EXPERIENCES OF MOTHERS WITH INVISIBLE ILLNESSES

We the members of this committee have approved this

thesis On behalf of the

The University of Wisconsin- Superior

May 17, 2018
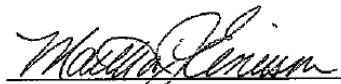
Coping mechanisms of mothers with invisible illnesses

Committee Members:

(signature)   5-17-18

Dr. Ephraim Nikoi   Date

(signature)   5-17-18

Dr. Martha Einerson   Date

(signature)   5-17-18

Dr. Chad Vollrath   Date

Table of Contents

<u>Abstract</u>

With research lacking in the area of mothers coping with invisible, chronic illnesses, this research explored the obstacles that mothers may face with an invisible illness, and how this may affect the everyday lives of these women. Issues that were faced included delegitimation of illness, self-doubt, caregiver fatigue, and mother guilt. Relations to the societal of expectations of mothers, what constitutes an illness, and women's health, are explored as well as topics for future research.

<u>Dedication</u>

For all the women out there struggling to find answers, you are not alone. It is not "just in your

head." You have a voice, and you deserve to be heard; you have been heard. You are enough.

<u>Acknowledgements</u>

Without the love, support, and motivation from my husband, Alex Koivisto, this research would not have been possible. He gives me confidence and reassurance that my words matter and they need to be heard. I cannot express enough gratitude to this man who encourages me to be better, and supports me on that journey. To a true partner, and a great father and role model to our children, I thank you.

I will forever be grateful to my fellow zebras who have comforted and supported me throughout my journey, and continue to do so. Without your experiences and determination, I would not have found the voice for this research.

I am truly indebted to Dr. Ephraim Nikoi for his guidance and support as a professor and a mentor. He gave me the motivation and tools to conduct this research and further my education.

Chapter 1

Introduction

In the fall of 2011, a 22-year-old mother of two began experiencing the following symptoms: dizziness/lightheadedness, vertigo, ear fullness/ringing, heart palpitations, chest pain, and numbness/tingling. This was the first time she had ever experienced these symptoms. The first trip to the emergency room entailed inquiring about caffeine/tobacco consumption and stress level, which led to a discharge with the assumption of a panic attack. The symptoms persisted for years and with this, multiple doctor's visits and hypotheses/diagnoses including endocarditis, allergies, migraines, depression, eustachian tube dysfunction, and generalized anxiety/panic disorder. The mother was told she was, "an overanxious mother looking for attention," and to, "perhaps have more children for your health." Despite the repeated disbelief and dismissive attitudes from medical professionals and loved ones, the mother continued to pursue a diagnosis, as nothing seemed to alleviate the symptoms.

After almost five years of searching, the diagnosis of dysautonomia was given. Dysautonomia International defines dysautonomia as:

> "[S]everal different medical conditions that cause a malfunction of the Autonomic Nervous System. The Autonomic Nervous System controls the 'automatic' functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils of the eye, kidney function, and temperature control. People living with various forms of dysautonomia have trouble regulating these systems, which can result in

lightheadedness, fainting, unstable blood pressure, abnormal heart rates,

malnutrition, and in severe cases, death" (2012).

The woman who experienced this, was me. I was repeatedly dismissed for being a

woman. For being a mother. It had to be anxiety. It had to be psychosomatic, not physical,

according to doctors. In my search for a diagnosis, I found an online support group with women

who shared my experiences, my struggles. This group introduced me to what is commonly

referred to as "invisible illnesses," and the experiences associated with being diagnosed and

living with such a diagnosis.

A variety of illnesses are categorized as "invisible illnesses" such as mental health

diagnoses including anxiety and depression, gastrointestinal issues such as irritable bowel

syndrome (IBS), chronic pain disorders like fibromyalgia, autonomic nervous system disorders

including dysautonomia, and more familiar disorders/diseases such as diabetes and hypertension.

What makes these ailments "invisible," are the lack of outward physical symptoms of

illness/disease and for many, the lack of traditional medical diagnostic tests (Masana, 2011). This

research focuses on the "not real" or "nonexistent" invisible illnesses that lack "legitimate"

medical diagnostic tests, not the "common" invisible illnesses including diabetes where typical

diagnostic tests exist.

In the United States, up to 90% of those diagnosed with fibromyalgia are female; along

with more than 70% diagnosed with irritable bowel syndrome (IBS), and the majority of those

diagnosed with chronic fatigue syndrome (CFS) are also women (PhRMA, 2011). The current

research regarding invisible illnesses does not specifically concentrate or investigate the relation

of sex to experiences in the process of diagnosis and coping with these conditions. This research

focuses on women with under recognized invisible illnesses such as dysutonomia and chronic fatigue syndrome where "delegitimization" is prevalent and the majority afflicted are female (Ware, 1992). Ware defines delegitimization as the trivialization of symptoms and/or the denial of any physical ailment at all, categorizing the ailment as psychosomatic rather than physical. Essentially, it is "all in their head."

In the United States, an estimated 85 percent of women under the age of 44 have children (Livingston, 2015). As the majority of those diagnosed with lesser-known invisible illnesses are female and more than half of the US female population become mothers, it is reasonable to consider that many of those living with an invisible illness are mothers. Motherhood is a status that affects every facet of a woman's life, including societal and personal expectations (Christopher, 2012). Research of mothers with invisible illnesses is extremely limited to new mothers with post-partum depression. While depression is categorized as an invisible illness, this is a very limited scope, neglecting several other areas of invisible illness. Due to insufficient research on women, specifically mothers, with invisible illnesses, further research evaluating how mothers cope with having an invisible illness may be beneficial. By examining personal narratives from mothers with invisible illnesses from across the globe, common themes and coping mechanisms are identified within this research. Specific focus is on the perception of support and reactions from self-identified support systems, the general public, and the healthcare community and how this impacts the role of being a mother.

Chapter 2

Literature Review

Literature regarding women, invisible illness, and misdiagnosis tends to be very difficult to find. Most articles focus on the impact of mothers raising children with invisible disabilities rather than focusing on the women themselves. For instance, "Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities" focuses on the woman's role as a mother and how the difficulties of the children impact the mothers psychologically and socially which lead to mother-blame and self-doubt. Though an important topic, this is not placing the lens on women, especially mothers, with an invisible illness.

Invisible illnesses include many illnesses such as mental illness, fibromyalgia, chronic fatigue syndrome, and several other ailments that are not seen with any outward physical signs. Many of these illnesses consist mainly of women as several diagnoses, such as chronic fatigue syndrome, are two to four times more likely for women than men (Chronic Fatigue Syndrome, 2014). Generalized Anxiety Disorder is most prevalent in women aged 45-59 years old in the United States (Hoge, Ivkovic, and Fricchione, 2012). Irritable Bowel Syndrome (IBS) consists of 70-90% of women (Johnson and Johnson, 2006). Despite these statistics, the focus of literature is not on women and these invisible illnesses.

Many articles that do focus on women with invisible illnesses primarily look at women with mental illness, most commonly depression (See Crocker & Shepard, 1999; Schlemer, 2006).

The literature on women and mental health goes back to the 19th century when the term "hysteria" was commonly used in the diagnosis of women. The term "hysteria" has now been replaced with "depression" and "anxiety" in modern literature, as referenced in previous articles,

though many of the conclusions are the same; women, especially mothers, can become burdened with their roles and become mentally distressed. Few articles include information of women being misdiagnosed with a psychological disorder that was in actuality a physical disorder. With this in mind, this literature review focuses on how women, specifically mothers, are being misdiagnosed with psychological disorders, and the factors contributing to this phenomenon.

Power

The concept of power is prevalent in many disciplines that utilize critical and feminist theory. While the traditional idea of power is physical, the ability to overtake someone/something with physical force, it is argued that the most impactful forms of power are from "broader systemic or constitutive conceptions of power – that is, those…systemically structuring possibilities for action, or, more strongly, as constituting actors and the social world in which they act" (Allen, 2016). This explanation grants that institutions such as churches, schools, and hospitals are major sources of power as was initially articulated by Michel Foucault. This type of power is enforced by these societal institutions that Foucault refers to as "disciplinary institutions" utilizing tactics such as surveillance, separatism, and laws (Fraser 1989, 24).

As stated, power in this context is not simply a physical manifestation of dominance, but a psychological tool to establish a hierarchy. This hierarchy can be seen within a home, a business, or any social group or organization. For women, it has been years of being placed as an "other" in relation to men as workers, citizens, and partners that has established an imbalance in power which is articulated and enforced with language, class exploitation, and the restriction of body (Allen, 2016). Some argue that it is with the consent of the less dominant, that power

exists and thrives: "Power is viewed as an attempt to overcome resistance that is already present. Power is viewed as a response to resistance or even a response to the response" (Fleming and Spicer, 2008). The power dynamic may not be physical, with the resistance being simple acts or mannerisms such as disregarding established seating, making decisions without input, or repeatedly questioning ideas and/or knowledge.

Power is multidimensional, ranging in application, appearances, and tools. Some argue that the more resistance, the more teamwork that occurs; the more dynamic the power-resistance relationship becomes; the more powerful the dominant party becomes (Crowley, Payne and Kennedy, 2013). This concept of power relations is seen in many articles concerning women and medicine (See Davies and McAlpine;1998 and Charney, 2002).

Statistically more men than women are medical professionals whether that is as a practicing diagnostician or as an educator (Hasser and Wilder, 2003). This means that men are the majority teaching the methods used in healthcare, as well as those utilizing these methods. Some medical studies that evaluate diseases experienced by both sexes are based on men, making women's experiences atypical (Mielke, Shields, and Broemeling, 2001). Men are the subjects for testing, determining the standards for tests, and the majority interpreting tests, giving men the power role in the medical experience for women.

Hoffmann and Tarzian (2002) found that, "Women who seek help are less likely than men to be taken seriously when they report pain and are less likely to have their pain adequately treated" (p 19). As to why this occurs, theories vary, and include biological differences in pain interpretation as well as proposed biases of the believability of women as patients.

Doctors are seen as experts, gaining a trust and dependence within society. In western medicine, objective evidence is relied on for diagnosis. In contrast, women may be deemed subjective in their reports to physicians. If a doctor does not recognize a person as ill, their expertise is what is relied on for verification (Ware, 1992).

In "Chronic Illness in Women: A Community Health Nursing Concern," a study was conducted concerning women who had been diagnosed with "ambiguous chronic illnesses" (Johnson and Johnson, 2006). Background was provided including why such illnesses were often dismissed as psychosomatic including that, "health care providers who are faced with symptoms that cannot be cured by biomedical technology are at a loss on how to proceed in caring for their patients" (Johnson and Johnson, 2006). This is an example of one type of power struggle that occurs for women with invisible illnesses. Medical professionals who are deemed "experts" do not want to relinquish such a title by acknowledging there may be areas of unknown. Patients who commonly did their own research and made suggestions to medical staff were often treated as hypochondriacs and their suggestions were dismissed. Rather than accepting the diagnoses, the women in the study sought out second, third, fourth, and even more medical opinions to have symptoms acknowledged as "real."

 Ware's (1992) work also focused on individuals diagnosed with an invisible illness, Chronic Fatigue Syndrome (CFS), who experienced power struggles with the medical community. Both men and women were included in this study though 80% consisted of women. The power struggle experienced for these individuals was not only to argue the definition of their ailment but also the soundness of their minds (Ware, 1992). This struggle was not only with medical practitioners but also with the patients themselves. As so many medical professionals

continuously pushed that the condition CFS was psychological, many of the patients began to

self-doubt: "I thought I was crazy. I thought I was a hypochondriac. There were things I didn't

want to tell the doctor because I thought he would think I was a fruitcake" (Ware, 1992, p. 352).

Patients began to struggle with a sense of self as so many aspects were being questioned by

medical professionals. It could be argued that these patients' integrity was being continually

questioned. These doubts led to internal struggles.

The last example of power emphasized was that of the male-dominance in medicine and

how this leads to different treatment and focus in regards to women's health. In the article

"Service and the Spin Cycle: Women's Health Outreach Project at a Laundromat," the

inequality of gender in medicine and medical education: "As of 1999, women constituted 45% of

medical students, 38% of residents, and 28% of medical faculty" (Hasser and Wilder, 2003, p.

160). This indicates that men are more likely to be practitioners as well as those teaching future

generations in medicine. The authors explain that medical school included inappropriate sexist

jokes when learning about feminine topics such as the female genitalia and "the more subtle

differential treatment of female patients, including minimizing women's symptoms and

misdiagnosis or less aggressive treatment for diseases in women" (Hasser and Wilder, 2003, p.

160). With these experiences, the authors decided to take part in a project geared at providing

information to women regarding proper healthcare as many women verbalized a distrust for

doctors and medical facilities because of past experiences. These efforts included educating

women on what institutions accepted lower-income forms of insurance (as women are more

likely to be economically impoverished), what facilities were low-cost for transportation and

time, and how to obtain medical insurance. All of this information was provided at a local

laundromat. This project sought to replace the lack of power many women felt in the doctor's

office, with the sense of power of being able to control one's medical decisions and family life.

Another common theme through all these articles was that of economic power. Women are

statistically more likely to be lacking in economic power. Mothers are even more susceptible as,

"mothers are in an especially vulnerable position due to their economic dependence on either

their husband or the state for assistance" (Davies and McAlpine, 1998, p. 370). This study also

illustrates the complex nature of healthcare accessibility for mothers.

Other articles, such as "The Psychosocial 'Diagnosis' of Depression in Mothers: an

Exploration and Analysis" focused on women involved in child and family care social work.

This article emphasized the skepticism of diagnostic tools of depression in the medical

community as, "Many social workers, particularly those influenced by feminist ideas, retain

suspicion of the association of the term 'depression' with medical ideology" (Crocker and

Sheppard, 1999, p. 603). Some view these tools as a form of women's oppression as men

dominate the medical field and the history of women's health including past diagnoses such as

hysteria and green sickness. The article mentions that there is some belief that women are only

diagnosed with depression if they do not portray female stereotypes therefore not being deemed

mentally healthy.

