interpretation
- Social construction

Feminist Theory
- Intersectionality
- Critical Perspective
- Identity
- Power

Figure 1. A visual representation of the ways of in which the three guiding theoretical perspectives overlap or complement each other to create an integrative theoretical framework. The feminist ecological interactionist approach considers the epistemological and conceptual traditions of each theory. It also dictates that the core constructs and ideas are *interaction* between individuals and their families as well as the medical system, *agency* on an individual and familial level, and that all occur within a multi-system and embedded *context*.

The Current Study

Research Questions

Research Question 1: Without a diagnosis, how do women and their families respond to illness uncertainty (i.e., make meaning out of interactions with symptoms and others)?

I sought to understand the ways illness uncertainty may have changed women and their family members. I also investigated how women and their family members make sense of themselves and others in the midst of ambiguity (living without a diagnosis). In-depth interview questions

focused on daily life, perception of self and others, and change as a result of illness uncertainty.

Research Question 2: What agentic processes do women enact in the midst of living without a diagnosis?

I investigated how women employed different forms of agency in the midst of illness uncertainty. I was interested in how women might assert control or how women might reframe or perceive their locus of control regarding their health and ability to get treatment (Shehan & Kaestle, 2009). In what ways do women and families employ creativity and innovation in their day-to-day life? In-depth interview questions focused on approaches to daily life, self-diagnosis and accessing treatment, and interactions among family (biolegal or chosen).

Research Question 3: What enables agency in the context of illness uncertainty?

I sought to uncover the individual or familial resources, contextual factors, and/or sociohistorical opportunities that enabled women to enact agency. I was interested in women's degree and ability to employ agency as it may shape conflict, satisfaction, and meaning-making. Interview questions asked about women's actions, advice, and perceptions of their experience.

Purpose and Overview of the Study

The issues and experiences of living without a diagnosis have historic roots that can be traced to systemic issues surrounding health, gender, and culture. Having set the historical and social backdrop, I put forward the argument that health is socially constructed and deserving of qualitative exploration. Those living without a diagnosis reside in an invisible margin of health and family research, but given what is known about health – it can be assumed that living without a diagnosis would also impact individual and relational processes. The purpose of this study was to explore illness uncertainty as experienced by women (aged 25 to 50) and their families in the United States. I examined illness uncertainty through a dialectical feminist

ecological interactionist (FEI) approach in which my three core constructs were interaction, agency, and context. This study built on previous research using a comprehensive theoretical approach in order to uncover the nuances of lived experiences.

In order to explore women and their families' experiences with illness uncertainty I utilized narrative-focused, semi-structured interviews with 15 women (aged 25-46) and 11 family members (aged 22 to 62) identified by each woman. I asked women and family members to talk about their daily lives, beliefs surrounding the medical system, relationships with others, and sense of self. I conducted constant comparative grounded theory analysis and findings contribute to our knowledge of women's lived experiences with symptoms and social support, interactions with the medical system, and agency in the context of such uncertainty. This research added to the knowledge base of individuals who occupy space between the legitimized, diagnosable "ill" and the symptom-free "well" (Dumit, 2006). This research's implications affect not only individuals and their families, but the politics of Western health systems.

Summary of the Chapter

I situated myself as a researcher and established the context and implications for this proposed research. My brief discussion of women's health brought to light the larger picture for my dissertation and helped lay the groundwork for the necessity of a dialectical approach to account for the tensions and ambiguity that women in illness uncertainty experience in society, in healthcare, and in their own families. I presented my three research questions and provided an overview of the study. Next, I discuss the state of literature regarding the dominant discourse of what it means to be sick and the ways in which women and their families occupy a marginalized space within the discourse.

CHAPTER II

Overview of the Chapter

In this chapter, I review and critique empirical, methodological, and theoretical approaches to studying illness uncertainty, which I define immediately following this overview. Next, I describe the nature of the literature, followed by a discussion of family researchers' traditional approaches to studying health. For the sake of clarity I organize the literature review around the discourse of what it means to be sick and to seek out a diagnosis (i.e., who is sick, how are they sick, what illness do they have). By discourse I refer to how individuals talk about illness and underlying assumptions regarding power, medical institutions, knowledge, and moral regulation of women's bodies (Gannon & Davies, 2007; Werner, Isaksen, & Malterud, 2004). To begin, I introduce the "players" of the literature: the individual, the family, and the medical system, as well as the common types of illnesses associated with illness uncertainty. From there, I use the literature to introduce and explain the hegemonic narrative (i.e., the authoritative influence) and to discuss relevant literature that problematizes each step of the narrative. My intention in using literature that problematizes the narrative is to demonstrate that women and family experiencing illness uncertainty disrupt the narrative of what it means to be sick and therefore, occupy a marginalized space. After discussing the available literature, I examine the gaps in research and where my proposed research fits into those gaps.

Illnesses Most Commonly Associated with Illness Uncertainty

Illness uncertainty is a term used to describe illnesses or symptoms that often include prolonged difficulty in reaching a diagnosis due to their symptom variability and lack of exact biomarkers (i.e., direct measures to determine a disease using saliva, blood, tissue, x-rays, MRI, PET scans). Researchers use a variety of terms including but not limited to *biomedically invisible*

illnesses (Japp & Japp, 2005), conditions with *medically unexplainable physical symptoms*

(MUPS; Kornelsen et al., 2016), idiopathic (unknown) illnesses, and diagnosis by exclusion

(Dumit, 2006; Fred, 2013).

Table 1

Illnesses common in the field of research with prevalence, age of onset, and disproportionately diagnosed populations

Illness	Prevalence in United States (aged 18+)	Age of Onset	Populations Disproportionately Diagnosed	Source
Crohn's Disease	Over 400,000	Before age 30	More common among Whites	Mayo Clinic, 2014 Lashner, 2013
Chronic Fatigue Syndrome (*myalgic encephalomyelitis[a]*)	1-4 million	Early 40s to 50s	More common among women	New York Times, 2008 NHS, 2015
Epilepsy	1 in 26 Americans	Any age	More common among women	Mayo Clinic, 2016 Schachter, Shafer, & Sirven, 2013
Fibromyalgia	5 million	Mostly middle aged	Significantly more common among women (80-90%)	NIAMS, 2014 Lawrence et al., 2008
Lupus	1 in 2,000 (chronic or acute form)	Ages 15-45	More common among women	Johns Hopkins Lupus Center, n.d.
Migraine Headaches	Nearly 3 million	Before age 40	More common among women	Mayo Clinic, 2013 Smitherman, Burch, Sheikh, & Loder, 2013
Multiple Sclerosis	400,000	Ages 20-40, mean age 32	More common among women More common among Whites	Mayo Clinic, 2015 Hersh & Fox, 2014
Psoriatic Arthritis	Nearly 1 million	Ages 30-50	Men and women at equal risk	Emery, Ash, and American College of Rheumatology, 2013
Rheumatoid Arthritis	1.5 million	Ages 30-60	More common among women	Ruffing & Bingham, 2016 Centers for Disease Control, 2015

[a] recognized in UK only

In Table 1, I provide the types and characteristics of illnesses most commonly associated with the area of research on illness uncertainty. The purpose of providing this overview of diagnosed symptoms is to orient the reader to the kind of research that has been completed in this area and provide an idea as to the kinds of illnesses that may involve years-long process of getting a diagnosis. It is worth noting, however, that I did not intend to seek out women with a particular diagnosis or set of symptoms for this study. In fact, I explicitly sought to talk with women who have not received a diagnosis for their symptoms. Therefore, I do not offer up this list to suggest the types of conditions the women in my sample have, but as a way to give readers an idea of the types of conditions that have been studied in previous research.

Nature of the Literature

Scholarship regarding illness uncertainty (as defined above) involves the nature, consequences, context, and politics of seeking out a diagnosis, and spans multiple decades, disciplines, and health conditions (Bury, 1982; Charmaz, 1983; Swoboda, 2006). Research on individuals seeking out, receiving, and living with diagnoses can be found in the biological sciences, sociology, public health, family therapy, psychological, health communication, and women's studies disciplines. Despite this ubiquitous presence in several disciplines, some gaps in understanding of illness uncertainty do exist (see Appendix A for search procedures).

Nature of Family Research and Health

Illness uncertainty is inevitably and conceptually tied to health. There, I begin by examining what family studies perspectives are on health and families. First and foremost, family researchers most often conceptualize health and illness through a family stress lens (Boss, 2002; Grzywacz & Ganong, 2009; Rolland, 2011). In this lens, illness is considered a stressor event (Boss, 2002) that can become grounds for a family crisis (Rolland, 1994), and through

coping and adaptation, families enact resiliency against the stress processes (Walsh, 2002). Other

researchers consider family as a force or factor that influences the health and wellbeing of its

members (Carr & Springer, 2010; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002).

Current conceptualizations of health in family studies offer a narrow view of health either as a

predictor or outcome, and often do not consider the context of health (aside from being a chronic

condition; Carr & Springer, 2010; Grzywacz & Ganong, 2009; Rolland, 1994).

Researchers using a family perspective to discuss issues of health often do so in the

confines of how families cope, live with, and provide care *with a known or named disease or*

illness, often overlooking the process of seeking out a diagnosis or living without a diagnosis.

For the purposes of the proposed research, the conversation regarding health as an outcome or

predictor is less relevant than the conversations regarding the meaning, process, and context of

determining whether one is truly "sick" or not. In the literature review that follows, I included

some notable and important contributions of family researchers that considered family processes

prior to receiving a diagnosis, as well as how families coped and dealt with a diagnosis.

Systems Interdependence and Interaction: The Major Players

In examining the discourse of what it means to be "sick", I focus on three major systems:

the individual, the family, and the medical system. Each of these systems interacts with each

other in direct or indirect ways in terms of what it means to be sick and in pursuit of a diagnosis.

Medical sociological and health research focuses heavily on the experiences and interactions

between the power and authority of the medical system (i.e., the macrosytem) and the individual

(i.e., the microsystem). Relatively less research focuses on the direct interactions of the family

and social networks of support (i.e., mesosystem) and the medical system.

The Process and Context of Seeking Out a Diagnosis: Disrupting the Discourse

There are several models by which to conceptualize the hegemonic or dominant discourse around getting a diagnosis, and thusly, being deemed a person with an illness. Some models frame the discourse as a family crisis (including diagnosis), followed by adjustment periods, chronic coping and eventually (Rolland, 1994; 2011); other models conceptualize the discourse beginning with the diagnosis and turning into a life-long process (Bury, 1982). For the purposes of this review, I adapted Campbell and colleagues' (2016) model of going from pre-diagnosis to post-diagnosis for its (a) conceptualization of chronic illness and its impact on individuals and family, (b) expanded view of the "crisis" stage that so many family scholars consider to be acute, (c) recognition that the dominant discourse can include an iterative, even non-linear process or components, and (d) unassuming articulation of the dominant discourse. I argue the dominant discourse includes the following steps:

1. The onset of symptoms, followed by

2. Reaching out for help, followed by

3. Undergoing testing, followed by

4. Receiving a diagnosis, and followed by

5. Adapting and negotiating identity, roles, and relationships.

In the following review, I begin by describing the dominant discourse for each of the five stages in more detail, explaining its underlying assumptions regarding expectations and meaning within the stage, and discussing literature that fits into the normative discourse. Next, I discuss literature that uncovers how experiences with illness uncertainty in each of the five stages disrupt the dominant discourse. I argue that literature related to illness uncertainty in and of itself challenges the discourse on what it means to be sick, and I apply the literature as evidence to the

ways this can happen. My intention with this literature review is to justify how and why I view women and families experiencing illness uncertainty as marginalized from the medical establishment and society, and family research in its current form.

Onset of Symptoms

The onset of symptoms is the first step in the dominant discourse on being sick. It is portrayed as the beginning of the crisis (Rolland, 2011), and is centered on individual processes such as interpretation and self-evaluation (Campbell et al., 2016; Jutel & Banister, 2013). The individual is the focal point in this first step - their subjective interpretation of something being wrong. Assumptions in this step include assuming that at the onset of symptoms individuals become self-aware of their illness and that there are cultural and individual scripts by which individuals can decipher their symptoms (normative and expected illnesses) (Campbell et al., 2016; Rolland, 2011). For example, in their interviews with 21 people (aged 18 to 56) suffering from influenza (i.e., the flu), a common infectious disease, Jutel and Bannister (2013) found that individuals performed self-evaluations of their symptoms in terms of symptom severity and in comparison with other common illnesses associated with the symptoms (i.e., a cold). Deciphering the symptoms as problematic was less ambiguous because the symptoms were normative with other common illnesses. Next, I turn to three documented areas of research that disrupt the dominant narrative of the prevailing onset of symptoms discourse.

Non-normative illnesses. Individuals have preconceived notions about what to expect and how long to manage symptoms alone without assistance of others (Jutel & Bannister, 2013). Chronic illness is typically associated with later life, and biomedically invisible illnesses come with less well-defined social scripts by which individuals and families can decipher symptoms (Swoboda, 2006). It is difficult for patients to examine and explain their symptoms to others

because they have nothing to which they can compare (Kuluski, Dow, Locock, Lyons, & Lasserman, 2014; Rodham, Rance, & Blake, 201). Without normative experiences or scripts individuals may have difficulty examining illness' severity and salience.

Severity and speed of symptoms. The severity and speed (i.e., gradual versus sudden) of the onset also influence the degree to which individuals "can normalize and control…[before symptoms] interrupt and made their everyday life impossible in various ways" (Lillrank, 2003, p. 1048). For example, young adults (aged 23-55) who suffered a stroke experienced immediate and sometimes severe impairments and interruptions to their daily lives and functioning (Kuluski et al., 2014), whereas others weighed the gradual onset of pain, joint stiffness, and loss of mobility that came with rheumatoid arthritis (Bury, 1982; Lillrank, 2003; Swoboda, 2006). The speed of onset can ease or blindside families into chronic illness (Rolland, 1994).

Social deciphering of symptoms. In addition to having to decipher the severity and impact of symptoms, individuals also contend with deciphering the social consequences of certain illnesses; individuals weigh these social consequences (i.e., stigma) in determining if and how they will disclose symptoms to others (Goffman, 2009). In their interviews with 10 women suffering from chronic muscular pain, Werner et al. (2004) found that from the onset of symptoms, women were assessing and determining the ways *others* would perceive their symptoms. Women internally assessed if their symptoms would be received in a "credible way" (Werner et al., 2004, p. 1037) and the social costs if they were not.

Reaching Out For Help

The dominant discourse suggests the second step involves individuals reaching out to formal and informal systems of help, recounting their "debut stories" or descriptions of the onset (Hydèn & Sachs, 1998). The dominant discourse assumes that sources of help (e.g., doctors,

nurses, specialists) are available and desired, are unquestioning (i.e., will not express skepticism regarding the illness), and are preferably doctors because they are knowledgeable and therefore, authoritative (Campbell et al., 2016; Rolland, 1994). For example, Rolland (1994) posits that in the crisis stage of illness, families reached out to doctors in order to learn as much as they could about the illness or condition, so that they might make sense of the condition. Yet, other scholars pointed out that individuals were just as quick to reach out to informal sources of support like family (Jutel & Bannister, 2013), friends, and perhaps online communities (Nath, Huh, Adupa, & Jonnalagadda, 2016). Regardless of the source for help, the dominant discourse posits that reaching out is a way of making sense of the illness or condition. Three types of experiences disrupt the dominant discourse.

      Dismissive experiences. Dismissive experiences with doctors and family members is commonplace in the literature on invisible illnesses (Dumit, 2006; Nettleton, 2006; Werner et al., 2004). Individuals, most often women, reported encountering skepticism, disbelief, and dismissal of symptoms and experiences when reaching out; help was not available (Dumit, 2006), knowledgeable (Rodham et al., 2010), or believing of one's reality (Swoboda, 2006). Women suffering from invisible illnesses described being disregarded by family. As one woman in Armentor's (2015) study on 20 patients with fibromyalgia stated,

> Nobody sees that there's anything wrong with you….If you have a broken leg, and it's in
> a cast, then your family doesn't expect you to get up, and clean house, and do dishes, and
> run five miles. When you look perfectly healthy, it's hard for them to accept that there's
> anything wrong with you. (p. 8)

However, women's experiences with being turned down by members of the medical establishment proved to be more upsetting. In their examination of blog posts relating to

experiences with chronic fatigue syndrome, Dumit (2006) uncovered patient narratives of doctors' inaction because they did not believe patients' symptoms. Ultimately, patients came to question their symptoms, right to care, and in some cases, sanity (Dumit, 2006; Swoboda, 2006).

The exam room of a doctor's office is not simply a setting where individuals go to receive help and advice about their health. This setting is also an arena of power and negotiation, where individuals and medical professionals engage in performance of their social locations (e.g., race, gender, age, class, sexual orientation; Hill, 2009; Mik-Meyer, 2012; Swoboda, 2008; Werner & Malterud, 2003; West & Zimmerman, 1987). It was in the doctor's office where individuals: juggled communicating their symptoms and illness (Dumit, 2006; Hydèn & Sachs, 1998); managed the degree of profiling based on cultural images (Goffman, 2009; Hill, 2009) and systemic racism, sexism, and classism (Feagin & Bennefield, 2014); and fought for credibility (Dumit, 2006; Werner & Malterud, 2003). Therefore, the hunt for a "good doctor," a doctor who took symptoms seriously, was the hunt for a doctor that was knowledgeable (Swoboda, 2006) and exercised his or her authority in ways that did not propagate systems of power and oppression (Dumit, 2006; Mik-Meyer 2012).

Family interpretation. Family scholars highlighted how individuals and families attached meaning to invisible illness in different ways that impacted if and how they reached out for formal help (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Lewis-Morton, Dallos, McClelland & Clempson, 2013). In an attempt to normalize symptoms of memory loss, Blieszner et al. (2007) found that couples, prior to seeking out a diagnosis, associated the changes with normative later life experiences. "Accepting [the] atypical…often delayed mentioning problems to physicians" and resulted in using several compensation strategies to manage daily life (Blieszner et al., 2007, p. 200). Families dealing with invisible illnesses

engaged in compensation strategies to account for and make their own meanings of illness, including avoidance (Armentor, 2015) without counsel of the medical establishment (Blieszner et al., 2007; Rolland, 1994).

        Self-diagnosis and contested information. Patients with common illnesses were often encouraged to engage in self-diagnosis (i.e., public health campaigns about recognizing the signs of the flu; Jutel & Barrister, 2013) or manage illness (McMullan, 2010), but the medical establishment considered information work (Nettleton, 2006) that patients with invisible illnesses performed to be illegitimate (Nath et al., 2016). Research documented that the medical establishment often dismissed or refused to treat invisible illnesses and thus, created a paradox (Swoboda, 2006). Individuals, turned away from the medical establishment, were forced to turn to less authoritative or legitimate sources of information in order to self-diagnose (Nath et al., 2016); yet, in seeking out information, medical professionals viewed them as inappropriately informed and bad patients (McMullan, 2006; Swoboda, 2006). For example, Barry and Edgman-Levitan (2012) argued that doctors' resistance to instances of self-diagnosis and patients' use of Internet information added layers of contention in the doctor-patient relationship.

Undergoing Testing or Evaluation

        At the third step, the dominant discourse purports that patients undergo testing and evaluation with the goal of finding a diagnosis. This step marks a crossroads of subjective, patient experiences and objective medical testing at which individuals can undergo testing under the purview of a doctor (Campbell et al., 2016). Step Three is the pinnacle of the crisis period (Rolland, 2011). The dominant discourse assumes that testing is available, desired, objective, and authoritative. Most family research on physical health assumes that health is observable either through biomedical tests and screenings – with a diagnosis as the ultimate result (the fourth step;

Lewis-Morton, 2013; Rolland, 2011); it is a permeating assumption in most research.

However, a few researchers problematized this discourse by revealing that positivistic, objective testing was often times unavailable (or non-existent), particularly for those experiencing chronic pain or fatigue. Furthermore, testing may have relied on how the medical establishment socially constructed individuals' symptoms as physical or psychological in origin (Swoboda, 2008). Research on invisible illnesses showed that the availability of a test may have been directly reliant on whether or not a doctor was willing to consider the symptoms as part of a legitimate disease. In a survey of United States physicians (n=445), Swoboda (2008) examined the factors that increased physicians' willingness, ability, and likelihood to attempt to diagnose for invisible illnesses. She found that only 51% of doctors in practice for an average of over 20 years provided diagnosis of chronic fatigue syndrome, and even lower rates of other, though admittedly rare, contested illnesses (i.e., Gulf War Syndrome; Swoboda, 2008). Doctors providing contested illness diagnosis were more willing to consider symptoms physiological as opposed to psychological (Werner & Malterud, 2003). They were more also likely to be considered medical experts, more willing to reach out to multiple sources for knowledge on conditions, and more likely to perform a holistic examination of their patients as opposed to reliance on a singular empirical test (Swoboda, 2008). As such, the illness uncertainty literature underscored that testing and evaluation was often at the discretion of the doctor (Swoboda, 2008; Werner & Malterud, 2003).

Receiving a Diagnosis

Following testing or evaluation, doctors determine the illness or condition; providing or denying validation to the individual and family (Campbell et al., 2016; Rolland, 2011). In this fourth step, the dominant discourse suggests that receiving a diagnosis is a turning point in

gaining understanding and insight about the illness facing the family (Rolland, 1994). It is here that most family research centered on illness in families begins (McCubbin et al., 2002; Walsh, 2002). The dominant discourse assumes that in this step that the medical establishment provides legitimacy in the form of a diagnosis (Nettleton, 2006) making individuals' experiences and subsequently, their bodies subject to external, medical regulation and validation (Shehan & Kaestle, 2009). Individuals living with illness uncertainty (i.e., without a diagnosis) knew the value and meaning of a diagnosis (Charmaz, 1983; Dumit, 2006; Nettleton, 2006; Swoboda, 2006), and I examined how their experiences of *not* receiving a diagnosis disrupt the discourse.

   Inconclusive/No diagnosis. When testing was inconclusive or doctors could not arrive at a diagnosis, patients lived with "embodied doubt" (Nettleton, 2006, p. 1168) or resided in a liminal, "diagnostic limbo" (Corbin & Strauss, 1985). Interviews with White, British neurology patients (n=18) who were deemed to be suffering from medically unexplainable symptoms (MUPS) revealed that not having a diagnosis made them question themselves and the "authenticity of their symptoms" (Nettleton, 2006, p. 1170). Furthermore, the longer time searching and testing for illness, the more ambivalent their relationship became with the medical establishment, in terms of (a) coming to feel that any diagnosis might be better than no diagnosis, (b) coming to understand the limits of the medical system yet feeling angry that it could not validate their experience, and (c) being "haunted by the idea" they may have a psychological condition (Nettleton, 2006, p. 1173).

   Individuals with no diagnosis were often left out of research, but they experienced hardship in managing daily life (Sitnick, Masyn, Ontai, & Conger, 2016), and accessing care and treatment (e.g., "no diagnostic code…no care"; Dumit, 2006, p. 582). In examining online forums and conducting in-depth interviews with six Norwegians suffering from undiagnosed

back-pain, Glenton (2003) found that patients with no diagnosis were considered drug-seekers or

whiners, and for the few patients who were able to locate a diagnosis (e.g., a slipped disc), they

lamented in not having proof of their illness so they could more easily access care and treatment.

For others, the extended and unsuccessful bouts of seeking a diagnosis weakened patients'

claims to a sick role, involved thousands of miles of travel, and resulted in deep "wounds at the

hand of [medical, mental health, and insurance] institutions" (Dumit, 2006, p. 583).

Negotiating and Managing Identities and Roles

The final step, according to the dominant discourse, involves if and how the individual

and family cope with diagnosis (i.e., move on with their lives; Campbell et al., 2016; Rolland,

1994). Here, for the first time in the dominant discourse the family is considered to be a major

part of the process. Prior to now, the dominant discourse assumed the family was in crisis and

therefore invisible from the narrative (Rolland, 1994). Overall, at this step, the dominant

discourse assumes that a diagnosis is accepted, and it ends the family crisis period (Rolland,

1994). Families can adapt to the illness and the changes it brings (Rolland, 2011). Many family

researchers hypothesized or explored chronic illness as a family stress and examined how

families were resilient in the face of this stress (Boss, 2002). However, most family research

typically revolved around managing illness onset in childhood or later life (Gilligan, Suitor,

Rurka, Con, & Pillemer, 2015; McCann & Roberto, 2012; Shapiro, 2013). Next, I discuss

research that illustrates how scholars studied individuals and families dealing with diagnosed or

known illnesses.

Coping as chronic stress. Managing the stress and strain of chronic illness often resulted

in inward family cohesion (Rolland, 2011) and involved interacting systems related to biological

health, personal development, social relationships, structural forces (i.e., finances), and beliefs

and values (Baanders & Heijmans, 2007; Harvey, Johnson, & Heath, 2013; McCann & Roberto,

2012). These interactions were not static and required families to develop flexible, yet strong

coping strategies (Boss, 2002). In their examination of 36 older women's personal and familial

relationships, McCann and Roberto (2012) found that patterns of coping and adapting to chronic

illness included balancing personal frustration, relational ambivalence, and desires for personal

independence. Other coping strategies included normalizing illness, humor, social support (Boss

2002; Maxted, Simpson & Weatherhead, 2013), adopting new views on life, and finding intrinsic

value in providing care (Baanders & Heijmans, 2007).

Chronic illness also tested intimate partnerships (Baanders & Heijmans, 2007),

friendships (Baanders & Heijmans, 2007), and intergenerational relationships (Gilligan, 2015).

Among families (romantic couples, siblings, adult child-parent) in the Netherlands (n=1093),

Baanders and Heijmans (2007) found that the impact of caring for someone with a chronic

illness did not affect individuals on a strictly personal level (e.g., only 3% reported having too

little time for self), but that it impacted the relationship (40% reporting growing closer, and 25%

reporting that they cannot plan for the future).

Another concept closely associated with family stress is resiliency (Walsh, 1996). Family

scholars that purport families' resiliency (Rolland, 2011) or hardiness in times of stress (Walsh,

1996) argued that family relationship processes could strengthen both the individual and the

family. Other scholars in health argue that these same processes that could promote resiliency

occur on an individual, family, and even community level (Benzies & Mychasiuk, 2009). In their

review of 40 articles on family resiliency, Benzies and Mychasiuk argued that there were 24

protective factors that could support individual and family resiliency including health, belief

systems gender, internal locus of control, social support, peer acceptance, and access to quality

healthcare (p. 105).

      Coping as biographical work. Other scholars have theorized about chronic illness as a disruption to varying degrees (Bury, 1982). A diagnosis assisted individuals and families in moving on with their lives through a process called biographical work. Bury's (1982) work with patients suffering from rheumatoid arthritis laid the foundation for conceptualizing illness as a status that unsettled one's sense of self or self-worth (Charmaz, 1983), suspended the normal daily activities, and blurred one's view for the future (Bury, 1982; 2001; Hubbard, Kidd, & Kearney, 2010). Disruption did not, however, only affect the individual. For example, couples in therapy experiencing chronic illness often experienced self-loss (among the patient with illness) and other-loss (among family members) (Weingarten, 2013). Furthermore, Locock, Ziebland, and Dumelow (2009) found that activity and identity changes in patients with Motor Neurone Disease (n=35) resulted in identity changes for the patients and caregivers who had experience with MND.

