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The Experience of American and Canadian Cancer Patients in Deciding to Seek Alternative Care in Mexican Cancer Clinics

Alicia Bright

Dominican University of California

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Running head: DECIDING TO SEEK TREATMENT IN MEXICO

The Experience of American and Canadian Cancer Patients in Deciding to Seek

Alternative Care in Mexican Cancer Clinics

Alicia Bright, MSN (c), RN

Submitted in Partial Fulfillment

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This thesis, written under the direction of the candidate's thesis advisor and approved by the Chair of the Master's program, has been presented to and accepted by the Faculty of the School of Nursing, Dominican University of California, in partial fulfillment of the requirements for the degree of Masters of Science, Nursing. The content and research methodologies presented in this work represent the work of the candidate alone.

Alicia L. Bright, Candidate

Date

Margaret Fink, Ed.D, RN, BC Thesis advisor

Date

Barbara Ganley, PhD., RN, Thesis Advisor

Date

Luanne Linnard-Palmer, Ed.D, RN Chair of the Nursing Department

Date

Dedication and Acknowledgments

This thesis is dedicated to the Life Source that inspires people to connect with one another to grow, and to heal.

Thanks to my mother, who's passivity in the face of her disease process contrasted so sharply with my fathers battle.

Special thanks to my father who's dedication to research and truth led him to explore all his options for cancer therapy and ultimately to seek care in Mexico.

Special thanks also to his sister and her husband, the Alturki's, who's constant love and generous support encouraged me to seek excellence in nursing care both in the process of providing care for my parents, then in acquiring a graduate degree.

Thanks as well, to my son, Akita, for whom I have always tried to set a good example and who now returns the favor in spades. He has always been my inspiration.

Great thanks to Dr.Ganley for demystifying the research process for me and for constantly encouraging me. Also to Marilee Ford, Melanie Elliot- Eller and D'vorah Rose for the way in which they nourished my spirit.

And finally my classmates, that amazing circle of women who continually amaze me with their wisdom, their dedication to nursing and to patient care, and their loyalty to the sisterhood that we formed in the course of our studies. Our circle continues to nurture me in a most profound way.

May I become a clear transmitter of divine healing truth.

Abstract

Background. Each year, despite warnings from the American Cancer Association, many US and Canadian citizens travel to Tijuana, Mexico, for cancer care. The main criticism of these clinics is that they provide treatments that are unproven, potentially unsafe, and expensive. Despite this, about 35 clinics exist in Tijuana that provide alternative care to patients who pay cash for these services.

Objectives. To understand the lived experience of people who have made the choice to receive cancer treatment at alternative cancer clinics in Tijuana, and gain insight into the process by which that decision occurs.

Population. 5 participants were interviewed. Three adult US citizens, one Canadian, and both parents of a US pediatric patient.

Method. A phenomenological approach was used. Participants were interviewed at clinics while undergoing treatment. The researcher conducted a review of the clinics and treatments offered, along with history of the political, social, and economic climate in which the phenomena exists.

Conclusions. Themes identified in the decision-making process are rational, social and emotional. People choose caregivers based on trusting relationships and reasons that seem rational to them. Decisions are often values based, such as quality of life.

Keywords. Alternative medicine, patient decision-making, Tijuana cancer clinics, lay referral network.

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The Experience of American and Canadian Cancer Patients in Deciding to Seek
Alternative Care In Mexican Cancer Clinics

Chapter One

Introduction

If you were diagnosed with cancer, what would you do to seek health? What if you believed that there was a better treatment available for you than your doctor could provide? Would you be content with the opinion of one doctor? Or seek another opinion? What if the opinions you heard about what you should do to treat it were radically different? How would you decide what to do?

In 2005, it was estimated that 1,372,910 people were diagnosed with cancer. Approximately 10.1 million Americans were alive with a history of invasive cancer in 2002, and about 570,280 people died of it in 2005 (US Cancer Statistics Working Group, 2005).

Individuals faced with this challenge respond in many ways, and have an increasing number of options as to how to respond. As international and cross cultural communication expands, options for health seekers are becoming more numerous. Use of the Internet gives people access to more and more information about cancer and different treatments.

Often, explanations for the causes of disease are contradictory because there are different ways of understanding the experience of health and the process of disease. It must be remembered that health perceptions and health care exist within

cultural context. Culture gives us a framework for understanding the nature of, the significance, and the appropriate response to illness (Helman, 2000).

Medicine in the United States is governed by the American Medical Association and Regulated by the Food and Drug Administration (FDA). This way of understanding and treating illness will be referred to as “conventional medicine”. The Canadian system also uses this approach. Conventional medicine, however, does not generally incorporate principals of nutrition or work with the dynamic between mind and body. In addition, there are some very different frameworks available now for understanding the way the body functions, such as orthomolecular approaches and Traditional Chinese and Aurvedic medicine. Two factors are apparent in the current increase of options available to patients. The first is the increasing cultural diversity in the US. This presents people with access to and acceptance of different traditions. The second is the availability and increased use of the Internet. As people have access to and become accustomed to a diversity of perspectives, they begin to access those as valid alternatives.

Significance of the Problem

Most health decisions are made privately by individuals. A family member or friend may serve as the first source of health advice. Finally, a health care professional may be consulted, if the individual, with his support system, is unable to resolve a health issue to his satisfaction.

For professionals, even within conventional medicine there are variations in diagnosis, and decisions to be made about treatment. Some of these decisions are based on physiology and the statistics associated with use of certain treatments, but

others are values based decisions, and incorporate issues such as quality of life issues, personal priorities, and economic factors. Several researchers have stated that many patients and family members feel overwhelmed by or even excluded from the decision-making process. The general assumption is that this alienation stems from a paternalistic attitude on the part of the physician, coupled with a lack of adequate time for discussion. This topic, however, is not well explored (Caspi, Koithan, & Criddle, 2004; Thorne, Paterson, Russel, & Schultz, 2001; Ritvo, Irvine, Katz, Matthew, Sacamano, & Shaw, 1999).

The ethical principle of informed consent requires that people understand, to the best of their ability, what the potential results of treatment will be, and that their preferences are respected. Cancer is a threat to ones health and to ones sense of self, and treatment presents challenges that impact the individual on many levels, and involves the family and community of that person. There are no guarantees that any given treatment will work for a particular patient, or that the patient will not have health problems that arise from the treatment.

From a legal perspective, informed consent is required for the practitioner to provide medical treatment. Any system that truly values the autonomy of an individual must honor the right of the individual to participate in decisions about their care. This process is rendered meaningless if the individual's right to refuse a given treatment and pursue other options is not respected and supported.

From an outcomes perspective, cancer care is complex and long term. The fact that each person's situation is unique mandates involvement of the patient and significant others whose lives are most deeply impacted by the decisions made. It is

very important to explore how treatment may impact the individual, not only physically, but psychologically, socially, and spiritually. Given the complexity of the situation, there is a risk that patients will choose things that are detrimental to themselves, not out of a value-based decision, but out of desperation, fear, or denial. A caring, supportive, educated counselor can moderate all these factors. Counseling clients, families and significant friends towards making the best health care choices possible under the circumstances can be viewed as a supportive intervention (Ritvo et al., 1999).

Nursing involvement in relation to client decision- making includes the roles of educator, clinical specialist, advocate and counselor. As patient advocates, the responsibility of the nurse is to support optimal health choice on the part of individuals. At the very least, patients by law must give consent in order for medical care to be administered. Nurses are usually involved in the process of obtaining informed consent.

When it comes to cancer care, however, things are rarely, if ever, as simple as a quick “informed consent”. Treatment is usually protracted and involves many aspects of life. Because of this, it is not sufficient to be familiar with treatment options; caregivers must be familiar with the issues that lead people in one direction or the other. What is most important in this decision-making process? Are there commonalities or themes to be identified that would help the nurse to better counsel people in this situation? What, cognitive, emotional, social or spiritual factors are involved? What leads some patients toward alternative medicine and away from conventional treatment and government regulations? What role does trust, or the lack

of it, play in the choice or rejection of treatment? How do caregivers build or betray trust? Who or what else is important to this process?

Cancer and Alternative Medicine

Cancer treatment in the United States is regulated by the FDA for patient (consumer) safety. The California Health and Safety Code provides for an advisory board that makes recommendations on what is considered “conventional” and what is “questionable” cancer care (State of California, 2005). Use of Complimentary and Alternative therapies for relief of the side effects of these approved treatments, however, has gained widespread acceptance. Caspi et al. (2004) differentiates between using complementary therapy in addition to conventional therapy, as opposed to alternative therapy, which is used instead of conventional therapy. Various studies have stated that anywhere between 9% and 86% of cancer patients utilize complementary or alternative therapies in their care (Boone, Brown, Gavin & Westlake, 2003). The variation obtained in those studies indicates that there is a need for more research and in particular better communication between patients and providers.

Another important point is that health care delivery exists within a cultural context. Conventional medicine has a reputation of being based on science, however, other factors figure in as well. The complexity of health care finance industry is one prominent factor. Value preferences, such as quality of life and spiritual issues, are other examples.

Inroads that Complementary and Alternative Medicine (CAM) therapies have made into mainstream medicine have been fueled in large part by the willingness of

cancer patients to participate in and to fund these therapies. While most of those people have chosen to compliment conventional therapy with alternative practices, each year, many people choose to disregard FDA regulations and leave the country to pursue therapies restricted by law or convention in the United States. In fact, there is enough of a demand for this that as many as 34 clinics in Mexican border cities such as Tijuana and Santa Rita, are currently supported by this privately funded demand (The Cancer Cure Foundation, 2005).

