GIVING VOICE TO MULTIPLE SCLEROSIS: A PATIENT

AND PROVIDER INVESTIGATION

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With the advent of the telephonic and technological healthcare revolution, pharmaceutical corporations seek to improve patient compliance and quality of life by contracting with services providers. As an employee of one such provider, working for more than three years on a medication for the neurologically degenerative disease, multiple sclerosis, this investigation utilizes a mixed methodological approach. In order to improve and diversify the clinical services provided to patients, I was contracted as a consultant. I interviewed phone and PRN nurses, developed and released a PRN survey, and interviewed patients living in the Dallas/Fort Worth, Texas area. The combined experiences and expertise of the three groups who participated would serve to inform and develop new programs and services for patients with differing disease states. The research resulted in a re-imagining of the social networking theory of health, as well as the works of Pierre Bourdieu and Michel Foucault, to serve the evolving tele-health and technologically based healthcare workplace.

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CHAPTER 1

INTRODUCTION

This thesis serves as the culmination of more than a year's worth of planning and execution. Developed for the clinical services department of both my employer and my thesis client, multiple sclerosis (MS) was selected as the disease state of focus due to my more than three years worth of experience working as a program coordinator on a program for patients living with MS. Combining both applied anthropological methodology and theory, with a public health framework, the project has undergone many changes and challenges, including layoffs, promotions, and the MS program itself being transferred to the care of another company. After all of that, the goal of completing an ethical and inclusive final product that could benefit not only MS patients and programs run by the client, but also potentially any patient living with a chronic, or difficult to manage, disease was nevertheless achieved.

The Client

The client is a patient services provider. Headquartered in the southern United States, the client has offices located in several states, including the office where I, as the researcher, found my thesis client. Primarily a call center, focusing on telephonic and technologically based patient services, the client prides itself by "putting the patient first" and developing new and innovative tools and services to provide to patients via e-health techniques. The client specializes in clinical services as well as reimbursement services; focusing on insurance navigation as well as benefit verification, my client's reach and ability concerning patient services has enjoyed virtually constant expansion since its inception in the 1980s.

The clinical services department of the client is first and foremost a call center, and operates through the combination of a variety of roles. For the sake of generalization, the list of potential positions will be shortened. The position with the highest population within clinical services is that of the phone nurse. Phone nurses are registered nurses, holding at least an associate's degree in nursing, who are responsible for a variety of responsibilities. Such tasks include patient case management, direct interaction with patients through telephonic nursing and healthcare, communicating with doctor's offices and clinics, and tracking assistance and funding applications on behalf of patients. Phone nurses may either work in an office setting, or may work remotely from home.

Nurses can also be contracted employees, utilized on a per case basis, called per diem registered nurses (PRNs). Located potentially in every state of the country, and even in Puerto Rico, PRNs are contracted on a case-by-case basis, assigned to travel to the patient's location to provide in-home training on proper medication use and administration. The final clinical services position discussed is that of the program coordinator (PC). Responsibilities included scheduling and tracking patient in-home training with PRNs, ordering supplies, keeping inventory on those same supplies, and maintaining bureaucratic integrity concerning all necessary program paperwork. There are also management positions, typically headed by another registered nurse, administrative assistant positions, as well as the necessary senior management team, including directors. I have worked for the client as a full-time associate with more than three of those years spent working on the same program for multiple sclerosis (MS) as a supportive program coordinator.

Project Overview

While the client does strive to put the patient first, the client is first and foremost a for-profit company, part of a larger international conglomerate. The process by which the client's business is maintained will now be briefly discussed. Programs are brought to the client by various pharmaceutical and drug manufacturers, a contract is negotiated and signed, and then the client is responsible for effectively administering the programs within the guidelines set down in the agreed upon contract. While the goals for such a partnership are numerous, patient compliance to their medication and treatment is paramount. A healthier patient, consistently and properly taking their medications, means a happier pharmaceutical manufacturer, and a happier manufacturer means a more profitable workplace for the client. So, truthfully, there are three major parties that the client is concerned about: the client itself, the pharmaceutical companies, and the patients. I have come to call these three parties, all relying and being contingent on one another, as the Big Three.

Client

Patients

The Big Three

Pharmaceutical
Manufacturers

Figure 1. The Big Three.

This research project was designed with the Big Three in mind, adhering to the company philosophy of putting the patient first, while not discrediting the reality of

meeting the company's numbers and providing the services contracted with pharmaceutical manufacturers who brought the client its work. Understanding that the work done by clinical services is helpful to the health and wellbeing of so many patients across the country, the purpose of this research project was conducted to potentially diversify and create new services for patients assisted by the client. I sought to combine provider's voices and experience, those employed by the client, with the voices and experiences of patients living with MS, to provide an evidence based list of recommendations for improving clinical services. In truth, this project was made to fulfill three components: first, to perform a needs assessment; second, to conduct a research investigation; and third, to compile evidence-based recommendations and deliverables to the client.

Justification

Through the implementation of the researcher's recommendations, the client can see a mutually assured benefit shared across the Big Three. Programs could have the potential become more patient-focused, supported by the wisdom and experience of actual patient participants. Programs can also be enhanced by the experience of existing employees, who shared their insights accordingly. The resulting alterations and improvements to the patient assistance services of the client can improve patient quality of life, provide an allure for existing and potential manufacturers, resulting in more contracts, thus, more work for the client. Revitalizing clinical services can in turn revitalize all departments that make up the client's business, keeping them at the foreground of the ever-changing telephonic and technological healthcare arenas. This

project influences sectors of the academic world as well. The findings serve to impart greater understanding of applied medical anthropology within the tele-health business. Results and analysis also impact public health and anthropology in general as they relate to healthcare and patient and provider relations.

Research Questions

My inquiries for this project were all interrelated. First, I wanted to understand the role of the nurses working for the client, both from a telephonic, or tele-health, setting, and as a per diem nurse (PRN) working and traveling out in the field. I sought to peel back the nurse experiences and how they provided care to their patients, and where the opportunities for improvement lay hidden. Second, I strove to comprehend the similarities and differences in the nurses' experience, whether on the phone or in the field, and how that expertise could influence the client's service programs. Finally, I wanted to learn from patients, living with multiple sclerosis, a disease that is difficult to prevent against by traditional means. If putting the patient first is truly important for the client's business, patient voices must carry intrinsic value for the future of programs meant to assist those patients. I wanted to find out how that assistance could be made manifest.

CHAPTER 2

MULTIPLE SCLEROSIS AND TELEHEALTH SERVICES

Multiple Sclerosis as a Disease

Multiple sclerosis (MS) is a neurologically degenerative disease and one of the major disorders of the central nervous system. MS is a progressively worsening chronic disease "characterized pathologically by the presence of numerous areas of demylinization in the central nervous system and a wide variety of neurological symptoms and signs which have a tendency toward remission and exacerbation" (Davis 1973, 5). To break the term down: "multiple" suggests there are more than one, and "sclerosis" refers to areas of sclerotic, or scarred, tissue (Webster 1989).

In the brain and all along the central nervous system, axons, or nerve fibers, serve as connections between muscles and organs, both primary and sensory. Axons are sheathed in myelin, a white substance that insulates and ensures rapid and uninterrupted communication from nerves to the rest of the body (Davis 1973; McDonald & Silberberg 1986; Webster 1989). If the electrical impulse between nerve fiber to the synapse to the next nerve cell is interrupted, this can cause a variety of reactions, such as muscle spasms. The lesions "of multiple sclerosis are areas of tissue damage arising from inflammation…which causes destruction of myelin" (Webster 1989, 16). To put it metaphorically, imagine that the nervous system is a length of electrical wiring, and the myelin is the rubber insulation that surrounds the conductive wires. The protective insulation ensures the electrical energy travels along the wiring and will effectively power a lamp or a laptop. Without that insulation, without the myelin, the electrical energy is not contained. It can then lash out to do damage to the surrounding objects, and the intended target (i.e. the lamp or laptop) cannot function

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properly. People living with MS have their insulation, their myelin, destroyed, and the resulting legion forms noticeable scar tissue via MRI (Webster 1989).

There are two typical classifications of MS: relapsing-remitting, and progressive. Relapsing-remitting MS is when a patient undergoes a cycle of activity and quiescence; where they can experience little to no immuno-deterioration for a significant span of time, even years (McDonald & Silberberg, 1986). During this period of peace, the patient's symptoms do not worsen, nor do they experience a relapse, where the nervous system's myelin is again attacked, resulting in new or worsening scar tissue. Naturally, in opposition, progressive MS is a diagnosis where it is "supposed that the [deterioration] process is continually active" (McDonald 1986, 130). These patients experience no period of peace, or remission, and their symptoms worsen with every attack experienced over a set period of time.

Typical symptoms of someone diagnosed with MS include, but are not limited to: fatigue, persistent and terrible pain, lack of control or sensation on one side of their body, spontaneous joint locking, and an inability to maintain one's equilibrium (NationalMSSociety.org). Stumbling and falling are common; often, patients with MS are forced to use canes, walkers, and wheelchairs, should their disease worsen (NationalMSSocity.org). Uncontrolled shaking, loss of memory, loss of eyesight, and speech and swallowing troubles have also been known to arise from MS (MultipleSclerosis.net). Consistency of symptoms across individuals is extremely rare; the unpredictability of MS remains a constant concern as well (Medscape.com).

As early as twenty to thirty years ago, MS was an extremely unpredictable and difficult diagnosis for many neurologists (McDonald & Silberberg 1986). Recent

research into the underlying causes and processes of MS continue, and advances in virology and immunology have greatly increased understanding of the disease, but precise etiology remains unclear (McDonald & Silberberg 1986). The disease itself is not visible; MS does not appear outside the body, where the public can see the legions. Because of this, misdiagnoses were not uncommon in the past. Interestingly, due to its invisible nature, the Centers for Disease Control and Prevention do not require new patient and MS symptoms to be reported (NationalMSSoceity.org).

Multiple Sclerosis: A Valid Public Health Concern

Due to the etiology, the cause, of MS remaining unknown in the biomedical sciences, and the fact that a cure for MS also remains out of reach, public health intervention and investigation would provide some of the best services for improving the health and wellbeing of patients living with MS. The entire practice of public health involves not only the prevention of diseases, but also to improve the lives and well-being of communities. A significant proportion of the work of the public health domain seeks to improve rates of healthy behavior for preventing preventable diseases. While this endeavor is both relevant and admirable, the existence of diseases like MS, which are not preventable by typical means (i.e. diet, exercise, etc.), and the number of people living with those diseases, both support the need for active public health concern. While any societal or community-based intervention for patients with MS would have little impact on the bio-chemical research that could lead to a cure, the potential cultural improvement to quality of life makes the work of public health professionals essential (McDonald & Silberberg 1986; Boiko et al. 1998).

The epidemiology of multiple sclerosis is of a chronic disease that seems to be both economically and geographically biased; "over the last [few decades], it has become clear that the distribution of the disease is regional with a distinct predilection for temperate climate and economically developed countries" (Gonzalez-Scarano et al. 1986, 38). Following the guidelines of the epidemiological transitional model of disease, MS tends to arise far more frequently among the developed nations. Figure 2 illustrates the epidemiological transition; it shows how the divide exists between developing nations and their tendency toward contracting infectious disease, and developed nations experiencing more chronic diseases. It should be noted that the terminology in Figure 2: "pre-modern," "urbanizing/industrializing," etc. have been coded according to the source's particular epistemological framework.
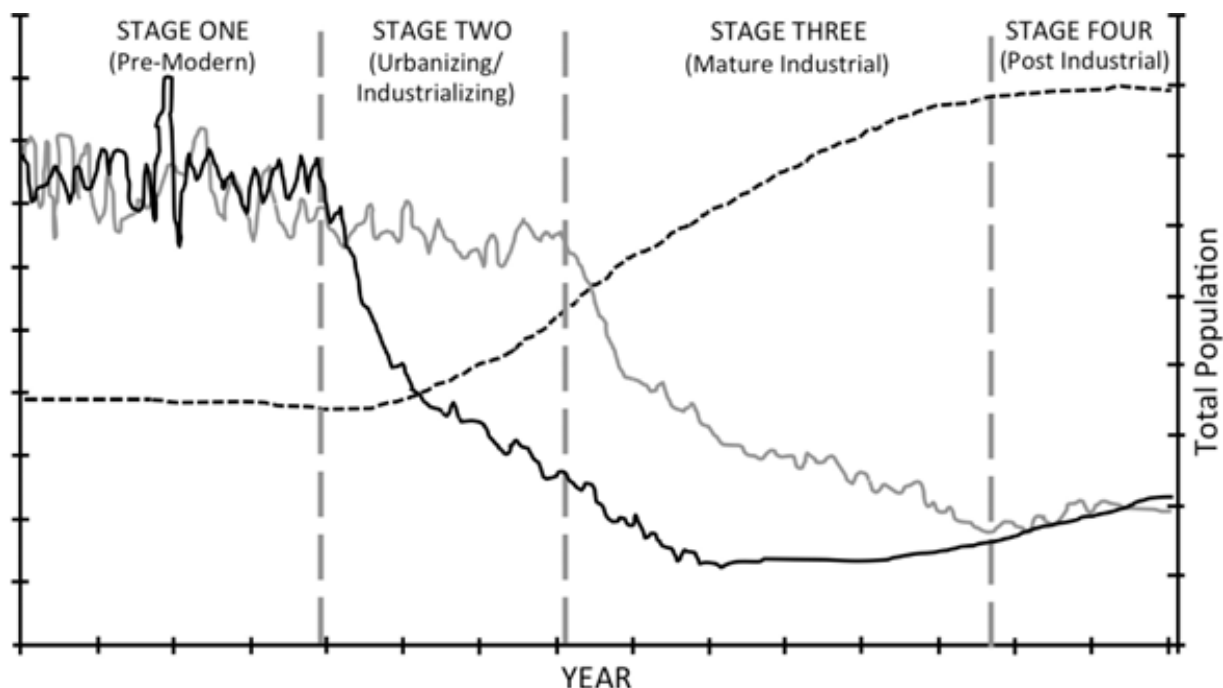
Figure 2. The epidemiological transition model (Zuckerman et al., 2014).

There are 2.3 million people living with MS worldwide, and the numbers continue to grow (MultipleSclerosis.net; NationalMSSociety.org). Prevalence of MS increases as the distance from the equator also increases. This lends itself to the traditionally observed frequency of Caucasian patients being diagnosed more often than persons of color (Boiko et al. 1998; Inglese 2006; NIH.gov). Women have also been diagnosed with MS far more frequently than men, with estimates ranging from three women to every one man, as well as up to five women for every one man (LaVela et al. 2012; NIH.gov; Noonan et al. 2002). Symptoms first tend to manifest between twenty and forty years of age, and as such as broad range would suggest, plenty of patients experience their onsets before and after this median span of time (Alonso & Hernan 2008; NIH.gov).

However, these numbers and trends are rapidly changing. In the United States, there are more than 400,000 existing patients living with MS, and more than 10,000 new cases diagnosed every year; that's more than 200 new cases per week (MultipleSclerosis.net). As more and more cases of MS are reported, more and more are being discovered in developing nations, more and more are appearing in persons of color, and there has been a significant rise in the number of cases found in men (Alonso & Hernan 2008; Inglese 2006). There is stipulation that these changes are linked to migration farther away from the equator, as well as certain nations transitioning to the chronic illness side of epidemiological model due to economic progression, but conclusive explanations remain elusive (McDonald & Silberberg 1986). The rising rates among previously unaffiliated nationalities, all genders, races and ethnicities, as well as

the severely debilitating nature of the disease, supports the great need that exists

for public health action concerning multiple sclerosis.

