“People Choose Wi-Fi Over Your Existence:”
The Management of Electromagnetic Hypersensitivity

by

Rory Gernert

A thesis submitted to the Graduate Faculty of
Auburn University
in partial fulfillment of the
requirements for the Degree of
Sociology, Master of Science

Auburn, Alabama
December 12, 2020

Keywords: electromagnetic hypersensitivity, microwave illness,
contested illness, experience, stigma

Approved by

Dr. Natalia Ruiz Junco, Chair, Associate Professor of Sociology
Dr. L. Allen Furr, Professor of Sociology
Dr. Matthew Cousineau, Assistant Professor of Sociology

Abstract

As sources of anthropogenic electromagnetic fields (EMFs) proliferate in the environment, the population of people living with electromagnetic hypersensitivity (EHS) is growing. Yet sociologists have only recently begun to examine this topic. In order to explore the lived experiences of EHS, the strategies people with EHS use to manage everyday life, and the potential origins of the stigma associated with this illness, I conducted interviews and participant observation in a rural county in which a community of EHS sufferers reside. The use of a grounded theory approach illuminated the immense challenges people with EHS face as they attempt to survive in a society driven by the technologies that make them physically ill. EHS sufferers were barred from participation in everyday life due to the ubiquity of EMFs and reported experiencing stigmatization from others who disbelieved their physical illness, phenomena which resulted in the loss of economic and social resources. To preserve or gain access to these resources, EHS sufferers endeavored to prove the legitimacy of their illness to others through a diversity of strategies. In addition, EHS sufferers had to contend with the physical management of EMFs, and a number of approaches to this challenge were identified and described. Finally, this study undertakes a theoretical exploration of the possible origins of the stigma associated with EHS.

Acknowledgments

First, I would like to thank Dr. Natalia Ruiz-Junco for her support and direction throughout this research process. This thesis greatly benefited from her expert advice and wisdom. I am also very grateful to committee members Dr. L. Allen Furr and Dr. Matthew Cousineau for their invaluable insights. In addition, thanks are due to Mrs. Niki Storey for her excellent assistance, as well as to Dr. Greg Weaver for his guidance. I would also like to thank Mr. Sears for his intelligent suggestions. Furthermore, I wish to thank Walter Douglas for his help. Finally, I am very grateful to the participants in this study for sharing their stories. You are all exceedingly brave. May society see you as the canaries you are; may your warnings be heeded.

Table of Contents

CHAPTER 1 INTRODUCTION

In 2006, United States district judge Gladys Kessler found that the tobacco industry had "publicly denied, distorted, and minimized the hazards of smoking for decades" (*United States v. Philip Morris USA Inc.* 2006). Indeed, this industry had been aware of the hazards of smoking since the 1950s (Glantz et al. 1996): In 1954, leading tobacco industry executives employed a public relations firm to dispute the growing scientific evidence that linked tobacco with cancer (Brandt 2012). For nearly half a century, the industry financed alternative studies to create doubt around the tobacco-cancer connection and disseminated information that supported the industry's interests to policymakers, the media, and doctors (Oreskes and Conway 2010).

According to Oreskes and Conway (2010), this strategy involved selecting favorable data and emphasizing unexplained scientific details. After all, "the industry had realized that you could create the impression of controversy simply by asking questions, even if you actually knew the answers and they didn't help your case" (Oreskes and Conway 2010:18). As one tobacco industry executive infamously stated in a 1969 memo, "doubt is our product, since it is the best means of competing with the 'body of fact' that exists in the minds of the general public" (Brown and Williamson 1969).

A parallel may be drawn between the history of the tobacco industry in the United States and the ongoing scientific debate over the safety of anthropogenic electromagnetic field exposures. Scientific evidence suggests that the electromagnetic fields (EMFs) produced by the use of Wi-Fi, mobile phones and the myriad other technologies ubiquitous in nearly every sphere of human life lead to adverse health effects (Havas 2013; National Toxicology Program 2018; Santini et al. 2018). Yet these studies have been largely ignored or disputed by regulatory organizations and telecommunication companies (Shuren 2018; Verizon Wireless 2019). Further evidence that the actions of the telecommunications industry are guided by the "tobacco strategy" (Oreskes and Conway 2010) is manifest in the countless studies funded exclusively by industry, which are "substantially less likely to report statistically significant effects on a range of end points that may be relevant to health" (Huss et al. 2007:3).

The World Health Organization reports that EMF exposures which fall below the safety limits suggested by the International Commission on Non-Ionizing Radiation Protection (ICNRP) "do not appear to have any known consequence on health" (World Health Organization 2019). The ICNRP guidelines, like those created by the Federal Communications Commission in the United States, however, are based only on thermal, or heating effects, from electromagnetic radiation (Carlo, Panagopoulos and Johansson 2013; Federal Communications Commission 2015; International Committee on Non-Ionizing Radiation Protection 1998). Yet as researchers argue, many of the recorded biological effects from anthropogenic EMF are non-thermal. Indeed, a large body of scientific literature shows that non-thermal exposures at levels below those suggested in the aforementioned safety guidelines produce a number of biological responses, including cancer, male and female infertility, sleep disruption, oxidative stress, breaks in cellular DNA, cardiac changes, and neuropsychiatric effects (Asghari et al. 2016; Belpomme et al. 2018; Carpenter 2013; Havas 2013; Miller et al. 2018; Pall 2015; Santini et al. 2018; Wilke 2018).

Further complicating the scientific discussion of the health risks of EMFs is the growing population of people who live with electromagnetic hypersensitivity (EHS) (De Luca et al. 2014). As early as the 1970s, the Soviet military recognized "microwave syndrome" among military personnel who worked with radar and radio equipment (Carpenter 2015). Many of the symptoms described by the Soviet military personnel are identical to those associated with EHS, such as “excessive fatigue, headache, tinnitus, insomnia, photophobia, a feeling of cognitive dysfunction and impaired memory, irritability, pain at various sites and often cardiovascular abnormalities” (Carpenter 2015:1).

The scientific evidence for the existence of EHS as a legitimate medical condition has not gone unnoticed (McCarty et al. 2011). The European Parliament asked its member states to recognize EHS as a disability in 2009 (European Parliament 2009), the condition is an officially fully recognized functional impairment in Sweden (Johansson 2009), and the Austrian Medical Association created guidelines for the diagnosis and treatment of EMF related illnesses (Austrian Medical Association 2012).

This illness remains highly contested, however, due to a lack of uniformity of opinion in the scientific community (Genuis and Lipp 2011). Brown et al. (2012:18) describe contested illnesses as “conditions whose causes are either unexplained by current medical knowledge or whose purported environmental explanations are in dispute.” EHS thus embodies the criteria of a contested illness as understood in the academic literature; the great body of evidence which connects symptoms associated with EHS to EMF exposures is disputed, and as such, the condition is widely considered scientifically unexplained. Therefore, in addition to suffering from bodily distress, people with EHS may also face the social stigma that is often directed at those who experience medically unexplained symptoms (Kirmayer et al. 2004).

Claims about the existence of contested illnesses challenge the dominant epidemiological paradigm, which Brown et al. (2012:24) conceptualize as the “codification of beliefs about a disease and its causation that are held by science, government, and the private sector.” Not only does the lack of a medical diagnosis prevent people from “health services, welfare benefits, unemployment certification, worker's compensation claims, and pensions” (Zavestoski et al.

2004), the stigma management strategies which are made possible when a condition is medicalized and thus made familiar to the general public are not available to those suffering from illnesses not recognized by this powerful set of institutions and belief structures (Brown et al. 2012; Pierret 2003).

In addition, Gibson (2009:190) shows that EMF exposures are causes of impairment and are therefore disability barriers to involvement in hypermodern society: these exposures can be found in nearly every public space, which "excludes environmentally sensitive people from public access and disables them through isolation and loss of resources." Indeed, unable to tolerate EMF exposures, some of those who live with EHS have fled industrial society to find relief from their symptoms (Goldberg 2015). Informal national and international networks have formed in order to help those with EHS procure lodging with minimal EMF exposures, and a few informal EHS communities have developed in North America and Europe (Goldberg 2015).

In light of the growing number of individuals who live with EHS (De Luca et al. 2014), and the approaching "roll out" of fifth generation wireless communication technologies (Russell 2018) that promise to facilitate an increasingly digital economy, examining the experiences of people with EHS is particularly important. While social scientists Chateauraynaud and Debaz (2010), De Graaff and Bröer (2012), and Dieudonné (2017) have studied this issue, EHS experienced in North American society has yet to be studied sociologically. Furthermore, the social stigma associated with EHS has not been examined through research.

This study thus endeavors to answer the following research questions: What are the lived experiences of people with EHS? Given that they inhabit a world in which toxic exposures that make them ill abound, what strategies do people with EHS use to manage everyday life? Furthermore, what are the possible origins of the stigma of EHS?

CHAPTER 2 LITERATURE REVIEW

A major theme to emerge from the field of study on the illness experience is the coping actions and strategies used to manage everyday life among those living with an illness (Pierret 2003). As Pierret (2003:11) explains, "By upsetting everyday routines, becoming ill and being ill are causes of uncertainty for patients and those close to them. This uncertainty affects various activities or even the person's whole existence. Patients work out strategies for coping with this upheaval and use various resources to re-organize their lives." Studies of the illness experience also often concentrate on social stigma (Pierret 2003), defined by Goffman (1963:3) as "an attribute that is deeply discrediting," which reduces one "from a whole and usual person to a tainted, discounted one."

For the purposes of this research study, it is the literature on the experience, management strategies, and the stigma of contested illness that provides for the focus and development of this thesis, as well as the interpretation of the data. Accordingly, in this chapter, I commence by focusing on research on the management strategies and origins of the stigma associated with chronic illness in general. Subsequently, I proceed to review the sociological literature on contested illness, including subsections on the experience, management strategies, and stigma of a number of medically disputed conditions.

Chronic Illness as Stigma

Researchers across a broad range of disciplines have explored the stigmatization of chronic illness and strategies utilized by illness sufferers to manage everyday life (Engebretson 2013). For example, Engebretson (2013:545) points out that individuals with chronic illness, unable to meet normative expectations, often become "shamed, ostracized, isolated, discredited, and socially and economically ostracized." It follows that individuals faced with such potential threats to their social identity will employ a variety of impression management strategies. In the case of epilepsy, methods of 'selective concealment' when interacting with others may be adopted (Scambler and Hopkins 1986), and the disclosure of the condition might be made to friends and potential spouses in cautiously deliberated and planned circumstances (Pierret 2003).

