

2015-07-27

# Gaining Insight into the Meaning of Complementary/Alternative Healing among Chronically Ill Individuals

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UNIVERSITY OF MIAMI

GAINING INSIGHT INTO THE MEANING OF  
COMPLEMENTARY/ALTERNATIVE HEALING AMONG CHRONICALLY ILL  
INDIVIDUALS

By

Anwesa Chatterjee

A DISSERTATION

Submitted to the Faculty  
of the University of Miami  
in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

Coral Gables, Florida

August 2015

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Gaining Insight into the Meaning  
of Complementary/Alternative Healing  
among Chronically Ill Individuals

(August 2015)

Abstract of a dissertation at the University of Miami.

Dissertation supervised by Professor Linda Liska Belgrave.  
No. of pages in text. (149)

Through this project I attempt to understand the meaning and experience of using complementary/alternative healing among chronically ill individuals. A chronic illness/condition typically generates some disturbance in people. In the context of this turmoil, some individuals might make a choice to use healing options outside of regular allopathic medicine. I interviewed 16 women and 5 men with varied chronic illnesses/conditions to understand their meaning and experience with complementary/alternative healing. I approached the project from a symbolic interactionist standpoint and used grounded theory methodology to collect and analyze data. In the context of exploring the main research question several sub-questions emerged from the data and guided my project. The five main themes that emerged from the data were, naming of complementary/alternative healing, making a choice for complementary/alternative healing, evaluating benefits of complementary/alternative healing, problems pursuing complementary/alternative healing and the role of the healer in complementary/alternative healing. Through my findings I suggest, that there is nothing definite about the definition of complementary/alternative healing, even food and

activities or pastimes get named as complementary/alternative healing if they hold meaning for a person. In addition, a multiplicity of factors affect the use and experience of complementary/alternative healing, whereby, the role of family, friends, location, influence of personalities and support groups are significant and relatively unexplored in the extant literature. There is also considerable complexity in the way people evaluate complementary/alternative healing. The type of healing technique, individual expectations, perceptions, major hurdles in pursuing other healing options, the connection with the healer for specific healing techniques are all important factors that affect the overall meaning and experience with complementary/alternative healing. These findings from my project have substantial implications for the understanding of complementary/alternative healing by future researchers and policy makers.

## ACKNOWLEDGEMENTS

I am grateful to my dissertation advisor Dr. Linda L. Belgrave for her continued support and guidance throughout the entire process. Her belief in this project was invaluable to my completion and I greatly appreciate all that she has done for me.

I would like to thank Dr. Marvin P. Dawkins, Dr. Doris N. Ugarriza, and Dr. Crystal Adams for serving as members of my committee. I appreciate all their insights, time and generosity in making this dissertation happen.

I would also like to thank the faculty, staff, and graduate students at the University of Miami. I am especially grateful to Dr. Amie L. Nielsen for serving as my academic advisor and being a constant source of support throughout my graduate years. I am also grateful to Teresa Amador for her unending patience and help on all administrative issues.

I would like to thank all my participants, who shared their stories and time with me and often helped me connect with other participants. Without their support this dissertation would not have been possible. Special thanks to Coky Michel and Paul Michel for providing me with a home away from home and showing so much love and support for all these years in Miami.

Finally, I would not have been able to accomplish the PhD without the support of my parents, brother and husband. Without the unconditional love, sacrifices, support and time of my parents I wouldn't be here. My brother has been the source of inspiration,

pillar of strength and encouragement that pulled me up during the difficult phases. My husband has seen the worst of me but is still with me to the end.



## Table of Contents

Chapter One: Introduction .....	1
Rationale for the project.....	3
Note on Complementary/Alternative Healing.....	4
Terminology .....	5
Organization of Chapters .....	6
Chapter Two: Review of the Literature .....	9
Reasons for using Complementary/Alternative Healing.....	9
How Do People Feel After Using Complementary/alternative healing? .....	34
Summary .....	38
Chapter Three: Theoretical Orientation .....	41
Chapter Four: Research Methods.....	48
Sampling and Recruiting.....	49
Interviews .....	51
Participants .....	53
Location.....	59
Data Analysis .....	60
Chapter Five: Findings.....	62
Naming of Complementary/Alternative healing.....	66
Making a Choice -How and Why Complementary/Alternative Healing? .....	75
Perceived Evaluation of Complementary/Alternative Healing.....	95
Problems Pursuing Complementary/Alternative Healing.....	106
Role of the Healer .....	115
Chapter Six: Discussion and Conclusion.....	121
Appendix 1 .....	136
Appendix 2.....	140
References.....	142

## **Chapter One: Introduction**

In recent years, healing techniques considered complementary or alternative have been undergoing renewal and growth in many countries (Eisenberg et al.1998; Fisher 1994; Maclennan et al. 1996). A large section of the population in the United States now utilizes a variety of complementary/alternative healing (Eisenberg et al. 1993; Eisenberg et al. 1998; WHO Global Atlas 2005). In the United States, complementary/alternative healing includes a broad range of therapeutic techniques and products with origins in a vast array of countries (Wardwell 1994).

Certain healing techniques considered complementary or alternative in the United States, are part of the integrated health care in the countries from which they originate. For instance, in China both Traditional Chinese medicine and allopathic medicine enjoy equal official recognition (Kaptchuk and Tomalin 2000). Kampo Medicine, a modified version of Traditional Chinese medicine, is a unified part of the modern health care system in Japan (Dharmananda 2002; WHO Global Atlas 2005). In the West, Germany is the ancestral home of homeopathy, naturopathy and phytotherapy. By an amendment of the law, these treatments are now recognized as special lines of therapy in Germany, and practitioners can train in these different healing techniques as medical vocations (WHO Global Atlas 2005).

In the United States, licensing of different complementary/alternative healing differs from state to state and few are licensed across all states (WHO Global Atlas 2005). In 1998, the National Center for Complementary and Alternative Medicine (NCCAM) was established in the US as part of the National Institute of Health. Since

then NCCAM as an institute has been responsible for overseeing research, and disseminating information, on complementary/alternative healing products and practices (NCCAM). The development of the NCCAM has augmented national interest and research in disparate forms of healing in the United States. While researchers have focused attention on the prevalence, safety, efficacy and utilization of complementary/alternative healing, the meaning and experience of complementary/alternative healing to individual users in the United States is still under-examined. In this dissertation project, I used a symbolic interactionist approach and grounded theory methods to understand the meaning and experience of using complementary/alternative healing for persons suffering from a chronic illness or condition. I interviewed people from different backgrounds to examine whether the meaning and experience of using complementary/alternative healing vary across cultural groups and contexts in South Florida, an ethnically and culturally diverse area. Through this project I attempt to answer the following questions. 1) What is the meaning and experience of complementary/alternative healing to chronically ill persons?

During the course of research, additional questions arose as is typical with grounded theory. These are actually sub-questions of the meaning and experience of complementary/alternative healing to chronically ill persons.

- a) How do participants define complementary/alternative healing and what do participants name as complementary/alternative healing?
- b) How and why do participants choose complementary/alternative healing?
- c) How do people evaluate benefits of complementary/alternative healing? What are their experiences like?

- d) What kind of relationships do participants expect and share with people connected to providing complementary/alternative healing?
- e) What are the problems that participants face when using complementary/alternative healing?
- f) If and how do participants from different cultural groups and contexts experience complementary/alternative healing differently?

To address the research questions, I approached the dissertation project from a symbolic interactionist standpoint and used grounded theory methods to collect and analyze data. I interviewed and tape-recorded the statements of chronically ill persons who were using complementary/alternative healing. In total, I interacted with 21 chronically ill persons coming from diverse backgrounds and living in Miami. Through this project, I attempted to understand the processes through which complementary/alternative healing is defined, experienced and understood by a certain section of people.

### **Rationale for the project**

Earlier researchers have placed too much emphasis on the prevalence of complementary/alternative healing without much attention to what it really means to individuals using these healing techniques. Through this project, I add to the existing research on complementary/alternative healing by presenting an in-depth understanding of the meaning and experience of complementary/alternative healing to chronically ill persons. Furthermore, though some scholars have explored experience with complementary/alternative healing among specific groups of people, this project provides a thorough and organized account of the experience with complementary/alternative

healing among persons suffering from a variety of chronic conditions or illnesses. In addition, this project involves a strong theoretical grounding in the sociological perspective of symbolic interactionism; the majority of prior research lacks a robust theoretical base. The interview location of Miami also provided me with a unique opportunity to gain insight from people of diverse backgrounds which further contributes to the importance of this project. Therefore, the findings of this project will serve as a means to consider the perspectives of chronically ill patients from various backgrounds and how they attach meaning to their experience with complementary/alternative healing.

### **Note on Complementary/Alternative Healing**

Some forms of healing like acupuncture or yoga considered complementary/alternative in contemporary times have been used for centuries (Kaptchuk and Tomalin 2000; Dharmananda 2002). Other variants of complementary/alternative healing such as biofeedback or craniosacral therapy have emerged in the last century. The techniques of healing incorporated into one broad umbrella term, specifically complementary and alternative medicine, are usually distinct from one another, with different histories, philosophies and countries of origin. For instance, chiropractic care, which has its origins in Iowa in the late 19<sup>th</sup> century, is widely used across the United States as a form of manual therapy that involves spinal manipulations or adjustments. On the other hand, Ayurveda which is a 3000-5000 year old healing technique with origins in ancient India and incorporating principles of maintaining a healthy metabolic system and the use of plant based medicines and treatments is also considered complementary/alternative healing. Furthermore, the National Center for Complementary and Alternative Medicine (NCCAM) in the United

States lists vitamin and mineral supplements and relaxation techniques like meditation and yoga as complementary/alternative healing. Hence, in the United States, any non-mainstream approach to healing or any non-allopathic procedure is considered a part of complementary/alternative healing.

### **Terminology**

In this project I use the words complementary/alternative healing over the more mainstream terms complementary and alternative medicine. I made this change to more clearly emphasize the distinction between allopathic medicine and other forms of healing procedures and to highlight that the word medicine subsumes certain assumptions that might not be applicable to other healing techniques. Even in cultures and places where allopathic medicine does not dominate, there are usually some people who are assumed to have the abilities to cure or treat sick people (Casell 2012). For example, shamans or curanderos are found in Native American and Hispanic cultures. These individuals are broadly termed “healers”. The practices of healers in different cultures vary and many people speculate that healers induce the body’s innate abilities to cure itself. As Cassell (2012) points out, after the scientific revolution in medicine during the 1930s the word “healing” had a negative connotation being linked to quackery. However, the word healing literally means to make whole and involves the restoration of sick persons to health. Unlike in medicine, where physicians usually make an effort to separate the body from the person, healing assumes that patients want to be regarded as individuals and be cared for as persons with identities (Cassell 2012).

Also, the term complementary and alternative medicine is conceptually misleading. The terms complementary and alternative are usually clubbed together as a

single entity. However, depending on the context, some people use particular healing procedures as an alternative or substitute for allopathic medicine, while others use certain healing techniques along with allopathic medicine to complement their allopathic treatment or to increase treatment options. In the literature and in common practice these two kinds of individuals are usually grouped together. In this project, I will make an effort to understand if there are differences between these two groups so to be more inclusive the words complementary/alternative are used together, but separated by a “/”.

### **Organization of Chapters**

In chapter two I highlight in detail the extant research on complementary/alternative healing. A large body of work exists on the reasons for use of complementary/alternative healing. Scholars have put forth theories and examined these theories with large and small samples of people. These existing theories are highlighted in the first part of the literature review along with the limitations of extant work. Some researchers have also explored experience and perceived satisfaction with complementary/alternative healing. The next part of my literature review focuses on these earlier studies on experience with complementary/alternative healing and highlights the shortcomings of prior research in this area.

In chapter three I provide an overview of Symbolic Interactionism, my preferred theoretical framework for this project. Here I highlight the main tenets and some of the more important ideas presented by the early proponents of symbolic interactionism. Why symbolic interactionism is an appropriate choice for this project and how it seamlessly complements grounded theory methods are also delineated in this section.

In chapter four I delineate the methods I have followed to conduct this project. I have used qualitative methods, specifically the constructivist grounded theory approach proposed by Charmaz (2006) to find answers to the research questions highlighted above. I chose this particular approach because it enables the researcher to engage in an interactive process with research participants while focusing on the context in which the participants express their views (Charmaz 2006). It was important that participants be able to use their own voice, language and meaning to communicate their opinions about complementary/alternative healing. Furthermore, qualitative research usually allows for an understanding of how and why the same things can be interpreted and understood in varying ways by different individuals from distinct cultures who live in the same nation or different nations (Denzin and Lincoln 2005). I think that the constructivist grounded theory approach enabled me to highlight the socially constructed nature of reality where the focus is on the researcher and the participants and the context in which the interaction takes place. In this chapter, I also provide a detailed description of how I sampled my participants, how I conducted the interviews, who my participants were, why the location of this project is unique and how I engaged in data analysis.

In chapter five I focus on the major findings of this project. I use diagrammatic representations to highlight the major themes that emerged from data collection and analysis. In this chapter, I also delineate in detail the processes by which chronically ill patients experience and attach meaning to complementary/alternative healing.

In the final chapter, chapter six I provide a detailed discussion of the major findings that emerged from this project. Making connections with prior research, I deliberate on the practical implications of the findings in the context of rising interest and use of



complementary/alternative healing among people in the United States. Researchers using large national surveys like the National Health Interview Survey have drawn attention to the widespread use of complementary/alternative healing (Nahin et al. 2007). In this context, where the American people are spending large amounts of money out of pocket on complementary/alternative healing, a study on what complementary/alternative healing actually means to individuals who are chronically ill and are using these healing options can prove to be extremely helpful for practical purposes.

## **Chapter Two: Review of the Literature**

Currently, the rising interest in complementary/alternative healing has led to widespread research on these diverse forms of healing. Research has shown that a large section of the population in Europe and America now utilize a variety of complementary/alternative healing (Eisenberg et al. 1993; Fisher 1994; Eisenberg et al. 1998). Though researchers have theorized and examined the utilization of complementary/alternative healing, much remains to be understood. In this literature review, the extant literature on complementary/alternative healing is examined highlighting problems and questions that still remain unanswered.

This review is divided into two parts. In the first part I address research on the reasons for utilization of complementary/alternative healing in the United States and other parts of the world. The second part is a discussion of research on the perceived effectiveness and experience with use of complementary/alternative healing in the United States and other parts of the world.

### **Reasons for using Complementary/Alternative Healing**

#### *Values*

Some theorists contend that there has been a radical change in all aspects of society from modernity to late modernity or post modernity. For instance, according to Giddens (1991) in the late modern age, markets place emphasis on individual freedom of choice, which then becomes the core of individual self-expression. The idea is that consumption has gained symbolic meaning in this late modern society and it has become a source for the development of the self (Giddens 1991). Furthermore, theorists like

Featherstone (1982) argue that the body and one's appearance are increasingly given importance in the postmodern age where these are considered to be visible expressions of the self and robust consumption. According to Featherstone (1982), in postmodernity the emphasis is on the creation and spread of symbolic elements highlighting the progress of consumerism and a shift from mass production. Hence, consumers in the late modern society as described by Giddens (1991) and postmodern society characterized by others are likely to put more effort into preserving the body, appraising all available options before making a choice in favor of one against the other (Featherstone 1982).

Scholars like Bakx (1991) and Siahpush (1998) theorize that in this postmodern era, allopathic medicine, which is an element of modernity, is currently not aligned with the values held by a large section of society. They surmise that in postmodernity the distinct value system that has emerged suggests unique views of health, technology, power, accountability and consumerism. Hence, those attuned to postmodern values are more likely to choose complementary/alternative healing over allopathic medicine as they are less likely to support treatment options that have a focus solely on curing symptoms. Instead, such persons are likely to advocate healing associated with holism and self-curative procedures. Siahpush (1998) conducted a telephone survey of 209 non-institutionalized adults in Australia. The results from this study show that adherence to postmodern values such as views on natural remedies (e.g. "Do you prefer to avoid taking prescription drugs"), anti-technology (e.g. "Technological progress creates an environment harmful for people"), and consumerism (e.g. "it's good that nowadays we have so many different types of therapies to choose from") were significantly associated (at  $p < 0.05$  and at  $p < 0.01$ ) with positive attitudes towards complementary/alternative

healing. However, the researchers in this study did not examine the actual use of complementary/alternative healing. Callaghan and Jordan (2003) expanded on Siahpush's (1998) study to examine if postmodern values (they used the same measures developed by Siahpush 1998) predict belief in and use of complementary/alternative healing. From a survey of 171 participants, they found that postmodern values of rejection of authority and use of natural remedies significantly predict both positive attitudes (at  $p < 0.005$ ) and utilization of complementary/alternative healing (at  $p < 0.005$ ). However, the results from this study should be treated with caution as the authors used a convenience sample, comprised of participants primarily female and with higher education. Earlier studies have shown that women, individuals with higher education, and those with private insurance are more likely to use complementary/alternative healing (Astin 1998; Barnes et al. 2004).

In line with the argument that consumption is the key in postmodern societies and complementary/alternative healing is a major source of consumption, Rayner and Easthope (2001) tested a number of hypotheses to validate these claims. They conducted a quantitative survey of 100 consumers and 134 advertisements from two conventional pharmacies, one homeopathic and one naturopathic pharmacy and two big health food outlets, all based in Australia. Findings from their study provide some evidence to support the claim that consumption of alternative medicine has certain characteristics of postmodern consumption. They found advertisers were more likely to direct attention to the symbolic rather than use value of complementary/alternative healing products. For instance, the subject of nature was represented by advertisers with images like trees and terms like natural or mother earth. They also found that consumers were more

enthusiastic about representations of holism, anti-technology, individual choice and control. Though the findings from their study align well with the postmodern emphasis on symbolic value of goods or products, the authors caution against oversimplification of the complexity of such consumption.

Some authors highlight that in the contemporary (postmodern/beyond modern) era there are many individuals who are skeptical about science and technology and who subscribe to a more nature conscious philosophy (Ray and Anderson 2000; Siahpush 1998). Ray and Anderson (2000) have written about a group of people termed the “Cultural Creatives” who make up about 1/4<sup>th</sup> of the US population. These individuals emphasize holistic living and have a commitment to social issues like social justice, civil rights, ecology, feminism, peace and jobs. Ray and Anderson (2000) contend that this group of “Cultural Creatives” is the primary consumer of complementary/alternative healing because of their heavy emphasis on a holistic existence. According to Ray and Anderson (2000) their identification of this cultural group is based on analysis of 22 years of survey data from almost 100,000 participants. These include thirteen years of consumer survey data from American LIVES Inc. with an array of questions on values and lifestyle and two other nationally representative mail surveys with similar questions on values headed by Ray, and 500 focus groups and 60 in-depth interviews. Astin (1998) examined whether those who could be identified as part of such a cultural group were more likely to be users of complementary/alternative healing. His study revealed that participants classified as “Cultural Creatives” were much more likely to utilize complementary/alternative healing.

Efforts to connect use of complementary/alternative healing with post modernism are remarkable; however, it is difficult to make definitive causal interpretations. Most researchers tend to highlight from cross sectional data how those using complementary/alternative healing also hold postmodern beliefs or values. Furthermore, it is important to highlight that these studies possibly do not capture the racial/ethnic/class/religious diversity in utilization of complementary/alternative healing. Some ethnic groups use certain forms of healing as it is part of their cultural beliefs and values and most researchers do not address this. For instance, Asians have an inclination towards mind-body interventions like yoga or meditation and healing practices like acupuncture or ayurveda which are linked to many of their religious and cultural practices. Similarly, Native Americans and Hispanics often use folk healing aligned with their cultural practices of visiting a Shaman or a Curandero. Furthermore, some sections of the African American population have also been found to use complementary/alternative healing more than Whites. Cuellar and colleagues' (2003) conducted a quantitative survey with a convenience sample of 183 elders to assess and compare complementary/alternative healing use among African American and White rural older adults. They found that African American seniors were more likely to use complementary/alternative healing than older Whites. Cuellar and colleagues (2003) suggest that in the early 1900s minorities did not enjoy similar levels of allopathic health care access to Whites. This might have propelled them to depend on alternative forms of care. However, surveys usually do not include questions on complementary/alternative practices that are inexpensive, based on folklore and likely to be more common among those in some minority groups living in poverty or with lower education (Cuellar et al.

2003). In addition, some researchers have highlighted that certain groups of people like those who are illiterate or cannot speak English are usually underrepresented in national surveys and other convenience based survey studies (Wolsko et al. 2002). Furthermore, most national surveys and other regional surveys do not collect information on certain types of complementary/alternative healing like Santeria which might be more common among the less educated and among some traditional ethnic minority groups. The question arises as to whether these people are close to being post-modern. A certain bias is apparent in the reviewed studies with regard to considering only those healing techniques that are more common among people of a certain socioeconomic background. For instance, use of herbal supplements, diet therapies or relaxation techniques like transcendental meditation or manipulative therapies like chiropractic care or massage are possibly more common among people with higher education and income.

In addition to the value congruence theory, other researchers have found that the treatment and illness beliefs of users of complementary/alternative healing differ from those of allopathic medicine users (Cassileth et al 1984; Vincent and Furnham 1997). Cassileth and colleagues (1984) conducted a quantitative study of 660 patients and 256 practitioners of complementary/alternative healing. They found that the cancer patients utilizing complementary/alternative healing were more likely to believe that their cancer could be thwarted through better nutrition (32%), psychological wellbeing (33%) and environmental changes (26%). Vincent and Furnham (1997) examined factors affecting beliefs in the apparent efficacy of complementary/alternative healing. They conducted a quantitative survey of 82 patients visiting a complementary/alternative healing center (acupuncture) in London. They found that stronger faith in science was associated with a

greater trust in allopathic medicine, whereas beliefs in the inter connectedness of psychology and health was associated with more confidence in the efficiency of different types of complementary/alternative healing (Vincent and Furnham 1997).

Barrett and colleagues (2000) conducted a qualitative study in Madison, Wisconsin directing attention to the way in which patients and practitioners represent and talk about complementary/alternative healing. Their study of 20 healers and 17 patients revealed that both patients and providers of complementary/alternative healing emphasize the holistic orientations of these therapies in contrast to allopathic medicine. They highlighted that patients felt a sense of empowerment in utilizing complementary/alternative healing. In another study, in the Madison area, Barrett and colleagues (2004) conducted a qualitative exploration to understand the beliefs and practices of complementary/alternative healers only. They interviewed 32 practitioners of 20 complementary/alternative healing modalities such as energy healing, touch, tai chi, yoga and others but excluding chiropractic care. Their findings revealed that complementary/alternative healers expressed themselves as being holistic emphasizing that they try to restore the whole body which includes the mind and not just try to find a cure for symptoms. The healers in this study also pointed out that they see themselves as mentors to the patients trying to induce a positive outlook among their patients, while placing importance on the value of healthy living. Another qualitative study by Richardson (2004) examined expectations from complementary/alternative healing among 327 patients visiting a British National Health Service outpatient clinic. They found that users of complementary/alternative healing tend to explain their preference for the same in terms of being treated as a whole person and being able to voice their



concerns in a more conducive amiable environment (Richardson 2004). These qualitative studies provide deep insights on the beliefs and values of users and providers of complementary/alternative healing. Qualitative studies often allow for a better understanding of unexplored areas and issues that are difficult to assess in quantitative surveys. Though quantitative researchers highlight major ideas regarding complementary/alternative healing, qualitative researchers provide in-depth descriptive definitions and representations of complementary/alternative healing to users and providers that are very significant for our understanding of these areas of healing.

Researchers of quantitative studies based on larger samples also highlight the emphasis on “holism” as an important value predictor of complementary/alternative healing use. Bishop and colleagues (2006) conducted a quantitative web based survey of 247 participants to examine whether treatment and illness beliefs were associated with use of complementary/alternative healing. They found that the idea of holism and emotions as causes of illness were significantly (at  $p < 0.01$ ) related to use of complementary/alternative healing. Similarly, Furnham and Forey (1994) assessed differences between complementary/alternative healing patients and conventional patients through their quantitative study of 160 participants. They found that complementary/alternative healing patients compared to patients of conventional medicine were significantly more likely to disagree with idea of treatment focusing only on symptoms rather than the whole person and the idea of seeking help from practitioners only when suffering from an illness (at  $p < 0.001$ ). Astin (1998), an author of a large representative survey of 1035 participants in the United States, found that identifying with values of holism was significantly associated with use of complementary/alternative

healing (at  $p < 0.05$ ). However, Furnham and Forey (1994) suggest that these associations might just be an outcome of having undergone complementary/alternative healing itself. They argue that typically practitioners of complementary/alternative healing techniques incorporate some descriptions of their primary philosophy in therapy which might in turn influence patient's perspectives (Furnham and Forey 1994). Thus, they suggest that the correlation does not necessarily reflect causation.

Researchers examining motivations for choosing a particular type of complementary/alternative healing, find support for the hypothesis that subscribers of complementary/alternative healing, endorse or advocate a different set of values. In a quantitative study of 87 participants, Furnham and Smith (1988) compared the belief systems of two sets of patients, one set visiting a general practitioner (43 participants) and the other visiting a homeopath (44 participants). The results of their study indicate that there were some differences between the groups that could help to distinguish them. For instance, the homeopathic group believed that there were ways to ameliorate the body's natural shield against disorder (at  $p < 0.05$ ). They were also more likely than the general practitioner group to believe in holistic healing rather than mere treatment of symptoms (at  $p < 0.001$ ). Furnham and Bhagrath (1993) in their quantitative study of 160 participants of patients visiting a homeopath versus a general practitioner found that homeopathy patients were more likely to attach weight to the healing of the whole person (at  $p < 0.001$ ) and the inherent curative potential of the individual body (at  $p < 0.01$ ). Another qualitative study of 8 participants conducted in South Africa by McIntosh and Ogunbanjo (2008) to specifically explore reasons for patient's choice of homeopathy also found ideas of holism to continually recur as a description of homeopathic treatment.