Delegitimization and Trivialization

Several studies included findings that many women who experience invisible illness are

often questioned in terms of truthfulness and whether their complaints were indeed legitimate. In

Ware's (1992) study, patients described that the journey to a proper diagnosis was long and

mentally exhausting because of the constant disbelief from friends, family, and medical

professionals: "Of the various forms of suffering that experiences of delegitimization can

engender, none was devastating for this group as the humiliation that resulted from having their

subjective perceptions and sensations of illness either trivialized or dismissed as psychosomatic"

(Ware, 1992, p. 353).   This trivialization of symptoms led many to not be diagnosed for many

years or to even cause the patients to question their own mentality and whether they were in fact

experiencing physical symptoms. For those medical professionals who did believe that patients

were experiencing symptoms, they were often minimized with comments that included: "Well

jeez, a lot of people are tired…I'm tired and I go to work," "I'm tired too," and "I've had sore

throats and I've been nauseous. So" (Ware, 1992, p. 350)? Even when individuals did claim to

believe symptoms, patients were still criticized for their level of importance. This idea of

delegitimization is related to the issue of power discussed prior but should be addressed

separately as it could be considered a tool in the struggle for power.

Men are also victims of such treatment with invisible illnesses but, "More common in

women, symptoms of ambiguous chronic illnesses are often feminized, trivialized, and dismissed

by health care providers as psychosomatic in origin" (Johnson and Johnson, 2006, p. 161). This

is what the researchers found in their study of patients diagnosed with several types of physical

invisible illnesses in the article, Johnson and Johnson, (2006), identified 80% of the patients in

their study as women who reported encounters with physicians that questioned the legitimacy of

their illness by either misdiagnosing the women with psychosomatic disorders or the blatant

disbelief of symptoms reported. If patients were not directly told that their symptoms were

unbelievable, "interviewees indicated that because they experienced fatigue, aches, pains, and

feelings of depression, their symptoms were viewed as the result of everyday living" (Johnson

and Johnson, 2006, p. 161). Once again, symptoms were minimized for these patients if not

dismissed altogether.

Other studies did not directly focus on invisible illnesses but women's health, still noted that women felt that they were treated disrespectfully in health care facilities which led to a distrust in the medical community as a whole. Because of this, women were not receiving proper healthcare due to a variety of reasons of which included either not pursuing healthcare at all or not having the means to travel to an institution that the women deemed more ideal (Hasser and Wilder, 2003).

Delegitimization was not just associated with the symptoms of women as patients, but the roles of women in society as a whole. One article, "The Relationship Between Sex Roles, Marital Status, and Mental Illness," looked at how the role of a woman as a wife, mother, and employee impacted mental health. The author did use language that delegitimizes the role of a woman as a housewife, "for virtually all women, whether educated or not, seem to be capable of being at least moderately competent housewives" (Gove, 1972, p. 34). This article argued that women who were employed outside of the home were less likely to become mentally ill as their responsibilities became more diverse and rewarding. This idea was based on the statistics provided that married women were more likely to struggle with mental illness than single, widowed, or divorced women. Being a mother and housewife was simply not enough as, "women are also less likely than men to get satisfaction out of being a parent" (Gove, 1972, p. 35). The article concludes that the three plausible explanations as to why women are more susceptible to mental illness includes biology, generalized sex roles, and gender roles in society. These seem to almost delegitimatize women's lifestyles as a whole.

Self-Doubt

One of the most prevalent themes found in the literature regarding women and mental illness was that concerning self-doubt. "The struggle to legitimately define their conditions leads many participants to self-doubt. Ultimately, they retreat into secrecy and experience alienation, humiliation and depression" (Johnson and Johnson, 2006, p. 161). Johnson and Johnson argue that the trivialization of symptoms and misdiagnosis of mental disorders is what actually leads to psychological symptoms such as depression and anxiety. Participants began feeling hopelessness as multiple physicians would suggest psychosomatic causes, undergo multiple diagnostic procedures with no answers, and experience skepticism from not only the medical community but from family and friends. Because of this, many participants would "suffer in silence" (Johnson and Johnson, 2006, p. 162). Patients would be complacent for a time accepting the psychological diagnosis for a period before seeking other medical professionals or alternative forms of medicine to explain their symptoms.

Other articles such as "Suffering and the Social Construction of Illness: The Delegitimization of Illness Experience in Chronic Fatigue Syndrome," reported similar results: "In explaining their reasons for choosing secrecy, study participants cited the awkwardness and embarrassment of trying to explain to someone that they have a an illness whose symptoms are ill-defined, that has no 'real' name or known cause" (Ware, 1992, p. 353). This was for the individuals who had been diagnosed with the proper invisible illness but still struggled with self-doubt because of society's perception of illness as visible and measurable with diagnostic tools such as blood tests and x-rays. If these individuals did not meet the criteria of a true illness could they possibly not be sick? This led many patients to question whether psychological diagnoses

were in fact correct. Some individuals began describing symptoms as cognitive rather than psychological to reinforce their beliefs that they were in fact experiencing physical symptoms even if they did not appear on diagnostic tests. This self-doubt was not only developed from the medical community but from society as a whole. One who does not look sick cannot be sick.

Critique

Though all of the articles included in this chapter discussed women and mental health, there was very little focus on mothers specifically. Some of the studies did not even specifically look at women though they did comprise of the majority of the sample. Those studies that did focus on only women were primarily trying to focus on the susceptibility of mental illness and did not question the reliability of diagnoses.

Davies and McAlpine (1998) did not even focus on mental health but "mental distress." Though the study did include measurements used in determining depression, it was never explained whether the women included in the article were in fact diagnosed with mental illnesses. Hasser and Wilder (2003) focused on women as well but did not limit to mental health but to all healthcare for women. Many researchers found that women are distrustful of doctors, but it was not limited to only those women who had been diagnosed with mental illness or other invisible illnesses.

Gove (1972) did focus on women with mental illness trying to determine if marital status played a role in the susceptibility to mental illness. This study found that while married women were diagnosed with mental illness more than men, all other marital statuses, single, widowed, and divorced, indicated that men were more susceptible to mental illness. Gove explained that this discrepancy is most likely due to the roles of housewives and how powerless and

unsatisfactory this role was for women. There is no tangible evidence that suggests this other

than the words of the author. Also, there is no information regarding mothers in this article.

Were all housewives susceptible or were stay-at-home mothers diagnosed more frequently? The

author assumes that most, if not all housewives are mothers. This article is relatively dated but

Gove's research is cited in many of the other articles supporting the relevance and importance of

the studies in relation to women and mental health. Gove never questions the validity of

diagnoses of women with mental illness, but simply states that they are more susceptible and

diagnosed more frequently. This can be explained by biology or societal roles; however, it is not

explored whether these roles are universal to all women from varying backgrounds such as

differing socioeconomic statuses, ethnicity, or country of origin. Gove states that, "some

characteristic of the woman's generalized sex role that makes women more susceptible to the

mental illness, or at least more susceptible to the appearance of mental illness" (Gove, 1972, p.

42). This does allude to the suspicion of misdiagnosis, though Gove never explores it further in

this study. With this, are the women included in this study accurately diagnosed with a mental

illness? Also, was the rate of diagnosis the same for those across race and socioeconomic status?

In comparison to Gove's (1972) research, Crocker and Sheppard (1999) measured that

"mental distress" was more in single mothers. This could be because the majority of the sample

in Crocker and Sheppard's research was single women since women are more likely to utilize

social services when unmarried. Other explanations for this discrepancy could be the time lapse

between studies or the fact that one was conducted in the United States and the other was

completed in Great Britain. A more sinister explanation could be that marital status plays more

of a role in medical diagnosis introducing a new bias beyond sex.

For those articles that did focus specifically on the misdiagnosis of women with mental illness, there was a lot of focus on the "how" of the process but not necessarily the "why." In Johnson and Johnson's (2006) article, misdiagnosis was determined to be mainly due to the lack of support in the medical community for chronic invisible illnesses that are difficult to define and diagnosis. It was mentioned that these illnesses are comprised mainly of women but it was never explained as to the hypothesis of why this is or if it is in fact significant. There was also no indication of how many women are believed to have been misdiagnosed with a mental disorder and then later diagnosed with a physical illness. Johnson and Johnson (2006) did report that many individuals with chronic invisible illnesses do experience depression so perhaps this is indicated that misdiagnosis is not the correct hypothesis but rather that depression should be considered a symptom more so than a diagnosis? The authors did not indicate whether other mental illnesses such as anxiety were also commonly present in individuals with chronic illnesses. There was also no mention of marital status in this study to either deny or confirm whether marital status played a role in misdiagnosis.

Two studies did specifically look at mothers, one from Davies and McAlpine (1998) and the other by Crocker and Sheppard (1999). Neither of these studies were conducted in the United States, one was in Britain and the other in Canada. This becomes problematic as medical diagnoses standards are different in each country as well as the system that is used for healthcare. Crocker and Sheppard (1999) noted that the diagnostic tools for depression in Britain appear to be biased towards women, as it also does in the United States. Once again, there is no mention whether this bias is more towards mothers than non-mothers.

Interestingly, several of these articles addressed that the majority of those women involved were white. Very few patients and participants were minorities. The lack of demographic diversity in these studies potentially obscures the ways these issues may intersect with race and/or class (Allen, 2011).   Many of the studies did not indicate age, race, or marital status of the participants. For those that did indicate, the ages of women varied significantly from 18-60 years old. This suggests that many of these women could also be potential mothers and be married though the majority of studies did not provide such information. None of the studies did a comparison of mothers to non-mothers. With the lack of research focused on mothers, the questions arise:

RQ 1: What are the impacts of invisible, chronic illnesses on mothers?

RQ 2: How do these women cope with having this illness(es) in their everyday lives?

These are the questions this study seeks to answer.

Chapter 3

Methods

To gather honest, open thoughts and feelings from participants, an online ethnographic approach was used within an online forum where I am not only a researcher, but also a member. Qualitative and quantitative research was conducted by collecting information utilizing a Qualtrics Survey containing 18 questions; eight are multiple choice and 10 are open-ended questions that individuals answered in an essay format.

Online or internet ethnomethodology is a relatively new approach of qualitative research conducted via the internet, utilizing both online and offline resources. This method focuses on not just the written responses of the participants, but also the information surrounding them such as the organized support group, to tell stories of social communities (Lindlof and Taylor, 2011). This survey was administered to an online Facebook forum for individuals with POTS (Postural Orthostatic Tachycardia Syndrome) and other forms of Dysautonomia. Additional IRB approval was pursued and approved by Dysautonomia International, a non-profit organization established to assist in the education and support of dysautonomia. This organization advertised and dispersed the survey. Gaining this additional layer of approval ensured integrity and increased the rate of responses due to the reputation and rapport the organization has with its members.

Conducting research online created its own layers of complexity, as individuals were able to participate at great distance where face-to-face research may not have been possible. How individuals respond and convey emotion differs online as well (Sade-Beck, 2004). The benefit of conducting research via a web questionnaire/survey has cost-savings associated with the research, as members were able to participate from different time zones, countries, and varying

abilities, which would not be possible without this methodology; however, access to technology

is stratified by class, race, and gender. Though it is also typical for online surveys/questionnaires

to have lower rates of completion than paper formats, the global capabilities and ease of use

more than justify the method (Murthy, 2008).The purpose of analyzing women's experiences in

this particular group was to identify common themes of mothers coping with invisible chronic

illnesses. Using online ethnography was beneficial as individuals from across the world can be

assessed allowing for a more diverse population. No identifiable information was collected or

published.

As I am also a member of this online community, this research is considered insider-

research. I was in a unique position where I have been an active member for approximately two

years prior to the study of this community. It is argued that my involvement and special

knowledge encompasses more passion and commitment (Saidin and Yaacob, 2016). While this

poses several positives including understanding the group, not altering the dynamics of the

group, and having established relationships within the group, there are possible negatives to

being an insider-researcher. Being a member of the group imposes a possibility of losing

objectivity and inferring external biases not related to the research collected. One challenge may

also be balancing the role of member and researcher (Unluer, 2012); however, I argue that my

dual role as a member and a researcher are intertwined and inseparable, providing me with more

understanding and motivation to conduct this research. Though I must be conscious of my

possible biases and be diligent in the review of survey responses to ensure that key concepts and

themes are not overlooked or misinterpreted based on personal knowledge and experiences,

every researcher must strive for this regardless of being an insider-researcher. My membership

and insider knowledge are an asset to this research.

Participants

All of the participants of this data collection were members of Facebook communities designated for individuals with various chronic invisible illnesses such as Ehlers-Danlos Syndrome, Dysautonomia, depression, and anxiety. This forum is an international forum focused on those with Postural Orthostatic Tachycardia Syndrome (POTS). Membership is not biased based on age or sex which means that both men and women are members though this research focused on the women of the forums, specifically those who are mothers. The majority of members of both forums are women as is characteristic of many of the invisible illnesses experienced by members.

There were approximately 15,000 members in this online forum internationally at the time the survey was dispensed. Membership does not denote having an invisible illness as family members and those not yet diagnosed may be members. As stated, members are also men, children under the age of 18, and women who are not mothers. Due to this, an estimated possible 7,000 members fulfill the criteria for the purposes of this survey. To limit responses, the survey was only accessible for one week. Participants self-identified and completed the survey voluntarily. Participants and members of the forum also dispersed this online survey via Facebook which possibly increased the rate of response, an unforeseen occurrence. This along with the reaching aspects of the survey, most likely increased the variety of respondents (Murthy, 2008).