The purpose of this study is to gain insight into the process by which patients explore their options and choose to leave the country for treatment. This insight would help nurses to better counsel patients considering these options. In addition, finding out why people are attracted to the services available in Mexico may reveal how to better meet patient's needs in the US.

Chapter Two

Theoretical Framework

This study was primarily guided by the Health Belief Model. The Health Belief Model is a public health model that describes health behavior. Briefly put, the model states that a person's likelihood of choosing an action in support of his or her health depends on his or her perception of four factors. The first is the perception of susceptibility to a condition. The second is the perceived seriousness of that condition. Third, a person will only take action if it is perceived that there will be benefits received. Finally, the person must balance the perceived barriers to performing that action with the benefits. If the barriers, such as cost, availability, or

social stigma, are considered to be too great, the person will not take action (Becker, 1974).

The “lay referral network” is another concept that is discussed within the context of the Health Belief Model. It describes how family members, friends and community members offer informal advice and support for people making health related decisions. This was discovered to be a strong factor in the decision-making process of the participants in the Mexican clinics visited by the researcher.

Although the basic premise of that theoretical framework is relevant for people choosing alternative care, the research that has been done with that model shows that it is unreliable in the case of chronic disease and particularly cancer care. It is theorized that cancer causes a high level of fear, or perceived threat, and that the effectiveness of available treatment is perceived as low (Kasl, 1974). Therefore, the usefulness of this model decreases with disease severity.

The question of how patients make decisions about seeking care for an illness is not widely studied in the current literature. Most studies about decision-making within the health care literature focus on clinical decision-making on the part of practitioners. Although the majority of day-to-day health care decisions are made by patients, most of the literature on decision-making within the health care professions is focused on clinicians (Broadstock 2000).

Ritvo et al. (1999) developed a Risk Adaptation Model to understand the patient's motivation in using CAM. The intention of the study was to provide a model for practitioners who assist patients through these decision-making processes. The model categorizes cognitive processes into six categories: modifiability,

consequentiality, response efficacy, self efficacy, attention regulation, and expectancies.

This model of decision-making was presented along with a discussion of the appropriate role of the clinician when assisting someone who is making health care decisions, particularly when those decisions involve unconventional therapies. There is a good discussion of the ethics involved when interacting with a patient in this process.

The authors state their ethical stance that clinicians must “assist rather than direct” the patients process of therapy seeking and identifies six cognitive processes thought to play a central role in choosing therapies. They noted the evidence in favor of the beneficial effects of optimism on health, and asserted that health care providers have a duty to support optimism in their patients. They also cited the placebo effect and note that “virtually any therapy can contribute to 'self -healing', especially if the patient has strong beliefs about its healing properties” (p.162). They acknowledged the primacy of the autonomy of the patient, and the duty of the care provider to respect the patient's process.

Another duty that the care provider has is to monitor the patient for dysfunctional attention. When the patient is perceived by the practitioner to be having difficulty attending to decision-making, it falls to the practitioner to offer more in-depth counseling about the options and their appropriateness. The desired outcome of the intervention by the practitioner is that patients show “realistic optimism” and choose therapies that have a certain amount of evidence (Ritvo et al., 1999). This approach makes a clear justification for the importance of the decision-

making process, and the significance of the positive impact a clinician who is comfortable with this process can have.

This model was most useful as a guide for a clinician interacting with a patient who is making decisions about his or her treatment options. The limits of the usefulness of this theoretical model within the context of this study, is that it emphasizes a logical, cognitive, analytical process. That part of the process was found by the researcher to account for only part of the decision-making process. The “naturalistic” model was found to describe the decision-making process more satisfactorily, and included images and social context, as well as rational thought processes.

The field of psychology offers more literature that focuses on the decision-making process itself, and a new model is emerging at this time. The classic model of decision-making is the rational, analytical model where options are examined and weighed and choice is based on logic. This model has been called into question, however, as artificial and somewhat less than applicable in real life situations. Another criticism is that it does not allow for more complex problem solving approaches, such as searching for or creating other options that are not immediately evident. Also, it has been suggested that an emphasis on rational thinking on the part of a clinician assisting a patient with a decision-making process may in fact decrease the patients confidence in their intuition. This may actually weaken their ability to make a good decision, since intuition is an intrinsic part of the way we make decisions on a day-to-day basis. A naturalistic model is currently being developed and

includes factors such as *automatic intuitive processing* and *heuristic short cuts* (Broadstock, 2000).

Chapter Three

Review of Relevant Literature

In order to understand the context in which the decision to go to Mexico for treatment is made, two areas of literature are examined. The first part of this review covers what is known about the decision to use CAM, and the second is a brief introduction to the clinics in Mexico and the treatments they offer. Some of the issues that surface around regulation of health care will also be addressed, since they are part of the reason people must cross an international border to receive certain treatments.

Choosing Complementary and Alternative Medicine

Use of CAM within the United States is growing. In 2004 The Centers for Disease Control issued a report that found 62% of Americans had used some form of Complementary and Alternative Medicine (CAM) within the last twelve months, if prayer were included in the definition of CAM (Barnes, Powell-Griner, McFann, and Nahin 2004). Research among health practitioners has begun to include questions about who would choose to pursue CAM, and why. Interestingly, although the Barnes, et al. report gathered extensive data about CAM use for fifteen different health problem categories, cancer was not one of the categories examined.

Several studies have focused on the characteristics of individuals who choose to use CAM and the thought processes involved in these decisions. Shumay, Maskarinec, Gotay, Heiby, & Kakai, (2002) found that use of CAM was associated

with higher level of education, being Caucasian, female, younger than non-CAM users, and having breast cancer. An increased problem with nausea and vomiting associated with cancer treatment also influenced patients to try CAM. Another positive correlation was found between the patient's perceived severity of disease and patient dissatisfaction with the physician (Shumay et al., 2002).

A study of 29 men diagnosed with prostate cancer categorized motivating factors in seeking alternative or complementary care into *pushes* and *pulls*. *Pulls* are factors that attracted people to alternative methods, including congruence of the practitioners' explanations of the disease process with their own belief systems. *Pushes* are factors that lead to dissatisfaction with conventional medicine, such as adverse reactions to treatment or unsatisfactory relationships with physicians. The authors found that the men were likely to have been influenced in their decision to seek CAM by dissatisfaction with conventional medicine. Further, a common theme of *fear and feelings of loss of control* were identified in analysis of the men's experience. CAM approaches were seen as a harmless way to regain a sense of control over ones health (Boone et al., 2003).

Thorne et al. (2001) conducted a qualitative secondary analysis of a large data set. They reviewed interviews, think aloud tapes, and focus groups. They conducted within and between comparisons and identified several themes among a group of people with the chronic disease states of diabetes, multiple sclerosis, and HIV/AIDS. All 21 participants used conventional health care services, and all but three also made regular use of CAM approaches. The participants felt that CAM approaches contributed to a more balanced self care strategy than was possible with conventional

medicine alone. They participated in behaviors and therapies aimed at nutrition and immune support, detoxification, bodywork for pain relief and improved mobility, and spiritual practices. One theme centered on the notion that the *physical illness* was only one component of how the illness affected them. Use of CAM approaches allowed them to heal emotionally, mentally and spiritually, as well. These are areas not covered at all by conventional medicine. In general, the participants valued self determination and personal responsibility for their health care. They described a process of “body listening” which was an ongoing self monitoring of their own subjective experience of their own bodies. (Thorne et al., 2001)

One question that may occur to clinicians is why CAM seems to appeal to some people but not others. Caspi, Koithan, and Criddle (2004) studied 12 adult patients with chronic rheumatoid disorders, classified them into three general categories, and mapped the decision pathways they used. The first group used allopathic (conventional) medicine. The second group used only alternative methods, and the third combined allopathic and alternative, which the researchers classified as “complementary”. The allopathic group tended to trust their physicians to make the best decisions for them. They tended to be more passive in terms of information gathering.

The alternative group, on the other hand, expressed skepticism about the expertise of allopathic physicians. They felt that physicians could not know everything, and that they, themselves were the authority on what was best for them. They voiced a need to *feel* that the decision was right for them, and depended more

on intuitive self evaluation, as well as recommendations from individuals for whom they felt trust.

The complementary group tended to approach information with a combination of optimism and skepticism. When offered a new approach, they would research it using library and Internet sources as well as advice from well informed others, which may or may not include a physician. They tended to make decisions based on the amount of evidence available.

The authors of the study note that patients may vary in their desire to be involved in making decisions and conclude that healthcare providers must take this into account when counseling patients. They state that the information itself maybe less important than the way in which it is framed and that emotional impact may heavily influence the decision-making process. The decision-making process is described as the combination by an individual of desire for what one wants with belief about what one thinks is possible in order to choose a course of action (Caspi et al., 2004).

Summary of CAM Decision Literature

The primary motivation to use CAM stems from a desire to take responsibility for one's health. Trust issues are part of the process as well, in that patients may trust their physicians less than themselves to make the right choices for their health. People who use CAM are generally informed about the choices they make, and more proactive about their health care in general. The process of how people actually make decisions is not well understood. With the exception of Caspi,

et al., the research has focused on the cognitive aspects. However, we know that decisions are not solely based on cognitive processes.

Review of Literature on Cancer Clinics in Tijuana

Tijuana, Mexico, just over the border from San Diego, California, has 34 separate cancer treatment centers, according to the web site for “The Cancer Cure Foundation” (The Cancer Cure Foundation, 2005). Some of the clinics have offices in the United States, but the treatment takes place in Mexico. There are tours that are available to show what clinics are available and what sorts of treatments are offered.

