“Don’t mask it, fix it”: Distinguishing Characteristics of Complementary and Alternative Medicine Patients with Chronic Pain and their Pathways toward Pain Resolution

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Abstract of the Dissertation

“Don’t mask it, fix it”: Distinguishing Characteristics of Complementary and Alternative Medicine Patients with Chronic Pain and their Pathways toward Pain Resolution by

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The sociological literature on pain and the body largely emphasizes the social and cultural dynamics of suffering. Within this realm, the medical institution is often paramount in regulating how pain is understood and the responses that are appropriate in managing pain. Less is known about other forms of healthcare that treat pain, namely Complementary and Alternative Medicine (CAM). While most research explains the overall “who” of the population of CAM users, few studies address the “why” and the overall effects of using a nonconventional system of medicine.

This research is aimed at discerning health beliefs and behaviors that are associated with engaging with a non-conventional system of healthcare and how treatment-seeking differs between patients choosing (CAM) and those choosing conventional medicine. Additionally, this study traces the trajectory of patients’ treatment-seeking behavior and explores whether non-conventional treatment changes outlooks on medicine and other health-related beliefs and behaviors.

A mixed method design was used to explore whether CAM users (compared with conventional medicine users) are more likely to possess beliefs associated with CAM. A survey-questionnaire was first distributed to pain patients (n=98) in two health office locations: pain management and acupuncture. Since little is known about CAM users' decision-making processes, qualitative interviews (n=20) were conducted with people using acupuncture to elaborate on the survey results.

Statistically significant differences were found among pain management and acupuncture users on measures of proactivity, medication use, and patient-centered care. Additionally, qualitative findings showed that most acupuncture users were initially skeptical of this non-conventional treatment and gradually grew to use it for ailments beyond pain. At the same time, they grew to value the time and intimacy that was shared with their acupuncturist, who often engaged them in holistic approaches to health. The findings suggest strong discontent and resistance to conventional forms of treatment, which were found to be non-validating of pain experiences of patients and their desires to find non-pharmaceutical solutions for pain. This research proposes that CAM patients are demonstrating their ability to make choices on their own behalf without the approval of traditional medical experts and suggests implications for this new autonomy.

Dedication Page

To Sarah Kaye for her unwavering support and encouragement through this tough journey. You have kept me afloat and lifted me even higher. Kob kun ka.

Table of Contents

List of Tables

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Chapter 1: Introduction

In this dissertation, I have conducted a mixed methods study on treatment-seeking, which aims to illuminate how people make the choice for complementary and alternative medicine (CAM) and how it fits into its users' lives. This research explores the question of how interaction with an unconventional system of medicine influences patients' capacities to manage their chronic pain. The study is based on both quantitative and qualitative data collected from people experiencing chronic pain. This first chapter of the dissertation presents the background of the study, specifies the research problem and questions, describes its significance, and presents an overview of the methodology used.

Background of the Study and Definition of Key Words

While chronic pain as a condition might appear to be rather subjective, it is now understood as a serious ailment towards which the medical establishment has recently turned its attention. Chronic pain can derive from injury or disease and affects any area of the body. It generally has substantial impacts on the patient causing physical discomfort as well as interfering with his or her lifestyle – hindering physical activity and having adverse effects on mental health. As defined by the American Chronic Pain Association, "Chronic pain is pain that continues a month or more beyond the usual recovery period for an injury or illness or that goes on for months or years due to a chronic condition" (American Chronic Pain Association website). As opposed to acute pain, which is experienced in the short term, chronic pain is variably pronounced by researchers, organizations, and medical professions to last from one month to six months or longer. Many chronic pain sufferers experience what is called *chronic benign pain,* which means that the physical source of pain cannot be determined. In the fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV 1994), chronic benign pain that does not have an organic origin can be classified as Chronic Pain Disorder. Because of the ambiguous definition of chronic pain and complications with diagnosing it, it is difficult to say how many people suffer from chronic pain. According to an online-based nationally representative survey of U.S. adults, nearly one-third (30.7%) of Americans reported chronic, recurrent, or long-lasting pain continuing for at least six months (Johannes et al. 2011: 1230). Chronic pain is said to affect 100 million people as reported by the Institute of Medicine Report from the Committee on Advancing Pain Research, Care, and Education (2011), which is more than diabetes, coronary heart disease, stroke and cancer combined (www.painmed.org). In addition, the national cost of chronic pain is estimated to be $560 billion to $635 billion annually (Institute of Medicine Report from the Committee on Advancing Pain Research, Care, and Education (2011). The National Institute of Health Statistics (2006) found the most common types of chronic pain to be low back pain (27%), severe headache or migraine pain (15%), neck pain (15%) and facial ache or pain (4%) (National Centers for Health Statistics 2006). Chronic pain is also one of the main reasons that people seek complementary and alternative medicine (CAM) (Eisenberg 1998: 1569).

The practice and dominion of American medicine has expanded, particularly since the 1970s, to include alternative forms of healing. What was once referred to as “quackery,” is now a set of assorted healing practices utilized by groves of ill people looking for relief. Although not generally considered to be a part of conventional medicine, some treatments have gained more legitimacy (and popularity) than others, and millions of people are seeking out these services, spending billions of dollars – many times out of pocket – for ailments ranging from chronic pain to diabetes to breast cancer. In most recent estimates, two out of five American adults had used some type of CAM in 2007 (Barnes et al 2008: 1) and spent $34-$47 billion on CAM therapies (American Pain Foundation website).

Complementary and alternative medicine (CAM) is defined as, "… a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine" (NCCAM website). The definition itself is not very specific. Some actually believe that the definition of CAM solely relies on its opposition to conventional medicine and that it has no distinctive qualities of its own (Frohock 2002: 214). When these practices are used as a substitute for conventional medicine, they are referred to as alternative medicine and when the treatments are used in conjunction with conventional medicine, they are referred to as complementary medicine. Much of the evidence today supports that idea that "People are not replacing conventional medicine with alternative medicine. They are using both according to their own assessments of appropriateness" (Ruggie 2004: 15). Another term that may give more explanatory power is "concurrent" healthcare. Using the term concurrent describes patients, "…using more than one form of healthcare at the same time" and indicates the non-cooperative element of these healing systems (Low 2001: 108). A study that surveyed chronic pain sufferers at twelve U.S. medical centers about their use of CAM found that over half (54%) of the sample had used CAM therapies in addition to their conventional care (Rosenberg et al 2008: 1068). Others have gone farther to define a Holistic Health Care-Conventional Medicine Continuum based on the ideological underpinnings of the treatment. Based in Australia, the researchers surveyed users of CAM on the level of acceptability among 27 CAM treatments. The continuum of acceptance that emerged from the data included four categories of CAM modalities ranging from “natural remedy” (naturopathy, homeopathy, Chinese medicine and herbalists), “wellness” (aromatherapy, kinesiology, spirtitual healing, shiatsu, reiki, reflexology, yoga and meditation), “accepted” (acupuncture, osteopathy, tai chi and hypnotherapy), and “established” (chiropractic, massage therapy, prayer, magnet therapy, and Bowen therapy). The fourth category, “established,” was viewed no differently from conventional health care as far as recognized practices. This study reflected the need to disaggregate the term CAM and to recognize the diverse practices within it (Robinson et al 2009: 156 & 161).

According to the NCCAM, CAM therapies are further classified into five (not mutually exclusive) categories, including: Whole Medical Systems (e.g. Homeopathic and naturopathic medicines); Mind Body Interventions (e.g. meditation, patient support groups); Biologically Based Therapies (e.g. using dietary supplements and herbal products); Manipulative and Body-Based Methods (e.g. chiropractor and massage); and Energy Therapies (e.g. qi gong, reiki, or use of magnetic fields). Some of the most popular treatments today include chiropractic, acupuncture and meditation therapies (NCCAM website). While some practitioners in these fields may work closely together, thereby giving the appearance of a unified CAM front, others see themselves as abiding by very different philosophies and practices. “Each therapy has its own practices and products, practitioners make recommendations based on the particular approach to healing found in their field of practice, and practitioners within the same field may differ in their interpretation of the information they have about any one patient” (Ruggie 2004: 9).

The above definition and the terminology, “alternative,” draws from the belief that alternative and conventional medicines operate under significantly different belief systems and represent different kinds of knowledge. How these systems differ can change depending upon who you ask, but indeed an oppositional sentiment remains. Drawing boundaries between conventional and CAM care is an easy task as both parties tend to advocate for their own superiority. Conventional medicine is based on scientific knowledge that derives from systematic and empirical testing. Many medical professionals will quickly point to the contested nature of alternative treatments; however, throughout the 1990’s the general movement moved from debunking CAM to promoting the evaluation of evidence of CAM’s efficacy, which has been largely difficult to interpret due to mixed findings. Still, some physicians have been “on board” and promote forms of CAM, like acupuncture, yoga, and herbal remedies, in an integrative approach.

Acupuncture is an ancient form of medicine that originated in China and is said to go back 3,500 years. Acupuncture has been used in the United States since the mid-1800’s but only became popular in the early 1970’s. The treatment, which is based on concepts of energy channels in the body, involves inserting thin needles into the epidermis for a variety of purposes, and may or may not use heat or electrostimulation as well. Because illness can be characterized as a blockage of energy (qi, pronounced “chi”) in the body’s system, most illnesses and health conditions can be treated with acupuncture. Since 1996, the Food and Drug Administration has declared needling to be safe and effective medical tools (Gecsedi & Decker 2011: 37- 38). Acupuncture is one of the most common forms of CAM used today (the most used if chiropractic care is not included). I have selected it as the focus of this study as a representation of CAM. According to the National Health Interview Survey of Adult Alternative Medicine Use, 6.5% of Americans had reported ever using acupuncture. This equals 3.1 million adults and 150,000 children. Of these, “25% of those who had tried acupuncture had done so once, and 70% had seen an acupuncturist fewer than 5 times”. Most of the people who had seen an acupuncturist had done so for some kind of pain, primarily arthritis and other orthopedic pain, headaches, or fibromyalgia (CDC 2007).

The Research Problem and Its Significance

This research is aimed at discerning which health beliefs and behaviors are associated with using a non-conventional system of healthcare as well as how treatment-seeking differs between patients choosing alternative medicine and patients choosing conventional medicine. Additionally, this study traces the trajectory of the patients’ treatment-seeking behavior, and seeks to understand how engaging with non-conventional treatment changed patients’ outlook on medicine and other health-related beliefs and behaviors.

The sociological literature on pain and the body largely emphasizes the social and cultural dynamics of suffering. It is well established that an actor’s cultural environment informs the experience of illness, the perception of what causes pain, what appropriate responses are, and even how to manage pain. The “illness narrative,” as it has come to be termed, is both a story a patient tells and a lens through which a patient makes sense of encounters with sickness or disability. Individuals develop the illness narrative, the language of pain, through a life’s worth of experiencing and navigating through medical institutions and grappling with the suffering body (Frank 1995). In doing so, patients sometimes encounter challenges when they approach medical institutions looking for help in what Arthur Klein describes as “disconnection” between those seeking treatment and those giving treatment (1988). Because physicians tend to look for pathology, and thus frequently attempt to re-categorize stories of illness into biological terms and disease, there is often a disjuncture between this re-categorization and the sufferer's actual experience, which can lead to undesirable and unsatisfying interactions with physicians. Furthermore, treatments for chronic pain can be limited in lessening pain for patients, leading to unsatisfactory results.

However, less is known about how the illness narrative is used with regard to CAM health care practices. While most research explains the overall "who" of the population of CAM users, few studies address the "why" and the overall effects of interacting with a nonconventional medical system. While the illness narrative described earlier is assumed to be a "given" in our knowledge about patients and their experiences with the medical world, I believe that the story is incomplete. With the growth of CAM, people are exploring new terrain, taking on new roles, and using healthcare organizations in novel ways. Studying the narratives of those who suffer from chronic pain in the acupuncture setting will inform the literature on how CAM fits into, extends, or otherwise influences the illness narrative. Important to this narrative will be the introduction of a language of empowerment and proactivity, as these are characteristics that are often associated with CAM treatments and providers.

Further, this research supplements the literature by bringing to the fore notions of deviance surrounding chronic pain as well as CAM use in the United States today and while addressing how chronic pain patients using CAM fit into the influential theories of sick role (Parsons 1951) and medicalization. Furthermore, the benefits of this research extend to the players involved in giving and receiving care. People with chronic pain often feel limited in their options for pain relief and experience marginality in various ways. This kind of research can make visible the vast number of people who experience chronic pain including the sentiments of those who use CAM. Likewise, this research can potentially offer insight to physicians who may be perplexed by why some patients' are drawn toward CAM and perhaps increase an understanding of the complexities of patients' needs.

Overview of the Methods

A mixed method design was used to explore and explain the dimensions of treatment choice among chronic pain patients. A survey-questionnaire was first distributed to 98 pain patients in two health office locations: pain management and acupuncture. The main purpose of this stage of data collection was to understand if acupuncture users (compared with conventional medicine users) either possess or are associated with qualities espoused by CAM. Namely, I wanted to know if it was more difficult for acupuncture patients (when compared to conventional medicine patients) to find medical diagnoses for their pain symptoms, if they were more proactive with regard to health, if they were less likely to use prescription medications for pain, and if they rated their care as more patient-oriented. Because little is known about CAM users, qualitative interviews focused on 20 people who were using acupuncture (most of whom were recruited through the initial survey-questionnaire) to elaborate and help explain the results of the questionnaire. I sought to find overall trends in the use of acupuncture and any changes in health-attitudes that come with using an alternative system of medicine.

Conclusion

In this introduction section, I have presented the main elements of this study from background information that describes the setting of chronic pain and complementary and alternative medicine in the U.S. today. I have also introduced the broad research problems and their significance. Lastly, I described an overview of this mixed methods study that captures data on treatment seeking for chronic pain users in both quantitative and qualitative ways. In the next chapter, I will introduce some of the literature on suffering, the rise of CAM in treating medical conditions, and theoretical contributions such as illness narratives, sick role, and medicalization that are pertinent to this study.

Chapter 2: Review of Literature and Theory

Pulling from the literatures on the sociology of suffering, sociology of the body, and medical sociology, this review covers the social construction of pain and diagnosis in relationship to medical encounters and patient credibility. I have considered the written work on the social experience of pain and suffering (including in-depth descriptions of illness narratives), the sick role, and how complementary and alternative medicine (CAM) is thought to be unique form of treatment that could change the experience of illness. In addition, I include the theoretical contributions of medicalization and look at the prospects of demedicalization through patient empowerment.

Pain and Suffering as Social Experience

Pain is a social experience that is affected by those with whom we interact and shaped by the social world in which we live. Suffering may be validated, minimized, amplified, silenced or otherwise defined -- all depending on where one lives, what social characteristics a person holds, and to what institutions he or she belongs. One's cultural context informs the actor about the experience, including what causes pain, what responses to pain are appropriate, and what possible routes of recourse are available. "How one regards the body and the phenomenon of pain can determine whether the suffering person will exhibit shame, guilt, anger, denial, stoicism, acceptance, or even masochistic pleasure" ("The Suffering Body: Asian and Western Perspectives" 2006: 1). Moreover, the specific ways that we learn to speak about pain (somatization) also come from a lifelong learning experience. As Frank notes, "The less evident social aspect of stories [about illness] is that people do not make up their stories by themselves. The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to 'tell the doctor what hurts' and to figure out what counted as the story that the doctor wanted to hear…storytellers have learned formal structures of narrative" (Frank 1995: 3). He further believes there are many ways in which people articulate their pain experiences; however there are certain difficulties with communicating the subjectivities of pain and suffering as words sometimes fail to truly represent the way someone is feeling (1995: 2).

This is not to say that all pain is treated equally, as some forms of pain or causes of pain can come with stigmatizing experiences. Although these meanings may change over time, there are cultural meanings attached with certain forms of illness, and similarly "certain parts of the body will carry different meanings than will other parts. These variations are culturally conditioned and are generally articulated with reference to ideological, moral, or religious traditions" (The Suffering Body, 2006: 1). Some people's pain is selectively "authorized", while others' are not recognized or validated. Further, because we encounter multiple, uncoordinated settings in our lives, with widely varying messages about pain and injury, we can find ourselves speaking and experiencing pain (and authorization) in many different ways throughout the day. So, even though we assert that having and experiencing pain is a universal experience, we cannot claim to know that all people suffer in the same way or under the same circumstances.

Kleinman attempts to explain the many meanings of illness in his book, *The Illness Narratives: Suffering, Healing & The Human Condition*. He does so by examining illness narratives, described as, "...[the] story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering" (Kleinman 1988: 49). Kleinman believes that the way people talk about their suffering reflects cultural and social components of suffering as much as it explains the experience of suffering. "Illness narratives edify us about how life problems are created, controlled, made meaningful. Illness narratives also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition" (Kleinman 1988: xiii). Susan Bell further describes this process: "Through narratives, people create order, coherence, and connection between events that are not obviously connected to one another and thereby create 'important reference points in the interface between self and society'" (2008: 212), and these "stories thus both represent past experiences and provide a frame for organizing our experiences as lived" (Kleinman 1992: 202).

Experiencing chronic illness is no small thing. Michael Bury, who studied the onset of rheumatoid arthritis in people who were referred to outpatient rheumatology clinic in the late 1970's, describes the interruptive capacity that illness can have on one's life:

> "My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possible even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting the normal rules of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here. Further, the expectations and plans that individuals hold for the further have to be re-examined. Thus, I want to maintain that the development of a chronic illness like rheumatoid arthritis is most usefully regarded as a 'critical situation', a form of *biographical disruption*, not only as a way of describing

> what happens, but also to provide a more explicit analytic focus" (Bury 1982: 169, emphasis added).

The making and telling of these stories is a cultural practice in itself. While navigating through the medical institution or grappling with phenomenology of the body, sufferers become aware of the necessity of speaking about their pain. "Giving accounts is, for both experts and laypersons, part of that business of dealing with disease and its consequences" (Radley & Billig 1999:28). As people are integrated into the culture of being ill, or being a sufferer, they learn how to talk about their experience and this in turn has an effect on the experience of suffering. "The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering" (Kleinman 1988: 49).

Drew Leder, a professor of philosophy and MD, elaborates further with the body-pain paradox in his book, *The Absent Body* (1990). While he believes that the body is rarely the "object of experience" as "… the body is the most abiding and inescapable presence in our lives, it is also essentially characterized by absence" (1990: 1), he also believes pain is the experience that creates bodily awareness. Many things about our existence, like the shelter over our heads and the technology that would alleviate strenuous work for humans, promote a disembodied way of living. In describing this decorporealized existence he points out that at any given moment, people are not usually attuned to the things that their bodies are doing or feeling—unless there is pain. And what is more, the way that we usually become aware of our bodies (through pain) makes us want to forget them altogether. Indeed, Leder's thesis is that the body disappears when it is functioning normally, but "it seizes our attention most strongly at times of dysfunction" (1990: 3). The disruptive nature of pain infiltrates and changes the lives of those who suffer with it. In addition to the struggles that people must negotiate in their daily lives, the medical field is another challenging terrain.

Social Construction of Illness and Diagnosis

Medical sociologists have long detailed the constructed nature of illness and responses to illness, even the supposed objectivity of medical science. For medical sociologists, the social constructionist approach is the lens through which interactions within the medical institution can be studied and understood to be less a reality, and more of a contextualized event. Cultural and historical features often dictate how we understand, define and contend with illness. As Fox states,

> "what is defined as health and illness, normality and abnormality, sanity and insanity varies from one society, culture and historical period to another. Thus, it is contended, medical diagnostic categories such as 'sick', 'abnormal', and 'insane' are not universal, objective, or necessarily reliable. Rather, they are culture-, class-, and time-bound, often ethnocentric, and as much artifacts of the preconceptions of socially biased observers as they are valid summaries of the characteristics of the observed. In this view, illness (especially mental illness) is largely a mythical construct, created and enforced by society" (Fox 1977: 17-18).

In the famous article "Naming and Framing: The Social Construction of Diagnosis and Illness", Phil Brown further distinguishes between the social construction of illness and the social construction of medical knowledge. The latter he explains as,

> "The social construction of medical knowledge deals mainly with the origin of professional beliefs, and with diagnosis. It deals with the ways of knowing that are based on the dominant biomedical framework, contemporary normal and ethical views, the socialization of medical providers, the professional and institutional practices of the health-care system, and the larger social structures… we consider the social construction of a phenomenon to involve a multiplicity of social forces. Rather than a given biomedical fact, we have a set of understandings, relationships and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux" (2008: 85).

The social constructionist approach leads medical sociologists through the process of diagnosis (social discovery), which includes: an individual's experience of symptoms to the use and interpretation of diagnostic testing conducted in doctor's offices and hospitals as well as the fitting of those results into known disease patterns; the experience of illness (the perception and adaptation to illness); and the treatment and outcome of illness (decisions of what treatment is given and how treatment is shaped by social support, including the choice of professional vs. self-care) (Brown 2008: 92-98).

In medical sociology, disease is a negative physical state and is associated with dysfunction in a physiological way (that the body cannot behave normally) and a social way (that a person is not able to perform social roles normally). Disease and sickness can mean pain for individuals as well as economic hardship for themselves and their families if they are unable to go work. Not going to work also affects the larger work organization. Because it is believed that these circumstances are generally unfavorable all around and that they disrupt the social order of things, much effort is placed on preventing sickness and, more, to urging those who are sick to become well quickly. Thus, when someone is sick, social norms reflect expectations of behavior and social control among societal institutions to promote conformity to getting better. In the case of illness, the medical institution has been largely charged with the task of assigning these roles and promoting conformity to them. The physician specifically is invested with the power to control deviance from the norm (Cockerham 2001: 158-159, 163). As Friedson has pointed out, the structural arrangement in society tends to give medical professionals the authority and the role of gatekeeper (1970: 117). And, the physician "rest(s) on the authority of his professional status without having to try to present persuasive evidence to the client that his findings and advice are correct" (Friedson 1970: 120-121).

In *Madness and Civilization* (1965), Foucault describes the history of madness from the 17th through 18th centuries in France. His perspective is unique in that he questions the way in which the history of madness is remembered (or not remembered) while examining the construction of these ideas and the context in which madness was understood. He writes about the social and moral distinctions that are made between sane and insane people and how definitions of madness changed overtime. These distinctions included considerations of: how certain illnesses were thought of and classified; who was affected or at risk; what remedies were thought to be effective; and what the causes were and the associations with institutions and ideology. Starting from the departure of leprosy as an illness that was socially feared and expelled, Foucault describes how confinement was the "solution" of choice and those who were thought to be mad were piled into madhouses (along with poor, unemployed, criminal people). These places, such as the Hospital General, were thought of as places for those who were idle, offering no productive role for society. It was still some time until madness was considered a mental illness and the asylums began to be oriented toward correction and reform (Foucault 1965). This historical tracing of madness exemplifies the very social constructedness that is essential to understanding the sociology of diagnosis and medicine as well as the concept called medicalization.

Medicalization

Since the 1970's, medical sociologists have been talking about the process of medicalization and its effect on patients, on medicine and on society as a whole. Medicalization is the process by which conditions that were once not under the umbrella of medical concerns have gradually become the responsibility of medical professionals to diagnosis and treat, or what Irving Zola has called, “the expansion of what in life is deemed relevant to the good practice of medicine” (1972: 472). Many conditions that were once under the guise of solely moral or criminal judgment have become the responsibility of the medical system. This transformation happens as medical professionals and researchers come to better understand human behavior and find innovations for alleviating potentially harmful conditions. Before these conditions were considered pathological, they may have shadowed their owners as sinful or deviant. For example, if someone suffered from hallucinations, he or she may have believed to be possessed by the devil, or if someone compulsively gambled or drank alcohol, he or she would have been viewed as having poor moral character. Today, these behaviors can be classified as illnesses, sickness, or disorders. This expansion of the medical model is what Conrad describes as the move from “badness” to “sickness” (Conrad & Schneider 1992). Sick people are not to be blamed for their deviance, certainly not in the way that criminals would be punished for their crimes. Instead, the medical institution provides therapeutic care for the sick (Cockerham 2001: 161). In addition, conditions that were once thought of as natural life processes have also been subsumed under the medical sphere. Menstruation, menopause, and aging - all of which were thought to be natural processes - have become medicalized (to varying degrees), and various problems stemming from them (P.M.S. and P.M.D.D., Premature Ovarian Failure or Hormone Replacement Therapy, or Alzheimer’s disease) can be treated in the doctor’s office. Another, widely cited example is pregnancy and childbirth:

> “…which produces the most illuminating illustration. For, again in the United States, it was barely seventy years ago that virtually all births and the concomitants of birth

> occurred outside the hospital as well as outside medical supervision. …as this medical claim was solidified, so too was medicine's claim to a whole host of related processes: not only to birth but to prenatal, postnatal, and pediatric care; not only to conception but to infertility; not only to the process of reproduction but to the process and problems of sexual activity itself; not only when life begins (in the issue of abortion) but whether it should be allowed to begin at all (e.g. in genetic counseling)" (Zola 2009: 475).

In fact, it is the treatment —or the offering of some therapy that provides the evidence of medicalization. Built into the concept of medicalization is a general belief of "overmedicalization," or that there are issues excessively placed under the medical gaze. This expansive process has led some to believe that, "there are few, if any, problems of human behavior that some group does not think of as medical problems" (Twaddle 1973: 756).

Medicalization's existence and growth can be understood as a coordination of result of a coordinated set of various social factors. From the lessening impact of traditional moral systems (secularization) to a growing trust in science and technology, and a complex system of professionals with vested interests in the medical complex succeeding, it is a recipe for the legitimization and authority of medicine (Goldstein 1998: 34-36). Lowenberg and Davis (1994) identify three central notions of medicalization: (1.) An undesirable or problematic condition in society brought within the purview of medicine; (2.) The people who exhibit this undesirable condition are not to be blamed for it, but rather undergo treatment for it; and (3.) Medical professionals serve as experts in the treatment of these patients, thereby creating asymmetric patient-practitioner relationships. Zola (2009) adds that medical professionals acquire and retain absolute control over technical skills and procedures as well as absolute ability to access "taboo" areas of the body – that is, "the inner working of our bodies and minds" (474).

Michel Foucault is particularly concerned with the growing power of medicine, first from the perspective that many non-medical things are now governed by medicine but also in the authority that it awards medical professionals in creating normative discourse in culture. “Today medicine is endowed with an authoritarian power with normalizing functions that go beyond the existence of diseases and the wishes of the patient” (Foucault 2004: 13). He views this social control as medical surveillance or what he calls the, “medical gaze” (Conrad 1992: 216). “Pathology has become a general form of social regulation. There is no longer anything outside of medicine” (Foucault 2004: 15). Perhaps the most horrifying example of extreme medical social control was the killing of “defective” persons (e.g. disabled, homosexual, and/or Jews) in Nazi Germany.

But we should not forget that medicalization is not only a change in what medical professionals treat. It is also a change in perspective among members of society who are likely to accept and desire medical treatments for undesirable conditions – especially if they were previously considered unseemly. The change that takes places is cultural. With the expansion of what is deemed medical, there is also more demand on medicine from its patients as well as higher expectations among patients about what the medical professional *should* be able to cure. This is evidenced by increases in malpractice suits petitioned by unsatisfied patients (Fox 1977: 10). Sometimes patients advocate for and even work alongside physicians for the medical recognition of their condition (Conrad 1992: 219), indicating that medicalization is not just the process of medical imperialism. Foucault would argue, however, that this idolatry of the medical system can be produced by the system itself. “Health becomes a consumer object, which can be produced by pharmaceutical laboratories, doctors, etc., and consumed by both potential and actual patients" (2004: 16). So we must remain cautious about the "naturalness" of the transition from religious and legal dominance to the dominance of medical authority.

Foucault's argument is indicative of his "biopower exegesis." In his text, *The History of Sexuality, Volume 1*, Foucault speaks about institutional forms of power, such as health care institutions, that configure behavior widely in society by imposing self-discipline on individuals. Biopower operates by policing and producing normalized subjects and "thus discipline produces subjected and practised bodies, 'docile' bodies" (Foucault 1978: 138). For Foucault the power that is exercised over the body is further intellectualized in two ways, "the disciplines of the body and the regulations of the population" (1977: 139). The first is the realm of psychiatrists, dieticians, and social workers, while the second is governed by panopticism, or the surveillance by asylums, factories, hospitals, and schools. It is through the medicalization of bodies – that is, the objectification and exact calculation of bodies -- by which people become controlled.

This perspective leaves little room for patient empowerment through collective action as medicalization is likely to continue to include more conditions currently not recognized by medicine. For example, the adaption of marijuana as a medicinal remedy for chronic illnesses, the treatment of addiction to sugar, and female sexual dysfunction are all illustrations of the expansive nature of medicalization.

The Sick Role

Talcot Parsons wrote about social norms in the early 1950's, defining terminology and a theoretical construct, called the "sick role", which remains as one of the most used concepts in the field of medical sociology today. The sick role describes the normative behaviors associated with sickness, which is viewed as an acceptable form of deviance if patients follow prescribed notions of appropriate illness behavior. Instead of the anomie, or social disorder affecting the stability of the social system that might follow with the onset of illness and thus the inability to perform daily roles, sick people face a new set of obligations. Patients, upon falling ill, find it their duty to seek the expertise of physicians, follow their advice, mostly in seclusion at home, and remain at home where the patient can rest and commit to getting better. Inherent in this process is the dedication that one should express towards wanting to rejoin society, as a healthy individual, as soon as possible. In doing so, the person is not blamed for their illness or treated negatively for committing a deviant act. As part of the larger structural-functional perspective of society, Parsons described the process by which well-being is brought about for patients and society as a whole because illness disrupts peoples' commitment to work and family. The sick role is absolutely intertwined with U.S. values toward achievement and capitalism and thus, "…health is crucial because it underlies the capacity for economic achievement" (Varul 2010: 75). The re-establishment of health is a collective goal, shared among sick people, physicians, and social fabric that makes the family and economic spheres function.

Parson's sick role has been criticized heavily over the years for being oriented toward the middle class only, for not being inclusive of preventative forms of behavior surrounding health (i.e. that patients also visit physicians when they are not ill), and for not recognizing the variation and subjectivity of pain and illness. This major area of criticism is concerned with chronic illness, as the sick role is believed to apply only to acute illness (Cockerham 2001: 169-172). Chronic illness is not a liminal state that one moves into and out of in a normative process. This inability to experience illness as a liminal state is precisely why some believe that chronic pain patients experience stigma with regard to their health status. With regard to chronic back pain patients, Glenton says, “Despite the limitations of the sick role concept in describing the realities of chronic back pain, it still appears to describe the expectations of doctors, families, colleagues, and the back pain sufferer himself” (2003: 2251). If illness behavior is typically meant to be transitional, according to Parsons, what happens when someone cannot or does not get better?

For people who have illnesses that are difficult to diagnose and treat, like chronic illnesses, this transition back to the norm is delayed, sometimes inevitably thereby violating the expectation to act quickly to seek a physician’s care and also get better in a timely fashion. Since the 1970’s the U.S. has grown more concerned with chronic and patients are finding themselves tethered to their medical professionals for extended periods of time as they manage their illnesses over the long-term. Some people are unable to work due to their illness and thus face the judgment of those around them and perhaps a loss of identity, or a ”loss of self” from no longer participating in the paid labor market (Charmaz 2000: 28). These patients may find that their new occupation is recovery, spending a great deal of time attending to their ailment, including managing diet and exercise as well as going to treatments and therapies (Varul 2010: 80). They may also experience stigma, which Goffman (1963) explains as, “a rupture between an individual’s virtual and actual social identity that is regarded in some way as failing” (quoted in Cockerham 2001: 180). This “failing” can be a result of the inability to carry out work and family responsibilities, or otherwise perform the sick role appropriately.

Other chronically sick people return to work and family responsibilities -- even though they are still ill – because of economic pressures and societal expectation that people should not be ill for too long. In essence, they take on the sick role and healthy role at the same time. For this kind of patient, "…balances must continually be struck between doing too little and doing too much. If sufferers ignore symptoms and press on as normal, they risk being perceived as 'reckless'. If they take great care of themselves, they run the risk of being seen as 'invalids' or as 'malingerers' (Radley 1994: 157). The chronically ill do not fit neatly into either a sick or healthy role and deviance can abound from any route they take. And when the patient is not given a diagnosis and barred access to routes of healing, their complaints of pain become suspicious. For these patients, "Central in this struggle for the sick role is the achievement of disease" (Glenton 2003: 2249). The medical confirmation of disease provides absolution in the struggle to achieve the sick role and dispels notions of hypochondria, malingering and mental illness (Glenton 2003: 2249-2250).

In essence, the main components of Parson's sick role are challenged, most often, when it comes to the experience of chronic medical conditions and chronic pain, in particular**.** In essence, the main components of the sick role are shaken when it comes to chronic medical conditions. However, some (Varul 2010, Radley 1994, Greco 1993) suggest that the same mechanisms of the sick role, i.e. the need to be healthy in order to be a productive member of society, can account for the increase in preventive approaches to illness in the U.S. today. Still, strong beliefs in the sick role remain, and in cases where people cling to its tenants those with chronic and ambiguous conditions will be viewed as deviant.

Pain and Suffering in the Medical Setting: Struggles for Legitimacy and Accountability

Just like other fields, the medical setting provides the standards by which pain and suffering are judged, acknowledged and treated. "…we know that people's understandings of illness are shaped in large part by health providers, and that the dynamic interaction between patient and provider leads to conflicted and/or negotiated diagnosis and treatment" (Brown 1995: 46). During somatization, a sufferer seeks help from a medical professional, offering an account of physical distress symptoms in order to be examined and in hope of finding out what's wrong.

> "Medical practices are culturally and socially framed by underlying conceptions of the nature of the human being and the human body in a way that defines both the parameters or what counts as 'healthy' or 'infirm' and the determination of the most appropriate response or intervention when dealing with suffering….The underlying worldview and/or cultural assumptions of 'patients' and health practitioners, in whatever context, clearly have some bearing upon the human experience and interpretation of pain, its significance, and the most appropriate response to that experience" (The Suffering Body, 2006: 2).

One key distinction that Kleinman makes in the use of narratives is that between "the patient's experience of illness and the doctor's attention to disease" (Kleinman 1988: xii). Many authors have homed in on what appears to be a disconnection in communication between the parties of illness and suffering. Physicians, with their tendency to look for pathology, attempt to re-categorize stories of illness into biological terms and disease. "However complicated to articulate and difficult to interpret, the patient's experience of pain is lived as a whole. Perception, experience, and coping run into each other and are lived as a unified experience. When reconstituted as a medical problem, however, that experience is fragmented into a series of dichotomies that represent the deep cultural logic of biomedicine" (Kleinman et al 1992: 8). A particularly problematic experience is that many chronic sufferers do not have easily identifiable origins of pain and which can lead to undesirable and unsatisfying interactions with physicians. When a patient's description of the problem falls outside of known disease symptoms, it may be ignored. Some parts of the story are denied or truncated as “parts of patients’ stories that do not fit neatly into these categories function as unwanted strangers in medical discourse” (Waitzkin 1991: 32). The patient may feel like he or she is not being heard or worse, that their complaints are invalid or unfounded. For the patient, “pain is constructed as a symptom in need of corroborating evidence….The dominant discourse of pain has at its heart the ‘truth’ that the pain has to be symptomatic (i.e. it must have a utility above suffering)” (Eccleston et al 1997: 700). “The patient career of chronic pain is largely one of protecting one’s legitimacy as a person and as a sufferer” (Eccleston et al 1997: 706). Given the asymmetric power structure here, the experts have the ability to “declare” that the sufferer is “imagining” the pain and/or to relocate the responsibility for the pain onto the patient. “Where resistance is evident and medicine is perceived to be failing, causes for suffering are located back with the sufferer or with the past” (Eccleston et al 1997: 707). In a qualitative study on repeat visits to the doctor among patients who had chronic back pain, the participants described several motivations for visiting the medical office repeatedly. These motivations included increases in pain and limitation in physical activity that resulted from the pain, the desire to discover the cause of their pain, and the frustration of having unanswered questions regarding this matter. In fact, many of the reasons given supported a need to seek validation for their suffering (McPhillips-Tangum et al 1998: 291-294). “As sociological studies of the experience of chronic illness demonstrate, people in pain, of whatever type, need the legitimacy of their pain and suffering accepted by others, both medically and socially, …and involves narrative reconstruction in the face of the biographically disruptive nature of pain and suffering (Bendelow et al. 1995: 162).