Since the majority of those afflicted with these illnesses are women, it is beneficial to investigate coping mechanisms and other common themes. Focusing on mothers is important as

there are very few studies that distinguish mothers from non-mothers. Motherhood affects all

aspects of life including work, social, emotional, and health. Based on the information gathered

from this survey, an investigation as to what themes may be prevalent for mother-members that

are not as impactful to non-mothers.

Collection of Data

In collaboration with Dysautonomia International, a survey was dispensed to an online

Facebook forum utilizing the Qualtrics Tool. This survey was available November 8, 2016 to

November 17, 2016 via a web link to a developed Qualtirx survey. Individuals were able to only

submit one survey per IP address verification. Unfinished surveys were stored through the

response period but were purged upon the survey end date. No identifiable information was

collected, only the IP address was recorded from which the survey was submitted. This means

only general location of where the survey was taken was recorded. 597 individuals responded to

the survey. Quantitative data was collected utilizing the first eight questions of the survey which

were multiple choice. These questions were demographic including age, marital status,

employment status, race/ethnicity, years to primary diagnosis, years since diagnosis, the number

of children they are a caregiver to, and the age of those children. The remaining 10 questions

were open-ended questions that were answered in an essay-style format. These questions

gathered qualitative data including support system structures, perceptions of these systems, and

the perceived challenges that mothers with invisible illnesses face. No transcription was

necessary as all responses were converted to a Microsoft Word document utilizing Qualtrix. All

the survey responses were reviewed to identify common themes and/or questions used by

mothers coping with invisible chronic illnesses.

Of those 597 submitted surveys, 471 were utilized for analysis as these surveys were completed entirely or only had one unanswered question. With this, 206 pages of quantitative and qualitative data was received and analyzed.

The process of analysis included converting the Qualtrix survey material into a word document for ease of data manipulation. Quantitative data was provided in the form of bar graphs. Qualitative data was dispensed as word text onto the word document. First a word count tool was used to determine the frequency of words used in responses. This was the gateway into the common themes.

Since the qualitative data were all essay type answers ranging in length from a single word to several sentences, all of the responses were individually read and cataloged based on the content in relation to the question that was asked. Determining the high frequency words, these were used in recognizing key passages and themes in this analysis. This utilized grounded theory which is relied on within the social sciences. Grounded theory creates order within a seemingly "messy" group of data by evaluating coded themes and interpreting the relation of these occurrences of "codes" to one another (Lindlof and Taylor, 2011). This was the basis of analysis for this research based on the answers provided in the open-text answers.

 Ethics

This forum is a closed group which means that membership is only granted with approval from the online administrators. Because of this, the privacy of all members was protected by not collecting identifiable information. Utilizing the Qualtrics tool, all data was collected and stored anonymously. This data is only accessible from campus computers using UW-Superior credentials as well. Participants disclosed health and family issues which may be distressing

which is why anonymity is vital. Because of this, pseudonyms were given to all women whose

responses were cited within the final research results. Research approval was granted from the

administrators of the online Facebook forum as well as Dysautonomia International. As approval

was granted from the administrators and Dysautonomia International, I self-identified in the

group explaining my research, and all identifiable information will be withheld, informed

consent is not required for this research.

Conducting online ethnographic research, the issue of conducting "covert research" or

"lurking" does arise. To avoid this, I self-identified my dual roles in the group as both a member

and a researcher (Murthy, 2008). The research was transparent and accessible to all members in

the online group. Participation was voluntary, with no information regarding the participants

from outside the online survey identified or utilized

Chapter 4

Results

Though respondents expressed themselves differently, many indicated shared experiences of feeling misunderstood by professionals and loved ones despite having a diagnosis. With this, many of the women described hiding their illness/symptoms for a variety of reasons which led to a seeming self-induced isolation, while attempting to maintain a façade of a "normal" life. The attempt to appear healthy and fulfill personal expectations contributed to greater fatigue and stress on the family. Mothers also emphasized a sense of loss of identity and previous life prior to diagnosis. Reasons behind this include feeling misunderstood and/or delegitimized.

"A Lack of Understanding"

The idea of "understanding" is very evident throughout respondents' answers. There are those who indicate that the understanding of their support system and others makes coping easier: "I have a very understanding family. My daughter cleans for me when I am unable to myself. My husband never gets mad or upset when I feel bad, which is often" (Faith).

Support systems varied but spouses or partners were the most depended on by the respondents. It was when there was understanding from all of these primary caregivers that there was a more positive tone throughout the responses.

"My husband is completely amazing now that we understand what is going on with me. He supports in every possible way. My mom is also a huge support emotionally and helps out with the kids when I'm having really bad days" (Kelly).

The husbands, mothers, siblings, children, friends, and coworkers of those diagnosed serve as their "rocks" helping with both physical and emotional support. Though many women mentioned that they were not entirely understood, they felt that individuals made the effort to understand through questions and education:

> "I feel like I have support from them, and that they try to understand what they can about dysautonomia but cannot fully know" (Lauryn,).

> "My husband is my rock. It's not an easy thing being a caretaker but he does an amazing job. It's hard for others outside your home to really know your difficulties. They see the few minutes of fun but not the days after of recovery. They are good supporters but it's not always easy to understand" (Patty).

This validation from support networks created a sense of hope and positivity for these women. Though some women did not necessarily believe that their support system or the public understood their struggles entirely, the women still indicated that they felt supported and that people attempted to understand and empathize.

This population of women was however in the minority. The majority of women indicated a lack of understanding by family, friends, the public as well as the medical community. Respondents indicated that this lack of understanding was because of a variety of reasons such as appearances: "They [support system] are sympathetic, but don't fully understand how I can look 'normal' and yet be so sick" (Adele). Some women felt a lack of attempting to understand entirely: "My partner often tells me 'I get dizzy too….I get tired also…suck it up…'" (Reba). Respondents indicated that, "There's almost no support and understanding," "There is little understanding and support for POTS," and that, "No one truly understands the struggle of

an invisible illness."   The lack of understanding, once indicated, carried through the majority of

the survey answers. If a mother felt misunderstood from her support system, it was likely that

she also felt misunderstood by the public and the medical community. The lack of understanding

was described in interactions with other parents, their children's education professionals, co-

workers, family, and friends.

Other school parents were described as commonly conveying a lack of understanding of

invisible illnesses. This was described in interactions at school pick-up, extracurricular

activities, and the park. Some respondents described difficulty with school professionals in

relation to arranging meetings, being unable to volunteer for the classroom or field trips, or

having disability accommodations for parking or seating at special events.

Many of the mothers responded that one of their biggest challenges as parents with an

invisible illness was the lack of understanding from society or "normals," a term used by some in

responses. Rather than being perceived as ill, mothers felt that others in society perceived them

as having substance abuse issues or being "lazy":

> "I have had nasty looks and comments from other parents in the playground at school
>
> pick-up. I have also had people assuming I am drunk when I faint" (Tori).

> "I have been accused of being drunk. I look like a staggering crazy homeless person
>
> sometimes in public and I know it. I used to be well off and good looking, so it is extra
>
> painful" (Tracy).

Another participant responded:

"They usually think I am on drugs or drinking. I have passed out in a store and people

cursed and stepped over me" (Regina).

With another stating:

"They wonder what could possibly wrong because I look so 'normal.' I get judged a lot.

I think people think I am lazy" (Erykah).

The lack of understanding from several aspects of their lives is indicated as being a

primary reason for isolation. There is no embarrassment or misunderstanding if there is no

interaction.

"Hideaway"

In relation to the lack of understanding from support systems and others, mothers

indicated that this led to "hiding" their illness. For many this meant isolating themselves from

the world to avoid judgement and embarrassment. For the majority this meant simply hiding

symptoms so as to not appear ill or "drunk." The act of hiding was described as being for many

reasons including avoiding the stigma of mental illness:

"While I was raising my children I tried to hide my illness as much as possible. My

illness was unfortunately thought to be psychological so I felt forced to hide my illness.

This left not much support outside of God in regards to emotional support for my illness"

(Whitney).

For others it was simply a method to avoid the frustrations of "defending" their

behaviors:

"I hide my symptoms as I don't think people understand and don't want to listen to me

moaning. I've previously been described as lazy or lucky if I've spent a day in bed. If I'm

ill I can't be bothered defending myself, so I'd rather just not tell people" (Bonnie).

Others described avoiding simply explaining their illness:

"I am very careful not to share how I feel in public. It's a very complicated illness and is

more frustrating to share than not" (Gillian).

While the majority of women stated that they hid their symptoms to benefit themselves,

others indicated that the act of hiding their illness was to protect those around them from worry

or from being considered a burden:

"My mom is a worrier and over protective and thinks I'm going to die every time

something is out of sorts so I hide a lot from her" (Toni).

"The parents get overly stressed and concerned. So I try to keep really bad days hidden

from them now" (Roberta).

With this emotional isolation, mothers indicated that this made them feel sad and lonely.

Whether it is to avoid worrying a family member or appearing abnormal in public, mothers did

not want to appear ill:

"I hide it well. Everyone comments how well I look, truly having no idea how awful I

feel. How sad I am that I am no longer who I used to be and how left behind I feel"

(Gretchen).

For some women, the reason for hiding their illness was much more vital, indicating the

possible loss of a job: "I do everything I can to hide it so I won't lose my job." Many women,

over 36 percent who responded to the survey, did indicate that they were unable to work or

disabled, but for those who were still employed, financial strains were mentioned emphasizing

the importance of their employment.

Whether the act of hiding their illness is to protect their job, their family, their sanity, or

their pride, the majority of mothers indicated it was a part of their life. If simply hiding their

symptoms did not suffice, some mothers resorted to physical isolation.

"I'm So Tired"

Throughout responses evidence of what is referred to as "caregiver fatigue" or "caregiver

burnout" was described. Caregiver fatigue or burnout is often associated with depression,

exhaustion, anger, and other physical and psychological impacts from being the primary

caregiver for an individual with an illness (Rodham, Rance, and Blake, 2010). Mothers indicated

that their partners, family, and friends experienced this fatigue:

> "My husband is pretty supportive, but gets very frustrated and stressed at the
>
> same time. He has a hard time understanding everything that's happening and how
>
> it effects young people and I constantly feel a burden to him as if I'm tying him
>
> down" (Aimee).

> "He does the best he can. But it's so much work for him. He is always tired,
>
> depressed and now has panic attacks. We have very little else for support
>
> systems" (Dar).

Respondents shared their thoughts as to their understanding of the causes of this fatigue which ranged from additional responsibilities at home including chores and taking care of the children, the financial implications of having a single income, the worry associated with having a family member with a chronic illness, as well as the lack of understanding associated with many invisible illnesses. These stresses not only impact the caregivers but also the entire family unit. Additional relationship stresses mean changes to the dynamic of the family:

> "I am grateful that I have them [support system], but even with their support it's still hard to cope and even though they all understand my health issues, they can get fed up at times when I need a lot of help. My husband would help more but, as I can't work due to my health, he has a high-pressure, long-hours job in order to bring in enough money to support the family. As a result of the above I often push myself too far, instead of asking for help. The end result being I then collapse and need even more help. I know this, but still end up doing it, as it's so hard for me to be constantly asking for help and begging favours off people" (Alicia).

With these changes in responsibilities, social changes are also evident. Mothers indicated caregivers experienced inconveniences in association with being relied on by the respondent. Less personal time and changes in schedules were cited as being common stressors for the caregivers as, "They are understanding and will help me through the symptoms. However, they have moments of impatience and intolerance of my symptoms because it interferes with daily life and scheduled activities" (Amy). With these reactions of their caregivers, many mothers described feeling guilty or being a burden to their family and friends.

"Burden of Tomorrow"

Asking for help was mentioned throughout responses; however, for many it was strictly

for necessity and with the request a sense of guilt was paired with it. Mothers stated that with the

additional help needed due to their illness, they felt guilty and more a burden than a contributing

member of their network. Partners were a key focus for respondents who were indicated as

being one of the most impacted. Many partners were attributed with being the primary income,

the primary caregiver for the respondent, as well as obtaining additional responsibilities at home

including household chores. The primary feeling emphasized was that of guilt:

> "My husband does much more than he should. I hate that he has to work full time
>
> AND take care of me AND our daughter. I feel very guilty that it's all placed on
>
> him" (Missy).

Personal expectations were described as not being met and a primary cause for guilt.

Respondents cannot be the partner, wife, employee, or friend that they once were or believe they

should be. Whether the mother self-identified as disabled or unable to work, all areas of

respondents mentioned feeling less productive than they wished, especially at home and in child

rearing.

With the guilt of having more responsibilities placed on their support system, a sense of

being a bad mother or partner was also articulated:

> "I have a lot of guilt around not being able to be as good a mother and wife as I
>
> would like to and indeed used to be and know I should probably try and sources

some counselling, but equally know how little there is available in the UK"

(Laura).

Many respondents discussed this "mother guilt" when asked specifically about their children and how their illness impacts them. Mothers described feeling less of a mother because of their illness due to physical restrictions which impacted play time with their children, caregiving, chores, school, and extracurricular activities:

"Not feeling able to do everything that is 'expected' of a mom of a teenager. Feeling guilty that I am letting others down when I am physically and mentally exhausted" (Ani).

"Not being able to have my kids do the activities they want to do, dealing with guilt over my limitations, dealing with guilt over the cost this had on my kids, trying to figure out how to be a parent when most of what I did in that role is now impossible for me to do" (Cat).

Other mothers such as Miranda indicated having guilt over adding additional stresses to a child's life that are associated with having an ill mother: "I feel terribly guilty that I can't do everything he deserves me to do for him. I don't want him to share the burden or fear of having a sick mother. I wish I could take it all away from him." With this, mothers stated not discussing their condition with their children and isolating themselves further.