In the United States, for example, MS patients often find themselves unable to

work, living with insufficient mobility and transportation, and struggling financially and

socially, as a direct result of their illness (Flensner et al. 2013; Kobelt et al. 2006).

Public health's inclusive perspective on health and wellness directly mirrors the holistic

ideology of applied and traditional anthropology. Public health recognizes the

importance of the social determinants of health: employment status, social relationships,

physical activity, and many more all influence health and wellness (Nelson et al. 2007;

Rafusson et al. 2015). Anthropology recognizes the inherent connection of all things

human, making up what we call culture. Medical anthropology teaches us the necessity

of acknowledging all aspects of a community, of an individual, and working to alter parts

of a whole to improve the whole big picture (Whiteford & Bennett 2005).

Multiple sclerosis is and has been a valid public health concern since its

discovery. The rapidly altering environments and circumstances being attributed to the

rates of the disease, as well as the rising number of active surviving cases, speak to the

need for increased public health involvement. Such improvement or involvements could

occur in the improvement of occupational compatibility with MS patients, or access to

effective mobility assistance. Anthropological methodology can contribute the

necessary skill set and expertise to advance public health's relationship with MS.

Anthropology examines all aspects of a culture, whether the intervention seeks to

realize MS friendly workplaces, or developing easily accessible mobility services, or any

other MS-related problem that needs addressing, public health has the tools necessary to influence and improve many lives.

Tele-Health Nursing and Technology Based Healthcare

As the realities and the dynamic of the ever-evolving technological world continue to shape and re-shape our understanding and access to information, so too will other sectors of human life change to accommodate. E-Health, tele-health, and tele-medicine are some of the ways that healthcare has recently adapted to the needs and wants of the medical world, shaped partially by the twenty-first century goal for high-quality healthcare available for everyone (Hamett 2006). Utilized by both patients and providers alike, these services have rapidly become a staple of the American healthcare industry, as well as the rest of the developed world (Newman et al. 2016).

Tele-health, or tele-medicine, shares its roots with the Greek word for "at a distance;" essentially, tele-health is healthcare provided at a distance (Maheu et al. 2001). Tele-health services, then, are services "delivered at a distance, to people who are not necessarily unwell, but who wish to remain well and independent" (Craig & Patterson 2006, 4). Services can be provided by any number of professionals, often licensed, and are included, but not limited to public health professionals, social workers, and nurses. The client of this research project prides its clinical services department being headed almost entirely by registered nurses.

Tele-health nursing, as well as any other medium of care, has accumulated its share of benefits and criticisms. Benefits have been found to include: improved access to information, improved access to services, increased care delivery, reduced

healthcare costs, and higher levels of patient agency and patient self-efficacy (Hjelm 2006). Concerns and criticism of tele-health include a potential breakdown of relationships between patient and provider, issues concerning the quality of information, and organizational, ethical, and bureaucratic difficulties (Hjelm 2006). Ethically, there are always concerns over the protection of personal health information; the misuse of that information can be extremely harmful to the patient as well as the organization seeking to provide them with care. However, the implementation of federal law, such as the Health Information Protection and Accountability Act (HIPAA) provide effective and universal guidelines for compliance, reducing the instances of ethical or organizational slip-ups or oversights (Rutenberg & Oberle 2008). So, in some ways, federally implemented laws have surmounted the ethical concerns.

Tele-health is not limited to healthcare over the phone; as the name implies, any distance between provider and patient can be considered tele-health (Craig and Patterson 2006). Distances can be crossed through many different forms of technology in today's world. The wide range of Internet and cell phone applications makes access to information unlike ever before (Smith 2004). Text-based, and email-based, communication has drastically altered how humans communicate and interact with one another (Espensen 2009). As the methods and modes of communication change, so must healthcare and health education also change. Tele-health is what arose of this need, and the companies specializing in tele-health remain an existing and expanding expectation of the pharmaceutical services industry. The tele-health industry has also served to greatly diversify the field of nursing as well; as discussed by Jenkins and White (2001), telemedicine allows for nurses to perform their traditional roles, but with

greater ability to reach more patients, virtually anywhere in the world, increasing patient

satisfaction and addressing limited resources.

CHAPTER 3

LITERATURE REVIEW

Considering the nascent nature of call centers and tele-health organizations, the fields of anthropology and public health have only just begun their investigations; the potential information to compliment my own research is rather limited. However, what research has been done directly reflects my own findings and theoretical frameworks, including the works of Michel Foucault and the distribution and surveillance of power (Beirne et al. 2004; Sinha 2000; Winiecki 2007; Winiecki and Wigman 2007). The following section details the works of my contemporaries and how their research compliments my own. I start with the subject of MS before turning to the works of anthropologists and public health professionals. Then we look at the works of tele-health organizations themselves, the issues of power and subjectivity in call centers settings, and finally the effects of tele-health on both patients and the providers who serve them.

To begin, in 1998, experts from around the world gathered at the World Health Organization's headquarters in Geneva, Switzerland to discuss the implications and changing dynamics of multiple sclerosis and how public health could best address that. Their publication, released in 1999, came when, in some circles, tele-health had only just celebrated its first decade of existence (Maheu et al. 2001). The experts in attendance at this WHO hosted meeting, Boiko et al. (1999) recommended:

> …gathering patient information on all aspects of MS world-wide relevant to healthcare including epidemiology, impact and cost to society, treatments and outcomes. This should be done through standardization and integration of the various existing data collection initatives…convey such information on an on-going basis…[and] to supervise and take follow-up action…and identify need for further projects. (6)

Counting tele-health services among the "growing number of organizations…developing clinical practices…that outline proper care…and performance," companies like the client of this project could contribute to the collection and dissemination of relevant public health information (Boiko et al. 1999, 6). Utilizing components and combinations of my recommendations, listed in chapter seven, would lend the client, or any other tele-health service provider to contribute to this theoretically ever-expanding public health resource.

Arushi Sinha's "Overview of Telemedicine," published in the year 2000, provides a poignant look at tele-health relating to the fields of medical and applied anthropology. Sinha's article stresses the importance and the implications of the "deterritorialization" of healthcare; tele-health provides a cheaper, more convenient form of communication, which "allows biomedicine to interact with previous remote populations" (Sinha 2000, 294). While the author questions the outcomes of clinics and services becoming more and more virtual, an argument is made that benefits for the stakeholders in telemedicine matter more. Her words hold particularly true for the patients: "telemedicine offers a means of overcoming patient isolation while preserving a measure of patient autonomy," expanding their sense of agency and self-efficacy (Sinha 2000, 299).

Turning now to look closer at the works of public health relating to tele-health, Alverson et al. wrote of the usefulness of tele-health services in responding to emergencies or disaster response in their article published in 2010. The authors encouraged the increased "interagency cooperation" with tele-health corporations, with the potential to "support community-based participatory, translational, and multicenter interdisciplinary research" (Alverson et al. 2010, 113). Tele-health is not a healthcare

service limited to one fixed location, and as my research shows, a multicenter mixed methodology interdisciplinary project is indeed possible, and beneficial.

Along a different vein concerning the tele-health divide, Schmeida and McNeal (2007) wrote of the disparities that persist, even in this age of technology and information. Those barriers "arise largely from socioeconomic characteristics such as income, race, and education, as well as geography…creating gaps in the distribution of services" (Schmeida and McNeal 2007, 644). Tele-health and telemedicine, if applied appropriately, could serve to bridge that divide, lessening the impact of disparity. Income would not be an issue as many programs, like those of the client, are free for patients. Race and education level would be less of a factor because all interaction would be taking place without any in-person interactions; everything would be shared through technology, and any bias would be mitigated. Finally, as discussed later, geographic hurdles that plagued traditional healthcare would be surmounted by tele-health (Schmeida and McNeal 2007).

Realizing the potential contribution of tele-health to the whole of public health and other academic fields, tele-health also has been found to be an effective method of care from a more specified viewpoint. There have been a fair number of investigations into the effectiveness of tele-health services. For example, Cady et al.'s (2015) study on meeting the needs of children and their families through the use of a tele-health care coordination model found that over time, the adequacy of care received increased significantly. This resulted in part from a diversified set of services to address patient needs, such as bilingual providers, as well as the relationships developed with providers over time (Cady et al. 2015).

Tele-health services have also been found to assist with lowering public health and community costs to healthcare. In Cady et al.'s 2009 study into hospitalization rates as they relate to the utilization of a tele-health program, it was observed that the use of tele-health services contributed to more than half of unplanned hospital visits being prevented over the course of the year. The use of tele-health services in low-resource settings, be it geographically or financially troubled, has proven to be extremely beneficial. The distribution of information, the availability of resources and services, are made possible by the far-reaching nature of tele-health; as the influence continues to expand, Wootton and Bonnardot (2015) stress the importance of prudent monitoring. Tele-health organizations must take care to accurately "evaluate the quality of services being delivered and…being maintained;" doing so would serve to "overcome the huge constraints imposed by low-resource settings," resulting in redistribution of power and improving the self-efficacy of patients living in those areas (Wootton and Bonnardot 2015, 2).

In postindustrial developed nations, the subject of labor completed and mediated by computer and telecommunication technologies has been a subject of wide study, but not as much from an anthropological perspective, as discussed by Winiecki (2007), and neither as a legitimate form of healthcare from a tele-health perspective. In his ethnographic examination of four call centers, all very small and frankly not all that comparable to that of the research client, Winiecki does bring up an interesting observation regarding power amongst call center workers and the center's customers. Much like my phone nurse participants, the constraints of their roles instilled a feeling of being overworked, and in some cases: controlled. His article concerning subjectivity in

the space of call centers spoke on workers having "to see [themselves] in the data;" employees had to make their cog-in-the-machine position into something important and relevant to themselves, thus increasing their share of power and improving the quality of their work with customers (Winiecki 2007, 364).

The relationship between a tele-health call center and the patients they serve is another under-examined area of anthropological and public health research. However, one article concerning agency and constraint in such centers, written by Beirne et al. (2004), spoke of the need to better understand those relationships. Doing so would improve productivity, influence the internal and bureaucratic machinations of the business, as well as easing the "frustrations, tensions, and dilemmas that could take their toll" on the employees and their customers (Beirne et al. 2004, 108). Many of my nurse participants spoke of their struggles with their jobs, how they were constrained by their positions, refrained from action. There was a sense of understanding about why they were so confined, but as Beirne et al. (2004) illustrates: to be so frequently restricted takes a toll on worker's emotional labor, perhaps lending to noticeably high rates of employee turnover in call center settings.

Then there is the struggle for "Teams Without Teamwork," and the title for van den Broek et al.'s article explicating and navigating the "call center paradox," published in 2004. The paradox is derived from a work environment that is "highly individualistic and technologically regulated…service interactions are scripted, and…they therefore appear to lack any of the normal criteria" for teamwork (van den Broek 2004, 197). With so many members of the same program scattered throughout the country, with no personal interaction but over the phone, it becomes apparent how the paradox is not so

easily addressed, let alone resolved. Their findings suggested that call centers attribute a kind of pseudo-camaraderie with teams formed by function with no collective character or shared experience, but van den Broek et al. (2004) stress the inherent danger of this. Nurses called for a kind of shared identity, beyond their titles or their professions, and team building and morale boosting are well documented to improve worker productivity. Studies show a need to acknowledge this paradox, and adapt appropriately.

While my research did not speak directly to patients served by my thesis client, every nurse spoke highly of their experiences empowering patients, but again, this is an area of provider-patient relations under-utilized by social scientific investigation. While examining a tele-health call center in the United Kingdom, O'Cathain et al. (2006) found that patient empowerment was not limited to self-care; it also had to do with beliefs or concepts relating to their care. Much like my own interactions with patients and nurses, empowerment worked much the same in the client's setting. But as the authors point out, what providers and corporations believe is appropriate for empowerment and what patients believe are often very different (O'Cathain et al. 2006). Both must be taken into account for new and existing programs, because evaluation is not a singular event. To improve the programs given for patients, patients must play a part, as is supported in my own research findings.

Finally, on the subject of nurse and provider empowerment in a tele-health call center, the work of Jenkins and White (2001) shares some interesting illumination. The authors found that the space of tele-health care actually serves to advance the fields of nursing to new heights, particularly with regards to the topic of accessibility. Several of

my nurse participants, as discussed in later chapters, shared their ignorance to tele-health nursing prior to their application for work with the client. Their newfound stretch in patient accessibility and care allowed for them to achieve new depths to patient relations and care for far more than what they could in a clinic or hospital. Over the phones, nurses could help patients to manage mental as well as physical health, financial concerns, and even social problems (Jenkins and White 2001). Learning more about how nurses give their care over great distances, what it means to them, and using their expertise to continue advancing the tele-health field is a major part of this investigation, after all.

CHAPTER 4

METHODOLOGY

Ethics and Research

Ethical clearance was obtained from the Institutional Review Board (IRB) of the University of North Texas (UNT) in the month of February 2016. Due to the complexity of this project, approval from the IRB was obtained in two separate increments. First, all materials and methodologies concerning phone and PRN nurses were obtained. Once data collection was completed from participants employed by the client, approval for MS patient interviews was secured from IRB in April 2016. As is paramount to the study of anthropology, the confidence and protection of all participants was essential. Any study involving patients, and any study concerned with their healthcare, anonymity and protection must be maintained and held to the highest standards. Any personal or identifying information that was shared was disguised by a pseudonym or generalized. All interview participants signed and received a copy of informed consent, and all aspects of the study were discussed thoroughly before beginning the recording. Survey participants also received an informed consent document, twice, along with multiple ways to contact me with any questions.

It was also agreed upon, between myself and the client, that no patient participants would be recruited through company resources. In the interest of protecting the interests of the pharmaceutical manufacturers and their position within the Big Three, patient participants were recruited outside the client's resources by partnering with the Dallas, Texas chapter of the National Multiple Sclerosis Society (NMSS). Local Dallas and Fort Worth support groups were contacted and permission was granted with the NMSS acting as go between for the researcher. To protect all patient participants,

much the same as the nurse participants, pseudonyms and generalization were used to protect their identities, privacy, and any sensitive information. All patient interviewees would also be eighteen years of age or older; this ensured only adult participation, avoiding children and the added ethical concerns and considerations that come with child participants.

<center>Client-Based and Field-Based Participant Observation</center>

Over the course of my research I made ample use of the staple method of anthropology, namely the practice of participant-observation. During my time as a program coordinator, I spent three years participating in the expected associate responsibilities, and observing the trends and changes to my client's business practices and culture. All the while I was analyzing the environment, my co-workers, the strengths and limitations of tele-healthcare, and the strengths and limitations of the programs I worked on. The relationships built with my co-workers established the necessary rapport and trust, lending itself to a higher level of communication and understanding during the interview process.