These contested conditions are categorized by Phil Brown (1995) as “medicalized definitions” in which the definition that is applied is a condition that is not generally accepted by biomedical practitioners (for example, chronic fatigue syndrome or chronic pain syndrome, which have been gaining ground and are more likely to be accepted today than when they were first introduced) (41). He sees the need for these types of definitions stemming from people who need to legitimate their condition as well as the continually expanding domain of the medical institution (medicalization). In fact, the social construction of diagnosis and illness guarantees us that these definitions of illness will always be shifting and changing (42).

In their study of patients’ and professionals’ understandings of chronic pain causes, Eccelston, De C. Williams and Stainton Rodgers found differing perspectives among patients and physicians with regard to causes of pain. Patients were far more likely to emphasize the perceived contested nature of pain and the importance of finding physical origins to pain. They were least likely to identify with statements that discounted physical causes, such as imagining pain. Further, blame was often attributed to medical professionals who failed to make accurate diagnoses, gave bad advice, or botched surgeries. There is little indication of self-implication among the patients, but for the professionals there was a great deal of patient-blaming in their interpretations of causes of chronic illness. While medical professionals did not attribute patient pain to psychological ailments (as patients perceive that physicians do), they did implicate (patient) personal wrong-doing in the form of managing pain poorly, developing bad habits that exacerbate pain (Eccelston et al 1997: 704). There was no automatic assumption among the physicians as there was for the patients about the relationship between pain and the physical body. In essence, what seemed to happen was a struggle for responsibility who should fix it (Eccleston et al 1997: 703- 705).

Doctor's visits can prove to be victimizing and demoralizing experiences because patients can be given the message that their own interpretations are inadequate or even falsely declared. "When confirmed medical models don't fit, one gets a heavy dose of social judgment often disguised as diagnosis" (Mechanic 1999: 10). Social judgment does not end at one's physical condition as, "Any shortfall in health has important implications for other areas of one's life (e.g. work, personal relationships), in terms of which people feel that they are evaluated. Accounts of health and illness are, therefore, more than descriptions of one's physical condition and more than views about what people in society should do to avoid disease" (Radley & Billig 1999: 19). This questioning of the patient's story and attempt to attribute the cause of illness to psychosocial origins by the medical practitioner, may actually encourage the patient to make his/her case more adamantly while demanding a legitimate somatic diagnosis (Kleinman 1988: 59). "We may feel great anger because no one can see our pain and therefore objectively determine that our disability is real. As a result we sense that our complaints are not believed, and we experience frustrating pressure to prove we are in constant pain" (Kleinman 1988: 4).

A study of a Norwegian back pain sufferers highlights this fear of being de-legitimized by others, namely medical and social contacts. For them, medical diagnoses were "proof" of suffering. With the cause of suffering in hand, patients felt relieved to be seen as "truly in pain" (Glenton 2003: 2246). Further, the attribution of pain to psychological and psychiatric origins was often a source of despair and frustration as widespread stigma toward mental illness put the patients' character in a questionable light (Glenton 2003: 2247). Patients find themselves at an impasse with their care-providers who believe that their pain is psychogenic while the patients believe it is as biogenic, with no room in between. Patients may, therefore, push for more testing, get second opinions or even seek out alternative forms of care.

A Rise in Demand for CAM: Push and Pull Factors

Feeling as though they are not listened to, not taken seriously, or not finding relief, patients with chronic pain might move from their conventional site of medicine to other options in the CAM realm. Depending on how dissatisfied and disenchanted they were in their previous encounters with conventional medicine, this group of people might then represent those who consider CAM treatments as *alternative* care. They would adopt new practices, while relinquishing the old. However, we also know that some people are attracted to CAM for its healthcare perspective and unique methodologies. In fact, it appears that both push and pull factors influence people's decisions to choose CAM and those reasons are plentiful.

People in poor health are known to use CAM as are those who suffer from chronic conditions (Palinkas et al 2000: 1124). "It is possible that people who are attracted to CAM have had worse experiences with their regular physicians because of their poorer health status" (Ruggie 2004: 50). Further, there is evidence to suggest that some consumers of healthcare are more prone than others to be unhappy with the care services they receive. Showing dissatisfaction with healthcare providers may be a result of the extreme amount of pain they experience. It may be that conventional medicine is not equipped to deal with chronic pain patients. "Chronic pain patients thus find themselves rejected by standard medical practice and referred to institutional settings that are then vilified as nonscientific, alternative, nonorthodox, and for which reimbursement is unavailable or only marginally legitimate and standards for competent medical practice ill-defined" (Kleinman et al 1992: 203). This might be because, "chronic pain is marginal to the dominant theories of biomedicine. Pain clinics, along with alternative therapies for pain, have evolved in the margins of medical institutions" (Kleinman et al 1992: 203). Given that the most recognized ailments for which people use CAM are musculoskeletal conditions (Eisenberg 1998), this could illustrate the continuation of the illness narrative. Alternative care, with its attention to pain management and holistic orientation, may provide more beneficial care to its patients. Even without strong evidence for CAM efficacy, there seems to be a willingness to use their techniques. Some suggest that risks are perceived to be low for CAM when compared to conventional medicine (risks such as side effects of medication or treatment) and the efficacy is perceived to be better (Hess 2005: 71).

In a California study that followed-up people who visited doctor's offices with concern of undiagnosed conditions, the researchers found 18.2% prevalence of unmet expectations for that medical visit. The unmet expectations ranged from: perceived ill preparation of the physician; subpar history-taking, examination or testing; and inadequate prescriptions, referrals, information and counseling (Kravitz et al. 1996: 187-189). Patients' expectations for care largely came from previous experiences with doctors' offices, patients' own training or specialized knowledge, knowledge from the media as well as feeling that the severity or seriousness of their symptoms (and the vulnerability that came from it and their family histories) were worthy of more attention (Kravitz et al. 1996: 188).

In a national random-digit-dial-telephone sample of the United States, researchers found that trust in the medical system was relatively low, with people finding distrust some

20% to 80% of the time depending on the measure. Eighty-two percent of the sample agreed to the following statement, “People die every day because of mistakes by the health care system,” and 64% agreed to, “The health care system cares more about holding costs down than it does about doing what is needed for my health” (Armstrong et al 2006: 295). The authors of the study found that distrust was associated with self-report health status, as people with poorer health were more likely to be distrustful (Armstrong et al 2006: 294).

In addition to the shortcomings of conventional medicine, however, there also appears to be a desirable set of beliefs that come with CAM care as well as economic and political factors that are making the trend toward CAM possible. Emily Martin, in her book, *Flexible Bodies: The Role of Immunity in American Culture from the Days of Polio to the Age of AIDS* found that the goals and methods of alternative therapies were contradictory to biomedicine. In interviews with alternative practitioner of various kinds, she found that they spoke about the incompatibility of these systems with regard to the “split that occurred in biomedicine between the mind and body” (84). One informant said, “I’m wondering whether the approach in conventional medicine isn’t trying to create something out of its individual parts which it can never do. Because there’s more to a tomato, as an example, than just the individual parts. There’s a whole integrated function” (86). In this perspective, alternative therapists are viewing the body (including the mind) as a whole wherein one part does not work in isolation or without coordination of the rest of the parts. Further, the concept of health is viewed as perpetually changing. A homeopathic M.D. explains that, “health is a matter not of obliterating pathogens but of establishing a balance with them, of keeping them in the right place and proportion…So the body is constantly striving to maintain balance, to keep those areas of the body that need to be separated, from each other, not only separated, but functioning and interacting in a balanced fashion" (88).

In a study that set out to find what reasons people give to seek CAM (among those seeking treatment in a British osteopathy center and an acupuncture center), researchers found several very common complaints. Of the 20 complaints given in total, there was the most agreement around the following: "because I value the emphasis on treating the whole person", "because I believe complementary therapy will be more effective for my problem than orthodox medicine", "because I believe that complementary medicine will enable me to take a more active part in maintaining my health", and "because orthodox medicine was not effective for my particular problems" (Vincent & Furnham 1996:316) These reasons highlighted both push and pull factors.

Likewise, in a systematic review of 52 studies for reasons to seek CAM and characteristics associated with CAM among cancer patients, the following were found to be the most cited reasons: "a therapeutic response", "wanting control", "a strong belief in CAM", "CAM as a last resort", and "finding hope" (Verhoef et al. 2005) Likewise, another study found that "Natural, empowering and under the patient's control" were the attributes most closely seeking associated with alternative treatments (Swartzman et al. 2002: 439).

A review of 94 research articles geared at understanding CAM's appeal found that CAM users want to participate in treatment decisions and are more likely to believe that they have more control over their health. They tend to have holistic, non-toxic beliefs about health, hold post-modern beliefs, and may see themselves as unconventional and spiritual. They also believe that lifestyle and emotional components are important to health (Bisop et al 2007:

862). Swartzman et al (2002)'s study on the appeal of CAM, used factor analysis to examine how beliefs toward types of medications differ. Herbal remedies were rated to be far more natural, as well as less invasive, less painful, less dangerous and have having few side effects than prescription medications (441).

Goldstein argues that patients may be turned off to conventional medicine because they see it as big business and believe that "economic forces driving the delivery of health care now frequently find themselves with a direct economic interest in moving the narrative of health and illness away from its traditional control by physicians….the financial interest of the government and the large corporations that pay the bills for healthcare is to reduce expenditure: (Goldstein 2002: 50). On the other hand, CAM finds support from various other movements that tend to criticize conventional medicine. Some of these movements include those that promote the rights of women, gays, older populations, the disabled and those with specific diseases like cancer or AIDS (59). Furthermore, many agree, somewhat speculatively, that the rise in demand for CAM treatments is helped by an aging population and a growing emphasis on chronic illness as opposed to acute care (Coulter & Willis 2004: 588). Widespread cultural acceptance is being gained for some CAM treatments. Chiropractic care is now seen as a nearly conventional practice, even though its origin was within the boundaries of CAM (Tillman 2002: 73). Medical schools are now integrating courses on alternative therapies into their curricula and physicians are learning more about the treatments, and either integrating them into their own practices or referring their patients to alternative providers. Moreover, more insurance companies are covering certain alternative care treatments (coverage varies by state according to the NCCAM website).

At the same time, there are obstacles to using CAM. Perhaps one of the biggest challenges is the lack of integration of CAM treatments into the American system of health insurance. When one takes chiropractic care out of the mix, a majority of health insurance companies plans do not cover CAM treatments (Tillman 2002: 67). The reluctance of health insurance companies and health maintenance organizations (HMOs) to provide benefits to patients for the use of alternative therapies stems from several problems which highlight the insurance industry's reliance on allopathic medicine. Because there has been a lack of scientific evidence demonstrating alternative medicine's outcome efficacy, insurance companies are not compelled to cover them. Although there has been increasing opportunities for CAM providers to find and apply for licensing and accreditation, alternative medicine practitioners tend to have training outside of accredited universities and medical schools meaning they have different, and sometimes not well developed, credentialing standards, making it difficult for insurance companies to include them in their networks (based on their standards of inclusion). In fact, it is often the incompatibility of the standards that make it difficult to fit CAM treatments into reimbursement codes for reporting procedure claims (Tillman 2002: 69-72). Like chiropractic care, some other CAM treatments are making gains towards health insurance coverage through improved licensure procedures and increased empirical evidence of beneficial outcomes. In addition, some insurance companies are opting to cover some CAM treatments due to increased consumer demand (Tillman 2002: 73). Starting in the 1990s , the companies have found ways to offer coverage either by designating alternative medicine practitioners as members of the network or creating add-ons for those who wish to opt into CAM treatments (Tillman 2002: 65-67).

With the backing of National Institute of Health, millions of dollars have been invested in the research of these alternative therapies. The purpose of this inquiry is to examine scientifically the effectiveness and safety of these procedures. Mary Ruggie refers to this process as mainstreaming, by which she means that researchers are investigating these practices to understand them from a medical perspective. “What mainstreaming is all about is an effort (1) to identify some of the similarities between CAM and conventional medicine, and (2) to strengthen the links between these two approaches to health care” (Ruggie 2004: 9-10). The relationship between conventional medicine and CAM is tenuous, but one that will continue to be questioned and altered in the coming years, most likely with a consumer–driven pressure for them to integrate and join forces.

Empowerment and Medicine

The concept of empowerment with regard to healthcare means that patients have power and control over their treatment (their care) and in the best case, are given the right to be primary decision maker when it comes to their own condition and its day to day management. “Patients are empowered when they believe they can think critically and have the knowledge, skills, attitudes, and self-awareness necessary to influence their own behavior and that of others to improve the quality of their lives (Anderson and Funnell 2010:) Catalysts to patient empowerment include: knowledge, understanding, information, right environment, right attitude, availability of resources, and health care professionals who have been educated in chronic pain management (Anderson and Funnel 2010).

Since 1957, with the introduction of informed consent laws to medical institutions, “patients’ rights” has been an integral component of the medical ethics movement. Informed consent essentially casts patients as decision-makers in their own health, requiring them to participate in their care. “Informed consent is intended to enable patients to make decisions about their own medical care by requiring physicians to provide them with sufficient information about the risks and benefits of treatments or procedures” (Zussman 1992: 82). Barring situations of unresponsiveness (as in the Intensive Care Unit or other emergency situations) or mental instability, in which cases Robert Zussman says, the patient “vanishes as a participant,” patients and/or families have been granted some degree of empowerment with a newfound position of knowledge and the right to refuse treatment (Zussman 1992: 30, 82). However, in the aforementioned material, a clear picture of disempowerment reigns, as physicians still hold the authority and expertise when it comes to their patients’ care. Physician visits are usually about “what doctors do to patients versus what patients do for themselves” (Zussman 1992: 30) and in the arena of complementary and alternative health, “what patients do for themselves” is prized.

While some medical professionals may encourage their patients to seek CAM therapies, other patients are primarily making decisions on their own to see other care providers. Survey evidence shows that there is often little communication between physicians and patients on the topic of alternative health. Patients commonly seek CAM without asking or informing their primary care physician (Eisenberg et al 2001), especially when seeing differing practitioners for different ailments, which has been recognized as one negative effect of the gap between CAM and conventional care. Patients may be afraid to divulge their alternative health use if they think their physician will not approve.

In addition, it is thought that some patients are more interested in controlling their own care. They may derive confidence in taking an active part in managing their care. In a 1994 study comparing patients using conventional and alternative treatments, those utilizing the conventional treatments were much more likely than those using alternative treatments (70% vs. 20%) to agree with the idea that "for most illnesses, it is the physician who can help them most" (Kelner & Wellman 1997: 210). "Patients of alternative practitioners clearly see an important role for themselves in their own health care. They emphasize the patient's responsibility toward his/her own health, as well as making it clear that they know their own body best and trust their own judgment most" (Kelner & Wellman 1997: 210). From interviews with CAM providers and patients, which asked participants to describe their feelings toward CAM, Barrett et al (2003) uncovered several themes. Among the four themes that emerged, empowerment appeared as a top theme with participants using terms and phrases such as "active, not passive", "making decisions", and "responsibility" to describe CAM (the other three themes were holism, access and legitimization – together creating the authors' conceptual framework acronym, "HEAL"). Participants noted feeling like they were "put in the driver's seat" regarding their own health decisions within CAM, in contrast to the "fragmented, impersonal nature of conventional medicine" (Barrett et al 2003: 940-941). Likewise, Eeva Sointu found in her interviews with CAM users in Britain a desire for a holistic sense of "wellbeing" (as opposed to health), one that transcends the physiological boundary. Furthermore, their experiences with alternative medicine were seen as personal journeys of self-discovery and reflection. These things can be achieved through the domain of CAM, which structures itself in such a way as to promote individual empowerment through patient autonomy and control (2006: 332 & 338-339).

Patient involvement is often cited as another reason that patients enjoy CAM. Like Szaz and Hollander's 1956 model of physician-patient relationships, they desire and get a "Mutual Participation" or cooperative relationship in which the provider facilitates the patient in getting better. Szasz and Hollander typified this type of relationship in chronic conditions in which patients sees their physicians often. Given the constraints of modern medicine, patients often do not feel that they get to spend enough time with their doctors and they are passively receiving expertise (like Szasz and Hollander's Activity-Passivity or Guidance-Cooperation models) rather than truly working together (1956).

Increasing approval of CAM may be reflective of widespread cultural shifts toward health consciousness and consumerism. "This kind of self-control patients with chronic illnesses are exercising may be based on sound knowledge about their conditions and needs, and it may indicate an increased aggressiveness in taking advantage of the expanding medical marketplace and the many and diverse options it is beginning to offer" (Ruggie 2004: 54). As much as some might describe patients as being rejected or turned off from conventional care because of bad experiences, others are making the argument that patients are drawn to alternative care because its ideology is amenable to those in contemporary America. "…in being selective in their choice of which CAM modality to use for their ailments, patients may be exercising self-control, but their choice also reflects broader social, cultural, geographical, and practical factors" (Ruggie 2004: 57).

As most people have come to equate health with self-improvement, there is a general awareness paid to the betterment of one's own health (Goldstein 2008: 34). The rise of individual concern for one's well-being, with trends of self-help and education, has promoted the rise of holistic medicine and its predilection of natural techniques and equal relationships with physicians (Goldstein 2008: 38). "Insofar as self-care is ipso facto potentially empowering for patients, it raises an issue in physical- patient relationships that have been receiving increasingly more attention – shared decision making. The new development destabilizes the traditional authority of physicians by suggesting a more substantial role on the part of patients in knowing about, conducting, and deciding on their own health care. At the same time, it is a necessary component of a patient-centered, consumer-oriented health care system (Ruggie 2004: 93).

Demedicalization and Resistance

Demedicalization is the reverse process of medicalization and oftentimes occurs as a response to "overmedicalization." This is the case when a condition that has been overseen by medical institutions loses its medical definition and relevance – that is, meaning when medical treatment no longer is viewed as the appropriate course of action. According to Conrad (1992), "Demedicalization could be said to have taken place, for example, if childbirth were defined as a family event with lay attendants, if chronic drunkenness were reconstituted as an educational problem, or if menopause reverted to a natural life event, inappropriate for an medical intervention" (225). Those with grievances toward medicalization may simply see little need for medical professionals to be involved, or they may believe that medical involvement is actually harmful (the iatrogenesis argument). Culturally, there have been growing concerns with adverse effects of technology and medication and some people are questioning whether their excessive use is of more harm than help. One example is people’s skepticism about the use of antibiotics and x-rays based on their known side effects, such as antibiotic resistance and cancer (Goldstein 1998: 37). Furthermore, the resurgence of spiritual beliefs in all dimensions of life could be impacting patients’ choices.

Demedicalization tends to happen from the bottom-up and represents a type of social movement approach. Rather than the institution of medicine revoking its control and expertise in the condition, the initiatives of those who see a lack of a rationale for medical involvement are usually the actors in extricating the condition from perceived medical vices. Perhaps the most well-known example of demedicalization is the removal of homosexuality from the Diagnostic and Statistical Manual of Mental Disorders (DSM-II) in 1974. This pursuit was largely taken on by gay rights activists who protested and picketed for a redefinition. Demedicalization is also an attempt to destabilize medical authority and shift choice and decision-making to patients. Some researchers believe that movements toward self-care can be seen as attempts to demedicalize. “Self-therapy techniques and programs have been developed for conditions as complicated and grave as terminal renal disease and hemophilia A and B. Proponents of such regiments affirm that many aspects of managing even serious chronic illnesses can be handled safely at home by the patient and his family, who will in turn benefit both financially and emotionally” (Fox 1977: 19). The Women’s Health Movement and the Disability Rights Movement have also been major contributors to the reexamination of the medical model approach to personal matters. One example from the Women’s Health movement to demedicalize is artificial insemination. While infertility has long remained under the umbrella of medical care, artificial insemination (a treatment for infertility) has been – to some extent – demedicalized. What is commonly known as the “turkey baster” method, has become an informal, self-performed procedure in the home, which is not performed under the observation of a physician. Some researchers describe this change from physician to self-insemination as a response to medical hegemony that only allowed artificial insemination to be granted to “deserving” groups of people, i.e. married, heterosexual women (Wikler & Wikler 1991). Performing self-insemination is a way to evade social control – through medical control – on individual’s reproductive plans where the expert physician served as a gatekeeper to fertility. Through the process of demedicalization, the procedure is effectively disentangled from decision-making authority of physicians and reproductive specialists. People are not dependent on medical professionals for access to semen (commercial sperm banks fill this role) or special skills to perform the insemination.   At the same time, the equipment needed for this technique becomes relatively low-tech as everyday instruments from the kitchen, such as a turkey baster, can be used, making it a more cost-effective way to become pregnant. In effect, self-inseminators see no reason why insemination should be considered a medical practice in the first place (Wikler & Wikler 1991). Another related arena where resistance to medicalization is taking place is the natural birth movement. If we look to the resurgence of midwives and natural childbirth in the 1970s as a response to the full medicalization of childbirth that was supplanted in hospitals by the 1940s, then we can imagine that today’s movement to homebirths and the use midwives, birth companions, or doulas represents yet another real and symbolic attempt for women to deliver, on their own terms, and resist labels offered by the medical institution that often depict them as debilitated (“high risk pregnancy”).

Clearly the process of medicalization works more quickly and effectively than the process of demedicalization as the number of conditions that are demedicalized are far fewer than those that are medicalized. As Peter Conrad has said, "While the medicalization process could be bidirectional and partial rather than complete, there is strong evidence for expansion rather than contraction of medical jurisdiction" (2008: 104). The expansive nature of medicalization can be explained by the vast power medical institutions have in our society. Not only are physicians viewed as experts, their tools and procedures are highly technologized and skilled, which enables physicians to maintain their authority while further entrenching the structure and bureaucracy built around care. Furthermore, there is a commercial enterprise and a media that fuels the medicalization process in their pursuit of selling pharmaceuticals.

> For example, if a new pharmaceutical treatment comes to the market, the drug industry may well pursue the promotions of new or underused medical definitions to legitimate their product (e.g. Paxil and SAD/GAD), attempt to change the definitions of a disorder (e.g. hGH and idiopathic short stature), or expand the definitions and lower the treatment threshold of an existing medicalized problem (e.g. Viagra and erectile dysfunction). Thus drug companies are having an increasing impact on the boundaries of the normal and the pathological, becoming active agents of social control (Conrad 2008: 113)

While Foucault's theory of biopower is sometimes assumed to be all-encompassing, paralyzing and pessimistic to individuals (e.g. *Discipline and Punish*), there are, in fact, many references to resistance in his work. Foucault's own impression of transgression changes through his career (Pickett 1996: 447). Early in his work, specifically in *Madness and Civilization*, Foucault addressed transgressions relatively softly, stating that they had their place in pushing limits and public discourse. His vision of these challenges included exposing the voices of the most marginalized people against the dominant discourse. In his "A Preface to

Transgression" in *Language, Counter-Memory, and Practice*, he argues that contestation is vital for culture. It challenges and undermines the idea of natural law that most people take for granted, such as the definition of madness. In his later writing, Foucault conceptualizes power and resistance more brazenly as he describes how institutions use their ideological constructs to support their own power and punish people who deviate from accepted discourse, which consequently prevents people from acting out against them. In these works, Foucault is more desirous of a revolutionary approach to transgression, one that collapses hierarchies and allows a real movement to gain coherence as a counter-power. "Giving agonism a greater emphasis within a society, according to Foucault, opens possibilities for changes within institutions, for altering how scientific discourses circulate, function and have effects on power" (Pickett 1996: 464). Furthermore, resistance is no longer merely small reversals of everyday conduct; it becomes more autonomous as people can creatively navigate institutions. It is in his later works that he explicitly unites power and resistance and speaks about the positive effects of such an uprising.

Conclusion

This chapter covers the vital research and theoretical insights that have been written in the sociological fields of pain, the body and medicine and lays the groundwork for this dissertation research**.** In much of the reviewed literature we can best see the patient experience with chronic pain, which is certainly shaped by the patient's environment, including, most importantly, medical encounters. Within medical encounters, patients face challenges to getting treatment and achieving a sense of validation that their pain is real. This kind of experience is created and captured in the illness narrative, or the stories that patients tell about their chronic illnesses. Medical sociologists remind us that illness is shaped by dominant definitions and procedures of diagnosis and illness that are present, but ever-changing, in the medical field. Medicalization continues to expand and as it does, we are left to question if conditions should be covered under its umbrella and if it is in the best interests of patients. With medicalization also comes a strong tendency to award physicians with absolute control and expertise over illness and the nature of the medical encounter. With the adoption of new modalities of care (desirable due to push and pull factors), namely CAM, questions are brought to light about the applicability of the sick role (which is still dominant for medical professionals) and the role of patients in their own care. The medical field leaves little room for patient empowerment, but recent research suggests that empowerment is at the core of CAM. Resistance to conventional medicine may be the result of perceived “overmedicalization” on the part of patients, who desire more autonomy in their healthcare decisions. Moreover, demedicalization is often achieved by grassroots social movements, in which people advocate for change in medical definitions and labels, which is particularly important for the current body of research that examines empowerment through the use of CAM. In the next chapter, data collection and analysis are discussed in detail to expose the background, research questions, and sampling techniques that were used in conducting this research.

Chapter 3: Collecting the Data

This chapter describes the methods of this study on the use of acupuncture for chronic pain patients.

The Mixed Methods Approach

Mixed methodology is a type of research design that blends quantitative and qualitative research to provide a more thorough explanation of social phenomena than a single approach would individually. Quantitative research, while strong in hypothesis testing and statistical analysis, can lack subjects' voices and experiences. Qualitative research, known for its ability to highlight human experience with rich description, usually relies on small sample sizes which may not be easily generalizable to the larger population. Further, while the quantitative approach does well with theory testing, qualitative analysis has strengths in theory building. In this way, the mixed methods approach is a more comprehensive and rigorous tactic to explain the complexities of health and healthcare decision-making while, at the same time, remedying some of the limitations of single approach social research designs. At the same time, mixed methodology highlights the meaning-making narratives of the subject's personal history and locality *and* the relationships between variables that show a trend or pattern for a large group of people.

For this study, a sequential, two-step process was used. Quantitative data was first gathered to survey the population of chronic pain sufferers for the purpose of determining if basic differences existed between acupuncture and pain management patients. This information then led the way to developing the interview protocol to further understand details about the quantitative findings. The method allows the researcher to build on quantitative results to explain significant as well as confounding findings by further questioning and purposeful sampling using qualitative methods. Using two styles of data collection not only provides triangulation, where one data set can validate the outcomes of the other, but it also allows the data collection to become more focused and detailed as it progresses from the first stage to the second stage. While qualitative research is typically viewed as exploratory in nature and often a precursor to quantitative research in mixed methodologies, the present research design reverses the order and logic in order for the qualitative inquiry to be focused on a more tangible and more in depth picture of how the populations are similar and different from one another.

Broad Research Questions and Aims

This research is aimed at discerning what health beliefs and behaviors are associated with engaging with a non-conventional system of healthcare. As discussed in the previous chapter, complementary and alternative medicine operates from an ideology that espouses unique characteristics to its process and patients. First, I ask, are patients who use acupuncture more likely to experience these characteristics in their beliefs and behaviors? And further, are these patients socialized into the characteristics that Complementary and Alternative Medicine uphold, or are they more likely to hold these beliefs prior to their treatment? In order to answer the second question, it is important to understand if treatment-seeking differs for patients who use alternative medicine and what that process looks like. It also important to explore the more provocative question, can engaging with a non-conventional form of medicine be empowering for chronic pain patients and if so, how does this happen?

These questions required two approaches towards their resolution. The first step was to establish if acupuncture patients, as a representation of patients utilizing alternative medicine, differ from their counterparts, pain management patients (conventional medicine) (1) in the experience of finding diagnosis and treatment and (2) in key aspects of healthcare experience that are claimed to be unique to CAM. These key aspects include: Use of Medication; Patient Health-related Proactivity; and Close Patient-Practitioner Relationships (rationales explained below). These main aims of the research were approached first through quantitative hypothesis testing to note larger-scale differences between the acupuncture and pain management pain populations. Then, the second stage of the research was a qualitative analysis that further explored the themes and findings of the quantitative portion of the study and addressed the process of learning in the alternative healthcare office[1].

Stage 1: Quantitative Research Methods

Quantitative Research Questions and Hypotheses

The research questions and hypotheses for this study were developed by examining the literature for established trends in care-seeking behavior and identifying gaps in the literature. Most often, these gaps existed in understanding how care-seeking applies to users of alternative medicine who have chronic pain, as this area has not been fully developed. Four hypotheses were designed to target different aspects of the chronic pain population experience as summarized in Table 1.

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[1] A note on terminology: There are a wide variety of terms that can used to denote the disparate forms of medicine used in the United States today. Alternative medicine, which could be labeled as holistic medicine, traditional medicine, Eastern medicine and natural medicine is referred to as Complementary and Alternative Medicine or CAM in this analysis. For Western, allopathic, mainstream, biomedicine, the term conventional medicine is used. Furthermore, healthcare provider or healthcare practitioner can be used for someone that practices medicine in either of these forms of medicine.

While many assumptions exist about the pathway toward acupuncture, little is actually known about what treatment seeking looks like for its patients. Therefore, I will compare acupuncture patients to pain management patients to see if this process differs with regard to time.

Research Question 1: How does treatment-seeking differ between patients who choose CAM and patients who choose conventional medicine? Specifically, does it take a longer time for acupuncture patients to get a diagnosis for their chronic pain than pain management patients? Length of time until diagnosis will be measured with survey-derived variables: self-reported length of time until diagnosis and number of healthcare practitioner seen until diagnosis. Hypothesis: Acupuncture patients will experience more difficulty in getting a diagnosis than their pain management complements. Because conventional medicine is the norm for most people seeking care for pain, alternative medicine tends to follow afterward, perhaps after conventional treatment(s) have failed to find a diagnosis or to treat the symptoms to alleviate the patients' pain. Alternative medicine is often referred to as a last resort (Verhoef et al 2005).

For the next three questions, an umbrella question asks whether CAM patients compared with conventional medicine patients are more likely to exhibit characteristics espoused by alternative medicine, such as having a natural approach towards healthcare, being proactive toward healthcare, and having a close relationship with their healthcare provider?

Research Question 2: Do acupuncture patients exhibit more naturalism in their use of medications than pain management patients? Here, the number of medications one uses and the use of homeopathic medicines are used as indicators of naturalism. Hypothesis:

Acupuncture patients will use fewer medications, but more homeopathic remedies, than pain management patients and will therefore exhibit a naturalist orientation towards healthcare. Patients of acupuncture treatments may be more likely to exhibit outlooks often touted by alternative medicine, such as a postmodern perspective of health that emphasizes holism and naturalism (O'Callaghan & Jordan 2003). With this, patients may be less inclined to take chemical prescription medications for pain relief, and instead use homeopathic remedies.

Research Question 3: Are acupuncture patients more proactive toward their healthcare than pain management patients? Proactivity, as measured by a self-designed scale of health-related self-efficacy, will discern who being more active with regard to their health. Hypothesis: Acupuncture patients will exhibit more proactivity with regard to their healthcare as compared to pain management patients. Perspectives of alternative medicine often stress the importance of active and empowered patients and previous research has indicated that patients of complementary and alternative medicine exhibit these qualities (Barret et al 2003; O'Callaghan & Jordan 2003).

Research Question 4: Do acupuncture patients have a closer relationship with their healthcare provider compared to pain management patients? Patient-Practitioner relationship is measured using a self-designed evaluation of patient-oriented care. Hypothesis: Acupuncture patients will rate their care as more patient-oriented than the pain management patients will rate their care. Previous research on chronic pain patients' experiences with conventional medicine has indicated that patients have felt their care to be impersonal (Barret et al 2003). By contrast, some researchers have indicated that alternative medicine destabilizes older notions of power imbalances that are typically present in traditional patient-practitioner relationships, thereby putting patients in the position to share decision making with their healthcare practitioners (Ruggie 2004).

Table 1: Summary of Stage 1 Research Questions & Hypotheses

	Research Questions:	*Hypotheses:*
	How does treatment-seeking differ between patients who choose CAM and patients who choose conventional medicine?	
1	Does it take a longer time for acupuncture patients to get a diagnosis for their chronic pain than pain management patients?	Acupuncture patients will experience more difficulty in getting a diagnosis than their pain management complements as evidenced by (1) Having a longer time until diagnosis and (2) Seeing more healthcare providers before getting a diagnosis.
	Are CAM patients compared with conventional medicine patients are more likely to exhibit characteristics espoused by CAM, such as having a natural approach towards healthcare, being proactive toward healthcare, and having a close relationship with their healthcare provider?	
2	Do acupuncture patients exhibit more naturalism in their use of medications than pain management patients?	Acupuncture patients will use fewer medications, but more homeopathic remedies, than pain management patients and will therefore exhibit a naturalist orientation towards healthcare.
3	Are acupuncture patients more proactive than pain management patients?	Acupuncture patients will exhibit more proactivity with regard to their healthcare as compared to pain management patients as evidenced by a self-report measure proactivity scale.
4	Do acupuncture patients have a closer relationship with their healthcare provider compared to pain management patients?	Acupuncture patients will rate their care as more patient-oriented than the pain management patients will rate their care as measured by a patient-centered-care scale.

Quantitative Data Collection

The first stage of the mixed methods research design is a survey-questionnaire intended to distinguish key differences between the acupuncture and pain management samples, including difficulty of getting diagnosis, frequency of medication use, levels of patient proactivity, and an evaluation of patient-centered care. The purpose of this part of the research is not to establish causality between the chosen variables as the data is cross-sectional and is limited in its ability to illuminate causal relationships between the variables.

Data Collection

Chronic pain patients completed self-administered survey-questionnaires in the waiting areas of one of two treatment locations -- a Pain Management office and an Acupuncture office -- both in suburban Long Island towns less than 15 miles apart from one another. The data collection sites were chosen as representations of conventional and alternative medicine practices, respectively. These specific locations were identified as convenient research sites due to their relatively close location to the University and the researcher's network of professional contacts that allowed her admittance.. Upon approval of the survey instrument, access was granted by the overseeing administration at each facility. The researcher was able to approach patients in the waiting areas of the health offices to ask for their participation in a study on healthcare beliefs. Eligibility for the study was based on the following criteria:

- Age (participants were required to be at least 18 years of age)
- English-speaking competency
- Chronic pain experience (participants must have had pain lasting for at least 3 months duration)
- Treatment duration (participants must have had treatment for their chronic pain at the facility where they were approached for at least one month)

Survey distribution for the pain management patients occurred during December 2011 and January 2012, during normal business hours (8 am – 6 pm). A total of 30 hours were devoted to the collection of these surveys at this treatment site. Due to substantially different patient loads between the facilities, survey distribution at the acupuncture office occurred during the time period of January – August 2012. While the acupuncturist (single practitioner) saw approximately 50 patients in a week, the pain management office with four practitioners saw nearly this same number of patients in a day. For this reason, nearly 50 hours were devoted to questionnaire distribution and collection.

The survey-questionnaire was designed to be completed in no more than 15 minutes since the goal was for patients to complete the questionnaires before the end of their office visits. While all of the respondents at the pain management office completed their survey-questionnaires during the time that they spent waiting in the waiting or treatment room, the acupuncture respondents often requested to leave with the questionnaire and return it at their next visit. This was mostly due to the fact that the acupuncture patients had virtually no waiting time -- again a characteristic of the smaller scale set-up of this office. As a result, acupuncture respondents were more likely to lose interest in or to forget to return the survey. This response rate also contributed to the differential lengths of time for data collection at the two treatment sites.