Respondents indicated guilt as one of their biggest obstacles:

"The biggest challenge I face is guilt. I always feel guilty that I'm not being the mom that I could be and want to be because my illness will prevent it. I have to

remind myself that it's okay to ask for help. I have to remind myself that I am

being the best mom that I can be and ultimately loving my child is the best gift I

can give him" (Judee).

Guilt is mentioned in all aspects of the mothers' lives including their social, professional,

and personal relationships. Their illness was referenced as impacting all areas of their lives

causing guilt for many different reasons though the most emphasized was that of not being the

parent that they believe they should be. With this guilt, a worry of not being present for their

children's lives was also a very voiced concern and point of guilt. Because of this, mothers

indicated trying to continue their lives as "normal" as possible.

"Lead a Normal Life"

Being a "normal" mother was of great concern for the majority of respondents. The

restrictions that their illness placed on them are described as being challenged by many mothers.

Though these women are diagnosed with invisible illnesses, all with varying degrees, most

described having to continue on with life as if there was no illness or restrictions:

"I try to act as normal as possible when I am together with my children and I do

not take a lot to them about being ill. I try to make it look like a normal family as

much as possible. For instance I rest when they are i school so I can be there for

them when they come home" (Beth).

Some mothers discussed their illness with their children while others did not for this very

rationale; wanting to appear "normal" and not having a negative impact on their lives.

With this, respondents indicated repercussions from appearing "normal" and living up to those expectations:

> "A lot of the time I use all of my 'spoons' to take care of my son's needs which leaves me with few to none for my own needs. I would gladly give them all to him every day, but it does make things challenging. I don't want him to share the burden of my illness, so I often fake being 'well' since he is too young to understand what is happening. This takes an extreme toll on me mentally and physically. There are days where I can barely get out of bed, but as a mom I never get days off" (Sarah).

These mothers explained that they will push themselves for a variety of reasons with the primary being to appear "normal" as is expected by those around them or because being a mother, there is no other option, especially as a single parent:

> "As a Mother... you do not want your children to see you ill. You do not want them to have to support you because you're meant to be the strong one. It's really difficult to admit that you need to lean on them that's the hardest thing and I haven't managed to do it yet in over 15 years. I still pretend that I'm normal and force myself to work full-time even though I'm exhausted. It's very rare I let them know I'm really unwell. Over the years I've managed to conceal my symptoms extremely well" (KD).

Many stated that a mother's duty is continuous regardless of illness:

"I grin and bear it. I have children, a house to run, and homeschool to teach. I

don't have time to fall apart or take care of myself. It's frustrating, but maybe a

blessing that I don't have time to think about it" (Allison).

This idea of having to push through their illness and maintain "normalcy" was iterated by many

of the mothers throughout the survey. Because of these expectations, many women explained

their reflection and perception on their current circumstances being in such a pivotal position as a

mother:

"Mothers in general are often undervalued by society, you are expected to be able

to do every single job/task that comes your way and still be smiling happy, loving

and take on even more. When you have a hidden disability and cannot do

absolutely everything you are judged harshly, not only by strangers, but

sometimes by your own family and definitely by yourself. You feel like nothing

you do is ever enough and that you fail at everything you try, but you have to

keep getting up and getting on with it, because ultimately your kids need you and

it's your job to be there for them" (Shania).

"Do You Know Who I Am?"

Throughout the responses, the women grieved the loss of who they once were or who

they thought they should be. This loss of self and identity grew more evident throughout the

survey:

"Before I got sick, I was always smiling and laughing and being my normal goofy

self. It's disheartening because I feel like I am always grieving the loss of who I

used to be. Even when it seems too much to bare, find something to pull you

through. Do not give up" (Taylor).

"Everyone comments how well I look, truly having no idea how awful I feel.

How sad I am that I am no longer who I used to be and how left behind I feel"

(Sade).

With this reflection of their identity, many women acknowledged that their illness

changed not only them but also those around them. Though their illness is physically tied to

them, their illness has effects that reach far and wide:

"It's been a journey for me to accept my illness, loss of my job, and loss of who I

used to be. My support network has had to accept these changes as well. We all

don't get there overnight. It's a process for all of us" (Emmylou).

Though the research on mothers with invisible illnesses is lacking, this does not indicate

the lack of necessity in this particular area. After surveying over 450 mothers globally who self-

identified as having an invisible illness, it is evident that the research of women in correlation to

invisible illnesses, including mental illnesses, though related, does not represent the unique

experience that mothers face who are also chronically ill with an invisible illness. Not only does

this research indicate a lack of representation for these women in existing research, but it also

identifies key societal concepts and expectations that are not addressed in other research based

around women with invisible illnesses.

Many roles were changed because of invisible illness. Mothers who are traditionally caretakers are now those who are being taken care of by their partners and children. With this shift in responsibilities and dependability, the sense of being a mother and wife is questioned.

Chapter 5

Discussion

Respondents varied in age, race, nationality, and abilities, but many ideas were shared by these women through their responses. These women repeatedly articulated being delegitimized as ill by doctors, loved ones, and the public. Many described sensing disbelief in all aspects of their lives frequently. With this, respondents expressed a loss of self, questioning their own bodies and illnesses.   Even those who described healthy support systems, these feelings of disbelief and loss of self were still common. The loss of what was or the loss of what the women thought they should be according to not only them, but to those around them.

Societal Perception of Illness

Much of the prior research does mention a lack of belief and delegitimization of women with invisible illnesses; however, there is little explanation as to where this skepticism originates. Ware (1992) argues that women are often dismissed and/or have their symptoms categorized as psychosomatic rather than physical simply based on their sex; however, there is minimal analysis or explanation as to whether this perception is truly based on the patients' sex or whether there is a larger underlying contributing cause. Ware (1992) extensively discusses the perception of illness in relation to medical testing and terms. However, there is not much focus on the influence this has on society's perception of illness. Although the majority of individuals who have an invisible illness are female patients, there are still male patients who report similar experiences of delegitimization (Ware, 1992). With this in mind, this leads to a larger issue than

simply a bias based on sex. What is perceived as "ill" becomes a major contributing factor when analyzing data of those with an invisible illness, regardless of sex or parental role.

Ware addresses specifically the delegitimization of individuals with Chronic Fatigue Syndrome due to the perceptions of what constitutes being "ill." As this particular illness, and many other invisible illnesses, cannot be detected through regular diagnostic protocols, or with the naked eye and the patient appears healthy, there is a high likelihood of no illness being present.

Appearances are held as a high standard in American society and many other societies across the globe, the appearance of being ill is paramount to legitimacy of being ill. When an individual appears healthy, the initial instinct is to treat that person as such. For many of those with invisible illnesses there is no external identifier to notify others that an illness is present. Because of this, self-identification is key for many with invisible illnesses; however, some other tangible "proof" is often necessary to legitimize an individual as sick. Many invisible illnesses such as diabetes, multiple sclerosis, asthma, and celiac disease have diagnostic tests that can identify an illness whether it is bloodwork, imaging technology, or some other type of physical test. For those with the "not real," "nonexistent," or "unknown and neglected" illnesses, there is no diagnostic test to substantiate that an illness is present (Masana, 2011, p. 129). Without a medical test or the outward physical characteristics validating an illness, society questions the existence of the illness and the integrity of the individual claiming to have said illness. Because of this, there are several different layers of "invisibility" that develop for individuals with an invisible illness.

Masana (2011) examines multiple layers of invisibility in relation to illness in her chapter, "Invisible Chronic Illnesses Inside Apparently Healthy Bodies." These layers are identified as physical, social, and medical. Without the diagnostic tests and physical appearance of being ill, there are obstacles to diagnosis. These obstacles are present regardless of sex; however, sex does impact the belief of medical professionals and therefore society. When a professional does not "see" an illness, this lack of validation will flow into society. Essentially this is a ripple effect. The lack of validation not only impacts this one individual but anyone who may be experiencing similar symptoms. For fear of stigma, many with invisible illnesses will not pursue further treatment or diagnosis leading to not only less reported occurrences but also less education on the illness leaving society unable to "see" these illnesses. This concept is present throughout responses of the mothers who responded to this survey.

When asked what their perceptions were of their treatment in the health care system, there was a lot of consistency in the answers. The vast majority of respondents reported a lack of faith in the medical community due to prior treatment or the lack thereof. Many responded that they were dismissed or demeaned when pursuing treatment:

> "[A]nytime I see a doctor I don't know if they are going to believe me or think I'm crazy. I have actually been told that due to my age and gender that I was most likely imagining some of my symptoms" (Nina).

This may explain the length of time it took for many respondents to be diagnosed with their invisible illness(es). As indicated in Figure 1-1, almost half of the respondents reported that it took more than six years to receive a diagnosis. Many respondents reported a lack of belief from their medical experiences, where many were initially treated for anxiety and/or depression.

Some described their diagnostic experiences as seeing doctors who wanted to help, but did not have the knowledge or patience to do so properly:

> "It took a long time get a diagnosis. For the most part, doctors wanted to help, but most of them have believed that my symptoms were mental and emotional, rather than physical…Doctors familiar with my illnesses are few and far between" (Candi).

These responses are consistent with Ware's (1992) findings. The figure below shows the number of years it took respondents to receive their diagnosis.

Figure 1-1 (Number of Years to Primary Diagnosis)
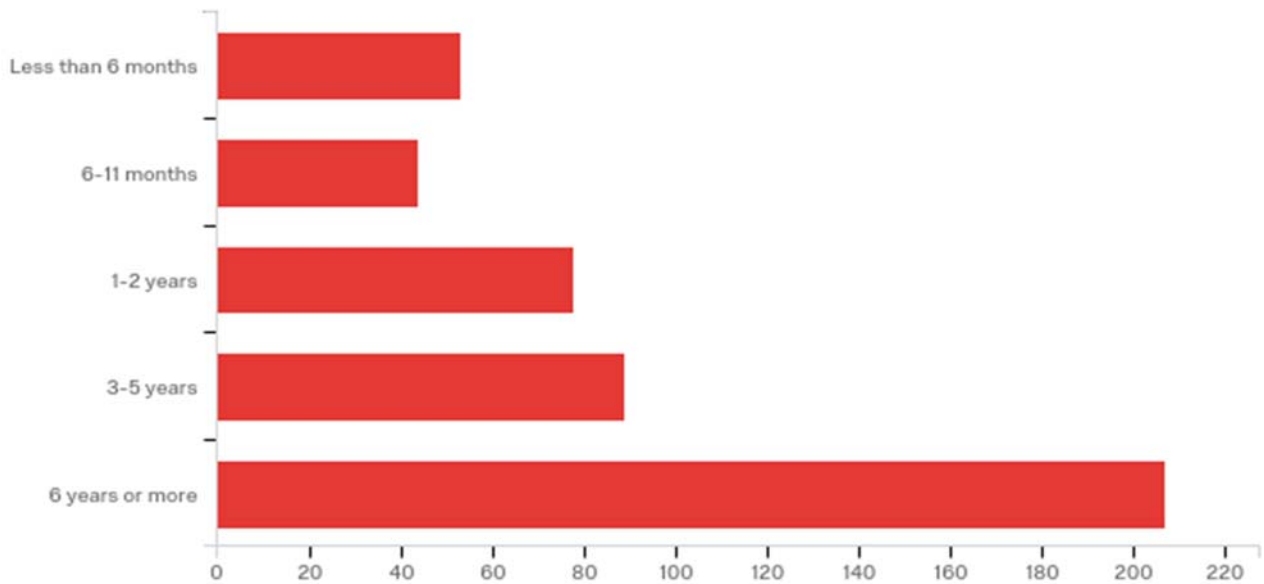
#	Answer	%	Count
1	Less than 6 months	11.25%	53
2	6-11 months	9.34%	44

3	1-2 years	16.56%	78
4	3-5 years	18.90%	89
5	6 years or more	43.95%	207
	Total	100%	471

The length to diagnosis could explain several other demographics collected in this research such as the age of the women. The majority of women were 25-54 years-old, with the largest population being 35-44 year-olds. As the time to diagnosis is reported as being several years, fewer women in younger generations responded, perhaps because of the lack of diagnosis. The struggle to be diagnosed was reported from women across ages, races, and employment statuses:

> "I could not believe the countless times that I was told that I had anxiety and to take stress off my plate. As a college graduate and successful business woman, having placed 1st in national sales with my company for 5 straight years I was astonished how abusive and dismissive doctors were of my symptoms" (Dorothy).

Despite these experiences of disregard, respondents kept pursuing answers to their ailments:

> "Initially when seeking a diagnosis I was told that everything was in my head and then I was misdiagnosed for 7 years. During that time I continued to pursue a correct diagnosis, but was met with very harsh criticism and felt like I was being treated like a nuisance" (Amy).

As previously indicated, how sex and parental status affect those with an invisible illness has not been explored in much research; however, many respondents described being dismissed, not only for having an invisible illness, but because of being a woman:

> "I feel like I was not taken seriously because I was a woman. I must have just
>
> been anxious or nervous or wanted attention from my husband. I feel strongly that
>
> if my husband had the same symptoms I had, he would have been diagnosed far
>
> earlier because they wouldn't have wasted so much time on if I was emotional"
>
> (Cynthia).

Research indicates that this dismissal or disbelief is prevalent for many women dealing with

other healthcare issues such as pain. Women statistically have to wait longer to be treated for

pain and are more likely to be undertreated for pain (Hoffmann and Tarzian, 2001).

Some respondents went beyond sex and identified motherhood as a reasoning to not

being taken seriously when pursuing medical treatment for their illness:

> "Treating me as a hysterical, depressed, anxious young mom that needs to get it
>
> together and adapt to life. I was told I had a huge giant hole in my soul and Dr
>
> told husband to take me to a local amusement park" (Valerie).