While conducting patient interviews, I also engaged in participant-observation out in the field. With the assistance of the National MS Society (NMSS), support groups for patients and their families and friends were identified in the Dallas and Fort Worth metropolitan areas. A representative from the Dallas chapter of the NMSS contacted the group leaders, explaining the purpose and components of my research. Once contact was established, and the leaders welcomed my attendance at their meetings, participant-observation in the field began. Meetings typically lasted between two and

three hours. Each of the meetings sponsored a guest speaker, as well as myself as a guest. Topics of presentation included transportation and mobility alteration services offered to vehicles and homes, as well as prosthetic, cane, and walker advancement and products for patients living with multiple sclerosis. Only one of the meetings was faith-based, founded on principles of the Baptist denomination of the Christian religion, but religion and faith was still a point of conversation at all gatherings.

Phone Nurse Interviews

In terms of data collection, ten phone nurses were interviewed, following recruitment through conversing with them in the office; five were conducted in person and five were conducted over the phone. Each phone nurse had worked on several different programs during their careers with the client; the programs targeted and provided care for many different disease states. The interviews were formal and semi-structured; a list of questions that guided the interview can be found in Appendix A. All interviews were audio recorded and transcribed. Interview durations lasted just over an hour, on average. Eight of the interviewees identified as female, and the remaining two as male. The average age of the participants was 50.4 years; the average number of years working as an employee of the client was 5 years. No compensation was offered to the phone nurses; they participated on their own time, out of a desire to assist me and my research, as well as improving the clinical services department.

PRN Interviews

Five per diem registered nurses (PRNs) were interviewed; all were conducted over the phone. PRN nurses, as mentioned earlier, are scattered throughout every state of the United States of America. The PRN nurses were selected for interviewing based upon their physical location, to achieve a wide reach across the country, as well as my relationship with them as a program coordinator on the MS program we all worked on together. The states they resided in were Florida, Michigan, Illinois, Hawaii, and Louisiana. Their strategic locations facilitate the ability of nurses to travel to most patients' homes for in-home training. These interviews were also formal and semi-structured; the list of questions for the PRN interviews are also in Appendix A. Interview durations also lasted over an hour on average; all participants identified as female. All interviews were recorded and transcribed. The average age of PRN participants were 60.6 years; they were contracted as PRNs with the client an average of 11.4 years; they worked on an average of 3.6 different programs. Similar to the phone nurses, the PRN nurses were not offered compensation to participate.

PRN Survey

In addition to the PRNs interviewed over the phone, all active PRNs contracted with the client were offered the opportunity to participate in a short survey. The invitation and the informed consent were sent through email; the survey was administered through the website SurveyMonkey.com. A generalized, cold-call for responses was open for just over two weeks from April 5 to April 22, 2016. There were a total of 54 respondents, resulting in around a 47% response rate from all

contracted PRNs at the time. Every survey was one hundred percent completed. The

gender ratio was divided between 51 participants identifying as female and 3 as male.

The survey combined multiple choice and open-ended questions. The goal of the

survey was to examine the effectiveness of the PRN programs and to determine the

strengths and opportunities for improvement. The full list of the questions can be found

in Appendix B. Once again, no compensation was offered to the survey respondents,

as completion took no more than ten to fifteen minutes of their time.

Patient Interviews

Ten patients living with multiple sclerosis were interviewed; nine were completed

in person, and one was completed over the phone. Nine interviews were only with the

patient, and one had a patient and her husband as caregiver participated. All patients

were recruited from support groups located throughout Dallas and Fort Worth, Texas.

All but one of the patients was diagnosed with relapsing-remitting MS; the last was

diagnosed with progressive MS. Interviews took place in a variety of locations including:

public libraries, coffee shops or other public venues, and in patient's homes or in their

places of business. The patient interviews were also formal and semi-structured; the

question guide is located in Appendix A. All interviews averaged over an hour in

duration; all interviews were audio recorded and transcribed.

CHAPTER 5

FINDINGS

The following chapter details the prominent themes from analysis of all

transcribed interviews, as well as the findings of the PRN survey. Transcriptions were

stored, excerpted, coded, and analyzed with the help of the online social scientific

database Dedoose.com. Excerpts from the interviews will be provided where

appropriate. For a brief introduction to all interviewed participants, please consult

Appendix C. The results of the multiple choice PRN survey questions were compiled

and examined through the Statistical Package for the Social Sciences (SPSS). The

responses for the open-ended PRN survey questions were appropriately coded for

recurring themes.

Phone Nurse Interviews

The first theme that we will discuss is the topic of **social support**, specifically

how the phone nurses provide support to their patients and so ingratiate themselves

within their patients' lives. The phone nurses can do this without ever meeting the

people they care for in person; the fascinating relationship dynamics that their rapport

and trust create are entirely developed over the phone. Take this example from phone

nurse Evelyn, which serves as an excellent generalized statement of this theme:

> …I am [a patient's] outlet for that little short amount of time. It makes a huge
> difference in her life and she didn't think it was going to be very important at the
> beginning [of the calls], and she really wouldn't need me…but now she calls me
> her best friend!

The scope of the phone nurses' relationships were always different for every patient.

The level of adaptability and critical thinking that the nurses have to employ is different

on every call. They must bring a different kind of care, a different level of care,

depending on how they relate to their patients.   Take some of the below quotations as further examples:

> No resources. This woman had nothing. She had no car. She had no way to the doctor's office. She could not afford in any other medications that she had. You know, none of this stuff. A church support is what this lady had… So I'm talking to her and I said, "Okay. If it's about cost, I have your enrollment form and I'm looking at what you make. I can help you with this today… I knew about another agency that helps patients with transportation. Over the course of six months that I had spoken with this patient once a month, she got in touch with the cancer support community who have been giving her rides to her doctor's office. She got the low-income subsidy and she was able to start the drug. She was able to start the drug with grant assistance with no co-pay, was able to make her doctor's visits with transportation through this other agency…She's doing better than her original prognosis… My call series with her is done, but I still talk to her, she still calls me. – Harry, Phone Nurse

> …some of these people would just talk to us and go on about, you know, stuff that's going on in their life and talk about their family and, you know, they just wanted to talk. So…that's a very positive aspect of my job. And even to this day with my current program, you know, just talking to the parents and about the patients. They--a lot of them just want someone else to talk to… so they're very appreciative of what we do. – Iris, Phone Nurse

Complex relationships like this are not a rare phenomenon in the nursing field, but in the tele-health industry is where we see these varied levels of intimacy take on a whole new dimension in patient care (Nasseri 2015).

The second theme that we will discuss from the phone nurse interviews was the theme found in numerous interview transcriptions: **overworked and/or understaffed**. Multiple nurses informed me of the love of their jobs, and more still spoke of how they never knew this exciting new type of nursing existed before being scouted, but they still often found there to be too much work for one person (Rhoads et al. 2009). In one way or another, nurses found ways to talk about their ever-increasing workload and the lack of time during the workday to get the work done:

…we need more nurses. We lost several nurses…I'll say the past year. They have not been replaced. Which makes our case load higher; we might not be able to get back with the patient, on the date that we specified, or that time of the day… – Ace, Phone Nurse

And I'm sure they're all loaded up anyway but there may be a reason behind that. 'Don't worry about the day-to-day,' you know, 'we'll worry about that later. We'll deal with that or whatever. We want you to do this over here.' But actually knowing what's going on sometimes is [probably] why so many have left, I'm sure, early. I mean…some went back to floor nurses because you get that overload. – Fredrick, Phone Nurse

They spoke of the challenges that would get in their way of completing their tasks; mentions of hurdles from pharmacy procedures, or insurance complications that effectively keep the nurses from providing assistance to patients in a timely manner, consistent with findings from other studies in other developed nations (Ponzio et al. 2015). Nurses often have new patients every day, depending on the scope of the program and the popularity of the medication, and they are expected to facilitate care throughout the entirety of their time with clinical services. There are many obstacles that appear in their way, and the lack of time or team members makes the work that much more trying.

Well, you know, some of the most challenging [cases] are the ones that you…(are) trying to get things done, but insurance companies are getting in the way, or pharmacies are getting in the way. It's just so difficult to work with them…it just doesn't fit with the patient's plan. – Joyce, Phone Nurse

So the process is there's always paperwork we'll send to the specialty pharmacy… then special pharmacy sends it to the patient. Well, it's between the manufacturer and the specialty pharmacy that something got disconnected… it's a vicious cycle and I just--whenever we have this situations, like a product complain or a replacement…it's time and frustration on the [patient's] part… trying to get that process completed, it should be a lot smoother. It shouldn't always be on us…there should be more of us, I don't know… – Billina, Phone Nurse

These complicated circumstances lend themselves to a work environment where the patient's care is pushed to the side to overcome difficulties of sectors of the healthcare industry outside of the client's control. With patient care, the central attribute of the phone nurse position, being limited by the very nature of their position, it should come as no great surprise that nurses feel overworked, and the turn around rate of associates makes them understaffed.

Another theme was categorized as **resources**, or the lack thereof. Per contractual guidelines with pharmaceutical companies, nurses have a number of services and resources at their disposal. The problem is that nurses are thereby inherently limited concerning what assistance they can give to patients. They are expected to address and resolve patient needs, as they relate to the boundaries of the medication program, and this limitation can certainly lend itself to feelings of being understaffed or overworked. This quote from phone nurse Dorothy sums up the dilemma quiet well:

> …there are a lot of services already in place that were just either being underutilized or underfunded, or there is just too much red tape…the only people able to use the resources were the scammers who knew how to work the system, and the legitimate people, we get so drowned up on the tape and the paperwork and the denial…that they gave up. And…say you would have just taken some of the services that are already existing and made them more convenient and easier to use.

While patients tend to voice their appreciation for the nurses working with them on securing additional funding to pay for their medication, or for helping them navigate their insurance policy to obtain their prescriptions, there is often little that the nurse can do on their own, and it becomes extremely time consuming. Just how time consuming can be explained from the quote from phone nurse Ace:

I spoke with a patient and she was having difficulty paying for the medication…
So, she was in need of assistance, she couldn't afford it, so there're several
foundations that we refer our patients to. So, I was able to refer her to a
foundation, she was able to obtain funding, thus able to get her medication…it
took, I'll say five days. A work week, because there has to be a referral, filling
out the application, the process of approving it, and then the approval and
contacting the specialty pharmacy.

That whole process that Ace describes is just what phone nurses have to do for one

patient. When considering the high caseload these nurses have, the amount of work

expectations can be quite staggering.

The next theme is **communication**. One aspect of the communication theme is

how the client is communicating with the patients. With the changing technological

advancements that seem to progress further every day, some nurses commented on

the possibility of communicating with the patient "by the patient's preference." That

might be by email, or by texting, in addition to calling them on the phone. This would

improve and diversify the means of reaching and providing care to the patients, based

on the method of communication that the patient most prefers.

And because of the nature of a call-center, most of work is conducted without

any face-to-face contact. The client also allows certain members of their teams to work

remotely from home, potentially anywhere in the United States of America. Then the

lack of face-to-face applies to client co-workers as well. Some nurses felt that this

caused a disconnect between them; in some cases, they felt they were sometimes

working with a stranger. Becoming more familiar with each other, developing more as a

team, would create those connections, potentially improving their group dynamics and

their quality of services to patients.

If we're working with these people five days of the week we need to know
them. We need to build trust in a team. We need to know you've got our

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backs and you've got our patients back and you're gonna take care of things that are priority while I'm out, take your teammates into consideration… Because I mean, I'm one of the people, you know that I'm very vested in my team and very much look for teamwork and accountability… But we don't know what they look like, if they are family person, there is no like a little autobiography or anything. Any little snippet just to get to know these people could help, right? – Evelyn, Phone Nurse

The one thing that I think would be beneficial for the whole program…we chat among ourselves…that would be nice. It's an affordability thing for the whole program in general. We go to meetings, you know…[but] they never give all of us time to actually get to know one another. And we really--I wish they would just give us, like, at least an afternoon to be able to socialize together so we could actually know who we're working with. Because, I mean, we talk, we know their names but, I mean, I think we could all be better--even better at the job if we [had a] little bit more camaraderie and formality, you know…it's one thing to talk on IMs and emails but when we're all together…pay for a little bit of time for us to get to know one another. – Glinda, Phone Nurse

There were also several instances of a need for better communication between team members as well. Several nurses spoke of a loss of opportunities for teams to share more, for managers to hear from associates, and vice versa, but again, the high workload prevented this from being realized.

I can't tell you how many people have said "I'm going to come sit with you." I mean, multiple people: managers, senior managers, only one has ever done it. And that was only about 30 minutes because they get loaded with work… Meetings [come up] and they never get there. So, then you're not able to sit with the team so to speak. So, to me, they miss out on the team--what's going on with [everyone]. They don't know…what's going on with these people they work with? – Frederick, Phone Nurse

While speaking with the phone nurses on the theme of communication, there was also talk of need for greater consistency in the messages being sent. For example, phone nurse Iris felt that with the client's business being so large, "a lot of things don't get communicated down to the associate…level." Several nurses felt they were being left

out, not intentionally of course, but that the client's information sharing techniques would need to be re-examined and potentially re-designed.

The final theme discussed here is **empowerment**. Every nurse spoke of their appreciation for their work and how much good can be done as a member of the client's organization. Whether they entered nursing to care and bolster patients, or they found that to be their passion later on, every nurse found successfully empowering their patients to live healthier, to handle their diseases more effectively, to increase their personal beliefs in their abilities to be healthy were the best parts of their jobs. And while several spoke of the conviction of the client to put the patients first, the success of empowering and educating patients were not often criteria for evaluating their performance as tele-health nurses (Chang et al. 2002).

PRN Interviews

Many of the themes that arose from PRN interviews shared commonalities with those of the phone nurses. There are fewer themes to discuss, however, due in part to the great geographic distances that separate each PRN I spoke with, and that the number of PRNs spoken with were only half as many phone nurses. When designing the project, it was my intention that by speaking with five PRNs in five different states, I would actually find many more unifying themes than I did. The two major themes that are discussed in this section, that were pertinent across most of the PRN interviews are **communication**, and **resources**.

The first theme: **communication**, does have similarities to the phone nurse theme. Several PRNs felt that there was a perpetual disconnect from the rest of the

program, and the ever-changing information of that program. They spoke of a desire to be kept better up-to-date on the medications they work on, as well as more information about the patients they educate.

> I wish, there was better support, but there isn't, as far as information about the drug [program], keeping up to date on the…you know, it's hard to keep up to date on drugs, when you're only training on that drug once a year. If you're doing it all the time, you are really on top of it. So, I think an educational component would be wonderful, maybe every three months, just to update…or to send out a newsletter… – Kim, PRN Nurse

Expanding further into communication brought a need for better infrastructural information to be shared with the PRNs. Often, when a question arises that the PRN cannot answer, they are required then to reach out to the appropriate individual who is authorized to handle that inquiry. Unfortunately, it has come to light that is not always that easy, this example from PRN nurse Mona:

> …because a lot of times, I don't know, especially with this [one] program. I mentioned they feel a little more disconnected…if I have like a nursing question come up, something more specific than the program coordinator can answer, [then I] don't really know who my contact is.

There was also a desire for more communication about the specific needs and situations of the patients before reaching out to them as a PRN. Often the home is their safest place, they're "going into their environment," and as PRN nurse Nora explained, it's best to know "the whole picture…to best assess the situation," to know what you're walking into and how to adjust your care accordingly. Not having that information can lead to difficult situations, tense and stressful, that the PRN must now diffuse to continue their training, when it could have been avoided in the first place with a little more communication.