Fortunately, most patients who were approached for participation in the survey agreed to participate. The small minority of those who declined to answer the questionnaire (6 people at pain clinic and 3 people at acupuncture office) did so for one of several reasons, including: glasses forgotten, unwillingness to sign consent form for fear of insurance involvement, disliking surveys, claiming to not have enough time and the like. No noted patterns could be discerned for those who declined participation. I am unsure if response rates for those who took surveys home varied in patterned ways as those participants were not tracked.

Respondents completed informed consent forms that explaining the nature of the study, their rights as a volunteer, and confidentiality granted to them. The researcher also verbally explained these rights when distributing questionnaires. This research protocol, deemed low-risk, was approved by Stony Brook University's Office of Research Compliance for Human Subjects, and has complied with all updates during the course of data collection.

Instrument Measures

In this section, the measures and operationalization are described for the various variables as summarized in Table 2. Through primarily closed-ended questions, data were collected on the subjects' health statuses and basic time line of health-seeking behavior (from symptoms to diagnosis to treatments). Other lines of questioning included where the subjects obtained trusted, reliable information, and how active they were in finding that information. Further, subjects were asked about their attitudes toward alternative medicine and to rate their current treatment on a scale of patient-centered care. A copy of the survey-questionnaire can be found in Appendix A.

Variables

Variable were selected from the survey-questionnaire to represent key aspects of care-seeking and attitudes toward healthcare for hypothesis testing. The variables were not labeled, however, as independent or dependent variables because under different circumstances they could act like either. For example, it is conceivable that the type of treatment that one engages with could affect health attitudes or behaviors, for example one's inclination to use homeopathic remedies or to be proactive in healthcare decision-making. For the purpose of stage one, these variables and the relationships between them will not address causality, but this issue of causality will be addressed in more detail in stage 2 of the data when participants speak about their pathways to healthcare and how their health-related beliefs and behaviors changed over time. Each variable is operationalized below.

Treatment Type - Treatment type is a dichotomous, nominal variable and has been designated for each participant by their location at one of the two data collection sites: (1) Pain Management Office, or (2) Acupuncture Office.

Time to Diagnosis- Time to Diagnosis is a relative measure of how long it took for the patient to receive a diagnosis after approaching a healthcare provider with symptoms of chronic pain. They chose from the following: “I was diagnosed right away,” “It took a short amount of time to get diagnosed,” “It took a long time to get diagnosed.”

Number of Healthcare Providers- Subjects were asked how many healthcare providers they saw in search of getting their pain symptoms diagnosed. Options included: 1 one healthcare provider, 2 or 3 healthcare providers, 4 or 5 healthcare providers, and 6 or more healthcare providers.

Number of Medications – Number of Medications is based on a list of types of medication drawn from chronic pain websites discussing common forms of medication for chronic pain. Participants were asked to mark all of the types of medications that they were currently taking for chronic pain symptoms. The choices were: Opiods/Narcotics, Non-Opoids/NSAIDs, Antidepressants, Anti-Convulsants, Topical Analgesics, Muscle Relaxants, Corticosteroids, Nerve block or Neuroblative therapy, Implanted Devices, and Other.

Use of Homeopathic Remedies – Use of Homeopathic Remedies is measured with a dichotomous variable of “Yes” or “No” indicating whether the subject selected homeopathics as a current form of medication to treat chronic pain symptoms.

Proactivity Self-Efficacy and Coping Self-Efficacy- In order to measure self-efficacy among the sampled groups, subjects were asked to rank how confident they were on a 5-point Likert scale ranging from 1 Not at all confident to 5 Totally confident on 9 different tasks. These tasks included performing daily activities and maintain relationships with friends and family as well as coping with pain, making good decisions regarding healthcare, accessing reliable information, and support and even helping others with similar health conditions. The results of a factor analysis testing the scale’s reliability will be discussed in the next chapter.

Patient-Centered Care Evaluation – Patient-Centered Care Evaluation is a scale of six questions created to assess participants’ perceptions of being heard by and having shared decision-making with the healthcare practitioner. The scale is composed of six statements that subjects responded to with their level of agreement by choosing from a 5-point Likert Scale, indicating: Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, and Strongly Agree. Because this was a new scale developed for this study, psychometric testing was needed to assess its reliability and those results are shared in the next chapter.

Table 2: Data Definitions

Construct:	*Definition:*
Treatment Type	The site where the subject was receiving treatment for chronic pain - Pain Management or Acupuncture
Time to Diagnosis	Length of time that it took to receive a diagnosis from a healthcare provider
Number of HCP's	The number of healthcare providers that the subject saw prior to diagnosis
Number of Medications	The number of medications that the subject is currently taking for chronic pain
Use of Homeopathics	Whether or not the subject currently uses homeopathic remedies
Proactivity Self-Efficacy	Score derived from a scale in which subjects rated their confidence in performing proactive pursuits
Patient Centered Care	Score derived from a scale in which patients rated their healthcare providers on a number of patient-centered statements

Data Analysis

Data analysis was conducted with the Statistical Package for the Social Sciences (SPSS 20.0). Relevant variables were examined for measures of central tendency and variability to check for outliers or data entry mistakes and understand the data descriptively. Then inferential statistics, including chi-square and t-tests, were utilized to test hypotheses using the above-mentioned variables.

Quantitative Summary

In Stage 1, a survey-questionnaire was used to elicit data from patients in two settings: an acupuncture office; and a pain management office. Nearly 100 respondents were asked questions about their health and pain, care-seeking trajectory, and attitudes toward their care.

This data was used to answer four research questions, which primarily aimed to discriminate if differences existed between the two samples with regard to the difficulty of getting diagnosis, frequency of medication use, levels of patient proactivity, and evaluations of patient-centered care. These differences were computed with inferential tests of variable relationships, namely chi-square and t-tests. The results of this portion of the data collection lead to Stage 2: Qualitative Data Collection.

Stage 2: Qualitative Research Methods

Qualitative Research Questions

The second step, once the differences (and similarities) were established between the samples, was to use a qualitative approach to understand and explain those differences more fully. The aims for this stage of the research were to collect more detailed information about the trajectory of the patients' care-seeking behavior and to understand, from the patients' perspective, how engaging with non-conventional treatment had changed their outlook on medicine and other health-related beliefs and behaviors. This entailed a very close look at the trajectory of treatment-seeking for chronic patient patients using acupuncture and close analysis of the whether key characteristics were learned from engaging with acupuncture, or if these characteristics were present before the start of treatment, or attributable to other forces in the patients' lives. Further, these questions raise the question of whether socialization or perhaps, empowerment, happens in the acupuncture office and if so, what microprocesses contribute to this development. Research questions are listed in Table 3.

Table 3: Summary of Stage 2 Research Questions

	Research Questions:
1	What does the trajectory of treatment-seeking look like for chronic pain patients using CAM?
2	For patients who align with CAM-espoused beliefs about naturalism, close practitioner-patient relationships, and health proactivity, do they experience a process of learning or socialization to acquire these characterstics?
3	Do CAM patients experience a process of empowerment by engaging with a non-conventional modality of treatment? If so, what microprocesses are at play in this transition?

Qualitative Data Collection

The second stage of the mixed method research design included in-person interviews designed to further understand patients' pathways to care, and how acupuncture chronic pain patients have or acquire key characteristics that set them apart from conventional patients. Since little is known about the illness narrative regarding the use of alternative medicine, in-depth interviews provide the nuance and detail which provide thick description of chronic pain sufferers' lived experiences. This stage of data collection was conducted after the results of the quantitative analyses so that the qualitative interviews could help in further explaining and clarifying some of the findings of the survey-questionnaire.

A mixed method approach attempts to lay to rest the long-standing methodological debate that exists between quantitative and qualitative orientations. As mentioned early in this chapter, mixed methodology uses the strengths of both forms of research to help alleviate the weaknesses of the other. In addition not only does each method reveal different aspects of the subjects' reality, but multiple methods of data collection provide more evidence for analysis.

> “A questionnaire is like a photograph. A qualitative study is like a documentary film. Both offer images. One, however – the photograph – captures and freezes a moment in time, like recording a respondent’s answer to a survey question at a moment in time. The other – the film – offers a fluid sense of development, movement, and change” (Patton 2002: 54).

The single methodologies are strengthened further by triangulation because the data from the qualitative analysis can serve as a test for consistency, or a “checks and balance” for the quantitative, and vice versa. Examining the topic with multiple, complementary methodologies can help to illuminate deeper insight and, at the same time, alleviate skepticism.

While survey-questionnaire research has its strength in standardized measures and the ability to fit experiences and perspectives into predetermined responses, qualitative inquiry has the ability to give more depth and detail to those experiences and perspectives. Interview data provides the researchers with description in the form of quotations, called narratives. From these narratives, we are able to discover important patterns, themes and relationships. Qualitative data is particularly strong when making inquiries into people’s lived experience, especially when little is known about the phenomenon under investigation. With qualitative methodology we can attempt to understand phenomena from the level of the subject, i.e. how he or she perceives reality.

Social constructionism is a term that is well known fundamental in the field of Sociology. In qualitative research, we are able to detect how people construct their reality and have their realities constructed by the social organizations around them. Further, we investigate the ways in which these “truths” about the social world affect their behaviors and worldviews.

Data Collection

For this research, purposeful sampling was used to select illuminative cases of acupuncture use for chronic pain. Some of the research subjects in the aforementioned survey-questionnaire were asked to further participate in hour-long interviews either at the time that the surveys were administered or with post-card advertisements displayed in the acupuncture office's lobby. A modest incentive in the form of a gift card for a national coffee chain was offered to participants to compensate them for their time. Participants were given the choice of face-to-face or telephone interview options because some subjects had mobility challenges that would make in-person interviews difficult physically or financially. Interviews took place over a 5-month period from November 2012 to March 2013. In-person interviews took place at various coffee shops, restaurants and, in a few instances, participants' homes or places of business.

Unlike larger scale, quantitative works, qualitative purposeful sampling is not meant to generalize to an entire population (Patton 2002: 3). Instead, sampling is aimed at information rich and insightful cases. In this study, the subgroup of acupuncture patients who had chronic pain was focused on in order to understand the processes unique to CAM use. While there are no hard and fast rules about sample size for qualitative work, there is an understanding that rich information from strategically selected cases can be more meaningful than surface level inquiry from a larger number of participants (Patton 2002: 244-245). The most widespread rule of sample size for qualitative inquiry is the rule of saturation or redundancy, in which further interviews no longer contribute much, if any, new information to the dataset (Patton 2002: 246). In this sample, careful attention was paid to finding variation within the sample based on gender, age, education, and type and duration of pain and confirming and disconfirming cases were included as well.

Interview Guide

Through semi-structured, open-ended questions (the complete interview guide can be found in Appendix B), information was ascertained about the participants' pain histories, including their self-reported degree of pain, the type and duration of illness or injury that are believed to cause the chronic pain, and how they managed in their daily lives with chronic pain (whether it interfered with lifestyles, what techniques they used on a daily basis for pain management). In order to understand patients' stories of illness and pathways toward treatment, the subjects were asked to lead the interviewer through their care-seeking history, which may or may not have included a number of treatment types and practitioners, specifically questioning them about their perceptions of being heard and understood by those practitioners. It was important to know what diagnosis(es) they were given and if the subjects accepted those diagnosis(es) and treatment(s). They were asked how they had typically located practitioners for treatment (doctor referral, recommendation of a friend/family member, through personal investigation, etc…) and how they came to choose their current treatment – acupuncture.

When focusing on acupuncture as a treatment for chronic pain, the participants were asked if acupuncture was different from other forms of treatment and if anything changed for them upon hearing the diagnosis and treatment plan. Reflecting on the duration of their treatment time, subjects were questioned as to whether they had experienced a reduction of pain as well as any other benefits. Subjects were also questioned about any obstacles that they encountered in seeking acupuncture as a treatment as well as disadvantages associated with it. Furthermore, they were questioned about their relationship with the acupuncturist (personal vs. professional relationship) and how involved they were in decision-making regarding their treatment. It was important to understand how they envisioned the ideal healthcare provider-patient relationship and what they believed the role of the patient should be. If they conceived of themselves as being proactive patients, extra steps were taken to determine if they always believed this or if the belief was newfound and possibly influenced by their current or recent forms of treatment.

This discussion about acupuncture was couched in a broader discussion about the subjects' use of non-traditional methods of treatment in order to understand if they exhibited a previous open-mindedness toward complementary and alternative healthcare, or if the current pain symptoms (and perhaps lack of results by other treatments) compelled them toward non-traditional care. With this, it was important to probe about the participants' perceptions of desperation for treatment. As seems to be the case, chronic pain patients may see several healthcare providers without received relief of their pain symptoms. In cases where they expressed frustration, desperation or being "at the end of their rope," the subjects were assessed for their perception of treatment options and sensitivity to running out of options.

Subjects were asked what goes into the decision to continue or discontinue with a treatment. With all that they had experienced, their opinions regarding the medical system (trust and confidence in the medical system as well as with alternative medicine) were assessed and if they felt that alternative medicines were compatible with conventional medicine – this is, whether an integrative system of care seems feasible and/or desirable to them.

In a more general sense, the factors go into making decisions about treatment were uncovered. Some potentially important elements were addressed, including: information about a treatment's efficacy; hearing personal testimonials; getting a doctor's approval or referral; whether treatment includes medications or surgery; and the cost and availability of health insurance.

Before concluding, the participants were engaged in a discussion about gender and healthcare. First they were asked if they knew or could speculate on why women, on a national scale, tend to use non-traditional medicine more frequently than men. Then they were asked if they felt their own gender had affected the care they have received at any point along the trajectory of care-seeking. The intention here was to gauge whether they identified their gender as a detriment or advantage to accessing pain treatment.

Probes were used when necessary to clarify further detail to patients' stories. All interviews were audio-recorded so that notes could be taken sparingly during the interview process. Hand-written notes were taken after the interviews had finished in order to draw general conclusions about the dialogue.

Sample Strategy

Personal interviews were conducted with a subset of the acupuncture survey participants as well as some participants who were recruited in the months after the survey-questionnaire (totaling 20 participants).   In this portion of the study, the sample purposefully shifted toward the acupuncture sample for several reasons. Overall, this population had been understudied with regard to illness narratives and choice of treatment, a qualitative examination of this group would potentially contribute original information to the literature.

Furthermore, during the analysis of the survey-questionnaire, it became clear that certain differences existed between the respondents in the two types of treatment. Of particular significance were the findings that acupuncture patients referred to themselves as being more desperate for care before finding their current treatment and also rated their treatment as more-patient centered. Because one aim of this research was to understand how patient-centered care affects its patients, this sample provided the foundation (more so than the pain management survey) to investigate the research questions.

In recruiting interview subjects, I interviewed people with the intent of getting as much variability as possible in categories such as gender, age, education, and duration and cause of pain. Some of those were easier than others. A detailed break-down of interview subjects can be found in Chapter 3.

Measures and Data Analysis

Audio-recordings were transcribed fully into Word documents and all transcriptions were checked for accuracy by listening to the audio and reading the transcript simultaneously. Narrative, or content, analysis was used to make sense of the many "stories" that were told by the participants in this study. For this, the researcher seeks to uncover what patient stories of chronic pain and CAM use reveal about the person and the world in which they exist. Essentially, content analysis of the interview transcripts is a method of data reduction and meaning-making. First the interview transcripts were manually coded inductively, or what is called "open-coding" (Patton 2002: 453). Broad codes were developed such as, "Relationship with Practitioner," "Medication Use," and "Negative Experience with Healthcare Provider." These were themes that were distinguished as observable patterns and were used as initial codes by which all transcripts were sorted. For this, a computer data management program called QRS Nvivo 8 was used for full thematic coding of the data. QRS Nvivo 8, which has been designed for qualitative researchers with text-based analyses to organize and reduce data into more useful forms, is used extensively in the social sciences. While the program assists in the management of the volume of data, the researcher decides which codes to use, how to label the content's passages and how to conduct the analysis. During the coding, a few additional coding categories were developed for passages that did not fit well into existing categories. The codes were then used deductively to affirm the appropriateness of the inductive content, and some codes were dropped when they were not used repeatedly. Quotations could be classified and categorized into multiple codes if the content represented the meaning of the codes. The final codebook contained 25 general categories and most general categories contained subcategories which divided the material into more precise categories. In following a standard and pragmatic code of "best practices" for qualitative analysis, beliefs and ideas that were shared with me more than once and from more than one person were weighted more heavily in my analysis than those that were only articulated once, although the explanations that appear limitedly were noted as possible competing or dissenting cases.

The data were first analyzed on a descriptive basis, which laid the foundation for the interpretative results. In this aspect of higher level theorizing, meanings and significance were attached to relationships among variables based on several criteria. Efforts were made to account for data irregularities and disconfirming cases and to deal with rival explanations. The challenge of qualitative research is resisting a simplistic linear logic between independent and dependent variables. This challenge actually becomes a strength of qualitative work, in that data can be viewed from a holistic perspective in which variables are inter-dependent and inter-related and have complex associations. What is shared in the following chapters is, I hope, a balanced reporting of descriptive and interpretative findings.

Precautions have been taken to strengthen the credibility of the work as well. While no research is objective, it is important to safeguard against unnecessary biases through systematic analysis of the data at every step of the way and by making transparent all aspects of the research process. As internal and external validity are to quantitative research, trustworthiness and dependability are to qualitative research (Patton 2002: 546), so it was important to describe the authenticity and confirmability of the data and I have reported on the legitimacy of the findings whenever possible. Lastly, credibility relies on “a philosophical belief in the value of qualitative inquiry, that is, a fundamental appreciation of naturalistic inquiry, qualitative methods, inductive analysis, purposeful sampling, and holistic thinking” (Patton 2002: 552). As an additional attempt to maximize validity, I shared the conclusions of the qualitative analysis with two research subjects for their input (and will report on their feedback). Thus, the themes and content of this research have been confirmed by the participants.

Summary of Qualitative Methods

This stage of the research was conducted to learn more about how chronic pain patients’ use of acupuncture and how interaction with a new, alternative modality of medicine affects their health beliefs and behaviors. This was completed by interviewing 20 chronic pain acupuncture patients, based on questions elucidated in the previous stage of quantitative research. The approximately one hour long interviews were transcribed and systematically coded, at first broadly and then narrowly in an iterative process. Ultimately, care was taken in interpreting the responses to maximize credibility and the strength of the findings.

A Note on Reflexivity

It is important for the researcher of any study to discuss his or her positionality and the factors about his or her identity that could “undermine the traditional notions of validity and neutrality” (Patton 2002: 93). This includes what shapes and has shaped the researcher’s perspective and perceptions of the data, field site and overall topic of sociological inquiry. This self-awareness has become a mainstay in qualitative research. To this aim, I will explain my position and overall approach to conducting this research. I became interested in this topic due to my geographic and experiential proximity to “all things alternative” with regard to medicine. In being a yoga instructor for many years, I had come in contact with many people who had used complementary and alternative medicine for various health issues. This list would include, but is not limited to, massage, vitamins, meditation, reiki, acupuncture, chiropractic care, healing crystals, yoga therapy, homeopathics, naturopathic care, Alexander Technique, and hypnosis. In fact, yoga has been utilized by plenty of people to enhance health and well-being and I have taught yoga seminars in therapeutic settings. In that way, I could be considered, perhaps loosely, a healthcare practitioner though I will be the first to admit that I have had very little formalized education on matters of disease and pathology. Furthermore, I became involved in the scene of maternity care first through my teaching and later by becoming a trained doula, or birth companion. In this capacity, I assist mothers in labor and childbirth and my clients are often people who prefer naturally oriented healthcare and sometimes natural birth with midwives. While this immersion into the “alternative realm” of medicine has been integral in forming my interests in an inquiry about CAM use for chronic pain and also equips me with the language and knowledge to navigate effectively within the CAM network, it may also create biases in my approach to data collection and analysis. Likewise, I am also a person that has experienced injury and, thus, chronic pain. These aspects of my identity prompted me to pay close attention to how these features of my biography may have affected my research.

Much of the literature on this refers to how much information a researcher should reveal in course of research, how to manage social difference in the field and how to minimize power differentials between the researcher and the research subjects (Tang 2002). Strategically, I attempted to reduce the effects of these differences by offering only the most basic information about myself to the participants in the research -- including my school affiliation and research aims, which were usually covered within the description of the informed consent form. I was able to establish rapport fairly easily due to my placement in the acupuncture (and, previously, pain management) office(s) and also through a friendly demeanor. It should be noted that my middle class, educated, Caucasian, female background very often matched that of my clients, which no doubt prompted the development of rapport as well. There were two types of personal information-sharing that became important through the process of data collection and had to be dealt with spontaneously. One, it was not uncommon for the acupuncture patients to ask me if I had tried acupuncture and two, one person asked (over the telephone) if I experienced chronic pain. I made no attempt to hide these answers, but I did not embellish or dwell on them either. To the best of my ability, I succinctly told them that I had tried acupuncture a few times and that I had experienced chronic muscular pain in my back over the last year. Not revealing pain or acupuncture use (among other characteristics of my identity) was used strategically not to distance myself from the participants, but instead to maintain a perceived “novice” identity for the participants. This allowed me to “play dumb” and ask questions about pain symptoms and CAM experiences (e.g. What happens when you go to the acupuncturist’s office?) that a more-experienced person may not have been able to ask.

With regard to how personal biographies can potentially affect research analysis, I can only point back to the previous section in which I described my methods to be rigorous, systematic, and driven by the theory and literature in the field.

Summary of Methodology

As a mixed methods study, this research used both quantitative and qualitative approaches to explain how acupuncture, as a representation of complementary and alternative healthcare, fit into chronic pain patients’ illness narratives and what distinguishing characteristics acupuncture patients have when compared to their pain management counterparts. The next three chapters present the research results (Chapter 4: Quantitative Results and Chapter 5 and 6: Qualitative Results) acquired by these methods.

Chapter 4: Confirming and Explaining Acupuncture Patients' Distinguishing Characteristics

Survey-questionnaire data were analyzed to answer the comprehensive research question, "In what ways do acupuncture patients differ from pain management patients in behavior and attitudes toward treatment-seeking for chronic pain?" The data were analyzed using inferential hypothesis testing, namely t-tests and chi-squares, to assess four related hypotheses about differences between the two populations (i.e., pain management and acupuncture) with regard to the process of getting treatment (difficulty of receiving a diagnosis) and characteristics espoused by CAM ideology (medication usage, proactivity toward health, and patient-centered care). Interview data were then collected and analyzed to further explain the circumstances and meanings behind these differences. While the data were collected and analyzed sequentially, the results and findings from each are integrated here to maximize the use of both qualitative and qualitative inquiry in a mixed method approach to answering the research questions. First, the demographic characteristics of the survey and interview samples will be reported.

Sample Demographics

Survey Sample Characteristics

Survey respondents consisted of 55 pain management patients and 44 acupuncture patients (n= 98) experiencing chronic pain (see Table 4).

Age. Participant age was spread out fairly evenly across age groups: 36-45 (20.9%); 46-55 (23.2%); 56-64 (19.2%); and 65+ (18.9%), with slightly fewer people in the youngest age categories -- 18-25 (7.2%) and 26-35 (10. 8%). Acupuncture patients were generally older than pain management patients. About half (48.9%) of the acupuncture sample consisted of people age 56 and older, while the bulk (51%) of the pain management respondents were 36-55 years old.

Gender. Nearly three-quarters (72.2%) of the sample consisted of female respondents and the rest (27.8%) were male. Acupuncture and Pain Management subsamples were similar with slightly more females in the Pain Management (74.1%) group than Acupuncture (69.8%).

Race and Ethnicity. The racial and ethnic makeup of the sample was primarily White/Caucasian (91.7%), with small percentages of Black/African Americans (2.1%) and Hispanic/Latinos (6.3%). The acupuncture group was less racially diverse and consisted of 10% fewer racial minorities than the pain management group.

Education. Education level varied widely across survey respondents. Two-fifths of the sample (42.3%) indicated their highest level of education as high school diploma, while another quarter (25.8% of the sample) reported Graduate Degree or Post Graduate Degree. Nearly one fifth (18.6%) had earned an Associate's Degree and the remainder (13.4%) had Bachelor's Degrees. Comparing the subsamples, the acupuncture patients were better educated and had far more Bachelor's and Master's degree holders than pain management (70% vs. 15%) and fewer patients with High School diplomas and Associate's degrees (85.2% vs. 30.2%).

Household Earnings. About two-fifths (38.9%) of the respondents earned household incomes less than \$50,000 with another third (30%) earning between \$50,000 and \$99,999. Smaller proportions of the group earned between \$100,000-\$149,999 (16.7%) and \$150,000 or more (14.4%). The acupuncture patients were skewed toward higher income brackets when compared to pain management; over half (51.2) of them had a household income of \$100,000 or higher and the grand majority (84.3%) of pain management patients earned less than $100,000 per year.

Average Pain Rating. On a Likert scale with 0 indicating “no pain” and 10 “the worst pain,” the survey sample mean for pain experienced on an average day was 5.65 with a standard deviation of 2.44, indicating a great deal of variation. Acupuncture patients had a lower self-reported average pain score when compared to pain management (6.8 vs 4.1).

Duration of Chronic Pain Symptoms. Half (49.5%) of the survey respondents had been experiencing chronic pain symptoms for 5 or more years. Just over a fifth (21.1%) experienced pain symptoms for 2-5 years. About another fifth (18.9%) had pain symptoms for less than a year and about a tenth (10.5%) of the sample for 1-2 years. The acupuncture group included more participants who were in pain for less than 1 year (25% vs. 14.5%) and also more than 5 years (57.5% vs. 43.6%), but fewer people who were in between those extremes (17.5% vs. 41.9%).

Length of Treatment. A majority (59.4%) had been receiving treatment from their current healthcare providers (either acupuncture or pain management) for over a year and two smaller segments (20.8% and 19.8%) had been receiving care for less than 3 months, or from 3 months to 1 year, respectively. When singling out the two groups, acupuncture patients were much more likely to be seeing their provider for over a year (81%), while pain management patients were more evenly distributed between less than 3 months (25.9%), 3 months to 1 year (31.5%) and more than 1 year (42.6%).

Table 4: Sample Characteristics - Full Survey Sample & By Pain Management and Acupuncture Patient Subsamples

		Survey Subsamples		
	Survey Sample (n=98)	Pain Mgmt (n=55)	Acupuncture (n=44)	
Age				
18-25 years	7.2%	7.3%	7.0%	
26-35 years	10.8%	14.5%	7.0%	
36-45 years	20.9%	25.5%	16.3%	
46-55 years	23.2%	25.5%	20.9%	
56-64 years	19.2%	12.7%	25.6%	
65+ years	18.9%	14.5%	23.3%	
Gender				
Female	72.2%	74.1%	69.8%	
Male	27.8%	25.9%	30.2%	
Ethnic/Racial Background				
White, Caucasian	91.7%	86.8%	97.7%	
Black, African-American	2.1%	3.8%	0.0%	
Hispanic, Latino	6.3%	9.4%	2.3%	
Education				**
High School Diploma	42.3%	59.3%	20.9%	
Associate's Degree	18.6%	25.9%	9.3%	
Bachelor's Degree	13.4%	5.6%	23.3%	
Graduate Degree	25.8%	9.3%	46.5%	
Household Income				**
Less than $50,000	38.9%	49.0%	25.6%	
$50,000-$99,999	30.0%	35.3%	23.1%	
$100,000-$149,999	16.7%	9.8%	25.6%	
$150,000 and over	14.4%	5.9%	25.6%	
Average Pain (10 point scale)				**
Mean	5.65 (2.44	6.8 (1.9)	4.1 (2.3)	
Duration of chronic pain symptoms				
Less than 1 year	18.9%	14.5%	25.0%	
1-2 years	10.5%	16.4%	2.5%	
2-5 years	21.1%	25.5%	15.0%	
More than 5 years	49.5%	43.6%	57.5%	
Length of treatment time				**
Less than 3 months	20.8%	25.9%	14.3%	
3 months to 1 year	19.8%	31.5%	4.8%	
More than 1 year	59.4%	42.6%	81.0%	

* *p* <.05. ***p* <.01.

Interview Sample Characteristics

Interview participants included 20 acupuncture patients experiencing chronic pain. The participants in this sample were largely drawn from the survey sample; however, due to shortage of people who wanted to contribute to the qualitative portion of the study, additional participants who had not completed the survey-questionnaire were recruited as well. The age of the participants in my sample ranged from 24 years old to 83 years with a mean age of 58 years old. In total, 15 women and 5 men were interviewed. Nearly the entire sample was Caucasian and only 2 people were of Hispanic descent. Education was skewed toward college education as more than half (11) of the sample had graduate degrees and an additional 3 had Bachelor's degrees as their highest degrees earned. The remaining participants (6) had high school diplomas as their highest educational degree achieved. As one might assume, the demographic characteristics of the acupuncture patients in this qualitative sample mirrors that of the larger, surveyed subsample of Acupuncture patients, giving me the ability to compare these findings from the qualitative sample to the survey sample.

In the survey sample, we did not know what ailments or injuries the patients had or the symptoms they experienced (aside from pain generally). The interview sample represented a wide variety of pain conditions, including muscular pain, migraines, sciatica, arthritis, hot flashes, spinal stenosis, nerve damage, and fibromyalgia. The chart below (Table 5) shows the various types of ailments or injuries that each interview participant experienced.

Table 5: Summary of Patient Gender, Age and Pain Symptoms

ID:	*Gender:*	*Age:*	*Type of Pain:*	*ID:*	*Gender:*	*Age:*	*Type of Pain:*
Amber	female	58	Joint pain & neck pain	Richard	male	76	Chemo side effects (gastro), Shoulder pain (arthritis), stuttering
Jane	female	64	Migraine, pain in neck	Nancy	female	80	Sciatica, arthritis, scoliosis, gastrointenstinal
Francis	female	39	Sciatica/calf pain	Daphne	female	61	Hand, back and neck pain
Courtney	female	24	Migraines	Georgia	female	37	Migraines, PMS
Beatrice	female	59	Neck pain, shoulder pain	Jill	female	54	Hot flashes brought on by chemo, joint pain, trouble sleeping
Gabrielle	female	66	Rheumatoid arthritis, headaches, divardiculitis	Jacob	male	62	Low back pain, shoulder pain
Keith	male	37	RSD, nerve damage	Fred	male	70	Bulging discs
Laurie	female	36	Neck, face pain, headache	Heather	female	76	Neck pain, IBS
Melissa	female	83	Pelvis/hip pain	Amy	female	72	Muscle pain
Matthew	male	63	Spinal stenosis	Samantha	female	45	Fibromyalgia

It was difficult to envision a picture of what life is like with chronic pain using survey results alone, but interview data provide a rich description of daily experience with persistent pain. Only two of the participants were retired from work at the time of their pain occurrence and eighteen people were working during the time they had pain (several retired from full time work in the years that followed). Their working status did not mean that their lives were not affected by their pain symptoms. To the contrary, much of the patients' reflections of their symptoms tell a story about how their everyday lives were disrupted and hindered from their normal, or before injury/illness, state.

Constancy, Disruption, and Coping: For many, it was a constant struggle and learning process to be able to manage their pain and be able to not make their pain worse by doing too much physically. For example, Melissa, who had an injury to her pelvis from a fall, describes the severity and persistent nature of her pain, “It was constant pain. You couldn't sit. You couldn't stand. You couldn't lay down. You couldn't turn over. It got to the point where the pain was really...I don't take drugs. If I took an Advil that was my drug of choice. There's no surgery for a fractured pelvis. It has to just get better by itself. From that day on, I have never been pain free. I have it. It's there. I live with it.” Melissa’s final statement conveys the difficulty of living with pain that would not go away, a sentiment expressed by many interview participants.

A few of the respondents suffered from migraine headaches, and for Courtney the consistency of her headaches intruded upon her life extensively. In a conversation about her history with migraines, she explains:

> Courtney: Yeah, every single day. I wouldn't be able to drive. I wouldn't be able to open my eyes until they were over. That was a lot of stress and a lot of neck pain and head pain. I didn't go to acupuncture until only recently. I'm wishing I would have. Yeah, I was miserable. I was barely going to work. I was barely doing anything. I would skip out of going to events. I used to snowboard a lot, and I couldn't do snowboarding. All the medicines just didn't make me feel right at all. I had to bail on school because I couldn't go, and I couldn't pay attention. It was a vicious circle.
>
> MC: How did you get through?
>
> Courtney: Sleeping, that was a main thing, just laying down and sleeping because I would get dizzy, nauseous and I would throw up. No one knew what was going on. I went to the hospital twice and they didn't do anything and I felt like I was going crazy.

This excerpt from our conversation illustrates her pain, but also her coping skills which included sleeping and essentially retreating from her daily, beloved activities. While these women had constant pain in one place, Samantha, due to her experience with fibromyalgia, had multiple, unpredictable types of pain that could be really disruptive in a different way. She said, “With Fibromyalgia pain, it migrates around...It's anywhere it wants to be at any particular time. It seems to me, if you injure something, with Fibromyalgia you'll have pain in that spot on and off maybe forever. Plus, you'll have some other weird pains moving around. Like my neck, or my wrist will act up, or my arm. You'll also have this migrating pain, this kind of stabbing pain that migrates around. There's no rhyme, or reason.” This statement underscores the complicated nature of not knowing what to expect, which was not limited to living with fibromyalgia. Even when people knew where pain would likely be located, they may not know when pain could strike. In describing her experience of constant pain, Nancy, someone with scoliosis and sciatic pain, also indicates an incident when her physical state became worse and left her unable to do the normal things that she always did. She said, “It's really the sciatic pain. Constant. It was excruciating. But the main reason I went to her [the acupuncturist] first was because of my neck. I have scoliosis and stenosis, and arthritis. Last year, my neck was down to my waist, I was in such pain. Yeah. I couldn't drive because my head was down. Could not drive at all.” It is also important to highlight that the disruption of everyday life that participants described also included ramifications to their paid work and relationships. Jake described how his shoulder injury affected not only his livelihood, but also his mood:

> Maybe if had an office-type job or was that type of an individual, I think I'd be fine. But I teach yoga, I practice, I run. Yeah, like when I do certain yoga poses taking my arm behind. That external rotation and lifting I can't do, but it's not

> normal. It's out of the normal range of motion. I've lost that. I talked to Peter [the massage therapist] about it, and he showed me what to do, some exercises to do, but it just brings on the pain. It creates the pain cycle again. So I do it today, I can do it, then tomorrow it's like, "Oh man, now I don't feel right." It affects lifestyle in that I'm not myself. Someone will say something and I'll answer, "No! No!" I get short. I get a little cranky, because I'm not level anymore. I'm a little tweaked.

In this case, Jake's work requires the use of his body and the ability to demonstrate yoga poses with ease. While not completely incapacitated, he could not be at the top of his game which was distressing and difficult for him to accept. Others with whom I spoke had even more debilitating injuries that rendered them unable to work at all. Fred tells the story of his on-the-job accident that left him incapacitated:

> I had back problems but not real severe until I took a bad fall here in 2008. I fell off a pole 21 feet and landed on my side onto this rock and everything got moved, I guess. From that point on, I've been bad, so pain ranged as a high I would say 10 for months and then in 2008 between now it varies anywhere from where I would say on a really good day it's a one. Back in 2008, I was bedridden from May until October. Then I slowly was able to walk again and I walk better now than a few years ago. Now, I walk more than two blocks, maybe three tops. Some days are worse, but it depends on if I try to walk past my limit because then it just gets worse. I walked a few hours, pushed myself, and I was crippled for a few days. I mean crippled, I couldn't do nothing. I couldn't walk so I had to sit. Actually, with the acupuncturist, I always walked down the stairs backward and I'm able to walk down the stairs forward now. Yeah, I'm afraid because the sciatica and the leg lets go until now. Going backwards feels different and I figure that if the leg lets go then instead of going forward, I'll fall into the steps.