In addition, researchers have also studied the origins, or cause, of stigma associated with illness. Stangor et al. (2000:74) propose that "a characteristic becomes stigmatizing when it is perceived, at either an individual or a social level, to pose a threat to the vitality of the individual or the culture." Stigma thus develops from a motivation to avoid danger posed by two discrete types of threat (Yang et al. 2013): tangible threats pose a threat to a material good, such as physical safety, financial resources, or health; symbolic threats, conversely, threaten "beliefs, ideology, and an understanding of how the social, political, and/or spiritual worlds work" (Stangor et al. 2000:74). Crandall and Moriarty (1995), for instance, suggest typhoid fever to be stigmatized due to the potentially high degree of instrumental peril this illness poses to others, while an example of symbolic threat is present in Kleinman et al.'s (1995) study of epilepsy in China, where the implications of the latter medical condition were found to threaten the moral standing of the affected person's family.

The Contested Illness Experience: Strategies for Managing Everyday Life and Stigma

Because contested illnesses are, as discussed earlier, conditions "whose causes are either unexplained by current medical knowledge or whose purported environmental explanations are in dispute" (Brown et al. 2012:18), the experiences, management strategies, and stigmatizing aspects of such illnesses may be expected to diverge from those observed among sufferers of medically recognized conditions in salient ways.

While those with a chronic illness are often unable to meet certain societal demands – and thus face stigmatization for failing to bridge the “discrepancy between virtual and actual social identity” (Goffman 1963:3) –individuals who adopt Parsons’ (1951) concept of the sick role may be exempt from many normative task obligations. As Segall (1976:162) explains, the occupant of the sick role “is exempt from responsibility for the incapacity, as it is beyond his control, and he is also exempt from normal social role obligations.” To gain these rights, however, the individual who is sick must recognize that “to be ill is inherently undesirable and hence there is an obligation to try to get well. In addition, the sick person has an obligation to seek technically competent help (i.e., a physician) and to cooperate in the process of getting well” (Segall 1976:163).

But because contested illnesses are not accepted as legitimate medical conditions by the dominant epidemiological paradigm (Brown et al. 2012), individuals living with such conditions are precluded from gaining admission to the sick role, and consequently, the validity of their illness is called into question by others. This occurrence has a great bearing on the experiences lived by those with contested illnesses, as the exemption from certain normative expectations, as we have seen, may mitigate the stigma generally associated with an illness. In order to facilitate a better understanding of the contested illness experience, an examination of the strategies used by illness sufferers to manage everyday life and the stigma associated with a number of contested conditions follows.

Fibromyalgia and chronic fatigue syndrome. Fibromyalgia and chronic fatigue syndrome (CFS), disorders characterized by symptoms of pain, fatigue, and sleep disturbance (Hawkins 2013), are present in approximately 2% and 0.4% of the population, respectively (Bradley et al. 2000). Despite their prevalence in the population, both of these chronic illnesses are characterized by medical uncertainty and contestation (Cooper and Gilbert 2017; Dumit

2006).

In order to better understand the stigma experienced by people with fibromyalgia and CFS, Äsbring and Närvänen (2002) interviewed twenty-five women suffering from these contested illnesses. They found that, above all, two aspects of their conditions were stigmatizing: First, the women's moral characters were called into question as they were challenged by others regarding the truthfulness of their claims of having an illness; second, the interviews revealed that the participants experienced distress due to the psychologizing of their health problems, which often occurred during medical encounters. A number of strategies utilized to handle the stigma associated with fibromyalgia and CFS were identified. While some interviewees withdrew from areas of social life to escape from the expectations of others, especially from people who had reacted negatively to their illness, some women instead reported "concealing the illness, maintaining a façade, and giving a self-presentation according to others' expectations" when interacting with others (Äsbring and Närvänen:155)

Findings from Armentor's (2017) study of experiences of managing relationships among women with fibromyalgia support Äsbring and Närvänen's (2002) research on the stigma associated with this condition. By conducting in-depth, semistructured interviews with women diagnosed with fibromyalgia, the author found that avoidance of interactions with others, "putting on a front", and ceasing contact with unsupportive people were approaches to dealing with stigma among participants. Armentor's identification of sources of stigma diverged from those presented by Äsbring and Närvänen, however; while the author also held that the moral characters of participants were called into question, she reported an additional source of stigmatization: in some cases, receiving a diagnosis compounded fibromyalgia-related stigma by further reinforcing others' skepticism of women with the illness.

Multiple chemical sensitivity. Multiple chemical sensitivity (MCS) is a syndrome that develops after chronic exposures to environmental contaminants at amounts below those considered noxious for the general population (Rossi and Pitidis 2018). As Rossi et al. (2019) note, however, the characteristics of the illness are largely disagreed upon among the scientific community and at the political level due to the condition's association with environmental pollution and policy-making.

While Äsbring and Närvänen (2002) and Armentor (2017) found that women with contested illnesses were stigmatized due to the psychologizing of their health problems and the questioning of their morality, Lipson (2004) identified cultural themes and economic influences as primary causes of stigma among people with MCS. Drawing on ethnographic research, the author described "stigma and social relationships in the context of having a hidden disability that is also medically contested." Sources of stigma identified by the author included the North American emphasis on individual "rights" rather than on an emphasis on group well-being (people with MCS were viewed as a threat to an individual's choice to use cosmetics); the media, which focuses on the most dramatic manifestations of MCS, thus reinforcing the stigma met by people with this illness; and corporate motives: representatives hired by chemical, pharmaceutical, pesticide and cosmetic industries engage in activities in order to discredit MCS.

Gulf war illness. Approximately 30% of the United States veterans of the 1990-1991 Persian Gulf War developed a number of symptoms such as "chronic musculoskeletal pain, headaches, fatigue, insomnia, cognitive problems, poor balance, rash, dyspnea, gastrointestinal symptoms and sensitivity to odors" (Kerr et al. 2019:1) associated with chemical warfare agents. Despite the considerable population of veterans living with Gulf War Illness, the condition has been the subject of extensive contestation among policy makers eager to capitalize upon "the inherent ambiguity of veterans' illnesses" and attribute their symptoms to psychological flaws rather than environmental problems (Cable and Shriver 2010:56).

By examining the dynamics of contested illnesses in the context of Gulf War illness, Shriver and Waskul (2006) explored how Gulf War veterans handle the stigma associated with this condition. Consistent with research findings from Äsbring and Närvänen's (2002) study of experiences of managing relationships among women with fibromyalgia, the authors reported that people with Gulf War illness were subjected to the psychologization of their health problems: the complaints of Gulf War veterans were suggested to be caused by post-traumatic stress disorder by federally funded researchers (Shriver and Waskul 2006). As Brown et al. note (2000:246), this emphasis on stress gives attention to "individual psychopathology and minimizes the effects of toxic substances and other environmental conditions."

Indeed, as Shriver and Waskul (2006) pointed out, the recognition of Gulf War illness as a veritable medical condition linked to war-related chemical exposures and environmental hazards would lead to great implications for corporate and government entities. Interviews with Gulf War veterans revealed patterns of (re)negotiation of their illness: veterans retreated from social circles; immersed themselves in a Gulf War community of soldiers experiencing similar problems; and transformed stigma into political activism.

While the management strategies and stigma of a number of contested illnesses have been focused upon by researchers, the sociological aspects of EHS have not been extensively studied. The majority of research on EHS has been authored by professionals working in the areas of medical science and public health; their quantitative studies have been chiefly concerned with the physiological aspects of this condition. A small body of qualitative literature on the research topic also exists, but few of these studies have focused on the illness experiences of EHS, and the experience of this illness as lived in the United States has yet to be studied. Furthermore, the stigma associated with this illness has not been examined by researchers in the field of sociology. In light of these limitations, the primary objective of this study is to examine the lived experiences of EHS; the strategies people with EHS use to manage everyday life; as well as the potential origins of the stigma associated with this illness.

CHAPTER 3 METHODOLOGY

While quantitative methods help show the existence of environmental exposures and health effects, this type of data only provides a partial representation of a problem (Brown et al. 2012). Researchers are increasingly employing qualitative methods to study health, as these approaches "give a voice to individuals and community organizations and provide fuller, more complex descriptions of the affected community," and can support laypeople's action on illness and hazards (Brown et al. 2012:33).

In-depth interviews are especially appropriate for research that demands thick, qualitative data that can depict the lived illness experiences of participants (Armentor 2017), while the use of open-ended questions "gives participants the opportunity to respond in their own words," and evokes responses that are "meaningful and culturally salient to the participant, unanticipated by the researcher," and "rich and explanatory in nature" (Mack et al. 2005:4). In addition, observation can aid in the interpretation of different forms of data and provide for additional perspectives (Corbin and Strauss 2008; Glaser and Strauss 1967).

In-depth interviews and observation, then, are germane when the goal is to examine the experiences of a contested illness. Accordingly, a qualitative classic grounded theory approach was utilized in order to explore this relatively understudied research topic (Glaser and Strauss 1967). In-depth interviews and observations were conducted in a rural county in which a small community of people with EHS reside.

Research Questions

The purpose of this research is to address the gap in the sociological literature on EHS by describing and analyzing the experiences of people with this illness. The essential questions include: What are the lived experiences of people with EHS? Given that they inhabit a world in which toxic exposures that make them ill abound, what strategies do people with EHS use to manage everyday life? Furthermore, what are the possible origins of the stigma of EHS?

Site

A rural county in the United States was selected as the research site for this study. Because of the scientific research activities that take place in the county, the use of technologies which emit EMFs are restricted. As a result of these regulations, approximately thirty people with EHS have moved to the area.

While researching more than one site could have generated additional theoretical insights, the paucity of EHS communities in the United States (and worldwide) severely limits the number of opportunities to study the sociological aspects of EHS. Furthermore, while many people with EHS flee mainstream society in order to find relief from the electromagnetic field exposures prevalent in cities and towns, the research site offered the unique opportunity to study a small community where people both with and without EHS interact. Finally, because those interviewed relocated to the research site due to their illness, their perspectives shed light on the diversity of circumstances and events that lead one to abandon one’s home in order to seek refuge; researchers can thus access an important amount of information about EHS by studying these cases.

Sample

This study's sample of individuals with EHS included seven participants. Due to the difficulty involved in obtaining a diagnosis of EHS, the only criteria for this study was a self-diagnosis of EHS. To find participants for the intensive focus of the study, snowball sampling was employed: informal leaders of the research site's EHS community were identified and were asked to suggest the study to their friends. After each interview, participants were also asked to aid in recruiting more participants for the study. Of the seven participants, six identified as female, and one identified as male. All participants identified as White, and ranged in age from 41 to 70, with a mean age of 57.

Furthermore, all but two of the participants had college degrees, and one participant without a college degree had a post-secondary certificate. Two participants had graduate degrees. Finally, it should also be noted that three participants had previously worked in the field of healthcare.