      Charmaz (2006b), Bury (2001), and other scholars argue that this disruption was not permanent, and people sought to restore lost aspects about themselves by engaging in biographical repair (Bury). Scholars also posited this was done through creating new or evolved identities (Charmaz, 2006b) or normalization (Williams, 2000). For example, in their interviews with 57 adult stroke victims (23 non-Hispanic White, 16 African American, and 18 Puerto-Rican Hispanics) aged 46 to 88, Faircloth, Boylstein, Rittman, Young, and Gubrium (2004) found that older adults viewed their stroke as a normative event or next chapter to their lives. Rather than "shattering lives" (Faircloth et al., 2004, p. 247), some individuals viewed the stroke as "part-and-parcel" challenge in life (p. 248). Age and social location influenced if and how normalization took place. Whether it was biographical repair (Bury, 2001), biographical work

(Asbring, 2001), or a more cohesive biographical flow (Faircloth et al., 2004), scholars agreed that these processes or construction of self emerged through interactions and meaning-making experiences with ourselves and others (Locock et al., 2009).

In this next section I discuss research related to living with chronic illness that used the same ideas (i.e., as a stressor or a biographical disruption) with *different outcomes*. I introduce issues of ambiguity in coping with illness to serve as examples of how women's experiences with illness uncertainty *lie outside* of the dominant discourse.

Ambiguous stress and loss. As noted, the dominant discourse suggests that a diagnosis provides a concrete framework through which families attempt to restore their functioning. Families accept the diagnosis, the family crisis period ends, and families and individuals move on (Rolland, 1994). If a stressor is beyond one's control (external), ambiguous, chronic, and integrated into multiple aspects of one's life, then it complicates if and how individuals and families interpret and manage the stress (Boss, 2002). For example, for individuals dealing with Crohn's disease, the daily stressors of not knowing if and when one will have an episode wreaked havoc on emotional well-being; the uncertainty became overwhelming (Boss & Couden, 2002; Moore, 2013). In an attempt to label a couple's experience with Crohn's disease, Boss and Couden (2002), postulated that families dealing with no diagnosis or uncertain prognosis (i.e., more questions than answers) experienced ambiguous loss. As their case study pointed out, often couples dealing with ambiguity did not cope with stress in ways that facilitated couple unity, functioning, and cohesion. Instead, couples facing health ambiguity did not validate each other's feelings (Boss & Couden, 2002), remained confused and unable to perform roles or rituals (Boss & Couden, 2002), and could potentially remain in a perpetual state of exhaustion (Boss & Couden, 2002; Shapiro, 2013).

Partners' and family's social support remained one of the biggest factors to help individuals cope with illness (Boss, 2002; Hoth et al., 2015). Individuals (n=462) faced with illness uncertainty judged and used their social surroundings to handle ambiguity in illness (Hoth et al., 2015). As Hoth and colleagues demonstrated, perceived criticism increased illness uncertainty, while social support decreased. Family who (a) believed, (b) were knowledgeable, and (c) supportive provided people with the resources needed to cope or compensate for the onset of ambiguous chronic illness (Boss, 2002; Hoth et al., 2015).

Biographical work in uncertainty. Until the medical community agrees on the existence and treatment of biomedically invisible or medically unexplainable illnesses, individuals experience different forms of biographical work and repair (Bury, 2001; Crooks, Chouinard, & Wilton, 2008; Williams, 2000). In illness uncertainty, people struggled with identity and relationship work in the context of struggling with the idea of what it meant to be legitimately sick (Crooks et al., 2008; Rodham, Rance, & Blake, 2010). Identity work took place in the space of everyday life (Charmaz, 2006b) and if the surrounding context questioned the reality of one's illness (i.e., denial or skepticism regarding illness), people struggled with identity integration, reframing, (Bury, 2001) or overhaul (Charmaz, 2006b).

Difficulties of biographical work extended to family members as well. Rodham et al.'s (2010) dyadic examination of four couples dealing with fibromyalgia suggested that for couples, it was "hard enough to have such a debilitating condition without having also to convince others of its reality" (p. 70). Spouses were also impacted by judgment and skepticism from family, coworkers, and friends, and experienced a loss of identity. They viewed the illness as gaining possession over the relationship and experienced feeling isolated (Rodham et al., 2010, p. 73). In dealing with invisible illness, couples put on a "veneer of normality" as a form of biographical

work (Rodham et al., 2010, p. 72) in order to avoid losing systems of support (Crooks et al., 2008; Moore, 2013; Rodham et al., 2010).

Disagreement with diagnosis. Lastly, there are those who disrupt the dominant discourse because they completely disagree with the diagnosis. Often times in the case of illness uncertainty, this rejection was a result of individuals' refusal to accept their condition as psychosomatic (i.e., psychological; Dumit, 2006). In these instances, disagreement may be traced back to the medical professional - unwilling to diagnosis and treat for seemingly psychosomatic conditions; and the patient - unwilling to accept psychosomatic explanation for their symptoms (Conrad & Baker, 2010; Swoboda, 2006). Regardless of the source of conflict, disagreements between doctors and individuals and families often led to pursuing further testing and treatment (Dumit, 2006), reaching out to online communities for self-diagnosis (McMullan, 2010; Swoboda, 2006), or risking the "uncooperative patient" label if they did not follow through with original orders (Swoboda, 2006).

Gaps in Research

The purpose of this chapter was to show the drawn out and complicated process and context embedded in the common discourse of what it means to be sick. So often the literature and research conducted on this topic of illness and families investigated those living and coping with illness following diagnosis (Shapiro, 2013; Rolland, 2011). The family literature assumed that families were already working with "the best possible understanding of the diagnosis and underlying medical condition" prior to attempting to cope and adapt (Shapiro, 2013, p. 21). By deconstructing the discourse about what it means to be sick, I brought the important intermediate steps that lie between onset of symptoms and coping with illness to the forefront of the conversation. Throughout this review, it was clear that the process and context of receiving a

diagnosis was not void of interactional, agentic, and relational processes. The medical

sociological literature focused on the experiences of the individual during this complicated

process (Nettleton, 2006; Dumit, 2006), and relatively few researchers have examined the role

families also play (Armentor, 2015; Dumit, 2006).

Secondly, research on living with chronic illness focused on those individuals and

families living with a named disease or condition. This is a vital field of research, but it

marginalizes those who live without a diagnosis. For those who do not reach the fourth step in

the discourse, finding out what is wrong, what does their negotiation of their identities and roles

and relationships look like? Can it be characterized similarly to those with a diagnosis, or are

families struggling to function in a state of uncertainty? What role does family play in the midst

of illness uncertainty? These gaps in the research, combined with the previous discussion about

disruptions to the dominant discourse, warrant further investigation on illness uncertainty.

Summary of Chapter

In this chapter, I deconstructed the discourse surrounding illness and what it means to be

sick in an effort to showcase the complicated and potentially drawn-out process of seeking a

diagnosis. I discussed the individual, familial, and contextual factors and processes that support

and disrupt the dominant narrative, using the literature to show the need and also, the ability to

investigate those who disrupt. Given the emphasis on the individual and their interactions with

the medical system, more research is needed on the ways in which the family operates during, or

perhaps mediates, the process of seeking out a diagnosis. Furthermore, investigating individual

and familial processes prior to receiving a diagnosis is warranted given the nature of

biomedically invisible and idiopathic illnesses. I next move on to discuss the method.

CHAPTER III

Overview of Research Design

In this study, I explored women's and families' experiences in ways that consider their agency, meaning-making processes, and context. I conducted semi-structured interviews using a narrative, phenomenologically informed (Chase, 2005; Sandelowski, 1995) method. My epistemological approach to my collection, deconstruction, and coding of interview data in this study was as a critical postmodern feminist (Allen & Baber, 1992). My FEI approach also informed my choices in weaving intersectionality into my approach and eventual analysis. In addition, my analysis was guided by my personal experience, and I provide a brief reflection on the role of insider knowledge (Blumer, 1969) in the midst of analysis. My analysis followed Glaser and Strauss (1967) constant comparative method and Charmaz's (2006a) grounded theory methodology as it allowed for iterative and constant comparative coding.

Epistemology

The FEI perspective prioritized the meaning-making, agentic, and contextual factors involved in illness uncertainty. My theoretical approach dialectically accommodated tension in power and meaning (Olson et al., 2005). My method worked in combination with, not opposition to my approach (Sprague, 2005). I worked to ensure my methodology adhered to the theoretical tenets of postmodern feminist epistemology (Allen & Baber, 1992; Sprague, 2005).

Discussion of critical postmodern feminist perspective. A critical, postmodern feminist perspective allows for consideration of subjective experiences and agentic processes while also challenging and critiquing larger systems of power (Allen & Baber, 1992). It recognizes that women's subjective experiences provide deep and meaningful insights into human behavior and development and problematize an essentialized nature of social locations (i.e., our identities such

as race, age, gender, class; McCall, 2005; Warner, 2008). However, as Allen and Baber (1992) point out, postmodern deconstructionist approaches can easily fall into the trap of relativism, avoiding a critical analysis of the context in which women live. Using a critical perspective, however, allows for discussion and critique on the larger systems of power, privilege, and oppression (Collins, 2000; Few-Demo et al., 2014).

Intersectionality in approach. The integration of what McCall (2005) and Few-Demo et al. (2014) call "intracategorical intersectionality" perspective acknowledges the socially constructed nature of identities (e.g., race, gender, class) but with an understanding of how these identities operate in society. However, with an intersectional approach, I was cognizant of avoiding an "othering" narrative in my analysis and results (Warner, 2008; Few-Demo et al., 2014). I did not consider women's experiences in comparison with a "norm" but instead, my research questions and analysis focused on the experiences of those within the margins; those who are left out, ignored (Warner, 2008). To be clear, my discussion of the dominant discourse did not compare experiences of those with illness uncertainty to those who have illness certainty. Rather I worked to contextualize women's experiences and in this way I worked to operationalize intracategorical intersectionality (Few-Demo, 2014; Few-Demo et al., 2014).

Method

I conducted a narrative inquiry, with phenomenological techniques (Sandelowski, 1995). It was not a life narrative of the individual, but instead utilized components of the narrative approach to gather data on the recent past, present, and thoughts on the future (Chase, 2005; Patton, 2015), in the same vein as biographical work (Bury, 1982). I used components of phenomenological approach to consider the subjective experience (Rossman & Rallis, 2011). The epistemological method examined the lived experience (Rossman & Rallis, 2011) and the

narrative method was most useful in "identifying the perceptual frame circulating in a given culture and how they shape group members' sense of their own experience" (Sprague, 2005, p. 142). A merged approach allowed me to engage in in-depth, exploratory interviews that considered women and family's subjective experiences, processes of meaning-making, and shed insights to the context within which to understand their experiences (Patton, 2015; Chase, 2005).

Recruitment Procedures

The target sample was developed in consultation with my committee and chair. Inclusion criteria for women to participate were:

- Women aged 25 to 50,

- Living with undiagnosed symptoms for at least three months,

- Residing in the Mid-Atlantic United States (Maryland, Virginia, North Carolina, South Carolina, Georgia, and District of Columbia), and

- Available to talk in-person or via online video for 60 minutes.

There were various conditions and health issues that I considered eligible. I based my demographic criteria (i.e., age, gender) on the common illnesses associated with prolonged periods of diagnosis seeking (see Table 1). The common age of onset for these conditions is between mid-20s and early 40s, they disproportionately affects women, and their symptoms can range from mild to severe (Hersh & Fox, 2014; Lawrence et al., 2008; Ruffing & Bingham, 2016; Smitherman, Burch, Sheikh, & Loder, 2013).

The Western medical establishment considers chronic conditions to be those that have symptoms that persist for at least 3 (Singh et al., 2015) to 6 months (Goodman, Posner, Huang, Parekh, & Koh, 2013). The three month minimum for experiencing symptoms sought to exclude those who experienced acute, disruptive illnesses and who, pending full recovery, are often able

to restore their identity, relationships, and roles (Bury, 1982). Secondly, the three month

minimum ensured the interview was not at the very onset of the illness with no time for self-

reflection, adjustments, or doctors' appointments (Brannen, 1988).

Recruitment

       Availability of sample. There is no one definition for illness uncertainty; making

accurate estimates for this population is nearly impossible. Researchers and patient advocates

speculate that as little as 2.6% (National Ambulatory Medical Care Statistics Branch, 2015) to as

many as 50% of primary care visits include discussions regarding some form of uncertain

illnesses (Edwards, Stern, Clarke, Ivbijar, & Kasney, 2010). The current study was not

specifically focused on one particular condition but rather on the process of living without a

diagnosis; population estimates are unknown. I suggest these qualities make it a hard-to-define,

and therefore, hard to reach population.

       Creation of website. Prior to the start of data collection, I purchased a domain, and

created and hosted a website using Google Domains (hosting service) and Wix.com, a website

creator. My site, www.storiesofsearching.org – nicknamed SOS Project - provided information

about the study, copies of informed consent, contact information, and access to the Virginia Tech

Qualtrics server with eligibility questions. I used the Virginia Tech Qualtrics Secure Server to

collect eligibility and contact information from women who wished to utilize the web. The

website served as a gatekeeper of information, a way to build rapport and trust with potential

participants, and a domain for recruitment through social media. Eventually, this site also will be

used to host published results and findings so that study participants and others have access to

information beyond this current study.

       Process of recruitment. I recruited participants between September 2016 and January

2017 following IRB approval. I engaged in *purposive* strategies followed by *snowball sampling* strategies (Patton, 2002; 2015) in order to collect an appropriate sample to answer my research questions. Because I did not designate a specific illness or condition, my sampling strategies allowed for "maximum variation" (i.e., a wide range) in both forms of purposive sampling (Patton, 1989, p. 107 as cited in Patton, 2002). Purposive sampling or intentional sampling acted as the wide net; recruitment materials were broadcasted out through several avenues (discussed below). Snowball sampling was used to reach those that might otherwise not have been reached (Patton, 2015).

The most recent research on Americans' access to the Internet revealed that the digital divide (Anderson, 2015; Norris, 2001) continues to shrink, especially among younger portions of the US population. Cellphone and smartphone ownership among adults between the ages of 18-49 has reached almost ubiquitous levels with 98% of adults aged 18-29 and 96% of adult aged 30-49 owning a cellphone. Smartphone ownership (with access to the Internet and social media sites) is also at 86% and 83% respectively (Anderson, 2015). Furthermore, adults below age 50 use social media sites at much higher rates than their older counterparts with over 90% of adults aged 18-29 and 77% of adults aged 30-49 report using social media sites such as Facebook, Twitter, Instagram, and Pinterest (Perrin, 2015). The ongoing Pew Institute American Life research project also found that women, those with higher incomes, and living in more suburban or urban areas are slightly more likely to use social media, but there were no significant differences with usage based on race or ethnicity (65% of Whites, 65% of Hispanics and 56% of African-Americans use social media today; Perrin, 2015). In all, these social media use trends and the right use of the platform provided me with potential inlets to participants that may otherwise not be reached (Heldman, Schindelar, & Weaver, 2013).

Social media recruitment. I used social media (i.e., Facebook and Twitter) to recruit for this study. I created social media profiles on Twitter (@_sosproject) and Facebook (SOS Project at Virginia Tech) to promote the website, post recruitment flyers, and post relevant news stories to generate interest in the study. The Twitter account biography served as a form of recruitment, "Official acct of #PhD student project w/ women aged 25-50 living with #nodiagnosis. #YourStoryMatters. RT/followers are not endorsements. sosproject@vt.edu #LetsTalk." A typical tweet consisted of,

> What can a diagnosis provide you? #LetsTalk #chronicillness #nodiagnosis #undiagnosed
>
> Share your story. RT welcomed. storiesofsearching.org [flyer picture attached]

I also followed different advocacy groups and organizations interested in health, healthcare, health insurance, rare illnesses, Syndromes Without A Name (SWAN), and hundreds of individuals. I re-tweeted (RT) health advocates and used different illness and health related hashtags (#spoonie; #nodiagnosis; #health) as it would increase the potential number of people who saw my tweet. The "twittersphere" as it is referred to in popular culture, can be a vast and overwhelming space. Rather than engage in an endless task of following thousands of individuals, I located organizations and surveyed their followers. From the list of followers, I selected potential "connections" to participants; I followed individuals as a passive form of recruitment as my bio would appear in their list of followers. At the end of recruitment I had 40 original tweets and 101 retweets, received 12 retweets and 25 likes, and gained 83 followers. My recruitment on Twitter resulted in two participants. As a way to more fully demonstrate the social media environment my profiles created, I provide a word cloud with the most common words and themes of my Twitter handle. See Figure 2 for my Twitter word cloud. I also created a Facebook page in the same respect as Twitter. Members of my personal network "liked" the page

and increased visibility. After two months of recruitment, I purchased an ad booster on

Facebook; I selected the target audience (interests, location, ages, gender) and a target time (24

hours, 48 hours) my advertisement would appear near the top of users' home-screens (Sorokina,

2014). The boost post feature is for businesses but I used it to promote my "product" – the page

for my study - on five occasions between the months of November and January (average of

$8.00 per boost, total spent $55.00 in ads). The highest reach of my boosts was 1,200 people.

Other posts not boosted also reached a maximum of 836 people. By the end of recruitment, I had

gained 20 followers and 30 likes on different posts. Facebook recruitment resulted in 50 visits to

my website, two participants, and was a cost effective way to achieve widespread visibility to

potential participants (Heldman et al., 2013).
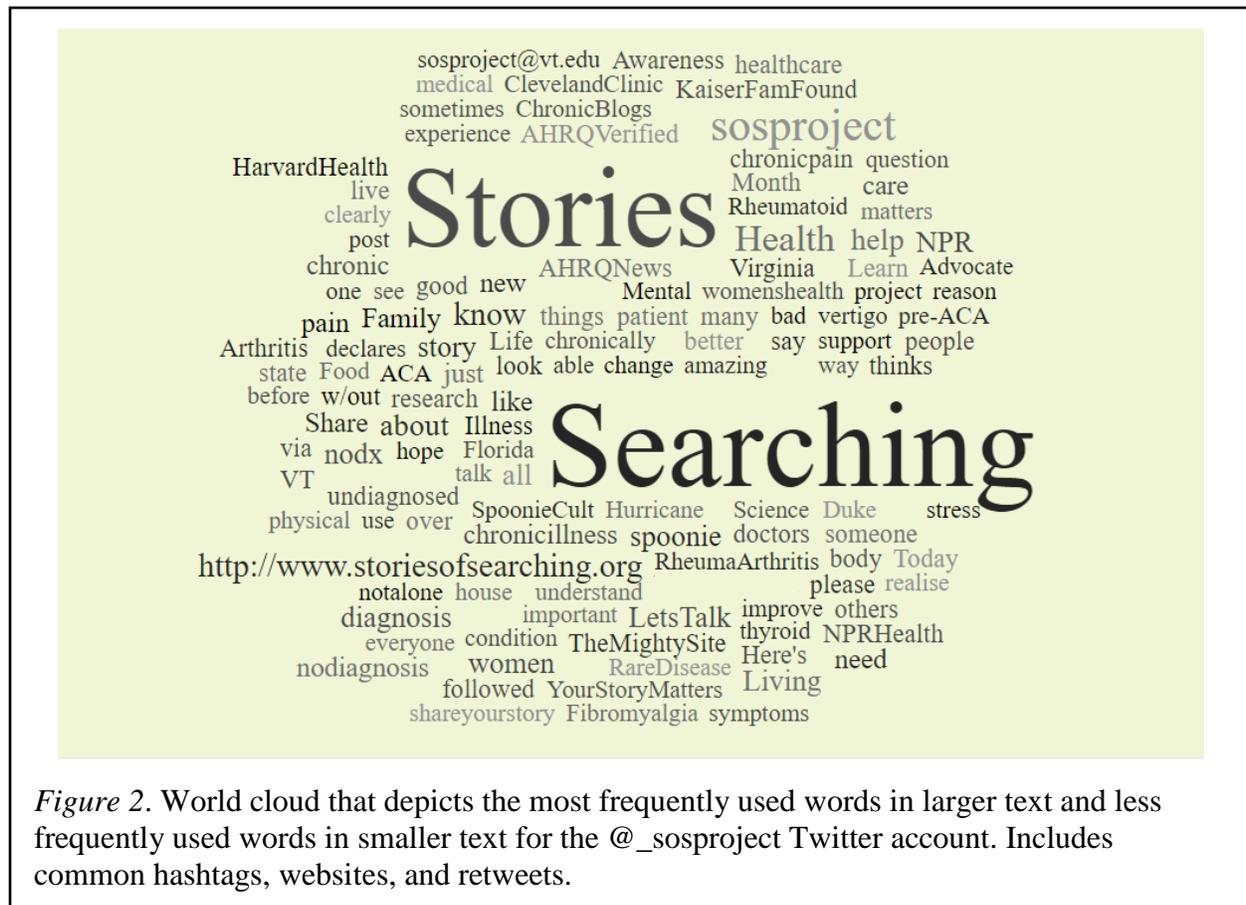
Figure 2. World cloud that depicts the most frequently used words in larger text and less frequently used words in smaller text for the @_sosproject Twitter account. Includes common hashtags, websites, and retweets.

Other forms of recruitment. In addition to social media, I utilized email list-serves and

word-of-mouth. I sent out PDF versions of flyers (See Appendix B) and short description emails with information regarding the study. I emailed faculty/staff and graduate student list serves associated with different colleges and universities in the Southeastern United States. Within three weeks of the start of recruitment, I had completed eight interviews for the study. Therefore, I did not send out additional emails to list serves in the region as I had more participants coming in. By November I had completed 10 interviews. Other forms of recruitment included word of mouth as activated by personal connections along the east coast. Members of my personal networks also engaged in social media recruitment; sharing and disseminating the project in their personal networks. I successfully recruited seven participants from my email list serve announcements and three participants were referred by word-of-mouth to my study.

At the end of recruitment, my site had received 193 visits with a peak of 83 visits in September and a low of six visits in January. The site collected 164 visits that originated from within the United States. Site visits also came from other locations around the world. Participants spent between three minutes and 19 minutes on the website. One hundred and twenty-seven visits were via desktop, 64 visits via mobile phone, and 1 visit via tablet. Ten potential participants contacted me via the website, with eight eligible for participation. Fourteen potential participants contacted me via email. In total, 24 women contacted me. Of the 24, 17 were deemed eligible. Two potential participants expressed they were not eligible, five potential participants did not participate due to loss of contact (after 3 attempts to follow-up), and two women expressed that they did not wish to be interviewed at this time. In all, I found that my recruiting process was streamlined and speedy; nearly all of the women who contacted me were eager to speak with me about their experiences.

Potential participants who used Qualtrics/website completed an eligibility form online

(see Appendix C) and were provided a copy of the informed consent. I sent potential participants who contacted me via email the eligibility form (as a word document). Women also completed a contact sheet (via Qualtrics or email). All interviews were scheduled via email or telephone. I offered in-person, telephone, or online video interview to all participants as those suffering from chronic conditions may see in-person interviews as an obstacle to participating in research (Dumit, 2006). Eleven interviews were conducted in person. Three interviews were conducted via online video (e.g., Google Hangout or Skype), and one interview was conducted via telephone as per participant request. Each participant was given a $20 gift card as compensation and as a token of my gratitude.

In addition to each woman with illness uncertainty, I also interviewed one member of a woman's support network who (a) was a family member, friend, or confidant, (b) was aware of the participant's health issues or condition, so that the illness had been discussed, and (c) had regular interactions (at least once a month, so that they can speak to the impact the illness has had on the woman's life) (See Appendix C). Family members' criteria also included being aged 18 or older and able to talk via telephone. I asked women to provide me with name and contact information of a family member or friend as I was interested in learning about how their experiences with undiagnosed symptoms impacted their relationships. Fourteen family members were identified by women as one woman had yet to reveal her symptoms to anyone (Hazel). I contacted five family members via email, and eight family members by phone. Of the 14 family members contacted, one family member declined to participate, one family member was unable to participate due to their own illness, and one family member was lost to contact (after 4 attempts). Nine family member interviews were conducted via telephone. I conducted one family member interview in person per participant request. One family member interview was

conducted by the woman as her mother did not speak English, and I was provided a translated

transcript of the conversation. Each family member was mailed a $15 gift card. Many women

identified a family member or friend they trusted and felt would be comfortable talking with me.

Sample Description

This study's sample included 15 women and 11 members of their support network.

Women were between the ages of 25 and 46 (M=29.7) and members of the support network were

aged 22 to 62 (M=42.5). Members of the support network included mothers (n=5), close friends

or roommates (n=3), romantic partners or spouses (n=2), or sibling (n=1). I refer to all members

of the support network as family. Two family members identified as men (18%) and the rest of

the family members and all target participants identified as women. The racial make-up of the

sample included women who identified as White (n=9), Asian or Pacific Islander (n=3), Black or

African American (n=2), and Biracial (n=1). The racial make-up of the families included men

and women who identified as White (n=6), Asian or Pacific Islander (n=3), Black or African

American (n=1), and Hispanic or Latina (n=1). Women participants were all located in the

Southeastern United States, however, family member telephone interviews took place with

participants located in the West Coast (n=1), Midwest (n=1), and East Coast (n=8) and one

interview took place online in China (n=1). See participant demographics in Table 2.

Data Collection Procedures

Pilot Work

In preparation for this study, informal conversations took place with several individuals

within my own personal network who have direct or indirect experiences with illness

uncertainty. I talked with members of my own social network about the preliminary stages of my

proposed research, discussed ideas for questions to ask, gathered feedback on questions, and

Table 2

Participant Characteristics

	Women (n=15)	Family Member (n=11)
Average age (range)	29.7 (25-46)	42.5 (22-62)
Area of Undiagnosed Symptom		
Musculoskeletal	4	--
Autoimmune	3	--
Neurological	4	--
Respiratory	1	--
Dermatological	2	--
Digestive	1	--
Relation to woman		
Mother	--	5
Friend	--	3
Spouse (husband)	--	2
Sibling (sister)	--	1
Race/Ethnicity		
Asian or Pacific Islander	3	3
Black or African American	2	1
Biracial	1	--
Hispanic or Latino(a)	--	1
White or Caucasian	9	6
Highest Level of Education Completed[a]		
Some college	1	1
College	5	5
Grad school	9	4
Employment		
Unemployed	2	1
Retired	--	2
Full-time	3	4
Other[b]	10	4
Relationship Status		
Single	7	2
Dating/Cohabitating	3	--
Married	5	8
Widowed	--	1
Health Insurance Status[a]		
Not insured	2	--
Insured (employer)	9	5
Insured (family)	3	5
Insured (public program)	1	--
Salary Range[a]		
Under $10,000	1	--
$10,000-20,000	4	--
$20,000-30,000	3	1
$30,000-40,000	2	1
$40,000-50,000	1	1
$50,000 or more	4	7
Parental status		
No children	13	5
1-3 children	2	6

[a] 1 missing family case; [b] Occupations include Consultant, Freelance, Graduate Student, Self-employed;

talked with them about their own experiences. I purposefully chose individuals within my own

social network with whom I have known for an extended period of time, with varying

demographic characteristics and experiences with different illnesses (including mental health

diagnoses) as a way to gauge what my eventual sample, questions, and area of research would

be. I developed memos of ideas that emerged from these informal conversations regarding their

reactions to my potential research, their own experiences with the issue of illness uncertainty,

and suggestions on where the research could go. These conversations were extremely helpful in

guiding my thought process as I formulated the research approach, design, and implementation.