The nature of the Tijuana Cancer Clinic phenomena is such that there is little scholarly writing criticizing the treatments offered there. The main criticism of the clinics, in fact, is the lack of research associated with the treatments. Therefore, the bulk of the criticism consists of warning potential patients away. On the other hand, supporters of the clinics site self-reported cases of success, and published research focuses on the treatments themselves, and gives histories of the development of the treatments, and practitioners who use them. Much of the information, supportive or critical, about the Tijuana Cancer Clinics is found on the Internet. As such, it is available to potential patients, as well as to clinicians. A google search on September 6, 2006, using the search term “Mexican Cancer Clinics”, brought up about 2,150,000 “hits”. Of the first 90 “hits”, 29 could be interpreted as supportive, 18 as critical, 22 as neutral reports, and there were also six advertisements for products or clinics, and 15 irrelevant topics.

The American Cancer Society has a web page that discusses the conventional view of treatments offered in the Tijuana clinics in lay terms. It states that the

treatments offered are unresearched, or have been researched and found to be ineffective. It also warns that some of the treatments can be dangerous and lists costs as exorbitant (American Cancer Society, 2006). These are the most common criticisms offered about the clinics, and of course offer great cause for concern. For the purposes of this study, it is more relevant to focus on the literature that supports the use of alternative treatments. People who choose the treatments do so for some reason. Therefore, to understand that decision, the focus is on why people would choose to receive alternative treatments, rather than why they would not.

In fact, more and more people are opting to receive complementary or alternative treatments. One study, published in 1992, reports that 9% of all cancer patients at that time had tried what they referred to as “questionable methods of cancer treatment”. These “questionable methods” included diet and nutritional supplements, drugs, massage, psychic and spiritual approaches and electrical stimulation. The authors stated that none of the treatments were effective and that some of them were dangerous. They emphasized the responsibility of health care practitioners, and third party payers to discourage the use of these therapies (Lerner and Kennedy, 1992). It is interesting to contrast the 9% statistic that Lerner and Kennedy obtained in 1992 with the Barnes study done in 2002 that found 62% of adults in the US had used some form of CAM (Barnes et al., 2004). It would appear that the use of CAM is increasing, despite the cautions of the medical community.

It is interesting to note that some of the more slanderous attacks on Mexican clinics have come from anonymous sources, and were somehow published, anyway. One article published in 1991 by “CA- A Cancer Journal for Clinicians” lists no

authors, but discusses several “metabolic” therapies offered in Tijuana, as well as in the US. The author completely condemns the treatments offered there. The lack of documentation about the efficacy of the treatments was the main argument against using these therapies, and the assessment tools used by practitioners were also criticized. The actor, Steve McQueen, who went to Tijuana for treatment and was not cured, is cited as an example of the treatments not working. It concludes by warning that travel to Tijuana for treatment can be dangerous and costly and states that the American Cancer Society “strongly urges individuals with cancer not to seek treatment” in Tijuana (Anonymous, 1991). One may assume that, since this was published anonymously, the author was not willing to stand by his opinions and accusations. The fact that a peer- reviewed journal would publish an article of this nature from an anonymous source raises questions about the politics or economic interests behind it.

Health care in the United States accounted for 1.7 trillion dollars in spending in 2003 (Appleby, 2004), and it is reasonable to ask what role politics and corporate interests play in the process of research and policy development. Many of the therapies offered in Mexico were developed in the US in the beginning of the 20th century (Hess, 2003). Others, such as laetril, were researched in the US as recently as the 1970's. Dr. Ralph Moss, PhD, describes being a writer at Memorial Sloan-Kettering Cancer Center and being fired for reporting positive results for laetril research during the 1970's (Moss, 2005). This is one example of stories that people have access to on the Internet. Stories like these may serve to undermine faith in the process by which conventional medicine makes decisions about what options to make

available for cancer treatment. It is possible that people who travel to Mexico for their care are “voting with their feet” in a statement of lack of confidence in the regulatory process of health care in the US.

There are other examples of stories easily accessed on the Internet and elsewhere that reinforce distrust of the conventional medical community. Essiac Tea is an herbal formula distributed by Rene Caisse, a Canadian Nurse. Her numerous case histories and her battle to maintain high standards of scientific inquiry are documented in the book “The Essiac Report” (Thomas, 1993). The author describes how, on several occasions, Sloan- Kettering Cancer Center offered to test her formula, but modified the formula or the research protocol in such a way as to ensure failure. Included in the book are copies of correspondence regarding the research, as well as case histories and letters from patients and families. Essiac Tea, now produced and distributed by several different companies as a nutritional or herbal supplement, is widely available as an option for cancer patients, while the story of its suppression circulates in the cancer community.

Hess (2003) describes a pattern of suppression of alternative cancer treatments. Several cases are described of physicians, nurses and researchers who were censored, harassed and ostracized for their work. He holds the American Medical Association responsible for the suppression of therapies, but does not report why the AMA would want to suppress these treatments. According to Hess, one historical problem with studying the techniques is that the practitioners are excluded from participating in the design of the studies. This has led to disagreements about the legitimacy of the studies conducted by the NCI .

Hess also describes how many of these treatments are associated with charismatic practitioners and their successfully cured patients who develop a network (Hess, 2003). What role personal relationships and social networks may play in the decisions of patients to seek alternative therapies is an important area for exploration. It is not known how many people go to Mexico each year for treatment. The fact that there are 34 clinics supported by this activity, however, would indicate that it is not a very small number. These are Americans who have chosen (and paid for) care that is specifically outside the confines of United States regulations, which are supposed to be there for their benefit.

A common complaint by researchers trying to do research on metabolic, herbal, or other nontoxic cancer treatments has been a lack of funding. The financial organization of health care research has been viewed as a strong impediment to research of any treatment that is not patentable with a high potential for profitability. In addition, the research processes that have led to great medical advances in the last 60 years may now be limiting progress in our understanding of health and illness and are in need of revision. Rather than clinging to what has worked in the past, the medical community is recognizing the importance of looking at patient outcomes, and the scientific community, particularly the human sciences, is developing new ways of observing, understanding, interpreting and documenting outcomes (Miller & Crabtree, 2005). The problem of lack of funding for research is slowly being addressed by the availability of research funding for Complementary and Alternative therapies through the National center for Complementary and Alternative Medicine. This organization has an annual budget of 122.7 million dollars as of 2006. However,

it does not list cancer as a special area of interest, and has funded very few studies on cancer treatment (NCCAM, 2006)

The Cancer Control Society is an organization of cancer patients, families, friends and interested professionals. It has evolved to support people who are searching for alternative cancer care. Their web site has on it a “green list” of doctors who practice alternative medicine for cancer, as well as a list of patients who feel they have been helped by these treatments and are willing to speak with others about the treatments they used. The Cancer Control Society also provides tours of the Tijuana Clinics and has a conference yearly in Los Angeles featuring speakers from the Tijuana clinics (Cancer Control Society, 2005).

Treatments available at these clinics include a wide variety of interventions. Some, such as the Gerson Diet therapy, have been formally studied, while others have not. Amygdalin, also known as laetrile, is used, often in conjunction with other therapies. In fact, most approaches listed at these clinics are used in combination. Common approaches are diet therapies, coffee enemas (used to detoxify, relieve pain and improve liver function), enzyme therapies, psychological approaches, herbal remedies, such as Essiac, Artemisia and Hoxsey formulas, various immune boosting approaches, and vaccines such as Coley's Toxin. Less common approaches are dendritic cell therapy, hyperthermia, various electronic therapies and magnetic bio-resonance, Rife machines, and insulin potentiation therapy (The Cancer Cure Foundation, 2005). Some of these, such as the Gonzales approach which combines diet therapy with enzymatic therapy, are currently being investigated in the US (Gonzales, 2005). Others, such as the Rife Machine, are outlawed by the FDA.

Ralph W. Moss, PhD, is an internationally known medical writer who has written eleven books and three film documentaries, mostly on the questions of cancer research and treatment. He was at one time, the Assistant Director of Public Affairs at Memorial Sloan-Kettering Cancer Center. Following the flurry of negative publicity about the Tijuana clinics that followed the death of Corretta Scot King, Moss published a report on the clinics there. (Moss, 2006)

Moss gives a very well informed historical account of the clinics, and reviews and evaluates the most common allegations against them. He cites numerous other reports, both supportive and deleterious, and gives his own observations as well. The main charges against the Tijuana clinics that pertain directly to patient care are as follows:

1. False diagnosis
2. Loss of crucial time
3. Lack of qualifications
5. Unsanitary condition
6. Extortionate prices
7. Fraudulent therapies.

Moss examines these charges, and discusses evidence for and against them, refuting many of the charges. A brief summary follows:

1. False diagnosis: It is possible that some people have been treated for cancer at these clinics without a clear diagnosis of cancer. However, the vast majority have gone there because of a diagnosis received in the US from the conventional system.

Also, there are some clinics, notably Hulda Clark's New Century Clinic, that offer to treat a condition called *pre-cancer* and offer treatments designed to prevent cancer.

2. Loss of crucial time: It is alleged that people may turn to clinics in Mexico first, and that this may delay their receiving conventional treatment. Moss asserts that there is no evidence to substantiate this claim. In fact, many of the patients at these clinics have already received conventional treatment and are in Mexico because they have been told there is nothing more that conventional medicine can do for them.

3. Lack of qualifications: Physicians in the Tijuana clinics are certainly working in a very different environment than conventional oncologists in the US. There is not an oncological certification process in Mexico, as there is in the US. American patients choose them because they use a different approach than American physicians. To be licensed to practice in Mexico, however, they must have medical credentials. Some of them have studied in Europe and the US and some of them are trained in Mexico. Their area of expertise is in alternative, not US conventional medical approaches. Dr. Donsbach, who ran the Hospital Santa Monica where Mrs. King died, is licensed as a chiropractor and had medical physicians working at his hospital, as well.