For the theme of **resources**, PRN resources are actually quiet different from nurses working over the phones. The major difference was concerning the need for those services or resource information might be greater depending on the geographic location of the patient that the PRN would be visiting, so they spoke of a need for "more attention" to be put on what is being shared and how it reaches the patient.

> And it's just difficult especially in rural areas, it's another think with many of the programs today, even when you ask them, they don't send out the [information] on things like symptom management like they used to…And I think that if we make a program available to them, and maybe in a limited way…we could get more information and support to [the patient]. – Ozma, PRN Nurse

PRN Survey

The major point for the PRN survey, again outlined in Appendix B, was to quantify the effectiveness of PRN programs through the responses of the contracted employees themselves. The overall consistency from the multiple choice responses show the client performs at an excellent level with regards to the attitudes and perceptions of the PRN nurses in their employ. As discussed earlier, PRN programs are assignments for nurses to go out into the field, typically entering the patient's home, and providing specialized training for administering medication and living with their disease.

Considering the largely positive responses to all questions, a generalized selection has been included here, to illustrate the trends. Figure 3 conveys the responses for the level of general satisfaction as a PRN employee with the client. According to the results, 92.6% of PRNs were at least "satisfied" with their experiences as a PRN, with a vast majority identifying as "very satisfied" (N=37).

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General Satisfaction as a PRN with Lash (N=54)
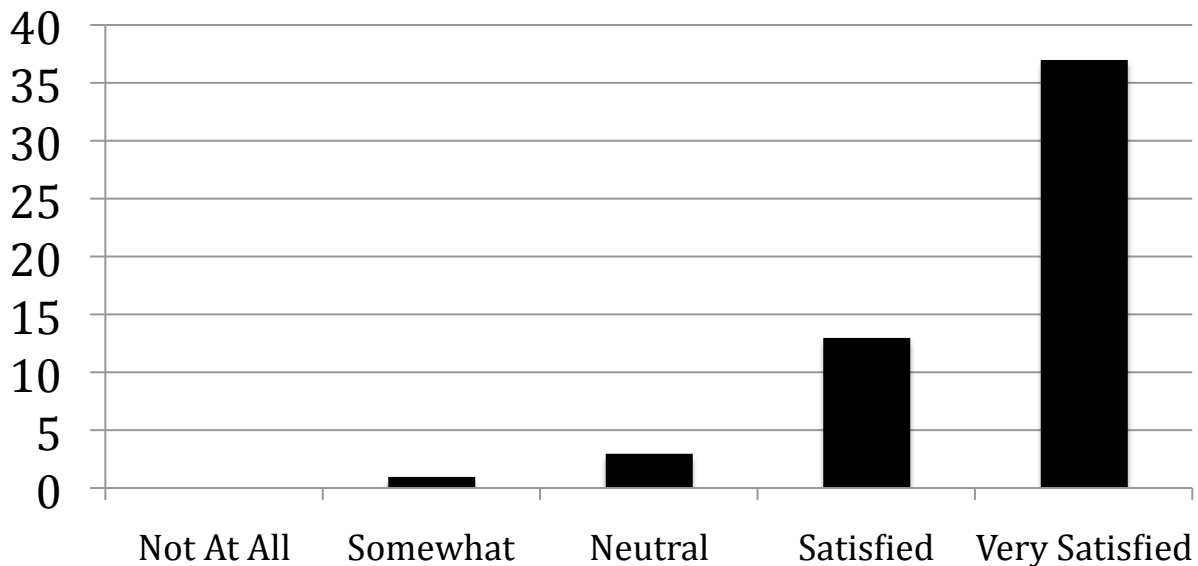
Figure 3. General satisfaction as a contracted PRN.

Following in the same vein, 92.6% of responses described their experiences with patients in the field as either consistently "above satisfactory" or "overall rewarding." Forty-one out of the total fifty-four responses considered their time in the field as "overall rewarding," with only one participant considering their work experience as "unsatisfactory." These responses fit rather well with results of the question investigating the occurrences of challenging and/or difficult situations in the field. All in all, these responses suggest that the client works well to have their PRNs appropriately prepared to do their jobs out in the field, as well as preparing them to handle unique situations before they should arise. Figures 4 and 5 depict the results.

Average Experience with Patients in the Field
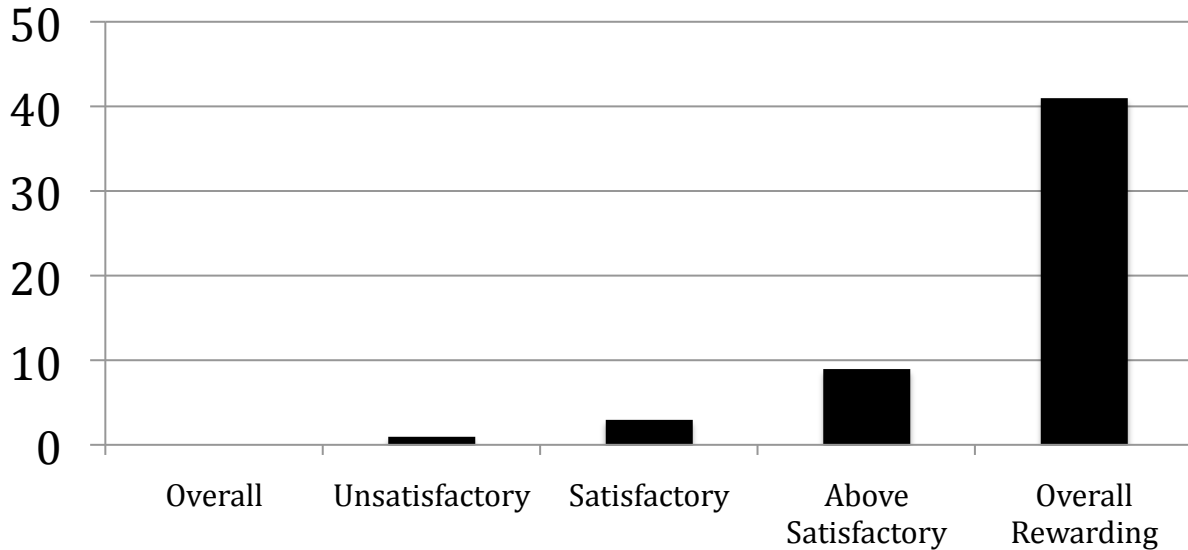
Figure 4. Average experience with patients in the field.

Occurrences of Challenging/Difficult Situations in the Field
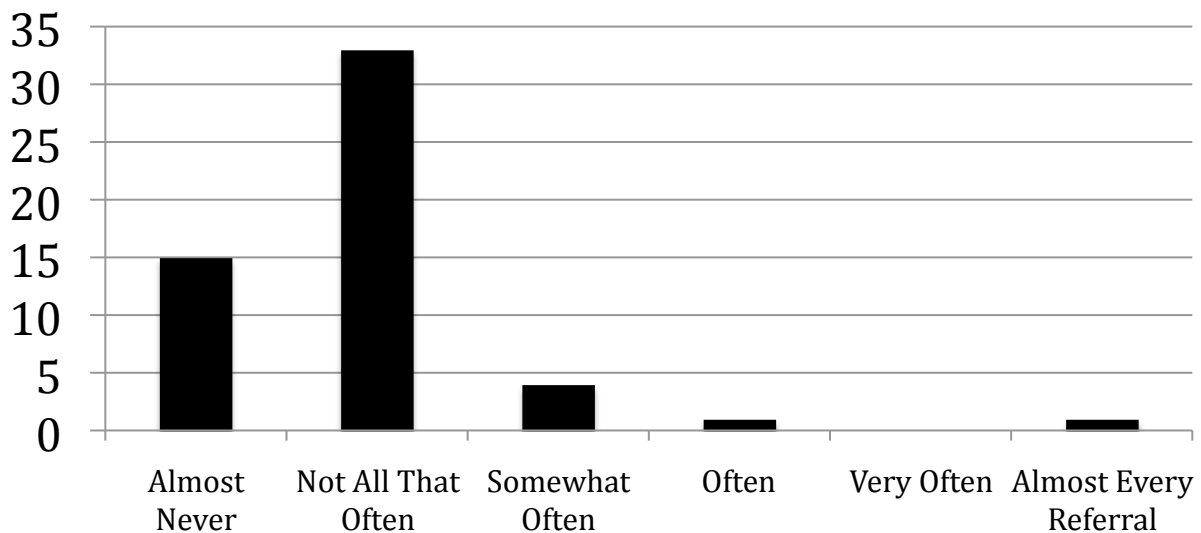
Figure 5. Occurrences of challenging/difficult situations in the field.

For the sake of disclosure, the participant who responded with an unsatisfactory experience in the field, was the same who encountered a challenging or difficult situation "almost every referral." They are also the same participant who remarked in the open-ended questions that they have only received one work order to train patients in the field. Such a striking lack of opportunities for that one participant could be attributed to overall fewer patients in the nurse's geographic area.

The final multiple-choice question that we will discuss here was meant to investigate how well the PRNs perceived the performance of their "in-office" partners. How did they find the work of the program coordinators, like myself, or the phone nurses, or the managers. Once again, the results were positive, showing a good relationship between PRNs and other client employees, potentially linking to the positive experiences out in the field.

Performance of In-Office Client Employees (PCs/Nurses/Managers, etc.)
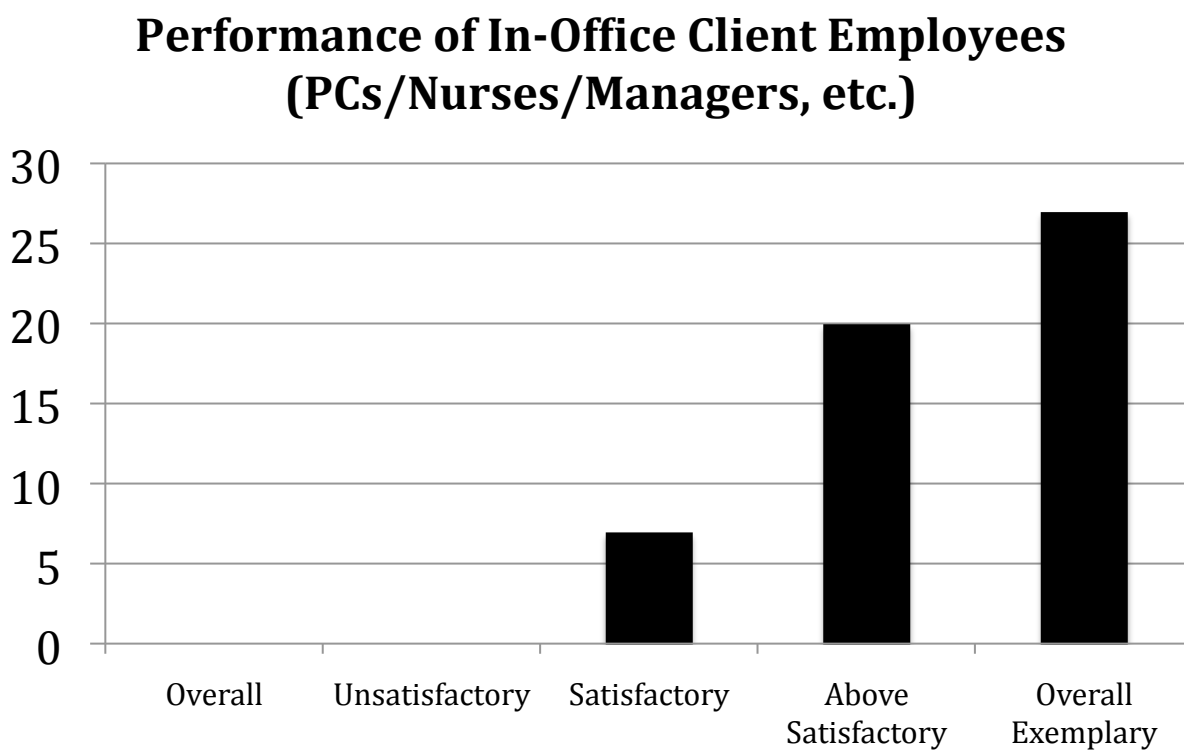
Figure 5. PRN perceptions of in-office employees.

As outlined in Appendix B, the open ended survey questions sought to look into three separate, but still intertwined areas: how patients felt about the services provided, what wishes or desires patients had for services, and any thoughts the PRNs had for strengthening the client's clinical services. This can be tricky, after all, how can nurses know the mind of their patients. However, as a program coordinator, and in my conversations speaking with nurses and patients, as a form of participant-observation, I know that patients often share with their nurses. And if the nurses had any information to share regarding patient perception of the programs, it would be beneficial to ask.

Overall, the expressions from the patients to the PRNs were positive and very thankful for their help. The PRNs spoke of a desire for more work, for more opportunities in the field. This makes sense, as they are contractual employees and work on a case-by-case basis. All three questions contained answers requesting improved communication: communication from patients with their providers, from service providers to patients, and from the client to the PRNs, to name a few of the specifics. Patients spoke of their frustration with insurance companies, or their pharmacies, speaking of their desires for faster or easier approval from them to obtain their medications. Unfortunately, the client has little to no control over the machinations of insurance corporations. Therefore, the only avenue where the client could work to make improvements in their communication strategies, which is central to the workings of a tele-health call center.

Patient Interviews

It was fascinating to me how consistently the following themes arose in most, if in some cases all, of the interviews with patients living with multiple sclerosis. I can only conclude that so many of the patient themes having so many similarities stems from a sense of shared experience (Webster 1989). An experience that, as of yet, has not been successfully addressed through medical or social means.

The first theme is **employment/unemployment**. A serious concern for people living with multiple sclerosis involves financial stability and a consistent form of employment (Schulte et al. 1996). Of the ten patients I interviewed, six were entirely without employment, two were employed part-time, and two were self-employed, but only worked part-time as well. Most of my patients were living on disability, or another supplemental form of income. Several ended up relying more often on family or their children who were grown as the means to survive. It is because of their disease that they cannot work, and because there are no opportunities for work that are available to people living with their type of disability that can accommodate.

> I work from home [as a travel agent]…If I have to go out and drive anywhere I'm good until 2 or 3, when it gets past noon…I have to rearrange my schedule and can't do any writing. By the time I get up do my errands and stuff its noon. Now I can't write anymore so I have to do something else. I can make my own hours, I can also do laundry or make things when I feel that I can do it…I also have the flexibility to make appointments at times when most people can't.

> That's about it she gets up, does as much [work] as she can in the morning, especially in the summer and that's about it.