Informed Consent

All participants were provided a PDF of the informed consent following initial contact. I

made arrangements with each of the participants about the best time, location and/or format for

the interview. The informed consent included all required information (details about the study,

participants' rights, risks, and benefits), as set forth by the Institutional Review Board, in easy to

read and understandable language (see Appendix D). Prior to the start of each interview, I went

over the informed consent with each participant and received their written or verbal consent

including consent for audio-recording of the conversation. All participants consented to the

interview and audio-recording. I then conducted the semi-structured interview according to the

interview protocol (see Appendix E). At the end of the interview women completed a

demographic form and provided the names and contact information of a family member.

At the end of the interview, most women noted that they wanted to talk with the family member

or friend prior to me contacting them. I waited until I received confirmation from the woman

before reaching out to family members. Family members were therefore introduced to the study

by the target woman. I contacted family members via telephone or email to ask for their

participation and scheduled a time to complete the interview. All but two family interviews took

place over the phone. Informed consent for family members took place prior to the start of the

interview (See Appendix D). All participants consented to the interview and audio-recording. As

a way to ensure credibility, all interviews followed the same semi-structured interview protocols.

The option of online video calling was a way to simulate an in-person interview and

allowed for face-to-face conversation. I found that no matter the format, establishing trust and

rapport was a smooth process – as over the course of the interview woman and family members

felt more comfortable speaking with me. The establishment of rapport began with the website,

interactions via email or social media, and in scheduling an interview. More information

regarding the interviews is found in Table 3.

Table 3

Interview Data

	Woman (n=15)	Family (n=11)
Average length of interview (minutes)	103	58.5
Interview conducted		
In-person	11	1
Online video	3[b]	1
Telephone	1[a]	9
Family members identified for interview	14	--

[a] per participant request [b] via woman as family member did not speak English

Instrumentation

I conducted semi-structured interviews (Appendix E) with women and family members.

With semi-structured interviews, I had a set of questions I would ask, but was able to explore

new ideas as they emerged in the midst of the interview Rossman & Rallis, 2011). For example, I

did not include a question related to the use of alternative medicines, but as the topic was

discussed in the interview, I asked follow up questions to explore the woman's experience. In

forming the interview protocol, I was cognizant of how I organized it to avoid having women leave the interview in any emotional distress (DeVault & Gross, 2007; Sprague, 2005). I am not a therapist, but it is a best practice for interviews to conclude with participants thinking about (a) things they can control or change, (b) support system, and (c) others' experiences (Chase, 2005). The interview protocol questions began with background questions in order to build rapport and ease into the conversation (e.g., Tell me a little bit about yourself/your family. What's a typical day like for you?) (Chase, 2005; Rossman & Rallis, 2011; Sprague, 2005). Next, I asked reflection questions regarding the woman's life prior to the illness onset (e.g., Think back to before you were sick and tell me a little bit about the onset of your symptoms. When did it start?). I then asked feeling questions about her views on the medical system (e.g., What kind of faith did you have in the medical system going into this?) (Sprague, 2005). I also asked questions regarding experience; it was easiest to begin interviews focused on the present (Chase, 2005; Sprague, 2005), and then move into discussing past and future (e.g., What kind of life are you building for yourself now? Have you had to rethink or give up things because of your symptoms?). I then asked questions relating to social relationships (e.g., What kinds of support have you had? Who knows about your symptoms?), and finally ended the interview on advice for others. Family interviews included similar questions and question order (See Appendix E).

Data Analysis

I engaged in an iterative, ongoing, and non-linear coding process in consultation with my chair. Analysis began during data collection through the writing of field notes immediately following interviews and continued until my eventual findings. I utilized Glaser and Strauss (1967) constant comparative and Charmaz's (2006a) grounded theory methodology for their ability to help me theorize, glean emergent findings, and make meaning from data.

Data Clean Up and Storage

Each interview was audio-recorded and transcribed with permission of each participant; each interview was saved to a password protected, encrypted external hard drive, and transcribed verbatim. All interviews were transcribed and verified by myself; I hired part-time assistant to help verify eight transcripts, and my chair verified two. Following transcription, text data was converted to Microsoft Word documents with all personally identifiable information removed to ensure continued participant confidentiality. The de-identified transcript was separated from the original and given a numeric and pseudonym code (Patton, 2002). I performed qualitative data analysis using MAXQDA 12.3.1, a qualitative data analysis program, on a password protected, encrypted external hard drive using the de-identified files.

Data Saturation

Data analysis was ongoing from the start of data collection. Once I completed four interviews I began to set my sights on saturation. In the context of grounded theory, I continuously assessed the substantive and demographic diversity of my sample. "Sample size is determined by informational consideration" (Patton, 2015, p. 300); there are no hard rules regarding sample size for all qualitative research (Dworkin, 2012; Patton, 2002; Sandelowski, 2015). Data saturation is determined if the sample has provided meaningful and comprehensive data to discuss experiences (Goldberg & Allen, 2015; Dworkin, 2012) and new insights cannot be gleaned from further sampling. This is not to say that I sought to ensure my data were representative or generalizable, but instead, I was looking for diversity in key concepts, relationships, and ideas that emerged from the data (Charmaz, 2006a). Following eight interviews I began to notice that issues like variation of time, access to resources, disclosing symptoms, and the severity of symptoms had theoretical holes. I was conscious of these areas

and as I conducted further interviews, I remained mindful to these issues. For example, following

the tenth interview, I felt that I still needed to speak with women who had prolonged experiences

with severe symptoms. Following my 12th interview, I felt I was nearing data saturation. I

completed three more interviews so as to assess my sample's saturation, and I felt new insights

could not gleaned with more interviews.

Coding

Coding is the process of organizing seemingly chaotic data; open coding, focused coding,

and thematic coding lead to an eventual narrative of the data (Charmaz, 2006a; Patton, 2002).

Using Charmaz (2006a) as my guide, I sought to "elucidate the meaning, structure, and essence

of the lived experience" (Patton, 2002, p. 482) using participant's experiences and words as my

guide. I collected and analyzed data from (a) interviews including demographic and eligibility

questionnaires, (b) field notes, and (c) personal artifacts women offered during interviews (e.g.,

paperwork, journal entries). I also engaged in memoing (Appendix F), created individual

narratives, and triangulated my coding to facilitate a credible analysis (Charmaz, 2006a).

Personal statement of reflexivity. It is sometimes, if not often, assumed that qualitative

researchers have an outsider knowledge of the experience under investigation (Blumer, 1969). It

is not often that researchers have the same shared experience with their participants. This is not

the case for the study. I continue to have first-hand, insider experience with the phenomena

under investigation. It is an unavoidable issue to address for my data collection and analysis. The

intention with this study was not to conduct research about my own life, but to learn from others.

I did not set out with the goal of talking with women who had the same symptoms, backgrounds,

philosophies, or outlooks as I have on my experience. This study was always inspired by, but not

driven by my own experiences. In my recruitment materials, I disclosed but did not highlight my

first-hand experience of living without a diagnosis. I instead focused on creating an environment

and materials that conveyed understanding and empathy with this lived experience (e.g., "Living

without a diagnosis can make you feel invisible. Let's talk about it.").

During interviews, I listened intently to my participant's stories – never interjecting my

own experiences, thoughts, or beliefs – keeping the focus and attention of this study on who it is

meant to be about – my participants. About a third of the women who spoke with me inquired at

the end of the interview if I had personal connection to this issue. Only after being posed with

this question did I acknowledge my personal connection but reiterated that I was here to learn.

The issue of personal connection also entered into data analysis. As a qualitative

researcher, I must be diligent in checking my biases, assumptions, limits, and judgment. As I

approached the data, I did not look for stories that looked "like me" (as close as some may be).

Instead, I approached the data in the same way I approached interviewing – looking to learn from

others' experiences. I always look to understand the "other's" experience. However, I recognize

the impossibility to claim complete distance from the data. At times, I found my insider

knowledge of this topic to be helpful in articulating women's experiences – as women expressed

their own difficulties and challenges to explaining their experience. I reflected on different

questions, "What is it that people don't understand?" "What kind of intensity is the feeling of

losing faith in doctors, and what are the ranges of feelings expressed in the data?" If I became

stuck on an idea, I reflected on my own experiences to think through the different components

and translated that to create conceptual clarity. For example, many women noted that others

could not understand their experience. I intuitively knew exactly what they meant but I

recognized that my intuition alone did not communicate this feeling to others. So I reflected on

my own experience, breaking the idea down into three component parts: my sense of self had

been shaken to the core, health was something that could not be given or shared with anyone else, and there was no easy way to convey this experience. I then went back to my data, looking for these codes or families (not these same narratives): sense of self, health as personal experience, and use of language.

I used my theoretical perspectives and my chair to ensure I avoided entangling with the data. It is possible to approach data in theoretically sound ways and still risk inserting too much of yourself in the data. Consultation with my chair helped ensure that I maintained appropriate distance to the data (Gilbert, 2011). In deliberations, my chair repeatedly pushed me to consider alternative ways to think about the same idea. I discuss this example in the focused coding section of this chapter. In all, this research was a valuable and meaningful process to undertake, and I have been acutely aware and cognizant of the opportunities and limitations of insider knowledge.

Use of sensitizing concepts. One of the essential characteristics of grounded theory methodology is its inductive, bottom-up approach (Charmaz, 2006a). Sensitizing concepts and research questions provided a "general sense of…approaching empirical instances" (Blumer, 1954, p. 7), but my purpose of analysis was to "remain open….and discover the main concern of the participants" (Glaser & Holton, 2004, paragraph 44). For the purposes of this research, I had three sensitizing concepts: interaction, agency, and context.

Triangulation. For the purposes of this study, I utilized consultations with my chair as well as family data to triangulation women's narratives. While coding family interviews I also examined data for confirmation of women's experiences with the onset and description of symptoms, family reaction, relationship characterization, views on health, and other areas in the findings. Many of the women's experiences, timelines, narratives, and descriptions aligned with

the family member's data and interviews. Women's interviews, however, were more in-depth in length and content. Their interviews provided more detailed and nuanced understanding to their own lived experiences, impact of symptoms, and changes in relationships. Therefore, given the alignment between women and family data, and women's depth of interviews, I focused primarily on women's experiences and narratives in data analysis and the findings.

Open coding. My chair and I collaborated in the coding process by reading each transcript individually and consulting with each other on the main ideas or key points that emerged from each of the cases. Following initial readings, I conducted open coding of my data. I coded using MAXQDA beginning with line-by-line coding. In line-by-line coding, I identified meaningful, interesting, and action-oriented words, phrases, segments of sentences (Patton, 2002). I coded for events ("I was running and thought I broke my leg"), interpretations (feelings, reflections, "It was weird"), actions ("They ruled out," "I fired a doctor," "I found this book") and personal beliefs (spiritual, philosophical, views, ideologies, "I was sold on natural," "I'm not a doctor," "I want to know what this is"), as those are often the "easiest inlets" to coding interviews (Bogdan & Biklen, 2007; Hardesty, personal communication, 2016). Open coding was an iterative process wherein I revisited each transcript repeatedly, gleaning new codes until saturation (Goldberg & Allen, 2015). Based on preliminary field notes during data collection I felt that my sampling was saturated, but in the midst of analysis, I worked to ensure that my analysis was thorough, in-depth, and comprehensive. My line-by-line coding helped ensure no major gaps appeared in my data (Charmaz, 2006a).

The continuously iterative and interactive exercise of open coding (Charmaz, 2006a) can become overwhelming. In these instances, I consulted with my chair and remained committed to my sensitizing concepts to guide my thinking. My initial round of open coding resulted in over

4000 coded segments and 836 codes – nearly half of which were in-vivo codes. Following this initial sweep, I engaged in the practice of creating coding families under advisement from my chair – not yet to the point of focused coding – but worked to reduce the sheer number of my open codes. For example, one of the biggest contributors to my high number of codes was what my chair and I deemed "one-liners"; these were phrases or sayings that women brought up in their interview that could not easily be collapsed into a category at this stage in the coding process, but they were meaningful excerpts. For example, one participant said, "I always call it the dizziness hangover where I feel like I'm hung over and…that really unsteady feeling all day. And I don't even drink anymore." I originally coded in-vivo as "dizziness hangover," which would not collapse into an open-code at this point in the analysis, but did convey this participant's feelings exactly in their own words (Charmaz, 2006a). By categorizing my one-liners, I was able to reduce my codes by over 200. I engaged in several iterations of creating coding families and ultimately, my number of open codes reduced to 212 codes.

Focused coding. After segmenting my data using open coding, I continued to use my sensitizing concepts and research questions to identify categorical links among my codes (Charmaz, 2000). The next stage of coding journey (Goldberg & Allen, 2015) included focused coding. Here, I turned my attention to the most prevalent codes and categories in the data (Bogdan & Biklen, 2007; Charmaz, 2006a) or those of particular importance to the research at hand (Glaser & Strauss, 1967). I purposefully looked for overlap between categories and using my sensitizing concepts, I organized and categorized codes. For example, I had open codes related to women's experiences with medications. Coding families included *Hesitation to Medication* ("medication ruined my life," "are risks worth it?" and "I'll try anything but funky drugs.") and *Limited Role of Medication* ("meds need to treat root cause," "short term solutions,"

and "people don't need to be on medication.") Using the sensitizing concept of interaction and

my participants' words, I came to categorize these two coding families as *I don't want to be on*

medications. At this stage, I worked to refine my codes, and sought consultation with my chair as

a way of continuing to hone and refine the process (Goldberg & Allen, 2015). I present my final

iteration of focused coding in Appendix G. The first iteration details focused coding with women

that resulted in 10 coding categories and 52 codes. The first iteration of family data resulted in

five coding categories and 20 codes. In a final iteration of both women's and families' coding, I

produced five coding categories and 38 codes.

   In the midst of focused coding, the consultations with my chair were helpful in

recognizing and checking my distance to the data. Part of qualitative research is about being

close to the data (Bogdan & Biklen, 2007; Charmaz, 2006a), but insider knowledge can work to

cloud the analysis at different points in the process. In my deliberations regarding my focused

coding with my chair, we engaged in reflexive exercises to determine if there would be a

different meaning to glean from the data. For example, in critically analyzing women's

expectations and experiences with doctors, I came to categorically connect coding families such

as "belief," "expectations," and "hope" to the concept of faith – more specifically, I connected it

as a coding family, *Faith in Doctors*. In analyzing their experiences I had codes related to

"frustration," "shock," "doctors aren't meeting expectations," and "questioning doctor"- which I

called *Upset by Doctors*. In trying to connect the two families together, I viewed women's

confidence in doctors as being lost and I wanted to categorically connect the two families as

"Losing Faith." However, at this stage in analysis, I knew that the process of "Losing Faith"

involved other factors (i.e., doing research, previous experiences, views before, continuing to go

back to doctors), but I faced difficulties in finding the conceptual connections between different

coding families. My chair and I went through the process of articulating other viewpoints or

opposites of the concept "Losing Faith" – to use a metaphor - we checked my own personal

experiences by deliberating on two sides of the same coin. We explicitly considered the opposite

view of experiences, which resulted the development of a coding category with a more positively

framed "enlightenment" of women's experiences; "faith" was but a part of the idea of

enlightenment. This process opened up new conceptual and categorical connections for analysis

(Charmaz, 2006a). I ultimately created the coding category 200 *Learning My Place in the*

Medical System. This coding category incorporated the aspects of hopes, expectations, research,

experiences with doctors, and loss of faith in doctors. This deliberation and step in analysis

ensured credibility, and allowed for a conceptually deeper category to emerge from the data

(Charmaz, 2006a).

     Thematic analysis. Thematic analysis is the last stage of data analysis in which I turned

my attention to locating a narrative across cases (Charmaz, 2006a). Using my sensitizing

concepts and new ideas that emerged from my findings, I worked to synthesize my focused

codes (Charmaz, 2006a; Goldberg & Allen, 2015). The ultimate goal with thematic analysis is to

tell a story. After constructing five major focused categories (see Appendix G), I still had no

story to tell, only bits and pieces of stories. I had the idea that women felt their experiences were

complicated and impacted different parts of their life (*100 This is Torture*), women had different

expectations and experiences with doctors (*200 Learning My Place*), had continued learning,

exploring, and trying new things (*300 Continued Activities*), women experienced a lot of

emotions (*400 Emotions or Feelings*), and an understanding for the role of support (*500 Role of*

Support) – but no "story" to tell. I found myself facing several challenges in synthesizing my

coding data because many of my coding categories did not create discreet typologies of

experiences. For example, I attempted to create a typology of women based on their continued

action to remain in the Western health system (I originally called this – Working in the System),

but I found that not only did that typology ignore the "lessons learned" but I immediately

recognized it only captured partial experiences for women like Cate, Jena, Meg, and Norah.

Furthermore, I grew increasingly concerned that I could draw no narrative from my data because

it was so diverse in experience and time with symptoms. I turned to my theoretical perspectives

to help orient me to how I could conceptualize the narrative in the data. Bronfenbrenner's (2005)

person-process-context-time model – as informed by Elder (1978) – was most helpful. I decided

to embrace the notion of time in these women's stories. It was embedded in many of my codes,

and as I worked to synthesize the codes, I created new distinctions using the concept of time. For

example, one participant had been living without a diagnosis for 15 years. I looked for the ways

that time was a factor in *her* story in the data. I approached my coding categories with new

meanings and formulated new connections. I already had the concept of time embedded in *200*

Learning My Place and *300 Continued Action*, but I was then able to draw new connections to

women's *400 Emotions and Feelings* with the idea of change over time. I began to see across

coding categories the emergence of a new narrative.

Summary of Chapter

In this chapter I have detailed the methodology, sampling, and analysis of this research. I

described the steps and process of my methods from start to completion. In the midst of data

analysis and collection, I remained in-tune with my role as a researcher with insider knowledge

and worked in consultation with my chair to ensure credibility of the findings that I discuss next.

CHAPTER IV: FINDINGS

In this chapter, I present my findings in five sections, and as discussed in the methods chapter – I prioritized the women's narratives in the creation of my findings. The first section, *Stepping into Their Symptoms*, is a descriptive introduction to the symptoms and lived experience of the women in this study. The second section, *The Complications of Living without a Diagnosis*, provides findings about women's interactions and meaning-making on individual and family levels. In the third section of the findings, *Venturing into Health System(s)*, I provide a narrative of women's expectations and experiences with medical system(s) throughout their experience with illness uncertainty. Here, I unpack women's expectations and beliefs about medical systems prior to the onset of symptoms and trace how women's experiences change their views over time. Fourth, in *Lessons Learned,* I discuss women's innovation and creativity in how they make meaning of their lived experience. Lastly, I discussed the creation of a model that captures the change over time that women experience in the *System of Illness Uncertainty*.

Stepping into their Symptoms

I asked women to describe and explain their undiagnosed symptoms, onset, and impact on their life. I categorized symptoms (see Table 2) so as to provide information on the symptom's location on women's bodies and a type of label for symptoms described. I recognized that categorization did little justice to women's lived experiences with undiagnosed symptoms. Overall, women's characterization of undiagnosed symptoms in this sample demonstrated the chronic and endless nature of symptoms. I now contextualize and provide a more detailed account of women's lived experience with symptoms.

Symptoms. The onset of symptoms varied, and women had lived with symptoms for a minimum of one year to as many as 15 years. On average, women in this sample lived with

undiagnosed symptoms for 5.3 years. Six women noticed their symptoms developed gradually, over the course of months or years; defining the exact timeline was harder. Hazel, a single, Chinese woman aged 28 living with a gut issue, recalled, "I started noticing [digestive issues] about 3 or 4 years ago." For four women, the onset of symptoms was marked by a more definitive or noticeable set of events over the course of days or weeks. Finn, a White woman aged 25 explained that her symptoms (hair loss, brain fog, and skin issues), "started like exactly one year ago." For the other five women, the onset of symptoms was marked by a sudden and severe event in which symptoms were noticed immediately. Symptoms occurred "all of a sudden" (Jena, a White woman aged 27 living with neurological symptoms). The exact timeline was clearly recalled. For example, Norah, a White woman aged 28 living with neurological symptoms recalled, "October 28, 2007. It was my second year of college…. I started up to the door of the music building and my left leg went weak. I was aware. It was *weird*. [original emphasis]."

While the symptoms were not life threatening (discussed later in the chapter), characterizing the degree of impact from mild to severe does not fully capture the ways in which symptoms impacted women's lives. Instead, symptoms impacted different areas of women's lives: psychological, physical, relational, and financial. All women discussed how symptoms negatively impacted their psychological health and well-being; it interrupted their sense of health and impacted their self-confidence. This was sometimes a result of the unpredictable nature of the symptoms. Danai, a Black woman aged 31 living with severe upper respiratory symptoms explained, "[Y]ou never know when it's going to —it kind of just hits you. It's not like you feel it coming on." Women lived on-edge. Symptoms also impacted women's psychological well-being as a result of limitations to physical functioning and mobility. Physical changes included

impaired mobility, changes in cognitive functioning, or both. For many women, these changes made them feel as if they lost a sense of themselves. Gwen, a White woman aged 28 living with suspected autoimmune symptoms explained, "I always tell people that I died in that moment. A lot of things left me….I don't play [instruments] anymore. I don't run anymore. A lot of things had to die in that moment." Others explained how the outward appearance of symptoms decreased their self-image and self-esteem. Kelsey, a White woman aged 28 living with severe skin lesions explained that her symptoms took a toll on her self-confidence and she questioned whether she was physically attractive enough for her current boyfriend.

Symptoms also impacted women's relationships with others. A majority of women (n=11) explained that their symptoms added stressors and created misunderstandings between women and members of their networks. Women described the loss of friends and past lovers due to the added stress. Norah explained, "Friends definitely stopped talking to me. The ambiguity was too much [for one friend] because I didn't get a diagnosis." Gwen's now ex-boyfriend saw her as "not bearing enough life for what he expected out of partner" and he ended their serious relationship. Interestingly, impacts on relationships were sometimes unbeknownst to friends and family. Piper, a White woman aged 35 living with what she termed as "dizziness" recalled how she had not confronted a friend whose words were interpreted as unsupportive, "It was the first time I was like, 'They don't believe me?'….I never told her about it." Hazel explained,

> I try to plan around all the healthy rules I have for myself....and it's recently become worse. I've become more sucked into it…..My close friends when they see my diet they think I'm just too - [pause] I'm like a cultural freak and what I am doing is unnecessary.

Lastly, symptoms impacted women's finances – eight women described the impact of spending money on seeking out a diagnosis or trying new regimens to manage symptoms. Jena

was living with neurological symptoms and two recently diagnosed conditions explained the toll after unveiling a five-inch binder of medical records and bills at the interview, "My God, I can't tell you how much money I've spent on medical testing in the past three years which you've seen my giant binder." The literal cost of living without a diagnosis often falls on the shoulders of women – not insurance companies. Even with health insurance, women described the limits and subsequent financial burden of living without a diagnosis.

        Context and resources. Women also had various financial resources and emotional support in their lives. Many of the women in this sample came from middle-class backgrounds growing up (n=13) but 10 women's total household income was less than $40,000 (five of which earned less than $20,000). Therefore, most of the women did not have unlimited funds through which to pursue costly diagnostic testing and five women remarked that financial stress was a top stressor in their life. Thirteen women did, however, have health insurance, which served as a financial resource that enabled women to access doctors, testing, and medications. Two women were without health insurance. Gwen was a single-mother to a toddler and was on a tight budget in which she relied on government programs for her daughter's insurance and was unable to afford her own insurance. Liza, a White woman aged 33 living with idiopathic and varied musculoskeletal symptoms, was unable to work, could not get disability without a diagnosis, and could not afford health insurance. She has relied on emergency room and hospital programs for the uninsured and more recently became connected to a charity to assist her in pursuing new genetic testing. Women's financial and insurance resources shaped the extent to which they engaged in different health systems.

        With one exception (Hazel), all women had at least one person in their life who was aware of illness and acted as a source of support in living with undiagnosed symptoms. All

family members interviewed provided emotional support to women with their health to varying

degrees, and women's sources of support beyond the interviewed family members differed as

well. Some women like Jena described their family and friends as "rock solid support." Other

women also had close, trusted relationships with family and friends. Emotional support was not

unlimited for women, with several women explaining that their relationships with family and

friends were ambivalent or tense at times given their relationship histories. Women like Piper,

felt rich in her emotional support network having reached out to extended family, friends, and

medical professionals with whom she had built relationships. Other women, like Liza, felt poor

in her emotional support network. Liza was perhaps the most severe in terms of limits to

emotional and financial resources. Having lived with undiagnosed symptoms for 12 years, Liza

had been rejected by her family, without a job, without insurance, and "living out of suitcase."

Liza described her current living situation as tense and like "walking on eggshells" as she did not

contribute money to the household and was living off the generosity of friends.

The Complications of Living without a Diagnosis

Signs of Illness: Body is Telling Me Something is Wrong

Living without a diagnosis was a contentious state in which to exist – without a medical

diagnosis, there was not an external validation of a pathology. Regardless of their varied

experiences with the onset, nature, and impact of symptoms, the women discussed their illness

through the signs they received from their bodies. They interpreted these signs to be indicators

that something was wrong.

Weird/normal. Embedded in all women's narratives about their symptoms was the idea

that their body gave them cues that something was not normal; their body was behaving out of

the ordinary or weird. That is, women were aware of ideas about what constituted the cultural

norm of everyday aches and pains, and differentiated their symptoms from what they perceived

to be normal. Meg, a White woman aged 35 living with undiagnosed pain and fatigue stated,

> I've always had bad knees so I just I chalked it up to – 'I have bad knees' – I mean I
>
> played sports a lot in high school and just some people have bad knees. But then they just
>
> kept getting worse and worse.

Women continuously compared their experience with symptoms to the experiences with others.

Liza situated her symptoms to others, "It's fatigue. With normal, healthy people – they work

hard, and they're exhausted but they recover from that at some point. I don't." Women also

compared their symptoms through interactions with others and initial research online. Evie, a

Black woman aged 25 living with neurological symptoms noted that "even when it's stuff that's

weird going on with your body, I'm always [mimics holding phone and searching on phone]…I

Google that…is this normal? [chuckles]." Women came to rely on their bodily and cultural

norms to determine whether something was wrong or normal.

What I can and cannot do. Viewing their symptoms as not normal often went hand-in-

hand with comparing their symptoms and abilities to a time before and up to now. Women saw

their symptoms and limitations in light of what they were once able to do or what was once

considered *their* normal state of being. Some women lost a part of themselves, and mourned the

loss. Cate, a Bi-racial woman aged 46 living with pain and swelling flare-ups explained, "My

whole life centered on physical activities and all of sudden I couldn't do any of that. I could

barely walk for a good year." Other women felt their whole life had been turned upside down.

Danai reflected on her life,

> I'm two completely different people right now. You know how Facebook reminds you of
>
> your memories from years ago? The one today for some reason really hit me. It was a

picture of me and all my girlfriends at a club, and I just said to myself, "I couldn't dare be

able to do that right now."