Results of the studies indicate the importance placed on the holistic perspective and the interconnectedness of mind, body, and spirit by users of complementary/alternative healing. However, since most of these studies are cross-sectional it is difficult to understand temporal ordering and cause effect relations. None of the authors of these studies indicate the length of time that participants used complementary/alternative healing only. For instance, though Furnham and Smith (1988) looked at alternative practitioner (homeopathy) patients and allopathic practitioner patients separately, it is unknown if the participants moved between the two types of practitioners prior to, or after the completion of the study. Many of the participants in Furnham and Bhagrath (1993) and McIntosh and Ogunbanjo's (2008) study used both complementary/alternative healing and allopathic medicine alongside each other. Therefore, it would be erroneous to make any causal references. Furthermore, it is also important to highlight that patients use particular complementary/alternative healing for particular health problems. For instance, in the quantitative study of 268 participants, Vincent and Furnham (1996) found that about 90% of persons using osteopathy had musculoskeletal problems or a good proportion of acupuncture patients had problems with psychological wellbeing. The characteristic features of these two sets of patients are likely to be different and it is incorrect to generalize the results from these studies to all people choosing complementary/alternative healing. Therefore, questions remain as to whether those who subscribe to certain distinct values make a definite choice for complementary/alternative healing as a substitute for allopathic medicine or if they develop an affinity for such values after having utilized some form of complementary/alternative healing.

***Emphasis on Fitness and Prevention rather than Cure***

Many like Goldstein (2000) have argued that the increasing popularity of health and fitness around the Western world has contributed to the revival of complementary/alternative healing. Goldstein (2000) theorizes that there are certain basic similarities in values between those who use alternative healing and those who engage in activities to stay fit. The fundamental values Goldstein (2000) highlights include a focus on holism, personal responsibility for health, interconnectedness of mind, body and spirit, emphasis on nature, skepticism of science and technology, and finally transcendence. Using the 2002 National Health Interview Survey that includes a large random sample of 31,044 adults in the United States, Nahin and colleagues (2007) examined whether those participating in positive health behaviors and displaying fewer risk factors were more likely to use complementary/alternative healing. The results of their study indicate that persons practicing positive health behaviors, like engaging in physical activities, have a higher likelihood of using complementary/alternative healing (OR- 2.92, CI 2.66-3.21). In a quantitative study of 187 participants, Furnham and Beard (1995) examined if there were differences in beliefs between general practitioner patients and complementary/alternative healing patients in London. They found that complementary/alternative healing users were much more likely than general practitioner patients to believe that psychological wellbeing ( $p < 0.05$ ) and self-medication ( $p < 0.01$ ) were important components for health and illness. However, they found no significant differences between complementary/alternative healing patients and general practitioner patients in their beliefs regarding leading a healthy lifestyle.

In another United States based quantitative study, Robinson and colleagues (2002) used a large convenience sample of 1593 Colorado 9Health Fair participants to assess the relationship between use of complementary/alternative healing and health related behaviors. They found that participants using herbs and supplements had significantly higher odds than non-users of complementary/alternative healing to engage in healthy behaviors like physical activity (OR-1.5, CI 1.1-1.9), not smoking (OR-1.5, CI 1.1-2.1), eating a low fat diet (OR-1.5, CI 1.1-1.9) and taking daily multivitamins (OR-2, CI 1.5-2.6). Results from other quantitative studies like the one by Furnham and Bhagrath (1993) of 160 participants, indicate that complementary/alternative healing patients (this study homeopathy) are more likely than conventional practitioner patients to believe in preventive health behaviors. However, again it is important to note that these studies do not include many healing techniques that are more commonly used by certain ethnic minority groups and or poor uneducated sections of the population. Thus, the results from these studies should be treated with caution as many researchers do not include a variety of healing options and tend to consider healing options that are likely to be pursued by certain educated sections of the population that might be more health conscious than others or simply have easier access. And the results from these empirical studies do not provide any definitive answers with regard to the association between belief and practice of health preventive behaviors and the use of complementary/alternative healing. Furthermore, often researchers are constrained for having used small and /or self-selected samples which reflects a certain bias towards considering healing procedures that might yield results in favor of their hypotheses (Furnham and Bhagrath 1993; Robinson et al. 2002).

### ***Complaints about Conventional Medicine***

Another common explanation for the rising utilization of complementary/alternative healing is the growing discontent among many individuals with allopathic medicine (McGregor and Peay 1996; Sirois and Gick 2002). Several scholars have examined this explanation empirically, finding inconclusive results. On the one hand, some researchers find that people visiting complementary/alternative healers are unhappy with allopathic medicine (Furnham and Smith 1988; Furnham and Bhagrath 1993). For instance, results from a study of a large sample of 660 cancer patients including patients who had used both allopathic medicine and complementary/alternative healing (325) and complementary/alternative healing only (53) revealed that regard for allopathic medicine dwindled ( $p < 0.001$ ) for patients who had used some form of alternative care compared to those who had used only allopathic medicine (Cassileth et al. 1984). Though researchers often find individuals using complementary/alternative healing to express decreased faith in allopathic medicine, only infrequently do such individuals terminate allopathic care altogether. This is evident from Furnham and Bhagrath's (1993) quantitative study of 160 homeopathic and conventional practitioner patients. The researchers found dissatisfaction with allopathic medicine to emerge as a significant predictor of homeopathic use ( $F = 22.42, p < 0.001$ ), however, that did not deter patients from continuing with allopathic care alongside homeopathy ( $F = 28.71, p < 0.01$ ). Other researchers have found that beliefs and attitudes serve as better indicators of utilization of complementary/alternative healing than discontent with allopathic medicine (Furnham and Forey 1994; Astin 1998; Bishop et al. 2006). Thomas and colleagues (1991) deny claims that patients visiting complementary/alternative healers are necessarily skeptical of allopathic medicine. From their survey of a large sample of 2152

complementary/alternative healers and 2473 patients in Great Britain, they found that 64% of patients reported having sought help from allopathic medicine for their primary health concern either before or simultaneously with use of complementary/alternative healing. The authors argue that complementary/alternative healing, for example, acupuncture, chiropractic care, homeopathy, naturopathy and osteopathy are most often used as an added healing option rather than as a replacement for allopathic medicine.

In contrast, the findings from a qualitative study of 327 patients indicate participants expressing uneasiness about using allopathic medicine and concern over the inherent side effects of allopathic drugs (Richardson 2004). Researchers conducting a telephone survey of 85 complementary/alternative healing patients allotted from a list of clients of a Touch for Health therapy center and 81 community participants roughly matched by socioeconomic status with the complementary/alternative healing patients near an Australian capital city, found that complementary/alternative healing patients were typically more likely to deem allopathic care as less efficacious (McGregor and Peay 1996). But the researchers also found that perceived inadequacy of allopathic medicine did not necessarily imply patients were disappointed with their last visit to an allopathic practitioner. There was some indication in this study that complementary/alternative healing patients were likely to consider allopathic treatment as limited especially in case of chronic conditions (McGregor and Peay 1996). Sirois and Gick (2002) conducted quantitative study of 199 allopathic and complementary/alternative healing patients in Canada, in which they distinguished between new and infrequent complementary/alternative healing patients and continued users of such therapies. The findings from their study revealed that the main variables

distinguishing new and infrequent complementary/alternative healing users from allopathic medicine users was patient dissatisfaction with allopathic medicine (at  $p < 0.000$ ) and health aware behaviors (at  $p = 0.003$ ) like monitoring intake of preservatives, making healthy food choices, exercise, caffeine consumption etc. Yet, the best indicators distinguishing continued users of complementary/alternative healing from infrequent users of complementary/alternative healing were health problems, like chronic pain and cardiovascular problems (at  $p = 0.013$ ) and more health aware behaviors (at  $p = 0.003$ ). The findings from this study highlight that even though dissatisfaction with allopathic medicine might initially motivate some people to try other healing techniques, it's not a powerful indicator of sustained use of complementary/alternative healing (Sirois and Gick 2002). In another quantitative study in Canada of 341 patients the authors found that individuals opting for complementary/alternative healing generally tend to express more discontent or doubt (42% very skeptical at  $p = 0.014$ ) with allopathic medicine (Sutherland and Verhoef 1994). However, though some researchers have found that dissatisfaction with allopathic medicine might influence or motivate some individuals to try complementary/alternative healing, as Sirois and Gick (2002) find, it is unlikely to be the only factor behind the persistent use of such healing.

There is a lack of research that makes a distinction between initial users and continued users of complementary/alternative healing and there is also a lack of longitudinal research that might help to make causal arguments. Also, qualitative research can help in gaining a better understanding regarding this explanation. Future research might help to elucidate the actual role that skepticism with allopathic medicine plays in the choice for complementary/alternative healing.



***Increasing Importance given to the Therapeutic Relationship between Healer and Patient***

Suchman and Mathews (1988) theorized about the importance of the physician patient relationship in healing (Suchman and Mathews 1988). According to them, this relationship should fulfill the basic human need of connection and meaning of patients and physicians (Suchman and Mathews 1988). But Suchman and Mathews (1988) surmise that physicians following the medical model are largely diverted away from building any subjective therapeutic relationships with patients. Drawing evidence from clinical studies, Barsky (1981) proposed that patients seek the help of a physician for a variety of reasons, which are not limited to cure of some physical problems. These reasons he suggested include relief from social isolation, pursuing health information and psychological wellbeing (Barsky 1981). Ideally, therefore the role of a physician should be to establish a therapeutic relationship with patients in treatment. However, the doctor patient relationship in medicine is such that the patient assumes a more passive role in treatment. The physician is usually in a position of power, his authority arising from his superior and exclusive knowledge that gives legitimacy to his profession (Friedson 1988). Thus, allopathic medicine usually denounces an egalitarian subjective association between physician and patient.

The role of the patient as a submissive participant in his/her own health care decisions has increasingly been questioned (Haug and Lavin 1981). Haug and Lavin (1981) proposed a model of a consumerist patient, arguing that there is a shift in emphasis on patient's preference and physician's accountability. The traditional model of the submissive patient is incompatible with newer ideas of consumerism, where patients are usually more well-informed through the media and they are less willing to surrender

completely to the physician. In contrast to medicine which aligns more with the traditional model, complementary/alternative healing provides an opportunity for patients to actively contribute to their own therapeutic care in possibly a more amiable environment. The prospect of being able to discuss and decide on one's own health care decisions, according to many scholars, contributes to the attraction towards complementary/alternative healing (e.g. Brinkhaus 1998; Kelner 2000; Kaptchuk 2002; Richardson 2004). However, researchers who have tested this proposition have found no definitive answers. For instance, Kelner (2000), using data of 300 patients visiting either family physicians or complementary/alternative practitioners found that patients of complementary/alternative healers usually noted being able to participate in their treatment process. But, Kelner (2000) was quick to alert the reader that there are considerable variations in levels of satisfaction among patients based on type of complementary/alternative healing. For instance, he found that Reiki healers usually were ranked on top by patients in terms of expectations being met, while Chinese doctors were usually ranked lowest by patients. Furthermore, Kelner (2000) reported no significant difference in overall levels of satisfaction between patients of family physicians and complementary/alternative healers. He argues that the main impetus to seek complementary/alternative healing is not necessarily the relationship between physician and patient but rather a search for cure of chronic problems.

Brinkhaus and colleagues (1998) conducted an epidemiological study of homeopathic (N=220) and allopathic patients (N=194) to assess their typical characteristics. The findings from their study revealed that homeopathic patients (52%) attached more meaning to the doctor/patient relationship than allopathic patients (39%).

Richardson (2004) also found therapeutic relationship to emerge as a distinct theme from patient's expectations in her qualitative study of 327 patients (Richardson 2004). In her study, many participants explained their wish to be addressed and treated in a relaxed individualized setting (Richardson 2004). In this context scholars like Kaptchuk (2002) surmise that a session with a complementary/alternative practitioner might produce an apt diagnosis because complementary/alternative practitioners are less likely to set aside patient's experiences as undependable. For many, this expectation of having their pain acknowledged and heard might contribute to the appeal of complementary/alternative healing. Nevertheless, there is a difference between expectation and motivation, and it is quite ambiguous whether the therapeutic relationship by itself can act as a catalyst for seeking complementary/alternative healing.

### ***Perceived Safety and Perceived Efficacy***

#### ***a) Perceived Safety***

The widespread use of complementary/alternative healing in many nations of the world might also arise from its anticipated safety (Jonas, Kaptchuk and Linde 2003). The popular notion is that complementary/alternative healing practices and products are usually free from harm because they are "natural" (Barnes 2003). But it has to be noted that complementary/alternative healing practices and products are not always scrutinized like medicinal drugs. Few complementary/alternative healing products and practices are subjected to the same methods of inspection now common in medicine, often termed "evidence based medicine." Research in complementary/alternative healing is deficient and often absent because not all manufacturers of complementary/alternative healing products have the means to undertake such methods of inquiry (Barnes 2003).

Furthermore, inducements for research are missing amongst complementary/alternative healing practitioners and manufacturers because most natural products cannot be patented and numerous complementary/alternative products and practices can be retailed without any verification (Barnes 2003). Furthermore, as Ernst (1995) notes with regard to homeopathic medicine, that even if there could be fewer risks attached with use of certain complementary/alternative healing products and practices, these are not devoid of other difficulties. For instance, not all complementary/alternative healers might be competent enough to take complete responsibility of their patients. On the other hand arbitrary usage of certain complementary/alternative therapies might also prove hazardous (Ernst 1995). In addition, foregoing effective and proven allopathic medicine for untested alternatives could indirectly be harmful for health and wellbeing.

***b) Perceived Efficacy***

Use of complementary/alternative healing may also arise from its perceived effectiveness. Often in the absence of adequate research on complementary/alternative healing, many allopathic practitioners or scientists tend to write off complementary/alternative healing products and practices as quackery and dangerous (Beyerstein 2001). This is possibly fallacious as the results of many studies conducted on specific types of complementary/alternative healing practices and products indicate support for their efficacy. For instance, researchers comparing the effectiveness of homeopathy and allopathic medicine in a primary care setting of 456 patients from four countries, found significantly better outcomes for homeopathy (Riley et al. 2000). The researchers compared allopathic and homeopathic patients with upper respiratory tract and lower respiratory tract troubles including allergies or ear complaints. Significantly

fewer adverse events were reported by the homeopathic treatment group than the allopathic treatment group and the homeopathic group also reported higher levels of satisfaction from treatment. In a meta-analysis of 105 controlled clinical trials of homeopathy, Kliejnen and colleagues (1991) found positive results affirmed in almost 81 trials. Though the authors point attention to publication bias and poor quality of some of these trials, they assert that even some of the best of these trials found positive effects of homeopathy. Another group of researchers argue that much of alternative healing's effectiveness can be attributed to placebo effects. But this is possibly erroneous as many researchers have shown from examination of specific types of alternative healing practices and products that effectiveness often stems from real rather than placebo effects. For instance, Kaptchuk and Tomalin (2000) note that numerous clinical studies and experiments on traditional Chinese Medicine conducted in China during the 1950s revealed that it can be proved effective by objective measures. They argue that this was one of the primary reasons why Chinese medicine became officially recognized and accepted as an efficient form of healing by majority of the Chinese people (Kaptchuk and Tomalin 2000).

Rigorous research is required in determining the effectiveness of any healing technique. Since complementary/alternative practitioners and researchers often do not get much financial support from external sources like pharmaceutical companies, it is difficult for them to execute quality research (Ernst 2000; Barnes 2003). Though publication bias is an issue in medical studies, the scope of research is more widespread for allopathic practitioners and scientists. Furthermore, the question arises as to whether randomized controlled trials (RCT) should be used at all in evaluating the effectiveness

of complementary/alternative healing. Since RCT's are geared towards assessing efficacy of allopathic medicine, they may not be the most appropriate method of evaluation for other healing techniques (Furnham and Forey 1994). New methods of evaluation specific to different forms of healing need to be devised that can help in ascertaining the true potential of these diverse forms of healing (Ernst 2000). For instance, Singh (2010) argues, that if Ayurveda (a nearly 3000 year old form of Indian healing technique) is to be authenticated by scientific methods, Ayurveda's own tenets must be taken in to consideration. A placebo controlled study of Ayurvedic treatment for 46 patients suffering from rheumatoid arthritis incorporated some of Ayurveda's principles (Furst et al. 2011). The researchers in this study gave complete liberty to Ayurvedic physicians to customize treatment according to patient needs, a requirement in Ayurvedic healing and other forms of complementary/alternative healing (Furst et al. 2011). Also, placebos in the study were developed in the allopathic dosage forms of ayurvedic medicines (Furst et al. 2011). Future researchers might adapt research methods according to specific complementary/alternative healing techniques, reasonably integrating methods of allopathic and other complementary/alternative healing practices to test effectiveness of different forms of practices and products. If complementary/alternative healing is safe or effective is still unclear, however, that does not deter its utilization. It is also not clear if perceived safety of complementary/alternative healing pulls people towards these healing techniques. Research in the future might help to clear this nebulous state of uncertainty regarding its safety and reasons for usage.

### *Health Utilization Models in the Use of Complementary/Alternative Healing*

Researchers have used models of health and illness behavior to understand and examine individual use of complementary/alternative healing. The most popular among these models of utilization are the health belief model (Rosenstock 1974; Janz and Becker 1984), the socio behavioral model (Anderson 1995) and the theory of reasoned action and theory of planned behavior (Ajzen and Fishbein 1980; Ajzen 1985). These models of utilization provide a basic framework to test manifold factors affecting utilization of complementary/alternative healing.

Anderson's (1995) Socio- Behavioral model incorporates three major types of factors that might affect utilization of health care. These are predisposing traits, which generally includes gender, age, education etc., need factors like poor health conditions and enabling factors like insurance, availability of doctors, etc. Findings from a quantitative exploration of the socio behavioral model of 300 patients in a Canadian study revealed that the model could be used effectively to explain the use of complementary/alternative healing (Kelner and Wellman 1997). The authors point to the multiplicity of factors affecting individual choice of health care (Kelner and Wellman 1997). For instance, in the study, Kelner and Wellman (1997) point to chronic illness as need, education as predisposing and income as enabling factors to be significant for the utilization of complementary/alternative healing. In another study, researchers used an extended Anderson model, which included health beliefs like self-rated spirituality, to understand allopathic and complementary/alternative healing use (Hildreth and Elman 2007). Using a nationally representative survey of 1672 non-institutionalized adults between the ages of 31-64 in the United States, Hildreth and Elman (2007) found predisposing factors like

higher education (at  $p < 0.001$ ), being white (at  $p < 0.001$ ) and female (at  $p < 0.001$ ) to be strongly associated with use of complementary/alternative healing. Furthermore, the authors found poor health status (need for services in Anderson's model) to be associated (at  $p < 0.001$ ) with a greater likelihood of utilization of complementary/alternative healing. Also, findings from their study indicate, that the health belief of self-rated spirituality (at  $p < 0.01$ ) is associated with use of complementary/alternative healing (Hildreth and Elman 2007). The authors however, found no connection between enabling factors of income or insurance with utilization of complementary/alternative healing (Hildreth and Elman 2007). Other authors also substantiate some of these findings. In general it is found that individuals with higher education, women and individuals with chronic conditions are more likely to use complementary/alternative healing (Astin 1998; Bausell, Lin-Lee and Berman 2001). The Anderson Socio-behavioral model is definitely the most popular of the utilization models used to understand the use of complementary/alternative healing. It is important to note here that in the United States the most common complementary/alternative healing techniques that are included in some health insurance plans are chiropractic care, massage and acupuncture (Pelletier et al. 1999; Arcury et al. 2007). Insurance coverage of most types of complementary/alternative healing is quite limited as there is little to no research on their clinical and cost efficacy (Pelletier et al. 1999). Furthermore, services are not always provided by licensed practitioners, and for the majority complementary/alternative healing there is no state mandate for their coverage (Pelletier et al. 1999). Besides, insurers do not cover complementary/alternative healing for preventive care or general wellbeing; the few complementary/alternative



healing procedures that are covered are reimbursable only in particular cases of ill health and in a limited dollar capacity (Pelletier et al. 1999).

In the theory of reasoned action and planned behavior Ajzein and Fisbein (1980) emphasize the importance of intention in predicting behavior. The authors highlight that intention to execute a behavior is influenced by three factors which include attitudes, subjective norms and perceived behavioral control (Ajzein and Fishbein 1980). The original theory of reasoned action included the elements of attitudes and subjective norms, where attitudes was the extent to which an individual has positive or negative opinions regarding a particular behavior or action, and subjective norms referred to the appraisal of significant others concerning that behavior. The authors introduced the component of perceived behavioral control in the theory of planned behavior, which indicates a person's idea of control over a behavior, assuming that this factor would mirror past difficulties faced by the individual in carrying out the specific behavior in question. The theories have been used to a limited extent to test the use of complementary/alternative healing. Furnham and Lovett (2001) used the theories of reasoned action and planned behavior to assess how the various elements within these theories affect the use of homeopathy in a sample of 343 participants. Mainly they examined the effect of "attitudes" and "subjective norms" on the intent to use homeopathy and the effect of such intent on "actual behavior". Furthermore, they also assessed the outcome of prior actions on the intent and actual use of homeopathy. Using a convenience sample and a prospective design they found considerable support for the theories of reasoned action and planned behavior. Their results indicate that the plan to utilize homeopathy was affected by beliefs and subjective norms, while actual behavior

was significantly affected by motives or intent to use homeopathy. Furnham and Lovett (2001) also demonstrate the role of prior actions in affecting both intent and current actions to use homeopathy. There is definitely a need for more empirical research in this area to attest the applicability of the theories of reasoned action and planned behavior.

The Health Belief Model is that four key components affect individual's health related actions (Rosenstock 1974; Janz and Becker 1984). These are severity of an illness, individual's vulnerability to the illness, benefits of taking action and the barriers to that action. In addition to these factors, the health belief model has certain modifying factors. These are demographic and other social psychological factors and certain "cues to action" which could include mass media campaigns, recommendation from family and friends etc. The health belief model has been successfully used to examine utilization of preventative and other health related services. Of late some scholars have used the health belief model to explain the utilization of complementary/alternative healing. Chang and colleagues (2012) conducted a quantitative study in Taiwan, examining the applicability of the health belief model in use of complementary/alternative healing in a sample of 326 Type 2 Diabetes patients. Results of their study revealed that health beliefs and attitudes of perceived severity, susceptibility, benefits and barriers to action significantly affect use of complementary/alternative healing. In addition, the study found strong support for the modifying factor of cues to action, which included variables of diabetes mellitus related symptom distress, attitudes toward self-care and complementary/alternative healing and social support. Most demographic factors were not found to be significant in this specific study. In another study, Jetland (2012) examined if elements of the health belief model could help explain the reasons for complementary/alternative use among 216

undergraduate students. Among the students who reported use of complementary/alternative healing, most components of the health belief model (perceived severity, perceived susceptibility, perceived barriers, perceived benefits and general self efficacy) had significant association with use of complementary/alternative healing for preventive purposes. Only the element of perceived severity of illness emerged as a strong predictor of complementary/alternative healing use for treatment purposes, whereas perceived barriers and cues to action emerged as strong predictors of no use. These findings are indicative of the applicability of the health belief model, though more research is still required to reach definitive conclusions.

### **How Do People Feel After Using Complementary/Alternative Healing?**

Up until now I reviewed extant theories and research on the reasons for use of complementary/alternative healing. In the next part of this chapter, I review research of scholars who have examined the experiences with use of complementary/alternative healing. Research in this area is much less developed.

Some researchers have examined patient satisfaction with complementary/alternative healing. These researchers usually find that majority of users report some contentment with complementary/alternative healing (Downer et al. 1994; Oldendick et al. 2000). However, satisfaction might vary based on type of complementary/alternative healing chosen. For instance, Downer and colleagues (1994) found in their study of 415 cancer patients from two hospitals in London, that 39 (82%) of the 65 patients reported both physiological and psychological benefits from use of complementary/alternative healing. For instance, individuals expressed feeling tranquil and at peace after utilizing relaxation and visualization techniques, while also reporting

greater emotional strength, and general positivity about the future (Downer 1994). However, a small number of individuals reported problems like weight loss, wastage of time, and feeling sick with diet therapies and herbalism. Similarly, Oldendick and colleagues (2000) found from a study of a large sample of 1584 South Carolina adults that about 64% of the sample said they found complementary/alternative healing very effective and about 85% of the participants would recommend these therapies to a friend. However, out of these participants those using commercial weight loss programs were much less likely to find these effective and a small percentage using these therapies and hypnosis also reported having bad experiences. On the other hand, they found individuals visiting spiritual healers, Native American healers, energy healing and relaxation techniques were much more likely to report positive experiences and likely to recommend these to others (Oldendick et al. 2000). Most researchers find that among individuals using complementary/alternative healing, few report any major side effects (e.g. Downer et. al 1994; Ardah 2003; Molassiotis et al. 2005).