Fred's mishap also highlights the great lengths that some people had to go through for recovery as well as the potential for future damage as a result of the instability of their conditions that makes them vulnerable to more pain and more rehabilitation.

Some people had chronic pain that was relatively short lived, but no less severe or troublesome. Francis experienced a debilitating pain in her leg that was diagnosed as sciatica by the emergency room:

> I had the pain in my calf, but it didn't affect my life at all except there was a little pain in the back of my calf. I had a few acupuncture treatments. I figured there must have been something a little out of line and this will fix it. My pain lasted for April, May, June. It lasted for three solid months before it imploded. My leg, it started shrinking and turning white. I couldn't walk on it. I couldn't stand up in the shower. It was useless. It was as if someone put a Q-tip there instead of my leg. I need to take a shower, and I can't stand up.

With the help of an acupuncturist, Francis recovered in about nine months of the emergency room visit and no longer has pain in her leg at all.   Most of the patients had not been as lucky; about three-quarters of the sample experienced long-term chronic pain.

Enduring and Adapting to Pain: A few respondents redefined chronic pain in that they endured physical discomfort for large proportions of their lives. Richard, for instance, developed osteoarthritis in his shoulder blades in his 20’s and it wasn’t until he was in his 70’s that he began having acupuncture treatment, which was initially sought after because of side effects of chemotherapy. He describes, “I had gotten used to the discomfort in my shoulders after 50 years….I knew what I could do and what I shouldn't do when I was reaching for things and trying to lift things. I just learned to live with it. Then, when the cancer hit, that took away all my thoughts of everything else and concentrated on just the problems with the cancer.” Richard’s case not only shows how pain can fall into the background and simultaneously be present in everyday life, but also how other, more pressing medical issues can trump the pain at least in the short term.   Gabrielle was another person who suffered from long-term rheumatoid arthritis in many of her joints. The following excerpt of our conversation shows her adaptive capacity as she learned to rearrange her schedule in order to compensate for the way that the RA affects her throughout the day:

> Gabrielle: I can't do anything early in the morning, because I can't move. I'm back to where I was. Yes, as you move, it gets better. That's why at night, I'm up until 1:00, 2:00 in the morning, because it's the only time that I can actually move around.
>
> MC: Is it mostly in your hands, or all over?
>
> Gabrielle: The smaller joints are affected the most. My feet are deformed. The toes are just rotting on top of one another. It just really attacks, and also attacks your dominant side. The right knee is the worst. Of course, I had a skiing injury back there. It attacks something that's weak, and then your dominant side. The right elbow. The hand is the worst. This one is very bad. It's called swan neck. Why that's worse in that finger is because I kept breaking the finger, and they found out the disease was eating away the bone. This was about 40 years ago, before RA hit. So they used the bone in my wrist to put it in my finger. So of course now RA is going to attack that, because it's a weak area. It's called "Search and destroy," and that's exactly what it does, until you're finally crippled. In fact, I used to plan how much can I get done in few steps. I would lay it out.
>
> MC: So, you have to be really strategic.
>
> Gabrielle: Exactly. I can remember planning everything [when going to walk across the room]. We're going to do this to this step and this to this step. Couldn't even sleep at night the pain was so severe so no rest at night.

Gabrielle’s comments reveal, as did the majority of the patients’ interview transcripts, how she makes two assumptions: (1) Pain will be present on a daily basis; and (2) Effort must be made hourly to minimize the pain. However, the effort to manage their pain can be wrought with tensions as they continue to navigate in both the regular world in which they have responsibilities such as employment and relationships as well as in the medical world, in which they hope to understand their pain conditions better and find pain relief.

Difficulty of Diagnosis

Given the wide variety of pain symptoms, it is important to understand how the patients came to be diagnosed with their conditions (if they were) and whether this process was straightforward or not.

Hypothesis one: Acupuncture patients have experienced more difficulty in getting a diagnosis than their pain management counterparts.

Table 6. Difficulty of Getting Diagnosis by Treatment Type

	Treatment Type		Significance Tests		
	Pain Management	Acupuncture	Test Statistic	p-Value	df
Time to diagnosis			χ2=5.394	0.067	2
Right away	23.5%	40.5%			
Short time	51.0%	27.0%			
Long time	25.5%	32.4%			
Number of health care providers seen prior to diagnosis			χ2=14.438	.002**	3
1	24.1%	45.0%			
2-3	57.4%	27.5%			
4-5	14.8%	7.5%			
6 or more	*3.7%*	20.0%			

**p*<.05. ***p*<.01.

As Table 6 shows, while the majority of pain management patients reported receiving a diagnosis in “a short amount of time” (51%), the acupuncture patients were fairly evenly distributed among the categories of receiving a diagnosis “right away” (40.5%), in a “short amount of time” (27%), and in a “long amount of time” (32.4%). A chi-square test was used to assess differences between type of treatment and time until diagnosis. These differences were not found to be statistically significant (χ2 = 5.394, p = .067, df = 2).

As shown in Table 6, acupuncture patients report more variation in the number of healthcare providers they have seen prior to diagnosis than their pain management counterparts. Acupuncture patients are split between people who have seen very few care providers and very many care providers in search of a diagnosis. Almost half reported seeing only 1 healthcare provider (45%). The other half were distributed among 2-3 healthcare providers (27.5%) and 6 or more healthcare providers (20%) before receiving a diagnosis for their pain. Most pain management respondents had seen 2-3 healthcare providers (57.4%) and another quarter (24.1%) of the sample saw only 1 healthcare provider prior to diagnosis. Few pain management patients had seen six or more healthcare providers (3.7%). A chi-square test was computed to evaluate differences between type of treatment and number of healthcare providers prior to diagnosis. A statistically significant difference was found at the .01 confidence level ($\chi2= 14.438$, $p = .002$, $df = 3$). Acupuncture patients are more likely to have seen more healthcare providers. These findings should be viewed with caution given that one cell in the crosstab had an expected count of less than 5, making the test-statistic and p-value less dependable findings. Given the measurement of the variable, no merge/collapse technique was available to remedy this problematic outcome.

Results of these tests, while marginal, suggest support for hypothesis 1. Acupuncture patients reported more variation in their care-seeking histories than pain management patients. However, it was unclear from the survey if chronic pain users of acupuncture could be typified with regard to how difficult it was to diagnosis their symptoms. Thus, in the qualitative approach, I sought to uncover more about what this process entails and why it seems difficult for some to receive a diagnosis and not for others. Is it solely an issue of the type of pain symptoms that these patients have? What are the forces at play that influence the way in which people find diagnoses? Findings from the interview suggested that the process of getting a diagnosis varied for this group too. Some had a straight forward medical encounter and others had elusive answers and winding journeys toward diagnosis.

In an effort to understand their pain and find resolution for it, all of the interview participants reached out to healthcare professionals – whether they were medically or alternatively oriented – for expertise and advice. Despite having various kinds chronic pain symptoms, more than half of the patients that I spoke to were diagnosed early in the course of their illness/injury. These people suffered from migraines, arthritis, hot flashes, bulging discs, scoliosis, rotator cuff tear, sciatica, and neck pain. I asked Matthew, who has spinal stenosis, if there was ever any trouble in finding out what was causing his pain and he responded, “No, when they took the MRI, they could see that it was spinal stenosis, that's all. Between L2, 3, and 4, it was a bulging herniated disc. When you've got that in your spinal canal, that's what happens.” This story of diagnosis seemed pretty straightforward, without confusion and relatively quick. The without difficulty type of diagnosis tended to include a visit to a specialist, a look at the MRI or x-ray and then case closed.

Elusive Diagnoses

For seven patients, however, this was not the case. This other group of patients faced situations in which the diagnoses were not initially clear or they received misdiagnoses – both of which delayed the process of finding resolution or pain relief. These people suffered from Fibromyalgia, arthritis, migraines, nerve damage, and arm/hand numbness. The time between the start of pain but before diagnosis, which varied substantially for the people to whom I spoke, was sometimes significantly lengthened by seeing multiple care providers, which included various kinds of specialists depending on the afflicted body part(s) and numerous forms of diagnostic testing in search of answers. As can be imagined, managing the appointments was itself a time-consuming endeavor. Samantha, a woman who was diagnosed with fibromyalgia, describes her journey to diagnosis:

> I did see my regular doctor. I was mentioning to him all of these different pains I was having and he suggested physical therapy. There was no testing or anything. He just said, "You could try physical therapy." I went for physical therapy for...I don't know how long I went, honestly. It was a long time ago. I did go for that and that wasn't really helpful. Then I was having the pain still. Then he sent me to a rheumatologist. It took, for a specialist and all, probably a few months to get an appointment with that guy. Meanwhile, I had gone to another rheumatologist and got diagnosed with fibromyalgia. Then I had my appointment with this specialist who had given me...God, I can't remember how many x‑rays he did...probably 36 x‑rays and blood work. He also diagnosed me with fibromyalgia. He also said you have some arthritis in your knees, like typical things that people would have. My neck, I always had pain in my neck since I was 18. First my neck, but then all these other ones on top. He was really the first one that started treating me for that.

Notice how Samantha's timeline includes wait times to see a specialist but also delays from going to physical therapy, which seemed to be used as a "catch all" for her ambiguous pain. Georgia similarly said that her diagnosis of migraines came after months of trying to discern what was wrong. She explained, "I've always suffered migraines since I was...They started when I was in high school, really badly. I went to a neurologist and they thought I had a brain tumor because they were really bad and paralyzing. The diagnosis of migraines took months, after they did CAT scans and all kinds of tests. Then when they couldn't find anything they tried out some migraine meds like Imitrex...when the pain stopped they said it was migraines." Jane too encountered a whirlwind of specialists when she described how her diagnosis went after suffering stroke-like symptoms that left her unable to speak one day at work:

> They took me there [to the hospital] and did all sorts of tests and could not find anything. Did MRIs and electrocardiograms and cardiograms and dyes and scans and everything, couldn't find anything. Now, what happened, then, is after a period of time, I don't think it even lasted a day, they had given me migraine medication and they concluded it was a migraine, because it was nothing else. It was really to try to label it. But they had eliminated everything else, because these tests showed nothing. There was no sign of stroke. There was no sign of heart condition, nothing. So I went from one pain doctor to another. I went to a neurologist, I went to pain management places, I went into the city, just trying to find out what it was. They didn't know how to label it, so they called it a migraine.

For Georgia and Jane, it appears that there was a process of elimination that led the doctors to the final pronouncement of migraines. Not only does Jane's story exemplify what happened to so many of my other participants with the search for the diagnosis that includes multiple tests and doctors, but it also brings to the fore the idea that patients might not feel fully confident in the label or diagnosis they have received. In another case, Keith was hit and dragged by an ATV while on duty as a police officer. With multiple injuries, he describes his pursuit to be diagnosed with additional pitfalls such as an early misdiagnosis of his injuries as well as time consuming bureaucratic procedures that slowed down the payment for his surgeries:

> Shattered my left ankle, so I had a bone graft on that. They took the bone out of my hip and rebuilt that. Then I had the right knee surgery because that fractured down the middle and it was all bone fragments underneath. None of these things were found at the emergency room because they didn't X-Ray them. The mother of the kid [who hit me] was a nurse, and very politically connected. There was a lot of, "Get me out of the hospital right from the start." They said, "Soft tissue damage," and sent me home. I got carried out of the hospital. They didn't even give me a wheelchair. I had two other officers carry me to the car. This knee, I had to go to my own doctor and he x-rayed everything. This one, fractured, dead down the center, and all the bone fragments were under there. Then because they didn't discover it in the hospital, I had to wait months before Workman's Comp would approve everything. I was hobbling around on it, crawling. It ended up wearing out my knee more. Then they had to re-groove everything. They removed the kneecap, ground everything down to make a new channel, and then put it back. Then from there, I went to an orthopedic surgeon.

> The orthopedic surgeon, he couldn't do the bone graft, so he said, "I don't want to do your knee now and not be able to do the bone graft." He goes, "Let me send you to another orthopedic surgeon." He would only deal with cadaver bones. He wouldn't use my own bones. I had to find another... They said that I had to go to the back doctor, and they looked at everything. They're the ones that...when I was laying on the table, my wife goes, "It just doesn't look right. His legs are two totally different sizes." The back doctor was like, "I don't want to say what I think it is. But I think you have a more serious problem. You need to go to a neurologist." With the neurologist, they did the PMG, the thermal scans, the whole...and they're like, "You have RSD. Sorry. There's really nothing we can do for you except give you medication to try to make the blood flow better and all that type of stuff."

As this interview excerpt suggests, patients can be bounced around in the system and become quite frustrated or disappointed with the end result. As was the case with Keith, hearing that he had nerve damage was discouraging because the prognosis for getting better was not very positive.

Additionally, there were a few cases of people who never received diagnoses from their physicians. Although they were examined and had diagnostic tests done on the afflicted area, for different reasons, the cause of the pain could not be pinpointed. Richard, a man who experienced pain in his shoulders, went for nearly 50 years without an answer for what was wrong with his shoulders. He describes the reaction from the specialist:

> Actually, I went to the student clinic. The head of the clinic recommended that I see the team physician that would come for the football games. He'd come out of Oklahoma City to watch the Cowboys play the football game. They took X-rays of my shoulder and I brought them up to the team doctor. He looked at them and said, "Well, we can't do anything for you." He didn't tell me what was wrong. He just said, "We can't do anything for you." That left me kind of OK, here I am. That was back in the 60s.

Daphne had a much more involved and complicated history with regard to tracking down the cause of her arm pain and numbness. In her case, she was passed from physician to physician, who one by one abdicated responsibility for her problem because it was not within their area of expertise. In this lengthy excerpt, she describes this confusing time in her life:

> They were trying to figure out all of the things that were wrong. First I was sent to a neurologist and they did an MRI. There was a concerning MRI of my skull and my brain. My husband, being an MD who read it, asked a friend of his to look at it. The friend said, "I don't agree with that" and he rewrote it and sent a letter to the doctor I had an appointment with for neurology before I ever saw the guy. I walked in and the guy said, "Why are you here you just saw somebody?" That was my introduction to finding an answer and pain management. There were a lot of disturbing things because my left hand would let go of things. There were a lot of symptoms that were very like stroke sort of symptoms. They were very frightening. It turned out that the neurologist was very bad. He was just not listening to what I was saying. He said, "I think you're having deep seizure something," so he set me up with this big, long expensive thing. I didn't have seizures and I didn't think that I was having seizures, but whatever. I think he wasn't really listening to what I was saying to him. Then he said, "You're still complaining that there's things going on with your hands and your arms and you get dizzy, so fine I'll do a nerve conduction study." They fooled around with that for a month because they were stealing somebody from Stony Brook. They didn't have someone on site, so they had to negotiate getting somebody to come off hours. I finally went and I got a call the next day from the guy saying, "I have to recheck this. This can't be right." There were a lot of low electrical signals to my hands, in both arms, starting way at my shoulders and going down. He said, "Obviously you have a severe Carpal Tunnel, or maybe this, or maybe that, so you have to go to a hand guy." I go to the hand guy and he started listening to my symptoms and reading my chart. He goes, "No, this is your neck. I'm not touching you. I'm not talking to you. You have to make another appointment." So a month later... So this is like four months of garbage. A month after that, the neck guy sees me, and he take all sorts of x-rays. They re-did a lot of things which was very annoying to me. Like one guy's here and one guy's here. And they re-did everything, and then they had an argument about whether it was the places in my neck that were causing the hand tingling and the dizziness, or was it the thing in my hands, and they couldn't decide. And the neck guy goes, "Well what do you want me to do? I'm going to send you back to the hand guy, and he can try shots in your hand, and that'll make it go away if it's your hand and then if it's not come back to me." You've spent four months of my life throwing me back and forth and making me A, frustrated [laughs] and B, probably increasing my symptoms with all the nonsense!

While remarkable for revealing the long, draw out process of searching for a diagnosis, or even a reason for the pain that Daphne felt, this interview segment also poignantly points to the stress of navigating the health terrain in the process of getting help. Several people felt that they were "going crazy" because doctors did not know what to do with them. The impact of a difficult diagnosis not only goes beyond having additional months of pain but also includes the emotional impact of not knowing what is wrong or how to fix it.

The survey results about diagnosis showed no discernible pattern that could be found for the acupuncture patients for whether it was more difficult for them to receive a diagnosis. For some people, it took a long time and many physicians and for others, a short time and fewer physicians. The qualitative supplement of this research is fairly consistent with the survey. Slightly more of the interviewed people encountered quick diagnosis, while slightly less than half of the sample faced a more challenging process to diagnosis. This could be partially due to the nature of their symptoms, but also points to flawed aspects of the medical arena. A frequent complaint among the participants who found it difficult to find a diagnosis was that they were sent to various specialists to no avail. In Daphne's case, she saw many specialists who only had expertise in certain organs or appendages and could not draw conclusions independently. At the end of her story, she exclaimed, "They all knew that there was something wrong. They all had x-rays and whatnot. Where's the orthopedic person that can treat my whole body, please?"

In nearly all of the difficult-to-diagnose cases, the patients were persistent about following the referral chain, or reaching out to new healthcare providers if they did not reach a diagnosis in their first attempt at finding one. Two of them were finally diagnosed by acupuncturists, when the conventional approaches did not find reasonable explanations of their symptoms. But for the vast majority of this sample, seeking out acupuncture was for the purpose of finding pain relief for previously diagnosed conditions (whether they took a long time to be diagnosed or not). The difficulty of finding pain resolution will be addressed in the following chapter.

Naturalist Orientation towards Healthcare

Hypothesis Two: Acupuncture patients will exhibit a naturalist orientation towards healthcare, as indicated by use of fewer medications and more homeopathic remedies than will pain management patients.

Table 7: Use of Medication by Treatment Type

	Treatment Type		Significance Tests		
	Pain Management	Acupuncture	Test Statistic	p-Value	df
Number of medications			t=4.34	.000**	95
Mean (s.d.)	2.6 (1.5)	1.4 (1.3)			
Use Homeopathic remedies			χ2=26.027	.000**	1
Yes	5.6%	51.2%			

**p*<.05. ***p*<.01.

An independent-samples t-test was conducted to compare the number of medications used for survey respondents in different treatments (see Table 7). Pain management patients used more medication types than the acupuncture patients (pain management mean=2.6, standard deviation=1.5 vs. acupuncture mean=1.4, standard deviation=1.3). There was a significant difference in the number of medications used for these groups (t-statistic = 4.34, p = .000). To see if there was a significant difference in the use of homeopathic remedies among the two groups, a chi-square test was calculated. As shown in Table 7, while very few (5.6%) of the pain management patients used homeopathics, over half (51.2%) of the acupuncture patients used them. This difference was found to be statistically significant ($\chi2$ = .001, p = 26.027, df = 1). With these two tests, it can be concluded that hypothesis two is supported by the data. Acupuncture patients use fewer medications than pain management patients—almost by half. The use of homeopathic medicine suggests an inclination or preference toward natural approaches to medicine.

As a supplement to the quantitative findings, the qualitative interviews explored how people make the decision to use or not use prescribed and homeopathic remedies. Among the acupuncture patients, speaking about medications was an inevitable and significant aspect of the interviews. Most every participant had taken prescription medication at some point for their chronic pain, whether it was a pain reliever or something geared at suppressing the condition causing pain. Their evaluations of medications, however, were not typically positive as almost everyone expressed a tendency to use medication sparingly. There were, of course, a variety of perspectives on medication from those people who saw benefit in using medication to those who were strongly opposed to taking anything, but present in most discussions was that using medications was often a frustrating occurrence. Most of my interviewees did not have reliably effective medication that helped with their pain condition and most of their explanations revolved around what did not work and what had bad, and sometimes debilitating, side effects. That list included: feeling “out of it” and other perception problems, having dental problems, having digestive problems, and having long term damage to the organs. Those with opposition to medications cited additional things such as concern about addiction, a belief that medication is only masking the problem (not healing the underlying problem), and feeling overloaded with medications as reasons why they were hesitant to use them. First we will look at examples of when medication had no benefit for the patients.

Fruitless and Harmful Medication Use

Francis was prescribed medications for her sciatic pain and she describes the outcome:

> They're like, "Take a Valium to relax," because if you relax, your leg will relax. I hate taking medicine. But they said, "It's just a little bit. It's just going to make you sleepy." They gave me that. They gave me muscle relaxers and they gave me Naproxen, which is just like Aleve, but a stronger, bigger dose of it. [I] take the Valium. I'm sleepy. I take the muscle relaxer. They say, "You might need to take a couple, because your pain is so severe." But you have to take it four hours apart. I take it, but none of my other muscles worked. I couldn't stand up. I couldn't hold a pencil. My muscles were so relaxed I was useless, except my leg still hurt. [laughs]

A number of people felt the same way. The medication just did not help. Jake, a retired construction worker and police officer, dealt with low back pain for over 30 years. He explains his attempt to treat it at pain management. He said, “She [the doctor] says, osteophytes, I guess it's called, or arthritis on the end of the vertebrae, just the beginning of arthritis. She recommended some cortisone shots. I went through one set of cortisone on my back. It really didn't work.” While receiving no benefit from medications was one kind of reaction, a more common reaction was adverse effects. This ranged from physical to psychological side effects and often further inhibited people’s daily lifestyles. Jane’s recollection of the medication that she took for migraines and neck pain reflects that the medication did not help her and that there were physiological and psychological effects:

> So I went from one pain doctor to another. I went to a neurologist, I went to pain management places, I went into the city, just trying to find out what it was. Every

> doctor gave me another color medication, I had pink pills, blue pills, green pills, every kind of pill that you could take. I was walking around and feeling like I was having an outside of body experience because I was on all this medication. One day I was driving home on the express way from a meeting that I had to attend in Garden City and I realized that I had no spatial awareness. I have lived where I had all these pills, these muscle relaxers and stress pills. I was popping pills, and I still had pain. So, I know that that was not the total story.

Another example of someone who felt the side effects were on par or maybe worse than the original pain symptoms was Georgia. For many years, she took prescription medication for migraines. The migraines were debilitating, but so was the medication:

> At that time, in the 90s, you would just take this really crazy medicine that basically just numbs you like shots, and these little things that dissolve under the tongue. They would take the pain away, but you would be a zombie for the next three days. It was odd, you didn't feel any pain, but you felt like sometimes they just press on your temples, and you're really stoned for three days. So, you can take this crazy medicine and it'll just dull the pain, make it bearable, but still you're a zombie. These medicines are just awful. In high school and in college, I was taking these medicines a lot. Finally, they were so paralyzing that my neurologist said just take Aleve, but don't take the two pills, you can take up to six. Again, it would dull the pain, but it messes up your stomach, this whole thing.

For Georgia, it was a tradeoff. She could rid herself of the pain of migraines but would have to pay the consequences with other side effects, one of which was stomach issues. Several people mentioned digestive problems with regard to medication use. Heather tells how the prescription medications had prompted gastrointestinal problems:

> Well, I really never took any medication for anything major until I was about, I guess, maybe mid-40s, and that's when I started to have some high blood pressure. That was a shocker to me. I remember sitting in the doctor's office and saying, "You mean I have to take this pill for the rest of my life?" I had never liked taking prescription medicine, but I guess you really have to. And then I would have side effects from some prescriptions. I had a lot of gastrointestinal problems. I had IBS, irritable bowel syndrome. Whenever I'm prescribed a different medication, right away it affects my digestive system, and I get some

> bloating and some diarrhea and some gas and everything else. That's why I really hate to take prescription medicine. … I think doctors...and I don't want to blame the medical society or anything, but you don't want to feel that as soon as you go to a doctor, they're going to say, "Hey, take this pill. Take that pill." I don't want to take all those pills. I don't mind taking vitamins and stuff like that, but these chemical pills, no, I don't want to do that.

Aside from digestive problems, people suffered other side effects. Jane described the reason why she approaches medication carefully when she said, "Through the years I have found out, I have a very low tolerance to chemicals in my body and prescriptions in my body. I have to be very, very cautious when someone hands me muscle relaxers and pills. I can't take the famous Z-Pak everybody takes as an antibiotic. Can't take that. It makes my heart palpitate. I still tolerate it so I hate when somebody gives me a pill as a way around it all and so I fear taking it because I know I don't do well with pills." This hesitation is something that developed over the years with exposure to different medications, and surely guides her in using medications sparingly.

Another type of adverse reaction to medication came from the reaction of multiple medications in patients' systems. Gabrielle, a retired school teacher with Rheumatoid Arthritis (R.A.), was on a considerable amount of medication at one point. She describes how drug interactions lead to the unfortunate side effect of losing her teeth:

> What it was is that, oh yeah, I kept getting dental problems, and I had gone to my own dentist, who's good friends with my oral surgeon, and they both put their heads together and had no idea what was going on. I was going for implants, one after another. I was losing my teeth. They would get so infected, I was losing them. I finally asked Vincent again and said, "What is going on? This pain I'm getting, it's constant. I'm losing my teeth left and right. Implants, I've had three of them, one after another." He said, "Bring in your list of medications you're on." And he said, "Who told you to take all this calcium?" You're destroying the natural calcium that you already have in your body by taking this extra. He said, "Stop all of that." I said right away, "Then I'll stop Calcitriol."

> Because that's a medication. He said, "For sure." Then I was just on calcium and Vitamin D only. That's been the end of all my dental problems.

The excess of calcium that Gabrielle had been prescribed was not all from one doctor so it was quite easy to unknowingly take an unnecessary prescription. With the help of the acupuncturist, she eventually reduced the amount of medications that she was taking drastically (more on this below). Like Gabrielle, Courtney also felt like the drugs that she was taking for migraines were interacting and in the end, hurting her. She also decreased the use of multiple medications with this realization:

> Courtney: I don't know what his title was. He was all the way in Manhasset, and coming from here it was far. You always had to wait like an hour and a half to see him, even when you made an appointment. He was always behind. Then I was in there it was only like 15 minutes. He wouldn't listen. He just put me on all these terrible medicines. They counteracted with each other, and it just wasn't a good mix. I was talking to Vincent about it, and he was like, "Try to get off of them. It's kind of toxic." I was like, "I agree," but the doctor wouldn't listen. So I went to my regular physician, and she weaned me off all of the medicine. Like the medicines were insane.
>
> MC: Tell me if I'm wrong. It sounds like you're averse to taking prescribed medications?
>
> Courtney: At first I was all about that. Let me try this. Let me try this. I'll try this. Give me anything. Then it was like, all right, these are toxic to my body. I saw everything it was doing to my body. I don't want to ever go back there. [Now] Every time I look up...when I'm taking a medicine I'm like, "Let me see the side effects? Is it good or bad? Is it going to be worth it? Are the pros going to outweigh the cons?" Now I'm skeptical about going on any medicines because of how bad it made me feel and how right he was. Every doctor is just like willing to write this [prescription] and not deal with the situation.

Courtney's explanation not only highlights how some people came to change their attitudes toward medications over time, it also points to a major complaint of the patients with whom I spoke. They felt like prescription pain medication was given out far too often in lieu of getting to the heart of the matter, or solving the source of the problem. Gabrielle (mentioned above) described her perspective toward medications and the people who proscribe them. She said, “I don't think I even have the list I once had. The only ones that I'm still on now, that Vincent said are important, is Armour Thyroid for a thyroid condition and Corgard for the tremors. Two prescription drugs. And I think I was on seventeen when I first met Vincent. Because doctors -- other kind of doctors -- are pill pushers. All of them are pill pushers. It's sad to say, even Dr. Clark, and I like her. But they're all pill pushers.” The concept of “pill pushing” was shared by about half of the acupuncture sample in which they felt pressured to take prescribed medication by their healthcare providers.

Fear of Addiction

While not as pervasive, some people did mention a desire to steer clear of medications for fear of chemical dependency. Jill took herself off of medication used to lessen the occurrence of hot flashes that came as a result of chemo-induced menopause. She described how she came to this decision:

> By that November even with the acupuncture and trying to meditate and all this, the flashing was just unbearable. I remember it was Veterans' Day or something, I called the doctor. I'm like, “That's it, I'll take the prescription”. I went on the Effexor, the lowest dose. Within two weeks half the flashes were gone. It was like this is so much better. But I broke through a few months later. By the following July I was starting to have more of them again. In fact I took myself off of it last fall. I went off of it because to cut them back again I would have to increase the dose and I didn't want to do that. Because those kind of medications, you get dependent on them and I just don't want that.

The prospect of having to continue for the long term and increase the dose of the medication was not something that she felt comfortable doing. Melissa was influenced by watching a close relative suffer with addiction and this experience led her to unilaterally resist the use of medications:

> I take vitamins and supplements, which I've been doing for years and years and years. I never ever take an antibiotic, even if I'm sick. I take all my natural stuff, my Echinacea and Vitamin C and Oscillococcinum. That nips it in the bud. … I don't take kindly to being told to take it. As Dr. Sue now knows. I feel it hurts you. My daughter is very ill. My daughter was an alcoholic and a drug addict… She's on you name the medicine. She's got colitis, she's got asthma, she's got an anti-depressant. She's got so many drugs that I say to her you have to stop, because what you're taking for this is killing you because it doesn't work with what that does. But when I see what she's become, that really turned me off to any kind of medicine. And she's going to die. She's 51 years old and she's bedridden. I just don't understand. In fact, when I had my hip replaced, and when I came out of the anesthesia, they were giving me morphine, and I said, "Why? Stop it." "But you're going to hurt." I said, "I don't care, I don't want morphine." They stopped it. So it hurts, but it goes away. It gets better. I don't like drugs, and I certainly don't like pain medicine. That to me is the worst, because it really clouds your mind.

Even in the face of surgical healing, Melissa refused pain medications (to the surprise of her care providers) due to her strong opinions about addiction and dependence.

Overmedicated

There were a handful of participants who were attempting to avoid medications, not necessarily because of staunch opposition to medication, but because they were overwhelmed with medications in other ways. Whether it was from childhood, or due to a current illness, there was a tendency to avoid medications in the pockets of places where they could. Interestingly, these narratives all linked in some way to cancer, which is known to require its patients to endure above average quantities of chemical medications. Jill shared her experience with taking medication during her bout with breast cancer:

> Oncology's a funny thing. It's really about giving people chemicals and stuff to try to get rid of things, and then they maintain. But it's all drugs. You go there and even when you have chemo, the first thing they do before you go is they give you something you've got to take for a week. Then the day before you go there you take something else. Then right before they give you the chemo they give you something so you don't get sick. Before they start chemo they give you

> something to calm you down in an IV. Then they give you something to help your stomach. It's a cocktail. Before they even started the chemo you've already had four things run in your bag. Then they start the treatments. Then at the end they give you something. Then you go home, and you take something to keep you from throwing up for a few days. After that, your counts drop so low they give you antibiotics so you don't get an infection. It was this very carefully orchestrated thing. You get a bag of drugs, medications, and you have to watch the calendar and take them all. It was this very typical thing. I had four cycles, so it was four times of that. But really that's what they do. I would call and I'd say ugh. "How was your first treatment?" "Well I woke up the next morning with this flaming rash. I was red like a beet." "Oh, OK, we're going to add dexa whatever to the next time before we go." Because it's a known thing, they put something else in there and then next time no rash. It's like that.

While immersed and sometimes overwhelmed by medications that controlling every outcome of her chemotherapy, Jill was resistant to taking an additional medication for hot flashes, a side of effect of the cancer treatments. She explains, “What they want to do right away when you have the really bad hot flashes is they want to put you on...There's different antidepressants that in a subclinical dose, the chemicals...It must alter that, must help take down whatever's causing the flashing. They kept saying you can go on Effexor. I'm like, "Oh, I don't want any more pills." In fact, avoiding more medication is how she initially decided to go to acupuncture. Richard, also a cancer patient, wanted to use acupuncture for the side effects of chemotherapy as well and indicated his resistance to added medication.

> I feel like I'm doing something good for myself [by using acupuncture]. The other thing I like about it is it doesn't involve any drugs. Now, from veterinary standpoint, I know I use drugs every day in my patients. I'm on a lot of drugs for different things. But this way is more of a natural way of trying to, maybe not cure things, but definitely help with the pain and the problems that are happening from all the stuff I've been taking. I guess that's why I feel good about it. No chemicals going into my body with this. I kind of like that.

For Amber, the decision to indulge in medication, after a childhood full of prescription medication for allergies that she believes suppressed her immune system, was even more extreme. She describes, “Then the doctor said, "Sometimes you just have to take the Advil, Ibuprofen or whatever it is to get the swelling down and that will help with the pain." I'm like, [groan] I don't take all that stuff…No because since I was four I was on medications every day of my life until I was in eighth grade. 12 years old. I had had it with being sick and taking medicine. Before I found out that I had the cancer, I had set my brain to myself and said, if I ever have cancer I'm never taking radiation.” And she stayed true to that belief. When she faced breast cancer, she had surgery but did not follow up with chemotherapy or radiation. Instead she took more natural routes to recovery (described later).

Masking the Pain

Sometimes the negative stance toward medication seemed to be rooted in a larger notion of the inability of pain medications to solve the problem. In other words, their opposition to medication was related to an opposition to placating the pain without reaching a resolution to the root problem. Courtney, who was mentioned earlier for disliking the effects of medication on her body, also commented upon her rationale for not using medication. She felt that the physicians who prescribed the medication to her were not dealing with the underlying issues causing her pain. She said, “That's how the other ones [doctors] were. Just hide it. Let's just hide it. Let's hide it." Matthew’s tendency to use medications sparingly was similarly rooted in the desire to want to get to the source of the matter. When asked if he takes medications for his back pain, he said:

> I have some pain pills if I want to take them. I got that originally from my primary physician, Oxycontin and some other kinds of things. I used it in the beginning, but I don't use it now unless I play a round of golf or something. Something where it really, really hurts. Then I'll maybe pop a pill, but not very often. I don't need to be taking Oxycontin every day, or some opiates. I'm Diabetic also, type

> two so I don't take a lot of Advil or anything like that either. … When you have chronic pain, the only alternative is to take some drugs and that only just numbs the pain, and it doesn't do anything to get it better.

Jake was also uncomfortable with the use of prescribed pain medications for the same reasons. For him, like Matthew, medication can only work to eliminate the pain in the short run and do nothing to contribute to its healing over the long term:

> I just feel what those medicines do is block the sensation. The injury is still there, but you can't feel it. Now you can just do what you want, but the injury is there. You don't feel it. You've deadened...made those receptors and pain go to sleep. At some point either you're going to be on the medicine forever, or you're going to stop the medicine and that injury's going to come back with a vengeance…I'm not big on the medication. I think it's a crutch.

Daphne also had the choice to take prescription medications for her arm and hand pain, but chose not to because she ultimately did not believe that it would make the problem better. "I don't take any sort of drugs for pain. I take Aspirin and whatever. I don't go that route. That was the other thing that the other people were like, 'Oh, well you should take muscle relaxants when you do this. You should have to take this prescription or that prescription.' That doesn't appeal to me because then you're masking what's wrong and it will not go away. It's because you're not actively working at it." Daphne conveys her dislike for medications and also points to another feature of what many others indicated. It takes more than medications to get better. It takes work to get better. For Daphne that meant doing a daily therapeutic yoga practice as well as utilizing acupuncture. It was not uncommon, in fact, for this notion of placating the pain to spill over into talking about natural alternatives to medications, which are often believed to be better at solving the problem. When I asked Keith about his aversion taking prescription medications, he said, "No, there's no need. If you have a headache then your body is telling you something, so go drink more water or do whatever you're supposed to do. You don't mask it, you fix it." Likewise, Jake continued to speak about his discontent with the pain management method of treating his back pain. He explained, "Because the pain management, it's just not for me. It's not for me. I just don't feel good about it. I feel like I'm poisoning myself a little bit. Yeah, those shots and stuff. It's not natural. It comes in, it does the job, but then you pay for it somewhere. You're fixing this, but what are you doing to the liver and the kidneys? I don't know, I just don't think it's good. Acupuncture is totally natural. The body is healing...I love that. The body is healing itself." For both of these men, the preference toward more natural approaches were clear and this reflected the sentiment for about half of the sample.