However, the complication for most women was trying to explain to others the severity

of their symptoms while still being able to complete most of their daily duties. Only Liza

explained that she was completely unable to work due to her symptoms; all other women were

currently or recently employed. Women had managed to hide their symptoms from others. Some,

like Norah, saw this as an advantage, "I'm lucky because I can pass as healthy" while others like

Danai encountered skepticism,

> [imitating conversation] I say "Why can't you understand I can't do this or that?" And
>
> they'll always say, "Well, you do all this other stuff for work." "Well, work *pays* me,
>
> [original emphasis] so I have to do those things first. That's an obligation. I have to pay
>
> bills, I have to do those things."

Women recognized in themselves their own limitations and changes, but trying to explain their

difficulties while "passing" as healthy remained a challenge.

Not life threatening. At some point in the interview all of the women in the study

acknowledged their symptoms were not considered terminal or life threatening. Often the first

line of testing and medical evaluation served to "rule out" the life threatening or terminal

illnesses with immediate threats – the life threatening often being cancer. Women took time to

qualify that their experiences were, "not like it's cancer or anything" (Meg). Their reflection on

the seriousness of their illness demonstrated women's awareness of what Liza described as a

"hierarchy of illness" and socially acceptable actions associated with severe, life threatening

conditions. Cancer and life threatening illness are deemed to be the serious illnesses, worth

taking the time to investigate.

Instead, living without a diagnosis included a different set of challenges that were often

ignored if the condition was not considered life threatening. Some women came to view the idea

of living with a diagnosed life threatening conditions as less stressful, less ambiguous. Alice, a

Chinese woman aged 25 living with neck spasms explained her view using the story of her father

who died unexpectedly from cancer last year,

> Even if you have a bad disease, like my father…you can know. I can even know if I have
>
> just one year to live. But for people with [an] undiagnosed problem, you cannot
>
> forecast…Women hope…but who knows? No one knows the future…and with my
>
> problem, I don't know either. It's better to be at least the diagnosed one.

Without a diagnosis, women did not have the luxury of certainty and the ability to enact a

cultural script surrounding health and illness. They struggled to have others view their

experiences as legitimate. Kelsey explained,

> Some doctors have just been completely not caring…I've literally thrown away shirts
>
> because I have blood on them and I can't get the blood out. And [voice breaks, whispers]
>
> I think that's a problem. [laughs frustrated] Ya know? So while it's not life threatening, it
>
> is *li-mit-ing*. [original emphasis]

This reflection did not suggest that women wished for others to treat them as if they had a life

threatening condition, and in many instances they rejected that idea out of fear of being "treated

differently" (Gwen). But women did recognize barriers to accessing empathy from others given

that their undiagnosed status was deemed non-life threatening.

Use of Metaphors and Analogies

The lack of agreed upon language surrounding their symptoms presented added

difficulties for women as well as families. As women answered interview questions about their

symptoms, rather than a clear and concise definition or explanation of their symptoms, women

had to work to find the right language to explain their symptoms. In recalling conversations with

others, women resorted to using vague and undefined terminology to discuss symptoms;

indicators like "this thing," "whatever this is," "it," "whatever you want to call it," "whatever

that hurt is," and "this condition." Gwen recounted, "I just remembered I would tell my bosses

that I have *this thing*.…so they kind of knew that something was going on." Women often

remarked on their uncertainty surrounding the appropriate language to use, and in an effort to

explain their symptoms, women located or developed their own metaphors and analogies to

explain their symptoms to others (i.e., "it's like…"). Some described their symptoms in relation

to other known symptoms. Danai offered, "It's like literally having walking pneumonia and you

can't do anything." Others created their own terms and put their symptoms in an experience

outside of other symptoms. Piper explained, "I'll just wake up and I'm off. I feel off… and I

always call it the dizziness hangover where I feel like I'm hungover, and I don't even drink

anymore…but I just have that *really* unsteady feeling all day." And others went as far as to use

metaphors they located from online, chronic illness communities (i.e., spoon theory, zebra

stripes) or created their own in-depth analogies. Jena provided no less than four metaphors and

analogies in her interview. In this excerpt she describes her analogy for her cognition difficulties,

> I have two analogies for my cognition. The first one…I realized wasn't quite accurate. It
>
> was more like someone put you in a room without any windows and no lights and took
>
> three boxes of puzzles and threw them on the floor. And they're like, "Put the puzzle
>
> together." You're lucky if you can find a piece, let alone how the pieces go together. So
>
> it's just a lot of blind groping. Every now and then you get lucky and some pieces fit
>
> together – but whether they're from the right puzzles or whether you can find pieces or

not can be lucky. So that's currently my life.

Living without a diagnosis also meant living without a clear and direct way to explain their symptoms or experiences to others. Women simply did not have the language to talk about it.

Hesitation to Reveal Struggle with Symptoms

A majority of the women had only revealed their symptoms or struggle to a select number of people; people they could trust. This most often included close family members and friends. Close family members included mothers, siblings, and sometimes fathers. Close friends included those who as Evie put it "were going through stuff" so they would understand. The people who knew had close, intimate contact with women on a regular basis – they knew these women. Gwen noted, "For the most part, I really don't share it with people unless I know them really, really well." Women living without a diagnosis sought out those who would empathize and understand their difficulties with symptoms.

Four women did experience rejection from others after they disclosed their symptoms. As a result, they grew more cautious about revealing their symptoms. Liza explained,

> The people who get little snippets and they acknowledge what I'm going through…they offer genuine non-judgmental suggestions…that's when I know this is somebody I can trust. But when they immediately jump in with these judgmental, inflammatory, abrasive, assuming, and snide little remarks I'm not gonna be able to trust you."

In short, disclosing symptoms was reserved for people women felt they could trust.

One woman, Hazel, discussed her symptoms with no one – friend or family – as she felt no one would understand or offer solutions to her problem. Four women decidedly became vocal about their symptoms and experience overtime – on social media and in their personal networks. Sharing with others was seen as a therapeutic release, a way of explaining the situation, and a

way to enact their networks to search for answers. Piper explained, "I'm looking for the family

history, so I'm gonna tell all my family. And when it came to my friends it was the idea that

maybe they've heard of someone – maybe that grapevine…" Decisions about sharing or not

sharing had multiple motivations.

Systems of Support: Role of Family and Friends

   Importance of believing. Given that a majority of women were actively working to hide

their symptoms and had only revealed symptoms to a select number of people – it became clear

that one of the most central roles for women's system of support was to believe the women's

experience. Liza explained the value of belief from friends and family, "She said three words, 'I

believe you.' And I *never* forgot that. Because just having that emotional support can be the *one*

thing that keeps you from being suicidal or the *one thing* that keeps you from giving up."

   For women with more gradual onset of symptoms, belief from their support system

developed overtime. Danai explained,

> At first [family] didn't believe me. [They] said it was just a summer cold…. two months
>
> later when it still did not go away and when they finally saw me…and seeing the pain in
>
> my eyes, they finally started believing.

Overtime, family members began to believe. Danai's sister, Dot, a Black woman aged 22,

described the process,

> I believed her [pause] but I also didn't know what to think… she either exaggerates or
>
> downplays a lot. So I never really know how to gauge the situation…I know that with
>
> your own health you downplay it because you don't want anyone to worry about you, so I
>
> wasn't sure exactly how serious it was when she first told me.

Dot went onto explain that she was not sure if Danai perceived her symptoms as more serious

than she did because Danai had another diagnosed condition, "if something is wrong [with that condition] then everything else is gonna be wrong afterwards." But over time, Dot came to better realize and believe Danai's symptoms.

Family interviews also emphasized the steadfast nature of belief. Regardless of the gradual or immediate nature of belief, family and friends interviewed implicitly and explicitly expressed their belief in their relative's experience. Liza's best friend Lynn, a Hispanic woman aged 33 who was "like a sister," did not falter in her support for Liza explaining, "I believe Liza. I believe Liza all the way." Others never mentioned having any doubts; they approached their role of support as never questioning the reality of the symptoms. Jena's husband Jude, a White man aged 27, noted,

> I generally take the viewpoint of just keep moving forward. What are you gonna do about it? And she always ends up being right about it in the end…So even if I can't connect to it [the symptoms]… she just ends up being right and I want to see her get better.

Feeling distant from support. The degree to which women were hiding their experience from others yet willing to share their experiences with me demonstrated a sense of isolation or distance from others in their experience. Indeed, women took it on themselves to protect others from the illness. They did not want to "burden people with it" (Norah). Women's choice of language demonstrated a distance from others in this experience. Meg, married to Marty for 10 years, described him as a great source of support, but readily acknowledged that she did not tell him about the amount of pain and fatigue she experienced, "I'm pretty tough too though. A lot of times I just don't tell him…I don't want to have to tell him all the time if I'm hurting or if I'm tired. So…[trails off] I try to mask it a lot too." Other women were "trying not to let [symptoms] impact [their] life or have [them] change anything" (Danai). Health was constructed as a

personal responsibility and women's language surrounding their experiences relied heavily on "I" or "my" language.

Family member interviews reiterated distance as very few family members discussed living without a diagnosis as a "we" or "our" experience – rather this was "her" experience. Only four family interviews included "we" language; those with a more intimate connection to women framed their experience in "we" terms. For those more directly involved in the women's lives, such as the two husbands in the sample, "we" language signified their involvement with major medical travel and decisions, as well as the ways in which her symptoms impacted the relationship. Piper's husband, Phillip, an Asian-American man aged 36, described how they were willing to try different treatments as a couple. Two mothers (Millie and Kim) described their involvement with assisting their daughter at the onset of symptoms, but as time went on – the narrative began to shift to "she" and "her" language. Meg's mother, Millie, a White woman aged 62 demonstrated, "Before she had children…we went to a medical specialist. I went with her. And now, sometimes if she's going to a doctor, I'll keep the children while she goes." However, even those with the most intimate connections framed the experience in "her" and "she" terms far more often than in "we" or "our" terms. For family members, overall, living without a diagnosis was not a struggle for "us" but was a struggle for "her."

The feeling of distance was also reiterated by women's appreciation for having a space to discuss these issues. At some point during the interview, several women discussed their draw to the study and their appreciation for having a space to talk about their experiences. Alice noted, "I'm not here for the gift card" and Danai explained, "I appreciate you doing this….I can't talk to anybody about this." Even after talking about their systems of support, women felt they could not openly share with people in their lives.

I am my mother's daughter – the role of mothers. Mothers were repeatedly referenced as a source of support and assistance. Only two women in the study had not revealed their symptoms to their mothers (Hazel and Ivy). Both women were Chinese and explained that it would be unnecessary to worry their mother from abroad. Thirteen women reported that their mothers were at least aware of their symptoms and 11 women described how mothers played at least some small role in support. When asked for a family member or friend to interview, nine women offered their mother as their 1st or 2nd choice for an interview. Of the six mothers I attempted to contact, I interviewed five. The almost ubiquitous presence of mothers revealed the importance of this adult-daughter and mother relationship in the event of illness.

Mothers provided their adult daughters with details about family health history and beliefs – acting as a resource for women in their information seeking as well as their appointments with doctors. Finn's mother Felicity, a White woman aged 56, explained her family's health history in the interview and how her own symptoms that were similar to Finn's,

> I'm just passing it along, just like my elders before me. Just passing down what kinds of things I have learned and if it's helpful, then that's just what you want to do. You want to make sure you explore all avenues.

Finn held onto her family health history as evidence for her symptoms and claim to a diagnosis. "So I have all these symptoms, I have a family history, but still just because I don't fall outside of this range, I don't get any treatment?" Felicity's imparting of family health history and beliefs served as a source of certainty and confidence for Finn as she pursued a diagnosis.

When help is not supportive. The expected sources of support (mothers, husbands, and family members) assumed a supportive role for most but not all women. Some women did not desire family support, but for others, family did not offer support in ways that were desired.

Gwen and Kelsey's ties to family were strained and stressful – but they both came to rely on their mothers for support in some ways. In Liza's case, however, the kind of support offered by family resulted in permanently damaged relationships. Her family dismissed her symptoms, claiming that Liza was only interested in getting free handouts. Liza explained, "They refuse to open their eyes and understand and respect what I am going through….And you would think that it's your family – they would be the *one* group of people you'd be able to go to…so I'm disappointed in *them*. [original emphasis]"

Furthermore, very few women expressed feeling personally connected to or supported by online communities with women who are experiencing similar symptoms. Danai explained,

> I realized that a lot of people on the forums and the group chats, it's just a lot of people in a room complaining sometimes—and not talking about symptoms and comparing it… a woe-is-me kind of thing…so I stayed away from the group chats or online forums or things like that.

Alice also noted her distance, "Someone [online says] 'I also have this problem and someone told me this is because blah blah blah blah.' But I don't believe the blah blah blah. [laughs]" Women felt they could not nor did not want to see themselves in online forum groups.

Support from unexpected places. One finding that emerged from women and family interviews was the idea that support did come from unexpected places. It is often assumed that those struggling with something would find comfort, empathy, and support from those who had lived with the same symptoms or experience. Six women had people in their lives that shared similar symptoms to them. Four women had mothers with similar symptoms. For example, Ivy and Irene experienced similar neck pain, and Jena and Jude both experienced migraines. Despite these symptom similarities, interviews revealed that expected sources of support did not always

provide unquestioning support. Rather, family members who had similar symptoms sometimes provided the most critical analysis of the woman's experience. For example, Ivy's friend Irene (aged 23) explained, "I think it's not a big problem. I have my own issues too so I know whether the problem is serious or not and from my judgment, the problem is not so serious." In her interview, Finn noted that her mother was originally dismissive of her symptoms, but validated her experience over time. Felicity, who had the same condition Finn suspects she did, noted, "I know I had the same issue myself in college, but you just gotta push through it, is what I would tell her. Because that's what I did."

Often support from unexpected places came from those who had a shared experience with searching for a diagnosis rather than a shared experience with symptoms. Women explained that these sources of support were more meaningful. Piper explained, "I feel a bond with somebody else that doesn't have a diagnosis." While working late, Piper discovered that a former co-worker was dealing with undiagnosed gut problems. Despite not being close to this co-worker before this moment, "We *bonded* over that. She doesn't work here anymore, but she'll still text me. 'Are you doing okay?' It was that support of *somebody* that knows what you're through." Norah's friend Noel, a White woman aged 29, demonstrated this point as she described her first impression of Norah,

> It was her birthday and I invited her to this quad part and she was like, 'I don't go to parties.' And I thought, 'Oh man, this girl and I aren't gonna connect at *allll*…and none of that could've been further from the truth.

With the onset of Norah's symptoms, Noel became a rock of support. Noel, having undergone a joint replacement at the age of 17 understood the sting of others' skepticism. When asked if she ever doubted Norah's experience, Noel replied emphatically,

Oh *no*. I totally get that since I had a bad joint. No one can see your pain, so I've often

felt like people *doubted* me when I was going through pain….I think because of that I

never thought to discount what she going through or question if it was sincere."

Norah and Noel's bonded experience resulted in a strong, lasting friendship and the two referred

to themselves as the "Gimp Sisters." The shared experience of living with symptoms that are

suspect without a diagnosis served to provide women with unexpected support from friends,

former acquaintances, and even strangers.

Learning the System: Priming Experiences with Western Health

In the midst of the interview, I asked women about their faith in and views of the medical

system. What resulted from their responses and throughout the entire interview was a narrative

about the beliefs and expectations women had for doctors and the medical system, and how their

own lived experiences did not align with these beliefs and expectations. Women, collectively,

produced a narrative in which they learned about a different side to the system, and ultimately

came to realize that the medical system was not poised to help them.

Cultural Norms about Health: Western and Non-Western Health Systems

In the midst of interviewing, I asked women to discuss what (if any) information-seeking

they had done (e.g., Did you try to diagnosis yourself? Where did you go for information?).

What emerged from their responses to this question (as well as others related to the medical

system) were the cultural norms and values about different systems of health (embedded in

women's perspectives on health and medicine). Beyond personal isolation and responsibility for

one's own health, women's and families' interviews uncovered a culturally-constructed

dichotomous view of Western and non-Western health systems. In the midst of researching,

women explained that they needed to be careful about the credibility and legitimacy of their

information sources. Liza explained,

> If I had to do this [living without a diagnosis] during the time before the Internet, I don't
>
> think I would be able to because there is *so much* information at my fingertips. But
>
> there's always that whole thing where you have to be careful with your sources, and I am.

As women began to search for information on their own, they did so with their own views about

medicine and health – views that reflected a cultural dichotomy of Western and non-Western

approaches to health. This finding was one that emerged from the data, and in relying on my

participant's words, I found that Western health system was not attached to any one specific

geographic location (United States), but was *an ideology* surrounding – as Gwen put it –

"mainstream medicine."

To elaborate, women and family responses collectively created an ideology about

Western medicine as health system dedicated to the training and authority of licensed doctors,

the prominent and valued role of pharmaceutical medication, the certainty of diagnostic testing to

determine a pathology, and the role of evidence-based, peer-reviewed practice and research.

Non-Western health systems were considered those that adhered to holistic, natural means by

which to treat unspecified illnesses or symptoms. Interviews discussed non-Western medicine as

adhering to strict all-organic, all-natural diets, spices/herbs, plants, energy workers, meditation,

supplements, and acupuncture. All other forms of holistic medical approaches were considered

"fringe" or "alternative." For conceptual clarity, I use the term Western health system to discuss

the medical and health care approaches that adhere to the ideology of "mainstream" medicine.

Women and their family members purported ideas that glorified and problematized

Western approaches to health. Finn explained she had faith in doctors because they "had 8 years

of medical schooling and 4 years of residency." Other women like Gwen explained that they had

problems with the "very authoritative relationship" with doctors, explaining that doctors should "point people who can't afford Western medicine…say hey there are other avenues." Several women explained their view of Western medicine was one in which doctors were "pill pushers" (Millie), and that even if women had doubts in some doctors, they had faith in diagnostic testing available in Western medicine. Alice explained, "Actually I trust [doctors] – well, more precisely I trust the data from the tests. The data won't lie to you." And lastly, women discussed how Western medicine is evidence-based. Cate's narrative best captured the cultural and normative values embedded in Western and non-Western medicine,

> I have been on Naproxen for about 10 years…but it's the only thing that they've [doctors] offered to do for me so I really don't know and I don't want to be on some narcotic or something."….There's apparently some drug…that's helping people with chronic pain, so I tried both of those and I felt like a zombie. So we decided not to continue with those.

After rounds with medications, Cate tried different methods still in the Western health system,

> They offered me was what they're calling dry needling - which let me tell you I'd rather have acupuncture any day. I went for several treatments, and I just felt like each time I was torturing myself. And I said to the doctor "I would much prefer acupuncture," [Chuckles] and she said, "Oh yes, but we are scientifically proven." And I'm like, "Yeah, and you've hurt me and I leave here with a bruise."

Unsatisfied with the treatments offered by doctors adhering to Western, "scientifically proven" approach, Cate turned to acupuncture. At the time of the interview, she explained acupuncture was her "primary resource" for medical care. However, in her language to describe her treatments using non-Western medicine, Cate's language changed from treatments, drugs, evidence-based medical care to "concoctions," "mantras," and "resource." Cate explained how

she had begun to use natural (herbs, spices, plants) as a pain remedy with some skepticism,

> My friend, he came over and told me, "It's probably this and that." And I'm like
> [sarcastically] "Yeah, mm-hmm." [chuckles] So he starts to write down all these
> supplements…and I'm like, "You're crazy!"….My concoction of turmeric and ginger,
> I'm drinking that every morning too. I don't know if that helps….A friend of mine, she's
> taking this every morning and she swears it helps her feel better in the mornings…so
> she's like, "Why don't you take it? I've told you this before." And I'm like, "I don't
> know." It just sounds weird to drink turmeric. [chuckles]

Jena expressed her willingness to try but also hesitations with acupuncture, "It's all about finding
the right practitioner. I don't know that I would find just any acupuncturist….as long as they're
literally a professional [chuckles] and not someone just trying to be like, "Hey take these things."
Women's caveats and hesitations with alternative forms of medicine demonstrate the power
embedded in Western medical approaches.

Women and their families' narratives revealed the embedded cultural values about
Western and non-Western medicine. Western society tends to value, legitimize, and promote
Western health system as the gold standard of care; this created a hierarchy of health systems
available to women. One with credibility (Western) and one with skepticism (non-Western); one
with power, one without.

Expectations of Doctors and the Medical System: What We're Led to Believe

Women and family interviews articulated the cultural expectations about interactions
with doctors and the medical system. Most of the women in this sample believed doctors and the
Western health system would work for them. A segment of the sample had their doubts about the
medical system before the onset of their symptoms. One of the major findings with the data is the

articulation of this belief and how many women experienced a paradigm shift as a result of their

experiences with doctors – detailed in the next section.

   Valorizing doctors. Most women and family members revealed their expectation of

doctors, with most valorizing the role that doctors play in society prior to the onset of their

symptoms. Women believed coming into this experience that they would be able to find answers

and solution to their symptoms. Women believed in the authority, power, and assistance that

doctors would provide to them as they came to them looking for answers. Norah's friend

explained, "I think I had a lot of naivety [sic] that I thought, 'Well of course [doctors] will figure

it out. They'll fix it." Kim explained that when she first began to take her daughter, Kelsey, to

appointments she thought, "Okay, we'll take her and they'll fix it." Some women's expectations

were based in admitted idealistic views on doctors. Finn noted, "I really believed….When I

graduated high school I wanted to be a medical doctor…I really respected them….You just had

this image [growing up] that doctors really care and they want to heal you." Women who

valorized doctors came into this experience with certain expectations for doctors – often at least

one or a combination of expectations.

   Doctors will know. One of the major expectations from women and families was that

doctors would have the knowledge and expertise to diagnose the problem and provide

appropriate treatment solutions. Often this belief rested on their ideas about medical school

training and certification – another reflection of the value they placed in Western health system.

Finn believed in doctors because "they go through the eight years in medical school and then

four years of residency and all that stuff. You would think that they would have enough

schooling to diagnose something." Women, like Piper, placed their confidence in doctor's

abilities and knowledge because "if there's a problem, they'll figure it out."

Doctors will care. At the start of symptoms, women and families thought doctors would

have a personal investment in them and would go the extra mile to help. Here interviews exposed

an underlying assumption: people become doctors in order to help people. Brie explained, "They

became a doctor for a reason – to help people." Liza reaffirmed this ideas, "[Doctors], if you

actually went into medicine to help people and get people feeling better, don't forget that."

Women had expectations that their case would be of importance to their doctor, as it was a

doctor's duty and obligation to care.

Counting on doctors. Another assumption for some women was the idea that doctors

were the appropriate source for help and support with their undiagnosed symptoms. In feeling

isolated with their health experience, women expected to be able to turn to doctors for help,

assistance, and understanding. Women were counting on doctors to listen to their symptoms,

hear their stories, and provide solutions. Whether doctors or specialty clinics, these medical

professionals were "the one place" for women to turn to for answers. In all, women's

expectations for doctors showcased their initial faith and belief in the medical system to provide

them with a knowledge, caring, and useful source for solutions.

Hoping for better. Not every woman in the sample had valorized expectations of doctors

prior to the onset of their symptoms. Through previous experience – whether their own or

someone they knew – six women had hesitations and different expectations of doctors. Doctors

were not expected to be all-knowing, all-caring, and all-useful to these women. Gwen explained

that because her own parents had experience working in the medical field, she "was always kind

of weary of the medical industry." Norah had the experience of doctors misdiagnosing her back

injury from childhood, and so when her current symptoms began she "knew the system had

stayed the same, and I knew it wasn't perfect." Therefore, six women hesitated to seek out

medical help or appointments and only four women did seek help. For the four that did, however, they did so under the guise of hoping that there would be a better outcome than previous experience.

  Race, class, trust. Nearly all women in this sample were from a middle-class background. Women who occupied multiple positions of privilege (i.e., White, middle-class, highly educated) – their expectations for doctors tended to valorize the role and position of doctors. For women with more working-class or middle-class racial minority backgrounds included in the sample, the issue of trust and hesitation with medical systems was prevalent. For the three Chinese women included in the sample, the issue of language and communication was also an issue to consider when engaging the American medical system. Hazel began her interview by explaining her last interaction with doctors and medical professionals left her feeling like doctors would not take her symptoms seriously. Hazel had not sought out medical advice for her current symptoms and explained that when she went looking for possible doctors, "I didn't have many options. I did look for a psychiatrist or psychologist…but in the end I didn't really find someone who I could trust – I don't know. I just didn't find a good fit."

  For Black or African American women, issues of trust arose with the medical system out of previous experience. Danai recalled her own prior experience with doctors,

   Trust in them? No I didn't have any trust in them….because of things that had happened

   in the past. During college, I was diagnosed with fibromyalgia and it kind of wasn't a

   diagnosis. It was just [imitating doctor] "Go home and Google this."

Both Evie and Dot explained that their hesitation with the medical system arose out of their education about the medical system's treatment of women and minorities – they were exposed to the flaws, ethical violations, and discrimination embedded in the healthcare system. As a result,

they were cautiously optimistic about seeking out help through doctors. Evie recounted her

hesitation with doctors through her own mother's experience with stereotyping,

> I'm really biased when it comes to [doctor's treatment of] ethnicities. My mom had her
>
> gallbladder removed and [doctors said] "Oh it's because you eat fried foods and hot
>
> sauce." [exclaiming] All Black people don't eat fried foods and hot sauce!"

Women with more of a working-class background (Jena, Liza) also expressed some of

their hesitations with the medical system. Jena, a woman who "grew up really poor" and without

health insurance until high school clarified that she was not expecting doctors to solve her

problem. When asked about her faith in the system Jena explained, "Oh geez. I have none. I

don't know if I ever did. Growing up without [health] insurance, I've always been on the

skeptical side of doctors."

Despite evidence to the contrary and different expectations, women who expressed some

distrust of Western health systems and doctors decided to engage the medical system anyway

because of testing credibility and hopes for a different outcome than their low expectations.

Danai offered the most meaningful insight into this decision,

> No, I didn't have any trust in them…once [my current symptoms] came on I was hoping
>
> that a doctor would listen and try to help….I was hoping because of all the technology
>
> that we have these days, all the bloodwork, all x-rays,…all that other stuff, I was hoping
>
> because of all that they would find something to at least figure out why this is happening.

Paradigm Shifts: Experiences with Doctors and the Medical System

Given women and their family's expectations of health and the Western health system,

the following section details their initial set of experiences with doctors regarding their current

symptoms. These experiences revealed how doctors did not meet expectations and primed

women for any future decisions or actions regarding their health. Ultimately, their initial experiences led to a paradigm shift about the Western health system.

      Doctors do not live up to expectations. All women expressed that in some way, doctors did not live up to expectations. For two women they had not engaged with the Western health system because of issues of trust and dissatisfaction with previous experiences with doctors. Both women felt that doctors took too narrow of a view of health. Other women explained that doctors simply did not live up to the expectations to know or care. Cate explained that despite having a doctor who was "very nice, emails, and who listens to me, she's baffled [with my symptoms] of course." Many women felt that doctors simply did not know and when faced with a mystery, resolved to just not know. Jena explained, "Most of the time they [doctors] just go with idiopathic….so they were like, 'It's idiopathic.' [imitates doctors shrugging]."