4. Unsanitary conditions: There are a few old reports of unsanitary conditions at clinics in Mexico, but Moss reports that during his visits, he has never seen evidence of this. Certainly, the facilities that cater to American and Canadians must adhere to certain standards in order to keep their clients. The decor in these establishments is Spartan by American standards, according to Moss, but typically quite clean.

Kitchens, in particular, are scrupulously clean, and constitute a point of pride for the

clinics. Prospective patients are shown the kitchens, and of course, nutrition constitutes the basis for many of the therapies offered.

5. Extortionate charges: Costs for a full round of treatment, usually including hospital care, vary from \$4,900 to \$36,500 and are individualized. This is a substantial cost. It should be remembered, though, that the cost of cancer care in the US is at least as high, and usually much higher. The difference is that patients who are covered by insurance are shielded from actual hospital charges, while the patient generally pays the entire bill in the Mexican clinics.

6. Fraudulent therapies: This is, of course, the most concerning charge to a patient trying to choose between treatments. The first point Moss makes is that there are a large variety of treatments that are offered, and to group them all together is an approach that is procrustean, at best. He then shows a chart that reports the number of research studies that have been done on specific treatments. The numbers of Pub Med citations ranges from zero to 8,579. The number of clinical trials ranges from zero to 22. Moss points out that some therapies that have recently been approved in the US, such as Ultraviolet blood treatment, have been available in Mexico for years, and recently gained approval. Insulin potentiation therapy is one example of a treatment that shows promise and is not yet available in the US, but is used in Mexico. Low dose chemotherapy is another. Finally, Moss points out that, ethical issues aside, it is not in the financial self interest of the clinics to offer a treatment that they know does not work. People are persuaded to go to a clinic based on what results they perceive. Therefore, the clinics that have good results to show will likely attract more patients.

Moss asserts that the clinics in Tijuana offer options to people who are suffering from a disease that constitutes a huge, unsolved problem in medicine today. He believes that it is important that cancer patients have more options, not less. He discusses political and regulatory challenges on both sides of the border, and cites the evolving nature of health care (Moss, 2006)

Summary of Mexican Clinic Literature

To summarize, while there is a dearth of scholarly work done on the Tijuana clinic phenomena, there is a fair amount of literature available to the lay public. The fact that regulations are less strict in Mexico allows for innovative practice. This also creates a potential for unscrupulous conduct. The clinics in Tijuana are the product of a colorful political and economic struggle, as well as a haven for alternative approaches to cancer treatment.

Chapter Four

Methods

Phenomenological Methodology

The purpose of this study was to explore the lived experience of US and Canadian cancer patients at the point where they had made the decision and acted upon it. The phenomenological approach was used in this study because it allows for open ended exploration of the lived experience of subjects, and imposes the fewest numbers of assumptions upon them as possible. There is not enough known about this population, or their process of decision-making, to devise a quantitative tool that would be appropriate.

Instrument

In qualitative research, the tool may be said to be the presence of the researcher. The interviewer strives to release assumptions and presuppositions and truly understand the information that is being offered by the informer. The intention of the interviewer is to elicit information that is relevant to the question and provides as close an understanding as can be shared of the participants experience. Questions asked by the interviewer are naturally guided by her knowledge of the subject, but she strives to allow the process to be informed by the data she is collecting on that subject. Knowledge of ones own biases are crucial to being able to set them aside and open fully to the truths being offered.

Qualifications and biases of the researcher

The researcher has been a registered nurse for nineteen years. She has practiced in critical care and emergency areas for most of that time, and has cared for patients in home care and disaster situations as well. The populations she has cared for have been culturally, socially, economically, and philosophically diverse. This has supported the development of a strong knowledge base of physiology and conventional health care, as well as years of interpersonal counseling experience with seriously ill people and their families.

In addition, the researcher has studied complementary and alternative approaches to health and illness both formally and independently. She has studied alternative perspectives on health, such as Traditional Oriental Medicine and homeopathy, and also examined the historical development of the current health care

system. This historical perspective is important because many of the techniques used in alternative treatments are based on theories or techniques that were originally developed within scientific medicine and then rejected, such as Coley's Toxins and pleomorphism, or were actively combated through legal means by the FDA or the AMA, such as Rife machines or Hoxey's Formula. It should be remembered that the health care system is constantly evolving.

Her interest in alternative cancer treatments, and the Tijuana clinics in particular, stemmed from experience she had with her own family members who developed cancer and sought alternatives when conventional therapy was deemed ineffective or unavailable. She accompanied her father to a clinic in Tijuana after watching his in-depth research of his condition and all the options available to him. Her father died of his illness five months after returning from Tijuana. She feels that having access to alternative therapies is, in general, desirable, while she acknowledges the risks and expenses involved in seeking and choosing alternatives. She sees the primary roles of the nurse as a patient counselor and advocate in this issue, rather than as a judge.

Since the researcher already had an intellectual familiarity with most of the primary techniques used, she was able to focus on the process that the patients went through to make the decision to take those therapies, rather than being distracted by the treatments themselves, which are in some cases radically different from conventional medicine. This also eased the development of rapport with study participants.

This familiarity was developed by extensive reading and, in part, through contact with researchers and practitioners. It also developed through previous conversations with patients who use alternative methods and believe alternative explanations for health and illness. It was her ability to converse with people on those terms and to accept their beliefs and practices that earned her the trust of practitioners to access their patient populations and enabled her to develop good rapport with the people she was interviewing.

In addition to a familiarity with the treatments and situations of the patients and their families, the researcher has excellent active listening skills and experience interviewing patients in debilitated physical conditions and during emotionally stressful events. She has received formal training in counseling and coaching. She also has a fundamental respect for the autonomy of individuals. This allows her to be very open to information that is offered, and helps people to feel comfortable offering information that they may otherwise disclose from a health care provider whom they feel would judge them negatively.

Assumptions

The researcher assumes that people go through a process by which they make a decision. This process may include, but is not limited to, cognitive processes that may be remembered with a fairly reasonable degree of accuracy. The researcher also assumes that elements other than cognitive, such as social, emotional or financial may play a role in the process.

Population

The population of interest for this study consisted of American and Canadian cancer patients who were currently in Mexico receiving treatment. This population was chosen because it was felt that the nature of that decision required a more conscious process than someone who stayed close to home and combined therapies to complement the conventional care they received. The nature of a decision to leave one's country of residence requires more thought, planning, time, and money, than staying home.

Sampling Plan

The sample was obtained through a snowball method, due to the need to interview people who had already acted on their decision, but did not yet know how it would affect their disease process. Patients and their families were contacted through physicians and a researcher who were known to the author prior to meeting the patients, except in the case where one physician was contacted by email, and permission was given after an email correspondence. Patients from a total of three clinics were interviewed to reduce the bias that may have been introduced by people basing their decisions on one kind of marketing strategy. Patients had to be strong enough to tolerate the interview process without distress. The exception to this was both members of a couple, who were interviewed together, and who had brought their five year old daughter for treatment.

Data Collection

The interviews were conducted in a semi-structured manner. Interviews were tape recorded and transcribed. Transcriptions were reviewed for accuracy, and corrected as needed. Certain areas were always explored during each interview, such as the thought processes that the patient went through and the social context within which they made the decision to act. The patients themselves volunteered other areas of discussion. Patients and family members were encouraged to “tell the story of how they came to Mexico for treatment” and the researcher then listened to their answers, asking for clarification on various concepts from time to time.

Interviewing the patients at the clinic during the course of treatment allowed the researcher to discuss the decision-making process after the decision had been made and acted upon, and before the long term results of that decision were known. It was hoped that this would remove bias about whether the decision was “right” or not, and it also gave the researcher an excellent opportunity to witness the experience of receiving care in these clinics.

With one exception, all patients were interviewed with a family member present. This was done in deference to each patient’s stated preference. The exception was someone who did not have family staying at the clinic that day, but had family actively involved in the process. This is significant because of the amount of research that points to the importance of social support to health and well-being. It should be noted that all clinics that were visited by the researcher encouraged family

participation in caring for the patient and provided sleeping accommodations for family in patient rooms and provided meals.

Data Analysis

Interviews were carefully reviewed for commonalities, differences, and themes. Responses were explored and then grouped into the following categories: cognitive/ analytical factors, social influence factors, imagery/ impressions, experience with conventional medicine providers, experience with alternative and/ or Mexican providers, and financial factors. These groupings fell into place after careful examination by the researcher, and were then validated by her thesis advisor for content validity.

Ethics

IRB approval was obtained prior to the beginning of data collection from the Dominican University of California Institutional Review Board. Consent was obtained from each patient or guardian prior to the beginning of the interview process.

The participants were encouraged to share only as much information as they felt comfortable sharing, and their identities were protected to assure anonymity during the process of writing and disseminating the results of the interviews.

If the participant became uncomfortable or developed physical or emotional needs at any point during the interview, the interview was suspended and the needs attended to by the interviewer. The interviewer did endeavor at all times to provide a supportive environment to the participant. The patients and their families were assured of confidentiality. It was acknowledged that the information was sometimes

of a sensitive nature, and they were assured that their identities would not, in any way, be inferable from the reported results. The comfort of the patient was the priority during the interview process. Measures were taken to assure privacy and physical comfort for each person involved. A decision was made to allow patients to have a family member present with them when they were being interviewed. All but one person chose to do so; the person who did not have family present did not because they had left town for several days. Both parents of the pediatric patient participated in the interview and they chose to have the child present during the interview as well. Having family present during the interviews turned out to be beneficial in several ways. Not only did it add to the comfort of the patient, but, as it turned out, the family members had also, without exception, been intimately involved in the decision-making process, and provided additional insights.