Natural, or Homeopathic, Remedies

So far we have examined the experiences that the respondents have had with prescription medications that have contributed to the cautious and conservative approach toward taking them. Now I will turn to looking at the ways homeopathic remedies fit into the lives of the acupuncture patients. Discussing natural remedies, in some ways, is a seamless discussion from speaking about prescription medications as many people expressed the desire to use medications frugally and natural remedies liberally. The choice between the two would certainly yield an easy decision for most of the people in this sample. Nancy shared with me her inclination toward the natural, should there be that option. She said, "Well, medications are good. But if I have an alternate, going holistically, I would do that. I think it should be a merge of eastern medicine and western medicine. Pain medication is good, but sometimes doctors are "OK, well, here, here, here." If you have a stomach problem like I do, I can't take all those medications." Jill echoes this desire for the non-medical, but for a different reason:

> I think that Chinese medicine has a place. It's been around for thousands of years. I have thought about it and when I go to the doctor now, I'm usually looking for a way to do anything that isn't taking more drugs. That's really what I would like now. Not to have to add more medications. I don't...you know, "Better living through chemistry." I know plenty of people who say that all time. [laughter] I just would prefer to...I guess I see it as a cleaner lifestyle. Not to have to take medications, to be able to take care of yourself, and heal yourself through sleeping, and eating well. I prefer that more holistic approach. That being said, would I be one of those people who found out she had cancer, and chose to go home, and eat Kale for six months? Probably not. [laughs]

Nancy is unable to take a lot of medications because of side effects and Jill, who has felt overloaded by medications due to her experience with chemotherapy, both have arguments for why the natural products are more to their liking. For the same reasons that people are avoiding or wishing to lessen their use of medications, they are looking toward homeopathics as an alternative or a supplement.

While not all of the study's participants used homeopathic remedies for their ailments, over half (12 people) of the sample did. Users of natural remedies spoke very differently about them in comparison to prescription medications. Natural remedies or herbal supplements, as they are often called, were not cast with the same suspicion or hesitancy as prescription medication, and they were mostly viewed positively and without consequence. Some people used them during a particular circumstance (i.e. an illness or a time of deficiency) and others firmly believed in integrating them into everyday life for an overall sense of health. A few people who exemplified the first were Laurie who used Chinese herbs and oxygents when she was recovering from her car accident and Georgia who took Chinese herbs during the period that she received acupuncture for infertility. Likewise, Francis used a combination of herbs during the recovery of her sciatic pain episode:

> But the good thing about Michelle is she does great things with herbs, so she gave me Yen deficiency which would make sure that my kidneys weren't so weak and dehydrated. She gave me the herb for the yen deficiency which she said was going to pump up my kidneys so that I would get more hydration. She told me to drink 32 ounces of water, is that a gallon? I think she told me to drink a gallon before I even got out of bed in the morning. She also gave me this powder that you scoop into water and you mix it. It helps you sleep and relaxes your whole body. That stuff was excellent, because I finally was able to sleep for the first time in three and a half weeks. That aspect of the treatment really helped a lot. I couldn't get that from someone who wasn't an acupuncturist or a herbologist.

In this circumstance, the use of the yen deficiency was discontinued once the injury was healed. Gabrielle, however, had come to use herbal supplements as a matter of course for both overall health, and for long-term ailments that she lives with. She explained and showed me when I spoke to her about what she takes:

> I take his herbs stuff and I order them myself now. The herbs are about all I take and maybe once in a while I might get into a Vicodin, maybe once every two months instead of every day. So thank heavens I met Vincent. I'm...all this herbal stuff. The list I show to everybody, medicines now... I think there are three that are prescription drugs and herbs are 20, all kind of herbs. In fact, I could actually show you. (Getting up from the kitchen table and leading me to a bureau in her bedroom where her medications were kept.) Come here. This, Vincent actually got me into -- excuse the room, I can't move the arm, I can't really make my bed anymore. And these are all my homeopathic stuff. Vincent got me into this stuff.

The previous two interview segments also reveal that several people were using homeopathic remedies in collaboration with their healthcare providers, which included not only acupuncturists and naturopaths but also general practitioners. Samantha, who had been seeing a physician for fibromyalgia describes how she came to use homeopathics: “My doctor that I'm going to for the fibromyalgia, I'm on the Neurontin still. She's had me on some other supplements. I also have things going for these IV drips of minerals and vitamins. Doing that every other week. It started out as every week. That's been helping fatigue levels and stuff like that. And a magnesium shot that's supposed to be for pain. I'm getting that also every other week.” So, Samantha was using minerals and vitamins in addition to her regularly prescribed medication. There are others who replaced their prescription medication with homeopathic remedies. Amber explained how she recovered from double mastectomy as a result of breast cancer using a homeopathic approach:

> The recuperation went pretty well because I was on this product, Select, which is a vitamin-mineral, nutritional type of a shake. It regulates your body chemistry according to the person that buys this particular product. He was a cancer patient for pancreatic cancer. He said, "I want to put you on a couple of things." One of them was olive leaf with colostrum and the other was a probiotic. He has a probiotic that has antibiotic resistance, which is good because when you have to take antibiotics and you take probiotics it cancels it out. His are probiotic with antibiotic resistance. Taking that.

While some patients were using natural remedies with the guidance of their healthcare providers, more prevalently others were investigating these remedies on their own and through informal paths, like asking for recommendations at the health food store. Melissa spoke adamantly about her daily regimen of homeopathics. She described for me the list that she takes regularly: “I take vitamins and supplements, which I've been doing for years and years and years. I never ever take an antibiotic, even if I'm sick. I take all my natural stuff, my Echinacea and Vitamin C and Oscillococcinum. That nips it in the bud. Strawberry rhubarb, I take. I take all my vitamins and all my supplements.” She was a firm believer that these homeopathic remedies keep her healthy and she had no recollection of any health professional telling her to take the items she listed. Still others believe that homeopathics can cure ailments as well. The person who probably best exemplifies this self-driven way of using natural supplements is Keith, who decided to take his health into his own hands when a surgeon told him he needed to have his gall bladder removed. He described his solution:

> Two shots of apple cider vinegar, and a teaspoon of honey afterwards. Did that every day for a year, and I ate no fat for a year. Gall bladder's healed. It's simple...You would think a gastroenterologist would have the knowledge of how to heal you, as opposed to cutting you. But if he told you to take two shots of apple cider vinegar and a spoonful of honey every day, he doesn't make $20,000 to cut your gall bladder out. Instead of saying, "Get some probiotics. Let's boost you up. Let's check your vitamin levels. Let's check your vitamin C. If you are deficient in anything, a month before the surgery we'll get all leveled out. Your body will be functioning properly. You won't need any antibiotics. You won't need the pain killers. You'll be healing twice as fast as anybody else.

A discovery that is perhaps not surprising is that the people, who were most against medical intervention, namely prescription medications, were ones most firmly in support of natural remedies. Also, discussions about homeopathics almost always lead to a broader discussion about how diet can affect and improve pain conditions and overall health.

> I sometimes drink these longevity smoothies or the anti-inflammatory smoothie. They all have turmeric or cayenne in it and ginger, these types of things. Apple cider vinegar and you make them into smoothies. It just tastes great, but I believe in that. I do that, and I take the vitamins. I go to the Vitamin Shoppe in Bellport Village because she is a yoga teacher and she's totally...If it's in her store, it's totally natural. It's a natural organic product, so I feel better going there. I take the supplements every day.

Notice how there is almost a seamless way of talking about nutrition and homeopathics. Another person who spoke about homeopathic remedies and nutrition inseparably was Amber who had a bit of novel approach when compared to the rest of the homeopathic users. She explained her recent change of perspective:

> I used to be a very big vitamin person. I researched a lot of stuff as far as what are the right vitamins for me to take. And also, my internist recommends the sort of things that…Let's say if I have a blood test, I might be deficient in or

> whatever. Or let's say something for my muscles or something like that. But lately, like this year, I've pared down a lot of things. I used to take vitamins...Calcium. I used to take calcium. Calcium, they came out with something this past year that women over the age of 65 should not be taking calcium supplements anymore because it can promote heart problems like hardening of the arteries, a stroke, and things like that. I don't drink milk but I do eat salads, leafy green vegetables. And then, you just have to be proactive at finding out what foods have calcium in it. I think, maybe almonds, and things like that. Walnuts are also very, very good for you. With vitamin E. There are certain things that you can do to promote health. So, you have to be knowledgeable, and a lot of my friends aren't. So that's that.

Amber, while clearly informed about what she should and should not put into her body, is the only person who expressed some hesitancy to taking a homeopathic approach, i.e. vitamins but it was in no way a condemnation of the premise of using a natural approach. Instead, she has replaced that idea of using vitamins with getting the nutrients from foods that she eats. Like Jake, she expressed a notion that there are more natural ways (through the actual foods or organic vitamins as opposed to synthetic pills) of receiving the benefits of homeopathics.

There was a strong inclination for natural approaches among this sample of acupuncture users who have chronic pain. About half of the sample integrated natural homeopathic remedies into their diet and lifestyle, many of whom made their own decisions (or without healthcare provider guidance) about doing so.

Proactivity in Healthcare

Hypothesis Three: Alternative medicine patients will exhibit more proactivity with regard to their healthcare compared to pain management patients (see Appendix C for psychometric analysis of the proactivity scale).

Table 8: Proactivity by Treatment Type

	Treatment Type		Significance Tests		
	Pain Management	Acupuncture	Test Statistic	p-Value	df
Proactivity self-efficacy scale					
Mean (s.d.)	3.5 (1.1)	4.1 (0.8)	t=-3.12	.002**	96

**p*<.05. ***p*<.01.

Acupuncture patients were more likely to feel confident in their ability to be proactive regarding their health (see Table 8; acupuncture mean=4.1, standard deviation=.08 vs. pain management mean=3.5, standard deviation=1.1). An independent-samples t-test was conducted to compare the means of patients' proactivity self-efficacy among the different treatment groups. There was a significant difference for these groups at the *p*<.01 level (t-statistic = 3.12, p = .002).

Strong support was found for the hypothesis 3, indicating that acupuncture patients judge themselves as more self-efficacious and self-directive with regard to the health. Acupuncture patients were more likely than pain management patients to rate themselves as proactive with regard to health.

While I did not directly ask the patients how proactive they were it was clear that they took steps to improve their health; steps that went beyond seeing physicians when feeling pain symptoms. These steps including changing their lifestyles, seeking out treatments for pain, and "taking on" health. Many of them were knowledgeable about how to take care of themselves and in fact saw acupuncture as being part of that plan. Amy explains the importance of doing what she can to benefit her health:

> I think patients have to do this themselves. They (doctors) give recommendations for somebody that maybe that you should try this or try that, but you have to be willing and open enough to do it. A lot of people aren't. So it becomes difficult for people, but for me I've always been this way. I am this way with my husband, finding alternatives for him, too, and trying to eat correctly. Sometimes it works and sometimes it doesn't work. But you try… you have to be knowledgeable, and a lot of my friends aren't. I don't even bother talking to them about it anymore, because if you're old enough to know what to do, and what not to do, and if they want my opinion, they'll ask me. So that's that. I'm very mindful. And I think that's what it takes for somebody to want to see an acupuncturist. If you're going to try to heal your body with acupuncture, you have to be intelligent enough to say, "What else can I heal my body with? What am I doing wrong? Am I drinking too much? Am I smoking? Am I eating too much meat or fatty, fried foods? What else can I do for my body?" Because I don't think that you can just go to an acupuncturist and say, "OK. Heal me." Maybe they could cure or maybe they could help me with my biceps or my calf pain that I have. But then you have to start to think what else I can do. I think that a lot of people don't do that. They would go to an acupuncturist and say, "I want you to heal me. I want you to take away the pain." But you have to walk the walk and talk the talk, so to speak. You have to do the work. You can't expect somebody else to do it for you…Yeah, I think that you have to be proactive, like I said before, with your own body, because if you're not proactive, nobody else is going to do it. You have to investigate things, by reading, by going online, by talking to people, and then find a program that really works for you so that you can live a healthy life. You have to. In order to survive, you have to evolve.

While it is unclear where Amy gained her proactive stance, it certainly seems that proactivity feeds proactivity. In other words, one act of exploring health alternatives leads to further inquiry. In addition, Amy exemplifies another important, perhaps self-evident, feature of proactivity – you do it on your own. While this does not mean that people are solitary in their pursuit to find pain relief, to be proactive takes individualistic efforts because it is not often the case that others will be focused on their wellbeing, even physicians. These are some themes that run through the dialogues with my participants.

Diet and Exercise

For some of the participants, proactivity came through in how they spoke about their diet and exercise. Keith, whose wife became a nutritionist partly as a result of his injury and ongoing health problems, talks about how he can alleviate some of his pain nutritionally. He said, “We try to eat a lot of anti-inflammatory foods and stuff to keep any of that...because after I got hit, obviously the first thing everybody says is, "Are you going to get arthritis from all the impact?" I just try to eat anti-inflammatory foods most of the time, a lot of turmeric.” He is hoping to prevent further painful symptoms from the damage to his joints while Heather wants to lower her blood pressure through diet:

> I went last Monday [to the naturopath] and she recommended a few things. I had a four-page form to fill out previously to that that they sent me in the mail asking all kinds of questions, and filled that out and she looked at everything. First of all, gave me a plan. "You really should be eating as much organic products as possible." I said, "I eat very healthy." I said, "I have Dannon Lite yogurt and skim-plus milk." She sat there and she shook her head. She said, "That's not healthy." She said, "You should be eating more protein. Get rid of all the diet stuff," because I've been a weight-watcher for like 20 years and I've always tried to watch very carefully what I eat. Here I was thinking I was really good. [laughs] Anyway, as it turns out, she sent me for lab work and gave me some medication to help me reduce the blood pressure. Also, she said, "If you can, stop taking the water pill." I had decided that already. I didn't want that water pill. Anyway, she created this combination to reduce the blood pressure. I take drops every day, and she gave me also some powder to put in juice for my stomach problems. She told me to increase the magnesium appreciably and sent me for lab work. The next day, last Tuesday, I went to the lab. 25 vials of blood, they took. [laughs] I've been to Trader Joe's. I've been to Whole Foods. I've done a lot of research on stuff, and I'm drinking organic milk and organic orange juice, and I'm trying to make some changes in my lifestyle. She wants me to drink more water, which I usually drink a lot of water and take more magnesium. You have to balance all of this stuff, and that's what's hard. She prescribed a bottle of vitamin K also. I'm not sure what that's for, but anyway I'm taking that. And she wants me to eat more protein so I'm eating eggs every other day. I'm changing a few things like that. And oatmeal. It's organic. Everything is organic. I want to know everything about my body and what I can do to help myself.

With the guidance of her naturopath, she discovers how to do even more to be healthy even though she already thought she was living a healthy lifestyle. Others honed in on physical activities that improve health. Matthew designed his own exercise practice that he uses to rehabilitate his back:

> I've been exercising and doing all kinds of things. I played golf and stuff last year, but not well. It's been ongoing since then. I'm still working on it. I'm pushing my back pretty much. I'm walking on a treadmill, I'm doing some exercises. I'm doing the exercises to the point where I'm really ecstatic. Like a physical therapy thing that I've been to years ago for a shoulder, but they don't put enough pressure...I put a lot of pressure on it, so I'm making it sore in some respects to get the good stretch. That may be aggravating it, but I don't know any other way. That's what I came up with for my therapy. Well, you've got to try it all.

Similarly, Daphne has a yoga practice that she uses therapeutically to help with her pain symptoms too:

> And you made it a priority for your body and your health, there was a result. And you were more in control of that result through your own commitment, rather than having someone see you for two minutes and go, "Oh here take this pink pill. That's going to fix everything." So instead of being outwardly, it's inwardly. I think that the acupuncture was the beginning, and the following up is essential for me. I know if I didn't do anything, let's say I just walked in off the street and I was Ted's patient… In order to deal with what happens when I don't move and I don't do my practice, I would be back seeing Ted for the acupuncture because everything would tighten up. Because it's skeletal, once the skeletal stuff begins to go, then my muscles tighten up and of course then it's that cycle of nerves getting pinched the wrong way, because you're like this. The more you're like this the more you hurt. Just what I said before. I think that I became more aware of the fact that when I became an active part and having the healer take an active part in the actual healing is beneficial for me.

She realized that when she committed herself to that practice, she could see beneficial changes. And when she could feel herself slipping from that practice that is when she would have to rely more heavily on the outside sources of help again. Realizing that it takes internal effort made the difference for Daphne as it did for Samantha who recognized the limitations of healthcare treatments that she used for pain relief. This prompted her to do more personally as well:

> I take it upon myself to do things like [go to] the doctor as well as the chiropractor, the doctor as well as acupuncture, because nobody is suggesting this to me. [laughs] I know they are just looking at what they know. These are the tools that they have to fix you. That's why I do the yoga on my own. I try to eat right. It's all these things work together. I was doing yoga, the Five Tibetan Rites, in the morning. That helped my wrist, and my arm, and a lot of the pain has been helped from doing those every morning.

Both of these women saw the connection between “tuning in” and actively being part of their own healing processes through supplementary physical activity.

For a smaller proportion of the sample, being proactive actually took the form of “doing less.” These individuals, in particular, were very physically active and found that their pain symptoms were amplified with continued physical activity. While “doing less” could be viewed as a lazy or sedentary lifestyle – perhaps the opposite of proactivity - for these individuals, it was so far outside of their routine and it took practice and determination to change their patterns. For the young veterinary student who had pain in his shoulder blades, pain intensified by activity meant a limited physical existence. He said, “I just gave up on that. It was taking ibuprofen and those things have pretty bad side effects over the long haul. I just stayed away from that. Like I said, I learned to live with it. It didn't incapacitate me, but it was annoying to live with it and knowing that. But I learned what I could do and couldn't do. So that was a big help to know, over the years, what my limitations were, as far as using my arms and things like that.” Jake also experienced an injury in which he had to learn how not to trigger further pain. He explains, “A combination of the acupuncture and some anti-inflammatories and mild stuff, like Advil. Once in a while I have a prescription for Meloxicam, But I know what I can't do. There's certain things… I just don't do yoga every day. I just adjust things. I'm very adaptable to kind of stuff. I stay away from any overhead lifting." For Jane, this "doing less" meant clearing items from her calendar thereby eliminating stress:,

> But learning to do PT treatments, learning to do some exercise to get some of the tension out of my body, going for the treatments, saying no to people. When that happened to me, number one, I'm in government relations which brought me into the world of being on a lot of not-for-profit boards and things like that and I just canceled everything. Everything stopped in my life. Now I have to say to myself, "Jane, you don't have to do 15 things. You don't have to do it. You're getting yourself sick again. Maybe do two that you like to do. You don't have to do all of them. Back off." That was a big eye-opener for me that I struggled with, and I use that word struggle because it's very hard for my personality, to just go through a day just being, just existing. Very hard for me. I said to myself, "Holy mackerel, how could you not relax?" I reached that point again this year when I said to myself I've forgot how to relax. I have taken no time to relax. No time to relax. This year vacations were taking care of grandkids and that's not a vacation. As much as I love my grandkids and they really de-stress me, sometimes it's good to be around them because then I forget about everything else, it's still not a vacation because you're physically active and working with them. Realizing I needed to take [a break], and I did, I took a week out of the office. I took a week and just did nothing at home.

Taking Control of Health

Another trend that showed patients' proactivity was the commitment to taking control of health, or healing oneself. This perspective was often mentioned while talking about acupuncture in that acupuncture allows for an approach that gives more control to the individual. Amy felt that there was more to health than listening to the recommendations of her doctors. She described quite thoroughly how the patient should do more for themselves:

> I think that people have to be proactive with their own bodies, and they have to investigate things, and they don't have to take things verbatim from their doctors, because maybe there are other ways that they can go. I don't do

> mindless things. I do things that are purposeful…So I'm very mindful, right now, to continue the wholeness product, with the acupuncture as part of it, to do other things also.

Jane describes how her thoughts toward health changed overtime and that the change in perspective meant that she had to take some personal responsibility for healing. She said, "As I said, it took a while. People say to me "did it work?" Yes, it worked for me, but it doesn't instantly work…Realizing that it's within yourself and you have to work on it within yourself to go away. So I think that some of that, in going to alternative medicines, is that they're willing to address that. They're willing to dig deeper than what the diagnostic test says. Because it says they know the be-all and end-all is what's causing it. I think that that's why I stick with it." Georgia also describes how she came to take control of her health and ultimately know more about her body and needs:

> Take a step back, yeah. Take a step back and see what is it your body needs. Yeah, when I have a stomach ache I don't grab the Pepto-Bismol, I make myself some chamomile tea, or some mint tea or ginger tea or something that...I try all that first. I've gotten to really know my body better. All the time. I'm like, "Why do I want to take medicine all the time? I don't need it." You have to take control of your health. I've learned this whole thing. You have to take matters into your own hands. So I think that, just being in control is so important and I think this kind of approach puts you in control.

Georgia's notion of taking control does exhibit some resistance to a conventional biomedical approach to healthcare. Beatrice takes this a step further when she describes how she questions the authority of the doctors who treat her.

> Because I think too many people, I've seen it with my parents, particularly my mom, that generation, I think. My generation is questioning, the doctors aren't the be all and end all and know everything. You have to be your own advocate. You have to know your own body. You have to be able to figure some of this stuff out. You can't just go in and because the doctor gave you a script, you go

> and you fill it and that's going to be the answer. You have to keep questioning and you've got to keep asking and you've got to keep pressuring them to get the right answers.

Unfortunately, another element is lurking in many of the patients' narratives of taking control -- that of not receiving support from medical advisers that they sought help from. Beatrice, a woman who suffered with pain in her shoulders and neck, alludes to being discarded by medical professionals when she says, "Yeah, you really need to get to that point I think. You have to get to that point. If you're not invested with what's happening with your own self going to these doctors, you're not going to go….And so you get to the point where it's like enough's enough. I'm going to go find somebody natural that's going to help me. I think that's what you crave. I think women crave. You want to be in balance or something. I like to feel like that." Like several others, Beatrice recognized the limitations of what healthcare providers can do. She describes a breaking point ("enough's enough"), while others described a realization, or an awareness that came from interacting with multiple providers and not feeling taken care of.

Whether or not the patients showed derision toward medical professionals, there were multiple ways in which these patients expressed proactivity in their daily lives. Doing more or doing less in their physical tasks was one way that people took on responsibility for their health. Many found that changing their diets was how they could do better for themselves. The group as a whole exhibited strong signs of capability with regard to their health, even when burdened with enduring pain. It was less easy to detect and classify where their proactivity originated. There were participants who clearly felt that their agentic qualities were something they always had, while others came to realizations – often through failed attempts to rely on healthcare professionals – that they had to do the work on their own. This subject will be further addressed in the following chapter, when I investigate if acupuncture serves as a resocializing agent for its patients.

Patient-Centered Care

Hypothesis Four: Alternative medicine patients will rate their care as more patient oriented than will the pain management patients (see Appendix C for psychometric analysis of the proactivity scale).

Table 9: Patient-Centered Care by Treatment Type

	Treatment Type		Significance Tests		
	Pain Management	Acupuncture	Test Statistic	p-Value	df
Patient-Centered Care Evaluation Scale			t=-2.47	0.015*	94
Mean (s.d.)	4.3 (0.7)	4.6 (0.7)			

**p*<.05. ***p*<.01.

Survey results revealed that, at the time of the survey, a majority of patients (59.4%) had been receiving treatment from their current healthcare providers (either acupuncture or pain management) for over a year and two smaller segments (20.8% and 19.8%) had been receiving care for less than 3 months, or from 3 months to 1 year, respectively. When comparing the two subsamples, acupuncture patients were much more likely to be seeing their provider for over a year (81%), while pain management patients were more evenly distributed between less than 3 months (25.9%), 3 months to 1 year (31.5%) and more than 1 year (42.6%

An independent-samples t-test was conducted to compare the rating of patient oriented care among respondents in different treatments (see Table 9). Acupuncture patients rated their care as more patient-oriented than pain management patients (acupuncture mean=4.3, standard deviation=.07 vs. pain management mean 4.6, standard deviation=.07). There was a statistically significant difference in the ratings of patient-oriented care for these groups at the *p*<.05 level (t-statistic = 2.47, p = .015). Acupuncture patients were more likely to rate their care as patient oriented than pain management patients. Therefore, hypothesis four finds support.

Patient-oriented care can mean a lot of things, but really comes down to the feeling of being taken care of by a healthcare practitioner. The patients in the qualitative portion of the study illustrated this in many ways, often in ways that used conventional medicine as a comparison to their acupuncture treatments. What was striking about the interviews was how the respondents described the closeness of their relationships with their acupuncturists. Even when not completely sold on acupuncture as a cure-all, they spoke very highly of the acupuncturist for his or her ability to spend a great deal of time with them and ask in-depth questions about their lives in addition to their immediate symptoms. Many of the patients felt that their acupuncturist knew them and that intimacy was developed between them was developed by sharing information about all aspects of their lives.

Time and Intimacy

Many described the amount of time that the acupuncture spent with surprise or amazement, in addition to their strong affection for it. Heather said, “Whereas when a doctor is seeing a person, and you feel...sometimes you feel like, well, in 5 or 10 minutes tops. That's all you're going to get. [laughs]” They felt that someone (finally) was paying attention and could respond to many symptoms or areas of their health. This description often came in sharp contrast to that of other practitioners they had seen. Beatrice sounds surprised as she described the novelty of talking about her life circumstances in relationship to her pain symptoms. She says, "[The acupuncturist wanted to know] what's happening in my life that was making this happen? No doctor ever did that before. That's why I liked him, and that's why I stuck with him." Georgia adds to this sentiment:

> They talk to you for half an hour before they even get you on the table. They sit with you. They look at your tongue. Yeah, they do pulses. They smell your back. They do all these things, right? Well, they talk to you about your diet. They talk about your stress, your stressors, like what in your life is stressing. How much exercise do you do? What types of exercise do you do? How do you feel when you do exercise that you don't like. All these things that no one ever asks but I totally think they're relevant. And then also, to be honest this half an hour that I meet with my practitioner, she's like my therapist. She cares about what's going on in your life because that affects how she treats you. She knows what's going on, she's got me figured out.

Interestingly, the respondents sometimes use the word "we" when talking about their treatment plans. The use of "we" indicates their feeling of collaboration or working together for their health. This is present in Jane's description of how she and acupuncture worked to uncover the source of her problems:

> But the takeaway is, again, maybe it's unique, because I've only gone to Vincent as an acupuncturist, but he treats the whole person, which he knows that mine is all stress related, he talks to me. Usually it's an hour, hour and a half visit, because he knows we've got to get to the stress, because that's what we need to work on. Then once I was there with him and he started saying these things to me. It was a good relationship from the beginning because I'm very irreverent. I'm a real child of the '60s and in authority. He can talk to me that way and I can talk to him that way. When he was able to say to me, "You've got to see how crazy you are. You've got to see that you can't wake up in the morning and not do something unless you're programmed. You've got to see this." He was able to be very Fred with me and I respected that he was so straightforward and Fred with me that he wasn't BS-ing me, and he was trying to get to the core of it. When you talk to him, he's bright and knowledgeable. I immediately said I was talking to these idiots in some of these doctors' offices. I respected what he was saying and what he was saying made sense. It made sense.

Matthew, as well, uses the word “we” when describing the almost puzzle-like process of solving his pain condition:

> It's a give and take. I tell her where it's sore or whatever and she's been doing it almost a year now, so she's got a pretty good idea of where the pain is and where I'm experiencing it. If she wants to try something new, I leave it up to her. We follow the pain, and see what we can do with it. Maybe there's pathways she can open up, or get something going there that's fine with me. It seems that whatever she's doing seems to be working. I don't go that often anymore. It's only once every couple of weeks. We have feedback back and forth. Does it feel any different, should I...I'm trying something different. Tell me if you feel any different from this, like we heat up the needles or something and put something on the tips to get a little penetration, whatever.

Likewise, Heather noted that she cooperates with her acupuncturist when she said, “Sometimes, I've said that to Caroline [the acupuncturist], too, when I'm undergoing a treatment. I'll say this area bothers me a little bit more. She will do that. I feel like I'm participating. [laughs] With a medical doctor, you don't do that.” In fact, it appeared that patients were pleasantly surprised that talking, even talking a lot, could be part of the acupuncture process and that ultimately, it made them feel taken care of. Courtney said:

> He made me feel perfectly comfortable, and that means the world to patients, just listening and understanding and even being there. I feel like he was a psychiatrist or whatever. I would vent about work and he'd be like, "All right, you should try this, try this." You know? I don't care if you don't mean it, but he made me feel like he did, and that meant everything. So I rave about him. He's great. "How is this going? How are you doing with this? Did you try this?" It was great. You know? He remembered. He wasn't just looking at the chart. I don't think I've ever seen the chart. His memory is very good. That's another thing that made you feel at home in a way, that it was like a friend doing it and not this random doctor. He's a sweetheart. That's what made it so much easier. He wasn't a dick. [laughs] Sorry.

Maybe even more than liking that talking, which is allowed and encouraged in the acupuncture visits, is that someone is listening and hearing them. Laurie, who was mourning the loss of her husband, described her first visit with the acupuncturist, “You go in, especially if you're in enough pain, you go in rambling about how your person died, then you start crying, then you start pointing at your eye or your pain, then you start rambling about something else. So he was very patient to listen to all that. Because usually in that case there was some mourning happening that it wasn't...I was able to lay that all out. It wasn't straightforward, at least what I remember when I presented my complaints to him.”

Treatment Tailored to the Individual

Furthermore, the patients frequently described the acupuncturist as meeting them where they were. The office visit could involve working on something different than planned or could include additional, multiple symptoms instead of the one designated thing. Jill pointed out that the visits are focused on what is current for the patient:

> Like I said, she always asked, "What's happened since the last time I've seen you?" Then she'd move on from there, "How's everything feeling?" and that kind of thing. Yeah, I guess at the end I did get the feeling that I was more in “maintenance mode”. We weren't treating any one thing. It was just for a general feeling of wellbeing is what I was going for, I guess. I'd say the last six months or so, maybe less. Because then there were the weeks when I would go to her and I'd say my shoulders and my arms really hurt. Or my knees really hurt, and my feet. She definitely would help out on those days. But it's not like you go to the doctor and you say I have this and they do something to it. It's a lot more fuzzy I guess.

Richard was shocked and impressed that his acupuncturist could help him with an uncommon problem that he sprung on her in the middle of an office visit. He describes that office visit:

> It went excellent, very well. She took down the full history and what was going on and the things that were bothering me at the time. We started working on those areas that were bothering me the most. As time goes on, it's like a shopping list. I have a list of things I want her to start working on as I go. Stuttering is one of the things that she's working on and believe it or not it's

> working. It might not sound like it to you, but I stutter a lot worse when she's not working on it. If I'd gone to any medical professional, you have to tell them your symptoms, so that they know what to start looking for and how to approach them, how to try to treat those symptoms. I treat her just that way, like she's my doctor. She's one of my doctors. I know she's not a doctor, but I treat her that way. I tell her my symptoms and she says, "OK." Even with the stuttering, I was blown away when she said, "There is a pathway for that." I thought she was kidding me at first. She said, "No. There's a pathway." She worked on that. I noticed marked improvement right away. I tell her what's bothering me for that week, that day and then she goes to work with the needles.

Above all, it appears that patients are appreciative of someone that is committed to working toward their benefit. Keith, who had been cast aside by multiple health-care providers, was pleased that someone took the time to work on his complicated problems:

> First of all, because of all the nerve damage, he's like, "You don't have a standard pathway." It took a long time for him to find where to adjust because the nerves that normally would go to your legs or whatever, mine were severed at certain spots. What happens is different nerves take over those pathways and give those signals. He used the pins, no response, the skin's not twitching or anything, so he's like, "We really need to find where the ends are and start stimulating them to create new growth and get you going again." All the symptoms of all the nerve damage, I used to sweat, shake, and had all the tremors and stuff, and the acupuncture suppresses all that stuff.

Francis pointed out that acupuncture has the ability to see beyond immediate symptoms and includes a look at patients' emotional impacts as well. After she suffered debilitating leg pain, she described the difference between her conventional medical treatment and her acupuncture treatment that ultimately helped to solve her problem. She described,

> When you go tell a doctor, "This hurts," they're like, "Don't do that." [laughs] You tell an acupuncturist, "This hurts," they're like, "OK, we can solve that and prevent things further down." Yeah. I do go to the acupuncturist for pain, any little thing that comes up. I think that's part of it, because when you tell your physician or the ER person, "My leg hurts," they look at your leg. When you tell the acupuncturist "My leg hurts," she's looking at your eyes, your skin, your tongue. She's like, "Oh, it hurts because you're dehydrated because you had so

> much emotional activity in your life the past couple of weeks, and then you don't take care of yourself."

Both spending time with an acupuncturist (who inquired about their lives) and feeling involved or consulted about their treatment was clearly impressive to patients to whom I spoke. They felt they were heard and that their treatments were tailored to them. These were meaningful differences from some of the other forms of care they had previously received where deep relationships with physicians or specialists rarely occurred, even with repeat visits. Furthermore, the provider-patient relationship was often close among the acupuncturists and their patients as evidenced by the warmness in which they spoke of their acupuncturist and the fact that it was not uncommon for the patients to refer to their acupuncturist as their counselor or friend. Overall, the patients felt taken care of and really basked in the feeling of having a companion on their journey toward being pain free.

Conclusion

With survey data, I was able to discern notable differences between the populations of chronic pain sufferers using pain management and acupuncture as treatments. Namely that acupuncture patients (1) use fewer medications on average than their pain management counterparts, (2) exhibit higher proactivity with regard to their health, and (3) rate their respective site of care as more patient centered. Further, difficulty of diagnosis was a more challenging finding to interpret as the evidence showed that some patients see few healthcare practitioners and others see numerous healthcare practitioners in the quest for diagnosis. However, we have been able to conclude that trait and behavioral differences exist between the two groups. Yet questions remained about how those differences occurred and what they mean for the patients and their pain resolution. The survey data noted patterns for a group who little is known about, acupuncture users with chronic pain. Findings drawn from the interview data reflected the survey findings and further described what difficulty of diagnosis, hesitancy of using prescription medications, health-related proactivity, and patient centered care look and feel like for the patients who experience them.

Chapter 5: Pathways to Acupuncture and Becoming a Believer

In this chapter, we turn to the research question concerning the trajectory patients follow as they seek out and begin using acupuncture as a treatment for chronic pain. Using data from the qualitative interviews, I will discuss patients' decision to use acupuncture as well as contributing factors to that decision. Then I will report on the patients' beliefs toward acupuncture and healthcare and how they changed given their experience in treatment seeking.

Previous Experience with Acupuncture

All but one of the patients engaged in other forms of complementary and alternative medicine. The most commonly used form of CAM was chiropractic treatment followed by yoga, massage and herbal supplements. Others that made the list, though only used sporadically, were meditation, cranial sacral therapy, guided imagery or visualization, hypnosis and biofeedback. Acupuncture was the first kind of CAM used for only a minority of the sample. The high majority had gotten their feet wet in other more popular forms of CAM prior to seeking out acupuncture. It is not surprising that visits to the chiropractor preceded acupuncture treatments as chiropractic care has become mainstream in the last 30 years and to some is not considered "alternative" but more closely aligned with and adopted by the medical sphere.