Data Collection

Because of the exploratory, qualitative nature of this study, in-depth, semi-structured interviewing was the primary method of data collection in order to examine this relatively understudied topic. Before beginning the data collection process, approval from Auburn University's Human Research Protection Program was obtained. Participation in this project was voluntary and confidential. Prior to the interviews, all participants were informed about the study, the option to withdraw their participation, and confidentiality; furthermore, each participant signed an Informed Consent form before being interviewed. The interviews were conducted face to face and were recorded. Each participant was interviewed once, and the length of interviews lasted for approximately one hour. Interview locations were agreed upon by the interviewer and the interviewees; locations included the interviewee's home, a public library, and a park.

A semi-structured interview guide developed by Armentor (2017) to study the experiences of women living with fibromyalgia was adapted to be made relevant for the case of EHS. Each study participant was asked open-ended questions concerning six topics relevant to people living with EHS: experiences with physicians and/or other medical practitioners; experiences with family members; experiences with spouse or significant other, if applicable; experiences with friends; and beneficial and troublesome aspects of relationships. In keeping with the ethos of an open-ended interview, each participant in the study had the opportunity at the end of being interviewed to contribute additional information that had not been previously discussed.

While in-depth interviews were the primary technique of data collection, “different kinds of data give the analyst different views or vantage points from which to understand a category and to develop its properties” (Glaser and Strauss 1967:64); as such, participant observation was also conducted at the research site in an effort to gain a deeper understanding of the experience and management of EHS. Rather than serving as a means to verify self-reported information from the previously discussed in-depth interviews, the data gleaned from field notes, when submitted to comparative analysis, aided in the generation of the properties of the categories which will be discussed in the proceeding section.

Data Analysis

As previously stated, the objective of this study is to examine the lived experiences and approaches to the management of EHS, as well as to theorize the possible origins of the stigma associated with this illness. Given the understudied nature of the research topic, the data analysis for this study was inspired by the inductive classic grounded theory approach originally developed by Glaser and Strauss (1967).

The data analysis process was accomplished in a number of stages. To begin, each audio recording was transcribed verbatim. Next, the transcribed interviews and notes taken while conducting participant observations were read through several times in order to gain an overall impression of the data. Subsequently, the data were subject to the *constant comparative method*, as set forth by Glaser and Strauss (1967).

First, the transcribed interviews and notes were coded line-by-line into emergent categories, and incidents applicable to each category were compared. By “coding an incident for a category,” and comparing it with the “previous incidents in the same and different groups coded in the same category”, theoretical properties of categories were generated (Glaser and Strauss 1967:106.)

Subsequently, categories and their properties were integrated by comparing incidents with properties of the category that were generated from initial incident comparisons. When the latter was accomplished, the theory was reduced and the categories became saturated, and the theory was thus delimited. Three major categories constitute the basis of the present analysis, and organize the presentation of the research findings in the next section of this Thesis: “Structural conditions," “consequences of living with EHS", and "salient processes." The first category emerged through the code “identifying EMF exposures as barriers to everyday life”; the second category was identified through the codes “stigma”, “social isolation”, and “the loss of social resources”; and the third category was revealed through the following codes: “managing the illness” and “proving its legitimacy”. Finally, with coded data, memos, and a theory in hand, the theory was written.

Limitations

The first limitation of this research originated from the difficulty of finding participants for the study: it is challenging to find participants from a small population – as discussed earlier, only approximately thirty people with EHS live in the county selected as the research site – and a tendency among people with EHS to be distrustful toward researchers was observed. While some participants were eager to discuss their experiences, others with EHS did not discuss their conditions with outsiders to avoid the disclosure of their medical condition to community members who did not have the illness. As a result, the sample size utilized in this study was smaller than originally intended. Despite this limitation, the in-depth, semi-structured interviews conducted with seven participants provided a wealth of information about the sociological aspects of EHS. This data, in conjunction with participant observations at the research site, afforded a better understanding of the lived experiences of EHS, the strategies that are undertaken by people with EHS to manage their illness, and the potential origins of the stigma associated with this contested condition.

Furthermore, while EHS is a condition that predominantly affects women, men also live with the illness; as discussed earlier, however, this study only included one man. Moreover, because all participants were White, and were all middle-aged or older, the data mostly reflect the voices of White women of these age groups, whose experiences may not apply to men or minority women who have EHS, nor to the young adults who live with this illness. In addition, because the participants of this study made the conscious decision to move to an area low in EMF exposures and become part of a community of others who share their illness, their experiences with stigma, and their approaches to managing this stigma, may vary greatly from the stigma encountered by individuals with EHS who do not live in such circumstances. Indeed, it can be expected that the experience of EHS as lived in an environment with rampant EMF exposures will differ greatly from those presented in this study.

Finally, the findings of this study reflect, in addition to the researcher's observations, the participants' descriptions of their experiences with EHS, and thus contain the limitations inherent in any self-reported data. And while the sample size and methods for participant selection may be appropriate for qualitative research, the results from this study will not be generalizable to a larger population of people with EHS.

CHAPTER 4 STUDY FINDINGS

Introduction

Several major conclusions may be drawn from the research data. Participants in the study were unable to fully participate in contemporary society due to the EMF exposures that abound in hypermodern environments. These barriers to employment, welfare, and other important means of obtaining access to financial support posed by EMF exposures led to the loss of economic resources among people with EHS.

EHS sufferers also experienced stigmatization and social isolation when their illness was interpreted as a psychological condition or as an attempt to attract attention or malinger. This phenomenon ultimately resulted in the loss of social resources among participants in the study, as contact was ceased with others who doubted the legitimacy of their physical condition in order to protect both their moral status and physical health.

People with EHS found ways to prove the legitimacy of their condition to others to maintain or gain economic and social resources, as well as to protect their moral status and ensure their physical safety. Specific strategies that allowed EHS sufferers to prove their illness to others included obtaining a medical diagnosis, educating others with scientific facts and subjective experiences, and making invisible EMF exposures and the adverse health effects they produce visible to the outside world.

In addition to contending with the material consequences of EMF exposures and the stigmatization and social isolation encountered when the physical nature of their condition was questioned by others, participants in the study also engaged in the physical management of EMF exposures to ensure their physical safety. Approaches that helped people with EHS physically manage exposures included identifying exposures with their bodies or measuring devices, calling upon others to refrain from utilizing certain technologies when in their presence, and leaving environments when exposures could not be mitigated, which, for some participants, gave way to homelessness and marginalization.

The following four sections will focus on EMF exposures as physical barriers to participation in hypermodern culture, the social consequences of living with EHS, strategies used by people with EHS to prove the legitimacy of their illness to the outside world, and the physical management of EMF exposures.

EMF Exposures as Physical Barriers to Participation in Everyday Life

Gibson (2009) views EMF exposures as barriers to participation in contemporary culture. This research finds that people with EHS are indeed excluded from participation in an array of public environments. All participants in the study had lost material resources throughout the course of their illness and from seeking refuge in the rural county in which the research was conducted, and continued to experience difficulty in gaining access to these resources.

Barriers to medical care.

Wi-Fi routers, flashing screens on walls and in hands and inside pockets, fluorescent lights: contemporary physicians' offices are riddled with EMF exposures that obstruct the access to medical care of people with EHS. One participant in the study, unable to tolerate the office of her doctor, finished a consultation outside in her car. As will be discussed later, physical EMF exposures in medical environments create additional problems for people with EHS as they seek a diagnosis.

Barriers to work.

EMF exposures also posed substantial barriers to employment, and subsequently led to losses of economic resources for the majority of the study's participants. A former successful architect, for example, became unable to go to work because of the fluorescent lighting and other sources of electromagnetic field exposures utilized in her workplace.

Difficulties at work caused by EMF exposures were particularly grave for the three participants who worked in the field of health care. These occupations required the use of EMF emitting technologies to a great degree. For instance, while working as a dental hygienist, one woman would lose the sensation in her hands when using an ultrasonic tool to clean patients' teeth; "there's no way to work like that," she explains.

After losing the ability to support oneself due to an illness, a person may seek aid by applying for disability benefits. But in the case of EHS, as with other contested illnesses, the path to such resources is tortuous and unreliable. As Dumit (2006:579) explains, "because the American biomedical system demands disease categories before compensation, and diagnosis before treatment, control of the codes can create situations where there are rules for "no code": explicit instructions that certain forms of suffering are illegitimate and therefore not-suffering at all."

Among the research participants, three had received disability benefits. Two women received the assistance for secondary conditions, which they view as caused by, or associated with, EHS. Only one participant received disability benefits for EHS. She refuted the notion that there did not exist a code for the condition, stating “they say there is no code but there can be codes for it.” However, gaining this elusive code required perseverance and economic resources, as it involved engaging with the judicial system, and undergoing psychological testing when a judge deemed it necessary to ensure her illness was somatic in nature.

Another woman was prevented from receiving disability benefits not because her illness failed to meet a bureaucratic definition of disability, but primarily because her condition prevented her from working long enough to qualify for assistance. She succinctly describes this irony: “It’s like I was too sick to even get disability.”

Barriers to Political Organization and Medical Legitimation.

Political action is necessary to effect structural changes to the previously discussed social programs. According to Brown et al. (2012:18), in order to establish a contested illness as a legitimate condition in the eyes of science, government, the private sector, and other important actors, health social movements both challenge the dominant epidemiological paradigm and cooperate with medical professionals and scientists in the pursuit of “treatment, prevention, research, and expanded funding.”

EMF exposures, however, also create barriers to participation in these endeavors. One man stated that he would like to attend protests around the issue of EMF regulation and EHS illness legitimation, but that these events are inevitably located near cellphone towers, and thus inaccessible to him. Despite the symptoms it caused for her, another participant in the study had traveled outside of the county to meet with key researchers and policymakers in person, but stated that others with EHS would not join her when invited due to the EMF exposures they would be sure to encounter.

A number of participants also viewed EMF exposures as creating problems of validity in studies on EHS, which hindered the path toward legitimation of the condition: because research on the illness is largely conducted in urban centers, it excludes those with the severest of electromagnetic sensitivities from participating.

PHYSICAL MANAGEMENT OF EMFs

Using the Body and Measuring Technologies to Detect EMFs

In their analysis of the process of establishing EMFs as a risk object, de Graaff and Bröer (2012) found that people living with EHS gradually discover how to understand their electromagnetic environment both through their bodies and with measuring technologies. A similar kind of behavior can be appreciated in the actions exhibited by individuals in this study. They have also come to rely upon measuring devices and their physical bodies to interpret their surroundings and subsequently take action to ensure their physical safety. However, from the research data, it can be concluded that these two approaches differ in important ways.

The majority of participants in this study relied primarily upon their bodies to detect EMF exposures in their environments. These bodily sensations varied from participant to participant, as the symptoms associated with EHS are numerous, but all warned the individual of the proximity of harmful exposures. One woman, for example, was made aware of the presence of EMFs in the vicinity when she experienced headaches: “When I get the headache, there is something wrong.”