The researcher felt a strong ethical mandate to support patients in their choices. The role of the researcher was not to counsel patients about the wisdom of their decision, but to carefully explore with them the process by which they had come to it. To shake their confidence in the decision that they had already made was felt to be potentially detrimental to the patient, and so the researcher was careful to maintain a neutral to supportive attitude about their choice.

Fundamentally, the value expressed during the interviews was respect for the autonomy of the patient within the context of their families and communities. The logic behind their decisions was never brought in to question; the conversation focused solely on the process they had gone through that had brought them to Mexico.

Tapes and transcripts of all interviews were kept strictly confidential, and held in a locked file. Every effort was made to avoid the potential for the identities of the patients to be disclosed through the reading of the study.

Potential benefits to participants

The process of telling one's story is often rewarding for the storyteller. People generally appreciate the opportunity to tell their stories. If listened to carefully, it allows the storyteller to review and reflect on his or her experience. This population, in particular, had had a very literal journey in pursuit of health care. Most participants perceived barriers in the course of their efforts, and felt that the telling of their stories might ease the journeys of others in similar situations. In general, many people appreciate an opportunity to contribute the benefit of their experience to society, and the interviewer hoped to provide just such an opportunity through the respectful and nonjudgmental process of listening to what they have to share, and honoring their experience.

Procedure

1. Approval was obtained from nursing faculty at Dominican University of California, including the director and the thesis advisor.
2. IRB approval was obtained at Dominican University.
3. A pilot interview was conducted prior to departure to Mexico. Interview technique and content was reviewed for validity and adjustments made.
4. Contact was made through the Cancer Control Society with clinics in Tijuana and Santa Rita, Mexico that provide alternative care to cancer patients, and approval was obtained from the appropriate parties at those clinics.

5. The interviewer traveled to sites located in Tijuana and Santa Rita, Mexico. Participants were adult Americans who are fluent in English and physically and emotionally able to participate in the interview process. The interviewer sought informers from at least three different clinics to provide a sample that would represent a variety of clinics. This would help ensure a focus on the participant's process, rather than a particular clinic's way of marketing its services.
6. Participants were approached after consultation with clinic staff and invited to share their story with the researcher. Written informed consent was obtained prior to the interview.
7. The interviews took place at or near clinics in private locations, convenient and agreeable for the participants. They were tape recorded and transcribed.
8. Information obtained is listed in Appendix I
9. Tapes were transcribed and reviewed. Narrative content was analyzed for common themes or patterns, and these were reviewed for validity by qualified university staff.

Chapter Five

Context/ Setting

The researcher traveled to Mexico in preparation for the study and attended a continuing education course offered by the Cancer Control Society that consisted of a tour of eight clinics in Tijuana. She had been introduced to the Cancer Control Society five years previously during the illness with cancer of several family members, and had been exposed to alternative approaches to cancer treatment through friends and family that had sought unorthodox treatment. She became intrigued by the

Tijuana cancer phenomena and developed a relationship with a well-regarded researcher, Gar Hildenbrand, and his wife Christine.

The research process was complicated by an incident that occurred during the time the interviews were being conducted. Coretta Scott King, the wife of the late Rev. Martin Luther King Jr., was brought to the Hospital Santa Monica , Donsbach clinic, three days before she died of ovarian cancer. She had not yet started treatment at the clinic. Efforts to resuscitate her were unsuccessful. This resulted in a flurry of popular press articles about the Mexican cancer clinics and the US government demanded a crackdown on the clinics. This resulted in eight of the clinics being closed, including the Donsbach clinic.

The researcher was in telephone contact with several of the clinics during this period, and heard about the process from the perspective of the clinicians trying to operate during this time. American Embassy officials, accompanied by Mexican officials, arrived at the Donsbach clinic to shut it down .Several patients who were receiving treatment at the Donbach clinic were told by the American officials that the practitioners at the clinic would “kill them” and that they should leave the country right away. When several patients found other clinics to continue the care that they had come to Mexico to receive, they were again located by these American officials and told to leave Mexico based on a visa requirement that had not been enforced within the border cities for many years.

Clinicians told the researcher that these sorts of harassments and closures happened periodically and that they would reopen when new licensure requirements were met, and that indeed happened. One requirement that was cited in the closure of

the CHIPSA clinic was that an operating room wall was in the wrong place.

Ironically, six months previously, the clinic had been told that in order to maintain licensure, they must put a wall in that exact place. Now they were told that the wall must be removed, and that they must remain closed until this had been done.

The CHIPSA clinic functions not only as an alternative cancer clinic, but also as a full service clinic and hospital for the nearby neighborhood, including a large school in that area. This shut down not only displaced seriously ill cancer patients, but deprived a community of local health care services and did not seem to be justified on the basis of one problem in the operating room. One could surmise that politics played a role in the closure, more so than patient safety.

The experience of the researcher in approaching clinics for permission to interview clinic patients, was that they were generally very supportive. The clinics feel that they offer an effective and important option for cancer patients. In general, they welcome research that they themselves do not have the time or resources to do, and all clinics that were contacted claim to keep long-term records of their patients for the rest of their lives. If this is true, it would be a goldmine of data to evaluate the effectiveness of these approaches. The clinics, however, are set up to treat patients, not to conduct research. With the exception of Dr. Victor Ortuno of CHIPSA who supported Gar Hildenbrand in conducting a retrospective review of melanoma treatment (Hildenbrand, 1995), Mexican clinicians have not attempted to publish research based on their findings. This may well be due to the fact that, not only are these clinics operating on fairly marginal budgets, but, as the interviews reveal, the provider-patient relationship is much more involved than the typical US or Canadian

relationship, and the therapies are usually complex and involve several different therapies, chosen and administered based on the individual patients needs, and not generally on a standard protocol. This kind of approach is fundamentally at odds with the research approach most commonly accepted in modern medicine.

Chapter Six

Findings

The researcher was invited by clinicians to meet several patients who were undergoing treatment at three different clinics in Tijuana. Informed consent was obtained, and a total of five interviews were conducted.

Demographics

Three of the patients who participated were adult US citizens and one was an adult Canadian citizen. Also, a married couple, parents who had brought their child for treatment, was interviewed. Patients ranged in age from 5 to 82, including a patient in the early 40's, one in the 50's and one in the 70's. All the adult participants had some college education or had family members that were reasonably well educated. The sample included a veterinarian and a lawyer. All had access to and were able to make use of the Internet.

Major Themes

It was made very clear to the researcher that the underlying motivation behind each family's decision process was a sense of personal responsibility. The patients who actively participated in the search did so out of a sense of self-efficacy, and the family members acted on their sense of familial responsibility. There were factors that influenced each decision toward the Mexican alternative and factors that

discouraged people from seeking conventional care in their home systems. The factor that motivated each process, however, was the desire to take a responsible course of action.

Several themes about the decision-making process emerged from the interview data. Each decision process involved all of these factors to varying degrees. The categories identified are as follows:

1. Rational reasons based on the patients or proxies' perception of their illness.
2. Social referral networks and trusted relationships.
3. Images that reflected an impression, along with a visceral or emotional response.

All participants had rational reasoning that supported the choices they had made. Many participants cited multiple sources for their rationales and could offer explanations for their treatment choices based on biological principals. Most had investigated the scientific principals behind the treatments to one degree or another. Also they could all discuss the political and economic issues involved to one degree or another.

Everyone described social networks that influenced their decision-making in one way or another and usually in multiple ways. *Trust* or *faith* was cited frequently. However, some people expressed a faith in God, some people talked about faith in a family member and some talked about carefully cultivated faith in hired advisors or health care professionals.

Participants were also influenced to one degree or another by the images they had internalized about treatment options and health care systems. These were

sometimes expressed in metaphorical language and carried an emotional impact. The emotion was evident when listening to them describe images and experiences. They may or may not have understood the scientific reasoning behind their treatment, but they had had strong emotional experiences that really shaped the way they felt about treatment.

If patients did not volunteer to discuss how finances played into their decisions, the researcher asked. Participants stated the belief that if one has a disease that will be terminal if one does not get treatment, the proper thing to do is to come up with the money, if at all possible, and seek treatment. They also compared the cost of the treatment they were receiving in Mexico with the cost of treatment they were receiving in the US. The Mexican treatment was significantly less costly than the American treatment would have been. It is notable that the individual with the least income cited the highest out of pocket costs for the drug that was being prescribed for him in the US. That drug offered less hope for him than did the treatment in Mexico, which cost more but also offered a better quality of life.

Finally, all the participants had had experience in both the conventional and the alternative systems and could compare their experience in Mexico with the experiences they had had in their home countries. This information is included because it is felt to be of interest, even though it did not figure into the decision-making process prior to their arrival. Since trust was a factor in the decision-making process, and the patients could leave at any time, the rapport built at time of arrival would seem to be a factor in their decision to stay and receive treatment.

Rational processes

The first factor is the cognitive, rational part of the decision-making process. All but one participant had researched multiple options. One man had become interested in nontoxic cancer cures in the 1960's when a friend of his had gone to Mexico for treatment. This man was well read and well educated. He was also very involved in his community and is a well respected elder within his church. He had followed the development of the Rife machines, had read Dr. Gerson's book "A Cancer Therapy: Results of Fifty Cases and the Cure of Advanced Cancer", and had followed stories of the suppression of cancer treatments by the American Medical Association and the FDA.