      As a result, four women even came to question the value of a medical school education. Finn expressed her outrage with her experience, "You would think that they would have enough schooling to really diagnose something!" Finn, who originally wanted to be a doctor, assumed they "would be intrigued by the puzzle." Jena shared,

> I expect[ed] them to try and be like, "Yes, I hear you. I don't know what it is but let me help you try to figure out what's going on…we're very used to the idea that doctors have all the knowledge and information.

      Women also came to see doctors as calloused and uncaring. Finn, who had originally idolized doctors, now viewed doctors as "just so apathetic to real people and real problems." Finn, and several other women grew "frustrated because all you are is a number." Anita (a Chinese woman aged 50), Alice's mom, reiterated this point, "Alice is just one of your thousands of patients. [And while] you are still a good doctor even if you make a mistake on her, but to her

and her family, she is the only one to us." Most women were surprised and some shocked by the experiences they had with the Western health system. Brie, a White woman aged 25 with skin rashes previously thought to be psoriasis explained her exposure to doctors, "It just shock[ed] me to see that because they became a doctor for a reason...and here you are saying it's hysteria or all in someone's head…just seems wrong."

Doctors only offer pills, not solutions. Six women explicitly described their doctors as providing only one form of help: medications. These same women came to view doctors simply as "pill pushers" – intent on putting women on medications rather than seeking out a root cause. Pill pushing was viewed as a negative component to the Western health system approach. Five women discussed having hesitations and an aversion to being put on medication. Some women's hesitation stemmed from previous experience with medication and not wanting to be back on it. Danai had an aversion to medications explaining, "I don't want to be on any type of heavy medication….I was put on medication [before] and it honestly ruined my life. I'm still recovering from some of the symptoms with it." Brie had a similar experience with Prednisone, "I think that helped a little, but then that just messed up my hormones like crazy." Others worried about the risks associated with medications. Jena noted, "That's cool that we can just throw pharmaceuticals at it [symptoms]" but warned "which come with their own side-effects." For five women medication came with ugly consequences (e.g., weight gain, loss of appetite, narcotics withdrawal, suppressed immune system, and further loss of balance). Meg, who began medication for some of her symptoms, expressed her fears with taking a medication,

> I know they have to put them but the side effects for this medication are horrible. You
>
> know, *cancer*. [original emphasis] But I - at the same time, I think – well [puts hands up]
>
> you got to take a risk. I mean, for me, it felt like a risk.

Others still felt that without a root cause or diagnosis, medications offered no solutions. Gwen explained, "Steroids don't treat the illness. It slows down the progression which creates its own complications as well." Without a root cause, women felt that doctors who "threw pills" only provided impractical, short-term solutions.

Learning how the system really works. In all, women's experiences with doctors resulted in no diagnosis, partial answers, and temporary or impractical solutions to their symptoms. Doctors served as the main actors in the Western health system, and women's doubts and concerns about doctors also resulted in doubts and concerns about the larger Western health system. For all of the women, their faith in the Western health system – especially doctors – changed. Their mismatched expectations and experiences created the space for a paradigm shift related to their views of the system. Women learned that their role as a patient was not a position of power, but a position of disadvantage. Jena captured this idea most succinctly, "At the end of the day [doctors] get to walk away and go home. I don't." These initial encounters with doctors taught women that without asserting themselves, the system will not work for them, and they would be beholden to a doctor's decision.

For three women, these experiences resulted in opening their eyes to the flaws of the system but ultimately did not prompt further action. Brie remained considering her next steps after several unsuccessful treatments, but had yet to proceed - "I'm starting to think that at my next check-up next month I'm going to be like, 'Can we run some tests?'" These women had their doubts, but remained unsure of how best to proceed forward. Alice noted, "I just have to tell myself, 'I'm good.'….but I'm nervous for when the symptoms will return." Ultimately, they were considering how to move forward while becoming increasingly frustrated by continuing symptoms.

At the onset of symptoms, women came into the Western health system with certain expectations. Their initial encounters with doctors disrupted or worsened all women's faith in this system. At the end of initial appointments and testing, women were left with no diagnosis and continuing symptoms. Women now faced a decision to continue venturing into different systems of health – they could choose to work outside or within Western health systems. But, at this point, women had been primed for what they might expect in their next steps.

Venturing into Health System(s)

The very nature of living without a diagnosis presented the choice for women to remain in a more passive position about their health or to take a more active position over their health. Women could venture or try different paths – work within or work outside of Western health system. Working within the system included pursing a diagnosis and more doctors and specialists (i.e., seeking a second or third opinion). Working outside the Western health system or in an alternative, non-Western health system included actively working to heal the symptoms themselves using alternative and natural medicine. Next, I present findings on how women ventured into different systems of health, actions surrounding health, and women's current relationship to health systems.

Taking Back Some Control: Gender, Age, Class, and Research

One of the main mechanisms of agency was women's decision-making surrounding their next steps for their health. After learning about the system and feeling disempowered in their position as a patient with undiagnosed symptoms, most of the women in this study decided to take back some control. This action always included doing their own research, and for 10 women included seeking a second, third, or even countless opinions from doctors and specialists. The decision to take further action was prompted by the nature of their continued, undiagnosed

symptoms, the age of onset, and their views of control and autonomy. Living with symptoms that began or flared up in women's twenties and early thirties was a signal for them that their health was not normal. Their symptoms interrupted what they perceived as the prime of their lives, and women decided to take action as they felt they still had their whole life in front of them. Finn illustrated the toll this has taken on her visions of herself and her future,

> The longer I go on without a diagnosis, the more miserable I'll be….and like the physical stuff. The hair loss. Guys can be bald and it's cool, girls really can't….Losing that – it's psychological. [laughs softly]…Like mid-twenties, you should be this picture of health – glowing. And you're not. That has been really freaky.

Others felt embarrassed over their limitations and not being able to live to their full potential. Liza explained, "I can't drive because I get confused or disoriented. I can't concentrate…So that doesn't make me feel good either. Being 33 years old and having to rely on other people for transportation."

In the course of the interviews, none of the women put forward the idea that they were powerless to do anything about their situation. There was frustration, anger, and sadness – but women did not view themselves as helpless. Gwen explained, "I was feeling really down about my life and realized that I had to take back some agency from the situation and kind of remove myself from everything going on. It had everything to do with my health." The intersection of age, class, and education enabled women to assert some form of control over their health. Through research, financial resources, and education – women decided to take some action towards their health: resisting or persisting the Western health system.

Resisting the Western Health System: I Can Heal Myself

Women choosing to reject Western approaches based their decisions on their own

research and previous encounters with medical doctors. At the time of the interview, three

women (Cate, Gwen, Hazel) were actively working outside of – or resisting - the Western health

system. At some point over the course of years, two other women (Meg and Jena) had

temporarily sought help outside of the Western health system looking for relief in other sources.

Treatments outside of Western medicine included the use of natural and herbal remedies,

acupuncture, energy workers and healers, and detoxification. These women decided to try and

deal with the problem through alternative means. In effect, these women believed they could heal

themselves without the help of a doctor.

  No medication. Women who rejected the Western health approach had the strongest

aversion to medication. Hazel, diagnosed with depression, was offered medication but refused to

take it. Cate, having tried other types of medications that made her feel "like a zombie" refused

to take heavy medications now and in the future. Gwen, a self-described "hippie," explained she

also would not take steroids for her suspected autoimmune condition because it was not a natural

solution. Meg also had a strong aversion to medications, "I was sold on natural being the only

way I should go." Medication became an impractical and undesired solution. When offered

impractical solutions these women sought relief and solutions outside Western health systems,

often creating new spaces and diet, exercise, and health habit "rules" for themselves about

health. Gwen explained, "I totally uprooted and changed my diet to all natural, organic…I juice a

lot. And that had immense effects on the reversal or progression of it [my symptoms]."

  Role of research. For all women who currently or previously rejected Western health

system, research was paramount to their approach. For Cate, Gwen, and Meg, their views of

medicine and health were changed by reading "eye-opening" books. Gwen described that after

having gone online and done research, she had learned about the prevalence of autoimmune

diseases, but

> then one day – one book really transformed my experience…I was in this old, gross, smelly bookstore and I found this book titled, *The Poisons in Your Food*….I open up this book and …got really enthralled and it's still sitting on my bookshelf….it did inspire me.

Women felt that these books enlightened them to another set of rules and another approach to health and medicine. Women like Cate were "reading everything [they] could" about their conditions, and came across books in which they found regimes that were viewed as interesting, convincing, and helpful. Research provided women like Hazel with the tools to "try and recover by myself."

Pressure to succeed at healing oneself. Women who rejected the Western health system underwent major overhauls to their lifestyle choices and dieting. These new attitudes to health were hard won and required women to take on a lot of work for their health. After reading a book and doing more research, women like Meg, Gwen, Hazel, and Cate dedicated their lives to trying to work outside Western health system and expected heal themselves naturally. Gwen demonstrated the pressure to remain loyal to a natural way of living as it is what she points to as the solution to her health problems, "with my diet being so *good* now and my relationship to health and care is in my opinion – supreme….I've done nothing but grow…and maybe now that I'm in remission, my relationship is different to [my symptoms]." However, for Cate, Hazel, and Meg, their attempts to heal themselves naturally did not result in elimination of their symptoms and their narratives revealed how resisting the Western health system was linked to a heightened sense of personal responsibility. These three women blamed themselves and revealed a pressure to succeed in controlling symptoms. Hazel admitted,

> I kind of tried, but it never really worked. And I guess I haven't really tried it enough.

Even though I'm doing yoga, I wasn't really relieving my stress. And even though I'm

trying to eat healthy…I'm really trying to eat really, really healthy…I've tried *everything*

but it seems like I'm doing worse than the average person.

Some of the pressure to succeed outside of the Western health system weighed heavily on the

women who were unable to remedy their symptoms. Cate, Hazel, and Meg expressed frustration

with themselves when they were unable to succeed through natural means. Meg illustrated the

guilt associated with selling out and taking medication,

I felt like a failure if I couldn't do it [naturally] and all these other people could. I felt

like, well if these people are successful, why can't [I] be successful? I really felt like a

failure – taking the medication.

The decision to work outside of the medical system offered women alternative means to help

themselves, but was accompanied with added pressures to succeed.

Persisting in Western Health System

At the time of the interview, most women (n=9) had or were pursuing further diagnostic

testing and appointments with doctors and specialists through the Western health system. After

learning how the system really works, these women opted to continue to work within the

Western health system – partly out of cultural views on the credibility of doctors (as opposed to

alternative medicine) and partly out of the desire for an official diagnosis. These women decided

to push doctors and the Western health system to ensure the system did work for them. Women

saw the need for doctors to help them locate an exact root cause and provide appropriate

treatment.

Women's continued interactions with the medical system was a major component of the

interviews. Some women viewed themselves as "full-time patients" (Liza). Women who

ventured to work within this system underwent numerous testing including bloodwork, imaging

(e.g., MRIs, x-rays, CT scans), stress tests, supervised diet changes, allergy tests, genetic tests,

and tried an array of topicals, medications, and licensed rehabilitation. Test results came back

negative or normal. Changes and experimentations with different suggestions from doctors

resulted in new or worsening symptoms, no change, or very mild relief. In essence, these women

worked within the system or persisted to try anything and everything. In many instances, the

pursuit of different options, testing, or trying new things was seen as a way to refute those who

doubted the existence of their symptoms. As Liza explained, "[I'm] always trying something….

Every single suggestion people throw out there, I can say with 100% certainty and confidence, I

have done that. I have tried that. Been there, done that, got the t-shirt. It didn't work."

As women discussed their research, testing, and diagnostic pursuits, three types of

interactions with doctors emerged. In the following section, I detail different doctor-patient

experiences: impersonal, demoralizing, and personally-invested.

Impersonal doctors. For women who persisted in Western health system, the most

common experience described was interacting with impersonal doctors. These doctors further

proved the notion that doctors did not care and were not personally invested in their health or

case. Kelsey explained, "You can't call their office. They don't say 'Call us if you have

concerns' because they're busy, ya know? And you may call and get a physician's assistant or

something, but then they don't really know your case." Impersonal doctors were not rude or

cruel in their treatment of women but did not work to pursue answers. As Cate reflected on her

time pursuing a diagnosis,

> I was going through all of these specialists and there seemed to be no reason, no answer,
>
> nothing. And I thought, "I have to figure this out for myself; they're not going to help me.

There's no help"….I [was going] to one doctor…and I know if my pain is really bad she

will not do anything for me, so I just don't even call her anymore because all I hear is,

"That's interesting."

Impersonal doctors were quick to give up and end contact with patients. When some

women pushed back and asked for further testing or raise questions they were often met with

hostility or pressure from doctors. Rather than seeing this as a personal attack, women like Jena

saw it as doctors simply giving up, "Neuro[logist], I liked. She was willing to run tests I asked

for. At the end though, she still [said], 'I don't know.' And then refused to see me anymore…– I

don't blame my neuro for giving up on me."

Demoralizing doctors. All nine of the persisting women had some form of a horror

story. In the midst of the interview, women detailed their experiences with doctors who they

perceived to be dismissive, rude, wrong, and unethical. These experiences unnerved women's

confidence in doctors, their sense of selves, and could have served to push them out of the

medical system. Ultimately, all of these women sought out new doctors and new expertise but

not without feeling demoralized by their experience. Six women raised questions to their doctor

about different options or possibilities that prompted extremely hostile and rude responses from

doctors. Cate explained,

> I've just left doctor's office when they've been condescending to me…when I were to
>
> ask doctors, "Well, I read about this." They would just flame me. [angry voice,
>
> intimidating doctors] "I KNOW WHAT TESTS TO ORDER!" Really? I'm asking
>
> because I'm curious. I just read this came out at Johns Hopkins and I don't know if
>
> you're aware of everything.

Women described their encounters with demoralizing doctors as "fights" and arguments. Jena

noted that if she ever saw one of her doctors again, "she would punch her in the face." The lesson women took away from their encounters with demoralized doctors was that raising questions resulted in hostility and dismissal.

Danai, Evie, Jena, Norah, and Piper had experiences with doctors that made them question the entire system of health and medicine, unprompted. Both Evie and Jena experienced being involuntarily dropped from a doctor and then given no contact information for the doctor. Evie explained,

I have seen a neurologist because it started and my whole head would just hurt….But then – [laughs] my mom called him a quack because it was out of date, and then when we tried to go back to him, his office wasn't there anymore.

Interviewer: What?

Evie: Yeah, it was weird…. He was gone. So as far as medical doctors, I've seen that "quack doctor."

Other women encountered doctors who outright dismissed their decision-making authority as a patient. Danai, un-married with a college degree, recalled,

[Doctor said], "Get used to it."…And this is the doctor that told me I couldn't make any decisions about bearing children on my own, that I had to be married first and have a husband sign off on the paperwork….I didn't have a boyfriend and this is my decision. If I can't breathe for myself right now, what makes you think I can actually bear a child?....So that doctor just honestly gave me no hope. I remember going home crying that day and calling my father and saying, "Dad, I can't do this anymore." To go to a doctor and pay all that money and for that man to not believe you is the worst thing.

Some doctors patronizingly reassured them that there was no illness. Women mockingly

reenacted the lecturing and condescending tone from doctors. "[imitating doctor] Oh it's just

because you're a woman." (Piper). "'Well, you'll outgrow it,'" recalled Norah, "I got that one a

lot. [imitating doctors] 'You'll outgrow it. Just give it some time. You're stressed.' That kind of

thing."

Faced with demoralizing experiences at a doctor's office, women had few courses of

action. Most chose to pursue another doctor, moving onto the next doctor with a bitter reminder

of how the system continued not to work for women in their position. Some considered writing

letters (Norah, Jena) and others took it upon themselves to ceremoniously "fire" their doctor.

Danai came to such a decision,

> I actually had to fire a doctor that I was working with and had been seeing pretty much
>
> since I got here from college. I told the doctor, "I am not leaving this room today without
>
> some type of remedy. I feel like I am going to die." And the doctor wrote on his notes,
>
> "We need to send you to a psychologist." And I said, "For what?" and he [interpreted that
>
> I was suicidal]. I said, "I'm going to die because of the symptoms' impact, not because
>
> I'm going to kill myself!"

Danai eventually returned to this doctor in the state of a severe symptom flare up and explained

that she was only offered a "stack" of prescriptions with lethal medication interactions. Danai

determined it was time to leave,

> They're not taking it seriously. I told the doctor that "If I die from this condition I want
>
> you to be legally responsible for it. I want you to know that because you ignored me for 4
>
> years, this is your fault. And I want you to write that down right next to the column where
>
> you wrote that I am going to kill myself. Write next to that it's not that I killed myself it's
>
> that you killed me. I want you to think about that." And I walked out of the doctor's

office after that. So it's just frustrating, doctors aren't taking it seriously…that's why I

appreciate you even doing study like this.

The de-humanizing experiences with doctors demonstrated that often in the pursuit of a

diagnosis, interactions with the medical system worsened before they improved.

Personally invested doctors. What occurred in the midst of the conversation with some,

but not all women who continued to persist in the Western health system was the success of

locating a doctor that was personally invested in working with women in their pursuit of a

diagnosis. For Danai, Jena, Meg, and Piper, they had "finally found someone" (Danai) - the right

kind of doctor. These were doctors that sat, listened, and talked with women. They were willing

to search for new testing, to refer, and they were open to suggestions. Jena described that in an

"army of doctors" her one trusted doctor was her internist, "When my internist doesn't know, I'll

come back to her office and she'll be like, 'Well, let's try something else.'…she'll figure out

what's wrong with me." These doctors showed their patients empathy, patience, and women felt

listened to and in a position of power. For Meg, "I had a good, patient dermatologist that talked

me through a lot of stuff and was encouraging…when I didn't want to [take medication], she

said, 'Let me know if you change your mind.' She didn't pressure me." Women recalled

conversations, a genuine back and forth with their doctors in which they asked questions, posed

alternative treatment options, and discussed the possibility of different tests to pursue. Women

felt they had found a doctor who had some personal investment in their rights as a patient and

their health as a person. While most women in this study believed they had no relationship with

anyone in the medical system these women believed they finally found a partnership and a

relationship. Having encountered demoralizing and personally invested doctors before, Jena

illustrated the difference,

> For doctors, don't be an asshole. [smirks] You don't know everything. And don't pick fights with your patients. And don't accuse us of doctor shopping because, guess what, you're a professional and I do get to pick who has my healthcare....Don't just throw up your hands and say, "There's nothing I can do. I don't know." Work with us. It's a partnership…it literally has to be a partnership…we have to work together or nothing will happen. We're partners, we're peers."

Of those nine women who at one point decided to push and persist within the Western health system, five women were currently persisting at the time of interview. Four out of the five that remained engaged with the medical system had finally found the personally invested doctor. Their experiences demonstrated that women's ties to the medical system were not necessarily determined by severity of symptoms, but by the resource and relationship ties to personally invested doctors.

Relationship to Western Health System

As discussed above, women ultimately chose between rejecting (resist) and pushing (persist) the Western health system. As time progressed and all women remain undiagnosed, women's relationship to the medical system remained fragile. In this section, I briefly summarize the benefits and conflict surrounding their decision to resist or persist.

Little victories. Throughout their experience living without a diagnosis, women's ties to the system and pursuit of different treatment regimens resulted from "a-ha" moments. For all women, research remained an important factor to women's continued pursuit for testing or continued adherence to a natural regimen. The internet served as a great resource for women to attempt at least a partial self-diagnosis of their symptoms. They used online resources to rule out certain illnesses and were able to "search by symptoms" (Norah) for other questions they had.

Research provided women with clues as to what was going on and helped them develop their health rules (for women rejecting the system) or new ideas for testing pursuits (for those women pushing the system).

A second "a-ha" moment or little victory was in the form of finally finding the right doctor. Eleven out of the 15 women had yet to achieve this small victory. Danai offered up encouragement for other women and showcased the importance of this small victory, "Don't give up. You're going to find a doctor who finally listens to you. It might take a lot of time. It might take a lot of money. But don't give up. Go look for that person." The value of having a relationship with a doctor proved to be an important moment and factor for women living without a diagnosis.

Anger and frustration. All of the women in this study expressed their anger and hostility towards the Western health system at some point in the interview. Whether they felt confused, betrayed, hurt, or insulted – anger and frustration were apparent in all interviews. As discussed, there were two lines for women to follow: reject the Western health system and be on your own or work within the system with increasing frustration and disappointment. Women's anger signified their shock, frustration, and enlightenment about how the system "really works." It was a symptom of a broken system.

Furthermore, for those 11 women who had not yet pursued or found the right doctor, they had a much bleaker outlook on the Western health system. Most women were outright critical of the system, but for three women, their outlook had turned into exhaustion. Evie, Kelsey, and Norah were fed up with the medical system, having spent years searching and opted to end engaging with the medical system for a diagnosis. They had, in some ways, dropped out from the system – fed up with their experiences with impersonal and demoralizing doctors. For these

women, their anger had grown weary and fatigued – resulting in burning out. These were the women now living in silence with their illness – relying on the resources they had available to them to manage and cope with their symptoms.

This might not end. In reflecting on their decisions about health and future plans, the potentially endless nature of their experience had entered the women's mind. Ultimately these women continued to live with unanswered questions about their symptoms, their lives, their doctors, and their futures. The same motivations for taking action – age, class, race, and research – were also stark reminders that their experience living without a diagnosis may last for the rest of their lives. Women continuing to pursue a diagnosis fought this possibility ("I want closure") and women rejecting the medical system believed they could change this possibility ("I can heal myself"). Face with the possibility of living with chronic, undiagnosed symptoms for the rest of their lives – women enacted agency in reflecting on the meaning of their experience.

Agency in Meaning-Making

Living without a diagnosis was to live in the margins of healthcare and society. Ultimately, all of the women in this study faced limitations to the degree of agency they can employ over their health status. None of the women in this study had been able to claim agency over their structural status as an undiagnosed woman. Rather agency was located in women's meaning-making of their experiences. Throughout the interviews women provided some snippets of the lessons they had taken away from living without a diagnosis, and to close the interview, I asked women to provide words of advice to other women, family members, and medical professionals. This opportunity for reflection provided women with a formal space to share their lessons learned and provided me with meaningful insights into the way they enacted agency over the interpretation of their lived experiences.

Meaning-Making: I've Learned So Much about Myself

As women told their stories and reflected on their lived experience, 10 women provided reflections on how they had become more in-tune with their own bodies and took away lessons about themselves. While struggled with their symptoms, these women had gained a bodily sense of themselves. Piper came to learn "when I'm pushing myself too much." Several women came to recognize what the initial signs were when something was wrong. Meg explained, "What I have is not like anybody else has it, and I have to figure things out based on how my body handles things." Women also came to trust their bodies' signals in this experience. For Jena, she explained that she often battled a "medical imposter syndrome" where she questioned her own sanity at times, "Is there something really wrong with me?" Jena came to realize over time that she needed to trust the signals from her body and silence her doubts, "I have to remind myself – doctors agree with me. No, I'm not making this up." For several women, this experience has been a process of coming into their knowledge and ownership of their own bodies.

Six women also presented a silver-lining in terms of their psychological battles and health. At the time of the interview, these women reflected on their determination and struggle. Liza found her silver lining to be "very difficult" but contended that she was able to learn who her true friends were in her time of need and that she could make it through with their support. For women like Norah, this experience did not completely break her will, "I wasn't broken by this experience," and she retained a part of her strength throughout her experience. Others had an easier time finding a silver lining. Danai, Evie, and Gwen considered their symptoms to be a valuable life lesson. All of the women felt that their symptoms were part of a larger lesson for themselves and said they were almost grateful for living this experience. Danai illustrated this point, "Even with this whatever it is—it's just brought about who cares about me and who does

not care about me. I'd rather know who people are that are not going to be supportive; I'd rather

know now than later." They viewed this experience as one in which they were put into a

vulnerable situation, learned a lot about themselves and others, and went through personal

transformation. Ultimately, however, they hoped they would no longer have to deal with the

undiagnosed symptoms.

Meaning-Making: I've Learned So Much about Health

Another 10 women also discussed the lessons they had gained about health-related topics

and issues, from human anatomy to treatment options to general practices in the Western health

system. Overall, these women felt they had a deeper and more meaningful understanding of

health than prior to the start of their symptoms. For five women, they had never had to think

about chronic health or issues as they grew up relatively healthy. This experience opened their

eyes to new ways to thinking about health and healthcare. Cate stressed the value of knowing

that there were "things going on in our bodies that doctors just simply don't understand." Finn

explained that her "digging" or research into family history, different testing methods, and

biomedical markers for different conditions gave her the courage to stand up to doctors. Without

learning so much, she would have felt completely powerless.

Through their experiences of learning how the medical system "really" works, women

came to make meaning of their experiences in ways that shifted some of the personal

responsibility and judgment of people who do not have a diagnosis away from the individual.

Piper, someone who worked in the medical field, came to have a deeper appreciation for patients

who came in complaining of different ailments and conditions,

> Now, with some of my patients - [coworkers] will be like, "Well, I don't know about
>
> blah, blah, blah." And I'm like, [lecturing] "*Welll,* you never know. This person has been

dealing with this for so long. And they know their body because it's been their body their

whole life. So if something's off, they know it.

Norah thanked Google for her lessons about the medical system,

When it comes to medicine, doctors are not good at providing a diagnosis [matter of

factly] unless it's a textbook case. Their school is so focused on the facts, and you have to

know that humans are not facts. We won't adhere to their schooling, we aren't

facts….Google helped me to realize that.

After learning so much about health and healthcare, women reframed their experiences as a

deficiency of the Western healthcare system, not a personal deficit.

Meaning-Making: Sharing and Learning from Other Women

At some point in the interview, nine women reflected on the connection they felt to other

women and recognized the power and limitations to learning about other women's struggles. For

women like Gwen and Norah, finding a community and learning that they were not alone was a

meaningful lesson to take away from their experience. Online communities could validate

experiences and serve as areas where women could learn from each other. Gwen explained,

"There's clearly no research. That's why there's an awareness group because people who deal

with it – there is no solution." For Meg, her lesson was reluctantly learned,

This was a hard one. I resented it [symptoms] so much for so long….and I remember for

the first time feeling thankful that I got it. 'Cause I resented it, hated it, and felt like it's

not *fair*. [original emphasis] And that was kind of a turning point for me, ya know?

Everybody has things that they deal with, a health issue that they deal with…but if they

don't, then they have somebody in their life that is dealing with a health issue. And that

we can all help each other.

Meg's sense of connection with other people struggling with health issues gave her a sense of connection and meaning.

There were, however, limitations to the connection and meaning for women. Kelsey explained that while she was partially grateful to have learned,

There's a lot of other – particularly women – who are in the same situation…[yet] it oddly made me feel worse because no one has a solution to this. You're going to keep struggling because everyone who is in your situation is [laughing] struggling too."

In the same vein, some communities that women found and wanted to connect to barred them from receiving support. Norah explained her experience with an online support group,

I reached out and I was literally turned away from them. They came back to me and said, "We cannot help you until you get a letter from your doctor." It was then that I realized the groups drew a line in the sand on who deserves support. I'll never forget that.

Despite feeling connections with online communities and learning that they were not alone in their struggle, there were limits to the amount of support women could or desired to access.