> I can take phone calls like I am with you now. And I can get all of the information and then tomorrow morning I would work on the trip. So it's actually a really good job because my cell phone is my work phone, so if I'm at the gym I can just take a call. - Velma, MS patient and Wren, her husband

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I guess I still can cope without help, but it's a challenge, it takes like three times as long to do everything as it used to as without the disease. Anyway, so I can still, you know, get up, bathe, get ready, go to work… I have -- about three months ago hired an apprentice to train in the locksmithing industry because it became too much of a challenge. I can probably do one call by myself but it takes just so, so long. And so, I have somebody that I can basically watch, observe and instruct. And he does most of the labor, I do some still.
- Xavier, MS Patient and Business Owner

I fell at work and hit my head and I thought that I had a head injury because I hit my head really hard and I had an MRI because following that injury I was having a lot of numbness in my hands, more than usual and some neurological symptoms with my head…Well when I was working I didn't want anybody to know that I had MS because I work for hospital that wasn't very good to the employees in my opinion. The most, I mean not just me but if you ever worked at a hospital they're really rough on their employees I don't know if you're aware of that or not.
- Rhonda, MS Patient, Unemployed

I want to do this and this and get this done. I don't necessarily do them, but the mind process is there. But the life, overall my frustration, the fact that I can't do stuff, that I can't accomplish the things that I want to accomplish. I was a successful working individual and my career was eliminated.
- Quistis, MS Patient, Unemployed

With an ever-present fatigue that behaves unpredictably, day-to-day, even hour-to-hour, many people living with MS are forced to end their careers prematurely, with no other option or opportunity available to them (Schulte et al. 1996).

The second patient theme is **symptom management**. While every patient I spoke with was making use of some form of biomedical treatment for managing their MS and preventing relapses where possible, many of the patients spoke of other methods of self-care that they engaged in. These complementary and alternative forms of care were varied and diverse (Salamonsen 2013; Salamonsen 2015; Salamonsen et al. 2012). The patients swore by their effectiveness while they discussed how making

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these healthier changes resulted in a better quality of life for them, living with MS.

There were several instances of changing their diet.

> …diet is very important to me because my digestive system whether it be related to MS or not is very sensitive, so I'm gluten free, dairy free, sugar fee and caffeine free… but I think in my case its more intolerance…I have no damage but when I eat [gluten] I'm very uncomfortable, like I feel nauseous and have diarrhea but there's no damage done to my system so it's a matter of staying away from it and feeling better. – Velma, MS Patient

> I changed to a vegan diet, because I found that it was more helpful, but not just for my MS. I also have Type II diabetes, it helps with that. I felt like it helped with my fatigue. [Someone] recommended using fish oil, about 1500 milligrams… I doubled it to 3,000. I'd say I have some benefit from the fatigue. The significant benefit, I have tremors in my hands, it dramatically reduced that. – Quistis, MS Patient

Another method of self-care was remaining physically active, despite their fatigue and muscular troubles. Several patients attested to the specialized gym Mindset. With several locations throughout the Dallas and Fort Worth Texas areas, Mindset employs personal trainers and makes use of equipment specific for clients living with disabilities.

> Exercise. Exercise is the really key…that is probably what I try most, train and maintain a healthy weight. Do all those things so that you minimize the other health issues that you might develop because of our bad choices in life… but probably exercise is really one of the key things that I do.
> – Yara, MS Patient

> And then I also find support just from being at Mindset where if you know for some reason you don't come in for a day or two there's somebody reaching out for you, you know? Whether it's a trainer or just somebody you exercise with, they're reaching out making sure you're okay. Trying to encourage other people… So I would say most of my support and my giving of support comes from Mindset. Just because you know when I'm there exercising there's a group of about four women who have just been doing it for a while at the same time and are pretty close. So we're always watching out for everyone. – Tina, MS Patient

Patients also mentioned just ensuring they get enough rest throughout the day, trying not to strain themselves with their activities, staying hydrated, and limiting what they do

during the hottest parts of the day. MS greatly diminishes the patient's perception of heat, and are far more susceptible to heat-related issues as a result (Salamonsen 2013; Skovgaard et al. 2012).

The third theme shared among the patient responses is **mobility** and **transportation**; the two I argue go together quite easily. For the purposes of this investigation, mobility and transportation both relate to an individual being able to move from one place to another. They differ in that mobility refers to the individual's ability or inability to physically move themselves with their own two legs, and transportation involves the use of a motorized vehicle.

It is not uncommon for a person living with MS to be seen using a cane, or a walker, or even a wheelchair to get around. It becomes a necessity, and even a trial, to obtain a mobility aid when they become too weak to support themselves without one.

> At first I was doing a cane, but now I do have this: what you call walker. My goal is to go to a quad cane… Not to walk but to use quad cane, that's the goal. And so, I'm just trying to do that. Again, given my age, given my health it's -- it will be a challenge to do that but if I could just, like, on certain days use a quad cane that would be good. – Pepper, MS Patient

> My sister got me that [cane] and she got me a walker which I use like when I went to my sons graduation. If I walk long distances I can walk, but like when she and I went to one of my sons games, I get tired and I really needed to sit down and I really didn't have a way to sit down so we realize if I had a walker I could of used the seat when I walk long distances and I just need to sometimes sit down. I don't look at those as negatives for myself. I look at them for positives just to say sometimes I just need to rest. – Zelda, MS Patient

All of the patients I spoke with were capable of driving themselves, and used their own vehicles, but the constant, sometimes looming, threat of not being able to drive any longer, if their MS progresses too far.

I think the biggest thing that I'm worried about that I would like to see happen is for the city to have [better] public transportation…Because the fact that I live alone and if I reach the stage where I can't drive even with adaptive devices I don't know what I'm going to do. For example, I couldn't go to Mindset anymore because it's [not on the route]. – Tina, MS Patient

Many patients spoke of an awareness of the lack of suitable public transportation in the Dallas/Fort Worth area, which if they would have to use, would actually lead to a lower quality of life than they currently enjoy. They were not aware of any other options they could have should they become unable to safety operate a car, other than public transportation, and to them, that is not a suitable alternative.

The forth theme is **support**. Patients all spoke of how they give and receive support relating to their MS. Whether it was from family, friends, or the support groups where I met them, they each spoke on the subject of support. Living with MS can sometimes result in the development of depression and other mental health concerns, but several of the patients I spoke with felt that they had sufficient support to handle those potential difficulties.

…the top of the list would have to be [the] support self-help group that meets once a month… It is very much a self-help group because we all bring things to it. Not just complaints. We bring solutions, and that's the biggest thing. And [the leader's] always online, doing research; she's our hero… And then, of course, my family and friends – who know I have MS
– are all supportive. Everybody's always looking for a cure or ways to alleviate any symptoms that they notice I have or think I might have. – Ursula, MS Patient

I learn a lot about people, and all of the support group, we've developed some good true friends over the years. And…I just – seeing the ways that they reach out to each other, the ways that they're there for each other, has just been huge because I learn so much from them. – Yara, MS Patient

…there's somebody reaching out to you, you know? Whether…or just someone you exercise with, they're reaching out, making sure you're

okay. Trying to encourage people, and help them get through their difficult days. – Tina, MS Patient

Others commented that they continue to feel removed socially, lacking support from family or others.

I can cry, I guess, because I don't have that camaraderie that people like I used to… So, when you're cutoff…there goes your socialization, I guess. I'm still struggling with that and one reason why I said I go to yoga because I got to know those people, [but]…I haven't meshed with that group of people. But, I really – the socialization thing: I'm having a really hard time with that. – Rhonda, MS Patient

My sister-in-law and [my brother] don't want to hear about it. She said she knows all about it and she doesn't want to hear about it. She won't even read the pamphlets and stuff that it bring bad from the meetings and whatever. She won't come to the meetings because I've tried to get her to go… I really don't have support at home. – Stephanie, MS Patient

Whether or not they have the support they need, support from others, and in some cases, giving support to others is just as important to people with MS as those without. There can be real beneficial improvements to health and wellness that come from an appropriate network of people who know of your troubles and actively assist you with them (Balick 2014).

The fifth and final patient theme is what I have come to call the **sense of self**. I define this theme as the conscious removal of the patient's identity as being separate from their MS diagnosis. They literally and metaphorically refuse to let their disease "keep them down," even though, by its nature, MS is a debilitating, degenerative disease. Often participants would remark of how their MS does not "define them," or it "just happens to them," they will not let their MS keep them from trying to live the lives they constantly enact every day.

So I'm always looking for ways to enjoy myself indoors and have a good time. So I'm looking for ways to have fun not looking for ways not to have

fun. To be around people. To have a good time and not worry about being hot because when I first got diagnosed I was telling them my son was in junior high and I got one of those vests those cooling vests and I had my umbrella, I had my cooling vest, and I would go out there with my umbrella and cheer for my son and I said people thought I had a bullet proof vest and I said yeah don't mess with me. – Zelda, MS Patient

I still I want to do stuff myself even though it takes longer. I've always been pretty much independent… In other words, I refinish the floor at our house, the wood floor in our dining room and I do brake tabs on the cars and I cook dinner for my kids on Wednesday nights. So, I do some of just about everything. – Xavier, MS Patient

I saw where a lot of people [with MS] like: 'I can't remember where I put my car key, I'm always losing them, it's MS' or I mean, everything that wasn't right, every, everything was blamed on MS…To me, everything is not MS's fault. But to some people everything is… like 'I don't, I don't cook anymore because I have MS' or 'I don't grocery shop because I have MS' maybe or just everything… And I'm more like: 'I'm going to do everything I can until I can't, possibly do it!' You know what I mean? – Rhonda, MS Patient

Adopting a thought process like this is a regular phenomenon for people living with MS, and other chronic disabling diseases. There is a constant drive to over come them, to not be brought low by something they cannot see, that they cannot understand, that their body just happens to be doing to them (Balick 2014). By combining this positive outlook, with a solid social network, appropriate biomedical care, and following good health behavior can make living with MS more than just living with a chronic, crippling, neurologically destructive disease.

CHAPTER 6

THEORETICAL IMPLICATIONS

The following chapter focuses on the theoretical frameworks that were influenced by the results of data collection, and subsequently influenced the deliverable recommendations for my thesis client. I begin with the works of French philosopher Michel Foucault and his interpretations of the intricacies of power in the social world. After Foucault, I turn to Pierre Bourdieu and the phenomenon of social capital. The next section focuses on the public health theory of social networking. Finally, the topics of patient self-efficacy and agency are explored. Each section builds upon the other, ultimately culminating in a series of theoretical accompaniments that can result in increasing patient self-efficacy in a tele-health setting with regards to their healthcare and disease management.

Foucault and Power

Power dynamics and how they relate to health, as well as healthy behavior, has been a topic of interest among medical anthropologists. The central phenomenon for this section can be boiled down to Samuelsen & Steffen (2004):

> The concept of power seems unavoidable in studies of health and illness, not only in the most obvious forms of institutional power or authoritative power as demonstrated in health care institutions, but also the configuration of power in specific settings in the more subtle form of self-discipline as pointed out by Foucault. (7)

Put simply, the distribution of power, among the many institutions has very much to do with the state of health and wellness within any population. If a wealth of power is in the hands of the government, the distribution is different than if a majority of that power resides within the private sector; whatever the design, the result is of a society with both

intentional and symbolic interaction (Blumer 1962). Symbols are enacted, and through that action, they reaffirm the reality of a culture. This happens to both the individual and the collective: the symbolic nature of power "both subjugates and makes subjects" (Samuelsen & Steffen 2004, 8).

Foucault wrote that power can take the form of any circumstance that a person uses to mark his sense of self, fashions his own identity, and thereby makes manifest his own form of power within the system (Foucault 2000). This can be found being encouraged in much of the health and medical fields today. Take, for example, the once predominant, but now reshaping, phenomenon of medicalization. Medicalization is the process by which more and more of humanity comes under the power of the biomedical sector (Jaye et al. 2006). However, rather recently, both within and outside of the fields of medicine are realizing the importance of individual agency in taking charge of individual healthcare. Healthcare professionals, like the phone nurses and PRNs that I spoke with for my research, recognize this in their care philosophies. The redistribution of power, from the institutions that have the power (i.e. hospitals, physicians, insurance agencies, etc.), results in the people having an unprecedentedly higher amount of control over their own healthcare (Jaye et al. 2006).

In Foucault's theory of discipline and punishment, a hypothetical prison setting is built surrounding a central tower, allowing constant and perpetual observation from the jailors upon the prisoners, who have no place to hide from the glaring presence of the powerful (Foucault 2000). It is possible to translate the functions of discipline to health behavior, and punishment to the onset of illness. Foucault wrote extensively on clinical medicine, medical education, and even public health (Hodges et al. 2014). By

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translating the prison phenomenon of Foucault's, we can see a change that simultaneously has happened in the past, and continues to happen within the public health and healthcare sectors even now. Foucault wrote of an intentional shift from external forces imposing control and punishment to an internalization of power via self-monitoring and self-efficacy (Hodges et al. 2014). Throughout his analysis of a variety of social constructs, as anthropologists understand as culture, Foucault's overarching theme pertaining to change is "the insight that knowledge functions as power" (Elden 2006, 42).

From my research, it became apparent that tele-health organizations, utilizing clinical practices for their patients, would be able to apply this re-examining of power relations to better influence the health of those they serve. Take a generalized example from my time as a program coordinator working on a program for patients with MS. In some ways, due to the metaphorically non-existent placement of the patient services professionals within a call center, as well as their high level of knowledge concerning patients' health and records due to the ever-expanding breadth of technology, companies like my client become the tower of the prison. They see so much of their patients' lives and know so much from speaking with them that companies like the client obtain an unprecedented level of power over health and wellness. Potential ways of address those power dynamics are discussed in the following chapter, regarding my evidence-based recommendations. And with the sheer number of patients to intervene on behalf of, the client would be able to potentially reach many of them at once, resulting in a shared increase of power among patients.

With appropriate preparation, tele-health programs could use that unprecedented position of both symbolic and actual power to share with their patients. Redistribution of power, would thereby challenge how the patient views themselves and their sense of influence over their own health and care, resulting in potential ways in which patients view their "natural body…[how it] is created" and kept healthy through "networks of power and knowledge" (Greenlee 1991, 80). This change to symbolic thought would give way to a change in reality; and the transitional behavior of the idea to actuality would be constantly reinforced by the relationships and intervention of tele-health nurses (Maines 1977). Before we move on, take this quote from Elden (2006) which directly speaks to the combined interaction of the imagined and the actual, relating to power:

> It is of this *oscillation* between the jurisdictional individual, ideological instruments of claiming power, and the disciplinary individual, real individuals with their physical exercise. It is of this [constant transition] between the power which one claims and the power which one exercises that is born this illusion and this reality which one calls Man. (49)

Bourdieu and Social Capital

Keeping in mind the previously discussed notions of power, I will now discuss how they can mesh with the works of Pierre Bourdieu. Let us begin by defining the concept of "habitus." Habitus is described by Samuelsen & Steffen (2004) as that which:

> …designates a set of generative and durable dispositions acquired through socialization. Habitus is also the organizing principle of action… the basis for regular modes of behavior…[it] constitutes a practical logic rather than conscious reasoning…Habitus is formed and forms the everyday practice of [everyone]. (5)

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Habitus, then, fits well with the anthropological concept of culture, as it is both enacted and acted upon by practitioners; it is symbolic by nature, but is made real by those who give it significance, often subconsciously, as most cultural aspects are not actively pondered while being performed. Habitus can also fit into the sectors of healthcare and health behavior as well. Many healthy behaviors have become such staples within our everyday lives, brought about through repeated socialization, that we no longer think about them (bathing regularly, washing food before preparation, looking both ways before crossing the street, etc.).