Use of complementary/alternative healing is now prevalent among cancer patients (Downer et al. 1994; Correa- Velez et al. 2005; Molassiotis et al. 2005). Molassiotis and colleagues (2005) conducted a cross national study across 14 European countries to assess the use of complementary/alternative healing among cancer patients. Their study included measures of satisfaction, benefits and side effects experienced from using complementary/alternative healing. The findings from their study revealed that about 35% of the total sample of 956 patients in the study reported using varied types of complementary/alternative healing ranging from diet therapies, energy therapies to Ayurveda, Homeopathy and others. Of those using complementary/alternative healing

techniques, the average satisfaction and perceived effectiveness scores were found to be high (Molassiotis et al. 2005). The majority of the cancer patients using other healing techniques argued that they used complementary/alternative healing to intensify the body's fighting capability against the disease and to ameliorate psychological and physiological wellbeing. About half of these patients reported gaining psychological benefits from using complementary/alternative healing and many also reported other physiological benefits. Only a very small minority reported no benefit and some side effects from using complementary and alternative healing (Molassiotis et al. 2005). Similarly, in a study of 1697 cancer patients in New South East Wales, researchers reported high prevalence of complementary/alternative healing use (Harris et al. 2003). Furthermore, patients in this study also indicated using complementary/alternative healing to get physical and emotional relief (Harris et al. 2003). The majority of the patients reported satisfaction, while about one fourth reported feeling uncertain about their experience with complementary/alternative healing (Harris et al. 2003). But very few patients in the study reported a negative experience or complete dissatisfaction with use of complementary/alternative healing. However, it is important to note here, that researchers using large surveys often do not provide an adequate definition or understanding of what they mean by satisfaction. Satisfaction measures are either a rating scale of 0-7 with higher scores indicating higher satisfaction or it is a single close ended question with three answer options (satisfied, dissatisfied, uncertain).

Another group of researchers from their qualitative study found, that many individuals with cancer use complementary/alternative healing because they perceive it as increasing their chances of survival and improving general wellbeing, while also

providing them relief from pain, symptoms and side effects of medicine (Correa- Velez et al. 2005). However, some other researchers have found adverse effects of having used complementary/alternative healing in cancer treatment. For instance, in a study on 480 patients with early-stage breast cancer, researchers found that those who used complementary/alternative healing noted poorer quality of life and psychological wellbeing than others who did not use other forms of healing (Burstein et al. 1999). Future researchers need to investigate in depth the reasons why some people report positive effects while others report negative effects of using complementary/alternative healing in cancer treatment.

Apart from the experience of individuals undergoing complementary cancer treatment, some studies have assessed complementary/alternative healing use by individuals afflicted with other chronic ailments. Foote-Ardah (2003) conducted a study on the meaning of complementary/alternative healing among 62 individuals with HIV in the United States. In this study, the author emphasized how many individuals use complementary/alternative healing for self-control and to continue with the uncertainties of day to day life (Foote-Ardah 2003). Thus, the meaning of complementary/alternative healing for HIV inflicted individuals in this study revolved around choice and autonomy because there were no compulsions placed on them like in medicine.

The above studies are some of the few qualitative explorations that allow for a deeper understanding of the experiences of complementary/alternative healing among individual users. Most efficacy studies on complementary/alternative healing rely on randomized controlled trials (RCT). These RCT's, as Verhoef and colleagues (2004) point out are important in some respects but limited. To appreciate the meaning of

complementary/alternative healing among users, and gauge their experiences, there is need for more qualitative studies in this area (Verhoef et al. 2004). This happens to be one of the primary aims of the current study.

### **Summary**

Several researchers have theorized and some have examined the reasons for use of complementary/alternative healing. One group of researchers argues for the value congruence theory in use of complementary/alternative healing (Barrett et al 2000; Bishop et al 2006; Callaghan and Jordan 2006; Siapush 1999). These researchers suggest that those who adhere to a particular set of beliefs and values (for example, holism, rejection of authority etc.) are more likely to use complementary/alternative healing. On the other hand, few other researchers suggest that those people who engage in, or attach weight to positive health behaviors are more likely to use complementary/alternative healing (Furnham and Bhagrath 1993; Goldstein 2000; Nahin et al 2007). Another common explanation forwarded by many researchers to explicate the use of complementary/alternative healing is the growing dissatisfaction with use of allopathic medicine among certain people (Cassileth et al 1984; Furnham and Smith 1988; McGregor and Paey 1996; Sirois and Gick 2002). Still other researchers contend that the therapeutic relationship between the healer and the patient him or herself contributes to the attraction towards complementary/alternative healing (Brinkhaus 1998; Kaptchuk 2002; Kelner 2000; Richardson 2004). The implication is that in complementary/alternative healing, patients have more opportunity to actively participate in their own health care decisions. In addition to these postulations, some other scholars point to the perceived safety and efficacy of complementary/alternative healing as pull

factors in their use (Barnes 2003; Jonas, Kaptchuk and Linde 2003; Riley et al. 2000). Finally, scholars have used health utilization models to test multiple factors affecting use of complementary/alternative healing (Chang et al. 2012; Furnham and Lovett 2001; Hildreth and Elman 2007; Kelner and Wellman 1997).

Research on the user experience with complementary/alternative healing is limited. However, some researchers have examined people's experience and perceptions of effectiveness with use of complementary/alternative healing. These researchers usually reveal some patient satisfaction both physiological and psychological (Downer and Oldendick 1994; Harris et al. 2003; Molassiotis et al. 2005). In addition, some results point to variation in satisfaction levels based on type of complementary/alternative healing (Oldendick et al. 2000). Furthermore, some researchers also highlight certain cases of side-effects from complementary/alternative healing. In the quantitative studies the measures of satisfaction are quite limited, usually a rating scale or a single close ended question (Molassiotis et al. 2005). Only a few qualitative explorations exist, where researchers have attempted to gauge the perceived effectiveness and experience with use of complementary/alternative healing (Correa- Velez et al. 2005; Foote- Ardah 2003).

Though the studies reviewed here are valuable contributions to the literature, they have certain limitations. First, since most studies are cross sectional, it is difficult to make causal interpretations regarding the use of complementary/alternative healing. Second, most studies do not capture the racial, ethnic, class, religious diversity that might exist in the use of complementary/alternative healing. Third, there are several complementary/alternative healing practices that do not find mention in most studies. Fourth, some studies are limited by a small sample size and or self selected samples.



Finally, from the existing studies it is difficult to understand the meaning of complementary/alternative healing to individuals who use other healing options and their experiences with it. In the current study I attempt to contribute to this gap in the literature.

### **Chapter Three: Theoretical Orientation**

In the previous chapter I outlined the existing research on complementary/alternative healing and the theories related to its use and experience. In this chapter I lay out my choice of theoretical orientation that will provide the guiding framework for my study. Specifically, I have used the theoretical paradigm of symbolic interactionism (SI), and here I delineate the main tenets of SI and why it is an apt choice for my research.

Symbolic Interactionism offers a theoretical framework that places emphasis on meaning, process and action. Symbolic interactionism assumes that we construct and reconstruct the social world through social interaction. George Herbert Mead, an early proponent of symbolic interactionism emphasized the relationship between the individual and society. For Mead the development of human beings and our interpretation of social objects and events are social processes that require the communication of various individuals (Mead 1967). Mead placed importance on language, the means by which communication is made possible. He highlighted language to be fundamental to the development of the self and society, which are emerging through a continuous process of social interaction (Mead 1967). Herbert Blumer (1969) continued the tradition started by Mead. He coined the term symbolic interactionism and highlighted the important tenets of this theoretical paradigm. First, he pointed out that people take action based on the meanings of things. Second, meanings are a social product that develops from the process of interaction between people; meanings are not an inherent aspect of the objects themselves. And third, the process is an interpretive one, where meanings can be

modified based on the interactions between people. These adjustments in meaning are possible because people enjoy the capability to interact with themselves and others and consider different choices along with their possible outcomes. Human beings have agency, the ability to think and make choices, an outgrowth of social interaction. The symbolic interactionist paradigm also recognizes that societal structures place external constraints on people, and that people's response to these constraints differs. The background for social interaction is society and society itself develops as a result of the continuous processes of interaction and action.

The concept of the self, which is our understanding of a recognizable and original personal identity that is distinct from others, is conceptualized in symbolic interactionism as developed and modified through social interaction over a person's lifetime (Blumer, 1969). The self is constantly evolving through an interactive process with other selves. The self is not a fixed object or being, but is in a state of continuous change, developed in the course of one's interaction with others in society. Mead identified the dual nature of the self and indicated that these were the "I" and the "me". The "I" in Mead's conception of the self is the subject component or the spontaneous, creative part of the self, whereas, "me" is the object component that is the self that is more dependent on others and socialized through interaction (Mead 1967). Though different selves may have a typical form, each "self" in reality is distinct, produced in particular societal contexts at particular time.

In the context of this research a symbolic interactionist framework is particularly suitable. A chronic illness or any illness usually generates some amount of turmoil among people. However, at the same time, it also gives rise to a situation in which people are

driven to consider choices and take decisions with regard to their health care. People's choices are not derived in vacuum, they are shaped by the social context in which they live and their interactions with other people. Here, plausibly both Mead's "I" and "me" are at work. While the "I", or the subject component of the self might be tempted to make spontaneous decisions, the "me", or the object component of the self counterbalances the "I" to reach decisions that have been socially conditioned. People while making choices refer to those social objects that having meaning in the specific context. A person is an "acting organism" who interprets meaning and ultimately takes action based on a process of construction and reconstruction of meanings (Blumer 1969). Furthermore, symbolic interactionism recognizes the dynamic nature of processes, such that ideas, meanings and actions are subject to change with additional knowledge and experience. The symbolic interactionist emphasis on the individual enables researchers to gauge how a person approaches difficulties, how the person constructs a plan of action and most importantly what holds significance or meaning for the person. Schwandt (1994) suggests that symbolic interactionists believe that the researcher needs to delineate processes by which meaning is constructed and explain why and how meanings are represented in the communication and actions of individuals. According to symbolic interactionists, human life and human beings can be understood through individual actions (Mead 1967).

The symbolic interactionist assumption that has an emphasis on meaning, interpretation of meaning and individual action as key to social interactions, and an understanding of verbal and non-verbal cultural symbols as important, is in congruence with the research plan of this study. The primary research assumption of my dissertation project, consistent with the symbolic interactionist view, is that if a person is faced with a

difficulty such as an illness, a person usually engages in a process of internal and external communication, weighing choices and choosing a course of action based on an organization of different ideas and what is meaningful in that situation. If a chronically ill person makes a choice for complementary/alternative healing, there is a certain significance of that choice.

The methodological position as proposed by Blumer (1969) is that in order to know the world, it is essential to examine it through participant's actions and interactions. The researcher should be in a position to interact with the participants, who are the subjects of the research and perceive the world from their standpoint and situation. Therefore, my role as a researcher here was to understand the meanings that are experienced by the participants in the context of their situation in life, the person's lived experiences and the person's perception of the situation from his/her vantage point. The aim was to uncover the process through which meaning is attached and interpreted and what is that meaning and experience like. Hence, the symbolic interactionist paradigm helps to reinforce this study of meaning and experience while taking into account the contextual differences that exist in meaning and experience over time.

There is also strong link between symbolic interactionism and grounded theory methods, my preferred methodology for this study. Grounded theory is a method of data collection and analysis that is, in short, "inductive, comparative, iterative and interactive" (Charmaz 2006). Grounded theory methods necessitate the researcher to handle data collection and analysis while providing them more command over the material. The method involves simultaneous data collection and analysis and aims to keep the researcher involved in the process of meaning making. In grounded theory, once the

researcher has engaged in initial data collection, those data are exposed to the constant comparative method of analysis (Charmaz 2006). This enables the research to progress from a study of objective realities to providing theoretical and abstract knowledge from the data (Charmaz 2006).

Symbolic interactionism almost works in tandem with grounded theory methods (Charmaz 2006; Charmaz and Belgrave 2012). Clarke (2005) goes as far as to assume that grounded theory methods are based within symbolic interactionist theory and that these comprise a “theory/methods package”. Especially, the constructivist grounded theory method proposed later by Charmaz (2006) is entrenched in symbolic interactionist thought.

Strauss and Corbin (1990) put forth two principles of symbolic interactionism that have been imbued into grounded theory methods. These are the changing nature of social phenomena and the availability of choices to social actors who can make decisions based on their perceptions and the context. Finding the processes that influence action in a particular context is at the center of grounded theory research. The symbolic interactionist underpinnings are quite pronounced in Charmaz’s development of constructivist grounded theory. Constructivism emphasizes the personal relationship between the researcher and the participant and the co-development of meaning. Researchers as human beings are not seen as value free and their presence in the research process is recognized. The researcher’s goal is to know about the inherent meanings within the experience of the participants and to develop it theoretically (Charmaz and Belgrave, 2012). Therefore, some of the overlapping assumptions in both symbolic interactionism and grounded theory are that multiple realities exist, meanings are

contextual, meanings are developed and modified in the interactions between the participants and the researcher in the research process, and that context is significant (Aldiabat and Navnec 2011; Charmaz and Belgrave 2012)

In medical sociology, Charmaz and Belgrave (2013) highlight symbolic interactionism as being particularly prominent in influencing studies related to the illness experience. They point out how symbolic interactionists have pursued research on people with chronic illnesses, taking into account their experiences and conduct in specific contexts. In addition, symbolic interactionists have sought to understand how people make sense of their experience and when there is a shift in perceptions. The symbolic interactionist paradigm in medical sociology also brings to the fore the examination of different and frequently contradictory “definitions of the situation” between individuals and collectivities in social settings (Charmaz and Belgrave 2013). Earlier studies using symbolic interactionism and grounded theory have analyzed the life of people with chronic illnesses. The emphasis in these earlier studies has been to uphold the lived experience of people suffering from a chronic illness. In the current study, I attempt to use the two to understand what makes people choose complementary/alternative healing when they suffer from a chronic illness, how they interpret their personal experience with these healing techniques, and how they construct meaning of complementary/alternative healing based on the social context of their lives. The symbolic interactionist framework and grounded theory could also prove useful as a guide to explore how complementary/alternative healing is defined as there is nothing absolute about the definition of complementary/alternative healing. To summarize in a few words, my study aims to uncover what is going on in the processes through which

complementary/alternative healing is defined, understood and experienced by chronically ill patients.



## **Chapter Four: Research Methods**

In this chapter I describe in detail the methods I used to conduct data collection and analysis to meet the aims of this project. As highlighted in the introduction chapter, my primary research question was “What is the meaning and experience of complementary/alternative healing to chronically ill persons?” To address this research question, in the current study I used a qualitative study design, specifically grounded theory methods.

Grounded theory methods are a collection of logical directions that allow researchers to focus their data collection and to build inductive middle range theories through successive levels of data analysis and development (Denzin and Lincoln 2005; Birks and Mills 2011). An advantage of grounded theory methods is that they equip the researcher with tools to analyze processes. Grounded theory data collection involves building abstract ideas about the participant’s meanings and actions and to pursue specific data to fill out, improve and review the developing conceptual categories (Denzin and Lincoln 2005; Birks and Mills 2011). In this study I am using a constructivist grounded theory approach developed by Charmaz (2006). The social constructivist paradigm emphasizes that human beings do not find or discover knowledge so much as construct or make it (Burr 2003). The social constructivist paradigm recognizes the complex nature of multiple realities, constructivism being the belief that the known world has no meaning except for what is attributed to it by individuals (Burr 2003). Charmaz’s (2006) constructivist grounded theory assumes the relative nature of multiple social realities and the co-creation of knowledge by the researcher and

participants. In this, the constructivist grounded theory approach emphasizes actions, processes and meanings (Charmaz 2006).

### **Sampling and Recruiting**

In qualitative research usually the sampling procedures are purposive and relevant to answer the research questions. Specifically, in grounded theory methods, the sampling technique followed is theoretical sampling, a key procedure that enables the researcher in theory building. This form of sampling allows the researcher to identify gaps and go back to the field and find new data to establish further conceptual categories and saturate the conceptual categories (Charmaz and Belgrave 2012). Ideally, individuals from varied situations and experiences are desired to saturate the categories and introduce complexity in the data. The aim is not generalization but description of something specific (Creswell 2006). Based on this premise I targeted interviews from 25-30 participants. However, after theoretical sampling, that is finding and gathering appropriate data to expand and clarify the categories I found, I was able to reach theoretical saturation after 21 interviews.

I attempted to interview people from different genders, age groups, ethnicities, and people suffering from diverse chronic ailments and using varied complementary/alternative healing. However, I was unable to gain access to people from socio-economically disadvantaged groups. Having lived in Miami/United States for only 5 years, I had to depend heavily on my participants to refer me to other people who might have been willing to share their experiences. Hence, limited access to people from lower socio-economic backgrounds thwarted my ability to conduct that type of theoretical sampling.

To start the snowball sampling procedure I initially contacted people from my connections requesting participation or references of individuals who might be able and willing to participate in this project. Three people from my contacts agreed to participate in the project. After conducting the first few interviews, and analyzing them, I came up with categories (like “using multiple healing options”, “giving importance to the healer”, “being averse to medications”) to channel subsequent data collection. I then requested my early contacts to guide me to other participants from diverse backgrounds that might be able and willing to help me saturate the initial categories and direct me to develop further conceptual categories. My early contacts shared the email or phone numbers of people that they thought would fit my research criteria and enabled me to establish contact with potential participants. I then approached these individuals through email or over the phone and scheduled interviews with them if they agreed to participate. Henceforth, I conducted interviews having followed the same procedure of identifying categories from my data and accordingly approaching potential participants from the contacts provided by previous participants. Some participants were very intrigued by the study and went out of their way to help me find more participants. One of my participants also invited me to her vegan potluck, where I was asked to provide a brief description of my study, so that anyone interested to participate could establish contact with me. Another participant invited me to his support group meeting for Parkinson’s disease and introduced me to a few people who I was able to contact later seeking participation. I continued to seek out people to interview until I was satisfied that I had reached theoretical saturation of the conceptual categories that emerged from data collection and analysis. My final sample

consisted of people from different genders, age groups, ethnicities, and suffering from varied chronic illnesses and using diverse complementary/alternative healing.

### **Interviews**

Grounded theory methods allow researchers to adapt methods which are simply tools, to be combined with observation and perspective to produce and understand data. There is data construction in the research process through the continuous interactions between the researcher and the participants. I conducted intensive interviews to explore the meaning and experience of complementary/alternative healing to users in Miami. According to Charmaz (2006) qualitative intensive interviewing is particularly suitable for grounded theory methods. This is because the constructivist grounded theory method places importance on the process of inquiry. The aim of those using this method is not merely to describe events, situations or settings but rather to focus on an in-depth understanding of a subject matter (Charmaz 2006). Hence, when individuals agreed to participate in the study, they were invited to take part in an in-depth face to face interview. The interviews were then conducted at either the participant's residence (for those who were quite ill and had to depend on others for travel) or at a convenient location of the participant's choosing.

I started each interview with a brief introduction of myself (this was usually the first meeting with most of my participants even though I had contacted them by phone or email) and a short explanation of the project. I then handed over the informed consent form to the participants for their consideration to participate in the project. The informed consent form was developed in accordance with the requirements of the University of Miami Institutional Review Board. It included important information regarding the

project encompassing the following areas- purpose, procedures, risks and benefits, confidentiality, compensation, opportunity to ask questions and freedom to withdraw and finally seeking consent (The informed consent form is included as an appendix with the dissertation). Some participants asked me to briefly state the contents of the informed consent form. I asked all participants to raise any questions or doubts they might have regarding the project before they provided consent. After participants had read the informed consent form and provided their written approval to participate in the project, I formally requested permission to switch on the audio-recorder and start the interview. Depending on the participants and their specific experiences with complementary/alternative healing the interviews lasted between 25 minutes to 3 hours 30 minutes. All the interviews were audio recorded and later transcribed. Sometimes, I also took notes during the interviews.

To ensure I did not miss out on asking for important information during the interviews, I always referred to an interview guide. The interview guide was developed in accordance with Charmaz's (2006) suggested questions recommended for grounded theory methods. Charmaz (2006) suggests that one should prepare a few broad open ended questions for a grounded theory study. The emphasis on open ended non-judgmental questions is to stimulate unexpected assertions or accounts to come out from the interview process (Charmaz 2006). Furthermore, Charmaz (2006) emphasizes the circumstantial nature of interviews, indicating that irrespective of whether participants talk without interruption or they are probed by the interviewer, the outcome is a continuous reconstruction of reality. Hence, keeping these points in mind my interview guide consisted of a few broad questions that were modified, expanded or deleted

depending on the context. Following Charmaz's (2006) recommendations the interview guide included some initial open-ended questions, followed by some intermediate questions and finally some ending questions. The questions sometimes overlapped, following Charmaz's (2006) suggestion that some questions should deliberately overlap to enable the researcher to weed out more information or delete irrelevant data or go back to sensitive issues. The interview guide is included as an appendix with this dissertation.

### **Participants**

A total of 16 women and 5 men participated in the study. The age range of the participants is between 32-77 years. The participants are an ethnically diverse group. There are 5 women who identified as Hispanic (3 Cubans, 1 Colombian, 1 Honduran), 1 woman identified as French, another woman as Scot English, in addition there were 2 Indians (1 man and 1 woman) and the rest identified as White American. Many of the participants had retired due to age or illness. Others were still in the work force or self employed. All the participants suffered from some chronic illness and were currently using or in the past had used two or more complementary/alternative healing. A brief profile of the participants stating their age, ethnicity, type of illness and complementary/alternative healing used is provided with their pseudonyms. This will enable the readers to readily identify the participants while reading the findings and discussion sections of this dissertation project.

## Participant Profiles

Participant's Pseudonym	Profile
Rachael	Rachael is a 70 year old White Hispanic woman (Cuban) who has been living in the United States for 54 years. She suffers from osteoarthritis, neck pain, and lower back pain. She has used a variety of complementary/alternative healing including -reiki, chiropractic, acupuncture, physical therapy, supplements, natural foods, yoga, and meditation. She prefers complementary/alternative healing to regular allopathic medicine and insists allopathic medicine is more suitable for acute emergency care. She is a retired high-school teacher but leads an active life volunteering and engaging in other interesting pursuits.
Nancy	Nancy is a 63 year old White American woman who suffers from chronic back pain. She has primarily used Chiropractic care along with some supplements and mindfulness practices. She insists that for some conditions there is no alternative, complementary/alternative healing is the primary means of care. However, she does not believe in the philosophy behind complementary, alternative healing, even though she sees results and knows it works. She is more comfortable with the general principles behind allopathic medicine. Nancy is currently working full time.
Amy	Amy is a 51 year old White Hispanic woman who has been living in the United States for 41 years. She suffers from a rare blood condition, thrombotic thrombocytopenic purpura (TTP). She has undergone a variety of allopathic procedures and has recently been exploring different complementary/alternative healing. She has tried several forms of healing including acupuncture, reiki, energy healing, color imagery, life line, shamanic healing, John of God healing, drumming healing, Chinese herbs and natural foods. She is unable to work on site at her work place but has been allowed by her employers to work from home for the past two years. She feels that complementary/alternative healing has improved her quality of life and mental well-being.

Anita	Anita is a 49 year old White American woman. She had an early onset of Parkinson's disease, and has been trying to combat it with both regular allopathic drugs and complementary/alternative healing. She uses various forms of complementary/alternative healing including natural foods, acupuncture, chiropractic, evolutionary healing, yoga, shamanic healing, massage, music therapy, reiki, meditation. She would like to get off the allopathic drugs completely but says she lacks the courage to do so. She is currently unable to work and is living on disability benefits.
Rita	Rita is a 57 year old White American woman. She suffers from hyperthyroidism and gluten sensitivity. She uses a small amount of regular allopathic drug but prefers complementary/alternative healing. She has used multiple forms of healing including-physical therapy, massage, chiropractic, holistic healing(functional medicine), DGL liquorice, chelation, sauna therapy, meditation, reiki, acupuncture, deep massage therapy, chinese medicine testing, applied Kinesiology. She says that unlike others, when faced with a problem she first visits a complementary/alternative practitioner. She is currently out of the work force.
Liza	Liza is a 66 year old White American woman and breast cancer survivor. After having undergone several surgeries to combat cancer, she turned to complementary/alternative healing for relief. She used several forms of healing including dietary supplements, metabolic enzyme therapy, Gerson therapy, Chinese herbs, acupuncture, Jin Shin Jyutshu, applied kinesiology, cold laser, different supplements, natural food and exercise. She believes that complementary/alternative healing finally helped her get rid of cancer. She is an avid advocate for natural therapies and travels around the country and outside to promote natural therapies for cancer.
Kelly	Kelly is a 56 year old Asian Indian woman from Trinidad. She suffers from Parkinson's disease and uses both regular allopathic drugs and complementary/alternative healing to stay well. Her use of complementary/alternative healing includes - acupuncture, chiropractic, yoga, meditation, music therapy, massage and supplements. She started with only complementary/alternative healing but henceforth had to rely on allopathic drugs. She uses complementary/alternative healing to improve her quality of life. She has taken voluntary retirement from work.