Over half of the participants who were interviewed were using acupuncture for the first time. They had no previous personal experience with acupuncture. An additional eight patients had used acupuncture in the past – two for the same ailment that they currently suffered from and the rest for different ailments than the current chronic pain issue. For those who had experienced acupuncture in the past, their reviews were mixed. Half had positive previous experiences with acupuncture and this is what prompted them to use acupuncture for the current issue. What constituted a positive experience was simply that it worked and they felt improvement in their conditions. Francis explains her evaluation of her first encounter with acupuncture. She said, "I had had experience with acupuncture before this event, Graves' disease, like, thyroid disease. I found that it was a good solution to a problem that I had because I was able to find...I could see and feel a difference as opposed to just taking pills and going for blood tests. I couldn't feel or see any difference in how I felt [with those]." As well as seeing and feeling results, Francis alluded to her preference to treat her thyroid condition without medication. A few other people expressed their inclination to go medication-free and described how that factored into the choice for acupuncture. Laurie was pleased to not use medication when she described what made her come back to acupuncture. She said, "What brought me into Dr. Callaghan's [acupuncturist] office was a prior experience with an acupuncturist, and with good results, without having to take medication or without having necessarily to go to a psychologist." Correspondingly, there was an attempt among patients to use acupuncture to lessen the number of medications that they were using. Georgia first used acupuncture for infertility and in doing so was able to wean away from the medications which made it possible to cope with frequent migraines:

> Then I got married, we were trying to have children and we stumble upon infertility issues. So, in Ann Arbor we did IVF [In Vitro Fertilization]. I said "OK, I have to get myself in the best possible health before we start this journey." I said, "We're starting these IVF treatments. I don't want to take any more Advil. Plus what if I get a migraine while I'm pregnant?" She [the acupuncturist] said "OK, we can control these migraines because we also have protocols to complement your IVF."

She went on to have a successful pregnancy (with twins) without migraines and without medication. Positive experiences brought these patients to meet their goals, likely without the use of medication and it makes sense that they would seek out acupuncture again for their needs. It is less intuitive that someone with a previous bad experience would use acupuncture again. However, bad previous experiences with acupuncture existed in this sample for just as many people. In this case, a negative outcome meant not seeing improvement in their symptoms. While you might not expect people try for a second time something that did not previously work for them, people in this group felt that trying again with a different provider or different style of acupuncture could perhaps lead to a better outcome. Amy revealed her intentions to try acupuncture again after previous failed attempts in this exchange:

> MC: OK. Now, you mentioned that you've been to a couple of different acupuncturists.
>
> Amy: Yes.
>
> MC: Has that been...?
>
> Amy: Not successful. I think she [the new acupuncturist] practices a different type of acupuncture…So she comes at it from a different place than I think other acupuncturists do.

So despite unsuccessful attempts in using acupuncture, she believed that another style of treatment could work for her. Another person simply felt that she too hastily decided to end acupuncture treatments previously. Courtney explained, “I attempted acupuncture, and it didn't work. It was not good. Then I went to Vincent [acupuncturist] and it was almost like the first treatment I felt a little better. The next time a little better. The next time was even more better. It was slowly, but it worked…Then, again, I didn't really give it a full chance then. I went once, so I didn't really give it the real chance it deserved that I wish I would have.” Both Amy and Courtney demonstrate how personal recommendations played a factor in their trying acupuncture again as both women felt compelled to try again after hearing about their current practitioners through word of mouth.

First-timers were often not familiar with acupuncture before someone suggested it as a possible treatment for pain relief. In fact, almost every participant noted that they did not have any close friends or relatives who had gone to acupuncture, thus showing how peripheral acupuncture appeared to them as a choice for pain relief.

Referrals, Recommendations and Approval

Referrals and Recommendations

There did not seem to be a discernible trend in how patients learned about acupuncture for treatment of chronic pain aside from that the patients did not think about or consider acupuncture before key players in their lives informed them about it. This suggestion was not always a memorable moment though, as some of the patients had to think hard to recall who initially told them about acupuncture. Six participants learned from family members, friends, acquaintances (such as coworkers or store employees). Six participants learned from complementary and alternative health providers from whom they were receiving treatment. This list of of CAM providers included massage therapists, yoga teachers, or chiropractors. Another five participants heard about acupuncture from their physicians. The physicians who recommended acupuncture to their patients were described by their patients as holistically-inclined practitioners who promoted natural approaches to pain management.   And the remaining three participants said that they sought out acupuncture on their own without the recommendation or referral from anyone they knew. Regardless of their credential or the closeness of their relationship to the patient, personal recommendations are clearly important to how one learns and uses acupuncture. Hearing about acupuncture from healthcare providers was weighted more heavily than hearing from non-professionals as nearly two-thirds of the sample learned about acupuncture that way. Medical and CAM providers were just as likely to recommend alternative treatments. Richard described how his general practitioner introduced him to the idea of acupuncture for his aches and pains from chemotherapy. He said, "As far as acupuncture, it never dawned on me to even consider, until Dr. Jackson recommended that I try it. I had limited bit of knowledge about it. Actually no knowledge, except it involved needles. That's all I knew." The process was the same for Fred, who heard about acupuncture from his massage therapist. This snippet from our conversation shows how he was introduced and persuaded to go:

> MC: When the massage therapist suggested it, had you ever thought of acupuncture before?
>
> Fred: No.
>
> MC: It seems like you were open to it.
>
> Fred: Yes.
>
> MC: Did you do any research for looking into acupuncture?
>
> Fred: No, I just went...a massage therapist told me to try it. I didn't think it would do anything. Then after talking to her, I decided to try it.

Regardless of the type of healthcare practitioner, the process of recommendation appears to be similar so long as the provider comes as a trusted source of information.

Even though the participants were steered toward acupuncture more often by healthcare practitioners, nearly all (17) of them stated that personal testimonials served as a form of recommendation that they considered in choosing new treatments. Personal testimonials from trusted sources of information (friends and coworkers specifically) can also make the decision to try acupuncture an easier one. Personal endorsements can be in regard to acupuncture in a general sense as when Samantha explained how knowing that her friend had a good experience with acupuncture influenced her opinion of it. She said, “Then also listening to other people, if I've heard people who something's worked for. Like I know a friend of mine goes to acupuncture and has good success with it. So I factor in all of that.” Testimonials can also endorse a particular provider as for Courtney, who said, “I'd really like to know if someone else has been to this person before. What was your reaction, and how did you like it? That's important to me.” For most of the people, having a personal story from someone they knew served to ease their apprehensions toward acupuncture.

Within this strong faction of people who considered personal testimonials when making treatment choices, a few people noted that the source of the information is important in evaluating its validity and that sometimes personal endorsements should be viewed skeptically. Gabrielle, for example, was swayed more by her acquaintance at the music store, who recommended that she go to a particular acupuncturist, than by her own sister. Gabrielle said, “I take it with a grain of salt. Because different strokes for different folks. It depends upon the person. Like my sister for instance has gone to my acupuncturist and she won't go to him again. ‘He talks too much.’ Exactly what she said.” For the semi-skeptics, there is a subtle process of assessment that goes along with hearing feedback from others with regard to their perspectives on treatments and this influences whether the acquired information is helpful. Francis, who works in healthcare, had a similar reaction:

> Francis: Yeah. I like hearing...I take it both ways. If it's someone who I feel is never going to be pleased, never going to be happy, I take it with a grain of salt. I'm like, "OK. No one ever made this patient happy, so of course I'm not going to reference all my decisions on that." If it's someone who has more of my approach to things...Like, if I like someone I'll stick to them. I'll accept that a lot easier. It depends on who tells me what…Some people are just grumpy. They like going from doctor to doctor, saying, "No one's ever helped me and you can't do it either. I'll make sure of it." [laughs]
>
> MC: That's not as helpful to you.
>
> Francis: Right. Just because someone says it, doesn't mean anything. It's like who are they who is saying it?

Personal testimonials, while deemed helpful for most of the sample, were also viewed critically by a smaller proportion. Like healthcare providers, having trust in the recommender was an important feature in being referred or recommended to acupuncture in the first place.

Approval – Direct and Indirect

Seventeen of the 20 participants did not feel like they needed approval from a physician to engage in acupuncture and many of them were receiving acupuncture treatment without their physicians' or specialists' awareness. The three people who did feel it was important to have their doctor's approval had different reasons for their reaction. One simply wanted approval in order to get reimbursement from her health insurance company. Daphne said, "You need it in order to get reimbursed. It's become like a physical therapy thing. It wasn't necessary for me personally to have that but the doctors say, yes, it was necessary for me to get reimbursed."

Two other people wanted approval from their doctors because they valued their opinions and looked to them for guidance. They also so happen to have full support from their physicians. Heather expressed this sentiment when she said, "That's a toughie. I'd definitely want to talk to my doctor about that and go over pros and cons." Likewise, Courtney, who had a particularly close relationship with her general practitioner said:

> I would personally like the approval just because they've seen more than I have, they've been through more than I have. They've seen what works with certain people and what doesn't work with certain people. I like to get their point of view on it and their intake. I'll go and be like, "What do you think about this?" "Go for it." "All right, well, how do you feel about this?" "I think you should definitely go and make an appointment. Let me know." I would trust her. I would ask her in a second about anything that I was questioning, because I value her opinion.

A much more prominent proportion of participants did not feel that it was necessary for their doctors to approve of acupuncture and cited a few reasons why this was the case. A few people simply did not believe that doctors had knowledge about acupuncture so they did not expect them to encourage what they did not have expertise in. When asked, "Would it be important for you to have a doctor's approval to try alternative medicine?", Samantha told me, "No. Because I know sometimes doctors get very fixed on what they think. They're not always looking at the whole picture." Another set of patients responded to this question with more personal authority. They were able to locate the decision to seek acupuncture to their own bodily knowledge and personal decision-making. For instance, I asked Matthew if it influenced him that his doctor had a negative opinion about acupuncture and he said, "No. It's how I feel. I feel better when I get out of there [acupuncture treatment], so whatever they say, it can't be a negative thing. My back tells me what's good, and what's bad. If I get relief by going to acupuncture, even if it's only for a few days, maybe over a long period of time it will work. It helps." Similarly, Beatrice said that she would preference her own judgment over the doctors. She said, "It's very nice. It is very nice to have their approval -- that they actually would think to even say that. It's not important to me. I don't care... No. Uh-uh. If I think it's going to help me, I'm doing it. I don't care [if the doctor approves].”

There were also people who had less confidence in physicians and their responses were more about their dislike and skepticism of them. Melissa, when asked “How about getting a doctor's approval? Does that matter to you?” responded, “Couldn't care less.” Jane said, “Have a doctor's approval? I think in the case of going to acupuncture, I didn't care what a doctor would have said at that point, I was making up my own mind.” And Amber said, “It doesn't make any difference to me if a doctor approves it or not, because I don't really go to doctors.” Whether the patients were fans of physicians or not, the vast majority said they did not feel it was important to have a doctor’s approval.

Still, I wanted to uncover participants’ perceptions of what doctors think about acupuncture to understand if that shaded their stance on the matter. More broadly, I asked them if they generally felt physicians approved of acupuncture. A few participants who had received recommendations from their physicians for acupuncture felt that they did approve of acupuncture. But, for the most part, the acupuncture patients did not think that physicians would approve of or suggest acupuncture. Some patients pointed to amenable physicians that they had encountered, however, they generally reported a mixed review, or a vague understanding of what physicians’ opinions were. Nancy was one of these people who had a green light from her physician. She said, “It helps a lot that the GP was on board. That she was really promoting... She said, ‘If I hadn't experienced it myself, I wouldn't have believed it.’" Richard also felt full acceptance from his general practitioner as well as his cancer specialists:

> You've got a seal of approval when Sloan Kettering is now recommending it for some of their patients. Oh yeah. It's either a full floor or a separate hospital unit right in the city, on the Upper East Side, that deals strictly with acupuncture, yoga, different modalities that might help their patients besides what they're trying to do to cure the cancer. Don't quote me on this, but from what I see on the TV talks from their representatives, they realize now that every little bit helps. In treating the cancer, you treat the whole patient. And that works well. Oh, yeah, absolutely. Especially my family physician. She's all for it. She's all in favor of it.

To the contrast are people who navigated more cautiously when speaking to their healthcare providers because of perceived negative opinions. For example, Jill, who works in a hospital, explained how she usually kept her acupuncture use private from her coworkers because she was aware of a medical/scientific bias in her workplace. One day she spoke to one of her colleagues about acupuncture:

> It's funny. One day I told one of the pathologists here because he's right down the hall, "Oh, you should try it." We were talking about somebody has acupuncture. [He said,] "Acupuncture doesn't work," and I go, "But it does. It works for some things." I don't know if I told him I had it or not. I said, "No, I think it does work." [He said,] "It's just like a placebo effect," he's just like, "It just doesn't work. There's no scientific explanation for why it works." Different from my husband, who he says, "I believe it does work. I don't know how it works." We haven't figured out how it works, and I'm not so sure it has to do with energy and meridian lines or whatever, and blockages. But it obviously works.

This kind of reaction was clearly what she was attempting to avoid and that made her proceed cautiously. When she spoke to her many doctors, she felt that they gave reactions that were often difficult to interpret. In another example, she described her plastic surgeon's response to finding out that she was using acupuncture (after having seen some bruising on her skin). She said, "I don't know, it wasn't that he was against it. I just think he wasn't suggesting it to people either." Jane was another person who found medical attitudes about acupuncture were difficult to decode. She realized through navigating both conventional and alternative healthcare settings that opinions vary drastically:

> Yeah, I usually tell whomever's treating me and it's mixed reaction. There are some people that will advocate it and there'll be some people who will say, "Well, that's what they do, but this is what I want you to do." There is an internist that I go to if I have a cold or something. She actually, sometimes, prescribes to me my stomach medication when my stomach is totally out of whack. She's a big proponent of acupuncture and Western medicine. There's two in the office where I go and they're both strong supporters of Eastern medicine. They always say, "No, that's a good idea. Continue to do that if you find it helpful." They're very encouraging and they'll do that. I had to laugh, when I was in Stony Brook just this September and a neurologist was in there and I mentioned that I go to an acupuncturist. They're like, "Well, you know, this is..." and they gave me one of these answers where, "Well, if that's what you think is going to help you, but this is what you need to do." But it was a mixed reaction, so I have to say, through the years, there'll be mixed reactions when you tell somebody. Some people will be proponents and say, "If that helps de-stress you and if that's what works for you, that's great and it's very helpful." And others will be strictly Western medicine and this other stuff is not acceptable.

Francis, who saw her physician after being treated with acupuncture and herbs for a pain occurrence in her leg, experienced a reaction that taught her that Eastern and Western types of medicine were not compatible with one another:

> “Yeah, because when I went to my physician for my pain, she was open-minded about acupuncture and herbs. But when she said, "What herbs did the acupuncturist give you?" I said yen deficiency. She rolled her eyes and crossed out what she had just written. Because there's no way a medical doctor's going to write “yen deficiency” in her book. Because it sounds wacky, even though it's an herb and it's in a box and you could buy it. I think there's a lack of understanding between my typical Western doctor, my primary care doctor and what an acupuncturist knows and does. There's no common language that they could really figure out what each other's doing. I think that's a tough thing. With that I would have liked to have been able to let my primary care doctor know what my acupuncture is doing at the same time. I would have loved to have been able to say, "Hi, Dr. Becker. This is Francis. I'm having trouble with my leg. I saw my acupuncturist and I'll send you the notes." But that's like saying, "Hi, Dr. Becker, I'm at the hairdresser. I'm going to have her send you my notes."

> [laughs] They just don't appreciate it. It's so complementary and alternative that it's not appreciated input all the time. And I have an open-minded doctor. That's what's a little scary.

Given the dearth of truly positive responses on the part of physicians, most of the participants in this sample proceeded with caution when talking about acupuncture as a treatment. This reticence could mean feeling out the situation to see if the doctor would be accepting, or not simply not revealing or asking their physicians for permission. Whether their decisions to not consult with their doctors were due to perceived negative reactions or not, clearly these acupuncture users were acting independently and in some cases they were asserting their judgment over typical authority figures, their physicians.

Initial Thoughts about Acupuncture

Most of the people in the sample could be considered skeptics of acupuncture at the start of their treatment. Most people had no previous exposure to acupuncture and did not have anyone in their immediate family network who had used acupuncture. Mostly, the participants simply didn’t know anything about acupuncture so their initial thoughts were void of much description but rather were full of mystery and curiosity. Keith said, “I didn't know what to expect because I've never been to one [acupuncturist] before.” Daphne’s impression of acupuncture before starting treatment was ambiguous as well:

> I had no preconceptions except I knew they used needles and I knew that it wasn't supposed to hurt. I was curious enough that I'd read about energy flow and of course being a yoga practitioner, I believe that there is an energy flow, and figured if we could move it, or change the flow or direction in another way without manipulating me in another way, then I was on board.

As Daphne mentioned, and others continued to indicate with more preoccupation and fear, acupuncture was known to have something to do with needles. Beatrice was initially afraid of the needles. She thought acupuncture would be, “Kind of scary….Yeah, because I don't like needles. Who likes them? Just to think about it and say, "Oh gosh, he's going to put these needles in me." I was totally, "Uh-uhh." Then it was great. Didn't feel anything. I felt a little teeny, not even like a shot needle. Can't even explain it, but it had nothing compared what I thought it was going to be.” Other respondents saw past the needles and, while not knowing much about acupuncture and finding it to be a bit mysterious, expressed that they were open to trying something new. Georgia shared with me her initial thoughts:

> Georgia: I was hoping it would work. I'm just always open minded to things. Whatever works. With my migraines, I always was the person who would try to relieve my pain with eucalyptus and mint and all these things to try.
>
> MC: Did you know anybody else who had done acupuncture? Did you have a sense from other people what it was like?
>
> Georgia: No. No, I remember I was just reading. I must have seen it somewhere, about acupuncture for treatment of migraines. I investigated acupuncture on my own before actually going, just to know more about it. And to see if the needles hurt. I hate needles. I hate needles. That was it, it was just the pain. I didn't have any stigma about the alternative medicine. I guess I was kind of like, oh, you know, it's going to hurt, you know. It was really important to me. I was like, "Wait a minute. Does the whole thing go in your arm?" I couldn't picture it. And I remember when I made the appointment that was the first thing I asked. "Wait, do they hurt?" And she was like, "No, not really." "Are you sure?" [laughs] Because I also scream.

In addition to being open to something new, some people specifically cited that they were looking for a different approach to pain management. Samantha, who had been diagnosed with fibromyalgia, said, “I think I got a referral from somebody, not from my doctor but just somebody who I knew that knew somebody. I am always interested in different aspects of medicine and also interested in holistic, looking at the whole body. I do believe in energy and things like that. I was open to it, yeah.” Melissa, while uncertain of acupuncture’s effectiveness, was open to a new form of treatment. She explained, “If it helps my hip and I don't have to have an operation, I'm all for it, absolutely. Because I didn't really know what acupuncture was. I had no idea if it was going to work or not going to work. I'd never been to acupuncture, and at that point I was looking for any alternative means to relieve my pain a little bit, which it did.” Further, there were quite a few people who simply thought that it was “worth a shot.” In other words, they may not have known much about acupuncture, or whether it would work for them, but they were curious enough to try it and find out if it could be efficacious. For example, Heather shared a common sentiment when she said, “I thought about it and I said, "What have I got to lose? I'll give it a try." Likewise, Richard, with the backing of his doctors said,

> It didn't require a lot of thinking on my part. I said, "Well, what's the harm?" If somebody had recommended that I go for alternative treatments like you read about in the paper and see on TV -- Mexico, for exotic treatments -- I don't think I would have given it much thought… People that I've watched on TV, from Sloan Kettering, said that the acupuncture won't cure the cancer but it will sure help with the side effects [of chemotherapy] a lot of times and make life better. That certainly has been my experience with the acupuncture. Honestly, I thought well it's worth a shot. The side effects [of chemo] were pretty bad. Even to the point where it was interfering with my work. Like I tell all the people that wonder why I'm still working at the age of 76, I said, "Well, I still want to eat." If I still want to eat, I work. If it interferes with my work then that's not good. I said I'll definitely give it a shot because I really need to keep working.

The true skeptics were in fact more guarded and it took more convincing for them to try acupuncture. Courtney, who had previously used acupuncture in the past with no success, said: “I was so skeptical about acupuncture. I'm not scared of needles, that stuff doesn't bother me. I knew it wasn't going to be painful, I was like, it's not going to work. I kept hearing stories, then my friend told me go see him [the acupuncturist], he's really good. You know it was time where I needed to start something new and I did.”

It seems that most of the participants were making a leap of faith in trying acupuncture. They had very little knowledge about acupuncture, including what treatments would entail and how effective it could be for treating their pain symptoms. Obviously, there was an openness to try a new treatment and, as we learned earlier, this openness was enhanced by personal and professional recommendations. However, the question remains. Would the patients have tried acupuncture if they were not in extreme need for pain relief?

Desperation for Pain Relief

When I interviewed the acupuncture users about their treatment seeking history, I learned that about half of my sample (8 participants) faced difficulty in finding a diagnosis for their pain, while the other half (10) had not faced a difficult diagnosis (two participants were not easily classified in either category). Difficulty of diagnosis was reported and discussed in the previous chapter. While the sample was divided on this issue, what they shared in common was having difficulty finding pain relief. Almost all (17) of the participants were not able to get relief for their chronic pain symptoms despite (many times) multiple attempts at seeking healthcare.

In describing why they chose acupuncture for a pain treatment, patients often referred to acupuncture as a "last resort". Some phrases that exemplified this sentiment included, "I'd try anything", "I'd run out of options", "What can I lose?" and "I can't afford not to". Desperation for treatment, or exhausting all other avenues of treatment, is perhaps a stereotype that exists popularly within popular culture regarding the use of CAM. However, this stereotype depicted at least half of my sample, thereby reinforcing the findings that reliable treatment was difficult to come by.   For example, after Jane described the process of seeing several different doctors and specialists, she said, “If you reach the point of no return, which is what I did with Western medicine, I said I have to try something else.” This quote also illuminates the long process of elimination with medical treatments which often led the patients to acupuncture. Courtney shared her story of going from physician to physician to no avail of pain relief. She said, “Alright, it's time. I've run out of options. [I] had nothing else. What can I lose? It wasn’t like rock bottom, but I was like where else can I go? That [acupuncture] was basically one of my only options.” Feeling like she hit a brick wall in the conventional realm of medicine made it easier to look beyond the boundaries of normative medicine. Jane expressed the same feeling when she said:

> I had been to every top doctor on Park Avenue that you can think of. I've been to all the fancy places. Now I'm sitting in his very homey kind of office and I'm saying, "What the hell am I doing here?" Because I'm saying and I'm talking to my mother because I do believe the dead are around you and I talk to her constantly. I'm saying to her, "What in God's name am I doing here?" I'm divorced many years so I'm by myself, nobody's with me. I'm saying, "Nobody's going to believe this. I'm sitting in here, I'm going to do acupuncture. I don't know what this is all about. Don't really know, but all I know is I'm in such pain and such misery and I feel like I'm out of my body experience all the time. I'll try anything. I would try anything.

Gabrielle described her experience navigating medical treatments, including a brief dive into complementary and alternative medicine, before deciding to try acupuncture.

> Gabrielle: It probably happened close to 30 years ago, when I had trouble bending my fingers. I went to a doctor and he said, "The blood tests did not come out saying rheumatoid." However, he said, "It acts like a rheumatoid. We'll just follow it." For me, unfortunately, I have never had a remission. A lot of people go dormant for a while. Mine is never dormant. I have gone through...you name all the remedies. I've been on every single one of them. My body becomes immune to it within a couple months. And then I've switched to another one. Then Humira I was on. I was on that maybe four months, and then that too, I got an allergic reaction. It just no longer worked. Then a couple years later, Dr. Ivock,

> my rheumatologist, said, "Humira, you did very well with. Let's go back to that one." When I went back to it the second time, I was really sick. So it's too bad. Once your body has seen this, then it's almost poison to it when you try to use it again. I'm going to another one at the university, he was a nice guy. I can't think of his name now. He put me on Gabitril, Gabapentin, something or other. All they do is prescribe medicine. I was just doctor hopping, really, and they were just feeding me full of medicines and getting no place and the bio-feedback did really nothing and hypnosis they gave up on me. Nothing worked.
>
> MC: Did you ever feel like you had run out of options?
>
> Gabrielle: Oh for sure. Oh yes. It was horrible. I got no satisfaction from anybody. I was wondering whether there were any competent people. Really it seemed like they were just taking my money.

This idea that “nothing was working” was also expressed by Courtney:

> Two years ago I just kept getting migraines every single day, and they would last all day. Then I wouldn't go again without a headache. It went like that for a year and a half, and I went to specialist, different doctors, and then one of my friends, actually a lady I used to work with, recommended Vincent (the acupuncturist). I'm like, "All right. Let me try that," and I was on dozens of medicines. Nothing was working, and then the doctor wasn't listening… I know it could have been worse and that people have it completely worse, but I was miserable.

In Georgia’s case, her attempt to manage her migraines through conventional paths hit a dead end too.

> So backup, I've always suffered migraines since I was...They started when I was in high school, really badly. I went to a neurologist and they thought I had a brain tumor because they were really bad and paralyzing. At that time, in the 90s, you would just take this really crazy medicine that basically just numbs you like shots, and these little things that dissolve under the tongue. They would take the pain away, but you would be a zombie for the next three days. It was odd, you didn't feel any pain, but you felt like sometimes they just pressure on your temples, and really stoned for three days, but they would take your pain away. I always ate very healthy and I got enough sleep and I drank enough water. They were just trying to tell me that I'm not doing those things. That was annoying. Yeah. That's actually one reason why I went for alternative medicine.

For a few people, feelings of desperation were expressed in relationship to looming surgeries. Surgery was an ever-present topic in the conversation with acupuncture patients living with chronic pain. Several participants had already had surgeries to remedy their pain condition and for others, surgeries were the cause of their pain as in the case of Jill who had trouble lifting her arms over her head after having a double mastectomy following the discovery that she had breast cancer. Several respondents knew that there was a likelihood of surgery in their future and were actively avoiding it. Some did not like the idea of surgery at all and others did not like the prospects that surgery would work for them. Matthew was invested in exploring all options before yielding to back surgery:

> I went to an orthopedic. He looked at it, and then we went and did an MRI. They suggested I talk to a surgeon. The surgeon suggested the first step would be to go to pain management before they operated on anything. I didn't want to operate on my back at all. I went to the pain management. I had a couple of shots within two, three months. I'm able to walk and do everything that I wanted to do, but it hurt. Well, yeah, there's no alternative. The only alternative that I have is stretching, acupuncture, and hoping it gets better on its own. The other option is go to surgery. I'm trying all the things that would give it a good shot so I don't have to go and have surgery on my back.

Beatrice finally had surgery on her shoulders after delaying the operations for years. She did this by using acupuncture for pain relief:

> My shoulders are OK now. I had shoulder surgery, but he [the acupuncturist] kept me from having shoulder surgery for three years. He eliminated all this pressure, and pain that I had, but I still needed surgery. He told me "This is not a way out, it's just to help you cope." I couldn't really lift my shoulder. Then finally he said to me "You can't do anymore. You're going to need surgery." They wanted to do it that first year but I was like, "uh-uhh." I was just scared to do surgery. You know? Three years I went before I got it.

Then there was the chance that surgery could possibly make them feel worse. Fred had this fear and explained:

> I'm seeing a doctor now and his name is Doctor Reed, over by Good Sam. He’s a back doctor. Then I went to Manhattan, I forgot that guy's name. He said there were too many problems and to leave it alone. I did the shots, didn't work. There's nothing else left except surgery. I'm not into that unless I'm crippled. Because there's a chance of it being worse. When you have five [discs]…Which ones did you take? Let's say he takes two discs. That may relieve some pain. It's not going to relieve all of the pain. What's the sense of going through all that and not...with a chance of being worse? I don't want it worse. That's why I'm leery of that.

Deterrents to Using Acupuncture

In examining reasons why people begin to use an alternative form of healthcare for their chronic pain, it is also important to understand their perceptions of what made that journey difficult as well. So, I will discuss the few obstacles that the participants spoke about that made choosing and going to acupuncture difficult. For the most part, the participants to I spoke were fairly positive about acupuncture. In fact, when I asked them if there are any disadvantages to receiving acupuncture, a full one-quarter of the sample simply said, “no.” Another quarter of the sample pointed to physical discomfort that they felt from the needle treatment. An additional quarter of the sample said that the cost of treatment was a deterrent to going. The remaining responses referred to having to drive a long distance to get to the acupuncture office from their homes (n=3), experiencing little continuity or communication between physicians and acupuncturists (n=1), and feeling that acupuncture foretold a slow process of healing (not a quick and easy solution) (n=1). Because discomfort and cost of treatment were the most prevalent, I will address those aspects and how they factored into the decision-making of the participants.

Pain for Pain-relief

While only one person in the sample found the pain of acupuncture treatment to be off-putting to the point of stopping treatment, several people expressed a discomfort with painful needling. Needle discomfort happened occasionally, rather than consistently and most of the participants were willing to endure it, albeit begrudgingly. Daphne said, “There are certain points that were painful, and I didn't care for them.” What Daphne shared was the general sentiment of those who complained of needle pain. They had a strong reaction to it, but because the experience was relatively quick, they could endure it. Jane explained it further in the following interview segment:

> I wouldn't say it's a disadvantage, but sometimes it's painful. People have said to me, "Oh, does it hurt?" When I went in with the carpal tunnel two weeks ago, he went it really deep. He [the acupuncturist] said, "I'm going in deep." All right, he knew that he wanted to reach a certain point...Three seconds, it lasted. So I wouldn't say that was a disadvantage, but if somebody asks me, I usually say, "Depends what they're doing to you. Yes, you can feel it and it could be painful." I know when he does my neck, because my neck has been so bad, he will go in deep and I know what that pain feels like when he hits the spot he wants to. But then it feels like he burst a balloon. I feel like, "Whoa," my whole neck is released. I don't think it's a disadvantage; it's just something that's part of it.

For most everyone who spoke about pain, they decided to tolerate needle pain even while they found it jarring. For one participant, the needle pain was more intense and disturbing. Samantha, who had Fibromyalgia, described her experience on the acupuncture table as it transpired, “I could feel every needle as she [laughs] put it in me. I would lay there and I would feel every needle in me. I think that's to do with the fibromyalgia…Your whole nervous system is almost like on fire. I would just lay there and think, ‘OK, you just got to put up with this, because if it's helping me [laughs], you grin and bear it’. I remember people saying, ‘Oh, you won't feel it.’ I felt every one of them. While I was lying there, I could feel [laughs] them.”

Samantha’s story reveals how acupuncture has the potential to be painful for certain people and some pain conditions and also how the common notion (among acupuncture goers) of “pain free” acupuncture could be a false assumption. Samantha was unable to continue acupuncture treatment due to the uncomfortable sensations that she experienced in her sessions.

So, while most of the sample was unfazed by acupuncture needles (after getting over initial worries), even those who expressed difficulty with painful needling were willing to overcome it in favor of long term solutions to chronic pain. Only one person was unable to accept painful treatments and ultimately her cost/benefit ratio urged her to abandon acupuncture.

Cost of Treatment

Most of the patients to whom I spoke were paying for their acupuncture treatments out of pocket, without the assistance of insurance; in fact only three people had insurance coverage for their treatments. These patients were quite pleased with their access to treatment and praised their insurance companies for their ability to have unlimited visits. Among those without coverage, nearly everyone mentioned that acupuncture was expensive (typically sessions cost between $60-$90 according to the participants). Ten people expressed that they were not concerned with the cost so long as the treatment worked and they could see benefits. The last remaining portion of the patients (7 people) found the price of acupuncture treatments prohibitive and either ended treatment early due to their inability to afford it or looked for ways to make the treatments less expensive.

As a side note, a few people were unsure if their insurance companies would cover their acupuncture treatments. They were currently paying out of pocket because the insurance company was non-responsive to their claims, or had wrongly denied them coverage. While this was an infrequent occurrence among the participants, mostly because insurance companies widely do not cover acupuncture, it does suggest an additional struggle that some of the patients were working through. Matthew was one of the people in the position in which he did not know if his insurance would pay for acupuncture. He said, “I wish I could go more, but the problem is the insurance. My old insurance is paying for it. So far, my new insurance hasn't paid for it. I sent the claims in, but I haven't heard from them or anything. I called them in February and they said they're still processing it, and that's the only answer I got. They didn't say yes or no.” This uncertainly affected how often he felt he could go for treatment, in other words taking a more conservative approach to treatment for fear that he would have to pay the bills in their entirety.

For those who felt that the cost of acupuncture was affordable, they expressed how their decision was often weighed against the benefit of feeling better. Jacob said, “Cost I would say is secondary. It's secondary, because...I don't know. I think that health is...You can't put a price on it. Yeah, it's worth it to me because I want to live...I don't care how long I live, but I want to be able to do what I did. I want to be able to do what I can do. I accept that I'm not going to chop trees down...I accept that, but certain other things I want to be able to do, so 500 bucks to let me do it. To me, it's worth it.” Other people echoed this idea, like Courtney who found that benefit of successful treatment outweighed the cost of treatment. She said, “Like that's why I went into acupuncture. I don't care if I'm spending $70 a week or whatever, because it's making me feel better, so why stop that, when I've been feeling better, and this is the only thing that's been making me feel better? Matthew thought similarly and said, “Yeah, but health insurance doesn't cover acupuncture. At least mine doesn't. No, that comes out of my pocket. It wasn't a factor at all. I was more concerned with the pain relief than anything else. Getting the back in better shape.” One participant took this a little further to describe how as she branched out from conventional treatments that were covered by her health insurance. The money, although costly, was worthwhile because she was investing in her health.

> I forget how often she had me going. At first, it was weekly or biweekly. But it's not covered by insurance. It does add up. If you're looking at something that you have to do long term, to get a benefit out of it, you can't just do it once. You're making a commitment… I like the idea of investing in yourself, investing in your health. My fiancé was saying, "This is important. If you don't have your health then what do you have?" It's true. And then saying, "I'm going to make a commitment, at least to give something this amount of time to see if it works." Even that other doctor I'm going to, that costs. A lot of that's not covered under my insurance. I said, "I'm going to look at it like I'm going to take this money and donate it to myself, invest it in me and see what happens." Then I did see a change. If I didn't see this working, any of the things I'm doing, I would probably end up stopping them. Because why am I spending all my money on something that's not even working? But when you start seeing that something's working, you're like, "I guess it's worth it."

Another participant put the cost into a different perspective and claimed the acupuncture, while costly, was actually a good deal because of the unique benefits of acupuncture that she introduces. For Francis, having dedicated time and attention from a practitioner was cost-effective:

> I'll budget for health care. Like I said, it was when they first saw me it was $185, and $85 for follow-up visits. But I said, "This is the thing that's helping me." I can't not go because of $85. If something that was important for me to go...it's worth it. It's fine. I didn't feel it was outrageous because at the time I didn't have health insurance, so going to my primary care doctor for 20 minutes of contact

> and two hours in the waiting room cost $75. Here I was getting a full hour, sometimes an hour and a half of a person's time. It's like, you know what? I'll pay $85 for a person to help me and actually have face time with me for this long. "Are you worried about anything? What's on your mind?" Like someone who really tracked all elements of your life into what he was doing to help me. I valued that, and I think, "Yeah, I'll give this guy 85 bucks for that." It was...you know, that's how I judge the cost factor. It's not just the number sign. It's what I get for the number.

About a third of the patients in this sample found the price of acupuncture prohibitive. For some, like Georgia, it was a constant struggle to justify the price of acupuncture to herself. She said, "I see Caroline once a month. It's $85, it's a lot of money. So that's my biggest obstacle. Sometimes I'm like, "Oh, maybe I should go every other month," but it makes me feel good. I look forward to it. I'm like, "You know, I'm worth it." The price made her doubt the necessity of acupuncture, but in the end she decided that she needed it. For others though, the bill meant that they had to cut back on acupuncture, or look for discounted ways of receiving treatment even when they found pain relief in it. Amber cut back on going to acupuncture due to cost. She said, "Naturally it [cost] is an issue, because right now we have insurance with a $6,000 deductible. So anything that I do, I have to pay for and we have no coverage for prescriptions. I just had a little surgery on my toe last Thursday, I had to pay the whole thing out of pocket. So the thing that I have on my neck with this lymph, I should be going more times per week, but I can't afford it. So I don't." The same reserved approach was expressed by Amy who said, "I have to pay out of network for it. It's expensive. I don't have a problem right now doing something like that. The every two weeks works for me. I would tell you that I probably should have gone this week, to see her. But I didn't do it." For Amy, visiting the acupuncturist twice a month was her limit and while she may have needed more treatment, she was unable to afford more. For others, like Daphne, they experienced a change in financial status and went from being able to handle the cost of their acupuncture treatment to a monetary circumstance that did not allow for it. Daphne was able to seek out a discount in order to continue with visits. She explained, “I had to pay [out of pocket]. Although, I have to preface that, I was in a very lucky position because my husband worked, I was working, we both had health insurance. We both had incomes. Now that I'm retired and I don't have that income there’s a couple of times I've said, ‘Ted could help me out with this?’ because I don't have that disposable income.” Negotiating the cost of acupuncture treatment was not unheard of. Whether it was patient-initiated, or practitioner-initiated, alternative payment arrangements were made that suited the patients’ needs and ultimately made it more affordable.