"Well I ran into the "Friends of Cancer", I forget who was studying it, I think that um, Gar Hildenbrand was involved with it then, and I started reading up and I subscribed to the literature there, a periodical they had. I don't remember the name of it. But I started to get interested in non-toxic cancer cures then. Around 1966. I read a lot of books since then. I read, um, I first read Dr. Gerson's "50 Cases" book, and over the years I've read Gaston Mason's book, from Quebec Canada. He invented a cure called x.. ah. 714X. That's his birthday. 714X.... Anyway, that's kind of my background. I've followed it for years, never thinking that I'd have cancer myself.... "

When he was diagnosed with cancer in his late 70's, it made no sense to him to engage in surgery, chemotherapy or radiation

“I was kinda surprised- I said “What do you suggest?” And I knew I wasn’t going to go with the cut and burn thing because I had studied too much of this other. She said well I suggest that you get in touch with a good surgeon. I thought “No way!” There’s no way to evenI mean you couldn’t get it out. The pathologist... said I had multiple nodules in the mesentery, had multiple tumors all down the colon, I have a big tumor here on the liver, I got a big one attached to the cecum along down this side, and the colon is all filled with tumors, and the nodules all down the mesentery. It’s inoperable. I mean they would have to disembowel me to take it all out.”

He felt that he knew what was right for him and went straight to a clinic where he felt he could receive the best nontoxic therapy available

Other participants were introduced to alternative methods only after they had tried conventional treatments or had been told there was nothing more that conventional medicine could offer.

This participant had been through chemo, surgery and radiation, and was told he had two months more to live. He rejected the final chemotherapy drug they offered him, and instead came to Tijuana for treatment.

“Well, my family doctor was very good. And with the oncologist, who took over after we discovered I had cancer, it was very good with him, too! I mean we did everything that we could, except taking the last thing which was only a 15% possibility of extending my life.... there does come a level when you say “ We’re going to pay all this for a drug that might extend his life by two months, or we can pay, you know maybe it’s a little more, maybe a little less, and maybe extend his life another however long he’s supposed to live naturally, if he hadn’t gotten cancer.”

Another participant had carefully researched all the conventional options when he received a phone call from his doctor’s office.

“I didn’t think chemo would work and I didn’t think the conventionalities that he was talking about would work. I really felt radiation is not going to work for me, I am metastatic, and hormone therapy isn’t going to work, there is nothing left. When I talk to my doctor, doctor’s nurse, she said we want to set up an appointment for you with the medical oncologist to discuss chemotherapy and I said but chemo doesn’t work in prostate cancer she paused and said there are trials that are available. Again because of my job, I mean my job is to know inflections and things like that, if people are telling the truth. This was not a pleasant call for her. I wasn’t making it tough. It’s just nobody wants to tell somebody there is no hope, so we’re passing you on to the next person. “

The parents who brought their child for treatment had gone through conventional therapy with her for another form of cancer when she was three. That therapy had been deemed successful. When a second kind of cancer developed a few years later, the prescribed conventional therapy was not having a beneficial effect.

“So when we got an MRI back that shows that it was not doing what the doctors had hoped, the tumor was not regressing, it was not advancing, said well, this thing ain’t going to stay the same for long. We’ve been hitting it with artillery for a month and a half and it hasn’t gone away at all, and there is only so much artillery they are willing to use, so that means we’d better find something else really fast.”

The parents talked to everyone they knew about alternatives and found a clinic in Tijuana.

Interviewer: “What were the major criteria (for your choice)?”

Parent: Well, one, results. You know, knowing people who got results, meaning cancer that went into remission. Two, from talking to Dr. and from looking at the website, basically interviewing him, “OK, what treatment modalities would you use?” “How do those work?” “Why are you using those?” Uh, “How does this work on sarcoma?”

This was their second trip to Mexico. The first time, their daughter had started treatment, and within two months the tumor had shrunk to half its previous size.

This was something that conventional medicine had been unable to accomplish, and they were back for a second round of treatment because it seemed the logical thing to do. This couple cited evidence that the treatment had had a beneficial effect, and felt that continuing treatment made sense.

Several of the participants also cited the irrationality of treating a sick person with “poisons”, or toxic chemotherapy.

“The concept of giving poisons to the body to try to make it well, that’s total insanity!”

In summary, all of the participants used rational processes in the decision-making process. Their concepts may have differed from those used by conventional medicine practitioners, but they based the rational part of their decisions on their understanding of the biological processes involved in cancer, and were oriented toward results.

Social Referral Networks and Trusting Relationships

Some people did more research than others. Some studied the science of cancer themselves and others developed trusting relationships with people whom they considered competent to judge these things. One man did very extensive research, learned enough about his condition to ask very incisive questions, and realized that conventional medicine had nothing to offer him. His assessment of how you make a decision like that was as follows:

“It took a long time to research all my options. You can't be sure who to trust, so you go to the tops in the field, right? You look around, talk to people, figure out who to trust and do what they recommend.”

He dialoged with many people in the US, Canada, Germany and Mexico, developed trusting relationships within a network of leading experts, checked credentials, and cross checked people's reliability with other experts in the field. He felt it was vital to research all options.

Oh, a ton of research. You wouldn't have got to believe Ralph Moss if you hadn't have done the research. You wouldn't have phoned Ralph Moss if you hadn't done the research, and hadn't had an intelligent conversation with them if you hadn't done the research.

He surprised himself when his very careful, rational research led him to clinics in Mexico. Interestingly, his very rational approach left him ultimately unable to make a final decision. He had chosen the approach that seemed to offer him the best chance of survival, but found that he was unable to decide between two providers. He abdicated responsibility for that choice to his wife whom he described as “very intuitive”.

“ I call my wife's cell phone and I ... I give up. I cannot make a decision.”
And she's very, very intuitive. I said “I need you to decide. I can't decide, I cannot decide.” I remember saying this, I can't remember if it was snowing, but

it was sure cold as hell, the end of January. I don't know what to do, You have to decide for me.

And we decide, she doesn't want to decide either, she can't, so she comes up with something great, come on down, so she comes. So the little group that goes down are me, her, and my engineer son. We said I'm anal, and I had the most knowledge, she's very intuitive, and he is going to keep everybody focused because he's very scientific and he won't be swayed by emotion.

So all 3 of us go down, interview both places, and decided here primarily—want to hear about that, what went into the decision? (one clinic) was more aggressive in the treatment, 8 photophoresis sessions vs. (the other clinic) “I don't know.” They would never commit, which scared me. But these guys said “If you want it, we think you should have 8, no more, and you could have less, but we would want 8.” And in my conversations with (the first clinic), I knew that was progressive. Subsequently I got to know more and more about photophoresis.

When I talked to (the second clinic), they said as many as you can tolerate, which I think is bullshit for 2 or 3. Which was my concern about (the second clinic) because they had—well Gar is saying they aren't aggressive. Do I trust Gar? Moss told me to trust him. So again it really comes down to trust, knowing who to believe. (X person) says (Y) Clinic is terrible; I had a shitty feeling about (X),

so I didn't trust him, but lots of people give you a good feeling and aren't to be trusted, so Gar is telling me all this stuff and Gar is telling me stuff about them, that when I apply against what I know about them it does make sense.

So when we go down, I have that background and we interview them both.

We go to (the second clinic). My son should love them. They got white smocks, they are professional, they are fabulous, we talk to them. They both say they wouldn't touch them with a fork, no passion, to interest, it was a job, no spark, no fire, and they agreed with Gar that they would not be aggressive because they seemed to lack aggression. Anyhow, it was basically guts and intuition resting upon the foundation of faith and trust.

Ultimately, they traveled to Mexico with another family member. Of these two chosen advisers, the patient saw the wife as intuitive and the other family member as scientific and rational, not likely to be swayed by emotion. When both these people agreed on one clinic and rejected the other, the patient was satisfied that the best decision possible had been made and was able to engage fully in the therapy.

This illustrates what is probably the major theme identified by the researcher. That is, each person who made the decision to go to Mexico did so in conjunction with at least one other person, and usually a whole community of people who supported their choice. Most research on health choice has been done on choices made by individuals, but individuals take counsel with other people who are in their

family or social network, and do not act in isolation. People have much greater access to family and friends than they do to health care providers, since time with professionals is limited by the nature of the professional relationship. Also, when communication with providers is less than satisfactory, people may be inclined to feel that the physician does not have time to learn enough about them to make good recommendations, and therefore be less confident of the advice. This leads them to seek elsewhere for opinions about what to do.

One person described a tumor being diagnosed through applied kinesiology by a chiropractor. The chiropractor advised immediate consultation with a physician and the patient complied.

In August, (the patient) had had, what was diagnosed as a sinus infection. She was on antibiotics for several weeks with nothing resolving. Uh, took her to uh, you know, a couple of different doctors and eventually took her into uh, Children's, to get checked in the oncology department. They did blood work and said "you're clean." (she) still wasn't doing well. Took her to a chiropractor, a friend of mine who also does . . . endocrine work and various other things. He said "she's got cancer."

Interviewer: A chiropractor diagnosed her.

Participant: Right. With no blood work, just Using, um, whatchamacallit, Something like applied kinesiology. He said you know whenever I've seen a specific set of reactions, it's always cancer. So Monday, (we) took her to the chiropractor, and we were completely upset. Tuesday

we went to the oncologist and they cleared her. They said “.Nope, everything’s fine.”

And then, then she still had this just, bloody nose that wouldn’t stop, and all kinds of, you know, discomfort and things. Unbelievable sinus infection if that’s what it was.

So then on Friday, I came home from work in the middle of the afternoon, and I said “I think we need to do something else—we need to go to another place.” So I called somebody and she got me an appointment right away with a nose specialist. Took her to a nose specialist Friday afternoon. He examined her nose and said you know, you need to get a CAT scan, there’s definitely something here. So he got the CAT scan right then, he scheduled a CAT scan just a few miles away and we went and did that. And I think around 10:00 at night he finally called us and he said “We’ve already called Children’s Hospital and they’re waiting for you and you need to go right now.”