Many of the testimonies provided by these women are consistent with the findings of

Ware's (1992) delegitimization of patients with chronic fatigue syndrome, a relatively well-

known invisible illness, and Masana's (2011) research surrounding the various levels of

"invisibility" when suffering from an invisible illness. These accounts of being dismissed for a

seemingly healthy physical appearance are consistent with Masana's idea of "physical

invisibility: presumption of health." These studies did not look specifically at women, mothers in

particular, to see if these presumptions were more prevalent when the patients were women or a

parent. These presumptions of illness being visible are not unique to the medical community,

however.

In addition to witnessing skepticism from medical professionals, experiences of negative

public interactions are described by many respondents simply from not appearing ill:

> "I look healthy. I have a high powered job and a PhD, looks like I'm fine. I've
>
> been taunted and yelled at for using the handicapped spot and scolded for not
>
> standing in church" (Lucinda).

This respondent is not alone in her experiences as many other women had similar reports

causing many to feel concerned about the reactions of the general public or to simply not want to

venture into the public's eye:

> "The public is judgmental. They have generalized my issues or acted like my
>
> issues are mental versus physical. I get very nervous about having symptoms
>
> outside of those who know me. If people cannot see the illness, apparently it
>
> doesn't exist to them" (Patti).

> "Because my illnesses are 'invisible' sadly, I am often met with judgmental
>
> remarks or looks. There is much more compassion for someone who physically
>
> looks unwell" (Chrissie).

Though the majority of provided examples of disbelief were from the medical community

and the public, friends and family were still indicated as perpetuating the societal ideal that to be

ill requires outward physical appearances:

> "My husband is basically the only person who offers any real support. Most of
>
> my friends and family think I am being dramatic/making it up (despite multiple

tests confirming pots- tilt table, ambulatory heart rate monitor, 3 EKGs, and

doctors/nurses checking my pulse changes)" (Ellie).

"My husband is very supportive when I am symptomatic. He is a little less

understanding when he can't see it. Like the fatigue or the nausea that effect me

most days but that I push through" (Carole).

Without outward physical signs of illness, even those closest to the women who

responded to this survey are noted as questioning the validity of symptoms and the invisible

illness itself. This questioning of credibility at all levels, medical and social, is reflective of the

societal expectation that being ill means looking ill. In the absence of visual evidence, all belief

is dependent on the reliability of the afflicted. This is the instance for all the women involved in

this survey as their illnesses are invisible.

Women are the majority diagnosed with invisible illnesses meaning that many mothers

are impacted. Because of this, my research on mothers with invisible illnesses is extremely

important due to the pivotal role that mothers hold in society. Understanding the experiences

and perceptions of these women who are diagnosed with invisible illnesses could not only

improve the diagnostics for these illnesses but the perceptions of these illnesses.

Societal Expectations of Mothers

The definition of a mother is very broad. One can be considered a mother as she has

birthed a child, being a biological mother. A woman can be considered a mother by being the

primary caretaker of a child; however, this title does not necessarily fade as the child becomes an

independent. Because of these varying definitions, the term "mother" is used in this research

with the definition that the woman was or is the primary caretaker of a child. This means that the

population of women included in this research include mothers of dependent biological/adopted

children, mothers of independent children, as well as step-mothers in these same roles.

There is extensive research on mothers ranging from post-partum depression, pregnancy

and child-rearing, economic disparities in correlation to the birth of children, and so on including

Davies and McAlpine (1998) and Crocker and Sheppard (1999); however, there is little research

that focuses specifically on mothers with invisible illnesses. Because of this, research focusing

on mothers with invisible illnesses is necessary due to the unique role that mothers serve in

society and how this role affects the perceptions of others in all aspects of life.

In the last 70 years, the role of women in society has transformed dramatically. Women

entered the workforce, the rate of children born out of wedlock grew significantly, as well as the

age of women bearing children continued to rise. Because of these along with many other

factors, including divorce rates, the family dynamic has evolved. Women are more likely to be

single parents meaning that the need for employment is vital for family survival (Guendouzi,

2006). Though employment is now expected more of women, many other previous

roles/expectations exist for mothers. For example, the responsibilities of household chores and

childcare defer to the mother regardless if she is single or not: "Currently, the time mothers

report spending in direct or primary childrearing activities is higher than that during the 1960s

when a far higher proportion of mothers were in the home full time" (Bianchi, 2011, p. 26). It is

noted that though women's childcare responsibilities have not decreased, their household

workload has decreased due to the increase of male support in the home. Though there is an

increase in assistance, the bulk of chore responsibilities lay with the woman: "In 2009/10,

women are estimated to do 1.6 times the amount of housework as men, on average (with wives

averaging 1.7 times the housework of husbands, and married mothers averaging 1.9 times the

housework of married fathers)" (Bianchi, Sayer, Milkie, and Robinson, 2012, p. 56). Though

men are contributing more to housework, the primary duties of men are still yard work and auto

maintenance repair, responsibilities that enforce traditional gender roles (Kroska, 2003).

With the changes of family dynamics and women in the workplace, mothers are being

conditioned to "do it all." This means being a working mother while still being the primary

caretaker of the children and the household. With this evolution, the ideas of "extensive" and

"intensive" mothering have been established and explored. Extensive mothering is described as

being more of a delegator, an organizer of lives, while intensive mothering is more hands-on

caregiving (Christopher, 2012). With this idea that mothers have the responsibilities of an

employee, a mother, and a partner, the style of parenting evolved; however, the perceptions of

what constitutes a good mother are often still tied to the traditional stay-at-home scenario.

Over a quarter of the respondents are employed full-time, with another 15 percent

employed part-time as indicated in Figure 2-1. Others reported themselves as disabled, unable to

work, but having been employed outside of the home at some capacity prior to their illness(es).

A significant number of respondents indicated that they are unable to work or disabled, with 36

percent self-reporting in this capacity. This is higher than the United States average rate for

disability: 19 percent of the United States' population reports having a disability (not indicating

severity) according to the 2010 United States Census Bureau (US Census, 2016). As the

population targeted has known medical issues, disability rates are expected to be higher.

While younger mothers tend to practice extensive mothering techniques, trying to balance family and work identities, older generations of mothers are more likely to practice intensive parenting techniques (Christopher, 2012). One study following the conversations of working mothers in the United Kingdom references the conflicting forces of being an employee, a wife, and a mother: "[T]hese conversations, however, reflected a model of parenting that is still constrained by the characteristics of the traditional, unemployed mother who is accessible to her family" (Guendouzi, 2006, p. 907). As reflected in Figure 2-1, a little over 30 percent of respondents indicated that they are currently employed which indicates a large portion are working mothers. Working mothers are held to the same ideals as a mother who does not work outside of the home.

Figure 2-1 (Employment Status)
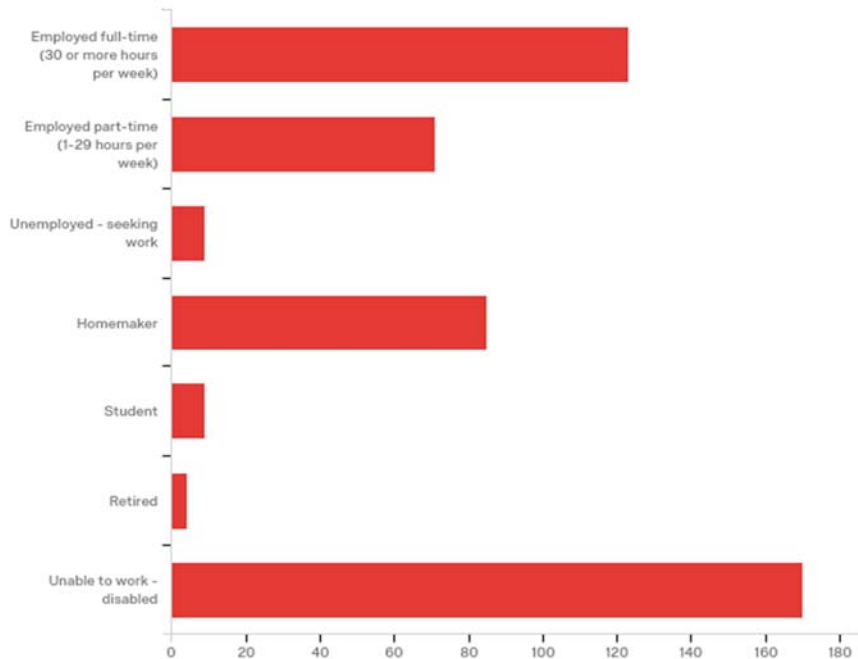
#	Answer	%	Count
1	Employed full-time (30 or more hours per week)	26.11%	123
2	Employed part-time (1-29 hours per week)	15.07%	71
3	Unemployed - seeking work	1.91%	9
4	Homemaker	18.05%	85
5	Student	1.91%	9
6	Retired	0.85%	4
7	Unable to work - disabled	36.09%	170
	Total	100%	471

These same ideals are evident in the responses provided in this research. Some women referred to themselves as "subpar" or "slacking" as a mother. Not doing the majority of household chores, planning activities and events, and not being able to do physical activities such as shop, play sports/games, or provide transportation, indicated by some participants, as areas that caused these impressions of inadequacy. The majority of respondents did not indicate employment, or the inability to work, as a personal critique of performing as a mother. Many of the women were concerned with their household duties:

> "I feel like I'm a bad parent and wife. If I clean I know I'll be down for days. I
> feel like I'm not good enough anymore" (Joni).

> "Maintaining a tidy house with food on the table is a huge challenge daily.
> Having clean clothes for my kids and husband. I am home so I should be able to
> get things done but it takes so much energy to keep my kids alive and not
> screaming and enjoy them during the day" (Stevie).

Though many of the respondents indicate they are ill and face many challenges doing the upkeep of the home, the expectation that the wife/mother is to complete these tasks persists. Guilt from not performing these duties was a common reaction for these women when asked what the biggest obstacle was being a mother with an invisible illness.

While many respondents focused on the "acts" of being a mother and wife in terms household duties, others focused more on the expectation of being the primary childcare provider and events coordinator:

> "I used to homeschool my kids, but cannot anymore. Now they have all sorts of school functions and sometimes I'm unable to go. I'm not the mother I set out to be and I feel guilty about that everyday" (Loretta).
>
> "Some days I can't take care of my son, I can't get up to feed him or change his diaper. I'm afraid that I'll faint and he'll hurt himself, that he'll be crying for help and I won't come. It terrifies me" (Kate).

As the survey was dispensed to an international group, respondents vary in their country of origin and their cultural expectations; however, the majority who gave specific examples of not fulfilling motherly responsibilities provided the traditional extensive mothering expectations of being a hands-on parent who supported the family with household chores and family organization. Almost 60 percent of women who responded indicated that they had one to two children, as can be seen in Figure 2-2. This is consistent with the average of 2.1 children per family in the United States (The World Family Map, 2012). As the majority of respondents were from developed countries, larger families are less common as represented in the data collected. This indicates an average family size, with "average" family duties. Though employment may

also be in conjunction to these ideals, that was not the focus of most when questioned regarding

the difficulties of being an ill parent.

Figure 2-2 (Number of Children as Primary Caregiver)
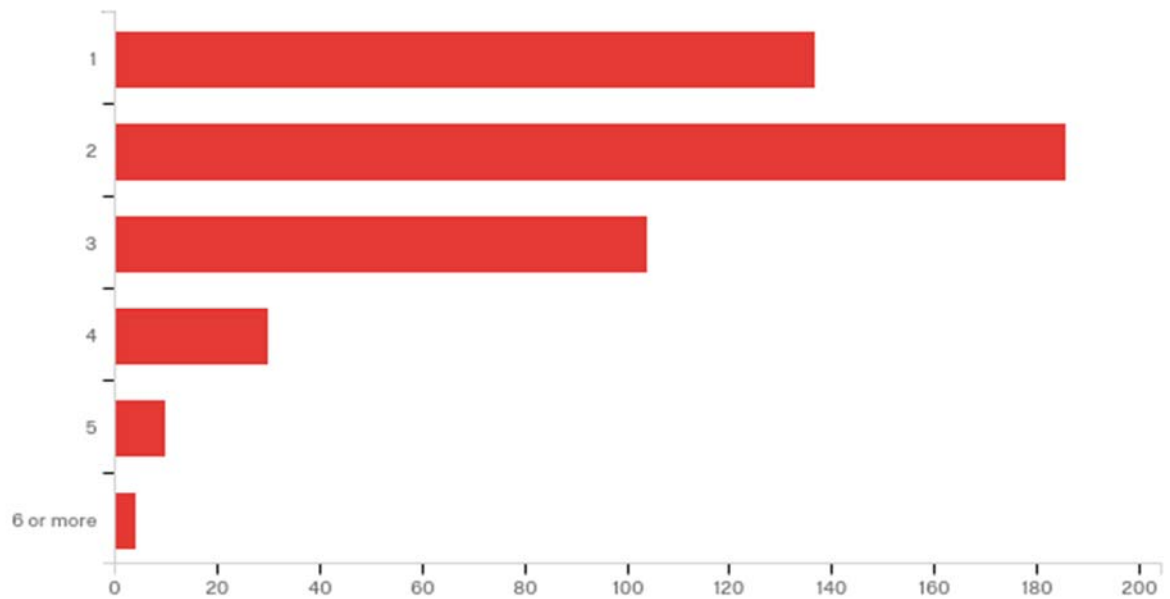
#	Answer	%	Count
1	1	29.09%	137
2	2	39.49%	186
3	3	22.08%	104
4	4	6.37%	30
5	5	2.12%	10
6	6 or more	0.85%	4
	Total	100%	471

Even though several responses contained allusions to the traditional mother role and not fulfilling those expectations, other responses were more ambiguous and simply state, "not being the mother I want to be," "Keeping up being a mom;" or "Being able to parent the way I used to." In these responses, it is unclear what the respondents' expectations of mothers are, but there is a definite indication of not being able to fulfill these expectations in their current state.