Another participant could detect particular types of EMF exposures because they triggered specific symptoms. She explains that “The longer you have this, the more your body starts to distinguish, since now I've had it 23 years. On the road, I guess if there's ham radio in the area, even if I don't see it, I'll get this dull sensation throughout my body.” In contrast, she described the corporeal feelings caused by Wi-Fi as “really severe pins and needles, but not a pleasant tingling. It's a very horrible metallic pins and needles jabbing you, and your stomach gets really sick in this microwave way that's just impossible to describe.”

Yet not all participants were able to detect EMF exposures in their surroundings through their bodily sensations. At least two participants relied chiefly on measuring technologies to protect themselves. One participant explains that she only learns of EMFs sometime after she is exposed to them, when she must experience the physical symptoms. To avoid these delayed negative effects, she employs a measuring device to investigate the location for sources of exposures, and if necessary, departs or makes changes to the environment.

Among the other participants, some eschewed the use of measuring technologies altogether, preferring to trust their body to alert them of EMFs, while others trusted in the knowledge learned through their bodies while still using these technologies to confirm what their bodies had discovered. As one woman in the study explains, “A meter can confirm that you may be feeling something that meter can record or demonstrate, but learn to trust your own body, what you're detecting.” This participant had truly come to rely on her body to assess the risk of the environments she encountered.

Leaving and Searching for Safe Environments

When individuals discover the presence of harmful EMFs in their living environments through corporeal sensations or by utilizing measuring technologies, they work to create tolerable housing conditions by managing these EMF exposures in the home. These strategies include opting for technologies such as incandescent lightbulbs, landline telephones, and wired internet connectivity; effecting structural changes to a built environment, such as rewiring a building’s electrical circuits; or not making use of things powered by electricity altogether.

Yet despite extensive efforts to minimize EMF exposures within a home, exterior EMF exposures, such as those emitted by their neighbors' Wi-Fi and cellphones, as well as power lines and ever-proliferating cellphone towers, may enter built environments and trigger physical symptoms among people living with EHS.

To manage EMFs which emanate from the outside of one's controlled environment, additional action is necessary. Just as de Graaff and Bröer (2012) noted that EHS sufferers attempt to shield their bodies from these EMFs through materials which reflect or absorb electromagnetic radiation, such as special paint applied to a home's walls, a number of participants in this study likewise employed the use of such strategies to ensure their physical safety.

Efforts to manage exterior EMF exposures are not always successful, and what cannot be shielded must be escaped. Individuals with EHS leave their homes in search of relief from the often debilitating and painful health problems associated with these exposures. Just as Gibson (2009:191) notes that people living with environmental sensitivities come to live "in cars, trailers, tents, or on others' porches" due to their increased sensitivity and loss of resources, most of the participants had gone to great lengths to find areas with less EMF exposures. Before moving to the county, at least three women in the study had driven to places that offered relief and slept in their cars, an approach that subjected them to the dangers of sleeping in public places.

For instance, because of her neighbors' Wi-Fi, one woman with EHS found it exceedingly difficult to be in her own home for long stretches of time. She sought relief by spending parts of the day in her car, which was parked on the street of her urban neighborhood.

This innocuous behavior, however, soon garnered the wrath of her neighbors, people with whom she had previously enjoyed good relationships. In her words, she states:

> One man said, "You know, you can't stay here on the street like this in your car. There's kids around here." And I said, "Yeah, you wanna know something? You're right. There are kids. I took your freaking kids to school every day for 10 years. Really, you're gonna – why don't you come out with a cup of coffee and say hey, why are you staying in your car?"

On one occasion, a neighbor went so far as to report her habit of sitting in her car to the police, making her the second participant in the study to report being approached by police for spending time in one's car in public places. This participant recalled another instance of distress caused by the inability to safely inhabit her own home. Upon returning home one day, she found that the few spots in her neighborhood which offered relief were occupied by other cars. That night, she slept near a highway overpass. As she explains, "In order for me to be safe, I had to put myself in harm's way, yeah." Another participant's account of the incidents leading to her move to the county further illustrates the dangerous circumstances and urgency these individuals are faced with, as well as an awareness of the dwindling number of safe environments in the world:

> I was 79 pounds and my family thought I was dying. I'd learned from a friend that there was this place where they didn't have any cell towers and I was here in 48 hours. I said, "You mean, there's a place on earth that has no cell towers?" I was already packed in my car because I couldn't live in the house.

Without exception, moves to the county were galvanized by desperation and came after extensive searching for relief from bodily suffering caused by EMF exposures, a quest that, in many instances, lasted for years. Indeed, one participant had moved back from Europe to the United States in search of relief, and a former member of the community had relocated from as far as the Middle East. At the research site, the author observed that a number of study participants lived in campers.

These occurrences can be explained by the lack of environmentally safe housing worldwide. While there are a few publicly funded environmental housing projects catering to the needs of people with MCS (The Chemical Sensitivity Foundation 2019), the author is not aware of any existing public housing projects constructed for individuals living with EHS other than a pioneering development in Zurich, Switzerland (Gesundes Wohnen MCS 2019).

Asking for Accommodations

As Charmaz (1999) explains, sharing stories of suffering imperils one’s moral status and personal dignity. One woman in the study, while recollecting about an earlier time of living with her illness, remarks, “You have a hard time talking to other people about what's wrong with you because there's a lot of judgement, and there's a lot of stigma behind things.”

Yet silence also raises medical risks (Charmaz 1999) that may ultimately outweigh concerns over being stigmatized. In order to avoid exposures to EMFs and the symptoms they produce, almost all of the participants in the study reported calling upon others to change certain behaviors and refrain from taking certain actions when within their presence. In doing so, women and men with EHS were obliged to disclose their condition to family, friends, co-workers and neighbors, and thus risked damaging their moral status in order to pursue physical safety.

These requests involved the everyday use of a wide array of EMF emitting technologies. The ubiquity of mobile devices posed a substantial challenge to the wellbeing of the participants, and, above all, it was the use of these devices that galvanized individuals with EHS to speak up about their illness and ask to be accordingly accommodated.

One woman in the study shared that she asks all visitors to her home to turn off their mobile phones and leave them in their automobiles or in a designated area outside of the built environment. Another woman reports a similar situation, but in addition, she had placed a sign at the entrance to her house which declared the use of mobile phones to be prohibited. At the research site, the author also witnessed and learned of instances in which participants in the study asked employees in business establishments and other public spaces to temporarily turn off fluorescent lights.

In addition, at least one participant requested that her neighbors modify their use of Wi-Fi due to the physical symptoms this technology causes. This involved a process of negotiation: one neighbor agreed to place their router on the other side of their house, and turned it off altogether at night. However, this approach was not always successful, and she reported instances of neighbors completely refusing to change their habits in any way to accommodate her medical condition.

STIGMATIZATION, SOCIAL ISOLATION, AND THE LOSS OF SOCIAL RESOURCES

Without recognition from the dominant epidemiological paradigm, people with EHS are denied the sick role; the purported objectivity of medical science, therefore, does not provide a socially legitimate explanation for their deviant behavior (Bury 1982). As other scholars of contested illness have shown, this situation leads to stigmatization (Armentor 2017; Cuesta et al. 2019).

The Stigma of Mental Illness

Most of the participants in the study appeared to experience the stigma of mental illness. Just as Äsbring and Närvänen (2002) and Shriver and Waskul (2006), in their respective studies on people living with CFS/fibromyalgia and Gulf War Illness, found that individuals with contested illnesses experienced the psychologization of their physical health problems, all of the participants in the study reported that their somatic symptoms had been viewed as psychological by others. Such incidents were manifold and involved an array of social actors.

The research data was replete with instances of participants witnessing their physical symptoms being attributed to psychological causes by family, friends, and doctors. But above all, doctors were the most implicated when asked about this topic. Every participant that sought medical care for their health concerns caused by EMF exposures had experienced this phenomenon. For instance, a woman was recommended by two doctors to consider taking anti-depressants, and another specialist suggested that she seek the services of a psychiatrist. But one appointment with a neurologist particularly stood out in her memory. She recalls: “He said to me after the follow-up visit, he said, I think what you need to do is go home and pamper yourself and maybe get a haircut.”

The reaction this woman received when discussing her symptoms with a doctor may be, at least in part, influenced by the news and entertainment media: a number of participants suggested that popular depictions of EHS, in which it has largely been framed as a psychological rather than somatic condition, contribute to the stigmatization of their illness. One man noted how a television series that featured a character with EHS portrayed the illness in such a histrionic way as to render it “ridiculous.”

Another participant had given numerous interviews to reporters and filmmakers who had traveled to the research site, and expressed frustration at how, despite sharing scientific literature and her subjective experiences, she had been repeatedly portrayed as having a psychological condition.

The Stigma of Moral Offense

For those living with a contested illness such as EHS, an additional consequence of the inability and resulting failure to adopt the sick role is having one's morality called into question. Stigmatization due to perceived moral offense was noted by Cuesta et al. (2019) in their study of fibromyalgia, MCS, and CFS, and was also a theme that emerged during interviews with participants in this study. Women and men with EHS thus appear to be situated at the bottom of the "hierarchy of moral suffering:" because of the contested nature of EHS, the participants' stories of suffering are perceived as questionable and lead to a diminished moral status (Charmaz 1999). This questioning came in the form of accusing one of malingering, or as one participant described it, "making this up."

The reaction one woman received when she first told her brother about her condition illustrates this type of moral questioning. She describes the incident in these words: "He just kind of rolled his eyes like, oh God, you know. He told my mom that he thinks I was doing this all for attention. Like I'm 50 something years old and I'm doing it for attention, really?"

Social Isolation

When immersed in illness, people often become socially isolated. As stated by Charmaz (1991):

> As illness recasts and redirects their lives, they lose common interests and no longer share pursuits with friends and associates from earlier days. And as they pull in to manage their illness, these others slip away from them. Immersion in illness erodes or entirely drowns most earlier friendships and casual relationships. (P. 95).

But in the case of EHS, the contested status of the illness creates additional consequences for a person’s social world. In the study, it was noted that first, the failure to be believed by family, friends, significant others and acquaintances resulted in the breakdown of relationships. In addition, disbelief in one’s EHS leads to the loss of social resources among those living with the condition: when others would not take action or change behaviors related to EMF exposures, contact with such individuals was stopped in order to avoid negative health effects.

Among the participants, being disbelieved by people who attributed their illness to other physical or psychological causes, or who perceived them to be feigning the illness in order to avoid one’s duties or for other reprehensible reasons, was impetus for seeking distance from others either temporarily or permanently. Experiences of being doubted were explained by a number of participants in the study as demoralizing and painful. A woman who had distanced herself from her brother for this reason muses: “How could I possibly even have a relationship with someone who doesn’t give me the basic decent respect of believing me, you know?”