Mahdi	Mahdi is a 67 year old White American woman. She suffers from a chronic migraine condition that has adversely affected her life. She has used various complementary/alternative healing for years. These include-mindfulness practices, readings, natural foods, supplements, one brain, yoga, 5 tibetan rites, meditation, rebirthing, breathing techniques, neti-pot, acupuncture, acupressure, massage, reflexology, magnets, chiropractic, cranial-sacral therapy, cranial plate realignment, essential oils, aroma therapy, chakra alignment, sauna, inversion table, reiki, tens unit, biofeedback, hypnotherapy and muscle testing. She places emphasis on healthy eating and healthy living. She took early retirement as a high-school principal.
Lucy	Lucy is a 72 year old Hispanic woman (Colombian), who has been living in the United States for the past 47 years. She was diagnosed with a rare cancer, multiple myeloma, 2.5 years back. She believes in the integration of complementary/alternative healing along with allopathic medicine. She has used/ and continues to use some complementary/alternative healing like yoga, Tai-Chi, meditation, reiki, acupuncture, natural foods. She argues that due to the advanced stage of her disease she is unable to try other forms of healing. She took retirement from her work following the diagnosis.
Ruth	Ruth is a 62 year old White American woman suffering from multiple sclerosis. Her condition affected her work in a veterinary clinic and she is currently out of the work force. However, she continues to volunteer in different organizations. She primarily uses complementary/alternative healing (acupuncture) on an as needed basis to deal with her condition. However, she relies on an allopathic drug for her atrial fibrillation problem. Ruth currently uses multiple forms of healing including acupuncture, massage, chiropractic, yoga, dance therapy, music therapy, art therapy, natural foods. Ruth herself worked as a massage therapist for some period of time but was unable to continue with it following the progression of her health condition. She currently volunteers in an environment group.
Shirin	Shirin is a 65 year old White English woman who has been living in the United States for 36 years. At the time of the interview she was suffering from cardiac problems and migraine. She has used some complementary/alternative healing like acupuncture, yoga, pilates, physical therapy, meditation and supplements. She was in the health care sector but is currently out of the work force. She believes in the integration of complementary/alternative healing with allopathic medicine. She attests to the importance of both in maintaining optimum health. She is currently out of the work force.

Liliana	Liliana is a 64 year old White American woman who survived cervical cancer. She believes she was able to successfully combat cancer with complementary/alternative healing. She primarily used acupuncture, chinese medicine, natural foods, and meditation. She asserts that allopathic medicine is good for emergency care but for chronic illnesses one should try all possibilities with complementary/alternative healing. She is currently a juicing coach.
Tete	Tete is a 56 year old Hispanic woman who has been living in the US for 37 years. She suffers from arthritis and has been trying to explore complementary/alternative healing for the past one year to reduce intake of allopathic drugs. She has used some complementary/alternative healing including natural foods, yoga, and acupuncture. She is currently working full time.
Lile	Lile is a 32 year old French woman who has been living in the US for the past 5 years. She suffers from chronic back pain and has used some complementary/alternative healing for relief. Though both her parents are allopathic doctors she has a propensity towards other forms of healing. She has used complementary/alternative healing like chiropractic, acupuncture, natural Foods, supplements, aroma Therapy, osteopathy, yoga, and reflexology. She is currently a university student and her health condition has not adversely affected her studies.
Miranda	Miranda is a 76 year old White woman of Irish/Spanish background. She suffers from Parkinson's disease and uses both allopathic medicines and complementary/alternative healing for her condition. She has used multiple forms of complementary/alternative healing including holistic healing, reiki, acupuncture, massage therapy, yoga, natural foods and supplements. She feels she cannot rely on complementary/alternative healing completely as it would make her family worried. She was never in the work force as she raised a large family.
Larissa	Larissa is a 53 year old Hispanic woman (Cuban) who has been living in the US for 46 years. She suffers from chronic back pain. She has used a variety of complementary/alternative healing including acupuncture, herbal supplements, energy medicine, color therapy, physical therapy, massage, body talk, yoga, meditation, and natural foods. She says that she is open to trying different modalities and exploring possibilities of receiving benefits from them. She is currently working full time.

Michael	Michael is a 77 year old White American man who suffers from osteoarthritis, sciatica and borderline diabetes mellitus. He has used a variety of complementary/alternative healing including reiki, chiropractic, acupuncture, physical therapy, supplements, natural foods, yoga and meditation. He asserts that because of his use of complementary/alternative healing he has been able to maintain an active lifestyle. He is a retired teacher but is active in the community.
Henry	Henry is a 56 year old White American man who suffers from Parkinson's disease. He depends heavily on allopathic drugs, but uses complementary/alternative healing to complement the regular medicines. The types of healing he uses are tai-chi, yoga and music therapy. He points out that he is a person that would earlier raise doubts about complementary/alternative healing but having used it, appreciates its worth. He believes that he has a significantly better quality of life that can be partially attributed to complementary/alternative healing. He is currently working part-time.
Phil	Phil is a 66 year old White American man who suffers from ulcerative colitis. He has been using complementary/alternative healing for many years. He contends that his interactions with people from around the world and travels to different parts of Central and South America has been instrumental in affecting his views on healing. On a regular basis he continues to use meditation and yoga but in the past he has used shamanic healing, physical therapy, acupuncture and chiropractic. He is retired but continues to be active in the community.
Matt	Matt is a 61 year old White American man who suffers from Parkinson's disease and has been using a variety of complementary/alternative healing. The types of healing that he has used include chelation therapy, hyperbaric chamber therapy, acupuncture, natural foods, supplements, yoga, Tai-Chi, Chinese medicine, chiropractic and massage. He insists that he has always been drawn to complementary/alternative healing more than regular allopathic medicine. Currently, he is on small dosage of allopathic drugs but continues to use other complementary/alternative healing. He is retired but active in the community.
Bobby	Bobby is a 68 year old Asian Indian male suffering from Parkinson's disease. He has been living in the US for the past 40 years and is currently retired. At the time of the interview the disease had heavily affected his communication abilities and he had to put in a lot of effort to speak. He was on a heavy dosage of allopathic drugs and had just started using complementary/alternative healing. He had primarily only used yoga and Tai-Chi but he was planning to travel for a few months in 2015 to India to undergo Ayurvedic treatment on the recommendation of a friend. I tried to contact him this year but he was unavailable at this time.

## **Location**

The 21 in-depth face to face interviews all took place in Miami. Though I chose Miami as my research location because it would be convenient for me to conduct the interviews here, Miami is also very unique in her country. It is considered an international tourist hotspot, a center of culture, and a global business and trade hub. The US Census Bureau highlights that Miami's metro area is amongst the most populous in the United States with a population over 5 million (World Population Review 2014). Miami's population is comprised of people from several ethnic and national origins and diversity is expected to increase (Leonard, Bouvier and Martin 1995). Interestingly, Miami is considered a multicultural city rather than a melting pot, implying that people from different ethnic groups/national origins tend to preserve their cultural distinctiveness here. Miami has also emerged as a healthcare hub with its Civic Center (Chang 2014). Prominent institutions include the Jackson Memorial Hospital (estd. 1915) and University of Miami Leonard M. Miller School of Medicine. Complementary/alternative healing that is part of the cultural practice of people of different ethnic and national origin groups are still likely practiced and thriving in parts of Miami. In addition, some complementary/alternative healing like chiropractic and acupuncture are covered by some insurance plans but it is difficult to generalize as the coverage of complementary/alternative healing varies according to insurance plan. Like in other places in the United States, over the counter herbal therapies and medication are also widely found in pharmacies across the city.

## **Data Analysis**

I started data analysis, as soon as I had completed the first interview. Once I had conducted the first interview, I myself transcribed the full audio recording of the interview in Microsoft word. Once I had finished typing out the interview I began the coding process.

I engaged in initial coding or line by line/word by word coding as proposed in Charmaz's (2006) constructivist grounded theory, beginning with the first interview. As soon as I completed the second interview, I began the constant comparison that is one of the hallmarks of grounded theory methodology. I used these comparisons to guide subsequent data collection and to generate and modify action codes as described by Charmaz (2006). In the next stage I engaged in focused coding, which is a more conceptual and selective form of coding, and entails the sorting of initial codes and selecting those codes that continually recur in the data (Charmaz and Belgrave 2012). These focused codes enabled me to identify the categories that I could construct from the data.

After I had engaged myself in focused coding, I took to memo writing which aids in connecting the process of coding to analyzing the data. Charmaz and Belgrave (2012) highlight the importance of 'memo writing' which provides the essential cues in developing conceptual categories and keeps the researcher occupied in writing within the research process. I tried to consider the full potential of the conceptual categories from memo-writing. This enabled me to make logical connections and opened up possibilities for exploring new areas from future interviews. I also used the memos to express my thoughts on certain codes and how they might be related to each other. Since I engaged in

a process of simultaneous data collection and analysis, my primary observations guided my later interviews and enabled me to fully saturate the categories. In the final stages of writing, I used the memos to organize the data and identify the major themes from the codes. I tried to express the organization of themes visually, and to highlight the connections between the categories. I have presented these visual representations in the findings chapter of the dissertation.

In my final analysis I tried to develop a theory that emerged from the data or the narrations of the participants. This theory is not generalizable to a larger population, but it sheds light on the significance of meanings created by specific persons in a particular context. The objective of the project was to understand the meaning and experience of complementary/alternative healing to chronically ill individuals and that aim has been fulfilled through the continuous data collection and analysis as suggested in constructivist grounded theory.

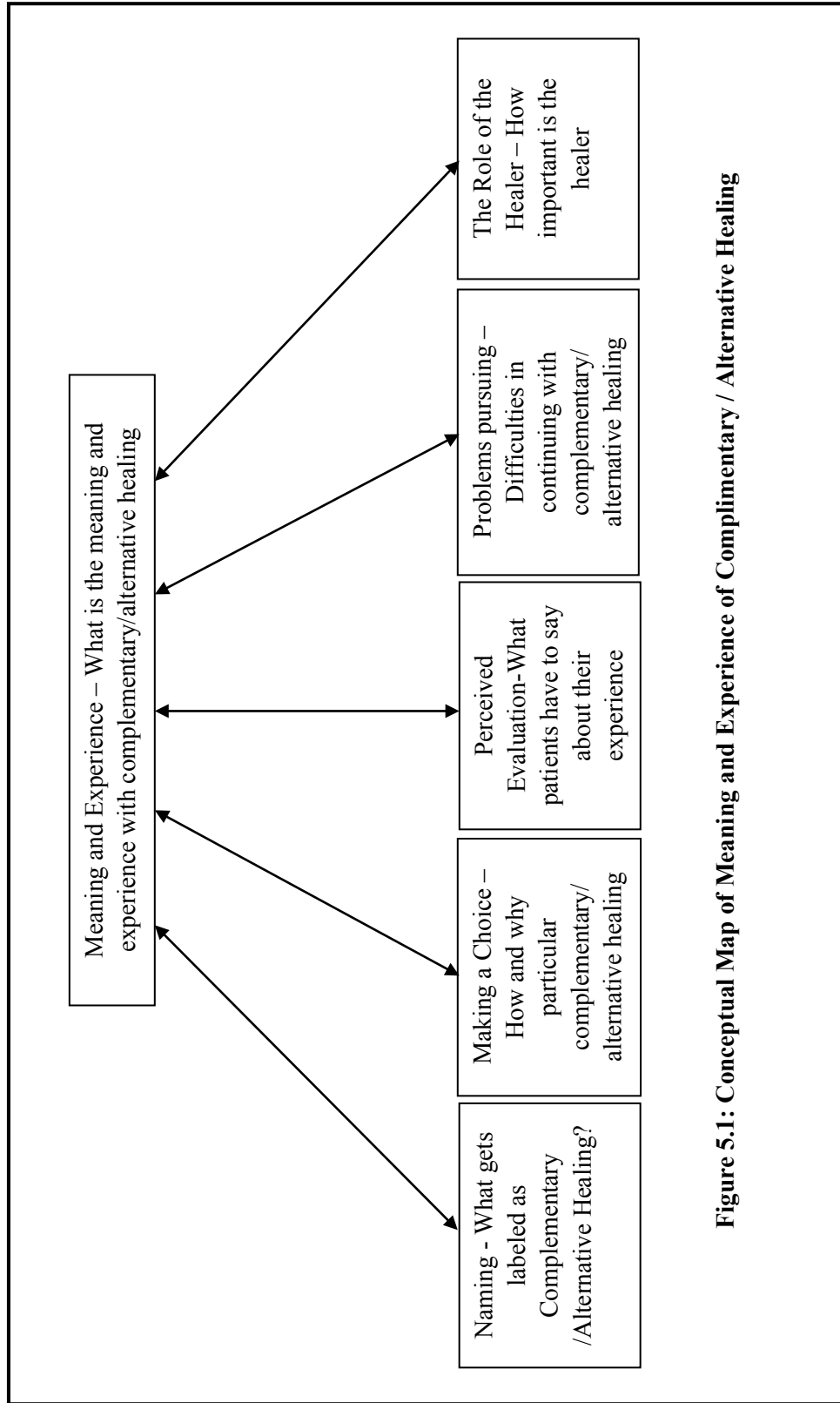


Figure 5.1: Conceptual Map of Meaning and Experience of Complementary / Alternative Healing

## **Findings**

This chapter is a detailed depiction of the themes that make up the meaning and experience of using complementary/alternative healing. Themes are typical patterns that emerge from the data in qualitative analysis and are essential for the description of a particular phenomenon. I developed a conceptual map to organize my findings and make it more coherent. This conceptual map illustrates the process of interplay of meaning, experience and use of complementary/alternative healing, and includes five major themes that emerged from the data. The illustration of the conceptual map is not derived from any pre-existing theory and is based my own data collection and analysis, which included line by line coding, focused coding, theoretical sampling and memo-writing. Although, meaning and experience of using complementary/alternative healing varies for participants with different chronic ailments, the themes helped in organization of the significant components associated with answering the specific research question for my project.

Each theme in my conceptual map further includes multiple categories with a focus on the main facets associated with that particular theme. The five major themes I defined include, (a) naming of complementary/alternative healing, (b) making a choice for complementary/alternative healing, (c) perceived evaluation of complementary/alternative healing, (d) problems pursuing complementary/alternative healing and (e) the role of the healer in complementary/alternative healing. The processes through which chronically ill patients attach meaning, and experience use of complementary/alternative healing is a mutually influencing process, whereby, each theme that comprises meaning and experience also in turn affects the meaning and



experience of complementary/alternative healing. A visual representation of the conceptual map is presented in Figure 5.1.

Furthermore, for each of the themes, I have presented a visual illustration of the categories that constitute the theme, followed by the findings related to each theme. Here, I begin with the first theme of naming of complementary/alternative healing.

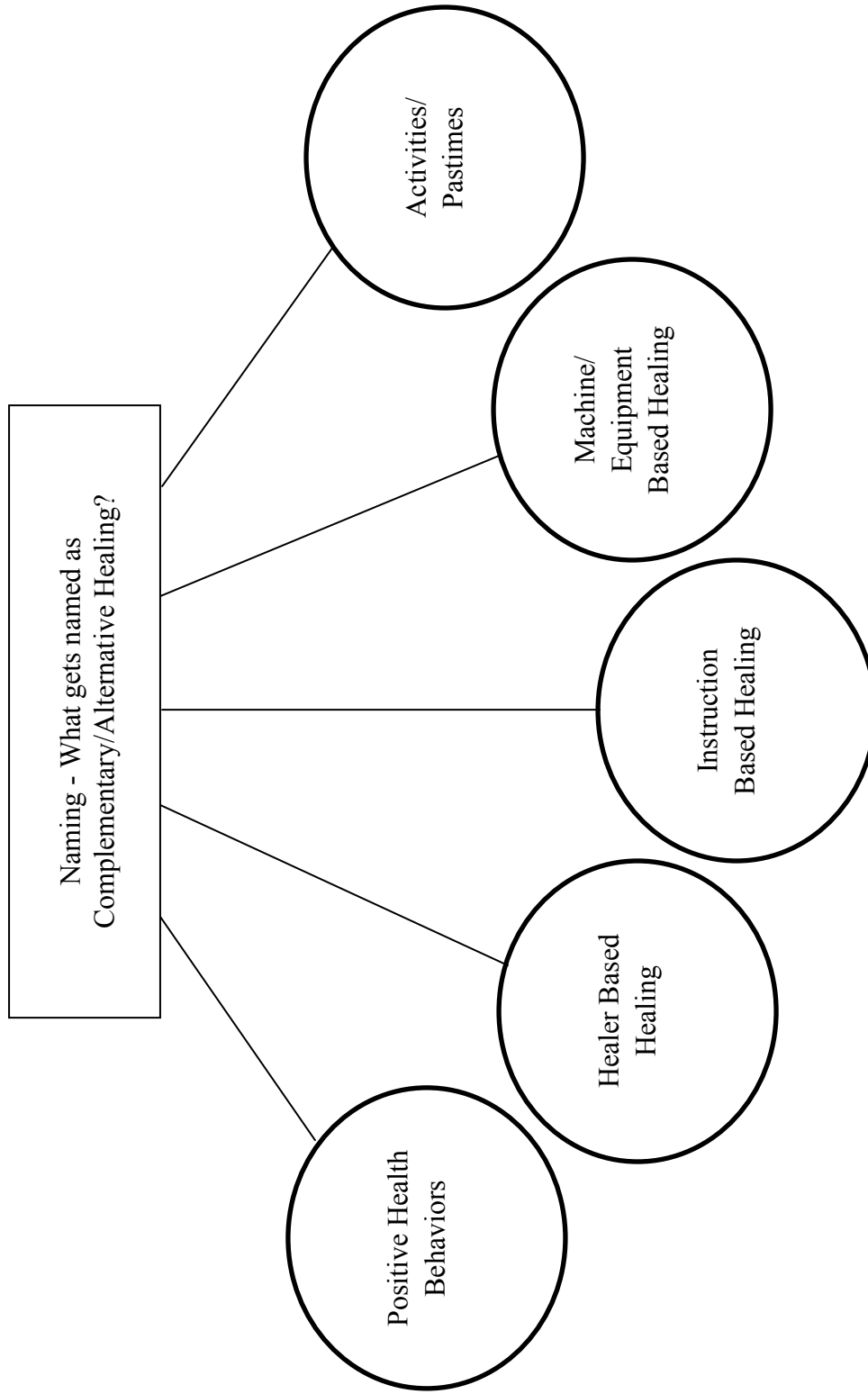


Figure 5.2: Theme 1

## **Naming of Complementary/Alternative Healing**

There is often ambiguity with regard to what can be considered complementary/alternative healing. Different people have different understandings of what constitutes or what can constitute complementary/alternative healing. The problem lies in defining the boundaries of complementary/alternative healing. When a patient was asked about what he/she had used for their health that could be considered complementary/alternative healing, the range was quite diverse.

### **a) Positive health behaviors as complementary/alternative healing**

Positive health behaviors like changes in diet, exercise and intake of vitamin supplements often got labeled as complementary/alternative healing. Most participants spoke about the importance of food and exercise and their realization that it's essential for maintaining good health. While some participants had brought about changes in their diet and exercise regimen through self-reading and relying on lay networks, other participants mentioned changes brought about in diet on the recommendation of a complementary/alternative healer. For instance, Liza says that she on her own improved her eating habits after she was diagnosed with breast cancer at the age of 44. She says,

So I had already stopped eating meat years before but I wasn't on a healthy diet... I had constipation issues for many years which were not addressed. Lots of doctors told me you're fine and of course I wasn't and they knew that but I didn't know how to go against what they said ...So now I am confronted with I have to do things on my own and I started to sharpen up my eating so that I only ate organic and I was exercising much more, I was taking dietary supplements....I tried to do a bunch of different things that I thought would make my health improve in a better way.

Similarly, Kelly here labels exercise as complementary/alternative healing, asserting that it should be used along with regular allopathic medicine.

Oh yes, yoga and exercise is complementary/alternative. Just the medicine alone is not enough and since I was part of a study about how exercise affects Parkinson's, so I would go twice a week for an hour and they had a specific program to do with legs and arms at the gym and they measured before and after how we walk and it was about how much you could lift, how much you could push with your legs, how much you could push up and pull down and they measured all that and every week they increased the weights until the end of the program I think it was 3 months, twice a week and then they measured again and I improved tremendously. It is mandatory that people do exercise you know whatever they have ..

While Liza had brought about changes in diet by herself and Kelly was introduced to an exercise regimen by her participation in a research study, Miranda, another patient with Parkinson's disease, highlights how she made some adjustments in her diet on the recommendation of her holistic healer.

She is a holistic healer, she is like a nutritionist, I would say mainly a nutritionist but here (shows file) I have some of her information, but this is what she got me onto, doing food, combining diet which I was pretty good with anyways but mainly keeping track of what I ate, I have a calendar now to fill in everything that I ate she always said just be careful with everything you eat, not have food coloring, artificial stuff, just more natural food so I found that to be very helpful....

In addition to highlighting the importance of food, some participants also emphasized how it was often neglected in talks about complementary/alternative healing. Larissa another participant with problems of back pain says,

A whole alternative thing that people are not really discussing that much is food as an alternative healing and there is so much out there, a whole slew of documentaries came out, the power of food to heal like what you eat and primarily what is the term that I love?, plant based diet which is like staying away from the meats. People don't even want to say vegetarian anymore, it's like an old term that has all these connotations

Furthermore, some participants consider specific food ingredients as a form of healing option for certain conditions. For instance, Michael says he uses bitter melon for treating his diabetes and he asserts that he has seen evidence of some positive effects on his health

from it. In contrast, Matt says he uses coconut oil daily for its neuro-protective benefits even though he is not completely certain about its benefits. Hence, consumption of certain foods or food products might also be considered by some individuals as complementary/alternative healing.

**b) Healer assisted healing outside allopathic medicine as complementary/alternative healing**

The definition of complementary/alternative healing is vague and the boundaries of what can be considered complementary/alternative healing are fuzzy. Usually, if participants sought the assistance of a healer outside the purview of allopathic medicine they considered it complementary/alternative healing. This was also true for healing that was less widely known or practiced such as shamanic healing, evolutionary healing, Chinese medicine and others. Healers who provided consultations through online channels were acknowledged as complementary/alternative healers. For instance, Amy says she did “John of God” healing online. In this case the healer is in a different country, but an online portal acts as a liaison between the patient and the healer.

So I went online looking for long distance healing for John of God. And I found this company that they do it for free. Well you do have to buy the herbs that you have to take after the healing happens but this company basically what they do is that they ask for a photo of you , they ask what are your ailments , they ask for your date of birth and location of birth and you sent that to them via email and then on Thursdays they represent you with your photo and then they see John Of God and he is channeling different entities I think he channels 6 different entities who are healers and whatever entity is channeling through him that day the entity will see your photo review your condition and he is in a trance , they put a piece of paper over your picture

Similarly, Anita highlights how she can receive consultations from her Shaman online. She says,

and I had done a few energy healing sessions with her, which interestingly enough she can do over Skype, I thought it had to be in person but it was great I mean I sat literally on my sofa here and I had her on Skype and I don't know how she does it , it all sounds very mystical to me but it's very, I find when I am done that I always feel more at ease more relaxed.

However, it is important to note that not everyone considers healer assisted healing that is not allopathic medicine as complementary/alternative healing. Nancy argues that even though she visits the Chiropractor she doesn't consider it complementary/alternative healing because for her that is the primary form of healing and her definition of complementary/alternative healing is different. She says,

See I don't really see Chiropractic as alternative, because I guess in order for it to be an alternative medicine there has to be a primary and really if I go into the doctor with this shoulder strain, there is nothing they can tell me to help me get better ....I look at alternative medicine to say ok here is I have liver disease or I have this disease I need to take this medicine that's primary now if I look at that and I decide no I don't want to take that medicine and I go somewhere else to treat it that's alternative medicine to me. See to me there doesn't seem to be any other choice.

Although, only a few participants, like Nancy, attach a different definition to some forms of complementary/alternative healing, it is part of the meaning and experience of some individuals.

### **c) Instruction based healing as complementary/alternative healing**

Participants often identified healing choices that were primarily instruction based as complementary/alternative healing. In these healing options there is frequently no direct personal consultation involved between the healer and the patient. The healer might just be a facilitator who provides rough guidelines on how to practice a certain art form. For instance, many participants talked about music therapy, art therapy, dance therapy, yoga, Tai-Chi, meditation as complementary/alternative healing. Here, Ruth describes her class in dance therapy, she says,

...dance therapy is similar too. Some of the movements we do (gets up and shows me the movements) with music and we are actually singing, we do simple steps you know (shows me the movements) and then we do some cha cha steps and when the music is going I feel like let me get up and do it. And we can do it if we feel good and I am like let's do the cha cha and it brought back all the dance that I used to do....

Similarly, Kelly highlights her experience with music therapy, she says,

...they teach music to the class and you can be slow...my speech was very low, very soft. I try to speak loud whenever I can but I go back into that, especially when I am tired, my voice goes down. I do the Kazu (they blow into this instrument) and it strengthens your vocal chords. But when I go there, we sing and I feel that my voice is scratchy after, so the vocal chords are getting some kind of exercise.

Some participants expressed uncertainty about labeling yoga as complementary/alternative healing. For instance, Miranda highlights the complementary/alternative healing she uses and asks if yoga would be considered complementary/alternative healing. She says,

Okay well I've used several. Massage therapy is one that I've used regularly and I really like that, Yoga, I don't know, is that considered too? I've done yoga, acupuncture, I've done the holistic medicine, and natural healing with diet and vitamins let me think what else. I think that's it.