One can understand how that patient and anyone hearing the story would develop more confidence in the chiropractor and his applied kinesiology, and less in the physician and the blood tests.

Trust, confidence in certain people, and faith were recurring themes. For some, it had to do with faith in a network of people, in one's own evaluation of the science involved in treating the disease, or in one person's case, faith in God. One individual described herself as very religious and stated,

“I feel that God carried me here”.

She was the exception, however. The other participants had investigated through both cognitive and social approaches and, it should be noted that at the time of her transfer to Mexico, the woman who felt that God had brought her had been very ill. Her husband, supported by a network of people, some of whom had been to Mexico for cancer treatment, had done the research and had acted on her behalf and with her trust. Her memories of the decision-making process itself were a little vague, but she trusted in her husband and family and believed that the decision had been right, ascribing how well it had worked out to "*God's hand*".

Religion was not cited as having a role in the participant's decisions to go to Mexico. Two of the five families discussed being involved in a church or synagogue and stated that people from their communities had been knowledgeable about the Mexican clinic option. These were both mainstream religious groups. The other three did not cite any religious affiliation. Although the concept of "mind-body-spirit" treatment was discussed, it is very important to distinguish between spirituality and religion.

The faith and trust that most of the participants relied upon was evident in the way other people were involved in their decision-making process. Patients take on a sick role because they are ill, and, as several of them described, there is a lot to process when you are ill. Evaluating cancer options is a demanding process, especially when you are not well and undergoing treatment with its side effects. In this situation, it is natural and normal for family members to support and assist in the process.

One elderly man, who had undergone chemotherapy and radiation, was described by his daughter as “*just not himself*” in the aftermath of treatment. She felt that it was her duty as his daughter, to seek options for him because the doctor had nothing more to offer. After several days in Tijuana at a clinic there, he reported feeling much better and was able to be interviewed. He described his attitude toward health care thus: “*I don't fool around. I go to the doctor.*” He felt that responsibility for one's health meant you sought care from appropriate people. When his doctor had no good options for him, his daughter looked on the Internet and talked with people. She found an option in Mexico that she felt offered him a reasonable hope of a better quality of life. They did not count on curing his cancer completely with the treatment, and the Mexican physician did not offer such a cure. The daughter consulted with the physician while the patient was still undergoing treatment in the States. The physician did not at all discourage the patient from treatment. On the contrary, he made suggestions as to how to ameliorate the side effects of treatment, then, when treatment was completed, they transferred him to the clinic in Mexico to receive support for his immune system and help him to recover from the side effects of treatment. Apparently, he was recovering well. His daughter described how he was getting stronger every day and was not experiencing side effects as badly as they had been led to expect.

This man had placed his trust in his daughter. She responded to his situation in the way that he would have done, had he been able. He would have sought effective treatment. He had not had experience with alternative treatment before, but apparently his sister, who was also involved in his care, had started giving him herbs,

and his daughter had found an alternative treatment that worked for a health condition she herself was dealing with when conventional medicine had told her she should simply accept the problem because there was nothing that could be done. Because of her success with her own condition, when told by doctors there was nothing that could be done for her father, she was disinclined to accept that judgment.

The rapport between caregivers and patients/families was a big factor in the decision to come to a particular clinic. The relationships with Mexican physicians that were described differed from most descriptions of relationships with US or Canadian physicians. Much of this could be ascribed to the need for Mexican clinicians to market their services, but it is a strong factor in the patient-physician relationship nonetheless. Each family described a willingness on the part of the physician in Mexico to work with them in a flexible and individualized manner. They had several phone conversations which helped to establish a good rapport with the person who would be responsible for their care while in Mexico (the physician or clinician). In two cases, alternatives in the United States and Germany were rejected because, although the clinics had good reputations and offered alternative care, they were unavailable for phone calls or they required people to travel to the facility and be admitted before the patient would receive an idea of what their protocol might look like. In Mexico they were able to establish rapport prior to travel, which considerably lowered the emotional barrier that might otherwise prevent someone from crossing the border.

Images and Impressions

Several people who were interviewed expressed strong images of care. One woman described her experience as follows:

“I went the regular Western route; chemo six months, a double mastectomy and when I finished I knew it was not anything that, if I had to do it over again, that I would choose to do.” She also stated *“I’ve witnessed one of my closest friend die. I watched her, you know, I couldn’t make any sense. For five years she never left chemotherapy. One treatment after another just to see what destroys you.”*

When this woman's cancer recurred, she decided to seek care that she was more comfortable with. Her husband, supported by community members, searched for and found alternative treatment for her in Tijuana. The patient had been too ill to participate in the search for alternatives. She had expressed her wishes to her husband and he had followed through with the process.

Another man, when offered surgery, had a strong image in his mind.

“All I thought of was a cow that had been butchered and was hanging out on the rack with all his intestines out and I thought 'No way!'... I see myself with a colostomy, I see myself having radiation therapy, I see myself with chemotherapy and I don't want none of it! I think it is better to die.”

This man had been diagnosed with late stage colon cancer. It is interesting to note that he had had several episodes of severe abdominal pain where he felt that his intestines had been obstructing prior to going to the clinic in Mexico. Since his

arrival, about ten days prior, he had had no episodes of that sort of pain, and had been improving. He had not had any treatment prior to arrival to the clinic in Mexico. He had nothing but praise for the doctor that had diagnosed his cancer; he simply wanted a treatment that she was not trained to offer.

Mexican Clinic Experiences

There was a uniformly high level of satisfaction with the care that was received in the Mexican clinics. One woman described how her abdomen had become very painfully bloated with trapped gas during the first few days of her stay there:

“The first day, the first ten days I had extreme, extreme pain, like trapped gas, like my stomach was seven months pregnant. (They) said it was my liver just really going to work, getting all the toxins out. And every night the doctors would come in and they would massage my stomach two or three times a night for like half an hour. You know, just to relieve the pain.” Tears came to her eyes and she said *“The doctors here are like angels!”*

She described the nurses as *“mothering”* and talked about how they would hug her, cry with her, and tickle her.

“And just all of them, you'd think I was either their sister, their daughter, or, you know, their friend. They have tremendous compassion.”

Other people described the caregivers in Mexico as having *“a very high degree of compassion”*, and one person described them as

“a little more caring towards, um... it's the little things, you know, like not shining a bright light in your eyes not waking you up at all hours in the night to do something that could be done during the day.”

In addition to compassion, which all the participants echoed, they also expressed confidence in the competence of the practitioners.

“They know what they're doing!”

“He knew my body better than I did!”

One participant stated that she had been told that physicians at the clinic she had attended had no more than eight patients at a time. Other clinics had even fewer. This contrasts sharply with the image of health care in the US that one patient described of as

“A cattlecall... very detached”.

Another patient summed up his medical care at home in one word.

“Heartless.”

This man described being informed that he had metastatic cancer in a four minute interview with his physician who then told him to call if he had questions, ushered him out the door and was immediately unavailable by the time the man could formulate a question two minutes later. He then described being shuttled from one practitioner to another, having care delayed for weeks at a time, and being offered faster care on the condition that he participate in a research study. This man was an established professional with a health insurance policy that should have covered all his care.

That was the worst story about care received north of the Mexican border. The expression that typically summed up the feeling about conventional treatment was

“I have nothing negative to say about conventional medicine in America, except they're going about it the wrong way!”

Most of the participants described very positive relationships with their physicians, and had only sought care elsewhere when the physicians had nothing more to offer them. In particular, the parents of the child who was being treated in Mexico were encouraged by their pediatric oncologist to try alternatives because he readily acknowledged that the treatments they had at his leading pediatric oncology center were not working for this child. The parents had glowing praise for this physician, and a lot of faith in him, even though he was unable to offer them the cure that their child required.

It is very interesting to note that, with the exception of one patient who was asymptomatic at the time of entering the clinic, everyone reported feeling better after several days of treatment. There were descriptions of severe digestive disturbance, consistent with the expected disease process, that were relieved after several days of treatment, and a report of a CT scan that showed a tumor halved in size after a previous month of treatment. Two patients described being able to go out for walks in the past two days, where as before, they could not walk that far. In two of these cases, improvement could possibly be linked to recovery following conventional chemotherapy and radiation received before arrival in Tijuana, but two of the patients had chosen to receive alternative care immediately and not received any treatment prior to arrival there.

Financial Factors

The issue of how treatment was being financed often came up, and if it did not, the researcher asked. Treatment in Mexico typically costs upwards of \$5,000 a week, and can occur over several weeks. The cost of treatment for one patient was estimated to be about \$ 70,000. This was a very significant out of pocket expense for everyone participating in the research interviews. It was generally felt, though, that treating the cancer justified the expense. One person said it would have been worth it to take out a loan if necessary. Another said that their daughter would not have the wedding they had planned for her, but would scale down in order to pay for her parent's care in Mexico. All patients had some form of health insurance that would have paid for conventional care.

It was pointed out more than once, however, that care in Mexico was, overall, quite a bit less expensive than care in the United States would have been. One course of chemotherapy in the US was reportedly billed at \$150,000. Another patient who had Medicare and Medicaid described a complicated payment arrangement that had just been ushered in by the beginning of the Medicare Part D prescription coverage. For a drug that had a 5% chance of extending his life, and several unpleasant side effects, he would have had to pay \$3,600 out of pocket for the first and second dose, then \$149 per month after that. His daughter described the process of trying to figure out his medication coverage as

“There's all kind of, like, hoops and ladders that you have to jump through and climb up, and anyway, it was like you paid only a portion of it the first month, then you had to pay the whole amount the second

month, then they paid for, I think 75 or 80% for the rest of it. I mean, it wasn't like, you know, this stuff is expensive, so you pay for the first month and then we pay for it, like a normal health insurance thing. You had to go to different 'levels' was how it was explained to me... I mean it was a help for the decision, whether to take it or not. It was like a three ringed circus!"