A participant noted that the emotional impact of being doubted hindered one’s physical energy, already taxed by managing her illness. She remarks, “I didn't bother talking to anybody about it, to be honest, because again, I wasn't in a strong enough space.... I knew, I knew where my weakness would be in that moment and I knew what I had to do.”

The strength or weakness of relationships prior to the onset of EHS may influence a person’s belief or disbelief in the condition, and therefore impact the preservation or dissolution of these social bonds: some participants in the study suggested that relationships which were already tenuous crumbled altogether due to the illness. As one woman stated, “Put it this way: a marriage, a relationship, anything that’s on the rocks, this can certainly tip it over.”

As discussed earlier, to ensure their physical safety, people with EHS are obliged to ask others to accommodate their illness by modifying their use of EMF emitting technologies when in their presence. When the everyday behaviors of others directly influence your health, ceasing contact with people who question the legitimacy of your illness becomes a question of survival. Such is the case of EHS. The majority of the research participants stated that they had ceased contact with individuals who would not refrain from engaging in actions which created EMF exposures when nearby.

The participants in the study recounted incidents in which family and friends refused to do something as simple as turn off their mobile phones when in their presence, and ultimately chose the unfettered and uninterrupted use of their mobile devices and other technologies over a relationship with the person with EHS. As one woman explained, “people choose Wi-Fi over your existence, you know.” At least one participant stated that her spouse’s frequent computer usage, which she viewed as an addiction, was a factor in the dissolution of her marriage.

Sometimes, EHS calls for structural changes to built environments. Indeed, EMF exposures abound in homes, and may require alterations to areas such as grounding systems, electrical wiring, and utility meters to improve a building’s environmental health (Baker-Laporte, Elliot, and Banta 2001; Lamech 2014; von Winterfeldt and Trauger 1996). Such modifications are difficult to achieve by one who is made unwell by EMFs, and people with EHS therefore depend on the aid of family and significant others to help create healthy environments.

At least one participant found that her partner’s unwillingness to effect changes in their home, which she attributed to his disbelief in her condition, led to marital problems. She recalls: “I said, could you change anything in the environment? You could help me change the environment, we're both architects, for God's sake. He said no, I'm not changing anything.”

Unable to safely live with her husband, the woman did not return to her home or marriage after leaving for medical treatment.

PROVING THE LEGITIMACY OF EHS

As we have seen, the failure of EHS to be accepted as a legitimate, physical illness by actors within medical, social and political arenas produces significant consequences for people who experience the daily reality of living with this problem. For participants in the study, being disbelieved resulted not only in economic losses, but losses of social resources as well. Proving the legitimacy of EHS to others, then, was crucial for both one's physical survival and moral standing. The failure of the dominant epidemiological paradigm to recognize EHS as legitimate ultimately obligates those living with the illness to have to prove their condition truly exists during daily interactions. An analysis of the strategies to achieve this end observed in the research data follows.

Obtaining a Medical Diagnosis

A medical diagnosis, and the medical code which this provides, is generally a prerequisite for access to the welfare benefits important for those unable to support themselves financially because of their health issues (Dumit 2006). Furthermore, official recognition of one's illness helps substantiate a person's symptoms and provides a sign that their behavior is warranted (Bury 1982). As Dumit (2006:579) explains, when "doctors can't name the illness, everyone – the patient's family, friends, health insurance, and in many cases the patient – comes to think of the patient as not really sick and not really suffering."

When asked about their experiences with doctors, three of the participants stated that they had been diagnosed with EHS. One participant, who had not suspected her health problems to be signs of EHS prior to being diagnosed with this medical condition, described receiving a diagnosis in the following words: “It made total sense. It just connected. I said, Oh my God, I think you’re right. It was like a light bulb moment for me.” For these three women, obtaining a diagnosis was a long, arduous, and expensive task. They all shared that they had met with an array of different doctors, and one participant had traveled extensively during this process.

This task is made more difficult by the EMF exposures which, as discussed earlier, are encountered in most doctors’ offices. One participant pointed out that not only does spending time in such an environment threaten one’s health; it also increases the risk of being psychologized by a doctor, and thus of not receiving medical legitimation. She remarks, “You can actually have the symptoms that are causing you agitation because you're actually in the doctor's office, okay. So you're actually feeling symptoms because of the exposure that you're getting. And you have to work really freaking hard at trying not to sound anxious.”

Not all who seek a diagnosis will receive it. Another participant had gone to great lengths to obtain a diagnosis of EHS, but was not successful in her efforts; official recognition of her illness from medical doctors was not granted. When discussing one particular experience with a medical doctor, she shared that she had spent a large amount of money and time going to appointments, only to have her concerns cursorily dismissed. She explains, “I waited three months for an appointment, she did testing, it took three more months for the follow up appointment, and she said, I can’t help you. There’s no consensus on diagnosis.”

Among the other participants in the study, however, receiving a diagnosis was given little importance. For these three individuals, consulting about EHS with medical doctors who worked within the confines of the dominant epidemiological paradigm was avoided in general. Because all of these participants had earlier been diagnosed with another contested illness, it is possible that previous negative experiences with medical doctors deterred them from seeking official legitimation of EHS.

Indeed, two participants who did not seek a medical diagnosis of EHS recounted instances of being disbelieved by medical doctors when seeking treatment for their initial contested illness. One man experienced the questioning of his chronic Lyme's disease, and stated that as a result of this experience, he did not seek a diagnosis of EHS. As he explains, "I've had very little faith in the mainstream medical system." Some of these participants tended to instead consult with alternative health practitioners. Furthermore, because all of the participants in the study who did not seek a diagnosis of EHS previously worked in the healthcare field, it is possible that these individuals draw upon their own expertise and past experiences to self-diagnosis and manage their illness.

Educating Others with Scientific Facts and Subjective Experiences

Almost all of the participants in the study made efforts to prove the legitimacy of EHS by educating others with scientific facts. This finding is similar to Dumit's (2006) observation that people with CFS and MCS share biomedical information about their contested illnesses in order to show others that their physical experiences are real. As Dumit explains, in scenarios involving "illnesses you have to fight to get," facts are forces in that they are mobilized to "prove" that a person truly suffers (p. 578).

Among the participants, efforts to prove the legitimacy of EHS were most often directed at family members. When asked about the way in which she explains her illness to members of her family, one participant shared that she provides them with relevant books, documentaries, and studies, such as the Bionitiative Report (2012). Another woman reported similar actions. This woman's siblings were skeptical about EHS, but eventually, after sharing various studies on the negative health effects of EMFs, some of them began to accept her illness as legitimate. This participant was frustrated, however, when one of her sisters nonetheless persisted in questioning her illness. She states, “I wanted to say, "I'm your sister. You don't even believe your own sister—I even gave you all the studies and you still don't believe it."

From the research data, it can also be concluded that two of the participants who pursued a medical diagnosis used scientific facts to prove the legitimacy of their illness to doctors. These individuals arrived at medical appointments prepared with peer-reviewed studies and other information on the various health effects of EMF exposures, as well as on EHS in particular. As such, in their pursuit of a diagnosis, it is evident that these participants both accept scientific explanations and utilize them to question medical authority.

One participant stated that she “had to educate” doctors about her medical condition. Her approach, however, was different; rather than make use of scientific research to prove her illness, she relied predominantly on her subjective experiences. As she states, “I told them my experiences.” By sharing these experiences with doctors, as well as with a wider audience through documentaries and television interviews, this participant had gained some recognition as an expert on EHS. As a result, she has indeed become a source of information for doctors. She explains, “I get telephone calls from doctors around the world a couple of times a month wanting to know what they could do to help their patients.” As Brown et al. (2012) contend, the lived experience of an illness gives individuals with a condition a standpoint not available to other people.

Making the Invisible Visible

EHS is characterized by a *double invisibility* that makes proving its existence to others difficult. First, the cause of symptoms, anthropogenic EMF exposures, are not visible to the human eye, are odorless, and are generally inaudible. Second, most, but not all, of the symptoms associated with EHS – such as physical pain, headache, and cardiovascular problems (Carpenter 2015) – cannot be readily perceived by others. From the research data, it can be gathered that by engaging in certain actions, the participants in the study made palpable both the presence of EMFs in the environment and the somatic sensations caused by these exposures.

That people with EHS utilize technologies which measure EMFs to ensure their physical safety has already been discussed. But in addition to this function, measuring devices also help participants in the study to prove the legitimacy of their illness to others: these technologies show others that though invisible, the sources of their symptoms indeed exist. In addition, such an approach demonstrates that EMF exposures may threaten the health of their family, friends, and doctors.

Furthermore, several participants reported that by making the somatic sensations caused by EMF exposures visible, others not only became more careful to not engage in behaviors which could cause them physical harm; they were also able to prove to others that they lived with a legitimate medical condition. These instances were generally spontaneous reactions to EMF exposures that inadvertently facilitated the process of proving the existence of one's EHS. One participant shares that by accurately announcing that a message to a nearby mobile phone had arrived, her father, who had previously questioned her illness, began to believe that she truly experienced somatic symptoms caused by electromagnetic field exposures. In her words, she explains:

> Well there was the time that me and my dad and my oldest daughter were standing in his kitchen and she had her phone outside – she was waiting for a phone call, she was waiting for an Uber – and I didn't know that her phone was outside and on, and I started

> feeling pain across here, and I said, Clare, where's your phone? "It's outside." I said, I think it just went off. She's like, "you can't feel it from there." I said, go check your phone, I think it just went off. And she went outside and it had went off. She had messages and there was no way I knew what was happening. So my dad was standing there for that interaction. My dad saw a lot of that happening and that's why he is very much on my side. He's like, "no, this is 100% real."

Another participant reports a similar situation. She had traveled to an urban area to meet with activists working toward increased regulation of EMF exposures. While sitting inside a building during a meeting, she reports having asked several times, “Did somebody just turn on a cellphone or something?” She explains that afterwards, an activist said to her, “Listen, I didn't want to tell you what was happening because I wanted to watch you, but you really should get with a scientist because every time you said you felt a cell phone or something, somebody had turned on the microwave in another room.” This participant views this occasion as one of the “inadvertent double-blind studies” she had unwittingly participated in.

In addition, one participant states that she had been “tested” on a number of occasions: in order to discern if her EHS was legitimate, others would intentionally bring a concealed mobile device nearby and observe her reaction. According to this participant, such behavior “is like breaking someone's leg and asking them, "Does it hurt to walk?” Though these occurrences may have helped to illustrate the legitimacy of her condition, such experiments also threatened her physical safety.

DISCUSSION

The preceding analysis illustrates the complexities of managing EHS, a process which involves both the social and the physical. In a society in which sources of EMF exposures are multitudinous and continue to proliferate at an alarming speed, people with EHS are barred from full participation in contemporary culture: because of the ubiquity of these exposures in contemporary public environments, people living with EHS experience difficulty in gaining access to medical care, employment, welfare, and are hindered in their efforts to work toward political organization and the medical legitimation of their contested illness. These physical barriers result in the loss of economic resources as they lead to a person's inability to financially support themselves. Due to the contested status of EHS, individuals living with this illness experience great difficulty in obtaining social benefits made more available to those with medically recognized conditions.