Understanding then that habitus is also both symbolic and enacted, we will now discuss the concept of "social capital." Originally coined by Bourdieu, social capital is defined by Richard Carpiano (2006) as:

> … a characteristic of groups—the total stock or quantity of resources tied to an institutionalized network. The benefits of…being a member of this network serve as the foundation of the solidarity that generates these benefits or profits. Like other forms of capital that he identified as critical for the pursuit of profits and maintenance of social class position, such as economic capital (money) or cultural capital (e.g., education, taste), social capital can be used to obtain resources in tandem with, or in the absence of, other forms of capital. (169)

Generally, the amount of social capital that one possesses, which is both symbolic to the individual as well as the collective, depends on the size of the network, and the types of capital owned by each member of the network (Carpiano 2006). The complexities of the social networking theory of health are discussed in the next section of this chapter.

Being that the client of this research project is a patient services provider with a unprecedentedly high level of power, due to its function as a tele-health call center, they occupy a profound position to influence both the habitus and the social capital of

patients. There has been, within the studies of healthcare and other organizations, a great amount of attention to many of Bourdieu's theoretical elements, but little focus on habitus (Emirbayer & Johnson 2006). For an organization like the client to make use of habitus for the good of their patients, several steps will need to be taken. First, the client will have to find what constitutes regular behavior for their patients and investigate what enforces that behavior. Second, they will have to translate their interventions and programs for ensuring patient compliance and improving their health status into a sound logic that meshes with their behaviors. And third, the client must find ways to re-enforce their intervention's results by contributing to the everyday life of the patients.

This would take time, and energy, and critical thinking on the part of all members of a program's team, but over time, change in habitus could be realized, as well as increasing the accumulation of their social capital. As the definition above purports, there is both a symbolic aspect to social capital, and a reality-based aspect. The resources that one has, and that one has access to, make up a part of social capital, and how those resources stretch from the individual to their community, and vise versa makes for a complex series of capitals (Rostila 2011). Disentangling them can be even more complex, if the focus were to remain entirely upon the big picture across time and space; looking at one section at a time, concerning with the specific of the patient and the disease they are living with would drastically simplify applying social capital (Landstedt et al. 2016).

Tele-health call centers like my client work with a wealth of information and contacts, simply with access to the Internet. An ever-expanding resource database, further elaborated on in the next chapter, would allow for the development of new

channels of social capital, or perhaps more specifically "health capital" for patients

across multiple programs. Because the patient's position within the socio-economic

strata might not change due to the intervention of tele-health programs, health capital

serves a more appropriate phrase due to the health status of the patient being a primary

concern. There is also the unique position that the client holds within every patient's

social network, which would also lend themselves to influence social and cultural capital

in ways rarely achieved in the healthcare industry.

Social Networking Theory of Health

The social networking theory as it applies to public health is concerned with the

relationships of an individual, called an "ego" or patient, to persons or entities, called

"alters" within that network; the examination of links and ties from the ego to their alters

serves understand the roles played to influence risky or healthy behavior (Glanz, Rimer,

& Viswanath 2008). Figure 7 depicts an example, a simplified network of these

relationships, what is called a "sociogram." Table 1 outlines the definitions of key
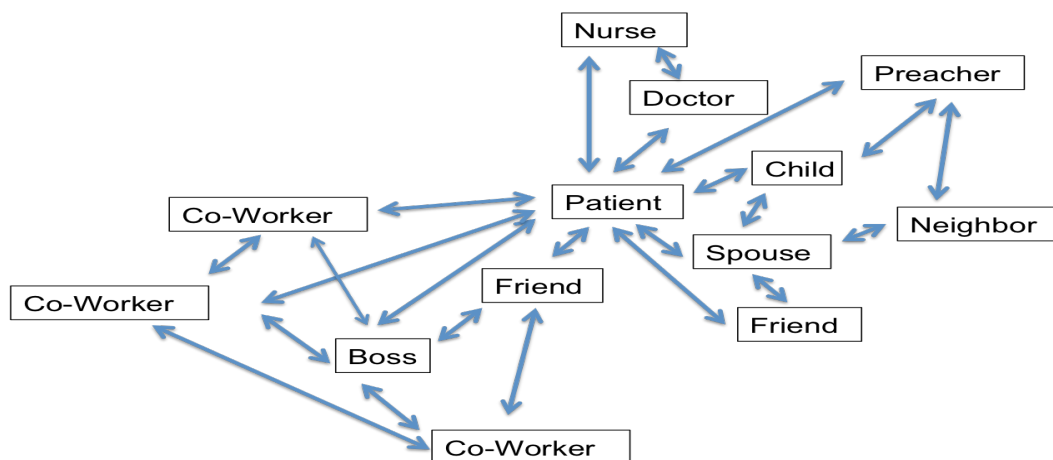
components to the theory.

Figure 7. Sample sociogram.

An understanding of the "impact of social relationships on health status, health behaviors, and health decision making can contribute" to the advancement of public health through the design of effective programs (Glanz, Rimer, & Viswanath 2008, 189).

Table 1.
Key Concepts and Definitions of Social Network Theory (Glanz, Rimer, & Viswanath 2008, 229)

Concepts	Definitions
Structural characteristics of social networks:	
Reciprocity	Extent to which resources and support are both given and received in a relationship
Intensity or strength	Extent to which social relationships offer emotional closeness
Complexity	Extent to which social relationships serve many functions
Formality	Extent to which social relationships exist in the context of organizational or institutional roles
Density	Extent to which network members know and interact with each other
Homogeneity	Extent to which network members are demographically similar
Geographic dispersion	Extent to which network members live in close proximity to focal person
Directionality	Extent to which members of the dyad share equal power and influence
Functions of social networks:	
Social capital	Resources characterized by norms of reciprocity and social trust
Social influence	Process by which thoughts and actions are changed by actions of others
Social undermining	Process by which others express negative affect or criticism or hinder one's attainment of goals
Companionship	Sharing leisure or other activities with network members
Social support	Aid and assistance exchanged through social relationships and interpersonal transactions
Types of social support:	
Emotional support	Expressions of empathy, love, trust, and caring
Instrumental support	Tangible aid and services
Informational support	Advice, suggestions, and information
Appraisal support	Information that is useful for self-evaluation

Before going into detail about the above terminology and its connections to companies like the client, I would first take a moment to discuss the pivotal alternation to the theory of social networking that I have mused from my findings. Normally, it is the patient who remains at the center of the sociogram, and the connections are made, and then the difficulties arise. Common criticisms of the social networking theory deal with measuring something as subjective as a personal relationship and comparing it with others in the network, judging the levels of intimacy and interaction, the potential homogeneity or diversity of persons in the network, and communication patterns (Glanz, Rimer, & Viswanath 2008). As Figure 8 will assist in conveying, rather than focusing on the network with the patient at the center, tele-health organization must put themselves at the center of the sociogram. That way, when companies like my client find their providers at a more personal level with their patients, they can address the kinds of care delivered. This would then, appropriately, contribute to a greater distribution of power and resources, as well as improving the patient's social capital relating to their health.

When any relationship begins, people are nothing more than as the strangers, even in the healthcare setting, and especially when you receive a call from someone claiming to be nurse with personal knowledge of you at their fingertips. That first call is always difficult; trust and rapport take time to cultivate. But once the connection is established, the nurse over the phone becomes another healthcare profession, like any doctor or assistant they see in an office. It is when those relationships become something more, when the repetition of having someone to speak with, who understands, and actively tries to improve, the lives of these patients, that tele-health call centers can become the closest of friends or even long-distance member of the

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family to these patients. This way, not only can social networking theory be used to understand the health behaviors and reasoning, like the work of Holman and Borgstrom (2016), but the theory can be used to effectively shape those behaviors based upon where the healthcare professional fits within the patient's social network.

The Client Relating to Patient's Social Network

EGO	FAMILY	FRIENDS	HEALTHCARE WORKERS	STRANGERS
Patient	Spouse	Best Friends	Doctors	CLIENT
	Children	Close Friends	Nurses	
	Relatives	Work Friends	CLIENT	
	CLIENT	Acquaintances		
	CLIENT			

Figure 8. Provider to patient: Social networking theory of health.

It is certainly no secret how the influence of positive social networks serves to benefit the physical, mental, social, and spiritual well-being of people. While wellness is certainly difficult to quantify, the subjective importance, via self-introspection, has been well documented from the earliest of ages in the human experience (Parker et al. 2015). With the changing communication and technological landscapes being more and more intimately intertwined, health information and health behaviors will follow suit. Research has already begun to realize the uses and challenges of online social networking, and with the expansive influence of tele-health services in the healthcare field, it seems only appropriate for the continued use of social networking theory to examine and develop new tele-health programs (Singleton et al. 2016).

So, harkening back to Table 1, how do the components of the theory fit into a tele-health clinical call center? Let us take it from the beginning. The reciprocal nature of the relationship from nurse to patient will be generalized, as in the case of my client's company, services and information is given with no expectation of the patient to compensate, financially or otherwise. The intensity or strength of the relationship would depend, and subsequently adjust depending on where the healthcare provider falls in relation to the patient's social network. The complexity would vary based on the programs and services affiliated with each illness and medication; formality would be subject to change as much as intensity. Homogeneity and geographic dispersion would take a lesser role in this version of a social network, as the distance between provider and patient, joined by technology, would tend to supersede demographic and proximity. Finally, the directionality would be almost exclusively one-side, on the side of the service provider, considering the generalized nature of the relationship.

We now turn to what Table 1 refers to as the functions of social networks. Recall earlier I discussed how social capital is enacted and constantly redefined. That process might take time, but as Bourdieu (1993) wrote:

> …constructing the concept [of social capital] one acquires the means of analyzing… whereby this particular kind of capital is accumulated, transmitted, and reproduced, the means of understanding how it [becomes other forms of capital]… and the means of grasping the functions of institutions… the main sites of accumulation and transmission. (32-33)

If tele-health centers were able to look closely at what they can provide to their patients, where they can expand those resources, how they could develop new services, they would be on track toward realizing their role in the development and dispersal of social capital to those they serve. Social influence, companionship, and social support would all improve and integrate as the network expands and the types of capital provided to patients evolves. Social undermining, on the other hand, would obviously be avoided; there should be no intention of tele-health programs resulting in negative outcomes for the patients, contributing to the hindrance of patients attaining their health goals.

Tele-health centers would also be able to provide all of the types of social support, as listed in Table 1. Providing emotional support, instrumental support from the physical products, medications, and PRN trainings, informational support from those working in the call centers, and appraisal support. Appraisal support involves helping others with information to improve themselves, to look inside and learn to expand their sense of worth and ability, which will be discussed next.

There already exists a present need for further exploration of social networking theory and tele-health organizations. As the world of technological advancements change, so to must the tools and methodologies of tele-health providers, according to

Ackerman et al. (2010). Keeping up with those complexities necessitates what Lee et al. (2012) described as "integrating connected health solutions with social networking and added…influence" (269). This can only be accomplished by a greater public health presence within the tele-health call center environments, studying the influence and nuances of the social networking theory of health in this virtually untapped and nascent sector of public health (Weitzel et al. 2009).

Patient Self-Efficacy

This section will discuss the theory of patient self-efficacy, but there are two concepts that I will discuss to better aid in understanding the complexities of this topic. The first is "self-efficacy" itself; it can defined as an individual's belief, or confidence, in his or her ability to take and perform actions (Strecher et al. 1986). Self-efficacy shares close ties with agency, or the ability of a person to actively shape his or her experience and environment (Strecher et al. 1986). The next term I will define is the "sick role;" this is a social phenomenon wherein an "ideal representation of how people in Western society should act when sick and describes a patterned set of expectations defining the norms and values appropriate to being sick" (De Moor 2005, 738). It has been argued that by occupying, essentially enacting, the sick role, no matter the illness or disability, individuals find themselves under a new system of subjugation or oppression (De Moor 2005). Subverting, or challenging, the systems of the sick role typically can lend themselves to self-efficacy.

For many disease states, including multiple sclerosis, because patients are constantly sick, they are culturally expected to occupy the sick role. Their disability

limits their employment opportunities, mobility, senses, and individuality, but because it is an invisible illness, it is not uncommon for MS patients to encounter social prejudices. For example, one of my patients spoke of the aggression she sometimes encounters for her handicapped parking spot, when there is no visible sign of her disability. Because they are not visibly sick, and because they are simultaneously always sick, by the cultural expectations of the sick role, people living with MS occupy a perpetual paradoxical liminal state. That is they are expected to be sick and accept the limitations of being sick, while also always enacting their sickness as a proof of status. This social impediment requires such persons to creatively increase their power over their lives, their capital within society, and their perceptions of self-efficacy.

One such way is through support groups, whether in person or over the internet, as we have previously discussed, support through social networks using all of the methods of communication at their disposal, sharing and meeting to increase their confidence (Lawlor & Kirakowski 2014). Various methods that call centers can make use of to increase patient self-efficacy with regards to their care will be discussed in greater detail in next chapter. The recommendations there can assist in enabling and empowering patients and their beliefs of their abilities for virtually any chronic disease (McCorkle et al. 2011). They would also compliment the existing self-management and health education services indicative of tele-health clinical services and programs (O'Connell et al. 2002).

It has been argued that using alternative or emerging channels of social support, like the Internet, may result in increased social avoidance, but I would posit the opposite to be true (Lawlor & Kirakowski 2014). Rather than retreating away from social

interaction, the increased self-efficacy will influence their decision making skills as

patients relating to their healthcare providers and disease management (O'Connell et al.

2002). Similar to the findings in Sosnowy's (2014) article, new social networking and

communication methods could act as a form of practice, to practice the subversion of

the sick role and improving their self-efficacy with the aid of healthcare providers like my

client and others living a similar experience:

> Accompanying the current discourse on health care reform, in which terms such as *patient empowerment* and *self-care* often appear, is the assumption that health-informed individuals will participate, alongside their healthcare providers, in a process of shared decision making. Ultimately, the logic follows, informed empowered patients will take responsibility for their health, including managing their health care…[by] mapping the transition of the internet-informed patient from nuisance to expert, partner, and manager of their illness…becoming a prescriptive norm that crowds out other ideologies and behaviors. (319)

The following chapter will detail the recommendations I created for my employers and

thesis client. It will detail how combining the results of my needs assessment research

and resource evaluation from chapter four, and the theoretical components of chapter

five, resulted in the proposals for improving the clinical services department.

CHAPTER 7

DELIVERABLES AND RECOMMENDATIONS

Client Deliverables

Per the contractual agreement with the client, a series of deliverables were

shared with site sponsors. The deliverables themselves combined a twenty-three-page

booklet detailing the recommendations, which will be expanded in the following section,

an accompanying presentation, and an extensive list of mobility services located

throughout the Dallas and Fort Worth, Texas area. Naturally, not every theme

discussed in chapter four was relevant for the recommendations for the client's clinical

services department, but the necessary connections between theme and

recommendation will be made clear. There were a total of five recommendations

presented; the two directors who acted as client sponsors to my research voiced their

appreciation, excitement, and pride at the quality and breadth of the work. The

information shared was to be presented to the office's vice president by the sponsors; a

pending program called a "lunch-and-learn" open to all employees to attend is also in

the works. As the researcher, I have assured the client of my continued involvement

should any of these recommendations move forward to becoming a practical realization

within clinical services.