When I probed Miranda to tell me if she considered yoga as complementary/alternative healing, she promptly said she did. However, another participant Matt had a different view point regarding yoga. He says,

Well it's kind of in the middle, it's not mainstream, it used to be alternative but now it's becoming more merging with mainstream....now it's becoming more mainstream and more acceptable but I mean it's not. I mean it is actually becoming even recommended by some doctors who'd say you know, it's very good for you even though they are probably American, it didn't used to be that way it used to "Oh you can try it if you want to try it but we don't have any recommendations" now doctors are more apt to say "they will probably help you."

Here Matt is possibly hinting at a reconstruction of what is considered mainstream and what is considered complementary/alternative suggesting more of a continuum rather than a dichotomy.

Larissa argues that yoga specifically for her would not qualify as complementary/alternative healing. She says,

No I don't consider these complementary/alternative but for someone who has never experienced it, it is alternative you know...because it's always been a part of my life, at least yoga and exercise you know since I discovered it and I had to discover it because Cuban girls are not like physical like that. They are not allowed to run and hit and pick and then I came to US and I started being involved in sports and it was always a part of me. And I used to run and run track and cross country and volley ball and on and on and biking.. but I see that when it is introduced to maybe somebody 30 years old and who has never done anything like that and they are like uhhh what is this..

Definitions of health practices are or can be tied to cultural norms and practices. However, definitions are also influenced by personal experiences. Here Larissa's definition of a particular form of complementary/alternative healing is tied to her discovery and experience with that form of healing.

#### **d) Machine/ Equipment based healing as complementary/alternative healing**

Certain healing options require specific machines or equipment to aid the healing process and might not involve or necessitate a healer. Some participants identified machines or equipment that to them were forms of complementary/alternative healing. For instance, Matt talks about hyperbaric chamber therapy which requires a person to be in a closed chamber, with an increased oxygen level. Matt explains,

I also did hyperbaric chamber therapy; it's about when you go inside this chamber where they increase the oxygen levels. Now that one did have an effect that was



noticeable, that I noticed and made me feel really good but now what I noticed wore off within a 24 hour period

Similarly, Rita highlights her use of sauna therapy, she says,

So I looked around one way that people were getting the toxins out of their body was through sauna therapy which is this little sauna that I have here , which I have nowhere to put it that's why it's here it's called the far infra-red sauna and I learned that a lot of people were using this to pull mercury out of their bodies, to pull a lot of toxins out of their body , because sweating will do it, it's not too too hot, it's not like sitting at a sauna in a gym and you do it at your own pace. The person that I saw wanted an hour a day but I could not tolerate an hour a day because it pulls all the electrolytes and all that out of your body as well and again I am hypersensitive so I think I started with 10 minutes a day and then I went to 15, 20 minutes.

It is interesting to note here, that despite a recommended usage for the sauna equipment, Rita adapted its use to her own bodily needs. Hence, there are people who do not follow health advice without carefully considering its implications for their own health.

In addition to the sauna and hyperbaric chamber simple equipments like a Neti-pot that can be purchased from a drugstore were also talked about as complementary/alternative healing.

#### **e) Activities or pastimes as complementary/alternative healing**

Certain pastimes or regular activities can stand out for some people as aiding in the healing process. A few participants suggested that they considered some specific activities or pastimes as complementary/alternative healing. For instance, Anita highlights working on her doll houses as therapeutic. She says,

I have a collection of miniature doll houses and that is something I absolutely adore but if your hands are shaking significantly, it's not a great combination, but I find that very therapeutic and when I am relaxed and I put on some music and I can do it and I sort of incorporate it. It's like my own artistic space. I think it helps keep your mind occupied, happy.

For Amy a regular activity of taking care of her dogs is a sort of healing. She says,

Playing with my dogs relaxes me that puts my blood pressure down. Like petting them, I even enjoy cleaning up after a pee and poop. Because I love her and those endorphins make you happy and that for me is a form of alternative healing having animals.

The participants who talked of activities or pastimes as complementary/alternative healing primarily alluded to their therapeutic benefits on emotional or mental health.

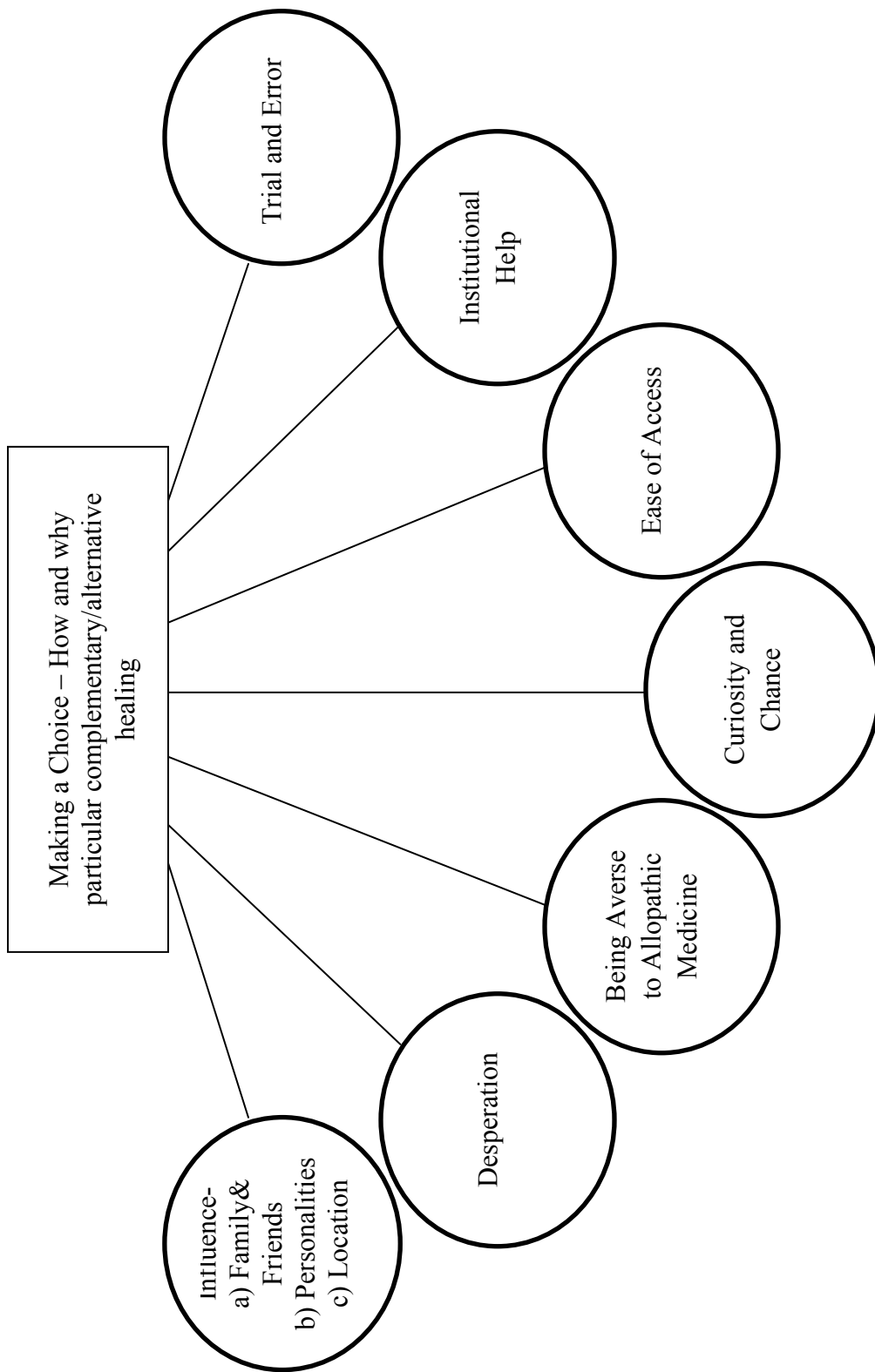


Figure 5.3: Theme 2

## **Making a Choice -How and Why Complementary/Alternative Healing?**

How and why people choose complementary/alternative healing depends on a variety of factors. Not only are there differences in the way participants discovered complementary/alternative healing, but there are also differences with regard to particular complementary/alternative healing. For instance, one might have been recommended by a friend to use acupuncture, but the same person might have brought about changes in diet and started using supplements based on his/her own reading and research. This theme is a description of processes through which participants discovered complementary/alternative healing and why they made a choice to try it.

### **a) Influences**

#### **i. Influence of family and friends**

Quite a few participants had been exposed to complementary/alternative healing early on in their lives by family members. These early family influences usually stuck with the participants and later in life affected their beliefs and decisions to seek help outside allopathic medicine. For instance, Ruth says her grandparents were massage therapists and that came to her mind when she heard a friend going in for a course in massage therapy and thought she would also give it a try and eventually took it up as her profession for a while.

My grandparents from my father's side were massage therapists. They called them masseur then, and then we switched to massage therapist. So as a kid I saw that with their hands they were healing people. It wasn't until I met this guy that I thought oh yeah grandma and grandpa did that and I loved it. And at the college they had a massage therapist teaching lay people you know people that weren't enrolled some simple things. You know nothing complex unless you went and paid for it and they paired us with a friend and they taught us things and I really liked it.

Nancy recounts how a single event in her childhood directed the path she would take for certain health problems.

When I was 12, we were on vacation and I had a diving injury. And the first memory I have is that my mother immediately rang up friends found a chiropractor and took me to a chiropractor. I had started with a horrible neck pain, I was unable to turn my neck as I remember it and it was my vacation so you don't wanna miss out and everything so the next day I was back up and fine. So that to me, you know, you go to a regular doctor he can't do that for you.

Sometimes, the family influence towards complementary/alternative healing might not have been as apparent. And only later did participants figure out how there was a propensity in their family towards complementary/alternative healing. For instance, when asked if any of her family members used complementary/alternative healing, Rita replied

So that's the funny part, my mom had books and things that I have come across now that are like good house-keeping ways to treat yourself or you know stuff like that and I remember my mom used to take stuff like wheat germ and just different stuff that I used to think like why are you taking that and even things to clean your house with that are non-toxic, my mom used to use vinegar to clean the floors and now that's like the healthiest thing around. It doesn't smell great because I don't use toxic products either but I don't recall having a conversation with her about these things

Similarly, Shirin says, that home remedies and old fashioned remedies is what her family depended on in her childhood, because allopathic medicine was quite expensive for them to afford.

No my parents had never been to doctors, never ever. They didn't think doctors knew anything, they had the old fashioned remedies for everything... All sorts, vinegar you had a cut you washed that with salt and water and vinegar, if you had sore throat you gargled with salt .... People had to pay and my parents couldn't afford to pay and it wasn't until my father had a heart attack when he was young in his forties, I think that was the first time, they went to a doctor. Most of the things my parents learnt from their parents about how to solve, not always solve but how to keep it at bay....Well that was it, there was nothing else

Phil on the other hand recalls how decisions taken by his parents when he was younger had affected the choices he made regarding his health later on. He says,

Going back even further than that when I was 8 years old my father had a real serious heart attack. He was 42 or so and he almost died. So he recovered and they wanted to take a vein out of his thighs and put it in his heart to do the bypass surgery and he said no and so he didn't go for it and he lived to be in his 70's, but so we went on a heart healthy diet after that so that's kind of an alternative. It worked and so it made me more aware of that kind of health. You know I was only 8 years old so I was really conscious that we were on a diet but we ate this way and that was all.

Although some participants had family members who had previously used complementary/alternative healing some other participants highlighted how they had never seen or heard about complementary/alternative healing in their families. They explained that it was primarily through friends that they got introduced to complementary/alternative healing. For instance Liza says,

I mean very few Americans did much with alternative stuff. I mean like my parents were not enlightened in that way at all and it would have been amazing if they were but they didn't know about it.

She further goes on to say,

Well I think because my close friend was the person involved that made it easier. You know if a total stranger had come up to me and said oh let me give you acupuncture I might not have been so happy about it. But she was someone I loved, she cared about this so deeply and I knew had spent 4 years in school and I knew she had a rigorous course. You know it wasn't like she had just decided to become an acupuncturist and not go to school. And when I saw all the things she went through in order to become an acupuncturist I realized that that was a real job. So that made it easier too.

Or Matt who says that though his parents never used complementary/alternative healing, it was through discussions with his friends that he was more aware of other healing options, besides allopathic medicine. He says,

No my father never did. My mother never did. No nobody that I can think of really recommended to me I just through friends mostly, you know friends that I would talk to about different health conditions and we'd say oh we should try this or that, maybe this is a good alternative.

Hence, the influence of family and close friends can be a significant factor affecting the health care choices of individuals.

## **ii. Influenced by Well-Known Personalities**

Some participants suggested that they took inspiration from, or were affected by particular well known personalities who had an influence on their use of complementary/alternative healing in general. The more common names indicated by participants were Louise Hay, Andrew Weil, Jeffrey Bland and others. Some of these mentioned personalities often do not promote a specific complementary/alternative healing; they emphasize on having a healthy lifestyle, eating well, thinking positive and having hope. Yet, their message of healthy living and positive thinking resonates more towards use of complementary/alternative healing. For instance, Amy says that all the complementary/alternative healing she has explored is primarily due to having drawn inspiration from Louise Hay. She says,

My head I am believing everything is fine, all is well, I am healthy and that's going on in my head. Louise Hay says everything is fine and Louise Hay is the creator of Hay House, the publishing company and Hay house radio. Pretty much everything that I have tried is because of that person, that radio station, the people out there, all these kind of people who look beyond the here and now.

Similarly, Rita says that having followed Andrew Weil's work for a long time, she was able to find her holistic healer as per his suggestions. She says,

So one of the people that is on television, is Andrew Weil he is probably the oldest ones around. He has got his own place now in Arizona and so you know I've been listening to him or watching him and reading his books for a long time and so the question that he often gets is how do I find an Andrew Weil in my city?

And now there are websites but at the time there weren't and so one way he said was call your local university, see if they have a complementary/alternative medicine department and if they do see if they have a graduate program... So I called and I was led to my holistic healer she has a PhD but not an MD and she is a little bit mainstream.

Therefore, influences drawn from popular personalities can go a long way while making a choice regarding complementary/alternative healing.

### **iii. Influenced by Location**

Often the surroundings we live in and the people we associate with can have an impact on the choices we make. Some participants noted that particular contexts and their presence in certain locations had a considerable impact on their choice of complementary/alternative healing. For instance, Phil highlights how his experience helping in the development of a botanical garden at the University of California, Santa Cruz and later in different parts of California influenced him to start using some types of complementary/alternative healing on a regular basis. He talks about his meeting with different people holding different perspectives from the regular Western perspective. He says,

..So the garden was completely organic and it brought all kinds of people that believed in different ways of living rather than the western civilization chop and cure and put drugs in it.. if someone donated land and they would want a community garden, we would make it as a group...We also did it for the Zen Buddhists of San Francisco...Meditating is one thing that I got from that process that also seemed to help with ulcerative colitis. And it really had an awesome impact on me, the ritual was really impressive ... A big barn they made into a Zendo and they had a huge brass bell that they would ring and then they would chant rhythmically....sitting at that hour in the morning, it's just a powerful ritual to have that many people all doing it and after that's over everybody turns into normal people again... And you can act, but when you are meditating its really strict rules..I found that any discipline really helps you in this type of disease that



I have. That teaches you how to manage your own mind. I also found that in yoga when I went to college after that, doing yoga helped a lot...

Larissa also was influenced by the location she was living in and the course of study she chose

I was a massage therapist for like 12 years, and that was like my field. And with that came studying and just living in Boulder and just being exposed to a lot of people. Studying it, practicing it, you know you went to anywhere socially and 1 out of 4 would be alternative because there was a really good school there, so there were many massage therapists.. but then they branched into other things continued studying other stuff. Also there was a school for Rolfing and so you are like surrounded with alternative type of people, practitioners...

Based on these experiences narrated by the participants, it was evident that location and associations made within these locations, affects the choices individuals make and the experiences they have with specific complementary/alternative healing.

#### **b) Desperation**

For some participants trying specific complementary/alternative healing was principally driven by being in pain. When in distress, some participants appeared to be open to anything that might relieve the pain. This is apparent in some of their narratives. For instance, Lucy says that she tried acupuncture almost out of desperation. Even though she did not have the money, she went ahead with the treatments because she wanted to try something that might relieve the pain. She says,

I didn't have \$1500 to give this guy but I was such in pain to do that. My husband said we have to do it, we are going to have to do it, put it in a credit card and we'll figure out how to pay it and all that stuff. It is a major thing, if the insurance were to open up to options to what you choose that would make a major difference but as it is now.

Along similar lines, when asked what makes her use complementary/alternative healing, Shirin says that it's primarily being in pain that pushed her towards it.

I think it's just the fact that when you are in pain and nobody can help you, you have to try whatever there is, well within reason, whatever option you have

It's interesting to note here that Shirin earlier suggested that her family often relied on home remedies for health problems. Hence, it is important to consider the possibility that there are multiple factors (like influence of location, family and friends etc.) affecting one's propensity and choice to use complementary/alternative healing. Furthermore, most participants use/used multiple forms of healing (like acupuncture, yoga, meditation) and the decisional pathways to each likely differ. For instance, Kelly asserts that she tried chiropractic care in Oakland because she was in discomfort and was open to trying things. She says,

No no we didn't know if to believe what we read totally you know when you are desperate you try things so I went out there for a month for Chiropractic and I liked visiting Oakland its beautiful but it didn't really help

Kelly had earlier suggested that her primary reason for seeing an acupuncturist in Honk Kong was being influenced by close family friends.

So when I was diagnosed in 2003, it was like in October, November and I didn't accept it...So my husband said let's go to Honk Kong. We knew some friends ...my husband went to school with the man and they became friends for life so they were living in Vancouver and they used to go often to Honk Kong too...The man became sick with prostate cancer and they believed in this guy so much and he is a healer, so we went. We scraped up enough money to go and we stayed, I could only stay a month..

Although Kelly did not get sustained relief from this treatment in Hong Kong, the failure did not lead Kelly to reject complementary/alternative healing altogether. She later pointed to seeking Chiropractic care out of desperation to feel better. Therefore, for most

participants there are possibly multiple pathways that affect one's decision to use different complementary/alternative healing.

**c) Being Averse to Allopathic Medicine and Allopathic Medical Practice**

Use of complementary/alternative healing often stems from disappointing experiences with allopathic practitioners or aversion to allopathic medicine. Almost all participants highlighted one or more problems they faced with allopathic medical practice. All but two participants in the course of their interview talked of the adverse effects of allopathic drugs. The participants made references to the harmful effects of allopathic drugs on the self and on others around them emphasizing the often detrimental consequences it can have on one's life. For instance, Anita points to the adverse effects that some medicines have had on her. She says,

Another downside of medication is that one or 2 of the medicines I am on cause an increase in appetite and I've gained like so much weight over a really short amount of time which is something that doesn't make me happy. And I look in the mirror and I am like who is that? And I am like none of my clothes fit, it's just really tough because and I just get so hungry but for all the naughty things you know. I don't crave like lettuce you know..

Some other participants highlighted how they were allergic to certain medications and hence complementary/alternative healing seemed a better fit for them. Rita says that cortisone shots and other anti-inflammatory drugs proved to be quite rough on her health. She says,

And they had given me like cortisone shots that didn't do anything but made me very uncomfortable and they had me on Celebrex those anti inflammatories that made me so sick that I had to get off of that stuff. And I realized through my own experience that what was really helping me was acupuncture, massage, physical therapy nothing that the real doctors were doing for me was helping me at all.

Other participants highlighted their extreme aversion to regular allopathic drugs in general for a variety of reasons. For instance, Lile highlights how she is totally averse to being dependent on medication even though both her parents are allopathic doctors. She says,

Yeah absolutely I hate drugs I take the least I can and if really I think I need them. So yeah absolutely I don't like drugs because for me I don't know I am afraid of drugs in the sense that I don't like the idea that it can alter the way you feel or even the way you think. If it's something that can have effects on your mental health.. So even though my parents are doctors, well they didn't prescribe too much, they weren't part of these doctors that are like absolutely bent on selling you drugs

Amy, another participant, who is vegan, highlights her reluctance and dislike to taking allopathic medication because she fears there was cruelty towards animals in the research process for the development of these drugs. She says,

I was taking a lot of medications, blood pressure medications, I was taking Crestor for my cholesterol, I was taking a medicine to regulate my blood flow from my heart and I was taking the Xarelto. And how uncomfortable I felt drinking all those medications, I saw them as poison every time I put those medications in my body I saw them as drinking poisonous blood because I know all those medications are there today because animals suffered for it. I don't approve of using animals in Laboratories even to save my life or to save anybody's life.

In addition to emphasizing the adverse effects of allopathic drugs and often their aversion to it, some participants also asserted their predicament with allopathic practitioners. However, most participants also indicated favorable and more desirables experiences with some allopathic practitioners.

Some participants had been misdiagnosed or not diagnosed on time by their respective allopathic physicians. Ruth here highlights how she had to wander between doctors before she received an accurate diagnosis for her condition.

So I never got on the medication once I got diagnosed which took a long time, I was going from neurologist to neurologist and they didn't really know what it was. I had an MRI which I totally don't understand why they couldn't pick up on it. I finally got to a neurologist whom I went to insurance out of network. Somebody finally told me that go to this neurologist, he is the guru on MS and neurological problems and maybe he can figure it out and he did. He looked at all my blood work and all the tests and he just mentioned something and he says look at this, why didn't they see this? You have MS and I was like OK at least I know what I have now. You know then I can find out what to expect.

Rita on the other hand points to the narrow guidelines that allopathic doctor's follow and how even though she was suffering, the allopathic physician did not pay any attention to her problems. She says

If you are talking to a traditional doctor especially an endocrinologist, they are very specific they just work with very narrow avenues of belief so he didn't have an explanation either but he certainly didn't believe what I was saying so it was just kind of interesting

Participants also highlight the lack of interest among doctors to treat the root cause of the problem, and their interest to mainly deal with the symptoms, often trying to cover up the symptoms with a drug. Larissa highlights the restrictions in allopathic medicine to focus primarily on symptoms and contrasts that with complementary/alternative healing. She says

Like in western medicine it's like what about your arm or the shoulder you know maybe that's producing something. Alternative medicine, they look at a bigger picture than the way we have narrowed down western medicine.

Another common complaint against some allopathic doctors was that they were often insensitive towards patients about their ailments and lacked time and patience to communicate vital information in a more amiable fashion. For instance, Kelly suggests she felt humiliated by the doctors she visited initially when she was diagnosed with Parkinson's disease. She says

In 2003 was the first visit to the doctor and my knees used to shake a little bit and I noticed it was getting worse so I went to a neurologist just out of the book and he said, “oh yeah you got Parkinson’s disease like that like it doesn't matter, yeah its Parkinson’s”, the first family doctor I went to he says so how long you got the shakes. I said the shakes? I felt insulted and I didn't go back to him

Participants also complained that often doctors prescribed procedures or drugs that seemed unnecessary and avoidable. As Liza points out that she had some unnecessary surgeries that she later realized could be avoided

You know my breast had 7 surgeries before I realized that surgery wasn't the answer. I had 3 lumpectomy, the wide incision biopsies and then I had the mastectomy on one side then a year later you have cancer in the other breast which I thought they knew and I didn't want to have a lot of surgeries so I went right to a mastectomy on my right side and then it turned out that it didn't have cancer. But you can't glue it back so now I had no breasts and that was an awful situation in many ways because I didn't realize they could be wrong but they were wrong and I had the type of cancer that didn't really show up on a mammogram so in a way it's not so surprising but everything unfolds step by step and I just did not understand for a long time what was going on but still here.”

A few participants also noted that arrogance was a prevailing factor among allopathic practitioners and few doctors allowed patients to actively participate in their own health care decisions. For instance, Matt says,

I went to a neurologist before that and I really didn't like him at all because he was very forceful and very like this is what you going to do and this is the medication you going to take and these are the tests you going to do and without even discussing with me. It's telling me this is what you going to do ...because they are trained in medical schools so I feel like it's kind of like a superiority complex. You know it's kind of like you are wearing the white coat because it's like power and authority, you know telling you this is what you have to do! Lot of people do that too... If the doctor says something they do it and I laugh at people that'll say they don't have results but they'll still do it because the doctor told them to do it. Like they might take medication, they don't feel good with the medication but they are afraid to tell the doctor because they are afraid the doctor will say oh no no that's what you have to do ...So I don't like that at all

Participants contrasted the differences in the general attitude and disposition of allopathic medical doctors and complementary/alternative healers. Though it is important to note that not all allopathic doctors are the same or all complementary/alternative healers are alike some basic differences were usually noted by participants in the general temperament of these two kinds of healers. For instance, Shirin highlights that doctors usually do not have enough time to communicate self-care strategies with patients, which complementary/alternative healers are more likely to guide patients about.

I think it's difficult to generalize because not everybody can be the same...I would say that a lot of them will encourage you to exercise and lose weight if necessary but many of them, themselves are not in the best of health if you look at them, they don't seem to be able to take care of themselves. Whereas when you go to an alternative, they emphasize on exercise and health and the whole body rather than just the symptoms and that's really difficult to get. It's also difficult from a doctor's point of view...they have many patients and you can't really talk to them about health because they don't want to know about it... Whereas in alternative medicine they don't do that....they are there just to supervise you and tell you what you should be doing to keep yourself well and fit.

Liza points out that, although diverse, because complementary/alternative healers are not covered by insurance they have less time constraints and are more likely to be receptive to patients. She says,

I mean because they are not covered by insurance, its good news and bad news, since they are not bound by insurance it gives them the ability to disregard the rules of the insurance companies and the rules of the insurance company are like you can't see a client for 2 hours. But if you are not under that you can see someone for as long as you need to.... in general yes complementary/alternative therapists are more interested, more willing to talk to the patient like they were real people but not everybody.