In addition to the loss of material resources, people with EHS face challenges to their social relationships. Without medical recognition of their somatic symptoms from social actors who adopt the dominant epidemiological paradigm, they experience the doubting of their illness by family members, spouses, and friends, which gives way to stigmatization: their physical issues come to be seen as psychological or attention-seeking in nature, and they come to bare the stigmas of mental illness and moral offense.

When others do not believe EHS to be legitimate, they are less likely to alter their behavior in the presence of the sufferer so as to avoid generating EMF exposures through their actions. Stigmatization from others also presents a threat to a sufferer's moral status. Consequently, in order to avoid harm to their physical health and moral status, contact with such individuals is ceased, and the social world of the EHS sufferer diminishes.

For people living with EHS, then, proving the existence of their illness to others is important for maintaining or obtaining economic and social resources. As the study revealed, people with EHS employed several strategies in order to prove the legitimacy of their condition to others. Obtaining a medical diagnosis aided some of these individuals in their efforts to illustrate the existence of their illness. In addition, individuals with EHS educated others with scientific facts and their subjective experiences in order to prove the legitimacy of their physical health problems. Finally, intentionally or inadvertently making EMF exposures and the physical symptoms they cause visible to others also helped prove the legitimacy of EHS.

While people with EHS attempted to prove the existence of their physical condition in order to avoid losing economic resources, relationships, and moral status, they also were faced with a more immediate concern, the physical management of EMF exposures. A number of approaches were taken by people with EHS to ensure their own physical safety. By detecting EMFs through their bodies or with measuring technologies, they were able to identify the presence of harmful exposures in a particular environment. This knowledge was acted upon by either leaving a harmful area or, when possible, by effecting changes to reduce exposures. When EMF exposures within an environment could not be managed, however, people with EHS left their homes in search of areas that offered corporeal relief. An additional strategy utilized by people with EHS was to ask that others modify certain behaviors related to the usage of mobile phones and other technologies when in their presence. The exploratory research conducted in this study reveals the great difficulty these people confront every day as they attempt to manage their EHS.

CHAPTER 5 CONCLUSION

The in-depth interviews and observations utilized in this exploratory qualitative study of the management of EHS illuminate the great challenges people with this condition face as they attempt to survive in a society driven by technologies that make them physically ill. The use of a grounded theory approach revealed a number of important themes. From the data, it can be gleaned that people with EHS are impeded from participating in everyday life because of the ubiquity of EMF exposures. One of the consequences of these barriers is the loss of economic resources, as all of the participants had lost their ability to work or were left without shelter, a situation that was seldom ameliorated by welfare, as the contested nature of EHS makes obtaining the assistance made available to those living with medically recognized conditions nearly impossible.

Additional themes that emerged from the data are the stigma and social isolation experienced by people with EHS. All of the participants reported being disbelieved by others, which led to the interpretation of their reported physical symptoms as psychological, as well as the accusation of feigning illness to avoid one’s duties or for other reprehensible motivations, two stigmas which Cuesta et al. (2019) respectively refer to as the stigma of mental illness and the stigma of moral offense. In this case, being disbelieved by others led to the loss of social resources, as people with EHS ceased contact with others who did not view their illness as a legitimate condition in order to preserve their moral status and ensure their physical safety.

As this study indicated, proving the existence of EHS is of great importance to people living with this illness, as it is essential for maintaining or obtaining material and social resources. As such, people with EHS must contend with what Dumit (2006) refers to as an *illness you have to fight to get*, a condition in which sufferers must develop strategies in response to being denied legitimacy. To prove the legitimacy of their contested illness, most of the participants in the study utilized a number of strategies.

One of the most important ways to prove the medical existence of this condition is by obtaining a medical diagnosis of EHS, as a diagnosis not only helped to show family, friends and spouses that the illness was real, but moreover was crucial for gaining access to welfare benefits.

Participants in the study who had lived with another contested illness before EHS, however, eschewed a medical diagnosis. For at least one of these participants, this was a choice directly influenced by previous instances of being disbelieved by medical doctors. Scientific facts were also used by participants in the study to prove the legitimacy of their illness. By sharing scientific studies, books, and documentaries about the adverse health effects caused by EMFs, participants reported that, in certain cases, they were able to successfully prove to others that their condition truly existed.

Because EHS is characterized by a *double invisibility*, in which both the *symptoms* of the illness and the *environmental origin* of the illness are largely invisible to the eye, another strategy used by the participants to prove the legitimacy of their condition was to make EMF exposures and the physical symptoms they produce tangible. To make exposures visible, people with EHS utilized measuring devices which, in addition to demonstrating that such exposures are rampant in the environment, also illustrate that these exposures pose a risk to all. The somatic symptoms of EHS, which are generally of the invisible kind, were made visible by a number of research participants when they reacted to the presence of EMF exposures in the environment by, for instance, announcing when a text message had been delivered to a silent mobile phone. These instances were mostly spontaneous reactions which had the felicitous effect of demonstrating that EMF exposures were indeed physically felt by the participants. One participant in the study had been unknowingly tested by people who doubted her illness and therefore covertly brought technologies that emitted EMFs near her to observe her reaction, an action which allowed the participant to prove their illness, but at the risk of being physically injured.

The ways in which the research participants physically managed EMF exposures also revealed a number of findings. As de Graaff and Broër (2012) had observed among individuals living with EHS, the participants in this study relied upon their bodies and measuring technologies to detect exposures in the environment and take the necessary actions to ensure their physical safety. From the data, however, additional insights about this phenomenon can be gained.

Different approaches to evaluating one's environment for risks could be observed among the participants; some preferred to rely on their bodily sensations to identify exposures, while others primarily utilized measuring technologies to achieve the aforementioned goal. The reason for this divide can be attributed to a participant's ability or inability to immediately feel the effects of EMF exposures. For those with this somatic capability, using the physical body was the chosen approach, and for at least one participant, this ability was so developed after an extensive period of living with EHS that the person was able to make the connection between certain symptoms and particular forms of EMF exposures. Those who could not accurately survey their surroundings somatically instead relied on measuring technologies to locate EMF exposures. It should also be noted that some of those who relied principally on their bodies for exposure detection additionally used measuring devices as a way to confirm what they had initially learned through somatic sensations.

In addition, to physically manage EMF exposures, it was sometimes necessary for participants in the study to ask that their family, friends, co-workers and neighbors refrain from using certain exposure creating technologies, such as mobile phones and Wi-Fi, when in their proximity, requests similar to those which might be made by one suffering from asthma of a nearby person smoking a cigarette.

Asking for such accommodations necessitated disclosing EHS not only to primary group members, but also to more distant relations such as co-workers and neighbors. Though stigmatization was an obvious concern for participants in the study, this approach to the physical management of EMF exposures suggests that the more immediate threat to one's wellbeing posed by exposure emitting technologies often outweighs the potential threat to one's moral status.

Among the research participants, another approach to the physical management of EMF exposures was to leave environments where exposures could not be reduced in pursuit of areas that offered relief. While making use of special materials or effecting structural changes to a built environment can help manage EMF exposures, such approaches are limited in their success when one is faced with the challenge of exterior sources of exposures, such as a neighbor's Wi-Fi or a cellphone tower. Because of the great difficulty of creating a home environment safe from the ever proliferating EMFs of the hypermodern era, all of the participants in the research study had left their homes in a way akin to the fleeing of a natural disaster, a phenomenon that has led some in the news media to refer to people with EHS as “Wi-Fi refugees” (O'brien and Danzico 2011).

In their search for relief from the effects of EMFs, the research participants experienced the diminution of their physical worlds. Indeed, in urban areas replete with sources of exposures, the only habitable space may be located near a highway, for example. Having to leave their homes to spend time in these public places, which, in some cases, involved sleeping in cars alongside roads and in parking lots, placed these participants in vulnerable situations

That these participants were obligated to leave their homes to find safety from EMF exposures, actions which, for some, led to persecution by the police, illuminates the institutionally marginalized existence in which people with EHS find themselves. Even national parks, long a refuge for citizens looking for relief from the stresses of urban living, have been increasingly polluted with EMF exposures in order to satisfy the voracious desires of contemporary tourists for mobile communication. The dwindling amount of areas not replete with sources of anthropogenic exposures is not a problem solely found within the United States, but is instead a global phenomenon. Indeed, a number of people with EHS had travelled to the research site from different countries after learning of the limited EMF exposures in the area.

The participants in the study reported being stigmatized because of their EHS. Heretofore, the discussion of this stigma has been primarily concerned with the social consequences it causes for people with EHS. Yet a theoretical exploration of the origins of the latter is also essential for a thorough understanding of the sociological aspects of this illness, an endeavor which, to the author’s knowledge, has not been pursued in the literature until now. The findings of this research allow for a tentative answer to the theoretical research question: Why are people with EHS stigmatized?

Stangor and Crandall’s (2000) theory of the origins of stigma offers a theoretical context to understand EHS as a condition which poses tangible and symbolic threats at the individual and societal level. It can be suggested that EHS poses a tangible threat to the telecommunications industry: if this contested illness comes to be widely recognized as a legitimate medical condition, this industry, which has played no small part in the proliferation of EMF exposures in all spheres of human life, will be liable to face great losses of economic resources and power. This contention is supported by the fact that, as stated previously, the numerous research studies funded exclusively by the telecommunications industry have been found to be considerably less likely to report significant effects on various end points that may be pertinent to health (Huss et al. 2007). Moreover, if the body of research which finds that EMF exposures lead to the adverse health effects associated with EHS were to become codified into the dominant epidemiological paradigm, the financial dealings of countless individuals and institutions would be endangered; in a “digital economy” built upon and fueled by wireless technologies (Zhang, Jin and Peng 2018), the idea that one’s means to economic resources could lead to illness is undeniably threatening.

Furthermore, due to the contested nature of their illness, people with EHS challenge the widely held medical and scientific beliefs of the dominant epidemiological paradigm, and therefore can be considered a threat to medical authority. This was well illustrated in the research data by the actions of participants who pursued a medical diagnosis. They entered doctors’ offices ready to counter claims that their illness was not a legitimate, physical condition with scientific studies and with knowledge learned from their own subjective experiences, and were often met with degrading comments made by medical professionals or were even told to leave.

But above all, EHS poses a threat to the very social order of contemporary Western societies. Perpetual connectivity to internet-enabled devices is becoming increasingly necessary for participation in everyday life (Gottschalk 2018). In asking that friends, family, spouses and coworkers refrain from using such technologies in their presence in order to ensure their physical safety, participants in the study disrupted this essential connection. Rather than mere tools to emerge from a long history of human ingenuity, these technologies are part of an expanding digital apparatus, defined by Gottschalk as “a nascent social system that is organized, powered, and expanded by computer technology” (2018:6).