Meaning-Making: Never Giving Up

Another major finding was that none of the women had given up on moving forward in some way with their health and with their life. With no guarantee that their experience of living without a diagnosis would conclude, none of the women completely lost hope for locating resources, pursuing a diagnosis, treating symptoms, or building a future for themselves. One of the values of including women who had lived with symptoms for a prolonged period of time was the long-term narrative provided in their experience. Looking across cases and across time, one major pattern emerged – women never gave up. This is not to suggest that women did not experience frustration or struggle, but that their resolve to continue to move forward did not

disappear. Instead women worked to prepare themselves for their symptoms, sought to take advantage of the "good days" (Piper), and continue doing their own research.

Some women experienced more hardship and frustration than others and could have been viewed as "giving up" – their experience was realized in context with time. For example, Kelsey repeatedly expressed her frustration with her symptoms and with the medical system, "as it went on, I just got more and more fed up. I had just been to *so* many doctors [original emphasis] and had so many people not even really diagnosing. I was [sighs] fed up really." However, as time passed and Kelsey noticed differences in her symptoms while traveling overseas, she reactivated the medical system upon her return. Following another round of disappointment, Kelsey found herself yet again, "fed up" with the medical system. Being fed up was not the equivalent to giving up as Kelsey remained open to the possibility of returning to see a doctor.

Alternatively, Meg, once considered herself "sold on the natural way being the only way for 4 or 5 years" experienced a general increase in her pain and fatigue symptoms. After rejecting the medical system and attempting to heal herself, Meg reached a decision, "I thought there's no way I would ever do a medicine, a systemic medicine, but then last year I just got to a point where I was just hurting." Meg, exhausted from the time commitment to meal preparation and natural remedies could not keep up the regimen. After some time struggling with her symptoms and striking a balance with her commitment to natural medicine, Meg decided to take medication to help alleviate her symptoms. At the time of the interview, Meg was working to create her own plan within the system – utilizing medicine, supplements, and diet. Overtime, Meg realized she could not heal herself and re-entered the Western health system.

Time became an important factor to consider in women's experience and shed insights into the trajectories or paths women had taken over the course of years living with undiagnosed

symptoms. Liza, a woman with the least resources or support, perhaps provided the most salient

explanation as to why she could not give up,

> When I don't ever stop, that's when I survive. That's been my only real tool this entire
>
> time is to just put one foot in front of the other and keep going. Having said that, there are
>
> times when I shut down because I can't do it anymore…and that's okay. As long as I am
>
> mindful of the difference between shutting down and giving up. There are times when I
>
> have to shut down for a week, and there are times when I have to shut down for a couple
>
> of months as long - as long as I don't give up. I allow myself to have that bereavement
>
> period because nobody can be a rock all the time. Nobody can be strong 24 hours a day
>
> and 7 days a week.

In the midst of struggle and frustration, women in this study never gave up.

System of Illness Uncertainty

A major narrative that emerged from analysis was one of change over time. In the final

stages of coding, I explored the role of time in women's stories. Here, the Elder (1978)-informed

chronosystem was a valuable theoretical tool. Findings demonstrated the fluid state of women

rejecting/resisting or pursuing/persisting within the Western health system. Women did not

venture into systems of health in a linear manner, and their experiences revealed the dynamic and

endless nature of living in uncertainty. Based on this emergent finding, I devised a visual figure

to demonstrate women's change over time: starting as a Believer, becoming a Doubter, acting as

a Resister or Persister, and experiencing Burnout. Next, I describe each point in time after

discussing the major concepts embedded within my figure. Women may spend prolonged

periods within each of these points in time, but what was made clear by the interviews was that

no woman has yet to resign from the system. There was no end point. Figure 3 depicts my model

for the System of Illness Uncertainty.

Experiences encompass the meaning-making (interactions) women have with family (microsystem), online communities (mesosystem), medical systems (exosystem), and larger cultural values (macrosystem). *Resources* indicate the factors that allowed or hindered women to remain in their current point in time. These include income and social support (microsystem), access to education and research (mesosystem), health insurance (exosystem), and higher amounts of time and energy (microsystem). My consideration of *identity* analyzed the ways in which systems of power, privilege, and oppression operated in and on women's lives and experiences. Here, I considered how personal identities (microsystem) functioned within systems of power, discrimination, and stigma (macrosystem) as it relates to age, gender, race, culture, and class. Lastly, *health* refers to both the biological and social processes of health and physical well-being. That is, I considered how symptoms manifested and the cyclical and dynamic nature of symptoms (microsystem), how women sought out health information from formal (research) and informal (family) sources (mesosystem), and how cultural values surrounding health emphasized personal responsibility and purported Western approaches to health (macrosystem).

Believers

The findings reveal that women had expectations or faith in the kind of treatment they would receive from a doctor and a Western health system. Being a believer is the first point in the system of uncertainty. At this point, women believe or put their faith in doctors to provide them with a diagnosis and appropriate treatment. Findings reveal the multi-dimensional component of this belief: doctors will know, care, and help. For most women in this study (n=9), they started out at this point at the onset of their symptoms. Believers are unquestioning of the medical model of care, view the Western health system as a system designed to help patients,

and ultimately, have had little experience with Western health system. It should be noted that

being a Believer is to adhere to strong, deeply engrained cultural values unquestioning of the

medical model of care, view the Western health system as a system designed to help patients,

and ultimately, have had little experience with Western health system. It should be noted that

being a Believer is to adhere to strong, deeply engrained cultural values about medicine and

health. This is the cultural norm – we are taught to believe in doctors.
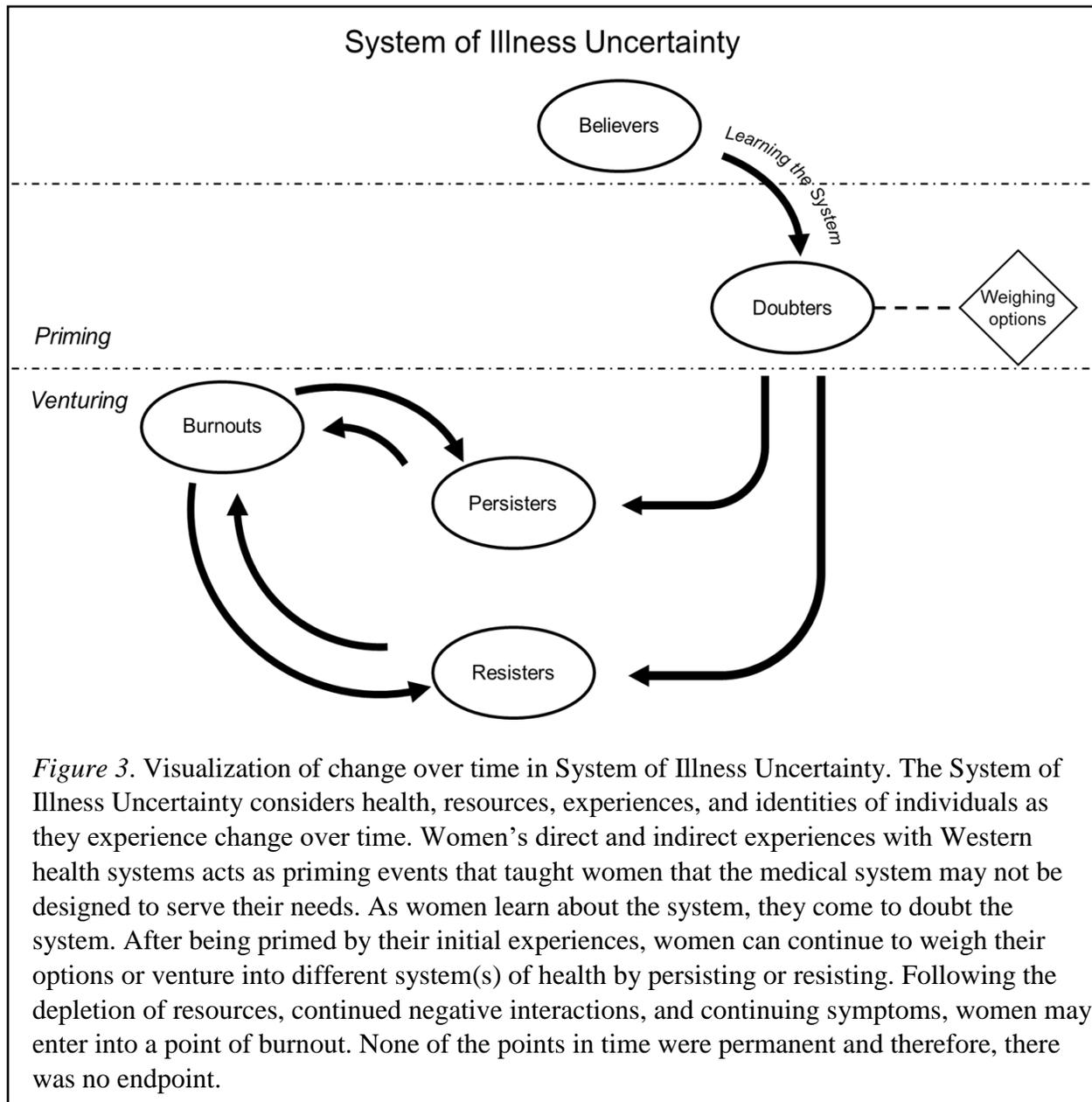
Figure 3. Visualization of change over time in System of Illness Uncertainty. The System of Illness Uncertainty considers health, resources, experiences, and identities of individuals as they experience change over time. Women's direct and indirect experiences with Western health systems acts as priming events that taught women that the medical system may not be designed to serve their needs. As women learn about the system, they come to doubt the system. After being primed by their initial experiences, women can continue to weigh their options or venture into different system(s) of health by persisting or resisting. Following the depletion of resources, continued negative interactions, and continuing symptoms, women may enter into a point of burnout. None of the points in time were permanent and therefore, there was no endpoint.

Doubters

I found several ways in which women come to learn about the Western health system through experiences (i.e., learning the system). The outcome of learning the system is that women come to question or doubt the system and doctors. All but two women (Hazel, Ivy) had taken some action within the Western health system (e.g., seen a doctor, undergone testing) with no success. Women who are doubters learned that the medical system is not meeting their expectations. As discussed in the findings, six women (Danai, Evie, Hazel, Ivy, Norah, Jena) had previous direct or indirect experiences with a Western health system and therefore, *started out* in the position of a Doubter at the onset of their current symptoms.

By the time of the interview, all women in this study had been and three women (Alice, Brie, Ivy) were currently Doubters. Current Doubters expressed discontent and questioning of the medical system but had not yet ventured deeper into systems of health. In effect, those who are Doubters are still weighing their options – work within or work outside of the Western health system. It is also of note that, while Doubters may have expressed questioning the medical systems and doctors in their interviews, they have not demonstrated questioning the system or doctors within the system. They have not pursued second, third, or countless opinions; they have not actively rejected western health system. They remain weighing options – determining the amount of resources next steps would take, the nature of their symptoms, and reflecting on their experiences with doctors. Overall, women who are or were at one point doubters have been primed to how the system works.

Persisters

After initial interactions with the medical system regarding their symptoms, women who persisted in the Western health system were working to ensure that the system did not disregard

or discount their symptoms and experiences. Persisters pushed the system by actively seeking out

as many resources as they could within the Western health system: doctors, specialists, testing,

imaging, etc. At the time of the interview six women were Persisters (Danai, Finn, Jena, Liza,

Meg, Piper) and they described the difficulties of working within the system.

Several factors enabled women to be Persisters. Women often engaged with the Western

health system due to cultural values surrounding different health systems. In short, they pursue

the Western health system as it is still the gold standard for health and medicine. The time spent

as a Persister depended on availability of resources (enough income, health insurance, time,

energy, social support) and class – the more resources, the more time spent. However,

interactions with and trust of doctors also played a significant role. Interactions with doctors

often got worse before they got better. Four out of the six Persisters, who had spent an average of

3.5 years working in the medical system, explained that they had finally been able to find a

doctor after years. Finn had less than one year's experience working within the system and

expressed her increasing frustration with the system; Liza had only recently re-engaged with the

medical system after finding assistance from medical charities willing to help her pursue testing.

As Persisters, these women knew that the system was not going to work for them unless they

insisted, but this came with increasing frustration and often, diminishing resources.

Resisters

After previous or initial encounters with the medical system, some women ventured into

non-Western or alternative medical systems in pursuit of locating the root cause or finding better

symptom relief. Previous interactions with doctors left them with no answers and impractical

treatment suggestions (i.e., Get used to it or take medication). Women who were Resisters

(Gwen, Cate, and Hazel) actively forged their own health plan outside of the Western health

system. In some ways these women saw themselves as rebels, actively working against the

establishment; but for some women, they only worked outside the system in desperation for

relief from symptoms – just trying to feel better. In many respects Resisters set out to heal

themselves. Over the years, five women had engaged Non-Western health systems in favor of

Western health system systems. At the time of interviews, three women were Resisters. All

expressed some form of dissatisfaction and discomfort with the medical system, and more

specifically, expressed strong resistance to the use of medications.

Factors that promoted and hindered Resisters were complicated and varied, but ultimately

research and resources played an important role for these women. After being enlightened by

previous experiences with doctors, women pursued further research into health systems and

illnesses and found themselves convinced by alternative materials they read. Working outside of

the system offered women practical options that took a holistic approach to medicine and health.

It also offered women the opportunity to take more control over their health if they had the time,

energy, and money to adhere to new regimens. This was a vital point to being a Resister as it

often involved new and strict health regimens and an overhauling of her lifestyle, diet, and

activities. Working outside the system meant that women's tied to their healthcare were not

beholden to health insurance. Women did, however, need to contend with cultural values and

perceptions of alternative medicine. Pursuing non-Western medicine approaches in effect went

against cultural norms and the gold standard of medicine. Some women acknowledged their

initial hesitations, but were willing to venture into non-Western health systems. Of all five

women who engaged in alternative medicine most expressed achieving some relief, but only one

woman (Gwen) explained she diagnosed herself as being in remission due to alternative

medicine. By taking on more responsibility over symptoms and treatment, women also placed

added pressure on themselves to succeed in managing symptoms.

Burnouts

A fifth point in time of the System of Illness Uncertainty involves what I call illness fatigue – a state of exhaustion with either system of health. For those persisting, Burnout was a form of fatigue; having grown exhausted and beyond frustrated by working within the system with no success. All three women who were currently in the point of Burnout (Evie, Kelsey, Norah) had been pursuers of the Western health system. Women discussed the physical, financial, and emotional demands of pursuing a diagnosis within the medical system. Women who experienced burnout did not describe having finally found the right doctor, felt they experienced discrimination, expressed limits to their financial and energy resources, and expressed the most cynicism regarding the medical system. They were in-effect, fed up.

For those resisting, Burnout was another form of fatigue - having grown exhausted from the rigor and demands of new health regimens associated with overhauling one's lifestyle and diet as part of resisting. Over the course of their narratives, four women's experiences with the System of Illness Uncertainty involved Burnout from resisting (Cate, Hazel, Jena, Meg). For these women, non-Western medicine had provided help, but not solutions. Rather than remain dedicated to the strict regimens or continue to pursue acupuncturists, healers, energy workers, or other health advisors these women took a break to regroup and consider other options.

One of the key components to the System of Illness Uncertainty is time and the temporary nature of each point in time – this is especially important for Burnouts. Burnouts have not resigned or stopped any and all activity related to living without a diagnosis, but have currently withdrawn from health systems. Depleted of time, energy, resources, and having negative interactions with doctors or medical systems – women enter Burnout. However, women

can be reactivated or reignited back into either system of health based on a variety of factors

including changing symptoms (cyclical nature of symptoms returning or worsening overtime),

replenished resources (time, energy, research), and the need for a diagnosis to access treatment

or programs. Women in Burnout often had the most limited resources (time, energy, money) and

acquiring these resources was the biggest hurdle to being reactivated. Women in Burnout could

also choose to engage in a different system than the one they had temporarily exited. For

example, upon burning out from the Western health system pursuits, Jena regrouped and decided

to pursue relief for her symptoms through non-Western health systems. Furthermore, women

could go in and out of Burnout numerous times, as Jena, having burnt out from resisting, became

a Persister once again. See Appendix H for examples of how women experienced the System of

Illness Uncertainty.

Chapter Summary

In this chapter I provided findings of my data as it relates to my three main sensitizing

concepts: interaction, context, and agency. I began this chapter with a descriptive recounting of

women's experiences with symptoms. I followed this descriptive section with findings on the

lived experiences for women and family members. The next section detailed women's

expectation and experiences (interaction) with the medical system (context) and demonstrated

the lessons learned about the Western health system in the United States. I then moved to how

women ventured into different systems of health. This involved women's decisions to either

reject the medical system or pursue a diagnosis and treatment within the medical system. I

concluded this chapter with findings related to how women enacted agency in their meaning-

making of living without a diagnosis. In the next chapter, I discuss my findings as it relates to

research, implications, and family process.

CHAPTER V: DISCUSSION

In this study I explored interaction, agency, and context of women living without a diagnosis. My findings centered around three sensitizing concepts and three research questions. In the findings, I provided the lived experience of women and families, and in the following chapter I interpret the meaning of the lived experiences in the context of the literature and my research questions. I begin by summarizing the major findings. Next, I discuss my finding in light of family research and theory before moving on to discussion my conclusions. I end by discussing the limitations, implications, and future research that could build on this research.

Summary of Findings

Living without a diagnosis included a different set of challenges that were often ignored if the condition was not considered life threatening. Women came to rely on their bodily cues – constantly comparing their lived experience with cultural norms and expectations to determine whether something was wrong or normal. Without a diagnosis, women could not enact a cultural script surrounding health and illness. Living without a diagnosis also meant living without a clear and direct way to explain their symptoms or experiences to others. Women simply did not have the language to talk about it. Giving the complications and difficulty in explaining the symptoms to others, many women resorted to hiding their symptoms from others.

Women and family experiences demonstrated a sense of isolation in women's experiences – they were in this struggle by themselves. But one of the most central roles for women's system of support was to believe the women's experience. Mothers' almost ubiquitous presence in women' narratives revealed the continuing importance of adult-daughter and mother relationship in the event of illness. Furthermore, findings revealed that support came from unexpected places.

Women ultimately realized the Western health system was not poised to function in ways that would help. Through research, financial resources, and education – women decided to take some action. Although women experienced frustration, anger, and sadness they did not view themselves as helpless. While living with undiagnosed symptoms women to asserted some form of control over their health: rejecting or pursuing the Western health system. Overtime, women's relationship to the system changed. Agency was not found in women's abilities to assert control in labeling their experience. Rather agency was located in women's meaning-making of their experiences, relationships to health, and never giving up.

Women's experience with illness uncertainty can be conceptualized through the System of Illness Uncertainty. In this system women encountered priming experiences with doctors in the Western health system and came to decide to resist outside of the Western health system or persist in the Western health system. Persisters and Resisters are vulnerable to Burnout at some point in the process, but can re-engage with either health system over time.

Discussion of Theory and Research

In Chapter 1, I presented the integrative theoretical framework that guided this study: intracategorical intersectionality (Few-Demo, 2014; McCall, 2005), bio-ecological theory (Bronfenbrenner, 2005), and symbolic interactionism (Blumer, 1969). Taken together, the FEI approach provides conceptual clarity on how the use of the Western health system contains powerful cultural norms and this norm dictates which systems of health are legitimate and illegitimate. Without a diagnosis, women struggled to make sense of themselves, their symptoms, and have any claim to cultural scripts on illness (*Complications of Living without a Diagnosis; Cultural Expectations*). FEI allowed for recognition of the interaction and shaping force of cultural ideas about doctors and Western health.

FEI also allowed for recognition and discussion on objective and subjective agency; an explicit consideration of the conflict, contradiction, and challenges of living without a diagnosis. As noted in Chapter IV, none of the women had been able to assert complete control over their undiagnosed status. Women remained beholden to the authority of doctors to diagnosis for their illness experiences to be recognized or legitimized for others (Nettleton, 2006) or to potentially resolve their symptom's root cause. The FEI approach recognized that women's ability to assert control and authority over their own symptoms was embedded in the context of systems of power and oppression. Regardless of resources available and resisting or persisting in the Western health system, none of the women objectively claimed total control in choices or options over their symptoms (i.e., were able to have and make choices regarding their symptoms, their diagnostic status, and asserting control over different health systems). That is, the social structures and systems of health did not allow for full agency or clarity on their lived experiences, but constrained agency within the confines of each system (Williams, 2003). Women's venturing into different health systems (Western or non-Western) was shaped by the systemic structures of medicine and health; the choice that remained for women was to work within the Western health system or outside Western health system. Persisting and resisting Western health systems required full commitment and dedication to either system; even those who sought to work outside the system encountered pressure to authentically overhaul and commit to a new health regimen. In all, FEI allowed for recognition of the embeddedness of agency within different systems of health (Western or non-Western).

However, FEI also allowed for consideration of the subjective or perceived nature of agency – how women felt they were able to engage resources to meet their needs (Bronfenbrenner, 2005). Faced with the inability to claim certainty over their symptoms, women

engaged in creative and innovative meaning-making about their experiences (Turner, 2000) and interactions at both personal and distal levels (Bronfenbrenner, 2005). That is, women *were* able to reframe their experiences based on their interactions with their symptoms, others, and systems of health. Social support, research, *Learning the System*, and *Venturing into the System* shaped how women *Agency in Meaning-Making*. Women came to view themselves and the Western health system in new ways. Using FEI, my findings highlighted the ways in which context did not dictate women's meaning-making about their experiences; women re-framed their experiences and lessons learned in ways that disrupt and challenge the larger cultural context.

It is important to note that each woman's reframing, interactions, and degree of objective agency was dependent on their intersecting positions of privilege and disadvantage (McCall, 2005). Each woman began her experience in the System of Illness Uncertainty from a different social location or position (Few-Demo et al., 2014). Intracategorical intersectionality asserts that aspects of identity (e.g., age, race, class, gender) are socially constructed, but that cultural values and systems of power (Few-Demo, 2014) shape how women experience illness uncertainty. That is, intracategorical intersectionality considers how gender, race, age, and class were operationalized in women's experiences. How women approached systems of health, adhered to Western notions of health, viewed doctors, adhered to treatments, and framed their experiences was shaped by their positions of privilege and disadvantage (Collins, 2000). It is important to consider women's gender, race, age, and class in their narratives, attitudes, and beliefs about health and health systems. In addition, women's experiences with health and anger should be considered through a feminist intersectionality lens, in that the intersection of race, gender, class, and age shaped women's reactions to the lived experiences that did not meet their expectations. White, middle-class women in this study, with more privileged standpoints, often perceived that

dismissive experiences they had with doctors were shocking and unnerving given their

expectations of doctors. As explained in the findings, all women have been enlightened by their

experiences with health systems, and have come to the realization that the health system is not

designed to work in their favor. For White, middle-class women, illness uncertainty may have, as

W.E.B. DeBois (1903) proffered, "lifted the veil" (as cited in Dilworth-Anderson, Burton, &

Klein, 2005, p. 47) on systems of power, privilege, and oppression embedded in health for the

first time in their lives. Most women came to understand their anger and frustration was a result

of a broken system, not a personal flaw.

   Findings from this research contribute to the understanding of normative and non-

normative life events as theorized in Elder's (1978) Life Course Perspective. This research

deepens the conceptualization of non-normative events as it revealed that women's experiences

are dynamic and change over time. Theorizing about "off-time," non-normative life events could

consider the unexpected timing (Elder, 1978) as well as the non-linear transitions associated with

illness uncertainty. This study also builds on theoretical concepts related to Boss's (2002)

ambiguous loss. Ambiguous loss as it relates to health and illness often centers on the event of a

diagnosis – Alzheimer's research, Crohn's disease – families experience ambiguous loss in the

confines of a known illness (Boss, 2002; Boss & Couden, 2005). Families have some idea of the

type of loss (psychological or physical) they are experiencing. This research provides an

expanded view of ambiguous loss in the context of the unknown – women and families were

unsure what they have lost or may lose.

   Women's anger, frustration, and hostility to medical systems were included in all

women's narratives about illness uncertainty. Women's anger was directed less at themselves

and more at doctors and the inability to reach a diagnosis. Women's anger was a symptom of

experiences with a broken system. Research on women's anger argues that sometimes anger can originate from when women's experiences on how they "do" gender does not align with cultural expectations (Jaramillo Sierra, 2013; West & Zimmerman, 1987). The same can be said of women's anger and health. Women faced increasing frustration when the ways in which they attempted to "do" health did not align with expectations about health and interactions with the medical system.

This research uncovered new insights into invisible gendered processes such as kin-keeping and emotional work (Allen, 1989). Findings revealed the importance and unique role of mothers in mid-life as they helped their adult daughters adapt and manage health when medical system was unwilling or unable to provide a much-needed diagnosis. Mid-life mothers' knowledge of family history offered women clues and ideas about their symptoms. The passage of family health history signifies the importance of on-going kin-keeping processes. Women often serve as the kin-keepers of extended family ties (Allen, 1989). Findings revealed another function of kin-keeping. Furthermore, imparting of their family health knowledge was a way that mothers directly and indirectly shaped their daughters' approaches to health. Little research has been done on the intergenerational relationship between aging mothers and their adult-daughters outside of caregiving and financial support. Findings provide insights into the ways mothers in mid-life continue to serve an important role in the health and well-being of their adult children.

This research confirms many of the experiences and findings researchers have documented in previous research. First and foremost, I found that women's expectations and attitudes about health reflected the dominant discourse of health from the onset of symptoms to receiving a diagnosis and coping with illness (Campbell, et al., 2016). That is, women expected to adhere to the dominant discourse. Second, this research reflected similar findings of previous

research regarding women's dismissive and negative experiences with doctors (Dumit, 2006). Findings also affirmed some of the difficulties of living without a diagnosis such as living with "embodied doubt" (Nettleton, 2006), confronting disbelief from others (Armentor, 2015), and accessing programs and treatment (Dumit, 2006).

This research also contributes to the previous research by exploring the consequences and interpretations of the experiences that have been documented in previous research. This research furthers understanding on the interactions with others (online communities, family members, doctors) and the consequences of negative and positive interactions with doctors. Women living with illness uncertainty underwent a paradigm shift – they came to view the Western health system as flawed and not poised to work for them. Furthermore, this research demonstrates that the women's experiences transcended the concept of resiliency (Benzies & Mychasiuk, 2009; Walsh, 1996). I argue that resiliency is not a comprehensive concept that adequately captures what it means to live in an (potentially) endless System of Illness Uncertainty. While none of the women in this study had given up, resiliency did not fully capture the impact of their experiences living without a diagnosis. Women lived with no clarity regarding their symptoms, their family cohesion and collaboration was weak or non-existent (Walsh, 2003), this was "her" struggle – not the family's struggle. Instead, this research sheds light on how women continue to struggle and move forward with a damaged view of Western health systems and for some, themselves.