Though most participants highlight some detrimental experience with a regular allopathic doctor, quite a few of them acknowledge to have found an allopathic physician of their

liking. Matt here suggests how there is a difference between doctors and how he prefers a doctor who gives him a voice.

Some doctors you know they are very open-minded or very understanding or whatever there are other doctors who are just very gruff and to me I definitely steer away from those kind of doctors, I always look for doctors who are different you know because I just can't deal with that kind of situation if they are not going to be wanting to hear what I have to say or wanting to hear what my opinion is I don't want to have to do anything with them.

Anita says about her current doctor,

The good thing about my doctor is that he is fairly conservative but he is quite open to what you are comfortable with and if you want, you know whatever you choose to do he will back you 100%.

Furthermore, along with problems with allopathic drugs and allopathic practitioners patients also highlighted flaws in the working of the allopathic medical system, especially its dependence on the pharmaceutical industry. As Michael says

The problem is that pharmaceuticals have really taken over they've hostaged the medical profession ...

Rachael also notes how complementary/alternative healing lacks the ability to compete with the money of pharmaceutical companies in terms of marketing their products.

and what the doctors really get is pharmaceutical companies coming over and telling them about their medicines. I am not sure alternative medicine companies/facilities have money to do that

Matt points out how the drug trials are often flawed and pharmaceutical companies, publish only those studies with significant results

the pharmaceutical studies even to get the pharmaceutical drugs approved cost they say hundreds of millions of dollars because of the type of testing they have to be put through, I've found out through the research that I've done through reading, a lot of these studies they keep doing the study over and over again till they get the test results they want , they don't tell you about the 10 studies that they did before that didn't get the results that they wanted but about the results that they wanted so its kind of like a biased study. It's not a very good situation.



Some participants see focused roles for allopathic medicine, such as acute emergency care rather than chronic illnesses. As Liliana says,

You know what allopathic doctors are good for, they are good for emergencies, if you break something and you are in need for emergency care you should go to them

Or as Rita says,

I am not saying if you have a heart attack or if you broke your foot or if you need acute care don't go to the regular doctor, it's not that, it's the more chronic, which is I believe I have heard statistics that 90- 95% of the ailments in this country are for the chronic type

Although, earlier Rita had spoken out quite vehemently against allopathic drugs and physicians, she certainly acknowledges its importance for certain ailments.

#### **d) Curiosity and Chance**

Some complementary/alternative healing is discovered by individuals on their own from reading, other sources of communication, or simply by chance. Especially with the advent of the internet, people have easy access to information and are more forthcoming about verifying, learning and researching about options to better health. Interestingly, some older participants pointed out the absence of information regarding complementary/alternative healing at an earlier time. For instance, Liza says,

It wasn't being talked about in 1993 or before that ya and you would be really lucky to find something about it in the news . It wasn't in the news and it wasn't available to me in anyway so my friend brought it to my life, I didn't know about it before that.

In contrast, Miranda points out that she found out about her holistic healer from a website offering deals on the internet.

You know how I did they have a deal saver on the computer either Groupon or deal saver and she was in there and I got it for my daughter and she went first and

she liked it, she felt so good after that and she would do that again, so then I went and I really liked it.

Some participants also point out discovering some complementary/alternative healing almost by chance. Shirin says she walked into an acupuncturist's office after seeing his sign board often while driving.

Especially, I didn't know about it, I used to see this sign of this acupuncturist when I was taking my son to school. And I thought well I've tried everything else might as well try this... Yeah driving and then I read up on it and what can happen when you use it, the therapy itself how it evolved etc. and I thought well, I've tried everything else and they didn't work so well.

Two other participants pointed to discovering particular complementary/alternative healing, when they tried to find help for their sick pets. For instance, Michael says,

I think we came to it in a very circuitous way because we had a dog that was very sick, we are talking about Reiki, and then we got introduced to Reiki because of the sick dog and then we saw the results on the dog, we took him to the vet and the vet would say things like 'This dog is still alive? He hasn't died yet, he should have been dead a long time ago how sick he was and then we talked about the Reiki and then he said apparently it's really working because this dog has made great strides and then from Reiki we went to other things and ended up with acupuncture. So it was a gradual process of discovery.

Irrespective of the form of complementary/alternative healing chosen, it was interesting to note that participants were willing to try out other healing options purely based on having come across them by chance.

#### **e) Ease of access**

In situations where people need help regarding health and they can get it more easily at a complementary/alternative healer rather than an allopathic doctor they might choose the more accessible option. Some participants emphasized how accessible some complementary/alternative healing was. Though, this is not the only reason why

participants sought complementary/alternative healing it certainly acted as an important reason for sustained use of particular forms of healing. For instance, Lile says,

And this chiropractor you can really go very easily... in the end its business for them and they know that here in the US people also like to go to Chiropractor because it doesn't necessarily take you too much time and its better than nothing and it can be insurance covered, especially if you have a car accident. So we go without appointment now. Also they can give you a massage, they have massage therapists there... My husband went for some free massage when he got into an accident and the insurance paid for a few massages and the therapist was pretty good ..So I would go to the chiropractor if I needed help immediately because it would mean that I could go immediately

On the other hand, Amy points out how she was able to get service from her energy healer over Skype and at home when it was difficult for her to drive due to her illness. She says,

..I started meeting with her. So we did a lot of visualization. And I wasn't actually able to drive so she would come over and we would do Skype and we would do all kinds of communications at least once or twice a week meetings.

Both these examples corroborate that flexibility of time and/or location also contributes towards making a choice with regard to complementary/alternative healing. Had an appointment with a chiropractor been more difficult to get or if it was a tough task to reach the energy healer's clinic, Lile and Amy might not have had good experiences to talk about.

#### **f) Institutional help**

Support groups for various chronic conditions provide relief and services to sufferers who are members of these groups. Interestingly, quite a few of the participants indicated that they had been introduced to certain complementary/alternative healing by the respective support groups catering to their specific chronic condition. This access was

especially true of instruction based complementary/alternative healing like yoga, music therapy, dance therapy and the like. Therefore, the role of certain institutions in introducing patients to other healing options is an interesting and important factor to consider. For instance, Henry says

I joined the support group Parkoptimus and after that I started doing yoga with them and also music therapy and then people here told me there was Tai-Chi that is not connected but a lot of people who do the yoga do the Tai-Chi and so I've been doing the Tai-Chi called Taoist Tai-Chi..

Lucy also highlights how though she had a propensity towards complementary/alternative healing like yoga, she was introduced to other forms of healing primarily by the support group she was referred into. She says,

I've been attracted to things like yoga before I was ill at all and I did have several years of yoga before I got in that and I was always attracted to things beyond. Specially the mind the interaction of the mind and the body but I just fell into it, I was referred to a place called the cancer community support and they do have the philosophy of the mind body integration and they have yoga, they have Tai chi, they have meditation and meditation is one of the things that have brought me ease..

Support groups provide a platform for individuals with similar ailments to come together and discuss their sufferings and experiences. If another individual with similar symptoms shares their experiences of finding relief from particular complementary/alternative healing, it might motivate or influence other members in making a choice for the same.

#### **g) Trial and Error**

All participants indicated using one or more complementary/alternative healing. However, some were quick to assert that not everything works for everyone. Some participants also noted that one has to indulge in a process of trial and error to find an

optimum treatment plan for oneself. Hence, one might be open to using complementary/alternative healing and make a choice for it but finding a particular one that is suited to one's health is vital for its sustained use. A few participants also suggested that the trial and error process of finding the right healing option is not restricted to complementary/alternative healing alone. Some doctors also engage in substantial guess work and trial and error to find the right treatment option in allopathic medicine. With respect to complementary/alternative healing, Ruth here highlights that though her views of complementary/alternative healing are positive she has to find something that works for her. She says,

My views are positive but I have to find one that works for me. Again with the sinus it doesn't work, anything around the head doesn't work. I don't know why I am sensitive, it's like I don't want to get a headache after the treatment I want to feel relaxed or better.

Mahdi highlights the aspect of trial error especially with regard to food and diet. She says

then nutritional intake, my diet, well diet has come to be a bad word meaning oh I am on this diet or that diet, for me diet is about nutrition. It's the old fashioned definition, the nutritional intake, and so you know over the years I've tried different things and found what works for me , not that I preach this for anybody else. By trial and error I've found what works for me, including for the migraines.

Miranda points out how the same complementary/alternative healing might not work for all. She says,

I know because my husband did it with me, he did acupuncture and he has a bad back and he thought that would help and he said oh I don't think this has done anything for me and I thought that it did help me, so maybe it's just not for everybody I don't know..

Shirin narrates how some complementary/alternative healing can be better suited for certain people than others. She says about meditation,

I am not a person who is good at just sitting down and doing nothing, I wish I could be but I am not, I am always thinking about what else I could be doing which is stupid, but there are many people who can do meditation...I've watched my younger son do meditation, he is really good at it and I watch him. He can just go into a sort of trance and his body just relaxes. My body never relaxes, whether I am sleeping or standing up, just I think that I am the A type personality.

In the absence of enough literature in the public domain attesting to the effectiveness of various forms of complementary/alternative healing, many participants deemed it right to try different forms of healing themselves and analyze benefits individually.

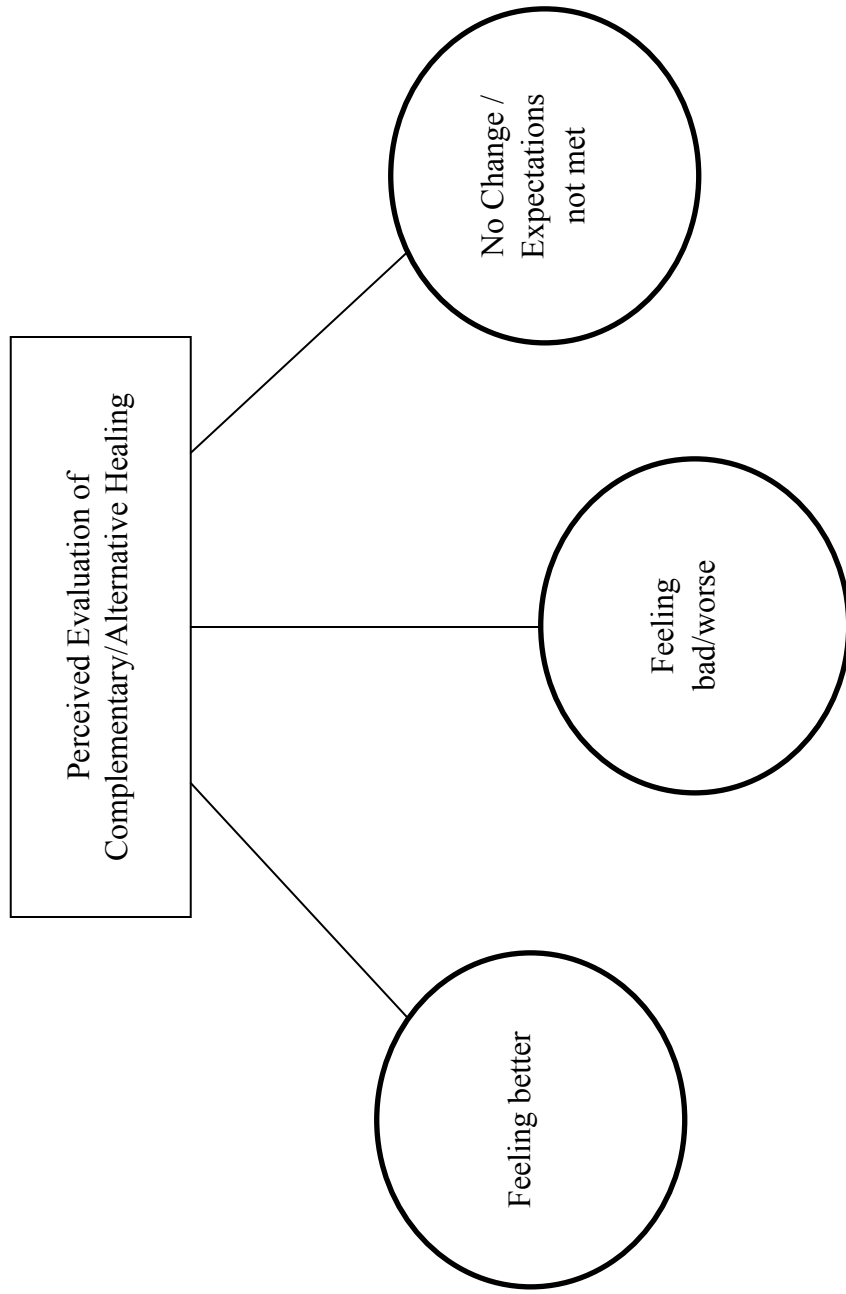


Figure 5.4: Theme 3

## **Perceived Evaluation of Complementary/Alternative Healing**

All participants use or had used more than two complementary/alternative healing. Some participants had used several complementary/alternative healing for various ailments over the course of their lifetime. As discussed earlier different participants had different pathways of discovery to the various complementary/alternative healing available to them. However, discovery and use of a particular complementary/alternative healing did not necessarily indicate that participant's were committed to its continued use. Whether or not participants engaged in sustained use of complementary/alternative healing depended a lot on their particular experiences with it. However, a good experience did not necessarily guarantee sustained use of complementary/alternative healing.

The experience of using complementary/alternative healing is categorized into three sections of feeling better, feeling bad/worse and experiencing no change or expectations not being met with use of complementary/alternative healing.

### **a) Feeling better with use complementary/alternative healing for acute injury/illness**

Use of complementary/alternative healing is not restricted to chronic illnesses alone. Some participants mentioned having used complementary/alternative healing for acute pain or injury pain as well. In most instances, these participants mentioned getting immediate relief from the use of particular complementary/alternative healing. In addition, some participants also asserted that options in allopathic medicine for certain acute pain/injury pain were invasive and hence they preferred the less invasive complementary/alternative healing. Furthermore, a few participants expressed



amazement at how quick and effective some complementary/alternative healing was in specific cases. For instance, Michael narrates how he got immediate relief for a pain in his right arm that had been bothering him for some time. He further notes how less invasive and lasting the treatment was, considering the pain never bothered him again.

I had a problem with my right arm and it was painful so I went to a neurologist and he said well after some examination he said that the problem is that the muscle and the nerve are wrapped around each other and we have to operate and separate them and then the problem will go away. Well I was a bit hesitant and so I waited and the process in which it got better was very interesting. So we were at a Yoga and Pilates class and there was a break in the middle and the class was conducted by Dr. Gill (who was an acupuncturist) and I was massaging my hand and he said what's wrong and I said well I have a problem in my arm and so he said let me take a look at it so he looked at it and maneuvered it for 30 secs 45 secs and he said yeah yeah the muscle was wrapped around the nerve but I unwrapped it and you will be fine. And I've never had a problem since... Yeah yeah the other guy wanted to cut me open and that was miraculous he took 45 seconds maybe and he said yeah I unwrapped it.

Rita says she was able to get back to normal after a car accident primarily with chiropractic care. She suggests that she used a few complementary/alternative healing after the accident and it was finally chiropractic that helped the most. She says,

when I was in that car accident that was none of my fault and so I went for physical therapy for that and I did massage therapy and somebody finally talked me into going to a chiropractor and I wasn't really thrilled with it at first but they did wonders for me.

On the other hand, Lile underlines her experience with osteopathy after she had a bad fall in the tub. She points out that her osteopath undertook a tricky manipulation that gave her a lot of relief.

A few years back when I arrived here ..I kind of fell in my tub and so from there I had like a real pain in my sacrum ...and when I had this fall in the tub unless I met this osteopath I am sure I would still be in pain today because he had to do a very risky maneuver like internal to be honest and it's not something people talk about and he was even telling me that some osteopaths don't even do that move.

But actually it really saved me..like it was so bad.. my sacrum was almost completely reversed, it was that bad..

It is important to note that participants who suggested they had used complementary/alternative healing for acute pain/injury pain usually spoke about getting relief from only three specific complementary/alternative healing. These were chiropractic, acupuncture and osteopathy, healing that usually includes some kind of physical treatment.

**b) Feeling better with use complementary/alternative healing for chronic conditions**

Most participants highlighted having experienced some health benefit from one or the other complementary/alternative healing for their chronic conditions. However, there wasn't any consensus on one particular complementary/alternative healing that worked for all. Since different people use or used different types of complementary/alternative healing, participants reported gains from different forms of healing. For instance, Amy highlights her beneficial experience with energy healing in treating her serious blood condition TTP. She says,

This time around when my friend tells me to meet the energy healer and see what's going on. I started meeting with her. So we did a lot of visualization....And I actually saw the clots in my legs dissolve. In my head as she taught me, she guides you through it, I saw the clots in my legs dissolve. When I had the ultrasound done it was found that it was actually gone, the clots were gone. So talk about the power of the mind. I saw the clots as long balloons, small because I knew where they were, I with my brain, with my mind made them deflate, and I saw them deflate. I get goose bumps thinking about it.

Henry alludes to the advantages of yoga and music therapy. He says,

Oh yeah, yes because I mean all my joints are all flexible. There is no stiffness and rigidity that is one of the hallmarks of Parkinson's, I don't have any of that because of the yoga exercises that I do

He further talks of music therapy,

Music therapy is, as I do it more and more, I feel it helping more and more. At first I said what is music therapy its silly, you are just singing songs, but the teachers we've had here have been excellent and they work on your breathing, they work on your voice. So many people who have Parkinson's have a soft voice but I come home and my wife knows when I've had music therapy and she can tell that you've had music therapy today your voice is stronger, so it definitely helps

Liza suggests that it was Chinese herbs that helped her in dealing with breast cancer. She points out, that initially she had a strong reaction to the herbs, but it worked out for the better later on.

And I started taking the herbs and I had an immediate reaction and really strong reaction and the reaction was that my entire immune system has like a giant jolt and after that I get like hives all over my body which was nerve wrecking but it turned out that those hives were a immune response. Cause within a few days my chemical sensitivity which had been the pain of my life for so long really changed. I began to have much less reaction in terms of the intensity and I didn't feel sick and it didn't last long. I wasn't spending days being sick and that was amazing because that had in itself been so hard for me to deal with and now all of a sudden I was better..And I noticed eventually that I wasn't having any more tumors. The Chinese herbalist had originally said to me you've got to stop what you're doing and just take my herbs. And I was like no that's impossible, I had to keep doing, what to me had kept me alive so we negotiated that and I kept on doing what I was doing which I think is what led to me having such a strong reaction, because I was doing a lot. And he said to me you are done, you can stop taking the herbs. And I couldn't, I just felt like how can I stop so quickly?

Though participants emphasized their good experiences with particular complementary/alternative healing, there wasn't any consensus on one particular complementary/alternative healing that worked for all. While one complementary/alternative healing like acupuncture might have proved beneficial for some participants, there were other participants who did not perceive any useful results from it even for the same illness. For instance, Miranda who suffers from Parkinson's disease narrates her experience with acupuncture. She says,

Yes and at that time in the beginning of my Parkinson's I had a lot of trouble with the pain in my ankles and legs and the acupuncture really to me it seemed to help, they would put the needle there and the pain went away more or less..

However, Matt who also suffers from Parkinson's disease highlights how acupuncture didn't really work for him. He says

The first thing I did was the acupuncture, it was a friend who recommended it and said it was very good and it was very good. But it seemed like I don't know I just wasn't getting again a measurable benefit from them. And I was really getting tired of getting stuck with those pins over and over again. When it got very tedious I guess, you could say and I thought like it wasn't helping enough to justify the discomfort... I've been there for three months which maybe wasn't a fair assessment I don't know how long you'd have to do it to make the results you wanted to get.

Above and beyond helping with their chronic ailments, quite a few participants suggested that they would attribute improvements in overall health and quality of life to use of complementary/alternative healing. For instance, Ruth says she feels healthier after yoga and dance therapy and also acupunctures helps when she is in pain from MS.

Well in some respects like the yoga and the dance therapy is somehow making me feel healthier. Since I am not doing the acupuncture on a regular basis, it's when I really need it and yes then it really helps and I think it shortens the relapse. I don't know if it's a science or something but most of the time it works. Sometimes maybe 1 treatment is not enough but it certainly shortens the relapse.

Kelly appoints a numerical to explain the benefits she has gained in her quality of life from complementary/alternative healing. She says,

I'd say it has improved my quality of life by 90%. Yes, cause I can do more and I don't like to sit around.

Some participants also indicated that certain complementary/alternative healing provide an energy boost and enable them to have more active lives. For instance, Michael says he

would definitely attribute his high energy levels to complementary/alternative healing he says,

Our energy levels are high . Lot of people our age , they are always tired etc. they are always falling apart but we are always pretty energetic. And we have been able to retain that energy level for so long.

Similarly, Mahdi too points out that she feels certain complementary/alternative healing are vital for maintenance of optimum health.

So I made up my own list of natural/ complementary/alternative health strategies. So I consider these vital. If they are not there you could do yourself a lot of damage. Just because they are natural doesn't mean they are not important and in many cases almost decisive. They are certainly prime movers either toward or away from our optimum health again remember my definition of health is not absence of disease, optimum health its being active, its being alive, feeling alive you know feeling that aliveness

Interestingly, two participants pointed out that they feel a dip in overall health because they have not been regular in practicing some complementary/ alternative healing. For instance, Larissa suggests that she was feeling better when she was practicing some complementary/alternative healing regularly, but now is fighting to get back to that discipline.

Well now I know that I am paying for not stretching like you know that I am tighter. Thus, there are things that definitely if I were practicing more often I would see a better you know improvement. So if I would be meditating more often maybe I would be sleeping better you know...I think having disciplines whether it could be martial arts, yoga, you know exercise these I think to me for sure make a difference. And I have definitely been struggling to sort of build it again. So I would say yes I was feeling better when I was doing more of them.

Some participants also emphasized that though the advantages from complementary/alternative healing were not always immediately visible or understood they believed in its use as they anticipated long term health benefits. For instance, Matt

says he feels better in the short term with some complementary/alternative healing like yoga, Tai-chi, Music therapy etc. but he also anticipates measurable health benefits in the long term. He says,

...Parkinson's is a very physical ailment so to do things that might increase your flexibility or make you feel better even if it only makes you feel better in the short term is definitely beneficial. It's something I see you know would be measurable in the long term. But it's definitely beneficial that's why I always try and pursue it even though I might not want to do it sometimes but I make myself, I say it's going to be beneficial for me.

Furthermore, it is necessary to note that perceived advantage from complementary/alternative healing did not necessarily translate into continued use or subsequent use of other complementary/alternative healing. For instance, Shirin says though she perceived some benefits from acupuncture she did not continue with its use.

She explains here:

Because I started to get better and it came up to the time when I was doing my exams and I had to concentrate on what I was doing so I started to get away from it... After that actually the headaches got so much better, I don't know if it was acupuncture or if it was menopause but post getting into menopause the headaches got less so I just stopped going and I never went back. I always intended to go back but never did.

For some participants, not only was some complementary/alternative healing helpful and beneficial for health but the treatment process itself was enjoyable. A few participants alluded to falling asleep during acupuncture sessions, or feeling happy during yoga or dance therapy classes or feeling relaxed during a massage session. Here, the method of treatment in some complementary/alternative healing, in itself, was providing relief to those using it. For instance, Anita narrates how she enjoys massage therapy even though it doesn't have a lasting effect. She says,

Sometimes I was very relaxed right away..the person that did the massages is really really good, because she knows how to release you know whatever is going on in your body. She will find it and she will release it through just her fingers. You know its magic, so that's extremely relaxing. The thing with that is the lasting of it. So although you feel really relaxed and great once you are kind of back in your regular routine, you get into your car and you get home, you start doing whatever you are doing, it doesn't stick with you ... But it certainly helps at the time.

Similarly, Rachael highlights how she finds acupuncture treatments relaxing. She says,

Now we have a Chinese acupuncturist from Surinam and he comes every two weeks to the house and I feel great and it's very relaxing and I feel that it's doing a lot of good...

Every participant used different forms of healing with different sets of expectations and different yardsticks for evaluating perceived benefits. There were some noticeable differences in experience among participants for one or more types of healing. However, it was evident overall that once the participants identified the form of healing they wanted to pursue in the long run, their experiences were mostly good.

### **c) Feeling bad/worse with use of complementary/alternative healing for chronic conditions**

There were a few participants who reported having some bad experiences with complementary/alternative healing. Although sometimes the bad experience was attributed to the healer, in some instances a harmful or unhelpful health related effect had ensued following use of particular complementary/alternative healing. For instance, Liliana suggests that when she had dysentery in a different country, she tried Ayurvedic medicines, which didn't help. She says,

Not really it didn't help at all, the Ayurvedic medicines tasted so bad and I was really so stupid, I really should have taken some western medicine and really been done with it. There is a time and place. Like I said in an emergency go to the hospital. If

it's not an emergency definitely try as many natural protocols as you can before and then just sort of, you have to come at it from many different angles , it's not just one.

On the other hand Ruth highlights a possible adverse reaction that she experienced from herbal medication

I had a headache, and I could be wrong because this is going back 20 years and they said well rub some of this on your temple and it will relieve your headache and my heart started racing which may have been the atrial-fib, I don't know if it aggravated it. But when my heart started to pound I was like no this is not for me. So it made me very leery of trying herbal medications.