Race/ethnicity, income, marital status, and various other factors all have an impact on the expectations of mothers, whether it is the mother's own expectation or societal expectation. Karen Christopher (2012) researches the impact of marital status and employment on mothering techniques and expectations finding that single mothers felt they were held to different standards of mothering than married mothers, Latina mothers had different expectations than white mothers, and upper class families had different expectations than lower/middle-working class families. Regardless of these variances, the mother was still expected to be the primary caregiver in one form or another across all races, marital statuses, and classes. In comparison, fathers are expected to assist in one primary area: financial support (Fox, Bruce, and Combs-Orme, 2000).

Taking into consideration this expectation that mothers hold the primary caregiver role as a mother and household coordinator, the research of mothers with invisible illnesses is pivotal. Many of the women included in this research are incapable of fulfilling the societal and personal expectations of caring for children as well as being the primary manager of a home due to the physical constraints of their illness(es).

The Impacts of Helping: Caregiver Fatigue

In the discussion of mothers with invisible illness, many constituted as chronic, the subject of caregivers must be included. While those with chronic illness are often under the supervision of a medical professional, many will depend on family, friends, or others to assist with everyday tasks. This assistance is characterized as caregiving. Schulz and Sherwood (2008) define caregiving as, "[C]are that is provided by a family member or friend rather than by a professional who is reimbursed for services" (p. 23). In this research caregivers range from spouses and parents to friends and children; any individual who assists/cares for the respondent while not being employed/paid for their contributions.

The majority of respondents indicate spouses/partners and parents to be the primary caregivers.   This is consistent with the majority of respondents identifying as married or with a domestic partner. As is seen in Figure 3-1, 78 percent of women reported being married or with a domestic partner. This is expected as the population being surveyed are mothers, who are still commonly married or in a committed relationship. 45 percent of women aged 18-49 in the United States are married (World Family Map, 2012), but this data was collected from across the globe including Italy, Australia, Canada, and so on, meaning that not only United States' statistics will be reflected in the results.

Figure 3-1 (Marital Status)
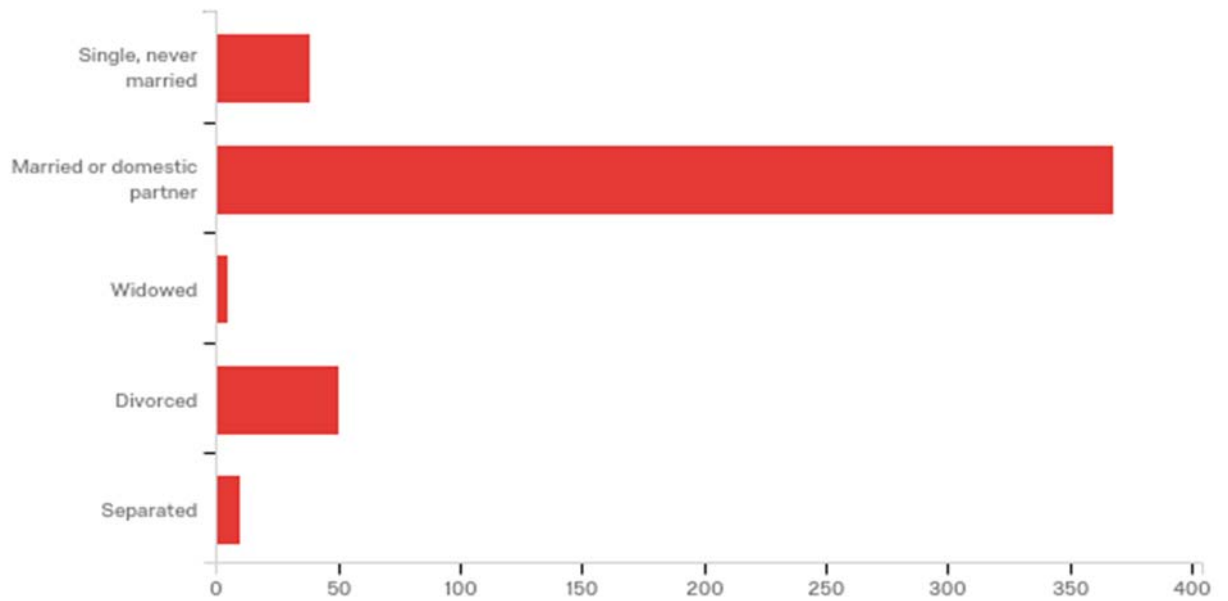
#	Answer	%	Count
1	Single, never married	8.07%	38
2	Married or domestic partner	78.13%	368
3	Widowed	1.06%	5
4	Divorced	10.62%	50
5	Separated	2.12%	10
	Total	100%	471

The tasks these caregivers complete vary in complexity and duration, but include such responsibilities as housecleaning and meal preparation, to more intricate duties such as fiscal management and physical care:

"My husband is very supportive; he basically takes over watching the children each evening so I can rest. He also takes care of the grocery shopping; some

homework; picking up dinner; and errands as I cannot drive. I also have a

supportive mother who helps with the children" (Kirsty).

Nina also noted:

"My husband is my major supporter financially, physically, and emotionally. I

have a lot of help from my mom and mother in law, as well as other family"

(Nina).

"My husband is a huge supporter. I cannot stress enough how much he helps

me….emotionally, physically, spiritually, financially. He takes over whatever

needs to be done when I'm going through a flare up" (Peggy).

As evidenced in the responses, many focused on the assistance needed with childcare rather than

on personal needs. Some respondents did indicate that paid help was utilized including nannies

and housekeepers, but this was in the minority. Driving was of great concern and mentioned as a

key task needing assistance for both themselves and their children; this was mentioned

repeatedly throughout the survey in areas of greatest challenges and support provided by support

systems.

Caregivers also provide emotional support beyond their physical duties. Those who are

primary caregivers often have other roles and responsibilities such as being employed and having

a family beyond the respondent who is being cared for. With this in mind:

"Clinical observation and early empirical research showed that assuming a

caregiving role can be stressful and burdensome. Caregiving has all the features

of a chronic stress experience: It creates physical and psychological strain over

extended periods of time, is accompanied by high levels of unpredictability and

uncontrollability, has the capacity to create secondary stress in multiple life

domains such as work and family relationships, and frequently requires high

levels of vigilance" (Schulz and Sherwood, 2008, p. 23).

Each caregiver's experience is different as diagnosis and severity of each individual being cared

for will vary. The level of necessity for the caregiver as well as other factors such as

socioeconomic status, the physical and mental health of the caregiver, and the chronically ill

individual's outlook will impact how/if the caregiver is affected by their caregiving

responsibilities. One of the most important factors is the family support structure: "Family

appraisal (from both sides) plays a role in developing a schema or beliefs about the situation

(coping with the adversities of chronic pain and coping with the challenges of having a family

member with chronic pain)" (Mercurio-Riley, Lee, Chronister, and Swiger, 2013, p. 6). In this

research family involvement/support is wide ranging from no involvement/support at all to

having a very involved, intricate system.

One of the data elements gathered was that of the ages of children that respondents were

caregivers for. Most of the respondents indicated that their children were in their teenage years

with over half being 11-17 years old as is reflected in Figure 3-2. The age of children is

important regarding support systems and perceived obstacles. Those with older children indicate

being more dependent for help and perceive their children as part of the support system.

Mothers with younger children identified more obstacles and the inability to discuss their

illness(es) with them.

For those who identified as having no support system, their responses were relatively

short stating, "None," "No one," or "On my own." For those who do elaborate, there is an

ongoing theme of misunderstanding leading to non-involvement: "None. My family does not get

it. They call me lazy. No one helps out and I talk to no one" (Nikki). It is unclear why some

lack a support system/caretaker, but there are numerous possibilities of why ranging from not

needing/wanting the support, geographic location, or being delegitimized with an invisible

illness.

Figure 3-2 (Ages of Children)
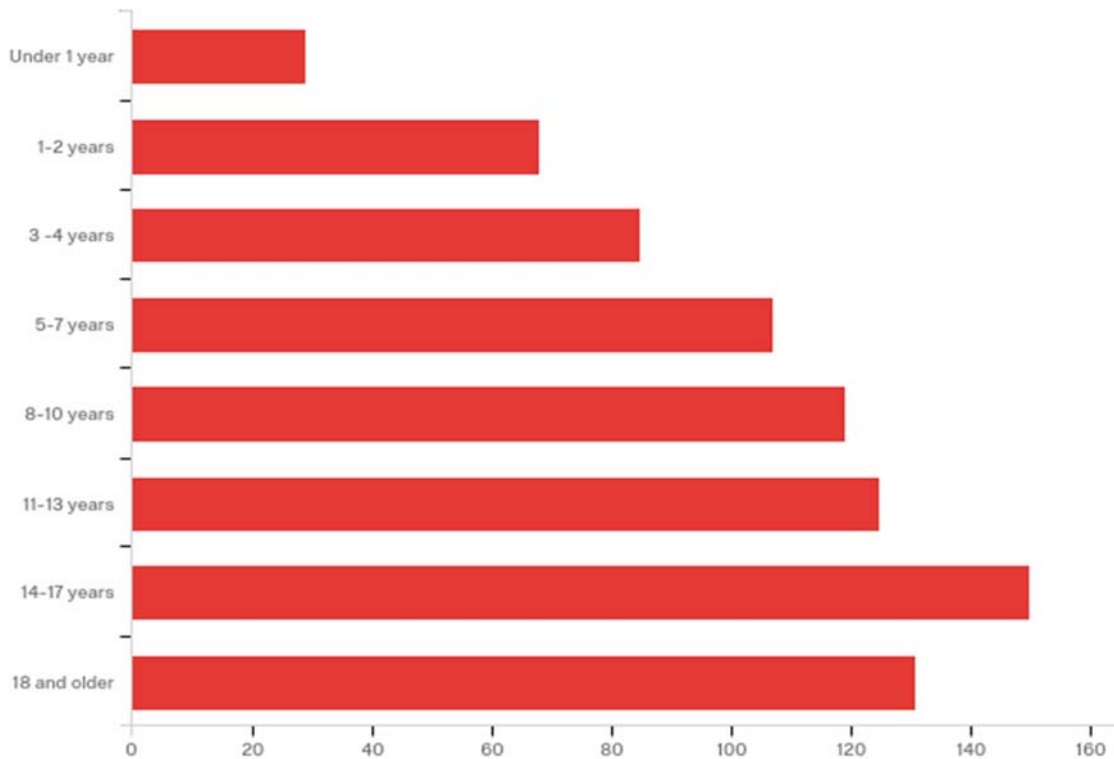
#	Answer	%	Count
1	Under 1 year	6.17%	29

2	1-2 years	14.47%	68
3	3 -4 years	18.09%	85
4	5-7 years	22.77%	107
5	8-10 years	25.32%	119
6	11-13 years	26.60%	125
7	14-17 years	31.91%	150
8	18 and older	27.87%	131
	Total	100%	470

The more intricate systems vary from having a sole caretaker of a spouse/partner or parent, to having many members including siblings, parents, friends, and children. These systems are described in a more positive manner and include providing various levels of support:

"My support system consists of my family- mom, dad, grandfather, brother, uncle etc. My live in boyfriend, and thankfully my work environment is supportive as well, as they have seen my 'episodes'" (Janis).

"My family, my husband tries hard, my coworkers, my closest friends all help me. Some even do research into my illness, which is Dysautonomia/POTS/EDS" (Sandy).

"My husband mostly, he's amazing. He's a nurse and does his best to manage my care as well as the kids and house. My mother in law works full time, but will take off work when we ask her to so I save that for times when I really need it like if I'm in the hospital or need to see specialists out of town. I also have a friend that will help whenever I ask (which I try not to because she has 4 kids herself)" (Edith).

For those individuals who indicated a strong support system, there was more positivity

throughout responses; however, many still provided examples of fatigue and stress that is placed

on even the most diverse support systems. Though the caregivers were not surveyed, respondents

described struggles when inquired about perceptions of their support systems.

The negative impacts of caregivers is much less significant when there is "acceptance"

and the acknowledgement of the contributions of the caregiver; however, this does not

completely eliminate the development of what is commonly referred to as "caregiver fatigue."

Respondents reported several symptoms associated with caregiver fatigue in their support

systems including exhaustion, irritability, and mental health issues such as depression/anxiety:

> "My husband is hurting mentally. He struggles with watching my go down hill.
> My mom went from not believing to overreacting about everything I do."
> "I am grateful that I have them, but even with their support it's still hard to cope
> and even though they all understand my health issues, they can get fed up at times
> when I need a lot of help" (Joan).
> "He does the best he can. But it's so much work for him. He is always tired,
> depressed and now has panic attacks" (PJ).

This fatigue stems from a variety of factors, both physical and psychological, but the most

commonly identified contributors are time, or the feeling of not having enough time, worries

about the care recipient and their future, and financial constraints compounded with the effects of

physical strain (Jowsey, Strazdins, and Yen, 2016).

Being a caregiver does not guarantee negative side effects. As previously indicated, the level of caregiving varies for each respondent, so not all caregivers will provide the same level of support or perform the same supporting tasks. Many of the respondents cite a "cyclical" pattern to their symptoms so the time a caregiver is needed may not necessarily be constant. While some respondents allude to caregiver fatigue from those providing support, many describe a very healthy, upbeat support system. Responses range from simple answers of, "I have a wonderful support system," or "It [support system] is awesome!" to more detailed responses including, "They are amazing!...I love my support system. I try to rotate between them when I need help, that way I don't have to bug anyone person too much."

This is consistent with research of family caregivers: " In studies with large population-based samples, about one third of caregivers report neither strain nor negative health effects…Even when caregiving demands become more intense and result in high levels of distress and depression, caregivers often cite positive aspects of the experience" (Schulz and Sherwood, 2008). Other positives include an improved self-image, strengthened relationships, and new life meaning.