Lastly, this research contributes to research on social support and relationships based on shared experience (Yalom & Leszcz, 2005) or shared "outsider-within" enlightenment (Collins, 1986). Black, feminist scholarship sheds the most valuable light on this finding, as Collins (1999) argued that "outsider-within identities are situational identities…attached to specific histories of social injustice" (p. 86). Cultural norms and expectations dictate that those struggling

with a health condition can find the most empathetic and appropriate support from those who have a shared experience (Yalom & Leszcz, 2005). For women in this study, they often turned to communities and sources of support among those that had experienced similar symptoms, such as mothers, family members, and online community boards. However, rather than finding meaningful support from individuals with shared symptom similarity, women's most meaningful sources of support came from those who shared a structural similarity (e.g., going through a non-normative hardship, being an undiagnosed person as well). The best sources of support may be from those who lie outside of the direct experience but have shared marginalization (Collins, 1999) from the Western health system – those that learned of some of the "most intimate secrets of White [Western] society" (Collins, 1986, p. 14). Women's deep bonds and connections to others who have also learned how the system works may reflect the power of connecting to women who have been enlightened (to some degree) about power, privilege, and oppression within the medical system. I theorize this based on intersectionality theory (which recognizes that individuals reside in structural and personal blocks of Collins' (2000) matrix of oppression) and use it to meaningfully explain the mechanisms and underpinnings that explain why women felt an intense bond with certain individuals and not others. The most powerful sources of support come from those who understand hardship while recognizing systemic injustice.

Major Conclusions

Research Question 1: How do women and their families respond to (i.e., make meaning out of) illness uncertainty?

Women perceived the experience as complicated and isolating; women often respond to illness uncertainty with anger and frustration. Over time, women viewed their experiences as life lessons about themselves, health, and the flaws of the Western health system. Women realized

that the impact of their symptoms went far beyond physical manifestation of symptoms;

symptoms impacted their sense of self, relationships, and ideas about health and doctors in

general. Living without a diagnosis unnerved most women's faith in the Wester system. Women

came to learn how the medical system was not poised to work for them, resulting in Doubt.

Family members and friends of women living without a diagnosis respond in different

ways. Family responses were shaped by cultural ideas about health. Family viewed illness

uncertainty as a personal experience in which their main role was to provide women with

comfort and support in their struggle.

Research Question 2: What agentic processes do women enact in the midst of seeking out a diagnosis?

In the midst of illness uncertainty, women enacted agency through venturing in Western

and non-Western systems of health and coming to view their experiences in new light. Women

acted agentically by working within or working outside of Western health system. In the System

of Illness Uncertainty, women's agency came through resisting or persisting. Women were

willing to try new things, pursue different testing, locate new doctors, overhaul their lifestyle,

and research into different systems and approaches to health, and never gave up. Second, women

engaged innovative and creative meaning-making as a form of agency. Women came to view

their experiences as life lessons about their body (coming to trust my own body), the medical

system (the system does not work unless I make it), and health (changed relationship to health).

This reframing of their experiences helped women to cope with the frustration and endless nature

of illness uncertainty.

Research Question 3: What enables agency in the context of illness uncertainty?

Several factors enabled women's agency in the context of illness uncertainty, most of

which I discuss in the System of Illness Uncertainty. In terms of women's venturing into health system(s), several factors enabled agency: access to resources (financial, health insurance), interactions with doctors, research, and family support – specifically mothers' support enabled agency. The financial, social, and emotional resources available to women helped them to engage social support and continue to persist or resist. Finding the "right" doctor also served as an important factor that enabled women to persist. Women felt that having a personally-invested doctor meant they were not alone in standing up to the Western health system. For all women, but particularly women resisting the medical system, research and information seeking were important enablers to pursuing alternatives and create a treatment regimen that matched their needs and wishes. Furthermore, having family members believe their symptoms was a bare-minimum for enabling agency. In illness uncertainty, mothers' support and passing along of family health history also offered women clues into health. Lastly, time enabled agency. Women living without a diagnosis used time to reflect on their experiences and lessons learned. See Appendix J for final matrix of findings.

Limitations

As with any research, there are limitations to consider. First, all participants in this study had been undiagnosed for over one year prior to the interview. All women had lived with undiagnosed symptoms for an extended period of time, so that the interviews did not capture the experiences of women when they were in the midst of testing or their reactions to symptoms were more chaotic and intensive. Second, the study does not include experiences of those who had engaged the medical system and had been able to rule out life threatening illnesses (i.e., cancer). Therefore, this study cannot speak to experiences of those women who may be in the midst of ruling out life threatening illnesses yet remained undiagnosed. Third, the sample

included in this study is a generally well-educated sample (nearly half having earned some form

of graduate degree) and therefore, many of these women had exposure to higher education

systems and access to informational resources. However, it is worth noting that nearly all women

relied in some way on the power of Google, a resource readily available to women from a variety

of educational and socioeconomic backgrounds. Lastly, the data for this study are cross-sectional

and are limited to women's reflections on their lives, rather than following them prospectively.

However, given the richness of this data and the prevalence of personal reflection, the findings

do enable conclusions about changes over time.

Future Research

Researchers need to critically unpack the meaning of a diagnosis - what does it mean to

have a label? As discussed in the limitations, all women in this study had lived with their

symptoms for at least a year. Perhaps this speaks to the larger idea that seeing oneself as

undiagnosed is a step in the process – this has yet to be fully explored. Researchers should work

to capture the experiences of others to see if identifying as "living without a diagnosis" requires a

process or unexplored step in defining health and illness. While this study includes the

experiences of two women who have yet to seek out medical advice or diagnostic testing, they

still see themselves as undiagnosed. Future research needs to further unpack the meanings

implied in living without a diagnosis.

Future research should also work to follow women and collect data at more than one

point in time in order to capture the paths to diagnosis (if and when diagnosis is reached). Future

research should investigate the experiences of women who went through a prolonged period of

time living without a diagnosis and then were eventually able to reach a diagnosis. This would

provide more conceptual clarity to the processes and role that a diagnosis plays in women's lives.

In this research, I provide a figure of illness uncertainty processes that critiques the medical system and doctors. Many of the women in this study, however, provided caveats to their critique of doctors and recognize some of the limitations they face as well. Future research should work to include the point of view from those working within the Western health system who deal with patients that leave a doctor's office without a diagnosis. Future research could also explore the perspectives and experiences of those working within non-western or alternative medical systems. This would provide a deeper understanding of the systemic tensions and processes that are present in the system of doubt.

Finally, future research should also purposefully examine the experiences of people of color and minority populations that are more likely to rely on alternative or non-Western health systems for their healthcare needs. Talking with individuals and family members may provide much-needed insights into the reasons why they do not pursue available Western health models that go beyond a rejection of the Western system.

Implications for Practice

As a family scholar my research examines the intersection and interactions of families and health with a particular focus on health uncertainty. This dissertation came about as a result of my passion to study family experiences in formal and informal systems of health. This dissertation uncovers hidden processes in both formal and informal systems of care, and therefore has implications in both. From a healthcare perspective, the system of doubt is a symptom of failures of a patient-centered model of care. Since 1988, the term patient-centered care was created as a call-to-action, "to stress [to the medical system] the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system" (Barry & Edgman-Levitan, 2012). For the

women in this study, their experience with the Western health system is one that does not put the patient's health and well-being at the center of attention. The experiences of the women from this study demonstrate that this is the exception rather than the rule. Clinicians, physicians, and all personnel in health fields must continue to work to improve the quality of care. This research provides insights to medical professionals "through the patient's eyes" and should be used to improve the quality and responsiveness of care (Barry & Edgman-Levitan, 2012).

With regards to informal systems of health, this study sheds light on the experiences of those who are at the front line of support and health promotion: the family. Family and friends provide a socially invisible life line of support to women who leave doctors' offices without any answers or with no clue as to her next steps. Family researchers and advocates must work to further understand the needs, wishes, and obstacles families face in meeting the demands and stressor of illness uncertainty.

Moving forward, research usually strives to end with a statement of action and call for community. What is made clear in this research is that community- or coalition-building among those living without a diagnosis-- provides vital opportunities of sharing, connecting, and uncovering hidden experiences. There is no universal experience to illness uncertainty, and as with any coalition – one must work to merge the interests, beliefs, and needs of persons with a variety of backgrounds and experiences. It is imperative that researchers and health advocates prioritize the creation of spaces for the *sharing* of experiences, provide materials from which to learn from *others*' experiences, and advocate for increased visibility and *credibility* in the Western health system for women dealing with illness uncertainty. Without such efforts, we perpetuate systems of uncertainty and marginalization.

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APPENDICES TABLE OF CONTENTS

Appendix A: Literature Review Methodology

Search Strategy
Relevant research concerning illness uncertainty was identified through a comprehensive search of biomedical, health, and social sciences databases. Five research databases were used to search for publications: EBSCOHost, MEDLINE, PsychoINFO, The Virginia Tech Addison system, and Google Scholar. In addition, specific queries were conducted for the following journals:
- Family Process,
- Family Relations,
- Journal of Family Issues,
- Journal of Family Theory and Review, and
- Journal of Marriage and Family.

Given the nature of the topic of illness uncertainty, search terms were varied and broad. Search terms included but were not limited to "biomedically invisible illnesses," "medically unexplained physical symptoms," "chronic illness," "chronic health," "seeking out a diagnosis," "no diagnosis," "idiopathic illnesses," "getting a diagnosis," AND "family relationships," "couples," "adulthood," "family life," "women," along with queries on specific illnesses including "fibromyalgia," "rheumatoid arthritis," "chronic fatigue syndrome," "lupus," "epilepsy," and "Crohn's disease." Any number of combinations of search terms were used in an attempt to gather literature on heath and family relationships.

Selection Criteria
Empirical works from 2000 to 2016 (present) were obtained primarily from EBSCOHost, Google Scholar, and the individual journal searches. Studies were eligible if (a) included discussion of a chronic illness in early to mid-adulthood, (b) focus of the study was on process of getting a diagnosis, (c) examined personal identity development in context of illness (e.g., fibromyalgia), (d) examined relationships with others in the context of similar types of illnesses (i.e., IBS, chronic fatigue, fibromyalgia), or (e) examined experiences of living without a diagnosis. Following this search, I broadened search criteria to include empirical work that looked at chronic illness as a stressor, coping with chronic illnesses, or ambiguity in health (e.g., MCI, Alzheimer's research). Research on terminal illnesses such as cancer, rare diseases, or severe illness with medical biomarkers (HIV/AIDS) were not included in the search criteria as these studies focused on living with a terminal or highly stigmatized illness in which biomarkers were more readily available, and therefore the process of getting a diagnosis was in many cases (though not all) acute or straightforward (i.e., one test).

One issue surrounding illness uncertainty that should be taken into account include the relationship between mental health and physical health. Research on mental health was most excluded from criteria as the intention with this study is to examine the physical nature of symptoms rather than the psychological or emotional nature of symptoms.

Appendix B: Recruitment Flyer Example (PDF)

Living without a diagnosis can make you feel invisible.
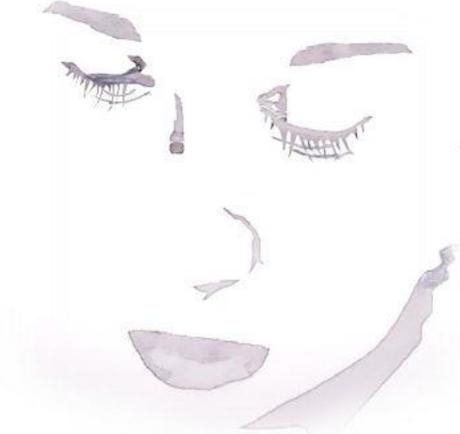
You are not alone in this.

Thousands of women live with conditions that are difficult to diagnose. Getting to the right diagnosis often takes a lot of time and searching. I want to talk with you about your experience.

Participants will take part in two (2) interviews and be compensated up to $35 for their time.

All interviews are confidential.

Looking for Participants who are…

- Women aged 25 to 50
- Living with undiagnosed symptoms for at least 3 months
- Residing in MD, DC, VA, NC area
- Available to complete two (2) interviews in-person or online

Let's Talk.

This study is not intended for medical consultation or evaluation. "Undiagnosed" refers to conditions that have not received official doctor's diagnostic code, are idiopathic, or are self-diagnosed. Participants will receive $20 for first interview and $15 dollars for second interview.

All information shared is confidential. Questions are welcomed. Contacting the researcher does not automatically sign you up. This study has been approved by the Institutional Review Board at Virginia Tech, IRB #16-584. Research study is part of a PhD dissertation.

MORE INFORMATION

www.storiesofsearching.org

VirginiaTech

CONTACT

SOSPROJECT@VT.EDU

Appendix C: Eligibility Forms and Contact Sheets

Thank you for your interest in the study. Please return this form to sosproject@vt.edu
All data collected on this form is used to determine your eligibility to participate in the study. Data collected will be destroyed if you are not eligible or choose not to participate. Data from this form may be used in results of dissertation. All data collected is confidential and will be stored securely.

Eligibility Questionnaire

Thank you for your interest in this study about women who are in the process of getting a diagnosis for a physical condition. Please complete the following eligibility questions and send back to the researcher.

Instructions

Please mark your responses with an "X" or fill in accordingly.

1) **How long has it been since the onset of your physical symptoms? (i.e., how long ago did you notice your condition or symptoms?)**

_____ Less than 3 months

_____ 3-6 months

_____ 6-18 months

_____ 18-24 months

_____ 24+ months

2) **What is your age? (in years)**

_____ years old

3) **Do you currently have a formal (from a doctor or medical specialist) diagnosis for your physical symptoms?**

_____ Yes

_____ No

_____ Not sure (please briefly explain): _____

_____ Not yet (please briefly explain): _____

4) **Do you identify as a woman?**

_____ Yes

_____ No

Interviews will be conducted in English.

Please fill out this form and return to sosproject@vt.edu

Contact Form (Woman)

Please return this form to sosproject@vt.edu
Contacting the researcher does not automatically sign you up for the project.

Contact Information and Scheduling an Interview

Please provide contact information and your availability for interviews.

First Name: _____

Please provide a way to contact you to schedule interviews:

Email Address: _____

Phone Number: ( ) _____

Is this a…. (mark with an "x")

_____ Home number?
_____ Cell phone number?

Method of Interview

This research is being conducted by researchers at Virginia Tech, located in Southwest Virginia. Interviews will be conducted in English and usually take place face-to-face or in-person if possible. For those living within driving distance of Virginia Tech, the researcher is available to travel and talk with you in person.

Face-to-face interviews can take place at your home or a quiet and safe location (e.g., a public library, room at a community center). However, the researcher also recognizes in-person interviews are not always preferred or possible.

Please provide your preference with "x" for whether or not the interview will take place in-person or over online video.

_____ In-person (if available)
_____ Online video (e.g., Skype, Google Hangout)

If you do not have access to online video technology or in-person interview, please contact the researcher at sosproject@vt.edu.

Interview Reminders
▪ Please allow at least 90 minutes for the first interview in order to allow enough time to talk.

▪ The interviewer can accommodate for work schedules and some weekends.

▪ The interviewer will contact you about setting up an interview within a week of your contact information submission.

By submitting this contact sheet, you are agreeing to be contacted by the researcher for this study. This does not automatically sign you up for the study. Please return this form to sosproject@vt.edu.

Contact Form (Family)

Family Member or Friend Contact

I am interested in how living without a diagnosis impacts women and their relationships with others, especially their close relationships. Is there a family member or friend, perhaps someone you consider to be like family that I may contact to talk to about your experience?

I would like to talk with a family member or friend during two interviews that would take place over the phone. The first interview would last between 45 minutes to 60 minutes, and the second interview would last about 15 minutes. This person just needs to be someone who knows about your symptoms or condition, has regular contact with you, is over the age of 18, and you think would be willing to talk to me. There is a $15 gift card for family members.

_____ Yes, I will provide name/contact   _____ No, I do not wish to provide name/contact

If *yes*:

_____ (*name of contact*)

_____ (*relation of contact*: friend, partner, sister, etc)

_____ (*contact information*)

All interviews are confidential. I will not share your answers with this person nor their answers with you.

Please let your family member or friend you have chosen know that I will be contacting them.

If you do not feel comfortable giving contact information but would be willing to provide your family member or friend with my contact information, please ask them to contact me at sosproject@vt.edu.

Appendix D: IRB and Informed Consent

VirginiaTech

Office of Research Compliance
Institutional Review Board
North End Center, Suite 4120, Virginia Tech
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-4606 Fax 540/231-0959
email irb@vt.edu
website http://www.irb.vt.edu

MEMORANDUM

DATE: September 16, 2016

TO: Katherine R Allen, Emma C Potter

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)

PROTOCOL TITLE: Illness Uncertainty: Experiences of Women and Their Families Seeking Out a Diagnosis

IRB NUMBER: 16-584

Effective September 16, 2016, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

http://www.irb.vt.edu/pages/responsibilities.htm

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As: Expedited, under 45 CFR 46.110 category(ies) 5,6,7
Protocol Approval Date: September 16, 2016
Protocol Expiration Date: September 15, 2017
Continuing Review Due Date*:   September 1, 2017

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

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VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution

VIRGINIA TECH
Informed Consent for Participants in Research Projects Involving Human Subjects

Title of Project: Women's Experiences with Illness Uncertainty

Investigators: Emma Potter, MS and Katherine R. Allen, PhD

Purpose of the study: The purpose of this study is to explore what it is like living without a diagnosis by investigating women's experiences with prolonged illness uncertainty. The ultimate goal of this research is to give voice to those who live with uncertainty and collectively share women's words of advice, unmet needs, and daily struggles. This study is for a research dissertation on families and uncertainty.

Procedures: Two interviews will be conducted. Each will be audio-recorded, with your permission, and the first interview should take 60 to 90 minutes. The second interview should take 45 to 60 minutes. Interviews will be conducted at a private place and time agreed upon by the participant and the researcher (if in-person), by telephone, or by Internet video. At the end of the interview, participants will be asked to provide a name and contact information for a family member or friend. Following the second interview participants will be asked if they wish to participate in an optional part of the study in which they give feedback on an online advice document. There are no right or wrong answers to my questions.

Risks: There are no anticipated risks beyond what can expected from normal daily conversation about one's life. You may have uncomfortable feelings when discussing more sensitive topics.

Benefits: Although I cannot guarantee direct benefits, you will be contributing to the significant gaps that still exist on what you impact illness and getting a diagnosis has on individuals' sense of self and daily life. In addition, this project contributes to the conversation on the role family plays in diagnosis process, power and authority in medical care, and personal relationships.

Compensation: As a token of appreciation, you will be given gift cards for up to $35 ($20 for first interview, $15 for second). If you choose to withdraw, you will be provided one-half of the compensation. If you choose with withdraw before the study is over, you will be compensated for interview you have participated in, and if you choose to withdraw early from an interview, you will be provided with half of the compensation.

Anonymity and Confidentiality: All information shared is confidential. All forms will be kept in a locked cabinet in the researcher's office. Only the researchers will have access to your information. If you agree, your interview will be audio-recorded and transcribed. The written version of the recording will be kept in a separate location, and the audio version will be kept on a password- protected computer. When writing reports, I may quote some of what you say, but I will never use your real name, the name of any others that you may talk about, or any other identifying information. The audiotapes will be destroyed at the end of the study.

Freedom to Withdraw: You are free to withdraw from the study at any time without penalty.

Approval of Research: This project has been approved, as required, by the Institutional Review Board for Research Involving Human Subjects at Virginia Tech.

Direct questions about the study to the researcher:

Emma Potter at sosproject@vt.edu

Questions or concerns about the study's conduct or your rights as a research subject, or need to report a research-related injury or event:

Dr. David Moore, IRB Chair at moored@vt.edu or (540) 231-4991.

Participant's Permission: I have read and understand this document. By signing below or giving verbal consent, I am consenting to participate in this study:

Printed Name _____ Date ___/____/____

Signature _____

Do you give consent to have this interview audio-recorded? _____ Yes _____ No

Virginia Tech Institutional Review Board Project No. 16-584
Approved September 16, 2016 to September 15, 2017

VIRGINIA TECH

Informed Consent for Participants in Research Projects Involving Human Subjects
[Family Member Form]

Title of Project: Women's Experiences with Illness Uncertainty

Investigators: Emma Potter, MS and Katherine R. Allen, PhD

Purpose of the study: The purpose of this study is to explore what it is like living without a diagnosis by investigating women's and families' experiences with prolonged illness uncertainty. Results from this study will be published and used in a dissertation.

Procedures: You are asked to participate in two telephone interviews. Each interview will be audio-recorded, with your permission, and the first interview should take about 45 to 60 minutes, and the second interview about 15 minutes. You will also be asked if you wish to provide feedback on the creation of an advice document, but this is an optional part of the project.

Risks: There are no anticipated risks beyond what can expected from normal daily conversation about one's life. You may have uncomfortable feelings when discussing more sensitive topics.

Benefits: Although I cannot guarantee direct benefits, you will be contributing to the significant gaps that still exist on what you impact illness and getting a diagnosis has on individuals' sense of self and daily life. In addition, this project contributes to the conversation on the role family plays in diagnosis process, power and authority in medical care, and personal relationships.

Compensation: As a token of appreciation, you will be given a $15 gift card following the first interview. If you choose to withdraw during the first interview, you will be provided one-half of the compensation. Participation in the second interview does not include compensation but your participation will contribute to much needed research on family relationships and health uncertainty.

Anonymity and Confidentiality: All information shared is confidential. All forms will be kept in a locked cabinet in the researcher's office. Only the researchers will have access to your information. If you agree to participate, your interview will be audio-recorded and transcribed. The written version of the recording will be kept in a separate location, and the audio version will be kept on a password-protected computer. When writing reports, I may quote some of what you say, but I will never use your real name, the name of any others that you may talk about, or any other identifying information. The audiotapes will be destroyed at the end of the study.

Freedom to Withdraw: You are free to withdraw from the study at any time without penalty.

Approval of Research: This project has been approved, as required, by the Institutional Review Board for Research Involving Human Subjects at Virginia Tech.

Direct questions about the study to the researcher: Emma Potter at sosproject@vt.edu

Questions or concerns about the study's conduct or your rights as a research subject, or need to report a research-related injury or event:

Dr. David Moore, IRB Chair at moored@vt.edu or (540) 231-4991.

Participant's Permission:
Do you agree to participate in this study and answer the questions asked?

_____ Yes   _____ No (*thank and hang up*)

Do you agree to have this interview audio-recorded?

_____ Yes   _____ No

By signing below I, the researcher, declare that I have received verbal consent from participant to participate:

Printed Name: _____ Date ___/___/___

Researcher signature _____

Appendix E: Interview Protocol and Research Questions; Demographic Forms

Interview Questions: Woman

		Purpose/ Research Question
1.	To begin, tell me a little bit about yourself and your day-to-day? *Probe: Who are you? Activities, obligations, family life, work, limitations?*	Context, begin life narrative RQ1
2.	Let's talk about others in your life. Tell me a bit about the people who are your family or the people who are family to you. *Probes: first names, key relatives, frequency of contact, quality of relationship w/ person*	RQ1
3.	Thinking back to before you got sick, how would you say your quality of life compares to now? *Probe: Timeline of illness (onset, gradual/sudden), degree of impact. What is a good day like for you? What is a bad day like?*	Interactions Context, narrative RQ 1
4.	Let's switch gears. What kind of faith did you have in the medical system going into this? *Probe: What did you think about the medical system or doctors before? What kind of trust did you have? Ability to diagnosis? How has that faith changed?*	Meaning-making Agency RQ1, RQ2
5.	Have you tried to diagnosis yourself, and why or why not? *Probe: Where did you turn to for information? What ideas do you have about your illness? What would a diagnosis provide for you?*	Self-directed agency RQ1, RQ2, RQ3
6.	Let's talk more about you. What kind of life are you building for yourself? *Probe: How do you see yourself now and in the future with respect to work? Relationships? Family planning?*	Narrative, agency meaning making RQ1, RQ2
7.	To what degree have (or are) your visions for your future changing as a result of your health issue/illness? *Probe: Which goals have changed? How do you see yourself now as compared to, say, a year ago?*	Agency RQ1, RQ2
8.	What kinds of support have you received from others? *Probe: What role has your family played in this process?*	RQ1, RQ3
9.	What have you learned about your family and friends during this experience? *Probe: Who in your family knows about your illness? Decide who/when to tell? Relationships changed?*	RQ3
10.	*If you could change anything about your life what would it be?* Probe: *What do you wish you had more of?* What are some of your biggest worries?	RQ2 RQ3
11.	Is there something else you would like to share with me to help me understand what this experience has been like for you?	ALL
12.	What advice do you have for others in a similar position to you? *Follow up: What advice do you have for family members? What advice do you have for medical professionals?*	RQ1, RQ2, RQ3

Interview Questions: Family Member

	Purpose/Research Question
1. To begin, tell me a little about yourself and your day-to-day life. *Probe: work, family, activities*	Context, begin life narrative RQ1
2. Tell me a little bit about your relationship with _____. *Probe: How long have you known, how would you characterize your relationship?*	Context, begin life narrative Life before and after RQ1
3. Let's think about _____'s health – when did you first hear or learn about her health issue? What did you think when she told you? *Probe: Did you believe her? How concerned were you?*	Context, begin life narrative Life before and after RQ1
4. How have you been involved in _____'s life since? *Probe: What are you providing? What is your role/job?*	Context, begin life narrative Life before and after RQ1
5. What kind of faith did you have in the medical system before learning about _____'s health? How has that faith changed? *Probe: Did you trust the medical system? What did you think about doctors and medicine?*	RQ1
6. Let's talk about more about you. What kind of life are you building for yourself? *Probe: How do you see yourself now and in the future with respect to work? Relationships? Family planning?*	RQ1, RQ2
7. To what degree have your visions for your life changed because of _____'s experience? *Probe: Have you given up or rethink any of your goals?*	RQ1, RQ2
8. How have you been involved in _____'s life since? *What is your role?*	ALL
9. What have you learned about _____? How about friends or family? Probe: *In what ways has she changed (or not)? What are new insights about her that you have gleaned? How have your relationships with others changed?*	ALL Ambivalence in relationships
10. How might you have done things differently had you been in a similar position to _____? *Probe: Are there times when you have disagreed on something related to his/her health? … you and family/friends have disagreed on something related to her health?*	RQ2, RQ3
11. What advice would you have for others in your position?	RQ2, RQ3

Demographic Form (Woman)

ID: _____   **Demographic Questions**   1
                              Illness Uncertainty
All data collected on this form is confidential and will be stored in a secure location. Form will be destroyed upon
              completion of the study. Results from the form will be used in publication or dissertation.

1. What is the zip code of your residence? ___ ___ ___ ___ ___ *(for determining rural/urban status only)*

2. How long have you lived in this community? _____ *(approximately)*

3. Which categories describe you? (Check all that apply)

    _____ American Indian or Alaska Native   _____ Native Hawaiian or Pacific Islander
    _____ Asian   _____ White or Caucasian
    _____ Black or African-American   _____ Some other race/ethnicity (describe):
    _____ Hispanic or Latina/o
    _____ Middle Eastern or North African   _____

4. How are you employed? (check one):

    _____ I have not been employed for pay   _____ I am employed part-time (< 34/week)
    _____ I am not employed but looking   _____ I am employed full-time (> 35/week)
    _____ I am not employed and not looking   _____ Other _____

5. What is your current relationship status?

    _____ Single, never married   _____ Divorced
    _____ Dating or Cohabiting   _____ Widowed
    _____ Married   _____ Other (specify) _____

6. What is the highest level of education you have completed? (check one)

    _____ Completed 8th grade or less   _____ Some college
    _____ Some high school   _____ Bachelor's degree (college)
    _____ Completed high school or GED   _____ Attended graduate school
    _____ Associate's degree (community   _____ Completed graduate school
          college or technical school)   _____ Other (specify) _____

7. Please list the first names of your children and their ages (if applicable):

    Sons: _____   Daughters: _____
    _____   _____
    _____   _____

8. Compared to other persons your age, would you say that your health is

    _____ Much better   _____ Worse
    _____ Better   _____ Much worse
    _____ The same

9. Do you currently have health insurance? (i.e., are you insured?) If yes, how are you insured? (circle)

    _____ Yes (insured: *individually purchased   employer   public program   family member/spouse*)
    _____ No, I do not have health insurance at this time

10. Which of the following best describes your ability to get along on your income?

    _____ I can't make ends meet.   _____ I have enough with a little extra sometimes.
    _____ I have just enough; no more.   _____ I always have money left over.