For a few respondents who struggled with the cost of acupuncture, they indicated that the acupuncturist “helped them” with cost of treatments when they were unable to afford it or pay on time. Some people were able to pay a discounted rate, and for others it was a matter of asking the acupuncturist to accept payments later than the date of the office visit. Amber explains how her acupuncturist insisted on giving her treatment even though she could no longer pay him. She said, “Then it got to a point where my insurance didn't pay for any more visits. Then that got too expensive and I stopped that. I have confidence in him, I trust him. He's a wonderful human being. He works with you monetarily, because we fell on some hard times and he still insisted on treating me. [laughs] I said to him, "I can't come anymore because I can't afford this!" He said, "Don't you tell me what you're going to do. [laughs]” In Courtney’s case, the acupuncturist allowed her to make late payments. She explained, “It's kind of a little expensive. He was good. He helped me out a little bit. I'd be like, ‘Oh, can I pay you this week because I get paid this week?’ He was like, ‘All right, no problem.’ That was also comforting because a lot of doctors are like, ‘No, you've got to pay on the spot or you're going to get charged like $10 extra.’”

One patient stopped going to acupuncture altogether because of the cost. Nancy was actually thankful that her doctor recommended physical therapy for a treatment in her most recent bout of pain because physical therapy, unlike acupuncture, is covered by her health insurance. She said, “Then at the end of last year, probably in maybe November, I would say, my neck started hurting me again. My doctor sent me to physical therapy and that really helped. Because very honestly, the acupuncture is expensive and it's not covered, and it waived my insurance. The consult was $135, and then each visit was $80, and three times a week, that's a lot of money, for anybody.” She did not employ any of the cost-altering tactics that a quarter of the sample did and was the only person that was captured in this sample who found the cost of treatment exorbitant to the point of not returning.

Interestingly, cost was an issue for many of the participants, but like painful needling, most endured it, because they were pleased with the results that it brought them. Both pain and cost were deterrents that did not entirely discourage acupuncture use, yet they did bring the participants to judge whether the disadvantages were worth the discomfort and inconvenience. Weighing the costs and benefits also reveals just some of the continuous decision-making that healthcare consumers experience when beginning their acupuncture journey and while continuing to use the treatment as well.

Becoming Believers and Other Changing Perspectives of Health

In addition to understanding narratives of pain of patients and their navigation of treatments, I wanted to understand how interaction with a new modality of care could affect their outlook on health, or future decisions regarding healthcare. Resocialization can be loosely defined as the process of learning new attitudes and norms required for a new role. Here the role I'm referencing is the healthcare consumer. It was clear that many patients, as an effect of "getting lost" in the medical system, had felt the need to step up and take control of their treatment and overall approach to health. This desire for control varied from a belief in having a positive attitude to dramatic overhauls of how to eat, exercise, and use medications. This meant becoming educated about their illness/injury and often, advocating for what they needed and sometimes meant dissenting from medical opinion. Often, it included adopting a more natural lifestyle with regard to nutrition, medication, and the use of acupuncture. In some cases, it appeared that people experienced transformative changes, and for others it appears that they were finally able to freely enact their long-held, deep-seated beliefs more confidently.

Openness to and Confidence in Acupuncture

When I asked the participants if they felt they had encountered any changes to their health care beliefs as a result of using acupuncture, the majority (15) believed that they had become more open to acupuncture as a treatment for pain and for other ailments. The remaining proportion of the sample had already felt open to acupuncture and alternative approaches to medicine. For example, Amy, who exhibited proactivity in her nutrition and exercise regimes, felt that her beliefs about medicine were long-standing. She explained, "I think they've always been along the same lines, as far as trying to heal yourself. I don't think it's changed. Because I've always been that way. That's why a person would seek out acupuncture, maybe. Because they are knowledgeable in becoming healthy, at functioning the best they can for the rest of their life. It's just part of their regime. It's like trying to drink enough water. It's just part of the routine, part of something that you add to the program." For Amy and others like her, acupuncture fell into their long-held beliefs structures about how to treat the body. They had little to no learning curve and little skepticism. Most people were not initially open to acupuncture though. Referring back to earlier in this chapter, most of the participants with whom I spoke were skeptical of acupuncture. Now that they were well into treatment, I wanted to know if their doubts and suspicions had changed.

I began by asking them about their confidence in acupuncture as an effective treatment for their pain. Four people felt moderately confident in acupuncture, meaning that they were unsure as to whether they were feeling benefits from acupuncture with regard to their pain symptoms. The rest of the sample rated their confidence very highly. When asked the question "Are you confident in acupuncture as an effective treatment?" their responses resembled the following: "100%" and "yes, definitely". Confidence and approval of acupuncture were also garnered by asking the participants how likely they were to use acupuncture in the future. Even the people who were moderately confident in acupuncture's efficacy, like Matthew, expressed a willingness to be treated for additional illnesses or health-related problems that might occur in the future. Matthew said, "I think I'm more open-minded towards the acupuncture if I had some other ailments besides the back, if I had a sinus or I had a real stiff neck or whatever, and I think if they zone in on this thing, they can get some results. I'd be more receptive to that than I would have been before." Seeing that most of the patients were originally skeptics of acupuncture, this shift in belief shows their "buy in," or newfound belief in acupuncture's efficacy. Richard also took a chance with acupuncture and began seeing the treatment as essential to his healthcare. He explained: “I don't exactly know if it's made big changes in my life in that direction except that now I really believe in acupuncture, definitely for myself. It's a lifetime choice. As long as I can afford it, I definitely want to [use it]. Right now, I'm pretty much in intensive treatment and eventually we hope to be able to just go for tune-ups. I feel a big difference when I leave there. That would definitely incorporate in the rest of my health care for the rest of my life.” While Richard and Matthew can envision themselves utilizing acupuncture in the future, some participants alluded to replacing conventional approaches to medicine with acupuncture. Courtney was one person who expressed that she became aware of treating sickness naturally, rather than using a medication approach, by using acupuncture. She said, “I feel like I would rather do that [acupuncture] instead of some help that could maybe mask it. It's more of a holistic way because you're not having any drugs. You're not feeling weird. You're not having any side effects.” As evidenced in the previous chapter, there were quite a few people who expressed the desire to treat their illnesses without medications and for some, the discovery that acupuncture could do that was meaningful and changed their perspectives of health. Jane explained that in the process of going to acupuncture to treat her neck pain, she learned that medications, with their quick fixes, were not the solution:

> It has to be definitely part of my regime, has to be the acupuncture, because I've seen the results. I have lived where I had all these pills, these muscle relaxers and stress pills. I was popping pills, and I still had pain. So, I know that that was not the total story. On the other hand, I know that the acupuncture...it took a while. I'm an instant person. I was like, "Put the needles in, I don't have time, make me better, I've got a lot of things to do." I thought that that was how it was going to work. I understand how I have to work with it.

Jane’s excerpt coveys what about half of people in this sample experienced: acupuncture changed their beliefs toward how to treat pain with regard to medication as they came to understand acupuncture as a viable replacement for (some) prescription medications. The other half of the sample seemed to initially approach acupuncture with that desire to treat things naturally already intact. For those who seemed to already hold minimalist views toward medications, the acupuncturist really seems to foster and support that belief. For example, Keith was relieved when he learned that the acupuncturist was on board with eliminating medications that were treating his nerve damage:

> I didn't know what to expect because I've never been to one (acupuncture office) before. I went in and...He looked over everything, and he said, "Let's get everything level again. Your body is out of control. Your pain receptors are the only thing that's functioning. We have to stimulate stuff to get blood flow and feeling. You can't walk around with no feeling all the time." He was like, "This is what we'll do. You don't want to take any of the medications? I think that you can achieve the same thing without them." I was like, "Good."

Keith had been searching for a non-medicinal way to treat his pain and the acupuncturist was the first of healthcare professionals that he encountered that seemed to uphold and agree with that approach. He was relieved to find a like-minded person who believed that medications were not the only answer.

Changes in attitudes toward health weren’t limited to just cutting back on medications. The importance of acupuncture in people’s lives became clear as some people even began to view the acupuncturist as their primary care provider.

Acupuncturist as a General Practitioner

A general practitioner is usually the first contact in healthcare for non-emergency cases of illness. With the exception of a few participants who saw emergency room doctors or acupuncturists, the participants started out at their general practitioner with complaints of ongoing pain. This common practice (to use the GP as home base) was beginning to change for about a quarter of the sample who said they had started to go to acupuncture first for their ailments (pain related or otherwise). Nancy told me that she prefers a natural approach and that going to acupuncture opened up this option for her. She said, "Before the acupuncture, I would go to the doctors. With acupuncture, my tendency is not to run to the doctor first, but to go to acupuncture." Similarly, Jane had come to view her acupuncturist as her primary care provider as she had other treatments in addition to the original pain occurrence over the years. Going to the acupuncturist repeatedly, with good results, had proven to her that the acupuncturist was the best place to start. She explained, "I would say a lot of my symptoms are a result of the stress. So when I get the headaches and I get the pains in the neck then it's all stress related. I can tell that it's stress related. That's most of why I go. I have this carpal tunnel and he works on that. My sinuses...I have a lot of allergies, and sometimes I'll go in and he'll just work on my sinuses. So I generally go to him almost like you would go to a GP." This was not to say that patients no longer saw their conventional medical doctors. Gabrielle explained how even though she was compelled to see her physicians for the ailments that afflict her, she had come to put her trust in her acupuncturist. Essentially, he became her "go-to" person for all health-related questions and concerns:

> I see the other doctors because I have to. But he [the acupuncturist] is my primary. He really is. He's just so knowledgeable. He's my main source now because he's got the know-how as for what is best for me. Clark mentioned an antibiotic which she told me where to get it and everything and Vincent says he's got something better so I didn't even have to go to the store. Same thing. It seems with all my doctors now I take what they say with a grain of salt and then I go to Vincent to get the real facts. That's with everything. My rheumatologist.

> Everything, really. I asked Vincent, this is what he's suggesting. Then I go with what Vincent says. He's never led me astray. Never led me astray. He's so honest and I like that.

Gabrielle's comments provide additional insight into the desire to utilize acupuncture in a way that resembles a general practitioner. The closeness of their relationship was central in how she decided where to go when she was sick. While Gabrielle and those like her were a minority of the sample, it is important to make the case that some people changed the way that viewed medical authority and the way that they seek out healthcare providers when getting help for sickness.

Conventional-Alternative Partnership

Along with an expressed appreciation for acupuncture, the participants in this sample desired partnerships or collaboration among the various types of health-care providers with whom they interacted. Several people wanted to see more collaboration or coordination between conventional and alternative systems of medicine. They felt specifically that patients would benefit if medical professionals could learn about and recommend CAM to those who could use it. Georgia expressed this when she said: "Yeah, and I believe that there should be a partnership between a holistic doctor, or practitioner, and a physician, absolutely. I think these options should always be offered to the patient. I think that to empower the patient more, by giving them other options is the biggest limitation in the healthcare system right now. Then again, it's also because things aren't covered and they're expensive." Georgia underscores a desire that nearly three-quarters of the sample expressed -- the ability to have both sides of the coin (alternative and conventional modalities of medicine) working in conjunction as an integrated system. For Jill, who worked among medical professionals and had herself been skeptical of alternative medicine, found that her experience with acupuncture had challenged her long-held biases:

> I always thought that things like that had a potential, but it just confirmed for me that it did. I had never tried it and I used to think, "Oh, needles, it look so awful." It gave me the creepies, but after all the other things I went through, those little needles were nothing. But no, it definitely opened my mind more to...That there's things we don't understand. That doesn't mean it doesn't work. Maybe they should be putting more time instead of fighting it, into figuring out why it works for some things. Get some numbers and why is it working?

As this interview excerpt suggests, not only did many of the participants become believers in acupuncture, but they are also advocating for it to be considered alongside conventional medicine, which has been the authority in medicine for their entire lifetimes. Their desire to see change in this system that largely does not condone alternative approaches not only reflects their firm belief of acupuncture as a valid treatment, but also values it by ideally placing it alongside mainstream medicine.

Critiques of Conventional Medicine

In summing up the interview, I asked the participants a question aimed at understanding their perspective toward the medical sphere and what they would like people in the medical profession to know about pain. I asked, “If you could say one thing to medical doctors or researchers who are trying to understand chronic pain, what would you say?” The question was not necessarily intended to elicit a critique of the medical system, but essentially the responses were focused on changes that the participants wanted to see and were often directly linked to their personal journeys navigating the medical landscape. Their commentary was not a condemnation of biomedicine, but rather a plea to alter the way that doctors and researchers approach chronic pain. Their responses centered around three main directives: (1)

be open to alternative forms of treatment; (2) attempt to treat pain without medications; and (3) listen to the patient and treat the person holistically. These requests cover some of the topics that have been addressed in the previous chapter, but give a sense of what it all boils down to – that is, what patients of acupuncture really need and want based on their experiences navigating to alternative medicine.

Be open to alternatives means of treating pain

Almost half (9) of the participants spoke directly about what they conceived as a boundary or blockade between conventional medicine and alternative health. On their pathways to acupuncture, they had encountered trouble finding pain relief in the initial stages and it was not until they encountered acupuncture (through various means) that they found some relief. Even for people who felt that they had the support of their physicians, their focus was on opening this barricade in which information about alternative medicine is not exposed to chronic pain patients within the medical world (they recognized that not all doctors are as open as theirs). For the majority of these participants, information about alternative medicine was not easy to come by and it is clear that they felt that they could have benefitted from the information or recommendation earlier in their plights to relieve their pain. Heather, who had recently begun to see a naturopath for her integrated health needs, said, "I wish doctors would be more open-minded about alternative medicine. No medical doctor has ever suggested to me to go to a chiropractor or try acupuncture. No medical doctor has ever suggested that. You're really out there alone." Amy similarly craved that information and suggested that doctors should be more knowledgeable about alternative methods. She said, "I would tell them to be open and to research other modalities to eliminate the pain." Beatrice also suggested that physicians who were not educated in alternative means were perhaps behind the times. Her response, filled with frustration, went like this: “Get with the program, just get with the program! Listen to people, just listen to them. All you can say. You need somebody who's really into it, you know? They aren't. You kids will be. You're the ones…” In addition to illustrating the tension that exists for the patients feeling “out there on their own,” her statement also reveals what she believes is a generational difference in the way that medical doctors treat patients. Her son was studying to become a doctor and she saw hope in the next generation of physicians to include alternative medicine in their practices, but had little hope for the current regime of doctors.

Richard, a veterinarian, actually invoked medical terminology when he explained why acupuncture should be made more available to patients who are suffering with pain:

> To me, the simplest thing is try it. It might help you. It's not going to do any harm. Maybe I don't know enough about acupuncture. But I don't see any areas where it would do any harm…In my humble opinion, it does no harm. Like the old medical thing. First, do no harm. With acupuncture, that's a very good way to look at it whereas with some of the stuff that we do in regular medicine -- I'm only speaking about veterinary medicine -- can do a lot of harm. It can do a lot of harm…But the way I see it, it first does no harm.

Matthew took this a step further as he envisioned his multiple practitioners working together for his benefit. He not only wanted his medical doctors to be open-minded and cognizant about alternative medicine, but he actually wanted to see some integration of the modalities:

> If I was talking to an orthopedist and I was going for my back, and I was doing all of these things, I would tell him, "Yes, I'm going to acupuncture. Yes, I'm still going to a chiropractor" or whatever. I would say, "You guys are all working in conjunction to get me better." I would tell them, show it up. If I get better, even if I wouldn't know who did the best, at least I tried all three and it worked. The end result is that I'm feeling better and that's the reason you go to a doctors, or

> acupuncturists, you want to get relief from whatever problem that you have. I think to get two of them working in conjunction isn't a bad thing.

In fact, when I asked the participants if they wanted to see collaboration or merging between conventional and alternative medicine, very few people experienced scenarios in which their care providers had communicated on their behalf but the majority of people desired something like that. For example, in speaking about the different modalities of medicine, Jane said, "They're not exclusive. They should be, I think, in a perfect world, really inclusive and intertwined." Samantha also thought this was the case and that having collaboration between the systems of health would advance care providers' abilities to treat patients:

> It's like our body and the systems are all working together or not functioning together. [laughs] To have a doctor just looking at one thing, which drives me crazy about the chiropractor...I heard this saying, probably in grad school. Something about if your only tool in your toolbox is a hammer, you look at every problem as a nail. If you're a surgeon and that's what you learned, you look at everything surgically. [laughs] If you're a chiropractor, you're looking at everything related to the spinal cord. That's what drives me crazy about doctors, because they're so pigeonholed into one thing.

Jill also expressed the desire to see more integration between the two worlds. She said, "I definitely believe in all those things, and I think there's a place for it. That's why it's complementary medicine, and I think it belongs in every medical center. I would like to see them bring it back here, but we'll see what happens. I'm here for 30 years. I've seen it come. I've seen it go. So far it hasn't come back...". These patients could not find and participate in formal integrative system of medicine that melds conventional medicine with CAM, but they essentially invented it for themselves by using both systems of medicine concurrently.

Treatment without Medication

Aside from the faction of participants, who wanted to be given the option to use alternative medicine, a quarter of the people had a message that addressed another aspect of treatment. This group wanted physicians to focus less on medicinal resolutions to pain and instead to look at the causes of the pain. They felt that there was a tendency to rely on prescription medications to manage or placate the pain, but these patients actually wanted more than that. They wanted to know the core causes for their pain and resolve them for long-term solutions. Jacob was someone who had dealt with back pain for over 30 years and had tried different (medicinal and non-medicinal) approaches to pain. He offered a message to doctors and researchers: “Don't be in such a rush to prescribe drugs to people. It's not the cure-all and it becomes a crutch. I think no matter how you gloss it over, all it's doing is masking the symptoms. You have to get to the root cause. The symptoms is not the way to go, but I think that's what they do. So I think I would say to them, Don't rush to the drugs. Try these other alternatives. There's so many other ways out there." Jacob’s natural approach toward the body was substantial is his refusal to treat his chronic pain with medication. Georgia, like Jacob, was a strong advocate of natural remedies and took a non-interventionist approach. She believed that natural remedies could be substituted for medicinal treatments. She explained:

> It would be to educate them [physicians] on other options for long-term treatments that don't rely on drugs, because I think part of the acupuncture, and other things, they're based on the understanding of pain. The pain and the body, I don't know if they [physicians] are taught that in medical school. I think it's important that you should be aware of other things. Even just like that, if a patient comes to you and says, "I'm all stuffed up." Well, have some honey. It's known to work. Don't go for the Robitussin. Don't immediately grab the crazy, powerful decongestants that aren't really good for you.

Keith similarly thought that less invasive methods could be used, but felt that doctors are simply not trained in these types of home remedies. He said, “The first thing is that they're not trained in how to deal with it. No matter how much school they go to, if they're not in pain then they won't know how to treat it. There are far more people with minor pain that could easily be treated through hot compresses, changing their lifestyle, eating non-inflammatory foods. Even like with the gluten thing. It's creating situations in their body where they're getting rheumatoid arthritis symptoms, but it's not really rheumatoid arthritis, it's allergies.” Nancy expressed yet another element of the message. In her previous experience with doctors, before finding her current general practitioner that is holistically-inclined, she had been through the pitfalls of taking medications with bad long-term effects: “For chronic pain...don't just treat the pain but get to the root of the problem. Not just treating it. That's superficial. But getting to the root of the problem -- why is this happening?” In looking at the origin of pain, with less focus on treating the symptoms with prescription drugs, the participants were really speaking to another aspect of care: treating the patient like a person.

Listen to the patient and treat the person holistically

Another area of participant responses concentrated on the patients’ feelings of being heard and properly evaluated by their physicians. About a third of the participants spoke about a lack of listening on the part of physicians who treat chronic pain in a limited way – that is, when physicians assess people’s symptoms only and do not inquire about other possible contributing factors. They felt that listening to the patients and analyzing all aspects of their lives, including emotional, nutritional, and lifestyle aspects, was important for gathering all of the pertinent information to understand pain and how it affects the patient’s life.

Courtney was one of the people who felt that her doctors had not listened to her. She said: “Just listen, to be open, and not jump to conclusions. Like, ‘Oh, it's this kind of headache, or you're dealing with this.…It’s like I know nothing. It shows an ego thing, I think. That's the main part of just listening. Some doctors what they do when they hear one or two things, and they got it. They're automatically right.” Her comment conveys how she felt that she was not heard by the specialists who examined her but also that her input was not important to their decision-making and treatment plan.

Jane, who had mysterious neck pain and stroke-like symptoms, addressed the importance of incorporating material about a person’s life into an understanding of where pain comes from and how it could be treated:

> I think to look at the whole person, and where the pain is coming from. I would say to them, if you're researching pain and you want to find out what's causing the pain and what could relieve the pain, you have to look beyond the biochemical side. I think you have to look at the full person in their life and the stress in their life. That's the balance. What I would say to the researcher is, there are certain things that absolutely, positively, you're going to take a test, you're going see you have to remove it, or you may have an antibiotic you have to give for it if you have an infection in something. But there are also other things that people may come to you with, pain that is beyond just the result of a test, and that you should be open to some of these alternatives that can address it.

Jane’s excerpt also highlights another concern that many patients had, which is the fact that diagnostic tests (x-rays, MRI’s CAT scans) may not show, and therefore validate their symptoms. This can be disconcerting and oftentimes a point of departure for the patient who is not able to be helped by that doctor.

Furthermore, Francis suggested that there are other indicators of chronic pain that can be seen by inquiring about the person:

> I would say, look at the whole person, because if a person has chronic pain, it's going to age them. It's going to inhibit their ability to go to work and have a functioning lifestyle. Chronic pain makes you irritable, angry, interferes with inter-human relationships, your ability to take care of your pets. It encumbers every part of your life. Someone comes to you and says, "I have chronic pain in whatever body part, or in however many body parts," don't look at the part, look at the person, because if everything's going to be impacted then everything needs to be corrected. Chronic pain is a person's problem. Not like a limb, or a neck or a nose. It's a huge impact on your life. Everything needs to be addressed.

Samantha added, “One thing is to not look at things so narrowly and to try to research a little bit more, have a more open mind towards causes of pain as well as treatments. But also to listen to the patients and hear what they have to say. And not assume that, nowadays especially, they're making up the pain to get a prescription and stuff like that... If these people knew what it felt like to have pain every day, they would spend a little more time listening to their patients and trying to find soothing that's going to relieve their pain.” Samantha’s response not only impresses upon the same notion as the women above, in which patients are viewed narrowly, but also points to another issue -- that doctors do not have empathy or compassion for their patients. While they were a small fraction of the sample, a few people wished that doctors understood how it feels to have pain with the implication that they might treat their patients differently if they did. When I asked Melissa what she would say to chronic pain doctors or researchers, she said:

> Melissa: Live with it.
>
> MC: Live with it?
>
> Melissa: Live with the pain...and see why it feels like it does, and what you can do to make it feel better. You cannot know what chronic pain is, unless you've got it, or had it. It's so easy to tell somebody what to do when they've never felt it.

Melissa did not believe that doctors had a good understanding of pain and this quote underscores how she did not think they knew how to address pain appropriately for their patients. Daphne, who similarly felt that doctors were not acting compassionately, also made a poignant statement about pain and the patient-practitioner relationship in which she revealed that her physicians did not initially believe that she had physical pain. She said: "I would wish that you could not inflict pain on people. But if you could...A lot of times, like when I was very young and I had the degenerative discs in my lower back, it took me a long time for someone not to ask me if I'd been depressed lately. Because I was a woman and I was too young to have something like that be happening. It's too bad we don't have a facility to have real physicians be in pain or to find that you have pain. Or trust that you have pain…" She would like to see more trust and understanding between patients and doctors.

Conclusion

In this chapter, I have presented data on the multiple aspects of patients navigating their way to acupuncture and how they are socialized into being alternative medicine patients. Few people knew anything about acupuncture at the start of their treatment. Acupuncture was a peripheral option for those to whom I spoke and it took a key informant to know it was there as a possibility. While some patients were informed about acupuncture by their medical doctors, most people proceeded with caution around physicians with regard to their acupuncture use because they were not certain if their doctors would approve of using an alternative method. Furthermore, the participants did not feel that they needed approval from physicians to use acupuncture and therefore exhibited some autonomy in choosing their healthcare treatment. Most of the participants were initially skeptical of acupuncture as a treatment for their chronic pain and many invoked terminology that suggested that they were desperate for help given their complex treatment histories. Deterrents to continued use of acupuncture included painful needles and the cost of treatment, both of which were widely tolerated and justified as necessary to receive pain relief in the long run.

Definite changes in attitude toward acupuncture could be noted. Participants became more open to acupuncture as evidenced by their rating of confidence for its efficacy and by their willingness to address other ailments with acupuncture. This exhibited their “buy in” and their ability to view acupuncture as a viable treatment, one that several people began to see as their primary form of care. Many people wished for an integrative system in which conventional and alternative forms of medicine could be accessed together, or in partnership with one another.

When the participants were asked what they would want doctors and researchers to know about chronic pain, their responses reflected a critique of the medical domain. Patients clearly felt that medical doctors were simply not open to alternative medicine, relied too heavily on medication to treat pain conditions, and did not listen to patients. For many of those interviewed, the response was that their physicians hardly treated them in holistic terms. Their pleas for change in medical treatment certainly echo the challenges that they have faced in their pathway toward pain resolution and suggest that at least some part of the pathway to -- and continued use of -- acupuncture is about taking control of their healthcare and finding benefit and preference in an alternative form of care. Acupuncture, then, in its role as an alternative to tradition medicine, offers patients an opportunity to both express dissatisfaction in their physicians and the hope they themselves can triumph in recovery.

Chapter 6: Discussion

This final chapter restates the research questions, reviews the major methods used in this study, summarizes the results of this research, and discusses their implications in connection to previous research and theoretical contributions. The chapter ends with a discussion the limitations of the research and a plan for future research that seeks to overcome identified weaknesses.

Research Problem and Methods

The purpose of this study was to understand the health beliefs and behaviors associated with engaging with a non-conventional system of healthcare and to reveal the dimensions of treatment choice important to chronic pain patients who choose to use complementary and alternative medicine for pain relief. Further, I intended to uncover whether these patients exhibited unique qualities thought to be associated with complementary and alternative medicine and if those qualities are obtained through a process of socialization by engaging with a new modality of healthcare. I investigated these questions with two methods of data collection. First, a survey-questionnaire (n=98) was designed to elicit information from chronic pain patients utilizing pain management or acupuncture for pain relief. The survey addressed several aspects of treatment seeking as well as ratings of health-related proactivity and patient centered care. The results were used to differentiate the pain management patients from the acupuncture patients on key measures identified in the literature about chronic pain and alternative medicine. The second stage of research entailed in-depth interviews with chronic pain acupuncture patients (n=20). With interview questions built on the first stage one of data collection, the results provided data that could situate and further describe the findings from the survey. Together, this mixed methods approach allowed me to combine the data from the two methodologies and use the descriptive strength of the interviews to explain and bolster the quantitative findings.

Summary of Major Findings

It was hypothesized that acupuncture patients would have more difficulty finding diagnoses than their pain management counterparts. This hypothesis only found marginal support in the survey because both acupuncture patients and pain management patients had variation in the length of time that it took to receive a diagnosis, but acupuncture patients were more likely to see more health care providers prior to diagnosis. In the interview portion of the study, there was a similar variation in difficulty of obtaining a diagnosis; some people were able to secure diagnoses relatively quickly and without confusion, and others struggled to be diagnosed (having to pursue multiple doctors and forms of diagnostic testing). Most of the acupuncture patients had received diagnoses by the time they arrived at acupuncture and at that point they were focused on pain relief.

The survey results were used to differentiate acupuncture patients from pain management patients on three CAM-espoused beliefs and characteristics: naturalist orientation toward healthcare (measured by the number of medications a patient takes for the chronic pain ailment and the use of homeopathic remedies); proactivity in healthcare (measured with a proactivity self-efficacy scale developed for this study); and patient-centered care (measured by a patient-centered care evaluation scale developed for this study). All tests of difference were found to be statistically significant, showing that acupuncture patients (and their providers) were more likely to exhibit the characteristics of CAM. Acupuncture patients were more likely to use homeopathic remedies and fewer prescription medications and were more likely to judge themselves as proactive with regard to their healthcare. When it came to treatment, the acupuncture patients were more likely than the pain management group to rate their care as patient-centered. The interview portion of this study found extensive evidence for the same. With regard to medication, acupuncture patients had often been unable to find reliably effective medications and were concerned with side and long-term effects of using medications. In addition, they felt that taking prescribed medications was masking the problem, when they really wanted solutions. Moreover, acupuncture patients expressed the desire to use natural remedies liberally, often of their own volition. Those who were most adamantly against prescription medication were most outspoken about homeopathics and nutrition generally. Acupuncture patients demonstrated their proactivity by changing aspects of their lifestyle (namely diet and exercise) and seeking out additional treatments in order to get better. They demonstrated their ability to make decisions about their own healthcare. With regard to patient-centered care, the people who used acupuncture were very satisfied with the time and intimacy they shared with their acupuncturists, which led them to feel that the treatment was tailored to them as individual persons (in a mutual participation model as described by Szasz & Hollander 1956).

The sample of acupuncture patients was a mixture of people who were using acupuncture for the first time and those who had used acupuncture in the past. Personal and professional referrals seemed to be significant to the patients in becoming aware of and deciding to use acupuncture. While some people tried acupuncture because of the recommendation of their physicians, most people in the sample did not feel that they needed a physician's approval to use acupuncture and many did not inform their physicians about it. This information was often kept private due to perceived negative opinions of acupuncture held by physicians and indicated a desire on the part of the patient to act autonomously in choosing acupuncture as a treatment. Most of the participants were skeptical of acupuncture and had little information on which to base what treatment would be like. The leap of faith to try acupuncture was influenced by the fact that for the majority of the participants acupuncture was viewed as a last resort; patients described themselves as being desperate for pain relief. Needle discomfort and cost were the two most often cited deterrents to using acupuncture however; both were endured for the majority of the sample in order to continue to benefit from the acupuncture treatments.

Having used acupuncture, most of the patients were no longer skeptical of it as a treatment for pain. This change in attitude was evidenced by their willingness to continue to use acupuncture, even for different ailments, in the future and some people who had already come to view their acupuncturists as their primary care providers. Furthermore, patients advocated seeing conventional practices adopt or condone alternative medicine in a more integrative system.

Finally, when critiquing the medical sphere, the acupuncture patients expressed three main areas where they wanted to see changed. They wanted doctors to be more open to alternative medicine, which was related to a desire to treat pain without prescription medications. They also wanted health care practitioners to observe their entire personhood when evaluating pain and really listen to them.

Interpretation and Discussion

In this section, I revisit many of the literature-based theoretical and research claims introduced in Chapter 2. Specifically, I want to address how my findings validate, criticize and extend the theoretical contributions of three popular and noteworthy theoretical perspectives: illness narrative; the sick role (and deviance); and medicalization to advance an understanding of the role of CAM therapies in contemporary society.

Illness Narrative

CAM therapies have been largely invisible in the literature regarding chronic illness. This is likely because biomedical approaches are so dominant and so widely used, while CAM remains at the periphery of medicine and thus not viewed as a primary form of care. This is the case for the literature on illness narratives as well. Illness narratives tend to focus on biomedical patient experiences. While, illness narratives shed light on the experience of pain and disease, they also report on the cultural acceptance and legitimacy of pain, which, in the medical realm, has been challenging and disparaging for patients. As I have found in my interviews with acupuncture patients, somatization is clearly a different process in the acupuncturist's office as opposed to the doctor or specialist's office. The patients to whom I spoke explained that they could take more time and go into detail about their lives when explaining their symptoms to the acupuncturist. This divulgence was often prompted by the acupuncturist who would ask leading questions to inquire about a person's stress levels, sleeping habits, exercise and nutrition patterns and emotional factors that could influence physical pain. These patients compared this experience with those that they had had previously in doctors' offices, which were described as short, cold and focused on symptoms. The acupuncture experience offered them the room to explain their symptoms, however complicated, and receive recognition of their pain. Most patients had diagnoses in hand when they reached the acupuncture office; however, and most importantly, they arrived without the corroboration and validation of their pain they so desired. For most, it was because their pain could not be helped (for many reasons) by conventional doctors, leaving them feeling contested and as Eccleston and associates called them, like “lost causes” (1997: 700). This sentiment was particularly evident in their statements about desperation for treatment. My research findings suggest that the illness narrative of chronic pain sufferers is modified, or more specifically, *extended* by the use of complementary and alternative medicines because the patients’ stories did not end with desperation. In a way, their stories were just beginning. The conclusion to the illness narrative from this research is wholly different from the prior story, which was often cloaked in frustration, despair, and defeat. I argue that acupuncture extends the illness narrative by adding recognition, validation, and acceptance, which has largely been invisible in descriptions of chronic sufferers’ experiences with care-seeking.

The process of becoming an acupuncture patient entailed learning about and trusting a new modality of healthcare (which was more holistic and relied less on medications) along with the adoption of new notions about one’s involvement in one’s own health. CAM has provided a new pathway for lessening the effects of chronic pain and has given voice to patients who were previously disgruntled and without recourse. Furthermore, their long-term use of acupuncture –whether they are outspoken about it or not - illuminates an inherent critique of medical authority and the byproducts of medicalization (one-size-fits-all care). By showing a preference towards patient-centered practices exhibited by CAM, patients are demonstrating their ability to make choices on their own behalf without the approval of traditional experts and authorities.

Because many of the patients with whom I spoke were initially skeptical about acupuncture, it can be concluded that “pull factors” were not what initially brought them to acupuncture, other than for the hope that it might work. Instead, “push factors”, namely having unmet needs, are what set them in the direction of acupuncture. Only after trying acupuncture did pull factors keep them using it and prompt them to see acupuncture as a valid treatment for other ailments as well. While other researchers (Kleinman 1992, Kravitz etal 1996, Vincent & Furnham 1996, Verhoef et al 2005, Bisop et al 2007) typically acknowledge push or pull factors as important features of beginning CAM treatment, it is novel to think of them as operating sequentially and in coordination with one another. In this study, pull factors were effective in retaining patients rather than recruiting them. The new users of acupuncture discussed the significance of push and full factors clearly when they described how little they knew about acupuncture as a treatment, but later found many beneficial reasons to maintain their treatments, including intimacy with their healthcare provider and feeling that they were viewed as a whole person. The inclusion of CAM in a broader discussion of illness narrative really allows us to pinpoint how monumentally important the patient-practitioner relationship is to patients and how suffering can be made worse by unfavorable relationships (i.e. sociogenic means, or effects that occur due to the social environment or social influences).

Another aspect of these findings, yet to be explored in the literature, is extended use of acupuncture. Once the patients had become accustomed to using acupuncture for their pain condition, they began to see acupuncture as a viable treatment for other ailments -- either with additional current ailments or for more generalized future ailments that *could* happen. The patients seemed very open to using acupuncture more. Their confidence levels in the practice were high and they felt that they could ultimately substitute acupuncture for something that would normally warrant a medical doctor. The majority of people used physicians as well as acupuncturists in a practice called concurrent care (Low 2001), but interestingly some patients had come to see their acupuncturist as their primary care provider. The latter had reduced their visits to conventional practitioners while concurrent users were using two modalities of healthcare separately but making their own judgments on which practice is more appropriate for their conditions (Ruggie 2004).