Some of these participants were quick to assert that the bad experience with specific complementary/alternative healing could be due to their incorrect or insufficient use. For instance, Liza suggests that she had an adverse reaction from a particular complementary/alternative healing due to improper and inappropriate use. She says,

I mean I did one thing that you have to be really really careful about, I wasn't careful enough and I did get a little sick. But I can say right away that I was doing the wrong thing and I stopped doing it... Yes it was hydrogen sulphate, it's a drug that's called an MAO inhibitor. An MAO inhibitor requires that you avoid a lot of food and some of the foods wasn't listed in the list that I saw and I made myself sick by eating bananas and I knew immediately that I was sick because I was very very weak . So I stopped doing it and later I found out what I did wrong and I also found out that one of my friend who was doing it , was doing really well on that treatment and I think still to this day is taking it and doing well

For a few participants, experience during the treatment process for specific complementary/alternative healing was less than satisfactory. For instance, Henry suggests that initially he wasn't pleased with yoga. He says,

I had done some yoga before I joined this group cause I had heard that Yoga was good for you but I didn't like it, my left leg which is the symptomatic leg wasn't strong enough to do yoga and I just didn't like it.

However, in spite of his initial experience with Yoga, Henry later took it up in his support group and currently practices it daily without fail.



**d) Expectations not being met for some Complementary/Alternative healing**

Some participants argued that their experience was not necessarily bad with regard to particular complementary/alternative healing, but it did not meet their desired expectations. These participants argued that with specific complementary/alternative healing, they felt they could do without it. For instance, Mahdi emphasizes that she did not get desired benefits from all complementary/alternative healing. She says,

There are some things I will be doing forever for as long as I am in this incarnation if you will, all the things in the beginning like self talk, nutrition, yoga, meditation, something like the 5 Tibetan rites, occasionally a massage, I will be doing for the rest of my life you know. But things like magnets I am more lukewarm about that, they may or may not help. I am not a 100% sure...the cranial plate realignment thing I probably wouldn't do it again, it's expensive and I am not quite sure what it did. And that may well be a lack in me and not in the process, the tens unit I don't find super helpful, I probably would not do that again.

Similarly, Anita mentions not getting any benefits from acupuncture, and finding the process of healing troublesome. However, she also asserts that she wouldn't really call it a negative experience but just something that didn't have the desired effect on her health.

I can't say anything was really negative, but the acupuncture to me felt more like just something else to try on the list and it just doesn't do anything for me. Because I found that after a while the needles would hurt a little bit and I didn't think that was right because I am like why am I inflicting pain on myself this is not good and maybe I didn't give it long enough, cause I know they had a lot of different supplements and things that they give people, shelves and shelves of different herbs but I didn't give that too much of a chance so I kind of backed out on that pretty quickly.

It was interesting to note that even though certain forms of complementary/alternative healing did not produce the expected results for participants like Mahdi and Anita, they were happy to give these healing options the benefit of doubt and preferred not to term their experiences as “negative”.

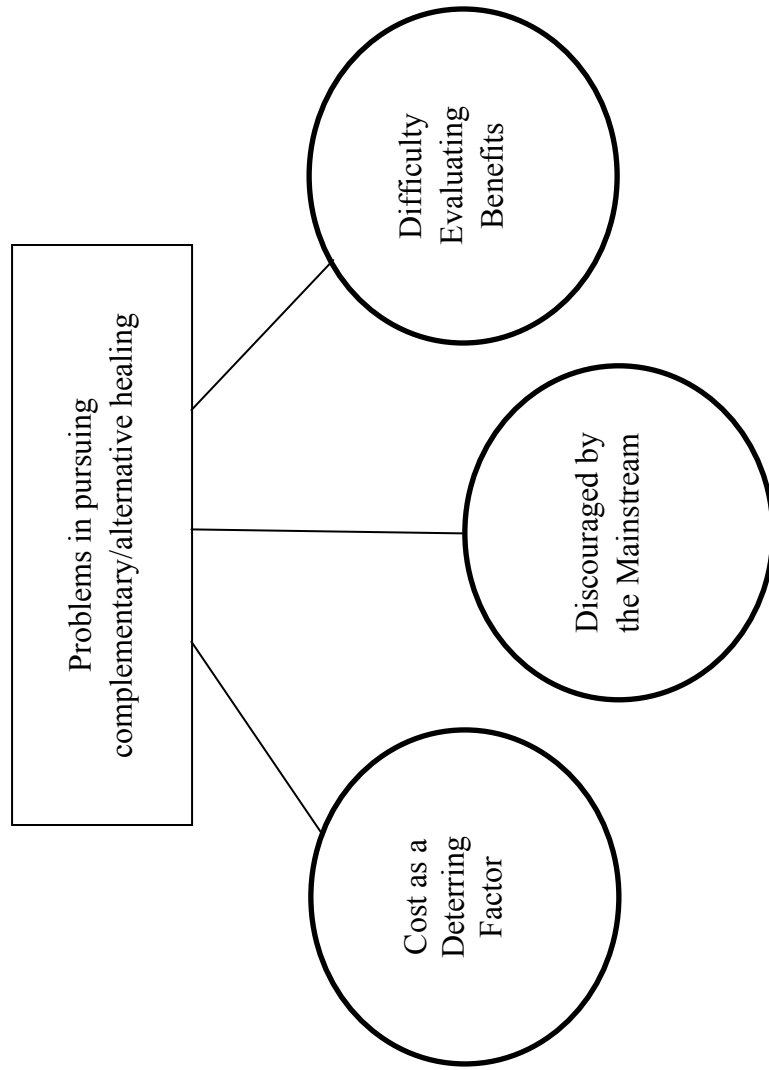


Figure 5.5: Theme 4

## **Problems Pursuing Complementary/Alternative Healing**

### **a) Expense as a deterring factor**

Most participants highlighted the cost of some complementary/alternative healing as an impediment to its use. While some participants had travelled that extra mile by securing a loan or considering taking up extra work to obtain the required complementary/alternative healing, some participants had also foregone treatments due to monetary concerns. Arguably some complementary/alternative healing like yoga or meditation can be practiced at home and are relatively inexpensive; however, other common complementary/alternative healing like acupuncture or chiropractic can be quite expensive without insurance. For instance, Lucy points out how she doesn't have an alternative to try other healers because she can't afford it

“I don't have the option of saying ok I am going to try naturoveda, I am going to try a doctor of alternative medicine, I don't have the money to do it, I can't afford to pay every treatment or the entire series of treatment. My Reiki healer is doing this because of the goodness of her heart because I can't afford it if its not insurance covered and insurance doesn't cover anything. I don't have an alternative, I don't even think about it because I don't have an alternative.”

Amy highlights how she would like to continue with all the complementary/alternative healing she is currently doing, but is hard-pressed for funds. She says,

“So I go to acupuncture every week, I do the Reiki which I am trying to do regularly but because of the expense. You see medical /traditional insurance doesn't cover any of this. So I have this great insurance that doesn't help me for what I want to do to heal. So I have to find money to fund all this alternative healing that really work.”

She goes on to mention the cost for some of the treatment

“There is another one that I haven't tried yet but would like, but because of the expense I can't. Reiki is like \$85 a week, if I wanted to go every week, every session is \$85 with a massage its \$105. So I cannot go every week, I cannot afford it. The only thing I can go to every week is the acupuncture because she is giving

me a really good deal. She calls it her family discount and I spend about \$350 a month on acupuncture and it's not insurance, it's out of pocket. The Reiki I am going to try to keep doing once a month, the massage maybe alternate months reiki and massage. The Shaman treatment I have one more treatment that I am holding on to . And those are like a \$150 a session. A session is about 2 and ½ hours so it's not very expensive if you consider how long it is but it is expensive if you consider all the other treatments. And nothing is covered by insurance.

Therefore, on average Amy spends around \$585 a month on complementary/alternative healing. Since, it's all out of pocket that is a substantial amount of money for a person with a fixed monthly income. Amy later pointed out, that she was considering tutoring to earn some extra income to pay for the healing choices she has made.

Matt highlights that often one's evaluation of particular complementary/alternative healing can also depend on its cost. He points out how not only is cost a worry but if one sees no immediate results then the expense can appear like a waste. He says,

Cost is always a factor and that's been a factor with me... the Chinese medicine doctor, every time I went to see her it would be like \$250 that would be for the treatment, herbs and stuff like that...they want you to come every week or twice a week and if you see it's a lot of money. And I had saved a lot and ill say that I had gone there for a month and I spent \$2000 and I am not sure if I got anything out of it. It made me try to think like oh should I really be doing this? And is it really a good decision? My wife was like what are you spending all that money for when you don't even know if you are getting the results. It definitely has a influence on whether you try it or not and how you stick with it, how you evaluate it cause then you get impatient if it costs you lot of money.

Mahdi explains how she took out a loan to cover the expenses for one complementary/alternative healing. She says,

The cranial sacral plating, I actually took out a loan to see if it would help me which I then repaid but at that moment in time was it the right thing for me to do, I am not sorry that I did that.

Though most participants mentioned cost of complementary/alternative healing as a cause for worry, some participants argued that expense was not a cause for worry if one

was getting measurable health benefits. Some participants asserted that they had paid considerably for complementary/alternative healing when they were in pain and they did not mind that. For instance, Shirin says when asked if the cost of complementary/alternative healing worries her.

No no I would never think of expense if something is, if I can afford it. If something is doing my body good. No I wouldn't think of it. I mean if you are going to somebody who you are paying a lot of money for classes etc. etc. and they are not doing a good job then I get very peeved and upset.

Mahdi explains that though she might be paying more for some complementary/alternative healing, in the long run she has a healthier body. She says,

Well some people would say that organic food is more expensive than non organic food that people eat, yes that's true. Do I spend more than somebody who has a miserable diet? Maybe, but I am not even sure cause I am not hungry as often and then again my whole thing about value and money is to just spend a couple of pennies more...And, other than the migraines, my life is in no way impacted by any physical challenge with my body.. I mean I couldn't sprint a marathon, I am not in that kind of shape or anything but I have a good dependable body to work with here..

It is important to note, that neither of the participants came from a low socio-economic status, and yet most of the participants at some point or the other had been affected by the cost of some complementary/alternative healing. Therefore, some forms of healing might not be easily accessible to a large section of the population.

#### **b) Discouraged by the Mainstream**

Participants often shared their use of complementary/alternative healing with their allopathic doctors. Depending on the allopathic practitioner and the type of complementary/alternative healing used participants were sometimes discouraged from using such forms of healing. For instance, Liza highlights how doctors did not emphasize on

strengthening of the immune system even after she was diagnosed with cancer and in the 1990s they discouraged her from continuing with complementary/alternative healing saying that it would be of no benefit to her.

So medical people were telling me oh it doesn't matter what you do. Don't do yoga, you'll hurt yourself. I mean just all sorts of stupid things and I knew they weren't on the correct path...I chose to do more of what I was doing and to stick with my program of disregard of anything that I thought was absurd that they were telling me and I think that was good choice because they were off track

Kelly highlights the reaction of her doctor when she and her husband insisted on trying complementary/alternative healing for Parkinson's first.

Well the first one, the lady doctor said, yeah you could try it but they don't have any proof or training that anything else could work but drugs and the drugs doesn't cure it, it just temporarily relieves the symptoms so my husband was insistent that we go and so he said we are going to go and so she said ok go and when you come back, come and see me and she had the pills ready so that was about it

Though the above mentioned participants went ahead and tried complementary/alternative healing, it possibly discourages some people to disclose their use of complementary/alternative healing to allopathic doctors in general. For instance, not all participants were as forthcoming about their use of all complementary/alternative healing with their doctors. Some participants mentioned that they selectively disclosed their use of complementary/alternative healing fearing a derisive response. For instance, Miranda says that she will probably not disclose her use of holistic healing to her allopathic doctor, because she feels there is inadequate recognition on their part. She says,

I probably will not tell my regular doctor, I mean not that there is anything wrong with it, it's just that sometimes I don't think they appreciate it, they never talk

about diet and yet that's so important what you put in your body and yet you don't hear them say anything.

She also highlights an instance when her allopathic doctor was almost disparaging of her use of complementary/alternative healing. She says,

I remember I told my doctor I was taking a Vitamin called Devil's claw and I told my doctor about it and he just laughed and he said “well I'll never tell my patients to take that, he said can you imagine what they would think if I told them to take Devils Claw”, we laugh but it's funny how some people think.

On the other hand Larissa says, that she tells her allopathic doctor of her use of some complementary/alternative healing while avoiding disclosing her use of one particular type. She says,

I think I share, the energy work I don't share too much because I know even my friends are like you know (“really”??)

When asked if she felt she was being deviant and hence did not disclose her use of energy work, she says

I don't know deviant, but I think like if I tell a lot of people are going to be like “Oh what an idiot you really think that you know energy can heal you?” My girlfriend is a science oriented person she goes like “You really really think that's possible, to be able to heal? And I go like, I am sort of the mindset like anything can be possible and I can say maybe it doesn't work and maybe it does.

However, other participants who were using complementary/alternative healing had either told their doctors about their use of complementary/alternative healing without worrying about their response or had found doctors that were more open to these. Few of these participants mentioned that their doctors were somewhat accepting of their use of complementary/alternative healing. For instance, Michael narrates how his allopathic doctor was more accepting of the benefits from complementary/alternative healing. He says,

When I went to the pain specialist again he said well you are getting better and you look good he said anything you want to ask me. So I hesitated somewhat and I said you know I came across this magnet business. He said it's incredible but he said that we've known about these magnets for a long time. And he said I'll show you an experiment and so he had his assistant come in and his assistant made a zero with his thumb and forefinger and then the doctor went like that and immediately broke it. And then he said to the assistant now put the magnets under your arm and then the doctor couldn't break it anymore. He said that we know this works, we don't know why or how we don't recommend it because it's not part of the protocol.

On the other hand, Matt says he was able to find an allopathic doctor that was more open to his ideas.

I don't know even with Parkinson's I was very resistant to it. On occasion I had to find a doctor that was actually agreeable with my philosophy because a lot of doctors are not at all; it's my way or the highway. Either you do what they say or they don't want you as their patient so luckily I found a Turkish neurologist who was very open minded he was like ok if you want to go very slow, we'll go very slow, with a slow treatment plan, you can try things out and see if you like them..

In general, views on complementary/alternative healing are evolving. In the light of these changing perceptions and development of integrative medicine centers, more and more allopathic practitioners will possibly be open and encouraging of their patient's use of complementary/alternative healing.

### **c) Difficulty Evaluating Benefits**

It is not always easy to evaluate the benefit of a particular form of healing. In case of allopathic medicine one often relies on evidence based research, however, such research is usually absent for complementary/alternative healing. Hence, frequently patients have to rely on anecdotal evidence or their own experience for assessing the benefits of complementary/alternative healing. In doing so, some patients get impatient when they are unable to see immediate results. Therefore, a few participants highlighted their difficulty in evaluating the benefits of complementary/alternative healing. However, a



couple of participants also pointed out that some complementary/alternative healing has long term benefits even though they might not be immediately noticeable. For instance, Kelly says that she didn't get enough opportunity to evaluate the acupuncture treatment that she underwent in Honk-Kong. She emphasized that because of time and money constraints she had to return to the US and hence she couldn't decide if it helped or not. She says,

he started doing treatments every day acupuncture and a lot of massage at the base of my skull and it's amazing how it hurt , rubbing deep down and stretching and he was a master in Chi- Gong and so he did mental healing also and I couldn't have stayed longer , he said I should have stayed longer up to 3 months but I had to come back also he did a purge by mouth and he said you know, not to eat junk food and stuff, well we never eat too much of that and I don't know if it helped or it didn't help because I didn't stay long enough

Matt who vouches for complementary/alternative healing otherwise also points out that he has had considerable difficulty in assessing the benefits of some complementary/alternative healing. He says

I also tried with the same person Chinese medicine and I also tried looking up on the internet different alternative supplements for dopamine apparently there is an Indian bean that is very high in dopamine I went an ordered it on the internet, I also took the bean to try, but then again I only did it for 30 days and then again I wasn't getting any measurable benefit. I am the kind of person that gets frustrated with himself or doesn't have a lot of patience for doing stuff like that so if I don't see any kind of results I give up on it, so I'll say oh it's not doing anything. Maybe that's not right but that's the way I am.

However, Larissa points out that it possibly takes time to see the benefits from complementary/alternative healing, she says

Like you know my friend she is an acupuncturist and she says people come in for 1 treatment and they feel better. But really you should maintain it so that there is sort of like a reversal. So she has difficulty, because they are paying out of pocket they are not paying through insurance, so for them to come for more than one session where they get relief..

Hence, the question remains as to how many people can afford to continue with some complementary/alternative healing (that is expensive and not covered by insurance), in the long term, to better evaluate its benefits.

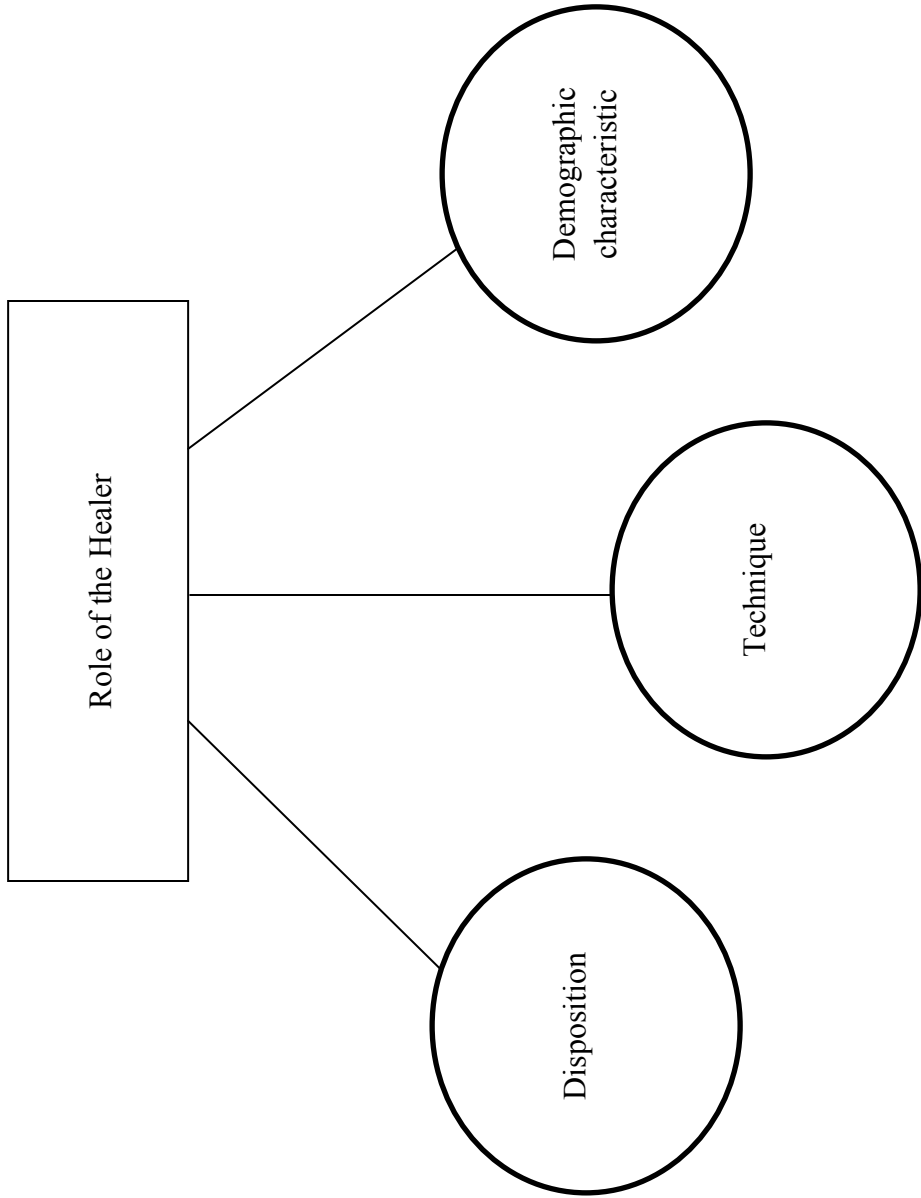


Figure 5.6: Theme 5

## **Role of the Healer**

When asked to compare and contrast the experience of visiting an allopathic doctor and a complementary/alternative healer, most participants described their experience with a complementary/alternative healer as more engaging and satisfying. However, in the course of the interviews it emerged that there were often significant differences in the experiences with complementary/alternative healing based on the healers.

Most participants gave considerable importance to the healers of complementary/alternative healing. The healer's personal disposition, technique and credentials, and in some rare cases also the healer's demographic characteristics were important factors that were brought up by participants as affecting their views and subsequent actions regarding particular forms of complementary/alternative healing. While some participants directly alluded to the importance of the healer, others made implicit references to it.

### **a) Disposition**

The healer's personality and ability to communicate and connect with participants was an important factor affecting patient's attitude towards not only the healer but also in some cases the specific form of healing practiced by the healer. In some cases participants reported very good experience and immediate connection with the healer, the experience itself working as a pull factor for subsequent use of their services. For instance, Mahdi compares and contrasts her experience with three acupuncturists and highlights how and why she felt most comfortable with her third acupuncturist. She says,

I actually related more to the third acupuncturist, even though there was a much greater age difference, there was a much closer mindset, approach in life, the plant based diet, being more aware about everything that surrounds us. So even though the years was much greater, the view point, the mindset, the perspective was much more harmonious, in that sense also I felt more connected to the third one because I could say things to her that I probably wouldn't say to one and two.

In contrast, Lucy points out how her acupuncturist's flippant nature to an extent caused her to be disinterested in acupuncture altogether. She says about her acupuncturist,

He was very flip, flip in the sense like kick all this and doo doo and that's not what I have the concept of that medicine it deals more with my spirit and that's what I like about it. You know people relate to you more to what your soul is going through and the intangible connection between that person and your soul. It's more like energy exchange of two persons and for some reason I don't know I always had a very good sense of people when you meet somebody you feel sense a connection and I didn't have that. He wasn't about to treat me unless I gave him \$1500.

While Mahdi was happy to experiment and tried three acupuncturists before she was completely satisfied, Lucy developed apathy towards acupuncture because of her negative experience with her first healer. It is interesting to note how an entire form of healing can at times, be perceived and judged based on the attitude and disposition of one particular healer.

### **b) Technique**

In some complementary/alternative healing, a healer's skill or technique is very significant as there are numerous ways to practice a specific form of healing. For instance, Liza says,

I think there are a lot of different ways to do acupuncture. You know acupuncture is not like conventional medicine, where everyone takes the same class of drugs. I mean it's possible to get a prescription for different drugs, you don't necessarily get the same one but you mostly do but with acupuncture for example because I had Lymph edema they couldn't put a needle in my left arm for years, so rather than a needle in my left arm they would do my back or my chest or my right arm or you know and it depended on the healer by what choices they made and it

wasn't clear cut. There was no single choice to be made, it was a variety of possibilities and I kind of enjoy that. I mean I tell people, like if someone tells me that acupuncture is not working for them, I tell them they have two choices, they can either stop doing acupuncture or they can consult a different acupuncturist because it's possible that with a different acupuncturist they will get a different approach. It's not always true but it might be worth trying.

The healer's technique and type of practice can also impact one's use of a particular complementary/alternative healing. For instance, Anita highlights her experience with chiropractic care and suggests it took her time to find a healer that practiced the kind she was looking for. She says,

Well it took me a while to find her cause I went to one first that did the standard kind of chiropractic and I walked out feeling worse than when I came in, and I was like this is no good. My back is killing me you know and even when I got to Florida I found a chiropractor named Dr. Sen, that was her name and she was very nice and I thought ok gentle chiropractic but even she it was a little rough and I found this is not helping me to relax, its making me more tense and that's not good.

So technique or skill was noted to be as important as the disposition of the healer based on participants' experiences.

### **c) Demographic Characteristics**

In rare instances, the healer's demographic characteristic was implied to be a factor in participants use and experience of particular complementary/alternative healing. A few participants alluded to specific experiences and expectations regarding the healer's demographics. For instance, Shirin says with regard to her acupuncturist,

I think the gentleman who was doing the acupuncture we had a hard time understanding each other. He was Chinese and his English wasn't great and of course I don't have, my accents very difficult for someone from that area of the world, so it was quite awkward, I would put it more awkward than negative.

While Shirin highlights a problem with understanding the healer's language, Lucy suggests that she expects healers of particular complementary/alternative healing to be of a certain ethnicity, people who have either inherited or learnt the type of healing through the generations. She says,

...not that I am necessarily looking for University of Beijing or whatever it is because some of the best ones learn it from their parents and some of it is not necessarily learned. Its inherited more than studied. It is training because they do train with their parents or in their village or wherever they learnt it. But still you should be able to know how they got to acquire certain skills but what you do is just go through with it and find out that if it works. And if it doesn't work and interesting this is, you blame it on the practitioner and not on you.

In contrast to Lucy, Lile says that for her gender and experience are more important than ethnicity for some complementary/alternative healing. She says

... in the Chiropractor field, I am a bit ashamed to say that because I am a woman, I guess guys are best because you really need to be strong. I mean, I am sure some women are good but some day there was a woman chiropractor and honestly she wasn't very good..I could feel that she didn't have enough strength to pressure the right places and I am a tiny person but can you imagine when you have these obese big guys, its true you need some strength. So maybe from the Chiropractic point of view I would say that gender can matter. Ethnicity no but I also see that experience also makes the difference, the more experienced you are in chiropractic care, the better it is.