Therefore, the inability and refusal to use communication technologies because of the EMF exposures they create, as well as the necessity to ask others to refrain from using such technologies in order to protect one's wellbeing, disobeys what Gottschalk (2018) refers to as *the regime of perpetual connectivity*, and challenges the ideology of surveillance capitalism.

All illnesses characterized by symptoms not recognized by the dominant epidemiological paradigm will subject those who live with them to stigmatization. But contested illnesses are not homogenous in terms of the stigma they place upon people who contend with these conditions. Contested *environmental* illnesses have a greater potential to be stigmatized for two primary reasons. First, these illnesses tend to implicate industrial risks as their causes, and thereby, as previously discussed, threaten the wealth and power of the entities responsible for the generation of toxic exposures. For example, unlike fibromyalgia, a disputed illness which has been less attributed to environmental causes, Gulf War Illness has been directly connected to war-related chemical exposures among Gulf War veterans who have called for governmental recognition of their medical conditions (Shriver and Waskul 2006).

Second, some contested environmental illnesses also call for changes of the everyday behavior of members of society as it is the actions of others that trigger their symptoms. EHS and MCS, for instance, are conditions largely provoked by the choice of others to engage in common practices such as wearing cosmetics with fragrance or utilizing mobile phones. In cultures which highly value individualism, this characteristic of environmental illness will be particularly stigmatizing. As such, it is here suggested that the greater an illness implicates industrial risks as its causation – thus imperiling the economic interests of capitalism – and the greater an illness calls for changes in personal choices among members of society for the sake of the wellbeing of the afflicted person, the greater will be the risk of stigmatization for the illness sufferer.

Recommendations for Further Study

The inchoate body of literature on the social aspects of EHS is informative, but this topic has nevertheless not been sufficiently researched to facilitate a thorough understanding of the lived experiences of this illness. Future research on the sociological aspects of EHS should delve deeper into the ways in which sufferers of this illness manage everyday life. In particular, researchers should compare experiences of EHS in both urban areas high in EMF exposures and locations low in exposures to discover differences in how this medical condition is lived in these discrete environments.

Additional research on this topic should also include the issue of stigmatization as it relates to EHS. It would behoove researchers to focus on the experiences of the stigma of EHS among groups of people stigmatized for other characteristics such as their race, sexuality, and so forth. In addition, while this study did examine the subjective experience of stigma among people with this illness, and a theoretical exploration of the potential origins of this stigma was undertaken, this research did not endeavor to understand the "stigmatizers." A focus on the latter will be important for a more thorough comprehension of the stigma associated with EHS.

Finally, and most importantly, the researcher here issues a call for a public sociology that focuses on the plight of sufferers of environmental sensitivities as victims of hypermodern industrial capitalism. Future research should continue to focus on the connection between the sociological aspects of EHS and social structure. Political and economic factors influencing the contestation of EHS must be scrutinized. If sufferers of these illnesses, such as EHS, are indeed "canaries in the coal mine," it is crucial that researchers lend their voices to illuminate their experiences. A failure to heed the warnings implicit in the stories of these populations may prove disastrous for society.

REFERENCES

Armentor, Janet L. 2017. “Living with a Contested, Stigmatized Illness: Experiences of Managing Relationships Among Women with Fibromyalgia.” *Qualitative Health Research* 27(4):462-473.

Äsbring, Pia and Anna-Lissa Närvänen. 2002. “Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia.” *Qualitative Health Research* 12(2):148-160.

Asghari, Ali, Amir A. Khaki, Asghar Rajabzadeh, and Arash Khaki. 2016. “A Review on Electromagnetic Fields (EMFs) and the Reproductive System.” *Electronic Physician* 8(7):2655-2662.

Baker-Laporte, Paula, Erica Elliot, and John Banta. 2001. *Prescriptions for a Healthy House.* Canada: New Society Publishers.

Belpomme, Dominique, Lennart Hardell, Igor Belyaev, Ernesto Burgio, and David O. Carpenter. 2018. “Thermal and Non-thermal Health Effects of Low Intensity Non-Ionizing Radiation: An International Perspective.” *Environmental Pollution* 242(Pt A):646-658.

Brandt, Allan M. 2012. “Inventing Conflicts of Interest: A History of Tobacco Industry Tactics.” *American Journal of Public Health* 102(1):63-71.

Bradley, Laurence A., Nancy L. McKendree Smith, and Graciela S. Alarcón. 2000. “Pain Complaints in Patients with Fibromyalgia Versus Chronic Fatigue Syndrome.” *Current Review of Pain* 4(2):148-57. doi: 10.1007/s11916-000-0050-2.

Brown, Phil, Rachel Morello-Frosch, Stephen Zavestoski, and the Contested Illnesses Research Group. 2012. *Contested Illnesses: Citizens, Science, and Health Social Movements.* Berkeley: University of California Press.

Brown, Phil, Steve Kroll-Smith, and Valerie J. Gunter. 2000. “Knowledge, Citizens, and Organizations: An Overview of Environments, Diseases, and Social Conflict.” Pp. 9–28 in *Illness and the*

Environment: A Reader in Contested Medicine, edited by S. Kroll-Smith, P. Brown, and V.J. Gunter. New York: New York University Press.

Brown and Williamson. 1969. Smoking and Health Proposal. Brown and Williamson document no. 680561778-1786. Available at: http://legacy.library.ucsf.edu/tid/nvs40foo.

Carpenter, David O. 2013. "Human Disease Resulting from Exposure to Electromagnetic Fields." *Reviews on Environmental Health* 28(4):159-72.

Carpenter, David O. 2015. "The Microwave Syndrome or Electro-hypersensitivity: Historical Background. *Reviews on Environmental Health* 30(4):217-22.

Chametzky, Barry. 2016. "Coding in Classic Grounded Theory: I've Done an Interview; Now What?" *Sociology Mind* 6:163-172.

Chateauraynaud, Francis and Josquin Debaz. 2010. "Giving a common Sense to Hypersensitivity: The Emergence of Electrohypersensitive People in Public Space." *Sciences Sociales et Sante* 28(3):5-33.

Cooper, Silvie and Leah Gilbert. 2017. "An Exploratory Study of the Experience of Fibromyalgia Diagnosis in South Africa. *Health (London)* 21(3):337-353. doi:10.1177/1363459316677623.

Corbin, Juliet and Anselm Strauss. 2008. *Basic of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 3rd Edition.* Thousand Oaks, California: Sage Publications, Inc.

De Graaff, M.B. And Christian Bröer. 2012. "'We are the Canary in a Coal Mine': Establishing a Disease Category and a New Health Risk." *Health, Risk, & Society* 14(2):129-147.

De Luca, Chiara, Jeffrey Chung Sheun Thai, Desanka Raskovic, Eleonora Cesareo, Daniela Caccamo, Arseny Trukhanov, Liudmila Korkina. 2014. "Metabolic and Genetic Screening of Electromagnetic Hypersensitive Subjects as a Feasible Tool for Diagnostics and Intervention." *Mediators of Inflammation.*

Dieudonné, Mael. 2017. “A Pathogenic Society? Environmental Hypersensitivities Through the Prism of Cognitive Sociology.” PhD dissertation, Institut des Sciences de l'Homme, ISH CNRS Centre Max Weber, Lyon, France.

Engebretson, Joan. 2013. “Understanding Stigma in Chronic Health Conditions: Implications for Nursing.” *Journal of the American Association of Nurse Practitioners* 25:545-550.

European Parliament. 2009. *European Parliament Resolution of 2 April 2009 on Health Concerns Associated with Electromagnetic Fields.* Brussels, Belgium: European Parliament. Retrieved March 28, 2019 (http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P6-TA-2009-0216+0+DOC+XML+V0//EN)

Federal Communications Commission. 2015. FCC Policy on Human Exposure. Washington, DC.

Genuis, Stephen and Christoper T Lipp. 2011. “Electromagnetic Hypersensitivity: Fact or Fiction?” *Science of the Total Environment* 414:103-12.

Gibson, Pamela Reed. 2009. “Chemical and Electromagnetic Exposures as Disability Barriers: Environmental Sensitivity.” *Disability & Society* 24(2):187-199.

Glantz, Stanton A., John Slade, Lisa A. Bero, Peter Hanauer, and Deborah E. Barnes. 1996. *The Cigarette Papers.* Berkeley: University of California Press.

Glaser, Barney G. and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Mill Valley, CA: Sociology Press.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon and Schuster, Inc.

Goldberg, Kim. 2015. “Sanctuaries.” Retrieved March 28, 2019 (https://electroplague.com/sanctuaries/).

Gottschalk, Simon. 2018. *The Terminal Self: Everyday Life in Hypermodern Times.* New York: Routledge.

Halayem, Soumeyya, Nouira Ons, Soumaya Bourgou, and Asma Bouden. 2010. “The Mobile: A New Addiction Upon Adolescents.” La Tunisie Médicale 88(8):593-6. Retrieved February 2, 2020 (https://www.researchgate.net/publication/45651860_The_mobile_a_new_addiction_upon_adolescents).

Havas, Magda. 2013. Radiation from Wireless Technology Affects the Blood, the Heart, and the Autonomic Nervous System.” *Reviews on Environmental Health* 28(2-3):75-84.

Hawkins, Robert A. 2013. “Fibromyalgia: A Clinical Update.” *The Journal of the American Osteopathic Association* 113:680-89. doi:https://doi.org/10.7556/jaoa.2013.034

Huss, Anke, Matthias Egger, Kerstin Hug, Karin Huwiler-Müntener, and Martin Röösli. 2007. “Source of Funding and Results of Studies of Health Effects of Mobile Phone Use: Systematic Review of Experimental Studies.” *Environmental Health Perspectives* 115(1):1—4.

International Commission on Non-Ionizing Radiation Protection. 1998. “ICNIRP Guidelines for Limiting Exposure to Time-Varying Electric, Magnetic and Electromagnetic Fields (Up to 300 GHz).” *Health Physics* 74(4):494-522.

Johansson, Olle. 2009. “Electrohypersensitivity: State-of-the-Art of a Functional Impairment.” *Electromagnetic Biology and Medicine”* 4:245-258.

Kerr, Kathleen, Gayle Morse, Donald Graves, Fei Zuo, Alain Lipowicz, and David O. Carpenter. 2019. “A Detoxification Intervention for Gulf War Illness: A Pilot Randomized Controlled Trial.” *International Journal of Environmental Research and Public Health* 16(21):4143. doi: 10.3390/ijerph16214143.

Kirmayer, Laurence J., Danielle Groleau, Karl J. Looper, Melissa Dominice Dao. 2004. “Explaining Medically Unexplained Symptoms.” *The Canadian Journal of Psychiatry* 49(10).