11. What range represents the total combined household income before taxes during the last 12 months?

    _____ Under $10,000   _____ $20,000–$29,999   _____ $40,000–$49,999
    _____ $10,000–$19,999   _____ $30,000–$39,999   _____ $50,000 or more

Demographic Form (Family)

ID: _____   **Demographic Questions**   1
                                              Illness Uncertainty
              All data collected on this form is confidential and will be stored in a secure location. Form will be destroyed upon
                          completion of the study. Results from the form will be used in publication or dissertation.

1. What is your age? ___ ___ *(years)*

2. How long have you lived in this community? _____ *(approximately)*

3. Which categories describe you? (Check all that apply)

   _____ American Indian or Alaska Native   _____ Native Hawaiian or Pacific Islander
   _____ Asian   _____ White or Caucasian
   _____ Black or African-American   _____ Some other race/ethnicity (describe):
   _____ Hispanic or Latina/o
   _____ Middle Eastern or North African   _____

4. How are you employed? (check one):

   _____ I have not been employed for pay   _____ I am employed part-time (< 34/week)
   _____ I am not employed but looking   _____ I am employed full-time (> 35/week)
   _____ I am not employed and not looking   _____ Other _____

5. What is your current relationship status?

   _____ Single, never married   _____ Divorced
   _____ Dating or Cohabiting   _____ Widowed
   _____ Married   _____ Other (specify) _____

6. What is the highest level of education you have completed? (check one)

   _____ Completed 8th grade or less   _____ Some college
   _____ Some high school   _____ Bachelor's degree (college)
   _____ Completed high school or GED   _____ Attended graduate school
   _____ Associate's degree (community   _____ Completed graduate school
         college or technical school)   _____ Other (specify) _____

7. Please list the first names of your children and their ages (if applicable):

   Sons: _____   Daughters: _____
   _____   _____
   _____   _____

8. Compared to other persons your age, would you say that your health is

   _____ Much better   _____ Worse
   _____ Better   _____ Much worse
   _____ The same

9. Do you currently have health insurance? (i.e., are you insured?) If yes, how are you insured? (circle)

   _____ Yes (insured: *individually purchased   employer   public program   family member/spouse*)
   _____ No, I do not have health insurance at this time

10. Which of the following best describes your ability to get along on your income?

    _____ I can't make ends meet.   _____ I have enough with a little extra sometimes.
    _____ I have just enough; no more.   _____ I always have money left over.

11. What range represents the total combined household income before taxes during the last 12 months?

    _____ Under $10,000   _____ $20,000–$29,999   _____ $40,000–$49,999
    _____ $10,000–$19,999   _____ $30,000–$39,999   _____ $50,000 or more

Thank You Letter Example
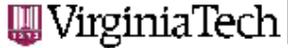
VirginiaTech
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and Human Sciences

Department of Human Development
409 Wallace Hall (0416)
295 West Campus Drive
Blacksburg, Virginia 24061
540.231.6817   Fax: 540.231.7012
www.humandevelopment.vt.edu

[XX/XX/2016, delivered via mail or email, electronic gift card code:]

Dear [insert participant name],

Thank you again for your willingness to participate in my study in which I talk with women about their experiences searching for a diagnosis. I am so appreciative of your willingness to meet with me for an interview and to share your thoughts about your experiences, which were extremely informative and useful.

Please find your **$20.00 gift card included** with this letter for the completion of the first interview. It represents only a small token of my appreciation for your willingness to participate in my study.

I would like to follow up with you over the phone in about 2-3 months. If you choose to talk with me for the follow-up, you will receive $15.00. Please look for a phone call from me in [insert month]. I do hope you are willing and able to complete this follow-up interview.

As discussed prior to the start of the interview, **all information shared with me is confidential.** I will not share your participation, responses, or answers with others – including your family member or friend. When I write up reports, I will change your name and any personally identifying information. All data collected from you (e.g., forms, addresses, contact information, and interview) will be kept in a locked office and on a password-protected and encrypted external hard drive.

I have greatly valued your participation in this research study and your willingness to share about your experience. **If you have any questions or concerns, please contact me at** sosproject@vt.edu. You may also call my office at (540) 231-6817. If you have any questions regarding my conduct as a researcher or your rights as a participant, you may contact the IRB Chair at Virginia Tech, Mr. David Moore at (540) 231-4991. **Again, thank you so very much** for your time and effort that made this research study possible.

With warm regards,

Emma Potter, MS
PhD Candidate, Lead Researcher of Stories of Searching
Department of Human Development, Virginia Tech

[See attached Amazon, Kroger, or Walmart gift card for the amount of $20.00]

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VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Appendix F: Examples of Two Analytical Memos

Memo 1: Time
I'm having a really difficult time in determining a typology or category for women in my sample. I fear that I have perhaps allowed for too much variability in my sample, but I ultimately want to unpack the experience of living without a diagnosis. I opened up my study to those who experienced symptoms for longer than two year with the intent of allowing for more variation – but I am wondering how I may be able to draw narratives from the data. Should I focus on women's experiences if they have lived without a diagnosis for less than two years, two to five years, and five to ten years, and then ten years or more? In my data I notice that women have tried different things during their time living without a diagnosis. Time tends to be a big factor in women's stories. Some women like Cate or Jena have similar experiences of working in and outside of a western medical model –but they're experience with time is different (Cate having lived with this for 15 years, Jena only 4). Furthermore, I do not see a common thread with women who have lived with it for X amount of years versus those who have lived with it for Y amount of years – except perhaps with those who have only lived with this for less than a year. I need to account for the ways in which women's experiences with illness change over time. Otherwise I will struggle to capture the experiences of those who moved in and out of the western medical system. Bronfenbrenner's bioecological theory provides insights into time – I want to steer clear of using language around transitions as I am not using a Life Course Perspective, but the idea of ontological time may be a helpful component to consider as well as change over time. What is it about these experiences that happened at this age? And why might women have gone through different points or stages of exploration or trying new things?

Memo 2: Health Systems
I am purposefully staying away from all literature related to the concept of working inside or outside of health systems. I fear it will cloud my approach and data analysis. With that in mind, I have revisited some of the basics of my theoretical work in an effort to figure out how best to represent and analyze the data related to women who are staying within the western model of medicine and those who venture outside of it. Ultimately, I feel that the discussions surrounding Western medicine and non-Western medicine reveal a power struggle between two different health systems. Women are caught in the middle of it. Those who venture outside of doctors know that their experiences will be considered with skepticism by others - but what others don't understand is that women are finding so answers or help in the Western medical model. Furthermore, women who do decide to stay within the system are not rosy-eyed in their approach to the health system, but instead may feel obligated to stay in a credible "lane" of medical care. Need to do more exploring of the tensions of power and medicine between these two systems of health and healthcare. There is a power struggle embedded in these stories.

Appendix G: Coding Schema
Refined Coding Categories: Focused Coding (Women and Family Data)

100 This is Torture
  101. *Weird, Body is Telling Me Something Is Wrong* (before/now, can't/can)
  102. *It's Not Life Threatening*
  103. *Impacts on Psychological* - Makes No Sense
  104. *Impacts on Relationships* – Careful Who I Tell (People don't believe me, a lot of stress between us; blame; learned who true friends are; expected family to support; mother didn't validate feelings; "permanently damaged some relationships")
  105. *Impacts on Financial* ("I've spent so much money" "can't afford to get a diagnosis")
  106. *Stress, Frustration, Sadness* ("I think I'm perfect, then symptoms come back" "frustrating and annoying"; "gotten to the point"; this might not end)
  107. *Having other diagnosed conditions* (
  108. *Whatever this is, it's like* (use of metaphors, analogies, no language to talk about it)

200 Learning My Place in the Medical System
  201. *Hope and Optimism in doctors*
  202. *Doctors have legitimacy, credibility*
  203. *Expectations of doctors* (doctors are supposed to help, try, care, know, fix)
  204. *Doing research to prepare* for appointment, have to be careful about what I read
  205. *Looking for solutions*: Need to find root cause = appropriate treatment
  206. *Counting on/trusting in doctors* ("one person I was counting on" "I'm not a doctor")
  207. *Experiences with Doctors* (doctors don't know, try, care, or fix; tried this and this)
  208. *Doctors are Pill-pushers and that's not a solution* (don't want to be on medication, people don't need to be meds, medications are short term fix, not a solution)
  209. *How the system really works* ("I have found/learned" "doctors don't know what to do with me"; others' horror stories; "make money off of you")
  2010. *Where doctors left it* (no answers, no solutions, no help, "doctors left it" "put up their hands" "come back when you're worse")
  2011. *Loss of faith in doctors* (shock,

300 Continued Activities
  301. *Taking back some control* ("I decided" "whole life ahead of me" "I have hope to do the things I want to do" "Had to switch majors, but stayed in school" "didn't break me")
  302. *Willingness to try* ("I'll try anything except")
  303. *I don't want to be on medications* (looking for solution)
  304. *Continuing Research* ("I learned I wasn't alone" "a lot of women are struggling with this kind of thing" "online women are struggling but they don't have answers either" "read this book" "found this book")
  305. *Rejecting the doctor and western medicine approach* ("I don't want to be on meds"; "I can heal myself"; "I'm going to try and figure this out on my own"; "convinced natural was the only way"; "doctors aren't helping, going to try acupuncture")
  306. *Learning and working the system* (Playing the game) ("I have learned tricks" "so many

doctors" "full-time patient" "specialist after specialist" medical expertise sought out)

307. *Trials with doctors* (things getting worse before getting better; own horror stories; mistakes by doctors; fired a doctor; kept pushing medication; aren't listening)

308. *Little victories with self and/or doctor* ("Finally found a doctor"; "we figured out other symptoms"; "sat down with me and said, we've got to figure this out"; "changed or reversed the progression of symptoms"; "symptoms have gotten better"; "ruled out life threatening")

309. *Living with Unanswered Questions* ("this might not end"; pushing system; "still haven't figured that one out"; "can't figure it out"; "don't know"; "whatever this is…"; "tell myself, 'I'm good.'")

3010. *Adapting* (changed relationship to body – mostly negative; recognizing signs from body; adapting; changes have become second nature; trusting myself; learning to love self)

400 Emotions or Feelings

401. *This continues to be torture* (impact on relationships, finances, psychological, imposter syndrome; doubting oneself)

402. *Knowing the Ropes/Becoming Enlightened* – Unveiling System's Flaws ("I have found/learned"; there is no room for me; learned so much about health; relationship to health has changed; almost thankful for it; has to be a compromise between natural and western medicine)

403. *This doesn't stay the same - Changes over time* ("symptoms have gotten to the point"; "I was constantly in pain"; gave in and started taking medication – "felt like a failure"; "gotten better since I can control some of the symptoms")

404. *Anger as a symptom of broken system* (frustration, fed up, "you have to ruffle feathers"; hostility towards doctors; serious deficiency in healthcare)

405. *Shutting Down Vs. Giving Up* ("fed up"; a lot of women are struggling; I struggle too; when I go back/if I go back; new experience with doctor for other reason; finally found the right doctor; it's my life)

500 Support in Her Struggle

501. *Lack of "we" language* ("she" "her" "my" vs. "we" "us" "our"; "cemented"; "distance"; "not gonna make her feel bad for feelin' bad")

502. *Believing as a base line for support* ("two words: Believe them"; "I never doubted her"; "I believe her 100%"; "How could I doubt her? She's always ended up right."; "I don't think it's that serious a problem"; "She's just gotta…"; permanently damaged relationships)

503. *I am my mother's daughter – role of mothers* ("I'm just passing down what I learned"; knowledge of family health history; "body can heal itself"; "don't settle for the first doctor"; "mama hen")

504. *Support from unexpected places* ("never thought I would be close to this person, but…"; "expected family to be there, no"; judgment from those with similar symptoms)

Final Coding Schema

I.   Life and Relationships
   a. Complicated by Symptoms
      i.   Not Life Threatening, But Something Is Wrong
      ii. Can and Cannot Do
   b. Isolated by Symptoms: Distance from Others
      i.   Use of Metaphors and Analogies: "It's like…"
      ii. Hesitation to Reveal Struggle: "People I know I can trust…"
   c. Role of support
      i.   Connection: Importance of believing: "Two words: Believe them."
      ii. Distanced Support: Absence of "we" language
      iii. The role of mothers: "Passing down what I know…"
      iv. Support from unexpected places: "Wouldn't expected to be close, but…"

II. Interactions and Agency with Health Systems
   a. Beliefs
      i.   Cultural Values of Western vs. Non-Western Health Systems
   b. Learning the System
      i.   Doctors do not meet expectations
      ii. Questioning the system: The system does not work
      iii. Primed for the future: Knowing what to expect moving forward
   c. Venturing into Different Health Systems
      i.   Taking back some control: "I decided…"
      ii. Rejecting western medicine approach: "I can heal myself…"
      iii. Pushing western medical system: "Listen…it's my health."
   d. Relationship to Medical System
      i.   Little Victories: "A-ha Moments"
      ii. Anger with Medical System: Fed Up
      iii. No Endpoint: Unanswered Questions

III. Agency in Meaning-Making
   a. Changes over Time: Lessons Learned
      i.   Learned So Much about Myself: Trusting Myself
      ii. Learned So Much about the System: Enlightenment, Not Detriment
   b. Reflections: I'm Not Alone
      i.   Other Women: We are Struggling, I am Struggling
   c. Reflections on Living with No Guaranteed Endpoint
      i.   Never Giving Up in Endless Circumstance

Appendix H: System of Uncertainty Examples

Brie

Cate

Danai

Gwen

Priming

Venturing

Believers

Learning the System

Doubters

Resisters

Liza

Priming

Venturing

Believers

Learning the System

Doubters

Burnouts

Persisters

Meg

Priming

Venturing

Believers

Learning the System

Doubters

Burnouts

Persisters

Resisters
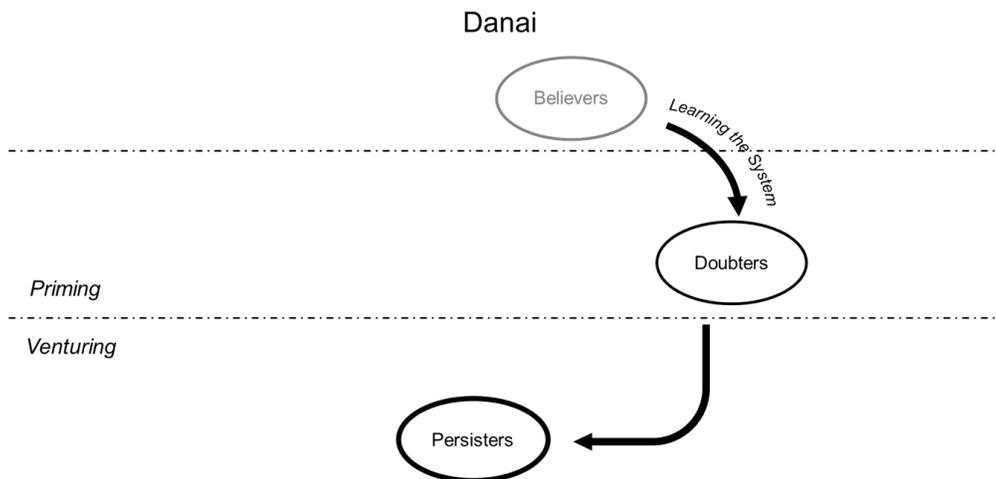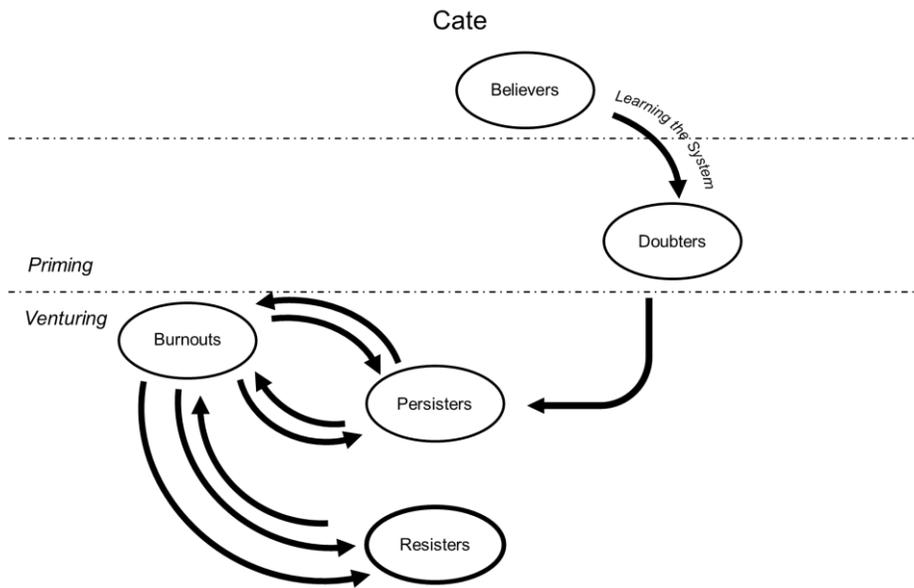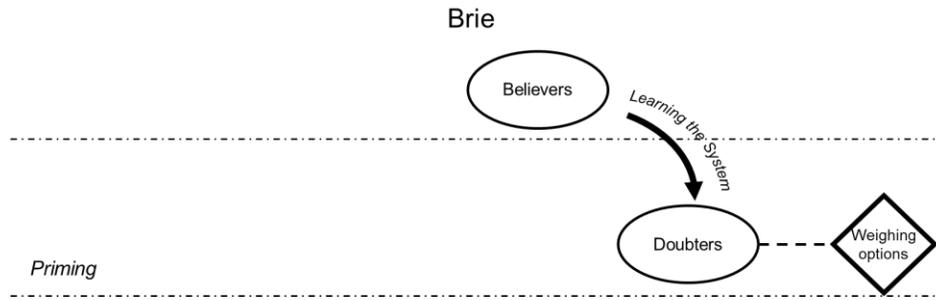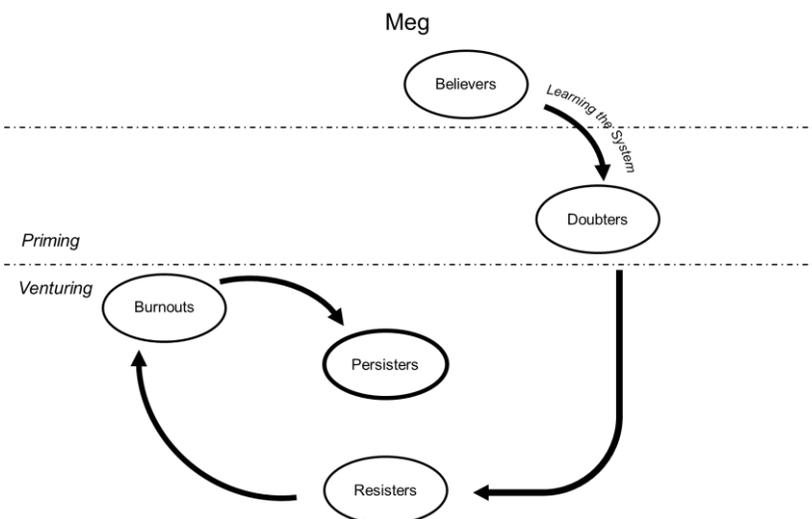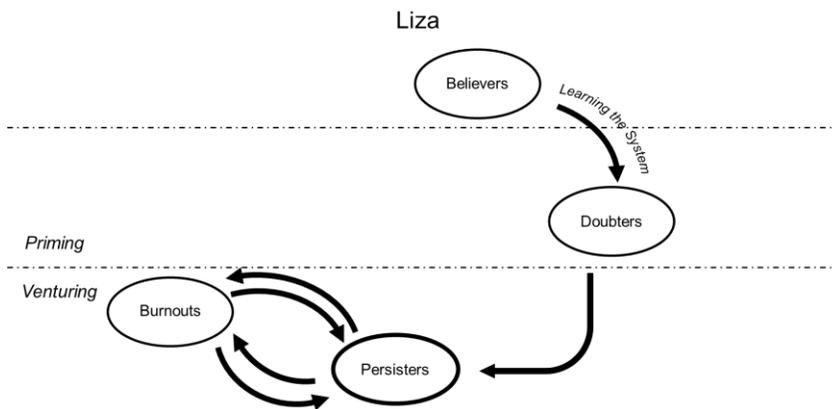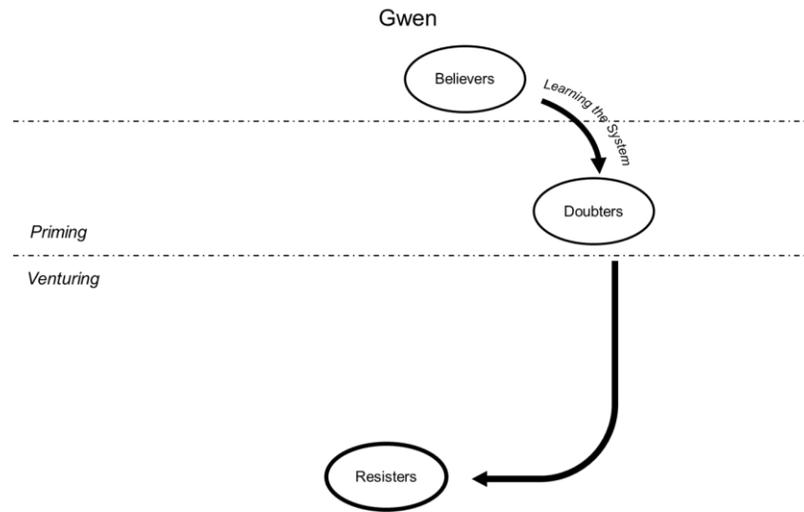
Appendix I: Additional Tables

Table 4

Participant Points in Time in System of Uncertainty Past and Present

Participant	Current Point (Doubter, Persister, Resister, Burnout)	Ventured (Yes/No)	Past Points in Time			Illness Certainty (Low to High)	Time with Symptoms (years)
			Persister	Resister	Burnout		
Alice	Doubter	No				Low	4
Brie	Doubter	No				High	3
Cate	Resister	Yes	✓	✓	✓	Low	15
Danai	Persister	Yes				Low	5
Evie	Burnout	Yes	✓			Low	3
Finn	Persister	Yes	✓			High	1
Gwen	Resister	Yes				High	8
Hazel	Resister	Yes			✓	Some	1
Ivy	Doubter	No				High	1
Jena	Persister	Yes	✓	✓	✓	Low	4
Kelsey	Burnout	Yes	✓		✓	Some	6
Liza	Persister	Yes	✓		✓	Low	12
Meg	Persister	Yes		✓	✓	High	5
Norah	Burnout	Yes	✓			Low	9
Piper	Persister	Yes				Some	3

Table 5

Participant Symptoms and Impact

Participant	Age at Onset	Onset Speed	Length of time (years)	Visited doctor[a]	Experience with doctors growing up	Psychological Impact (*Loss of…*)	Physical Impact		Financial Impact	Relational Impact
							Functional Limitation[b]	Visible Symptom[c]		
Alice	21	Set of events	4	Yes	Often	Reliable Health; Faith in Doc; Confidence	Mild			Yes
Brie	15	Set of events	8	Yes	Some	Reliable Health; Faith in Doc; Confidence	None	Yes	Yes	
Cate	31	Sudden	15	Yes	Rarely/Never	Reliable Health; Self; Faith in Doc	Moderate		Yes	Yes
Danai	26	Gradual	5	Yes	Some	Reliable Health; Self	Severe	Yes	Yes	Yes
Evie	21	Gradual	3	Yes	Some	Reliable Health; Self	Mild			Yes
Finn	24	Set of events	1	Yes	Rarely/Never	Reliable Health; Faith in Doc	Mild	Yes	Yes	Yes
Gwen	21	Sudden	8	Yes	Some	Reliable Health; Self	Mild		Yes	Yes
Hazel	24	Gradual	3		Some	Reliable Health; Confidence	None			Yes
Ivy	28	Gradual	1		Rarely/Never	Reliable Health	None			Yes
Jena	23	Sudden	4	Yes	Rarely/Never	Reliable Health; Self	Moderate		Yes	
Kelsey	21	Gradual	6	Yes	Some	Faith in Doc; Confidence	None	Yes		
Liza	21	Gradual	12	Yes	Rarely/Never	Reliable Health; Self; Faith in Doc; Confidence	Severe		Yes	Yes
Meg	29	Set of events	5	Yes	Rarely/Never	Reliable Health; Faith in Doc	Mild		Yes	
Norah	19	Sudden	9	Yes	Some	Reliable Health	Moderate			Yes
Piper	32	Sudden	3	Yes	Rarely/Never	Reliable Health; Self; Faith in Doc	Moderate			Yes

[a] denotes having gone to a doctor about current symptoms [b] denotes symptoms impair or impeded physical functioning such as mobility, impediment to daily functioning [c] denotes symptoms that provide visible display of illness (skin irritation, cough, hair loss)

Appendix J: Final Matrix

Connection of Research Purpose, Questions, Interviews, Findings, and Conclusions

Purpose	Research Questions	Interview Questions	Findings as Related to Theory			Conclusions
			Interaction	Agency	Context	
To explore illness uncertainty as experienced by women (aged 25 to 50) and their families To uncover the nuances of lived experiences	*Without a diagnosis, how do women and their families respond to illness uncertainty (i.e., make meaning out of interactions with symptoms and others)?*	Woman Interview 1, 2, 3, 4, 5, 6, 7, 8, 11, 12 Family Interview 1, 2, 3, 4, 5, 6, 7, 8, 9, 11	Complicated Learning the System Experiences with Doctors	Venturing into Health Systems Lessons Learned	Cultural Values Trust	Illness socially constructed Paradigm Shift on medical system
To examine illness uncertainty through a dialectical feminist ecological interactionist (FEI) approach	*What agentic processes do women enact in the midst of living without a diagnosis?*	Woman Interview 4, 5, 6, 10, 11, 12 Family Interview 6, 7, 8, 9, 10, 11	Reflections Beliefs	Rejecting Pushing Reflections	Cultural Expectations	Resisting Persisting Reframing of Experience
	What enables agency in the context of illness uncertainty?	Women Interview 5, 8, 9, 10, 11, 12 Family Interview 8, 9, 10, 11	Reflections Relationship to Medical System	Age, Race, Class	Role of Support	Time Resources Experiences Health