In later interviews when I asked participants if they thought that ethnicity/gender of the healer mattered, participants refuted it and said that individuality was most important.

Like Larissa says

My ex-husband he loved his first acupuncturist a Chinese guy and he never really found somebody that could replace him. And we went to Colorado and he went to a Chinese guy over there because his expectations of Chinese people are higher than like whatever a non Chinese Asian person and he had terrible experience in Colorado. And then my ex-roommate treated him and then he did very well. So I don't know it just goes down to individuals I think people are gifted regardless of

their ethnicity. So I don't think you can put people down just because they are not practicing something native to their culture.

Although, gender or ethnicity of the healer might not be the key deciding factor for all participants, at times it does play a role based on the perceptions that individuals have.

### **Summary**

There are five important themes that make up the meaning and experience of complementary/alternative healing among chronically ill individuals. Though most participants had a rough idea of what constitutes complementary/alternative healing their definitions often varied. Participants' named a variety of health practices/healing options as complementary/alternative healing. Also, participants' physical, social, economic and biographical contexts combined an array of factors to affect their choice of using complementary/alternative healing. Typically, a single participant might have used a variety of complementary/alternative healing, but their reasons for choice of each healing option differed.

In the course of using complementary/alternative healing, participants' perceived to have good, bad or neutral experiences with the respective healing options they used. It is essential to note that participants did not use a standard criterion for evaluation. Factors that influenced perceived evaluation of complementary/alternative healing included but were not limited to, individual expectations from particular forms of healing and individual experience with particular forms of healing.

In addition, meaning and experience of complementary/alternative healing was also affected by barriers that included cost, perceptions of the mainstream and difficulty evaluating benefits of various forms of healing. Different participants approached these



constraints differently based on their situation in life. Finally, the experience with healers or persons connected with particular complementary/alternative healing also affected the overall meaning and experience of complementary/alternative healing.

In the following chapter, I will consider these above mentioned themes in more detail in light of the limitations of the study.

## **Chapter Six: Discussion and Conclusion**

In this concluding chapter I provide an analytical assessment of the major findings presented in chapter five considering them in the context of the limitations of this project. I develop the meaning of complementary/alternative healing to chronically ill patients by describing the processes through which people name, make a choice for, evaluate, and deal with problems and people associated with complementary/alternative healing. Furthermore, in providing an illustration of how chronically ill persons experience complementary/alternative healing, I contribute to enhancing our understanding of complementary/alternative healing and the way in which it is addressed by researchers and policy makers.

My project is limited in scope as the sample did not allow me to identify general patterns with regard to diversity in meaning and experience of using complementary/alternative healing by class, race/ethnicity, gender and age. Sociologists and other researchers should explore how different groups attach different meanings to complementary/alternative healing. Furthermore, efforts to match interviewer with interviewee on demographic characteristics might be significant in this regard. Interviewer matching might help to yield sensitive information regarding some participants' use of ethnic specific complementary/alternative healing, that participants might not be comfortable in disclosing to all. In addition, I approached the research question such that, I asked participants to tell me about their experiences with healing options/health practices that they considered complementary/alternative healing. The use of the word "healing" instead of "medicine" possibly enabled participants to include a

range of health practices/healing options that they identified with as complementary/alternative healing. However, the use of the words “complementary/alternative” might have restricted their perspective and elicited a certain kind of response from the participants. For instance, religious healing like prayer was not mentioned by a single participant. A revision of the question wordings and a different approach to the research question might yield a different viewpoint. Also, my study was based entirely in Miami and though Miami provides a unique location it would be interesting to learn how people in different regions and places attach meaning differently to complementary/alternative healing. Hence future research in these two areas would contribute to a broader understanding of the meaning and experience of using complementary/alternative healing that was outside the scope of this project.

In developing a theory of the meaning and experience of complementary/alternative healing among chronically ill individuals, I found that there is a well-founded reciprocity between meaning, experience and use of complementary/alternative healing. The conceptual map in the findings chapter visually illustrates this interconnected process of meaning making and experience with use of complementary/alternative healing. I conclude that the meaning and experience of complementary/alternative healing not only consists of the five themes of naming, making a choice, perceived evaluation, problems pursuing and the role of the healer, but also is shaped by these overarching themes. Individuals draw from an array of influences and combine a range of factors to use other healing options. They name and rename activities and health practices as complementary/alternative healing based on their perceptions and the way they approach such health practices/healing options. Once

named people's perceived evaluation of complementary/alternative healing varies based on their individual expectations from specific healing options and the constraints they face in the use of these. However, the process of naming itself is also influenced by experience with specific healing options/health practices. Individuals also face external constraints in the use of complementary/alternative healing. However, their approach of these constraints differs and is often influenced by their situation in life. In naming healing options that require the help of another individual as complementary/alternative healing, people also place substantial importance on such persons that provide the healing. These themes are all inter-connected and mutually influence each other and the overall meaning and experience of complementary/alternative healing.

This theory might not be generalizable, but it contributes to our understanding of complementary/alternative healing. Henceforth, I consider the primary findings in more detail connecting it back to my preferred theoretical framework and the extant literature.

Participants in the current project named a variety of health practices and healing techniques as complementary/alternative healing. As some participants provided their own definitions of complementary/alternative healing it became clear that, for users, there was nothing definite about the definition of complementary/alternative healing. While some participants had ambiguity in their minds regarding what could constitute complementary/alternative healing, others were more assertive and unambiguous about what they named as complementary/alternative healing. It was evident that different people attach the label complementary/alternative healing to varied health practices and healing techniques based on their perceptions and experiences with it. Even those individuals who name the same health practices and healing techniques as

complementary/alternative healing have different stories to tell about them. As Blumer (1969) noted, meanings are not an inherent aspect of the objects themselves, but develop from the process of interaction between people. Here, I found that participants were the primary agents defining and naming healing options as complementary/alterative healing based on their understanding and interactions with people around them. For instance, while some people consider yoga as a form of complementary/alternative healing (like Kelly), other people are more uncertain and believe yoga falls somewhere between mainstream health practices and complementary/alternative healing (like Matt). The process of naming of complementary/alternative healing is also plausibly affected by societal changes in a particular context. For instance, Matt's view of a continuum is interesting to note in light of the change in name of the National Center for Complementary and Alternative Medicine to National Center for Complementary and Integrative Health (from December 17, 2014). The center, which is one of the centers of the National Institute of Health, defines Integrative Medicine or Health care as bringing conventional and complementary approaches together in an organized way. The change in the name of the institute possibly indicates a move towards greater integration of non-mainstream approaches to health care with mainstream medicine.

Naming includes a process of circumscribing ones relationship to the object or phenomenon named, and typically elicits an opinion or judgment regarding the phenomenon (Charmaz and Belgrave 2013). On the other hand, renaming concerns a modification of one's relationship to a particular phenomenon (Charmaz and Belgrave 2013). One interesting finding from this project was that positive health behaviors like eating well and doing regular exercise were named as complementary/alternative healing

by many participants. Therefore, these positive health behaviors underwent a process of renaming, whereby the way these were approached and evaluated by individuals changed. Earlier researchers have theorized and examined the connection between positive health behaviors and the use of complementary/alternative healing (Goldstein 2000; Nahin et al. 2007). However, naming of food and exercise as forms of complementary/alternative healing is underexplored. Also, I found that some participants rename regular activities that give them comfort as complementary/alternative healing. In this context, the role of regular activities and pastimes as being therapeutic and falling under the purview of complementary/alternative healing should be examined in more detail by latter researchers.

Another important finding from this project was that the process of meaning-making involving choice of complementary/alternative healing is multidimensional. People make sense of and react to their physical health condition in complex ways. In opting for treatment that includes complementary/alternative healing, individual's social, economic and biographical contexts combine a broad range of factors. Usually, there is no single reason for the use of complementary/alternative healing. A variety of factors contribute to the use of different complementary/alternative healing. In my study, though participants might have sought help only when a need (like a chronic or acute illness) arose, a combination of different influences generally affected their choice of using other healing options. I found that influence of family and friends, influence of well known personalities, the influence of location and context, and the role of institutions such as support groups were often important determinants of use of complementary/alternative healing. These often vital factors remain relatively unexplored by prior researchers.

Sociologists can contribute to research in this area by assessing the impact of family socialization, the role of social interactions, and impact of mass and social media on use of complementary/alternative healing.

In addition, I found that desperation to get relief from pain and aversion to allopathic medicine often acted as important determinants in the use of complementary/alternative healing. The factors of aversion to allopathic medicine and chronic need have been investigated more extensively by prior researchers as explanations for use of complementary/alternative healing (Furnham and Bhagrath 1993; Sirois and Gick 2002). However, like Furnham and Bhagrath (1993) I found that though most participants highlighted one or another adverse experience with allopathic medicine, not all participants had stopped use of allopathic medicine altogether. Interestingly, I also learned that some participants were led to complementary/alternative healing simply by curiosity and chance and a few of them often relied on a process of trial and error to discover the most suitable complementary/alternative healing for their health. Since many of my participants were elderly and some of them had been using complementary/alternative healing for a while, often their discovery of complementary/alternative healing had been purely incidental. Again, as information on the efficacy of complementary/alternative healing is limited, participants often relied on informal discussions with friends and acquaintances and testimonials to decide what might work for them or sometimes they just went ahead and tried a particular healing technique to check its feasibility. Another factor, the ease of accessing complementary/alternative healing also appeared to attract some participants for sustained use of some complementary/alternative healing. This was in juxtaposition to the

barrier of cost (see below). Hence, choice of using complementary/alternative healing among chronically ill patients is a complex issue. Many of these aspects of discovering and using complementary/alternative healing are not wholly tapped into by prior scholars. Future researchers need to consider the complexity and multiplicity of factors that affect individual choice of using complementary/alternative healing.

People's perceived experience with complementary/alternative healing and their perceived evaluation of different healing options is also multifaceted. The overall experience and evaluation with complementary/alternative healing is influenced by the processes of naming particular healing options as complementary/alternative healing and drawing upon social and environmental factors to opt for these. In addition, people use expectations and perceptions to evaluate different forms of healing. However, expectations and perceptions are also products of interaction and can change over time, affecting overall evaluation and experience with particular complementary/alternative healing. I found that perceived experience and evaluation of complementary/alternative healing varied greatly based on type of healing technique. Downer and colleagues (1994) had also found that satisfaction with complementary/alternative healing differs with particular healing techniques. In this project, I divided participant's perceived experience and evaluation of complementary/alternative healing into three broad categories of feeling better, feeling worse and experiencing no change. However, these broad categories do not do justice to the complexity of participant's experiences. Though almost all participants alluded to some experience of feeling better from one or more complementary/alternative healing, on probing deeper I learned that individual experiences was much more complex. A participant might have felt better with one



complementary/alternative healing, felt worse using another healing option, and experienced no change using a third healing technique (e.g. Ruth).

Moreover, a participant's perceived experience and evaluation of a particular complementary/alternative healing might have changed over the years or the participant might expect and anticipate long term benefits from some complementary/alternative healing and does not use the same measures of assessment as he/she does with other complementary/alternative healing (e.g. Mahdi). Hence, a single participants' experience was typically varied depending on the type of health practice or healing technique he or she engaged in. A significant finding from my project is that, while one participant might have felt better with a particular complementary/alternative healing (like acupuncture), another participant might have felt worse with that specific complementary/alternative healing while a third participant might have experienced no change or felt that his/her expectations regarding that particular complementary/alternative healing was not met. Hence it is difficult to generalize the findings. However, typically only a few participants narrated some experience/experiences of feeling worse with particular healing practices and other participants asserted that they had not necessarily felt bad or worse but felt their expectations were not met with regard to specific complementary/alternative healing. Quite a few participants maintained that they were able to sustain an active lifestyle or improve their general well-being or quality of life due to the use of particular complementary/alternative healing (like yoga). Correa-Velez and colleagues (2005) also found in their study that cancer patients generally believed that complementary/alternative healing improved general well-being and increased chances of survival. Also, the treatment process in some complementary/alternative healing was

highlighted by some participants to provide comfort and relaxation. I argue that experience with all complementary/alternative healing cannot be assessed by the same parameters. Especially for instruction-based healing and healer-assisted healing, the role of the healer is paramount and experience and evaluation for these types of healing is affected by the patient's connection and interaction with the healer. Therefore, latter researchers need to make a distinction between types of complementary/alternative healing and how it might affect individual experience and evaluation.

Another major finding from my project is that participants who make a choice for complementary/alternative healing often have to deal with certain constraints. Symbolic Interactionism as a theoretical perspective acknowledges the presence of external constraints from societal structures and institutions (Charmaz and Belgrave 2013). How people counter these constraints varies, as some people might confront, dodge or altogether overlook these barriers (Charmaz and Belgrave 2013). The primary hindrance cited by many participants to use of complementary/alternative healing is the expense individuals have to bear out of pocket. Not all complementary/alternative healing is expensive but since insurance coverage is absent for most healing option outside allopathic medicine, the entire burden of cost falls on the patient. Participants argued that only a few complementary/alternative healing like chiropractic and in some cases acupuncture are covered by insurance companies. Many of my participants alluded to facing financial difficulties in using complementary/alternative healing. It can be argued that benefits from complementary /alternative healing are not verifiable and could even be harmful if not practiced appropriately. However, the same is true for some allopathic treatments. I argue that lack of insurance coverage limits health care choices for people in

general. Many forms of complementary /alternative healing are largely inaccessible to the economically disadvantaged section of the population. Some complementary/alternative healing might be beneficial and people should have the opportunity to make a choice for what they feel is appropriate for their health. If insurance companies do not expand policies to include plans for more complementary/alternative healing, access to other healing options will remain confined to only those people who are able to afford them. It can be argued that a lot of poor people do not have insurance coverage and for them some complementary/alternative healing might provide a relatively inexpensive and accessible option of health care. Due to limitations of my sample, I was unable to explore this area but it could be a viable area of research for future scholars.

In addition to expense as an obstacle, some participants pointed out being discouraged by allopathic doctors to use complementary/alternative healing. A few participants mentioned having to find allopathic practitioners who would be more open to their use of other health practices or healing techniques as they desired to make active decisions about their health. However, interestingly some participants also mentioned being encouraged by their allopathic practitioners to use some complementary/alternative healing. It would be interesting to examine the current perceptions of allopathic doctors regarding complementary/alternative healing and understand why some allopathic practitioners might discourage complementary/alternative healing, while others might be more open to it.

Another problem that was highlighted by some participants is the inability to evaluate whether complementary/alternative healing is actually beneficial. Most often participants have to rely on anecdotal evidence to assess the benefits from

complementary/alternative healing. Few participants noted the lack of research on complementary/alternative healing and how they sometimes faced considerable difficulty in assessing the benefits of complementary/alternative healing. In this context it is important to conduct more research to assess the efficacy of particular complementary/alternative healing and make it more widely available to the public. There are some clinical trials by prior researchers assessing the effectiveness of some complementary/alternative healing like Homeopathy or Ayurveda (Riley et al. 2000; Furst et al. 2011). However, findings of these clinical trials are not widely disseminated to the public. Some participants highlighted that they were aware that most complementary/alternative lacked the resources to compete with allopathic medicine and invest in research in the same way as allopathic medicine. With the establishment of the National Center for Complementary and Alternative Medicine, there has been an augmentation in research on complementary/alternative healing. Also, centers or departments of complementary and alternative medicine or integrative medicine have been set up in major universities across the country. It can be said that in the future, with the further growth of these departments and centers of research and education there will be more widespread understanding on the efficacy of different types of complementary/alternative healing. However, it is important to evaluate the criteria used for such research and training. For instance, in the introduction to my project, I cited reasons for having used the term “healing” over “medicine”. A fundamental difference between the two terms is that, healing in contrast to medicine subsumes the notion that individuals want to be treated as whole persons without the separation of the body and the person’s identity (Cassell 2012). Hence, if complementary/alternative healing is

judged by allopathic models of medicine, many of the benefits cited here and elsewhere will be missed.

In symbolic interactionism, Blumer (1969) noted that we act towards things on the basis of their meaning, but meanings can be modified or changed through interaction. The final theme of my project is on the role of the healer in complementary/alternative healing. An important finding here was that the healer plays a significant role for complementary/alternative healing that is healer assisted or instruction based. I found that overall meaning and experience with particular complementary/alternative healing could be affected and changed in interaction with healers. On probing deeper into this theme I found that healers were usually evaluated by participants based on three important criteria. These were the healer's disposition, technique, and demographic characteristics. Often whether a participant continued with a particular complementary/alternative healing was dependent on the connection he/she established with the healer along with expectations the person had from the healer.

In general, most participants argued that complementary/alternative healers, in contrast to allopathic physicians, were usually more attentive, treated patients more as human beings and usually gave voice to the patients. However, some participants also clarified that some complementary/alternative healers were quite egoistic, similar to their perception of some allopathic doctors. I also found that in some cases participant's experience with a particular healer affected his/her overall experience with that specific complementary/alternative healing technique. Some earlier researchers have examined whether the therapeutic relationship between the healer and the patient in complementary/alternative healing contributes to its utilization (e.g. Brinkhaus and

colleagues 1998 and Kelner 2000). Kelner (2000) found that patients using complementary/alternative healing expressed their ability to be treated in a more informal setting, while Brinkhaus and colleagues (1998) found that patients using complementary/alternative healing in general attached more meaning to the therapeutic relationship. I argue that the relationship between the healer and the patient in complementary/alternative healing contributes manifold to the overall meaning and experience people attach to other healing options. Furthermore, since some complementary/alternative healing includes direct contact between the healer and the patient, the therapeutic relationship is possibly more important. Hence, any discussion of healer-assisted or instruction-based complementary/alternative healing is incomplete without an understanding of the role of the healer.

Finally, though I attempted to understand if there was variation in meaning and experience of complementary/alternative healing by cultural groups, I was unable to find any general pattern. My sample was comprised of 9 participants (out of 21) belonging to immigrants of varied nationalities. However, there was no unique element that distinguished meaning and experience of these participants from those who identified as white American. For instance, I speculated that a person of Indian origin would have some knowledge of complementary/alternative healing from his/her family or childhood and would be more likely to use only ethnic specific complementary/alternative healing like Ayurveda or Yoga. However, neither of the two Indian participants in my project had been introduced to complementary/alternative healing early on in life. Their decisional pathways to complementary/alternative healing did not differ considerably from that of others. Furthermore, they were using a range of complementary/alternative healing and

were not confined to use of only yoga or Ayurveda. It is possible that since most of the participants born elsewhere in my project had been living in the United States for a substantial period of time, their meaning and experience of using complementary/alternative healing did not differ substantially. However, my sample was limited and did not include enough participants to make important conclusions about the differences in meaning and experience of use of complementary/alternative healing by ethnicity.

### **Thoughts for Future Research in Sociology**

In conclusion, it can be said that it would be erroneous to treat all complementary/alternative healing and users of complementary/alternative healing as a homogenous entity. The variety of healing practices that are named complementary/alternative healing is quite broad. The definition of complementary/alternative healing is complex and encompasses multiple meanings attributed to it by people who use other health practices and healing techniques. Sociologists might contribute to determining the definition of complementary/alternative healing, by incorporating the meanings that participants attribute to different healing options and their experiences with each of these.

There are a lot of explanations for use of complementary/alternative healing, but sociologists can increase our understanding of meaning and experience of use of complementary/alternative healing by analyzing influences that affect people's choices in other healing options. For instance, the role of family socialization, role of social interactions and the influence of the mass and social media are some areas that sociologists can positively contribute to developing. Numerous factors like barriers to use

of complementary/alternative healing, role of healers, individual perceptions and expectations all affect evaluation of complementary/alternative healing. Sociologists can analyze the complexity in perceived experience and evaluation of complementary/alternative healing in greater detail and systematically contribute to this area of research by providing the perspectives of participants.

Certain interesting forms of healing, like mainstream prayer, religious healing practiced by child preachers of Brazil, the practice of Haitian vodou, Santeria and others, were not named or did not come up in the course of my project. However, people who consider these forms of healing could provide fascinating narratives, expanding our understanding of the meaning and experience with these healing options. Sociologists can seek to learn more about these disparate forms of healing and analytically compare how meaning of complementary/alternative healing varies based on type of healing option.



## Appendix 1

### Interview Guide

Date

Pseudonym

Introduction

Informed consent form

Request permission to switch on audio-recording equipment

Start

Initial Open-ended Questions

Tell me about how you came to use complementary/alternative healing?

1. When did you first use this form of healing?
2. What type do you use?
3. What was it like? What did you think of it then?
4. How did you happen to know about this complementary/alternative healing?  
Who, if anyone influenced you to try this form of healing? Tell me how s/he or they influenced you?
5. Could you describe the events that led to you trying this form of complementary/alternative healing?
6. What contributed to your using this form of healing?

7. What was going on in your life then? How would you describe how you viewed this form of healing before .(your illness) happened? How, if at all, has your view of complementary/alternative healing changed?
8. How would you describe the person you were then?

#### Intermediate Questions

1. What, if anything, did you know about complementary/alternative healing?
2. Tell me about your thoughts and feelings when you learned about this form of healing?
3. What happened next?
4. Who, if anyone, was involved? When was that? How were they involved?
5. Tell me how you learned to handle your illness?
6. How if at all, have your thoughts and feelings about complementary/alternative healing changed since the first time you used it?
7. What positive changes have occurred in your life (or not) since using this form of healing?
8. What negative changes, if any have occurred in your life (or not) since using this form of healing?
9. Could you describe a typical day for you when you are **not** using this form of healing? (probe for different times). Now tell me about a typical day when you are using this form of healing?
10. Tell me how you would describe your personal health now? What most contributed to this change?

11. As you look back on complementary/alternative healing, are there any other events that stand out in your mind? Could you describe (each one) it? How did this event affect what happened? How did you respond to this event and use of complementary/alternative healing?
12. Where do you see yourself in two years? Describe the person you hope to be then. How would you compare the person you hope to be and the person you see yourself as now?
13. What problems do you encounter in using this form of healing? Tell me the sources of these problems?
14. Who has been the most helpful to you during your use of this form of healing? How has he/she been helpful?
15. Has any organization been helpful? What did this organization help you with? How has it been helpful?

#### Ending Questions

1. What do you think are the most important things that you would like to share about complementary/alternative healing? How did you discover these? How has your experience before affected how you handled this form of healing?
2. Tell me about how your views about complementary/alternative healing and/or actions regarding complementary/alternative healing changed since you have started using these forms of healing.
3. How have you grown/ changed as a person since you started using complementary/alternative healing? Tell me about your strengths that you discovered or developed through your use of complementary/alternative healing

(if appropriate)? What do you most value about yourself now? What do others value in you?

4. After having these experiences, what advice would you give to someone who has just discovered complementary/alternative healing?
5. Is there anything that you might not have thought about before that occurred to you during this interview?
6. Is there anything else you think I should know to understand complementary/alternative healing better?
7. Is there anything you would like to ask me?

#### Demographic Information

1. Gender \_\_\_\_\_
2. Race/Ethnicity \_\_\_\_\_
3. Age \_\_\_\_\_
4. Highest Educational Level \_\_\_\_\_
5. Years Living in the United States \_\_\_\_\_
6. Average household income per month in US\$ \_\_\_\_\_

## Appendix 2

### Informed Consent Form

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Dear Participant,

You are invited to participate in a research study that will attempt to understand the meaning of complementary/ alternative healing for people who use these for chronic illnesses. You can decide not to participate. The following information is provided in order to help you make an informed decision on whether or not you would like to participate. If you have any questions please do not hesitate to ask. You are eligible to participate in this study because you have reported suffering from some chronic illness (like diabetes/ hypertension/ arthritis/ cancer etc) and using some form of complementary/alternative healing.

**Project** \_\_\_\_\_

**Purpose of the project-** In this project I will investigate the meaning of using complementary/ alternative healing for individuals suffering from some chronic illness in the US and then examine how meaning of complementary and alternative healing use differs for people across various cultural groups.

**Procedures-** I will ask you to participate in an interview which will take approximately 1-2 hours of your time. The interview will be audio-recorded and will take place at a location convenient to you. During this interview you will be asked a series of questions. These questions are designed to allow you to share your experiences of using complementary/alternative healing. I might call you back to clarify some things or ask additional questions.

**Risks/and or Discomforts-** There are no known risks associated with this research. However, all of your information will be identified only by a pseudonym (pretend name) to protect your confidentiality, in case of unanticipated situations like lost or stolen laptop or USB. Furthermore, during the interview you may decline to answer any questions you prefer not to answer.

**Benefits-** There are no direct benefits to participants. However, the information gained from this study may help us to better understand the meaning of complementary/ alternative healing use and how this meaning is different across cultures. The interviews will be audio- recorded only for the purpose of transcribing the interviews. You will not be asked to provide your name at anytime during the interview. The information received during this interview may be published in academic journals or presented at academic conferences, but only your pseudonym will be used. The tapes will be destroyed after the interviews have been transcribed and checked for accuracy.

**Confidentiality** – You will be asked to provide a pseudonym at the beginning of the interview. This will be used for to label all your information, to ensure that your information won't be identified.

**Compensation-** You will not receive any compensation for participating in this study.

**Opportunity to ask questions-** You may ask any questions that you might have before agreeing to participate or during the study.

**Freedom to Withdraw-** You are free to decide not to enroll in this study or to withdraw at any time without adversely affecting your relationship with the investigator. You can decline to answer any questions asked

**Consent-**If you wish to participate in this study, you will be interviewed.

You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

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Signature of Participant

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Date

I hereby give consent to audio- record my interview

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