As caregivers are not the respondents in this research, only the respondent's perceived worries and symptoms of caregiver fatigue can be examined. Only assumptions and observations by the respondents are included and given as evidence; however, this is still key in exploring how mothers with invisible illnesses cope.

Mothering with Chronic Illness: Mother Guilt

As previously stated, there is very little research focused on mothers with invisible/chronic illnesses, therefore there is no literature regarding how these mothers are impacted in terms of their perception of their performance as a mother. There is research targeted at new mothers, working mothers, single mothers, and mothers with children who have a chronic illness. Very few studies specifically look at the perspectives of mothers with invisible/chronic illnesses. The studies that do concentrate on mothers with illnesses are specific to those with mental health issues. While mental health diagnoses are included as invisible illnesses, there are many more physiological invisible illnesses that are not psychosomatic. Most focus on the challenges many of these mothers and their families face including financial and social issues (Montgomery, Mossey, Bailey, and Forchuk, 2011). Because of this, the research of mothers' perspectives and coping mechanisms with invisible illnesses is imperative and is applicable to other research in understanding the impacts of mothering with an illness.

This research includes a lot of references of feeling guilty and ashamed which is present in the other areas of research discussed. For example, in a study of mother's with mental health issues, "Although they [the mothers] expended the effort to 'pretend that things were OK,' they spoke of, 'tremendous guilt' associated with the 'kids seeing suffering,' and 'illness invading their (children's) lives'" (Montgomery et al., 2011, p. 4). Other areas of guilt included not fulfilling "motherly" duties of protection and meeting basic needs.

For purposes of this research, these feelings of inadequacies as a mother, in all facets, will be referred to as, "mother guilt." This will include circumstances of not fulfilling traditional mother roles. As explained prior, the expectations of mothers varies from race/ethnicity, income,

marital status, and so on, so each respondent's expectation will be different as well as their

definition of "failing" to meet these expectations. One mother may deem herself inadequate by

not being able to attend school activities while another will express guilt from simply being an

"ill" mother. There is no single portrayal of mother guilt or what is sometimes referred to as

"maternal guilt," as each woman experiences guilt or shame for differing reasons and at differing

levels; however, "guilt" and "shame" are words that are present throughout the surveys used

within this research. These words are used over 60 times in responses. Most of this guilt was

expressed when asked what the greatest challenge was as a mother with an invisible illness:

> "The biggest challenge I face is guilt. I always feel guilty that I'm not being the
> mom that I could be and want to be because my illness will prevent it. I have to
> remind myself that I am being the best mom that I can be and ultimately loving
> my child is the best gift I can give him" (Joan).

> "I have a lot of guilt around not being able to be as good a mother and wife as I
> would like to and indeed used to be…" (Debbie).

> "The guilt is so bad sometimes…I know I'm doing my best…he is happy and
> healthy…but the picture I had of the kind of mom I would has been completely
> different than my reality" (Carly).

Mothers in this survey expressed their guilt for not performing basic tasks such as house cleaning

and cooking to not being able to plan and participate in more family functions such as family

gatherings (i.e. birthdays) or sport events. Many acknowledged the physical conditions that

cause these limitations, but mother guilt prevailed.

Chapter 6

Future Research

The aim of this research was to identify key impacts that invisible, chronic illnesses have on mothers, and how these women cope with having this illness(es) in their everyday lives. This was obtained through online ethnographic research utilizing an online questionnaire, where participants self-identified as mothers with invisible illnesses. There was no verification that the participants were either mothers or in fact had been diagnosed with an invisible illness. Members of the online forum where this online questionnaire was administered includes women who are not mothers, men, and members of support systems for these individuals which means that there was potential for participants to fit neither criteria. The term "invisible illness" is also broad and may have been interpreted differently by potential participants either restricting or broadening the base for eligibility.

Being a member of the group and being researcher also posed great benefit including understanding the questions to ask, colloquial language, and the personal connection and motivation to complete said research.

As this was an online survey completed anonymously, there was no opportunity for follow-up questions to ensure interpretation of the answers provided.

Utilizing an online forum to collect data was chosen in order to capture the experiences and perceptions of women from various backgrounds and locations. With this method, women from across the globe with differing ages, ethnicities, socioeconomic statuses, and nationalities were able to participate in this research. Though there was a restriction for those who do not have access to technology, the cost-savings of this method far outweighed the

limitation. This method allowed for more women to be included in the research providing more of a base population to develop key themes and generalizations. The sense of anonymity that this method provided also proved to gather more candid, honest answers, where a face-to-face conversation may not have provided such freedom. With this anonymity, the option to collect follow-up data was sacrificed, but this allowed initial data to be honest and analyzed to develop a foundation for what is necessary for future research in this area.

With the marginalization of this particular group, the self-identification of being both a mother and a patient with an invisible illness was the best method for this research. Invisible illnesses are not well known, lessening the chances for those not eligible to participate in this research as well. This self-identification empowers the group and legitimizes their experiences, while giving the participants the choice whether to participate or not.

Being a member of this community, though it causes potential biases, creates a rapport with the participants, increasing perceived legitimacy and participation. Having experienced an invisible illness, knowing the correct questions to ask was also beneficial; however, there may have been other questions that were inadvertently overlooked from being included in the research. The membership of the community is what led to the research in which is lacking and necessary.

Other methods of research such as individual interviews or identifiable questionnaires may be a positive next step, as this would allow for follow-up questions regarding the experiences described. Gathering the information verbally may also prove to influence the research as writing answers may be more difficult for some, including those who suffer from an invisible illness of differing abilities. The tone interpreted in writing may also be misconstrued.

Not only would having verbal accounts assist in interpretation, but also assist in establishing the "why" or "how" for many of the themes that were identified in this research. Research could also be specialized more regarding multiple themes established here to develop themes that are more detailed.

Chapter 7

Conclusion

The purpose of this research was to identify key themes or coping mechanisms for mothers diagnosed with invisible illnesses, if any were present. Those women with dysautonomia were specifically targeted for this research, though many participants indicated multiple diagnoses of various invisible illnesses. This particular invisible illness was selected, as it is lesser known and a "true" invisible illness where traditional diagnostic testing is lacking (Masana, 2011), and as mentioned previously, the researcher's own diagnosis and membership in the community.

While research has been conducted including other invisible illnesses such as chronic fatigue syndrome (CFS) and post-partum depression, the research surrounding mothers with invisible illnesses is minimal. Irritable Bowel Syndrome (IBS) consists of 70-90 percent of women (Johnson and Johnson, 2006); and two to four times of those diagnosed with chronic fatigue syndrome (CFS) are also women (Chronic Fatigue Syndrome, 2014). Since the majority of those diagnosed with many invisible illnesses are women, research focused on women with invisible illnesses is necessary.

Mothers diagnosed with invisible, chronic illnesses reported repeated instances of delegitimization from their support system, medical professionals, and society. This disbelief often cascaded into self-doubt and isolation, with mothers attempting to appear healthy and unaffected by their ailments. This coincides with the idea of Foucault's power and disciplinary tactics. The respondents indicated feeling watched and judged by others: surveillance. To escape judgement or doubt, women reported hiding symptoms or simply not venturing out of

their homes: separatism (Allen, 2016). These experiences are evidence of critical theory's

concept of power.

Social institutions such as hospitals and schools were identified as key barriers for

mothers, perpetuating the expectations of what it is to be ill and how to be a "good" mother.

Individuals within the institutions as well as the mothers themselves are dominated by the ideas

of what it is to be legitimately ill and what is expected of a mother and partner as defined by

these "disciplinary institutions." These mothers reported initially questioning themselves, but

later questioning the legitimacy of the definitions and tools used by others, especially the

medical community.

Many indicated that anxiety/depression was an initial misdiagnosis, which led to

repeated questioning of their mental state, presence of illness, and the eventual facades of good

health. The societal expectations of diagnosis and the perception of what illness "looks" like is

indicated as a major contributor to these experiences and were shared by the vast number of

respondents. Some mothers suggested that there is more support for mothers with a visible,

accepted illness from loved ones and the community. Mothers with invisible illnesses were held

to the same standards as healthy mothers, but lacked the understanding and support that would

otherwise be available.

Though these women are diagnosed with chronic, invisible illnesses, they still held

themselves to the same expectations as mothers to those who are healthy. Being active and

present in their families' lives was of the most importance. When these expectations could not be

met, mother guilt ensued. It can be argued that mothers with invisible illnesses are more likely to

experience delegitimization and mother guilt than healthy mothers or those with socially

recognized illnesses.

While the focal point of this research was that of mothers, it was not just the mother who

was affected. The family as a whole was impacted with indications of family dynamics changing

such as the mother being cared for rather than being the primary caretaker. This role change may

also explain the reports of caregiver fatigue within the family. This area was also recognized as a

source for guilt as respondents were not fulfilling expectations of themselves being mothers and

partners.

Despite facing multiple instances of delegitimization, many of these women expressed

optimism and a transformation of self. Though there is grief for the loss of their previous

identities, these women describe being advocates for themselves and others, to change the

perception of what it is to be ill, and the expectations that go with that, especially mothers.

Mothers with invisible illnesses struggle with power at the doctor's office, at the grocery store,

their children's school, and even their own homes, yet many reported overcoming these obstacles

and rebuilding with new, achievable expectations as mothers, partners, and women.

As there is not much research on the impacts of invisible illnesses on mothers, this

research is vital to the foundation of continued progress in assessing the causes of these instances

of deglegitimization, and how to support women in coping with their illnesses. Due to the lack

of research in this area, more research is needed regarding invisible illnesses and motherhood,

exploring instances of misdiagnosis, delegitimization, how this relates to power and mother guilt,

and beyond.

References

Allen, Amy, "Feminist Perspectives on Power", *The Stanford Encyclopedia of Philosophy* (Fall

    2016 Edition), Edward N. Zalta (ed.), URL =

    <https://plato.stanford.edu/archives/fall2016/entries/feminist-power/>.

Allen, B. J. (2011). *Difference Matters: Communicating Social Identity* (2nd Ed.). Long Grove,

    IL: Waveland Press Inc.

Bianchi, S. M., Sayer, L. C., Milkie, M. A., & Robinson, J. P. (2012). Housework: Who Did,

    Does or Will Do It, and How Much Does It Matter? *Social Forces, 91*(1), 55-63.

    doi:10.1093/sf/sos120

Bianchi, S. M. (2011). Family Change and Time Allocation in American Families. *The ANNALS*

    of the American Academy of Political and Social Science, 638(1), 21-44.

    doi:10.1177/0002716211413731

Blum, L. M. (2007). Mother-Blame in the Prozac Nation: Raising Kids with Invisible

    Disabilities. *Gender & Society*, *21*(2), 202-226. Doi: 10.1177/0891243206298178

Christopher, K. (2012). Extensive Mothering. *Gender & Society, 26*(1), 73-96.

    doi:10.1177/0891243211427700

Crocker, G., & Sheppard, M. (1999). The Psychosocial 'Diagnosis' of Depression in Mothers:

    An Exploration and Analysis. *British Journal of Social Work*, *29*(4), 601-620.

    doi:10.1093/bjsw/29.4.601

Crowley, M., Payne, J. C., & Kennedy, E. (2013). Working better together? Empowerment,

    panopticon and conflict approaches to teamwork. *Economic and Industrial Democracy,*

    35(3), 483-506. doi:10.1177/0143831x13488003

Davies, L., & McAlpine, D. D. (1998). The Significance of Family, Work, and Power Relations

    for Mothers' Mental Health. *Canadian Journal of Sociology / Cahiers canadiens de*

    sociologie, *23*(4), 369. doi:10.2307/3341806

Dysautonomia International. (2014). Retrieved November 27, 2016, from

    http://dysautonomiainternational.org/

Fleming, P., & Spicer, A. (2008). Beyond Power and Resistance. *Management Communication*

    Quarterly, 21(3), 301-309. doi:10.1177/0893318907309928

Fraser, N. (1989). *Unruly Practices Power, Discourse and Gender in Contemporary Social*

    Theory. Minneapolis, MN: University of Minnesota Press.

Gove, W. R. (1972). The Relationship between Sex Roles, Marital Status, and Mental Illness.

    Social Forces, *51*(1), 34-44.

Guendouzi, J. (2006). "The Guilt Thing": Balancing Domestic and Professional Roles. *Journal*

    of Marriage and Family, 68(4), 901-909. doi:10.1111/j.1741-3737.2006.00303.x

Hasser, C. E., & Wilder, C. M. (2003). Service and the Spin Cycle: Women's Health Outreach

    Project at a Laundromat. *Women's Studies Quarterly*, *31*(1/2), 160-167.

Hoffmann, D. E., & Tarzian, A. J. (2003). The Girl Who Cried Pain: A Bias Against Women in

    the Treatment of Pain. *SSRN Electronic Journal*. doi:10.2139/ssrn.383803

Hoge, E. A., Ivkovic, A., & Fricchione, G. L. (2012). Generalized anxiety disorder: diagnosis

    and treatment. *BMJ*, *345*(nov27 2), e7500-e7500. doi:10.1136/bmj.e7500

Johnson, J. E., & Johnson, K. E. (2006). Ambiguous Chronic Illness in Women: Community

    Health Nursing Concern. *Journal of Community Health Nursing*, *23*(3), 159-167. Doi:

    10.1207/s15327655jchn2303_3

Jowsey, T., Strazdins, L., & Yen, L. (2016). Worry and time: The unseen costs of informal care. *Chronic Illness, 12*(4), 249-260. doi:10.1177/1742395316647788

Kroska, A. (2003). Investigating Gender Differences in the Meaning of Household Chores and Child Care. *Journal of Marriage and Family, 65*(2), 456-473. doi:10.1111/j.1741-3737.2003.00456.x

Lindlof, T. R., & Taylor, B. C. (2011). *Qualitative Communication Research Methods*. London: SAGE.