Recommendation: Foundational and Navigation Support Team

The first recommendation is the Foundational and Navigation Support Team, or

the FNS Team. Phone nurses, during interviews, commented on their enjoyment and

appreciation for the work they are able to do with the client, but another theme that

arose with great frequency was the perception of being either overworked or

understaffed. The daily rollover of responsibilities result in a constant influx of new patients and tasks, which can take its toll; as is often the case: a high employee turn around rate. Solutions are not so simple as hiring new nurses to redistribute the work, especially since the pharmaceutical manufacturers and their contracts dictate programs and their parameters. Often registered nurses have a higher salary expectation, and with limited funding constrained by contracts, the number of nurses that can be hired are also controlled.

The FNS team would serve to address multiple needs revealed from phone nurse interviews. First, the team would be comprised of various trained and licensed professionals. These individuals would be able to support the nurses, behind the scenes, taking some of the daily tasks off the phone nurses' lists. Professionals I imagined could be licensed social workers, public health workers, or health management professionals. They would have the training necessary to handle helping the nurses and patients with gaining financial assistance, processing foundational applications, and navigating insurance plans and benefits. Due to the broad range of responsibilities that the FNS team would handle, combined with the specified specialization that would make up the team members, the FNS team could stretch across multiple drug programs.

Team members would have the same training as the nurses to perform their tasks, and their diverse licenses, credentials, and abilities would be attractive to the pharmaceutical companies seeking the client's business. Not to mention, no matter who would be hired, be they a social worker or a public health professional, they would cost less to employ than registered nurses. The inclusion of the FNS team could have

many benefits to a tele-health call center, not just to this client and their business.

Phone nurses would have more time in their day to reach more patients, and while they

still work on addressing patient needs and fulfilling obligations, the FNS team would be

available. The team would be readily available and constantly devoted to the task

discussed above, the needs discussed in chapter four, and more.

The FNS team would also positively affect the client's position as a member of

the patient's social network. Partnering with the FNS team, the patient would find a

resource that occupies a position as a patient services provider, but also a source of

supportive advocacy for obtaining resources and funding. With a greater level of

professional diversity, the clinical services would be capable of assisting and providing

care in more complex ways. With more patients interacting with their nurses, the

business as a structure of power, harkening back to the observational tower as

described by Foucault, the distribution of power lending to self-efficacy would increase.

By observing the patient, even across great distances and over the phone, the

department with the power can better share that power with patients. With a greater

ease of obtaining Bourdieu's social capital, both literally and metaphorically, through

financial aid applications and insurance navigation, the patient would also experience

higher agency with regards to their health and controlling their illnesses.

Recommendation: Patient-to-Patient Program

Every patient interviewed spoke of how beneficial and life affirming their MS

support groups were to their quality of life. As mentioned before, some groups were

activist based, while others were faith based, but during participant-observation, the

community and camaraderie that the men and women have built was impressive and endearing. The groups, their messages, and their activities transcended ethnicity, gender, socio-economic status, and most importantly, their disease. The proposed patient-to-patient recommendation could be a component of any of the client's existing clinical services program.

It would be one that would benefit new patients by connecting them with existing patients, already participating in their drug-specific program. In practice, the phone nurse would connect the patients over the phone, the existing with the new, to provide a valuable and relatable contact for both moving forward in their treatment. Naturally, there would be ethical considerations to account for, but even with a short pronouncement, the phone nurse could communicate that without a clinical services representative on the line, the conversation is out of the company's responsibility. A signed, or even a verbal, waiver collected by patients would help to comply with protecting personal health information as well as following the federal standards set down by the Health Insurance Portability and Accountability Act (HIPAA).

With a tele-health services provider at the helm, initiating and guiding the relationship fostered between patients, there would be greater benefit to the social network of all patients involved. A community of sorts, only made possible by the connection of technology, would serve the greater good of the many over the individual. Self-efficacy of the new patients would increase; their knowledge improved by the guidance of their peers. Their beliefs in themselves, in their abilities for managing their disease would be fostered, or born entirely anew. Skills shared between patients would improve quality of life as well as ensuring a higher potential rate of medication

compliance. New patients would have a contact, a potential friend, who knows what they are going through. This would also contribute to increasing both the new and the established patients' collection of social capital. As discussed before, social capital takes on many forms, often symbolic, or only significant to the individual themselves. This does not diminish its importance. On the contrary, beliefs hold tremendous power in human culture, especially when considering the behaviors and the sharing of health knowledge.

Recommendation: Patient Resource Database

The three interview groups: phone nurses, PRN nurses, and patients all spoke of a common desire to improve patient quality of life. The reality of the situation, albeit somewhat ironic, is that there exist countless potential resources available for people in need of assistance. What it comes down to is knowing how to find those services, and how to make use of them.

The third proposed recommendation is for an ever-expanding, constantly improved-upon patient resource database. This database can, once again, be adapted and utilized across many different medication programs of clinical services. This recommendation could even be a responsibility of the Foundational and Navigation Support Team discussed earlier. The components of the database would include contact information, any web-based resources, and potential personnel, if those resources were used in the past. Virtually any need of the patient, within reason, could be a part of the database. Potential services provided to the client were founded on patient and provider interview themes.

One service could be transportation services, for those without their own or are unable to transport themselves. Public transit schedules, information of routes, and disability taxi services would fit well in this category of the database. Another service would be mobility services: charities and funding for helping patients secure affordable canes, walkers, wheelchairs, or prosthetics. While attending one support group meeting, a guest speaker from a local vehicle and home alteration business shared a short list of other such organization and non-profits his business partner with. I took his information and expanded on it, compiling a list of over one hundred local, state, and national mobility supporter to begin my client's resource database. I included the name, website, and a contact number if one was available.

Foundational and advocacy support services would be another sector of the database. Listing non-profit and governmental services, the workers with the database would provide access and assistance for all the numerous national charities and societies that serve those with various medical conditions. Researching and compiling local wellness opportunities, such as specialized gyms or alternative medical treatments, would help enhance quality of life of patients, based on their needs.

The existence, access, and distribution of resources is directly linked to the concepts of social capital, and by extension: habitus, as revealed by Bourdieu. The recommended resource database provides a realistically realizable method of narrowing down the complexity of social capital needs with potential resources to address those needs. The database would also serve to track and calculate where these services and organizations are as they relate to patients, further addressing the cultural and social dynamics of the patient's environment.

Recommendation: Training Diversification

Many of the nurses, both phone and per diem, called for more training, and a diversification of the kinds of training being performed. This call was not necessarily concerned with a lack of knowledge to do their jobs, but more for interpersonal connections. Thematically, there was a consensus found that with so many remote nurses, spread out over the entire United States of America, many nurses feel that they do not know their own team members. They partner on the same program, interact with the same patients, and are responsible for working together on complex healthcare systems, but often hardly ever meet in person.

This fourth recommendation proposes that bi-annually, or perhaps only once a fiscal year, teams would have two different training sessions. One session would be intra-team, with members of the same drug program connecting together via phone, web-cam, or in person to increase team morale and to just get to know each other better in general. This would also include any PRNs contracted for that program, allowing them to have a greater insight into the workings of the company as a whole.

The second training session would be inter-team; working with other teams, on other drug programs, keeping specifics of both programs confidential, would allow both teams to share work strategies and care philosophies. This would improve communication and morale of all employees, increasing the understanding and inner-workings of the company and the department. Practices and level of assistance would also improve based on the shared collection of knowledge and beliefs as they relate to healthcare and nursing.

The professional expression of nurses, and how they actualize their theories and philosophies of care, influences many aspects of their interactions with patients. Sharing their expertise with one another would allow for not only an important exercise in communication strategies, but would also improve the network of client employees and their morale. In any setting involving teams, it is best for that team to work together as effectively as possible to improve productivity, and in the case of patient services, how the whole team empowers patients together by increasing their sense of power and capital.

Recommendation: Technological Advancement

Technology continues to change much of what we understand of the world around us. The advancement progresses so quickly, it is advantageous for tele-health, or e-health, organizations to be as far in the forefront of these developments as much as possible. Being a call center allows the clinical services department of my research client to metaphorically have one foot in the door in the path of progress.

More and more people are electing for the use of cellular phones as opposed to home phones or dedicated landlines. Those cell phones are being used more for texting, email, and for other applications. The final recommendation of my deliverables calls for increased technological development. The client would invest in a software, or application, program to use texting, email, or other communication applications to complement their existing telephone services. I found that there are numerous existing software programs available for purchase that can send, receive, track, store, and analyze text messages and emails that can be sent from a computer. Patients that I

recruited for interviews remarked of their desire to be contacted via text message or email; only one of the many I recruited wished to be specifically called on the phone.

As communication vehicles evolve, so to do the social and cultural components of human relationships. The digital age is not slowing down, and the age of technology has required a change in how we learn and how we share information. By adapting health messages to meet patient desires, as well as diversifying the potential of tele-health call centers, the on-going evolution of social networks and where those call centers reside on those network will potentially spread-head the industry to the forefront of health education, case management, and patient resources. This would be due to all these benefits and more being right at the patient's fingertips.

Each of these deliverables were designed to be realistically recognizable, cost-effective, sustainable across many drug programs, and technologically feasible. While these recommendations were supported by the input of patients living with multiple sclerosis, implementing any of these programs could have lasting positive impact on patients. They could also be configured to meet the needs of other organizations, such as other pharmaceutical service providers, public health departments, or even physician clinics on a smaller scale.

CHAPTER 8

CONCLUSIONS

Discussion

The relevance of my research would be beneficial and contribute to the ongoing

scientific fields of applied medical anthropology and public health, as well as the

movement toward advancing healthcare and the tele-health industries. By its very

nature, in working for communities and improving the cultural and societal limitations of

those communities, applied anthropology seeks to establish a critical presence beyond

the halls of academia (Baer 2001). Anthropology remains a theoretical and practical

skill set that most of the world remains ignorant of its uses (Mazzarella 2002). As an

applied anthropologist, I know the discipline can provide just the tools necessary to

carve out a place for anthropology in the development of the future. Applied

anthropology could very well pave the way for social science and development in

general, but the path to such position would be arduous and would require constant

evaluation on the part of anthropology and what it can offer (Hoben 1982).

Some of the most prominent leaders of the anthropological field have written on

what applied anthropology must do to realize its position within and beyond the

academy. Rylko-Bauer, Singer, and van Willigen (2006) wrote on pragmatic

engagement being key to repositioning the disciple, saying:

> If pragmatic engagement becomes the realized goal of anthropology, the
> relevance will surely follow…this requires a willingness to take stands on
> pressing social issues, to be ethically and politically subjective while
> methodologically objective, and to accept advocacy…that already values theory
> and research excellence (186).

The tele-health industry, and the healthcare industry in general, always remains a

pressing concern within the realms of research and development, embodying one of the

most "pressing social issues" prevalent around the world. To ensure the melding of theory and practice into action, applied anthropologists should strive to link their findings to "existing and future practical programs…[and] contribute to anthropological theory" (Foster 2002, 175).

My research effectively contributes to the field of applied medical anthropology. My interviews with tele-health nurses, my participant-observation as an employee of the client, and my recommendations for improving patient services marked the potential for applied anthropology to benefit and improve tele-health businesses. Each of the recommendations are evidence-based, but are still adaptable to many different disease states, allowing for the necessary synthesized approach to medical anthropology theory and research findings to develop appropriate patient programs (Dressler 2001).

This thesis project has also contributed to the field of public health, and there are a couple ways that this contribution has been made manifest. The first involves the design, implementation, and evaluation of tele-health based programs (Vinson et al. 2011). With the relatively recent advent of the e-health and tele-health industries, there are few investigations into positioning public health within the industry itself. With my insight as an employee, and the socio-cultural theory combined with the social networking theory of health, this project can serve as a springboard for public health to enter this new arena.

The second contribution to public health would be the deeper and more personal insight into the state of multiple sclerosis as a public health concern. The findings of my interviews with patients provide a more intimate view into the realities of MS as a lived experience. More research, and therefore more public health interventions, to address

the needs of people living with MS would help to improve their quality of life, ensuring a subsequently easier life for people newly diagnosed (Boiko et al. 1998).

One more way that my project would benefit other areas of research and health concern would be the humanization of healthcare and health research. Often, the case will be, that health research will be very quantitative, very numbers driven. While these methodologies certainly has an essential and eternally relevant part to play in healthcare development, qualitative can be just as pertinent. If the scientific community recognizes that application, more specified interventions and programs could be implemented. Speaking with patients and providers to have their wisdom, their experiences, and their expertise included in their care would allow for that care to be much more personalized. The process of bringing humans into the research mix is called "humanization;" the results of my investigation, as well as the design of my recommendations, would serve to show the importance and significance of developing healthcare advances with actual humans in mind (Todres et al. 2009).

Limitations

Like any research project, like any anthropological investigation, there are limitations that arose during the course of the venture. Perhaps the most pertinent limitation is the issue of bias. Bias was to be expected with the use of participant-observation and qualitative research techniques. Given my position as a program coordinator, and my established relationships with many of the phone nurses and all PRNs interviewed, no matter how I controlled with non-leading questions, allowing participants to truly share their own responses unhindered, there was an inevitable bias.

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We shared an intimate inside perspective on the inner workings of the client's business, more so than any anthropologist brought in strictly as a consultant could achieve. Our discussions could become far more candid than intended, and mutually accepted "common sense" as employees ran the risk of being lost and not expanded upon.

That same bias stretched to the analysis process as well. Put frankly, my thesis client was also my employer, my source of income, and my livelihood. While I am confident in my findings, as well as how those findings were put to use in my deliverables, the reality of my position, as well as the integrity of the client was ever present in my mind, in every step of the process. While it was assured that my status as a specialist consultant for my thesis research would not impact my position as an associate, and while it was also assured that no employee participant would run the risk of losing his or her jobs by speaking with me, everything was challenged for me. From the phrasing of questions, to the theoretical framework of my analysis, and even to the structure and presentation of the deliverables as well as this thesis itself was carefully monitored. However, steps were taken to account for this inevitability; and even simply realizing the potential for bias is itself a measure of control.

Another limitation of this project comes from a gendered perspective. While it was anticipated, a disproportionately high number of participants, in every phase of this study, identified as female. Culturally, nursing is still considered a female profession, and the incidence of patients diagnosed with multiple sclerosis certainly does linger more heavily on the feminine side of the spectrum. However, only two nurse interviewees, only three PRN survey respondents, and only one patient interviewee was male. With a total of eighty-nine participants across all phases of this investigation, and

only six answering with their gender as male, this invariably skews the type and generalization of responses. Of course, the voices of women are essential for understanding and developing the world, and feminist theory has become a staple in both anthropology and social development. Sadly, the lack of male participants in my research, and the lack of distinction in their responses as men, resulted in the thematic generalization being almost exclusively female-driven.

A third limitation, strictly on the patient phase of my project, follows an ethnic consideration. While the trends do point to an increase in persons of color being diagnosed with MS, only two of my patients were women of color, African-American to be specific. It was not a specified topic for discussion, but some questions asked did lend themselves to the issue of socio-economic status and how patients found their status changing as a result of their MS. With the changing dynamics of the MS ethnicity landscape and the observable differences of socio-economic status across races in the United States, having more persons of color as participants could have resulted in greater insight. However, for better or for worse, eighty percent of patients I interviewed were Caucasian, and so that reality had to be taken into consideration during analysis.