Kheifets, Leeka, John Swanson, Shaiela Kandel, and Timothy F. Malloy. 2010. “Risk

Governance for Mobile Phones, Power Lines, and Other Electromagnetic Fields Technologies." *Risk Analysis* 30 (10):1481–1494.

Lamech, Federica. 2014. "Self-reporting of Symptom Development from Exposure to Radiofrequency Fields of Wireless Smart Meters in Victoria, Australia: A Case Series." *Alternative Therapies in Health and Medicine* 20(6):28-39.

Lipson, Juliene G. 2004. "Multiple Chemical Sensitivities: Stigma and Social Experiences." *Medical Anthropology Quarterly* 18(2):200-213.

Lu, Xi, Junko Watanabe, Qingbo Liu, Masayo Uji, Masahiro Shono, and Toshinori Kitamura. 2011. "Internet and Mobile Phone Text-messaging Dependency: Factor Structure and Correlation with Dysphoric Mood Among Japanese Adults." *Computers in Human Behavior* 27(5):1702-1709. doi: 10.1016/j.chb.2011.02.009.

McCarty, David E., Simona Carrubba, Andrew L. Chesson, Clifton Frilot, Eduardo Gonzalez-Toledo, Andrew A. Marino. 2011. "Electromagnetic Hypersensitivity: Evidence for a Novel Neurological Syndrome." *The International Journal of Neuroscience* 121(12):670-6.

Mack, Natasha, Cynthia Woodsong, Kathleen Macqueen, Greg Guest and Emily Namey. 2005. "Qualitative Research Methods Overview." Pp. 1-12 in *Qualitative Research Methods: A Data Collector's Field Guide.* USAID.

Major, Brenda, John F. Dovidio, Bruce G. Link, and Sarah K. Calabrese. "Stigma and Its Implications for Health: Introduction and Overview." Pp. 3-28 in *The Oxford Handbook of Stigma, Discrimination, and Health,* edited by B. Major, J.F. Dovidio, and B.G. Link. Oxford: Oxford University Press.

Miller, Anthony, L. Lloyd Morgan, Iris Udasin, and Devra L. Davis. 2018. “Cancer Epidemiology Update, Following the 2011 IARC Evaluation of Radiofrequency Electromagnetic Fields (Monograph 102).” *Environmental Research* 167:673-638.

National Toxicology Program. 2018. *NTP Technical Report on the Toxicology and Carcinogenesis Studies in Sprague Dawley (Hsd:Sprague Dawley® SD®) Rats Exposed to Whole-body Radio Frequency Radiation at a Frequency (900 Mhz) and Modulations (GSM and CDMA) Used by Cell Phones.* Technical Report. Retrieved September 25, 2020 (https://ntp.niehs.nih.gov/ntp/htdocs/lt_rpts/tr595_508.pdf?utm_source=direct&utm_medium=prod&utm_campaign=ntpgolinks&utm_term=tr595).

Neuberg, Steven L, Dylan M. Smith, and Terrilee Asher. 2000. “Why People Stigmatize: Toward a Biocultural Framework.” Pp. 31-61 in *The Social Psychology of Stigma*, edited by T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull. New York, NY: Guilford Press.

O’brien, Jane and Matt Danzico. 2011. “‘Wi-fi Refugees Shelter in West Virginia Mountains’”. *BBC*. Retrieved September 29, 2020 (https://www.bbc.com/news/world-us-canada-14887428).

Oreskes, Niomi and Erik M. Conway. 2010. *Merchants of Doubt.* New York: Bloomsbury Press.

Orne, Jason and Michael M. Bell. 2015. *An Invitation to Qualitative Fieldwork.* New York, NY: Routledge.

Pall, Martin L. 2015. “Scientific Evidence Contradicts Findings and Assumptions of Canadian Safety Panel 6: Microwaves Act Through Voltage-gated Calcium Channel Activation to Induce Biological Impacts at Non-thermal Levels, Supporting a Paradigm Shift for Microwave/Lower Frequency Electromagnetic Field Action.” *Reviews on Environmental Health* 30(2):99-116.

Panagopoulos, Dimitris J., Olle Johansson, and George L. Carlo. 2013. “Evaluation of Specific Absorption Rate as a Dosimetric Quantity for Electromagnetic Fields Bioeffects.” PLOS One 8(11).

Parson, Talcott. 1951. *The Social System.* New York: Free Press.

Pierret, Janine. 2003. “The Illness Experience: State of Knowledge and Perspectives for Research.” *Sociology of Health and Illness* 25:4-22.

Rossi, Sabrina and Alessio Pitidis. 2018. “Multiple Chemical Sensitivity: Review of the State of the Art in Epidemiology, Diagnosis, and Future Perspectives.” *Journal of Occupational and Environmental Medicine* 60(2):138-46. doi: 10.1007/s11916-000-0050-2.

Rossi, Sabrina, Nicola Vanacore and Pietro Comba. 2019. “Multiple Chemical Sensitivity: Pursuit of a Scientific Consensus, Need for a Public Health Response.” *Annali dell’Istituto Superiore di Sanità* 55(4):319-22. doi:10.4415/ANN_19_04_03.

Russell, Cindy L. 2018. “5 G Wireless Telecommunications Expansion: Public Health and Environmental Implications.” *Environmental Research* 165:484-495.

Santini, Silvano J., Valeria Cordone, Stefano Falone, Carla Tatone, Fernanda Amicarelli, and Giovanna Di Emidio. 2018. “Role of Mitochondria in the Oxidative Stress Induced by Electromagnetic Fields: Focus on Reproductive Systems.” *Oxidative Medicine and Cellular Longevity* 3.

Scambler, Graham and Anthony Hopkins. 2008. “Being Epileptic: Coming to Terms with Stigma.” *Sociology of Health and Illness* 8(1):26-43.

Schaller, Mark. 1999. *Intergroup Vigilance Theory: An Evolutionary Theory of Intergoup Cognition.* Manuscript submitted for publication.

Segall, Alexander. 1976. “The Sick Role Concept: Understanding Illness Behavior.” *Journal of Health and Social Behavior* 17(2):162-169.

Shriver, Thomas E., and Dennis D. Waskul. 2006. “Managing the Uncertainties of Gulf War Illness: The Challenges of Living with Contested Illnesses.” *Symbolic Interaction* 29(4): 465-486.

Shuren, Jeffrey E. 2018. *Statement from Jeffrey Shuren, M.D., J.D., Director of the FDA’s Center for Devices and Radiological Health on the National Toxicology Program’s Report on Radiofrequency Energy Exposure.* U.S. Food and Drug Administration Statement.

Stangor, Charles and Christian S. Crandall. 2000. “Threat and the Social Construction of Stigma.” Pp. 62-87 in *The Social Psychology of Stigma,* edited by T.F. Heatherton, R.E. Kleck, M.R. Hebl, and J.G. Hull. New York: The Guilford Press.

Stuber, Jennifer, Ilan Meyer, and Brunce Link 2008. “Stigma, Prejudice, Discrimination and Health.” *Social Science and Medicine* 67(3):351-357.

United States v. Philip Morris USA Inc., 449 F. Supp. 2d 1 (D.D.C. 2006), aff’d in part & vacated in part, 566 F 3d 1095 (D.C. Cir. 2009) (per curiam), cert. denied, 561 U.S. ___, 130 S. Ct. 3501 (2010).

Verizon Wireless. 2019. *4G LTE Router – Important Consumer Information.* Retrieved December 22, 2019 (https://www.verizonwireless.com/support/4g-lte-router-legal/).

Von Winterfeldt, Detlof and T. Trauger. 1996. “Managing Electromagnetic Fields from Residential Electrode Grounding Systems: A Predecision Analysis.” *Bioelectromagnetics* 17(2): 71–84.

Wilke, Isabel. 2018. “Biological and Pathological Effects of 2.45 GHz Radiation on Cells, Fertility, Brain, and Behavior.” *Umwelt Medizin Gessellschaft* 31:1-38.

World Health Organization. 2019. Electromagnetic Fields (EMF). Retrieved November 2, 2019 (https://www.who.int/peh-emf/standards/en/).

Yang, Lawrence H., Valerie Purdie-Vaughns, Hiroki Kotabe, Bruce G. Link, Anne Saw, Gloria Wong, and Jo C. Phelan. 2013. “Culture, Threat, and Mental Illness Stigma: Identifying Culture-Specific Threat Among Chinese-American Groups*.” Social Science & Medicine* 88:56-67.

Zavestoski, Stephen, Brown, Phil, McMormick, Sabrina,Mayer, Brian, D'Ottavi, Maryhelen, Lucove, Jaime C. 2004. “Patient Activism and the Struggle for Diagnosis: Gulf War Illnesses and Other Medically Unexplained Physical Symptoms in the US.” *Social Science and Medicine* 58:161–75.

Zhang, Bin, Zhiye Jin and Zhidao Peng. 2018. "Bridging the Digital Divide: Making the Digital Economy Benefit to the Entire Society," 22nd ITS Biennial Conference, Seoul 2018. Beyond the boundaries: Challenges for business, policy and society 190412, International Telecommunications Society (ITS).

APPENDIX. INTERVIEW GUIDE

1. What is your gender?
2. What race/ethnicity do you identify with?
3. What is your educational background?
4. What is your age?
5. What is your occupation?
6. When did you initially experience the symptoms of electromagnetic hypersensitivity (EHS)?
7. Were you diagnosed with electromagnetic hypersensitivity?
8. Can you tell me about the kinds of doctors you have consulted?
9. How have doctors responded to your EHS?
10. Can you tell me about how you explain your health concerns to doctors?
11. In what ways do you manage your relationship with doctors? What approaches have been most and least successful?
12. Can you tell me if EHS has affected your relationship with family members? If so, in what ways?
13. How do you describe EHS to your family?
14. Can you tell me about how your family responded to your EHS?
15. After you learned that you had EHS, did your relationships with family members change? If so, how?
16. In what ways do you manage your relationships with family members? What approaches have been most and least successful?
17. Can you tell me if EHS has affected your relationships with friends? If so, in what ways?

18. How do you describe EHS to friends?
19. Can you tell me about how your friends responded to your EHS?
20. After you learned that you had EHS, did your relationships with friends change? If so, how?
21. In what ways do you manage your relationships with your friends? What approaches have been most and least successful?
22. Do you work presently? If so, has EHS affected your relationship with coworkers? If so, how?
23. If you do not work, did EHS lead to this situation?
24. Is there a common view that people tend to have about EHS? If so, do you think that view has affected your relationships with others in the past?
25. Did you move to the research site? If so, why did you move here?
26. What do you like about living here?
27. What do you dislike about living here?
28. What has it been like living in a community with others who share your illness?
29. Can you tell me about your relationships with people at the research site who have EHS?
30. Can you tell me about your relationships with people at the research site who do not have EHS?