Livingston, G. (2015, May 07). Childlessness Falls, Family Size Grows Among Highly Educated Women. Retrieved March 8, 2017, from http://www.pewsocialtrends.org/2015/05/07/childlessness-falls-family-size-grows-among-highly-educated-women/

Masana, L. (2011). Invisible chronic illnesses inside apparently healthy bodies. In *Of Bodies and Symptoms. Anthropological Perspectives on their Social and Medical Treatment* (Col-leccio ed., Antropologia Medica, pp. 127-149). Publicacions URV. doi:ResearchGate

Mercurio-Riley, D., Lee, G. K., Chronister, J., & Swigar, E. A. (2013). Psychosocial Adjustment of Spousal Caregivers of Patients With Chronic Pain. *SAGE Open, 3*(4), 215824401351213. doi:10.1177/2158244013512130

Mielke, C. H., Shields, J. P., & Broemeling, L. D. (2001). Risk Factors and Coronary Artery Disease for Asymptomatic Women Using Electron Beam Computed Tomography. *European Journal of Cardiovascular Prevention & Rehabilitation, 8*(2), 81-85. doi:10.1177/174182670100800204

Montgomery, P., Mossey, S., Bailey, P., & Forchuk, C. (2011). Mothers with Serious Mental

　　　　Illness: Their Experience of "Hitting Bottom". *ISRN Nursing, 2011*, 1-8.

　　　　doi:10.5402/2011/708318

Murthy, D. (2008). Digital Ethnography. *Sociology, 42*(5), 837-855.

　　　　doi:10.1177/0038038508094565

Rodham, K., PhD, Rance, N., MSc, & Blake, D., FRCP MB. (2010). A Qualitative Exploration

　　　　of Carers' and 'Patients' Experiences of Fibromyalgia: One Illness, Different

　　　　Perspectives. *Musculoskelet. Care, 8*, 68-77. doi:10.1002/msc.167

Sade-Beck, L. (2004). Internet Ethnography: Online and Offline. *International Journal of*

　　　　Qualitative Methods, 3(2), 45-51. doi:10.1177/160940690400300204

Saidin, K. (2016). Insider Researchers: Challenges & Opportunities. *Proceedings of the*

　　　　ICECRS, 1(1), 849-854. doi:10.21070/picecrs.v1i1.563

Schulz, R., & Sherwood, P. R. (2008). Physical and Mental Health Effects of Family

　　　　Caregiving. *AJN, American Journal of Nursing, 108*(Supplement), 23-27.

　　　　doi:10.1097/01.naj.0000336406.45248.4c

Unluer, S. (2012). Being an Insider Researcher While Conducting Case Study Research. *The*

　　　　Qualitative Report, 17(29), 1-14. Retrieved March 20, 2018, from

　　　　http://nsuworks.nova.edu/tqr/vol17/iss29/2

US Census Bureau Public Information Office. (2016, May 19). Nearly 1 in 5 People Have a

　　　　Disability in the U.S., Census Bureau Reports - Miscellaneous - Newsroom - U.S.

　　　　Census Bureau. Retrieved March 3, 2017, from

　　　　https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html

World Family Map 2012. (n.d.). Retrieved March 03, 2018, from

      http://worldfamilymap.ifstudies.org/2012/

Ware, N. C. (1992). Suffering and the Social Construction of Illness: The Delegitimation of

      Illness Experience in Chronic Fatigue Syndrome. *Medical Anthropology Quarterly*, *6*(4),

      347-361. doi:10.1525/maq.1992.6.4.02a00030

Appendix A- IRB Forms

NOTE TO RESEARCHERS: ALL DOCUMENTS FOR RESEARCH MUST BE INCLUDED IN A SINGLE FILE!!!

Name: Jami Koivisto

Email: jkoivis3@uwsuper.edu

Phone number: 218-341-3713

Status: Staff/faculty   <mark>Graduate Student</mark>   Undergraduate Student

Name of faculty sponsor/mentor (if applicable): Dr. Ephraim Nikoi

Faculty member's email address: enikoi@uwsuper.edu

Anticipated start date: 10/01/2016

Anticipated end date: 12/23/2016

Does this project specifically recruit any vulnerable populations including but not limited to:

Minors?	Yes	<mark>No</mark>
Pregnant women?	Yes	<mark>No</mark>
Prisoners?	Yes	<mark>No</mark>
People with cognitive delays?	Yes	<mark>No</mark>
People hospitalized in nursing homes, etc?	Yes	<mark>No</mark>
Other vulnerable groups:	<mark>Yes</mark>	

Will you be deceiving your participants? Please note: withholding details about the specifics of your hypothesis **does not** constitute deception. However, misleading participants about the nature of the research question or about the nature of the task they will be completing **does** constitute deception.

Yes   No

Are the names/identities of your participants included on the data itself? Or, if someone looked at your data would s/he be able to identify the participant from the data or instrument?   Yes   No

Are you gathering any biological samples as part of your research?   Yes   No

Minimal risk is when the likelihood that participating in your research will not cause harm or discomfort (including physical, mental, emotional, social, or economic) that is greater than those a person would normally encounter in daily life.

Does this research pose greater than minimal risk to participants?   Yes   No

1. **What is the title of your project?**

   Coping Mechanisms of Mothers with Invisible Illnesses

2. **Briefly describe your research question (50 words or less)**:

   Using information collected from a Qualtrics Survey administered on an online Facebook forum for individuals with POTS (Postural Orthostatic Tachycardia Syndrome) and other forms of Dysautonomia, I will investigate what coping mechanisms are used with mothers with invisible illnesses.

3. **Will participants include individuals from specific populations (e.g. children, pregnant women, prisoners or people with cognitive delays)?**

   Yes

   a. **If your participants will include individuals from specific populations, please specify the population(s) and briefly describe any special precautions you will use**.

      I will be examining data from mothers with invisible illnesses such as dysautonomia. No identifiable information will be collected or published. Participation will be elective with an online survey administered on an online forum.

4. **Briefly describe how you will recruit participants from your study (make sure to include any institutional affiliations of your participants). Please include any recruiting materials in an appendix**.

   Recruitment is not necessary as I will be administrating the survey to a group that consists primarily of individuals with invisible illnesses.

5. **How many individuals do you expect to participate in your study?**

   There are currently over 15,000 members of this group. Membership does not denote having an invisible illness or being a mother as family members will join for information as support and both men and women, parents and non-parents are active in the group. With this in mind, I am anticipating perhaps 7000 members being eligible for the survey. I will only have the survey open for one week which will lessen the responses.

6. **Briefly describe what participants in your study will do and where it will take place. Make sure to reference any and all materials/surveys/tests/assessments that will be used. (All materials *must* be included in an Appendix.)**

   Members will access an online survey voluntarily through a link provided on an online Facebook group for individuals with POTS and other invisible illnesses. The survey will consist of 18

questions, 8 are multiple choice and 10 that are open-ended questions that individuals will be able to answer in an essay format.

7. **Please describe any risks and benefits your research may have for your participants. Please make sure to include whether the data could damage your participants' reputation or make them liable to conviction. (For example, one study's risks might include boredom and eye-strain. The same study's benefits might include satisfaction from contributing to scientific knowledge and greater self-awareness.)**

   Risks associated with this research may be a perceived breach of confidence. There is personal information such as self-disclosed health issues as well as family issues that may be posted within the survey which may be embarrassing for some individuals (this is key as to why identifiable information will not be collected). Benefits for this research are significant as this is an underrepresented population with very little research. There is also the benefit of educating individuals about what constitutes an invisible illness and how this impacts patients' lives, especially mothers.   Dysautonomia, the illness that connects this forum, though not rare, is commonly misdiagnosed and is unknown to the general population; this research would help with awareness of this illness.

8. **What procedures will you use to ensure that the information your participants provide will remain confidential? In other words, how will you keep your data secure?**

   Using the tool Qualtrics, all data will be collected and stored anonymously. Also, all of my data will be electronic and will be Qualtrics which is only accessible from campus computers using UW-Superior credentials.

9. **Will your study use deception? (Please note: withholding details about the specifics of your hypothesis *does not* constitute deception. However, misleading participants about the nature of the research question or about the nature of the task they will be completing *does* constitute deception.)**

   No

   a. **If your project includes deception, please fully describe the process you will use, why the deception is necessary and a full description of your debriefing procedures. Projects using deception should include their full debriefing statement here**.

10. **Do you have funding for this research?** Yes No
    a. **If so, state the name of the funding agency or department (For example, NIH, NSF, Faculty Development Grant, McNair Scholar)**.

11. **Where do you plan to present/publish or share your research?**

    This research will be used for my thesis to complete my master's program. I will be sharing this research with thesis committee which consists of four members, and the Communicating Arts Department at the University of Wisconsin – Superior.

12. **Will participants be compensated? How?**

    No

13. **Will a written informed consent form be used and signed by participants?**

    No

    a. **If yes, attach the informed consent form (see below)**

    b. **If no, explain how the research meets each of the following criteria such that the research qualifies for a waiver of informed consent**:

        i. **Research could not be conducted practicably without the waiver**;

            Several thousand participants' will eligible for this survey which would require several thousand consent forms from across the globe as this is an international forum.

        ii. **Research involves no more than minimal risk to participants**;

            As participant information will be kept confidential and participation is voluntary, there will be minimal risk to participants.

        iii. **Waiver will not adversely affect the rights and welfare of participants**;

            Participation in the survey is completely elective. No identifiable information is requested or will be shared.

        iv. **Participants will be provided with pertinent information in some other format**.

            I have self-identified in the group and informed individuals of my research. Feedback has been positive. Also, Administrators are in support of this research and can make announcements they deem necessary.

ONLY FOR PEOPLE USING RECORDING (VIDEO OR AUDIO):

1. **Will you conduct all interviews yourself or will you have assistance (including a translator)?**
   Alone   With Assistance

2. **How will you secure the data so that the participants' image and/or voice are kept confidential?**

Please read the following statement carefully:

I have read the UWS IRB Regulations. I will comply with the informed consent requirement, and I will inform the IRB if significant changes are made in the proposed study. I certify that all the information contained in this proposal is truthful.

Submitting this proposal means that you affirm the above and will comply with the content. This counts as your legally binding signature.

WAIT!!!

Did you include your Informed Consent Document and any materials that you will use during your study?

Jami Koivisto

University of Wisconsin – Superior

Jkoivis3@uwsuper.edu

Coping Mechanisms of Mothers with Invisible Illnesses

Thank you for participating in this survey. Your feedback is important and appreciated. Please answer the following questions as honestly as possible. These questions concern being a mother with an invisible illness.

Benefits for this research are significant as this is an underrepresented population with very little research. There is also the benefit of educating individuals about what constitutes an invisible illness and how this impacts patients' lives, especially mothers.

There are no anticipated risks to taking this survey or inconvenience. Furthermore, your participation is strictly voluntary and you may withdraw your participation at any time without penalty.

All information collected will be used only for my research and will be kept confidential. There will be no connection to you specifically in the results or in future publication of the results. Once the study is completed, I would be happy to share the results with you. In the meantime, you have any questions please ask or contact:

Jami Koivisto jkoivis3@uwsuper.edu

Or

Ephraim Nikoi enikoi@uwsuper.edu

Additionally, if you have concerns about your treatment as a participant in this study, please call or write:

Eric Edwards
Institutional Review Board Chair
University of Wisconsin - Superior
Telephone: *(715) 394-8283*
Email: irb@uwsuper.edu

By clicking "Start Survey" you are verifying that you have read the explanation of the study, are 18 years of age or older, and indicate your consent to participate in this survey.

Appendix B- Survey Questions

Invisible Illness Survey – Coping Mechanisms of Mothers:

1. What is your age?
    a. 17 or younger
    b. 18-24
    c. 25-34
    d. 35-44
    e. 45-54
    f. 55-64
    g. 65-74
    h. 75 or older
2. What is your current marital status?
    a. Single, never married
    b. Married or domestic partnership
    c. Widowed
    d. Divorced
    e. Separated
3. What is your current employment status?
    a. Employed Full-time (30 or more hours per week)
    b. Employed Part-Time (1-29 hours per week)
    c. Unemployed – Seeking Work
    d. Homemaker
    e. Student
    f. Retired
    g. Unable to Work – Disabled
4. Please specify your race/ethnicity:
    a. White
    b. Hispanic or Latino
    c. Black or African American
    d. Native American or American Indian
    e. Asian
    f. Native Hawaiian or Pacific Islander
    g. Other
    h. Prefer Not to Answer
5. How many years did it take for your primary diagnosis?
    a. Less than 6 months
    b. 6 - 11 months
    c. 1-2 years

   d. 3-5 years
   e. 6 years or more
6. How many years has it been since your primary diagnosis?
   a. Less than 6 months
   b. 6 - 11 months
   c. 1-2 years
   d. 3-5 years
   e. 6 years or more
7. How many children are/were you the primary caregiver for in your family?
   a. 1
   b. 2
   c. 3
   d. 4
   e. 5
   f. 6 or more
8. What are the ages of all the children in your family? Indicate as many that apply:
   a. Under 1 Year
   b. 1-2 Years
   c. 3-4 Years
   d. 5-7 Years
   e. 8-10 Years
   f. 11-13 Years
   g. 14-17 Years
   h. 18 and older

9. Please describe your support system (those who provide practical and/or emotional support):

10. What are your perceptions of your support system/network?

11. What is your support system's reaction during a period in which you are symptomatic?

12. What is the public's reaction when you are symptomatic?

13. What are your coping methods when you are symptomatic? (please include both physical and emotional)

14. What are your perceptions of your treatment in healthcare? (not limited to your primary doctor)

15. How do you discuss your illness with your children? What are their reactions?

16. What are some of your biggest challenges as a parent with an invisible illness?

17. What are some of your greatest successes as a parent with an invisible illness?

18. Any other information that you would like to provide about coping and/or your support system as a mother with an invisible illness?