The next limitation concerns numbers, specifically the number of participants. While I was extremely pleased with the surprising response rate for the survey, especially considering it was a two-week general cold-call for responses, the number of interviews casts a different shadow. While designing this project, I had no idea what to except. I had no way of predicting the answers I would receive, or how many participants would respond similarly enough to reach data saturation. In some respects, for some questions, saturation was either reached or was being quickly approached.

Still, to follow the old adage: there is always more to learn. I did not plan for follow-up interviews, nor did I organize dialogues in group settings like focus groups, so expanding upon emerging themes and gathering more specific information was not possible. If I had more time, I would certainly entertain the possibility of submitting a revision to the university's IRB to organize follow-up interviews, or just interview a few more patients living with MS.

One final limitation that I will discuss is that of the disease state itself. While I have argued that MS is a valid and pertinent public health concern, the rates of afflicted persons, compared to other illnesses, is rather small. MS is also a very specific and troublesome disease in how it presents itself; it marks itself differently than even other neurological diseases. The needs and health concerns of MS patients might be comparable to other patients living with cancer or Parkinson's, but the potential crossover is often arbitrary at best. I designed this project to assist multiple programs of the clinical services department, targeting many different disease states, and in some ways I succeeded. The resource database and the patient-to-patient recommendations could be successfully and sustainably implemented across many programs, but the needs of MS patients are different to most others.

Reflection

Since I began planning the proposal for this project, time and again I was told by my instructors, by my peers, by my coworkers, and by fellow applied anthropologists at conferences just how ambitious this research was for a Master's candidate. I took that to be both a compliment and a challenge. Every time I heard it, their words bolstered

my drive to complete something so "ambitious." Still, I knew I needed to plan

accordingly, and as a someone who was virtually simultaneously a full-time student and

working full-time, I knew there would be roadblocks that I would need time to surmount.

So I began the necessary IRB proceedings more than a year before my intended

graduation date, when most of my classes had been completed.

The first hurdle was the contractual agreement with the legal department of the

client. From the beginning, both my site sponsors as well as the representative of the

legal team assured me that I not only had a thesis client in my employer, but that they

would also work with me to see a program that I designed being realized. However,

their concern was, first and foremost, the image and wellbeing of the company. This

resulted in many phone calls and many meetings between my sponsors, my advisor

and thesis chair, the legal representative, and myself. It was during these meetings that

I learned the value of language, and how to be like a chameleon with my phrasing and

syntax. Even just using a different word, one more suited for the business world rather

than the academic world, but still holding the same intrinsic meaning can make all the

difference. Suddenly, where there used to be confusion and disconnect in messaging,

a turn of phrase can bring enlightenment and agreement. While the journey took over a

month, what with the difficulties that come with scheduling for so many different people,

it was a major accomplishment for me to conform to the ethics of the business and

maintain my academic integrity, all through just using the right words at the right time.

I was one of the few members of my graduate school cohort who was employed

full-time as well as working on my degrees full-time. This resulted in a necessary

flexibility and a need for constant time management and awareness with which few of

my classmates could relate. Where my classmates would have their whole days to

work on assignments and their fieldwork and their analysis, I only had nights and

weekends. And after a hard day at work, it is understandably difficult to muster the

energy to continue working on academic responsibilities. Still, with every semester

brought new opportunities and challenges, and during my time in the field, those months

of scheduling even more connections and interviews have certainly honed those skills.

Immediately prior to beginning the process of applying for IRB approval, after

completing and signing the client contract to perform my research, my program working

for MS patients was effectively terminated, and I found myself facing unemployment and

a loss of a thesis client. The stress and despair that came from almost being laid off

persisted until my final day of employment, October 31, 2015. Following tradition, the

client allows its employees to dress up for Halloween, within reason, and so I decided to

celebrate my intended final day in costume. And it was my intended last day, until I

received an email from the Director of Reimbursement asking to meet me in his office.

This was a man I interacted with at most a handful of times, seeing as this was an

entirely different department from clinical services. Nevertheless, I journeyed down a

floor to this office, wearing my Halloween outfit and covered in makeup, to learn that

one of their reimbursement programs had a vacancy. I was offered the position and so

found myself in the paradoxical situation of being laid off from one job to return to a new

job at the same company the next business day. As it turns out, my thesis sponsors,

the Directors of Clinical Services and Operations had worked with the Reimbursement

Director to find a place for me, to ensure I would be able to continue my project. My

good fortune considering the unlikely nature of the situation has not been overlooked on

my part; I am exceedingly grateful to my client for looking out for my financial wellbeing and realizing my academic goals.

My time out in the field, conducting interviews and following my timeline concerning the phases of my research, passed relatively without incident. All interviews were completed on the date they were scheduled; there was little overlap of responsibilities because I took care to manage my dates and interviews accordingly. Interactions with the interviewees were pleasant, and after the first few sessions, I returned to a higher level of communication, locking on to pertinent statements to ask follow-up questions. We worked together to ensure complete understanding, resulting in more in-depth and longer interview sessions as time passed.

All in all, this has been one of the most rewarding experiences of my life thus far. My journey through the thesis process, all of the triumphs and pitfalls that I overcame, have provided me with the knowledge and experience I desired to round out my Master's career. I conclude this project with a greater understanding of the benefits of public health research, the ever-increasing and dynamic role of tele-health in the healthcare industries, and the experiences, strengths, and needs of the MS community. I look forward to continuing my work toward improving the lives of patient living with MS and other neurologically degenerative and chronic diseases.

APPENDIX A

INTERVIEW QUESTIONS

For Phone Nurses:

1) Name, Age, Gender, Education Level, Years Practicing Nursing, Years with the Client
2) Please tell me the story of what brought you to the nursing field.
3) How did you come to work for the Client?
4) How many programs have you worked on with the Client?
5) Please tell me about a particularly positive patient interaction you've had working for the Client.
6) Please tell me about a particularly negative patient interaction you've had working for the Client.
7) Have patients expressed wishes or desires for healthcare services they believed would improve their quality of life? Even hypothetically? If yes, what specifically?
8) What are some improvements to the Client's clinical services department that you have thought of?
9) What are some strengths that you feel the Client has as a business? As a healthcare provider?
10) What ways would you like to see the Client progress as a service provider to patients?
11) Final thoughts, comments, questions, concerns, etc.

For PRN Nurses:
1) Name, Age, Gender, Education Level, Years Practicing Nursing, Years with the Client, Number of Programs
2) Please tell me the story of what brought you to the nursing field.
3) How did you come to work as a PRN for the Client?
4) Please tell me about a particularly positive patient interaction you've had while in the field as a PRN.
5) Please tell me about a particularly negative patient interaction you've had while in the field as a PRN.
6) Have patients expressed wishes or desires for healthcare services they believed would improve their quality of life? Even hypothetically? If yes, what specifically?
7) How have patients, out in the field, have had their lives improved by the services provided by the Client?
8) What are some improvements to the Client's clinical services department that you have thought of?
9) What are the strengths that you feel the Client has as a business? As a healthcare provider?
10) Final thoughts, comments, questions, concerns, etc.

Questions for MS Patients:

1) Name, Age, Gender, Education Level, Occupation
2) How many years have you lived with MS? How old were you at diagnosis?
3) What type of MS were you diagnosed with?
4) How did treatment begin?
5) How are you currently treating you MS? What prescription? Any alternative or complementary medicines or treatments?
6) Please, walk me through one of your average days.
7) Please, walk me through one of your more difficult days.
8) Please, walk me through on of your better, or above average, days.
9) What are your most common recurring symptoms of MS?
10) How do you feel your life has been most impacted by MS? How have you dealt with these impacts?
11) Please tell me about your family life. How has MS influences or impacted your family dynamic.
12) Do you have any wishes or desires that you believe would improve your quality of life?
13) Do you find support with others living with MS? Do you find support through your family and friends? Please, tell me the ways you give support to others, and how you receive support from others.
14) Please, tell me about your relationships with your healthcare providers. Tell me about your relationships, your interactions. How accessible do you find their services?
15) Do you have any ideas for services that would benefit you or others living MS or another chronic disease?
16) Final thoughts, comments, questions, concerns, etc.

APPENDIX B

PRN SURVEY QUESTIONS

1) Full Legal Name:
2) Age Range:
    a. 18-24
    b. 25-34
    c. 35-44
    d. 45-54
    e. 55-64
    f. 65-74
    g. 75 or older
3) What is your gender?
    a. Female
    b. Male
    c. Choose Not to Disclose
    d. Other (please specify)
4) What is the highest level of education you have completed?
    a. Associate's Degree
    b. Bachelor's Degree
    c. Master's Degree
    d. Doctorate of Philosophy
    e. Other (please specify)
5) How many years have you worked as a Registered Nurse (RN)?
6) How many years have you worked as a contracted Per Diem Nurse (PRN) for the Client?
    a. Less than one year
    b. 1 year
    c. 2 years
    d. 3 years
    e. 4 years
    f. 5 years or longer
    g. If longer than 5 years, please specify:
7) How many medication programs have you worked on for the Client?
    a. One
    b. Two
    c. Three
    d. Four
    e. Five or more
8) Please name the programs you have worked on:

9) Please describe your general level of satisfaction as a contracted employee of the Client.
   a. Not at all satisfied
   b. Somewhat satisfied
   c. Neutral
   d. Satisfied
   e. Very satisfied
10) Please describe your general level of satisfaction of the programs you have worked on.
   a. Not at all satisfied
   b. Somewhat satisfied
   c. Neutral
   d. Satisfied
   e. Very satisfied
11) How would you rate your average experience with patients out in the field?
   a. Overall disappointing
   b. Unsatisfactory
   c. Satisfactory
   d. Above satisfactory
   e. Overall rewarding
12) How often do challenging/unexpected situations arise while you are out in the field?
   a. Almost never
   b. Not all that often
   c. Somewhat often
   d. Often
   e. Very often
   f. Almost every referral
13) How would you rate the associates in the Client office? (i.e. the Program Coordinators, the Phone Nurses, the Managers, etc.)
   a. Overall disappointing
   b. Somewhat unsatisfactory
   c. Satisfactory
   d. Above satisfactory
   e. Overall exemplary
14) In the field, how have patients described the quality of the programs or services they receive?
15) Based on your patient interactions, have the Client's patients expressed any wishes or desires regarding their healthcare? If yes, please elaborate.
16) Based on your PRN experiences, how would you, as a nurse, suggest to improve the services the clients provide to patients?

APPENDIX C

PARTICIPANT DESCRIPTIONS

Phone Nurses

- **Ace** has practiced nursing for 26 years and has been a phone nurse for the clinical services department for 3 years. She was the first interview participant of my thesis project. She currently works on a program for patients with multiple sclerosis and has a great passion for the psychological aspect of healthcare.

- **Billina** has practiced nursing since 1981 and has worked for clinical services for over 6 years. She has worked on multiple programs during her years as a phone nurse with clinical services. She currently works on a growth hormone program designed and developed for teenagers.

- **Catherine** has worked for more than thirty years as a registered nurse and has been with the client for seven years. She was inspired to become a nurse by the performance of a character of the television show "ER." Her current program as a phone nurse is for a drug treating cystic fibrosis.

- **Dorothy** has practiced nursing for more than 19 years and has been with the client for 8 of those years. She strives to empower every patient she speaks with through education on every call. Presently, she works on another growth hormone injection program for youth.

- **Evelyn** has practiced nursing for the past fifteen years, and has been a phone nurse for 4 years. She will be completing her Master's of Science in nursing late 2016. Her program is targeted toward managing tuber sclerosis, preventing tumor growth and seizing in children.

- **Fredrick** has worked more than 23 years as a nurse, with 8 of those years with clinical services. Different than most nurses, he entered the field for the security and opportunity above all else. He too works on a program for a growth hormone medication.

- **Glinda** has been a registered nurse for twenty-two years, and has been a phone nurse of clinical services for three. She prides herself to quickly connect with patients, easily finding similarities they share. She currently works on a program for treating multiple sclerosis.

- **Harry** has worked for 16 years as a registered nurse, and has been with the client a little over five years. A wealth of information, he was willing to share many heartfelt stories of his phone nurse experiences. After several programs, he now works on a program for an oncology medication.

- **Iris** has practiced nursing for over 21 years, and has been a phone nurse for three years with the client. Her favorite calls are the ones with patients who

actively apply her teachings to their care. She works with Evelyn, on the same program that manages tuber sclerosis.

- **Joyce** has been a registered nurse for twenty-five years, and has been with the client for three and a half. Rather soft-spoken, but full of ideas for improving clinical services, she too works on the program for treating tuber sclerosis.

PRN Nurses

- **Kim** has practiced nursing for over 45 years, and has been a contracted PRN for fifteen. An avid volunteer, she also performs with a local dance trope at various basketball half-time shows. She currently works on two PRN programs for clinical services.

- **Lois** has been a registered nurse for twenty years, 16 of those years have been as a PRN with clinical services. A native of India, she comes from a family tradition of nursing; her mother, father, sisters, and husband are all nurses. She currently works on two PRN programs.

- **Maria** has practiced nursing for 23 years, and has worked as a PRN for close to eight years. She often commented on the healthcare teamwork of her family, with her husband working as a pharmaceutical sales representative. She currently works on two PRN programs.

- **Nora** has worked as a nurse for thirty-four years, and has been a PRN with the client for over nine years. She has a degree in psychology, and also works with veterans and their families struggling with clinical PTSD. She currently works on one PRN program.

- **Ozma** obtained her license as a registered nurse twenty-eight years ago, and was contracted as a PRN nine years ago. Her major medical interest is also in multiple sclerosis, particularly the changing trends in male patients. She currently works on two PRN programs.

Patients

- **Pepper** was diagnosed with relapsing-remitting MS around thirty years ago. A mother of one, she is a proud woman of faith, an ever-active mind, and a friendly disposition.

- **Quistis** has lived with relapsing-remitting MS for over 17 years. Once working as a speech pathologist, she passionately advocates for the mutual benefits of Parkinson's services for patients with MS.

- **Rhonda** has lived with progressive MS for seventeen years. As interested in me as much as I was in her, she is a mother of two, who freely shared many facets of her life, including that her daughter was diagnosed with MS as well.

- **Stephanie** was diagnosed with relapsing-remitting MS around 14 years ago. Despite living with a debilitating disease herself, she cares for her family diligently, including her sister-in-law, struggling with her own illness.

- **Tina** has lived with relapsing-remitting MS for a little over a decade. She likes to say that her job is to stay in shape. She supports and advocates for Mindset, a specialized gym for disabled individuals.

- **Ursula** was diagnosed with relapsing-remitting MS over 14 years ago. She is a proud grandmother, making sure that everybody knows that about her. Her job is looking after her grandchildren during summer vacations.

- **Velma** has lived with relapsing-remitting MS for over 19 years. She and her husband **Wren** have been married for twenty-nine years. She works as a travel agent, so naturally, she and her husband love to travel, even despite her MS.

- **Xavier** has lived with relapsing-remitting MS for almost seven years. A small business owner, generations in the making, he diligently trains his new apprentice and his daughter to inherent the family business when he steps down.

- **Yara** was diagnosed with relapsing-remitting MS some thirteen years ago. She is the leader of her local support group, and she is heavily active in political and health activism. She's even spoken on capital hill regarding MS care bills.

- **Zelda** was diagnosed with relapsing-remitting MS only four years ago, but she believes she's lived with symptoms for years before that. A mother of three, she works part-time in the information and technology industry.

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