An additional way that patients in this sample expressed autonomy was in choosing to use fewer medications for their pain conditions. The majority of the people in this sample were quite adamant about their desires to have a more natural approach to pain relief. Many participants were unsatisfied with previous use of prescribed medications that only masked the pain. This finding is unusual for the literature, which is mostly focused on the traditional medical sphere and on people who are looking for any means possible to feel better. In this group, nearly everyone took a conservative approach to pain medication because of possible side-effects, long-term effects or the unnatural quality of such medication. Of even greater importance, these patients wanted real resolution to the pain condition; they felt that prescription medications were not getting to the heart of the matter. They did not want to settle for a method that camouflaged the pain, or did “good enough,” they attempted (and achieved) more.

Having options and decision-making control are deemed by many to be important elements of autonomy and empowerment when it comes to health (Barrett et al 2003). CAM patients are often depicted as being more active and in control as healthcare consumers (Barret et al 2003, Ruggie 2004), and in this study the patients exhibited proactivity in their approach to health by taking control of their treatments and lifestyles. In many ways, they were in charge of their own care and could control which practitioners were needed, oftentimes with the support of the acupuncturist. It is unclear how this control might translate into the larger scheme of their lives, but with regard to health it is conceivable that proactivity in this instance allowed patients to be discriminating about future treatments and motivated to make choices about their health.

Sick Role and Deviance

The ironic aspect of having newfound options for pain relief is that the patients find legitimacy from a healthcare practice that is perhaps illegitimate in the eyes of the dominant medical field. There is no question that chronic pain acupuncture patients experience stigma in the course of their care-seeking. They are doubly labeled in that they have pain that does not go away quickly and they are using a treatment that is not mainstream. This labeling process leads us to the question: Can using complementary and alternative medicine fulfill the requirements of the sick role if the practice is outside of the scope of normative medicine? In the sick role model, whether someone is labeled *deviant* depends on the medical field substantiating claims of illness and giving instructions to patients on how to recover quickly. Complying with a medical professional creates an acceptable way for people to become temporarily, situationally and acceptably deviant. In doing so, the sick person is allowed to forgo their responsibilities and generally be dependent on others (physicians and social support) for their caretaking, which is seen as beneficial toward their recovery. Using complementary and alternative medicine, like conventional medicine, succeeds in carrying out many of the attributes of this theory. First, patients demonstrate a desire to become healthier by visiting a practitioner of complementary and alternative medicine. And, because complementary and alternative medicine is known to have a proclivity for preventative medicine, they may even be considered functional, preferential behaviors to prevent sickness and to obstruct or delay the sick role from being necessary. Second, patients withdraw themselves from society for a short amount of time while they recover from their illness. Chronic conditions can cause interferences in being able to return to work and function normatively in society, but this delay applies regardless whether someone uses conventional or complementary and alternative medicine (the sick role has been criticized for not encompassing chronically ill patients 2008, Glenton 2003)). Third, the patient must be under the care of a physician. While patients of complementary and alternative medicine may spend more time with their care providers, the actual practice of visiting health care practitioners does not vary substantially from conventional medicine. Using a new form of healthcare, like acupuncture, follows the traditional pattern of practitioner-assisted help seeking, except that, in this case, the expert is not a traditional medical authority. For Parsons and the functionalist perspective, the patients appear to have followed and satisfied the normative steps (aside from using a CAM provider) of recovery. For social stability, the patient has complied with what was required of them and achieved the goal of becoming well. Still, it is curious that patients of acupuncture often feel stigmatized for using non-conventional methods of care, even if it works to make them healthier. For example, the patients in this sample knew few people who used acupuncture, often felt disapproval from their physicians, and were mostly unable to have health insurance coverage for their treatment, which gave them the sense of marginalization. The patients to whom I spoke were well aware of disapproval and/or condescension of medical professionals (and regular members of society). However, it does not appear that informal methods of dissuasion were entirely effective for this group of people. The fact that most of the participants assumed that doctors would not approve of acupuncture yet claimed not to need approval, shows a break from medical authority. This disjuncture is likely because they had conviction in their own judgments, which deemed acupuncture to be legitimate. The patients to whom I spoke wanted to see CAM treated with more respect and legitimacy to the point that they wanted integrative systems of care – putting acupuncture alongside the traditionally dominant medical field. The patients have come to see acupuncture as a perfectly acceptable and effective means of treatment and would authorize it if they were in their control. However, they recognize that the medical field that has the power to legitimate certain alternative therapies (the medical-scientific field) would be unlikely to formally open its arms to acupuncture. The medical field not only has the power to define who is sick, they also define how to acceptably treat it.

Using acupuncture can be seen as strategy for patients to resist a label of deviance for their chronic pain by becoming healthier (as prescribed by the sick role), yet in doing so, they acquired another deviant label of a CAM user. For these patients, the latter may be the lesser of two evils in that it brings about pain relief which allows them to function more fully in society. And as we saw with the acupuncture users in this sample, acupuncture use can be hidden away from the people who might judge it to be invalid as a form of care.

Medicalization and Dedemedicalization

Medicalization is the process by which non-medical conditions come to be seen as medical conditions and are given medical diagnoses and treatment. Inherent in this theory is the notion that definitions of health and disease change overtime. Things that were once immoral or personal failures are subsumed under the umbrella of the medical field. In the case of chronic pain, it may be to the benefit of patients that medicalization occurs (or has occurred) because previous to having a language or diagnoses about on-going pain, they may have been even more challenged to find help – that is, physicians would not have considered their symptoms to be worthy problems. Because, as the literature shows, that diagnosis is another way that validation is obtained by patients (Eccleston et al 1997, McPhillips-Tangum et al 1998 Brown 1995, Mechanic 1999 Kleinman 1988), it is probably good that the medical field has incorporated chronic pain under their umbrella.

Medicalization (and demedicalization) promises us that there will be change in how we judge conditions and how we believe those conditions should be treated. Since the process of medicalization is known to be a stronger force than demedicalization, we can assume that the medical sphere will grow and that there will be a further entrenchment of medical authority (medical professionals and their methods of treatment). Because this one way to treat chronic pain reigns dominant, acupuncture-using chronic pain patients will find difficulty in achieving support and validation for their choice of treatment. Most of the patients to whom I spoke were clearly not fond of the practices and treatments that come along with medicalization.

Namely, the drawbacks of medicalization entailed formal and distant relationships practitioner-patient relationships, one-size-fits-all care, and treatment of pain with an overreliance on pharmaceuticals. These shortcomings are the very things that the patients in this study praised acupuncture for *not* doing. While one could argue that CAM's approach is just another form of medicalization because by definition the expanse of what ailments it treats could be expanding over time, the usual side-effects of medicalization are not as present. In fact, CAM's model of practice seems to conflict with or act as a critique of consequences of medicalization in a few ways. For example, CAM practitioners are known to have more symmetric relationships with their patients, whereby both parties are on equal levels and informality (for example, using the first name of the practitioner) and sharing information about one's personal life is more common (Lowenberg & Davis: 1994: 590). My research participants exhibited equal relationships when they spoke about the closeness of their relationships with their acupuncturists. Alternative therapies are also more likely to stress the importance of preventative and holistic lifestyle changes, including the reduction of stress and improved exercise, nutrition and rest. With this, they are also more likely to address the multi-dimensional causes of illness that are beyond the physical, including the mental, the emotional and the spiritual (Lowenberg & Davis: 1994: 592). The patients in this study found satisfaction in knowing that their acupuncturists were treating more than their symptoms, but their entire personhood as well.

The process of medicalization assures that medical authorities will continue to have the ability to deem CAM as illegitimate. Despite this, people are electing to try and continue to use CAM all the time (for reasons explained earlier). By doing so they are, in small ways, resisting dominant medical opinion. What power do individuals, or the consumers, really have when it comes to rejecting dominant models of healthcare and advocating for alternative ones?

Demedicalization tends to happen from the bottom-up and can be recognized as a social movement. Rather than the institution of medicine revoking its control and expertise in the condition, the initiatives of those who see a lack of a rationale for medical means of treatment are usually the actors in extricating the condition from medical vices. By definition, patients making the move to CAM are not exhibiting demedialization because although CAM is an alternative form of medicine, it is still medicine. Patients' conditions are still viewed through a medical lens, albeit one that may view the body in a different way (More research must be conducted to examine if the shift from conventional medicine to CAM can be classified as "remedicalization", meaning that practitioners and patients reclassify and redefine their conditions through an alternative perspective, including differently labeling pathology, physiology of the body, and origins of sickness (Conrad & Angell 2004)). Beyond definitions, though, demedicalization is an attempt to destabilize medical authority and shift choice and decision-making to patients. Through the process of demedicalization, decision-making authority is allocated away from physicians and toward individual patients. There was indeed evidence for this kind of shift of control in the patients' resistance to accept the conventional approaches to chronic pain. While the acupuncture users in this sample were not overthrowing the system and they were not even grassroots activists, they did carve out a small space in which they took individual stands. Their criticisms of the medical methods of practice point to their abilities to critically discern what is wrong and unhelpful in the treatment of people with chronic pain and how acupuncture, the thing that has improved their wellbeing, is not acknowledged or compensated in a way that authorizes it. For the most part, the patients in this sample had not terminated their connections to medical treatment, signifying some reluctance for now, but they were creatively using acupuncture to fill the gaps of medical care. Consumer demand will drive physicians, insurance companies, and medical research to pay more attention (more than it already has) to CAM in the coming years, but it is unlikely that CAM practitioners (and their patients) will be authorized to play on a playing field level with biomedicine. Ultimately, this means medicalization will continue to make CAM users second-class citizens.

Limitations and Future Research

There are several limitations to this study. These limitations are related to the methodologies used for data collection: representativeness; sample size; and recruitment bias. I will discuss these shortcomings and how they have informed my plans for future research.

Since data were drawn from convenience samples, efforts were made to sample the populations on different days of the week and times of the day in order to capture a representation of the patients who utilize those treatment centers. While there is no reason to believe that the samples chosen would not demographically match that of the larger population (no trends were discerned with regard to those who declined to participate), it is difficult to verify if a sampling bias occurred. No client records were kept at either institution that could be used to compare to the sample I have drawn. Despite efforts to sample the widest breadth of the patients, these methods lead to highly a homogeneous sample with regard to race, ethnicity, and social class, especially at the pain management site. Therefore, on a grander scale the chosen institutions in which the surveys were distributed may not mirror the regional demographics in which the offices are located and therefore may not be representative of all pain management and acupuncture patients overall. In the future, it will be important to sample from multiple pain management and acupuncture offices to capture more diversity in the sample and be able to generalize to a larger population of chronic pain users who seek pain management and acupuncture as treatments.

In addition, the survey and interview samples were limited in their size. Determining an adequate sample size is often a matter of judgment, but of statistical importance too. In the survey data analysis, some hypothesis testing was rendered questionable due to too few cases in the cells. Respondent numbers were largely constrained by lack of access to patients. Future research would be geared at targeting and gaining access to several more offices (of both types) to which the surveys could be distributed and interview participants could be recruited. More patients would lend more credibility to the results reported here.

With regard to the acupuncture interview sample, there is likely to have been some recruitment bias. It is possible that people who agreed to participate further in the interview portion of the research were more likely to like, support, or find benefit in acupuncture. While it is very difficult to recruit people who do not like acupuncture (because they most likely have terminated treatment), it might be important to capture their attitude toward acupuncture and other forms of treatment to compare to those who did continue with treatment. Likewise, the obvious comparison for of the acupuncture interviews would be interviews with a subsample of the pain management patients. While pain management patients were not the focus of this exploratory research (rather they were the comparison group within the survey analysis), their positions would help to substantiate the claims made here about the uniqueness of acupuncture patients' behavior of branching outside of conventional medicine. Therefore, I would like to conduct in-depth interviews with pain management patients to ask them about their decision-making processes and perceptions of treatment accessibility (including conventional and alternative medicine modalities).

In generalizing acupuncture to CAM, it is important to note that acupuncture is a practitioner-based type of CAM and thus a more narrow definition of this kind of health modality. This research can only speak to practitioner or office-based CAM, and not to other forms that are not guided by practitioners, such as vitamin use only or self-help remedies. It would be beneficial to expand upon the types of CAM in future research, including patients who use massage, hypnosis, yoga therapy, biofeedback as well as modalities that are completely self-driven (like using vitamins) to be able to speak about a wider range of complementary and alternative medicine.

The next step in my program of study will be to obtain the perspective of the healthcare professionals who treat chronic pain patients with CAM. Who better to report from the front lines what patients are looking for and how providers can navigate or become part of that pathway process? I think healthcare practitioners would add another level of how differing systems of care (conventional and alternative) conceive of patients, pain, and treatment and thus, further broaden and deepen the research findings by pulling together all players of the healthcare systems. I intend to conduct interviews with certified acupuncturists in order to collect data on the professionalization of the field and perceived discourses with regard to power, status, and roles, in addition to patient-practitioner relationships and techniques of treatment. I plan to recruit acupuncturists initially through online directories and then through snowball sampling. After sampling saturation has been reached, I anticipate interviewing professionals from other practitioner-led CAM fields, including naturopaths and homeopaths). Added to this sample will be interview data from interviews that were conducted previously with yoga therapists. With data from a more diverse group or practitioners, I will be able to make a more convincing argument about the role of CAM in today's healthcare system, its practitioners' views toward patient treatment, as well as opinions and challenges toward integrative medicine. In addition, this piece of the study will allow me to link the micro interactions of patients and their providers (current study) with the macro, or structure of CAM.

Conclusion

One aim of this research was to differentiate chronic pain patients using either pain management or acupuncture on several CAM-espoused characteristics. Another objective was to provide description of these characteristics as well as the pathways that some patients follow as they find and become acupuncture users. Finally, the data were examined to look at the effects of using a new system of healthcare to understand what is learned or what changes for people who adopt a new modality of CAM. I distributed a survey-questionnaire to people who used pain management and acupuncture for their chronic pain. The results were used to differentiate between pain management and acupuncture users and these findings became the basis of in-depth interviews conducted with acupuncture users. These findings added the description that was needed to understand how pain patients navigate to and become long-term users of acupuncture. Taken together, the findings of the research on treatment-seeking for chronic pain tell us how people with chronic pain find their way to acupuncture and become exposed to new approaches and techniques for understanding pain. Along the way, they are drawn to characteristics of the practice that create intimacy among the practitioner and the patient while they receive validation for their pain and suffering. This newfound confidence in acupuncture empowers them to continue to use acupuncture for other ailments, despite deviant labels that they may acquire from doing so. In small ways, their resistance to the dominant medical authorities promises change for the future, yet the force and strength of medicalization casts a picture of continued marginality for CAM and its users. This study has contributed to the literature on illness narratives, patient empowerment, Parsons' sick role as well as medicalization and demedicalization. Patients with chronic pain might benefit from this material by gaining insight into other peoples' challenges in securing pain relief and the validating and empowering prospects of using acupuncture for their own pain. Physicians could surely profit by understanding why their patients have unmet needs and why some ultimately elect for CAM therapies. More to the point, I argue physicians will likely benefit from the knowledge that there is indeed growing demand to seek patient-oriented care (as well as non-pharmaceutical care) and in moving forward in the current climate of healthcare, they will want to proceed accordingly.

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Appendix A: Survey Instrument

The purpose of this survey-questionnaire is to better understand how people make choices about their healthcare in pursuit of chronic pain treatments. Your responses are voluntary and will remain completely confidential. Please answer the following questions to the best of your ability.

First, I'd like to ask you some questions about how you're feeling and your health history.

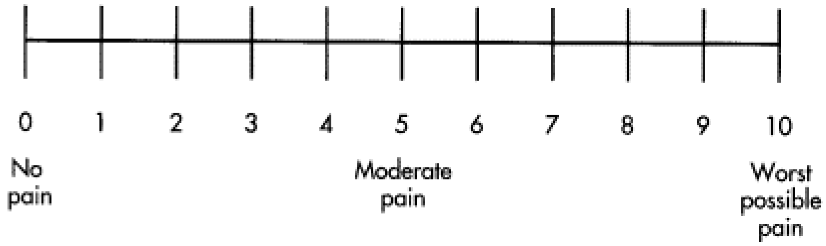
1. How would you rate your general health compared to others of your own age?
    [ ] Much better
    [ ] Slightly better
    [ ] Neither better or worse (about the same as others my age)
    [ ] Slightly worse
    [ ] Much worse

2. How would you rate your general health compared to one year ago?
    [ ] Much better
    [ ] Slightly better
    [ ] Neither better or worse (about the same as a year ago)
    [ ] Slightly worse
    [ ] Much worse

3. How often do you think about your health?
    [ ] Once a week, or even less than that
    [ ] Once every few days
    [ ] Everyday
    [ ] Several times per day
    [ ] Continuously

4. How long have you been experiencing chronic pain symptoms?
    [ ] Less than 3 months
    [ ] 3 months – 1 year
    [ ] 1 year – 2 years
    [ ] 2 years – 5 years
    [ ] More than five years

5. On the following scale (with 0 indicating "No pain" and 10 indicating "Worst possible pain"), please circle the number that reflects the amount of pain you feel on an average day.



6. Do you know the cause of your pain?

[ ] My experience of chronic pain started as a result of a physical injury (i.e. sports injury, car accident, repetitive stress injury, etc…) or an illness (arthritis, sciatica, fibromyalgia, etc….)
Please specify the type of injury or illness: ____
[ ] The source of my pain is a mystery to me.
[ ] Other, please explain: ____

7. How long did you wait before you went to see a healthcare provider for your pain symptoms?

[ ] Less than 3 months from the start of the pain
[ ] Between 3 to 6 months from the start of the pain
[ ] Between 6 months to a year from the start of the pain
[ ] Between a year to 2 years from the start of the pain
[ ] 2 years or more from the start of the pain

8. After you went to see a healthcare provider with symptoms of chronic pain, approximately how long did it take before you received a diagnosis?

[ ] I was diagnosed right away
[ ] It took a short amount of time to get diagnosed
[ ] It took a long time to get diagnosed
[ ] I never received a diagnosis from a healthcare provider
[ ] Not sure/can't remember

9. If you received a diagnosis, who first diagnosed you with this condition?

[ ] General Practitioner (for example: Physician, Physician's Assistant, etc…)
[ ] Pain Specialist (for example: Neurologist, Orthopedist, Anesthesiologist, etc…)
[ ] Mental Health Professional (for example: Psychiatrist, Psychologist, Social Worker, etc…)
[ ] Alternative Healthcare Practitioner (for example: Chiropractor, Acupuncturist, Massage Therapist, etc…)
[ ] Other, please specify: ____________________________
[ ] I never received a diagnosis from a healthcare provider.

10. Did you go to multiple healthcare providers in search of a diagnosis?

[ ] No, I only saw one healthcare provider before getting a diagnosis
[ ] Yes, I saw 2 or 3 healthcare providers before getting a diagnosis
[ ] Yes, I saw 4 or 5 healthcare providers before getting a diagnosis
[ ] Yes, I saw 6 or more healthcare providers before getting a diagnosis
[ ] I never received a diagnosis from a healthcare provider.

11. What do you take for your chronic pain symptoms? (Please check all that apply)
[ ] Opiods/Narcotics (Codeine, Morphine, Oxycoton, etc…)
[ ] Non-Opiods/NSAIDs (Acetamitophen, Ibuprofin, Naproxen, Meloxicam, etc…)
[ ] Antidepressants (Amitriptyline, Nortriptyline, Desipramine, etc…)
[ ] Anti-convulsants (Gabapentin, Pregabalin, etc…)
[ ] Topical Analgesics (creams, lotions, or patches, etc…)
[ ] Muscle Relaxants
[ ] Corticosteroids (Prednisone, Dexamethasone, etc…)
[ ] Nerve block or Neuroblative therapy
[ ] Implanted Devices
[ ] Homeopathic Remedies (Herbs, Roots, Vitamins, etc…)
[ ] Other, please specify: ________________________

12. How would you characterize your ability to pay for the healthcare treatments that you receive?
[ ] It's not difficult to afford the payments.
[ ] It's sometimes difficult, but most of the time I can afford the payments.
[ ] It's always difficult, but I manage to afford the payments.
[ ] It's very difficult for me to afford the payments and sometimes I have to skip treatment.

13. Using the scales below (1 indicating "Not at all Confident" to 5 indicating "Totally Confident"), please circle the number that best describes your feelings on the following statements.

Given your chronic pain, how confident are you that you can…	Not at all Confident		Moderately Confident		Totally Confident
….perform most of your daily activities?	1	2	3	4	5
...enjoy the things that you normally enjoy?	1	2	3	4	5
…go to places that you want to go?	1	2	3	4	5
…maintain relationships with your family and/or friends?	1	2	3	4	5
…cope with mild to moderate pain?	1	2	3	4	5
…make good decisions regarding your healthcare?	1	2	3	4	5
….access reliable information regarding your chronic pain condition?	1	2	3	4	5
…get support from other people when you need it?	1	2	3	4	5
…help other people with a similar health condition as yours?	1	2	3	4	5

In the next section, I'd like to ask some questions about your knowledge and where you obtain it.

14. When you have questions regarding your health, where do you get reliable information?
(Check all that apply)
[ ] Friends or family
[ ] Other people who have similar symptoms
[ ] Healthcare providers
[ ] Internet
[ ] Television, magazines, or books
[ ] Others, please specify: ____________________________________

15. When it comes to making a final decision about your treatment for chronic pain, who is the person that you trust most to get reliable information?
(Check only one)
[ ] Friends or family
[ ] Other people who have similar symptoms
[ ] Healthcare providers
[ ] Internet
[ ] Television, magazines, or books
[ ] Others, please specify: ____________________________________

16. When you don't understand something that a healthcare provider has told you, how often do you ask that person for more information?
[ ] All of the time
[ ] Most of the time
[ ] Sometimes
[ ] Rarely
[ ] Never

17. When you don't understand something that a healthcare provider has told you, how often do you educate yourself on the topic after leaving the office?
[ ] All of the time
[ ] Most of the time
[ ] Sometimes
[ ] Rarely
[ ] Never

18. How often do you trust your "gut feelings" when it comes to your healthcare decisions?
[ ] All of the time
[ ] Most of the time
[ ] Sometimes
[ ] Rarely
[ ] Never

19. How often do you trust the recommendations of your healthcare providers when it comes to making decisions about your healthcare?

[ ] All of the time
[ ] Most of the time
[ ] Sometimes
[ ] Rarely
[ ] Never

In the next section, I'd like to ask you about different forms of Alternative Medicine that you may have used.

20. Please see the chart below. In Column A, circle any of the healthcare providers that you have EVER SEEN for chronic pain symptoms and then answer the questions in Column B and Column C for any of the providers that you have seen.

**If you've never seen any of these practitioners, please move onto the question #21.

Column A	Column B	Column C
START HERE: Circle all of the healthcare providers in the list below that you have EVER SEEN for your chronic pain symptoms.	Were you referred by a Doctor/Physician to see this provider?	Did your health insurance cover the treatment(s) from this provider?
Example: Any Practitioner	[ ] Yes [ ] No	[ ] Yes [ ] No
Chiropractor	[ ] Yes [ ] No	[ ] Yes [ ] No
Acupuncturist or Acupressurist	[ ] Yes [ ] No	[ ] Yes [ ] No
Massage Therapist	[ ] Yes [ ] No	[ ] Yes [ ] No
Herbalist	[ ] Yes [ ] No	[ ] Yes [ ] No
Yoga Therapist	[ ] Yes [ ] No	[ ] Yes [ ] No
Energy Healer or Reiki Master	[ ] Yes [ ] No	[ ] Yes [ ] No
Reflexologist	[ ] Yes [ ] No	[ ] Yes [ ] No
Biofeedback Practitioner	[ ] Yes [ ] No	[ ] Yes [ ] No
Hypnosis Practitioner	[ ] Yes [ ] No	[ ] Yes [ ] No
Other, please specify: ______________________________	[ ] Yes [ ] No	[ ] Yes [ ] No

21. Using the scale below (1 indicating "Strongly Disagree" and 5 indicating "Strongly Agree"), please circle the number that best describes your opinions on **Alternative Medicine**, which includes therapies such as: Acupuncture, Massage, Reiki and Hypnosis (see list in question 20).

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
Alternative Medicine therapies hold promise for the treatment of chronic pain symptoms.	1	2	3	4	5
Alternative Medicine therapies that are not tested in a scientific manner should be discouraged from use.	1	2	3	4	5
Healthcare providers should advise their patients about Alternative Medicine therapies.	1	2	3	4	5
Alternative Medicine therapies are a threat to public health.	1	2	3	4	5
Alternative Medicine therapies include ideas and methods that conventional medicine could benefit from.	1	2	3	4	5

For the next section, please think of the care that you receive at this acupuncture office.

22. How long have you been coming to this acupuncture office?

[ ] Less than 3 months
[ ] 3 months to 6 months
[ ] 6 months to 12 months
[ ] More than 12 months

23. What motivated you to seek acupuncture? *Please explain in the space below.*

____

____

____

____

____

24. Using the scale below (1 indicating "Strongly Disagree" and 5 indicating "Strongly Agree"), please circle the number that best describes your feeling on the following statement:

With regard to the care that I have received here, I feel….	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
…my concerns are taken seriously by the healthcare provider.	1	2	3	4	5
…the healthcare provider explains everything to me in ways that are easy to understand.	1	2	3	4	5
…the healthcare provider is doing everything he can to help me.	1	2	3	4	5
…the healthcare provider understands me when I describe my experience of chronic pain symptoms.	1	2	3	4	5
…the atmosphere here allows me to make my own decisions about my healthcare.	1	2	3	4	5
…I could openly disagree with the provider's diagnosis or treatment plan if I don't agree with it.	1	2	3	4	5
…I am likely to follow through with the recommendations of the healthcare provider.	1	2	3	4	5
… I have a range of healthcare options to choose from for chronic pain treatments.	1	2	3	4	5

To finish, here are some questions about your background.

25. Please check the box that includes your age:

[ ] 18-25 years
[ ] 26-35 years
[ ] 36-45 years
[ ] 46-55 years
[ ] 56-64 years
[ ] 65+ years

26. Please check the box of your highest level of education achieved.

[ ] High School Diploma
[ ] Associate's Degree
[ ] Bachelor's Degree
[ ] Graduate Degree (Post Bachelor's Degree)
[ ] Other, please specify: ________________________________

27. Please check the box next to the term that best describes your ethnic/racial background:

[ ] White, Caucasian
[ ] Black, African-American
[ ] Hispanic, Latino
[ ] Alaskan Native
[ ] Asian
[ ] Pacific Islander
[ ] American Indian
[ ] Biracial or Multiracial
[ ] Other, please specify: ___________

28. Please check the box next to the term that best describes your gender:

[ ] Male
[ ] Female
[ ] Other, please specify: ___________

29. In the past year, what was your total *household* income?

[ ] Less than $10,000
[ ] $10,000-$14,999
[ ] $15,000-$24,999
[ ] $25,000-$49,999
[ ] $50,000-$99,999
[ ] $100,000-$149,999
[ ] $150,000-$199,999
[ ] $200,000 and over

Please use the space below for any additional comments.

____

____

____

____

____

____

____

Thank you for participating!

Appendix B: Interview Guide

Pain Symptoms

For how long have you been experiencing pain? When did it start?
Can you describe what the pain is like?
Do you ever have to alter your behavior when you experience pain?

Care Seeking

What made you seek medical help?
Do you see a doctor regularly/on a normal basis (for pain or other reasons)?
When you initially went to the doctor for your pain, how did the office visit go?
Did you accept this diagnosis/explanation of the cause of pain? Did it make sense to you?
How did you feel about the treatment proposed to you?
2nd, 3rd, etc… What was different about that visit?

What is/was your confidence level that 1st, 2nd, 3rd approaches would alleviate your pain?
Before we move on to another topic, is there anything else that you want to add?

Experience with Acupuncture

How did you come to learn about acupuncture (specifically) as a treatment & what motivated you to seek acupuncture?
What did you think of acupuncture before you were considering it for care?
What was your first visit like? What was your initial impression?
What was the acupuncturist's response to your pain symptoms?
How did you feel about the acupuncturist's diagnosis/opinion? Did you agree with his assessment?
What treatment did he suggest? Did you try them? If not, why didn't you want to go that route?
Did hearing this diagnosis/treatment plan change anything for you?

As you continued with your care, what results have you experienced from your acupuncture treatment? How well has it worked? (Pain rating then/ pain rating now)
Why do you think it's been (in)effective?
What disadvantages, if any, have you encountered from acupuncture treatments?
How confident are you about this treatment as far as lessening your pain?
Does acupuncture do something for you that other treatments do/did not?

Has going to acupuncture changed the way you think about your health/healthcare? If so, how?
Is there any other way – beyond the physical - that you felt you've benefitted from getting acupuncture?
How do you feel about your relationship with your acupuncturist as compared to other healthcare providers that you've gone to? Why is this?
At acupuncture, do you have a say in your course of treatment? If yes, how so?
Is this a good thing or a bad thing? How active do you believe that patients should be in their own healthcare?
Did you always feel this way?
Are you able to experience this in other forms of healthcare that you've mentioned?

Complementary/Alternative/Concurrent & Interactions Between Alternative & Conventional Care (Integrative Medicine)

Let's review…So who are the health care providers that you're still with? How frequently do you see these providers?
Are you still seeing your acupuncturist? Have you discussed other ailments or illnesses and/or had treatments for things beyond your initial inquiry about pain?
From all that you've described to me, do you think that these treatments are compatible with one another? How well do you believe these different treatments work together?
Have you let anyone else know that you're receiving acupuncture? What did they think about it (each one)?
Do your care providers communicate with one another either with follow-up reports or over the telephone?
Would you want your acupuncturist and doctors to work together?

Choices in health treatments

If you were considering a new form of treatment, would it important for you to see research that shows the treatment's efficacy?
Is it important for you to hear personal testimonials about its success?
Is it important to have a doctor's approval?
How influential would the pain be?
What are other the types of things that you consider when making choices about your healthcare?
How does cost factor into how you chose treatments?

Gender

According to previous research, women are more likely than men to use Alternative Medicine. Why do you think that is?
Do you feel that being Male/Female has impacted the care that you've received at any point along this trajectory of treatment- seeking?

Conclusion

If you could say one thing to doctors or medical researchers who are trying to understand chronic pain, what would you say?
Are there any other questions that I should be asking?

Additional Inquiries:

Medication Use – Past & Present

Up until this point, had you taken any medications for your pain symptoms – prescription, OTC or homeopathics? Do you still take them?
Any resistance? Have you always felt this way?
Did you have any surgeries related your pain symptoms? If no, was surgery ever offered to you as an option?
Any resistance? Have you always felt this way?

Desperation

Did you ever feel like you had run out of options? Desperation/End of Rope →What does that mean? How were you feeling about obtaining treatment for your pain at that point? Were there any other options for you?

Trust

Out of all the care providers that you've seen with regard to your chronic pain, who do you trust the most?
Who do you trust the least?

Experiences with non-traditional treatments – Massage, Herbalist, Reiki, Hypnosis, Biofeedback, Reflexologist, Herbalist

Had you ever used Alternative Medicine before going to acupuncture? What kind of treatment? What for?
Did you know others who have used non-traditional treatments? If so, what for and what was their outcome?
Would you use other kinds of alternative treatments? Have your attitudes towards different treatments changed over time? Since you consulted acupuncture?

Appendix C: Scale Psychometrics and Measure Reliability

Evaluation of Patient-Centered Care

Six items were used in this scale designed to understand how close of a relationship patients and practitioners had at the site of treatment. This included the patients feeling "heard" and well taken care of and that they could make decisions and disagree with the practitioner freely. The respondents marked these six statements with a 5-point Likert scale from strongly disagree to strongly agree so higher scores theoretically indicate higher patients' evaluations of patient-centered care. Factor Analysis, a general linear model (GLM) technique used to look for clusters of questions that measure the same concepts, was used to ensure that all items were measuring the same underlying construct: patient-centered care. Factor analysis with Varimax Rotation identified all six items as one factor, which explains 100% of the variance. Factor loading Eigenberg values are listed in Table x.

Next, a reliability analysis was conducted (in SPSS) to assess whether these items form a reliable scale, i.e. a scale with high correlations between the items. Cronbach's alpha proved this scale to be excellent in internal consistency at .95 (Kline 1999). It is now verified that Patient-Centered Care Evaluation is a reliable measure. A new variable was created (see Table 10) that represents the average of the raw scores of these six statements (range 1-5). The average scores were calculated instead of the sum of scores in order to retain the established scale, which allows for easy interpretation.

Table 10: Factor Analysis of Evaluation of Patient-Centered Care

	Loading Scores Principal Components Analysis
Factor 1	
My concerns are taken seriously by the healthcare provider (v42)	0.854
The healthcare provider explains everything to me in ways that are easy to understand (v43)	0.907
The healthcare provider is doing everything he can to help me (v44)	0.938
The healthcare provider understands me when I describe my experience of chronic pain symptoms (v45)	0.917
The atmosphere here allows me to make my own decisions about my healthcare (v46)	0.901
I could openly disagree with the provider's diagnosis or treatment plan if I don't agree with it (v47)	0.849
% of variance explained	100.00%
Cronbach's alpha	0.95

Note: Values correspond to factor loading as per Component Matrix, Percentages reflect explained variance as per Eigenvalues, Cronbach's alpha is based on standardized items

Proactivity Self-efficacy

A self-efficacy scale was constructed by selecting statements pertinent to chronic pain and health proactivity from a published scale (items 1-7, Lorig et al 2005) and creating others (items 8-9). Some items were slightly re-worded to fit the population and purpose of this study. In the end, nine items were used in the study. Participants were asked to respond on a 5-point Likert-scale of strongly disagree to strongly agree according to how the statements depicted their thoughts, feelings, behaviors in their lives. Therefore, theoretically, higher scores reflect higher levels of self-efficacy with regard to health.

Factor analysis identified 2 factors (see Table 11), one that was indicating a coping self-efficacy (explaining 88.23% of the total variance) and another indicating a pro-activity self-efficacy (explaining 11.77% of the total variance). The coping self-efficacy scale measured one's ability to take care of oneself and deal with chronic pain (maintaining a daily schedule and managing to deal with the pain), while the proactivity self-efficacy factor indicated one's ability to be active toward one's health, i.e. in making decisions, locating information, finding support and also helping others. Next, a reliability analysis was conducted (in SPSS) to be sure that these items form a reliable scale—that is a scale with high correlations between the items. For both factors, Cronbach's alpha proved to be fairly high internal consistency at .90 and .84 respectively (Kline 1999). Therefore, we can assume that both coping and proactivity self-efficacy are reliable measures. Two new variables were created from these factors by averaging the responses to the statements in each factor (range 1-5) as indicated by Eigenberg values listed in Table X. Proactivity self-efficacy was selected for analysis in this stage of the research because the statements within this factor more precisely indicate the ability to be active in one's health, as opposed to coping behavior which is more about maintaining one's daily schedule and responsibilities.

Table 11: Factor Analysis of Self-efficacy

	Loading Scores Principal Components Analysis
<u>Factor 1 - Coping</u>	
Perform most of your daily activities	0.81
Enjoy the things that you normally enjoy	0.87
Go to places that you want to go	0.82
Maintain relationships with your family and/or friends	0.71
Cope with mind to moderate pain	0.75
% of variance explained	88.23%
Cronbach's alpha	0.90
<u>Factor 2 - Proactivity</u>	
Make good decisions regarding your healthcare	0.76
Access reliable information regarding your chronic pain condition	0.82
Get support from other people when you need it	0.77
Help other people with a similar health condition as yours	0.76
% of variance explained	11.77%
Cronbach's alpha	0.84

Note: Values correspond to factor loading as per Rotated Component Matrix, Percentages reflect explained variance as per Eigenvalues, Cronbach's alpha is based on standardized items