The patient decided not to take the drug. They went to Mexico instead, where the treatment had a track record of alleviating the side effects of the treatment he had had so far. They opted for a better quality of life for him, even if it was a little more expensive than the one drug would have been had they stayed in the states. The patient, who relied on his daughter to help him figure out the Medicaid part D issues, added,

"I don't know what Congress was thinking of when they whipped that together!"

Other comments marveled at the fact that insurance companies did not see non toxic care as a good bargain.

"You'd think the insurance companies would, you know... this kind of treatment is so much less expensive!"

The woman who had been through breast cancer treatment expressed anger and resentment that her insurance would pay for chemotherapy, surgery and radiation, or pay for hospice care, but not for a treatment that was aligned with her individual needs, and from which she felt she was deriving benefit. She felt that requiring someone to choose between a treatment they did not want and no treatment at all was

unethical when other options were available. She and her husband were unsure how they were going to pay for the treatment, but, with children at home, they felt they had to do the best they could to help her survive. She did not think she could tolerate conventional treatment again.

While acknowledging that the alternative treatments do not work for everyone, the participants state correctly that conventional medicine does not work for everyone either. Several people felt that physicians north of the border were restricted in their practices by political pressure. The person who had followed nontoxic therapies for over forty years stated that the American Medical Association had persecuted alternative cancer treatments in order

“... to eliminate the competition.”

Autonomy and Informed Consent

A strong belief was expressed supporting a patient's right to seek treatment that they felt was effective and consistent with their own values. This was especially true when conventional medicine had nothing to offer. However, it was also true when a patient freely chose an alternative to conventional medicine, against the advice of the conventional practitioner.

The disruption of clinic function in the aftermath of Corretta Scott King's death was discussed, as were other issues affecting the decision to seek care in Mexico. This disruption was seen uniformly as an infringement of the rights of people to seek what they felt to be appropriate health care. Far from reassuring them about the concern their government felt for their safety, the raids and closures left the whole community even more distrustful of the intentions of the FDA and other

governmental regulatory organizations. They were more inclined than before to believe that proprietary concerns were prioritized over their health needs, and that the raids were an attempt to reduce the competition offered by the clinics to the large pharmaceutical companies and the AMA. This was a concern voiced by many people that the researcher spoke with throughout the visits to the clinics.

Chapter Seven

Discussion and implications for practice

Discussion

The themes identified during the data analysis process were as follows:

1. Rational reasons based on the patients or proxies' perception of their illness.
2. Social referral networks and trusted relationships.
3. Images that reflected an impression, along with a visceral or emotional response.

The theoretical frameworks described in Chapter Two are as follows:

1. The Health Belief Model
2. Ritvo's discussion of the interaction between clinicians and patients
3. The Naturalistic Decision model

The themes identified in this study can be understood in the context of a combination of these three models of decision-making, but not by any one model by itself.

The first theme is addressed by the traditional theories about the decision-making. Both the Health Belief Model and Ritvo's model presume that people have

rational reasons for making the decisions that they do. This was clearly a strong factor in the decision-making processes of the participants in this study, but not the only factor. Cognitive factors found to be involved had to do with people's perceptions of the nature of the disease and what it would take to restore health.

It was interesting that the person who was most familiar with biology on a practical level, the veterinarian, was also one who opted for care in Tijuana before and instead of any conventional treatment in the US. The care there more closely corresponded with his belief system than did the radiation, chemotherapy and surgical options offered him in the US. He also had a very clear negative image about the potential that surgery offered, based on his knowledge of anatomy and physiology.

Each person interviewed exhibited some degree of critical thinking ability. They had a rational reason why the therapies they chose fit in with their understandings of the way the human body worked. The participants described views of biology and the healing process that, while differing from conventional oncology, nonetheless provided them with a rationale for their choice. They made what they felt was the best decision they could, based on all the information that they had available to them. What differed was what they chose to believe, and where that led them.

The second theme is also described by the Health Belief Model. Participants used the lay referral network to find alternative treatment. This helped them to determine what to believe. They built these networks, or chose to access them, based on trusting relationships. People trusted their family members and members of the community, or built trusting relationships with new acquaintances for the purpose of seeking treatment. Rejection of conventional treatment did not necessarily indicate

distrust of the conventional practitioner, but a choice to trust the alternative provider more. Apparently, the trust factor was one that more reliably “pulled” people in to alternative care rather than “pushing” them out of conventional care. (Referring here to the “pushes” and “pulls” identified by Boon et al.,2003).

Some people had trusting relationships with the physicians that had cared for them at home, and some did not, so lack of trust was not a universal prerequisite to rejection of a plan of care. All, however, had developed trust in the clinician in Mexico who now supervised and directed their care. All had glowing words of praise for these physician/ healers and the nurses and other staff who worked with them.

Social networks and connections, trust, and faith in certain individuals seemed to be the most influential factors identified. The process of building that trusting relationship was sometimes more rational and sometimes more intuitive, but the result was confidence enough in the choice to travel away from home to Mexico, and place ones health and money in the hands of a clinic there.

The third theme was the imaging, or emotional component of the process of deciding. This is perhaps the most significant observation. This may provide information about how people sort through the information available to them. As was suggested by the first theme, people have access to different versions about what is true about biology, their disease process, and their options. Why is it that some people believe that chemotherapy has the potential to save their lives, and others see it as a deadly poison that will kill them faster than the cancer? This may be explained by the second and third themes identified in this study.

People exposed to differing belief systems tend to gravitate toward one or another system to explain phenomena and make decisions. This process is influenced by the people around them. It is also influenced by images and experiences, along with the emotional content that these provide.

Religion did not seem to play a large role in the processes of the people interviewed. The ones who identified a religious community perceived support by some members of the congregation. Some people made contact through members of their congregation, but it was made clear that this was a social function, and not connected with the views of the religious community. It could be argued that those social connections are an expression of religion in the sense that congregations generally are encouraged to care for one another. However, social connections exist both within and without the structure of religion. And it was noted that the participants and the practitioners represented several different religious traditions, and two participants were not religiously affiliated in any way. However, most expressed some form of conscious spirituality, and everyone spoken with expressed their value of compassion. Compassion is typically associated with spirituality.

The caregiver behaviors that seemed to foster the establishment of trust included availability and compassion. It was significant to patients when caregivers take the time to really listen to patients, express concern and compassion, and respect the rights of the patient to have preferences that are not necessarily consistent with the opinions of the physician.

Limitations

The most obvious limitation of the study was the limited number of interviews. There were time and resource limits to what could be done, and it was felt that, given the circumstances, five interviews would be sufficient as a pilot study of this issue, as there had been no research like this prior to its inception.

Another limitation is the fact that each participant was referred to the researcher by the practitioner in charge of their care. This most likely biased the sample in favor of people who had positive experiences with those practitioners, as those practitioners may indeed have been reluctant to have referred someone who they did not feel would speak positively about them. That was fairly unavoidable, however, given the need to access patients who were currently undergoing treatment at the clinics themselves. It is also true that the researcher had social access to all the patients at three clinics at one point or another, and so had a good chance of hearing about a more negative situation if one had existed at that time.

Implications for Nursing Practice

It is vital to understand that the underlying motivation to pursue alternative therapies arose from a sense of responsibility and self-efficacy. This is consistent with the literature review about Complementary and Alternative choices. Every patient interviewed was there because they felt that they were acting to care for themselves or their family members health in the best way they had available to them.

There is a growing emphasis on patient education and patient self-responsibility. Health care providers encourage people to take responsibility for their health. There is a vast amount of health information that is available to the general public now, through the Internet and lay organizations. When people are exploring

those options and thinking for themselves, they will sometimes come up with different results than health care providers might expect.

There are more and more options available to the patient. Some of these have been researched and some have not, and the health care field is developing more rapidly than clinicians can hope to keep pace with. It should be remembered, though, that even carefully researched medical treatments have no guarantee of success for an individual. Each individual is unique and deserves recognition of her or his specific situation.

Nurses provide counseling and support to people going through the crisis created by a diagnosis of cancer. It is important to understand that the decision-making process is multifaceted. This means that the cognitive process is only part of the process. Families, friends, and community members influence people. In addition, they have images, impressions of cancer and cancer care. This may color their judgment and influence what kinds of information they are able to process.

When interacting with patients and family members, the nurse would do well to listen carefully to the belief systems that people have, and to interact respectfully with them. This is how rapport is established. As this study has shown, rapport is the first step toward building a trusting relationship. Without that trust, people will be disinclined to believe what is said, despite the credentials of the speaker.

Further research

Further areas for research in this area include many topics. It would be worthwhile to interview a larger number of patients about the process they go through

when making decisions. The themes identified in this study could be validated and expanded upon.

Obviously, it would be good to have more research done on the therapies themselves that are offered in the Tijuana clinics. The clinics all claim to keep records, and it should be possible to examine those records and describe case histories from which statistics about effectiveness could be derived. That would address the most common complaint against the clinics.

What role does the placebo response play in the healing process? What about interactions with caregivers? Does the quality of the relationship between a caregiver and a patient influence the outcome of an illness?

Another area for future research would be to explore the experience of nurses in counseling patients about making decisions about their care. How well do nurses understand the process of patient's decision-making? How can we interact in a way that better supports people to make good decisions?

Indeed, what is a “good decision” in health care? What factors contribute to satisfaction with a decision? Medical science uses survival rates, and quality of life indicators are now part of the evaluation process. What else needs to be considered?

It is clear that people do not make these decisions in a vacuum, or even solely with their physicians. How do people access their social networks for support in that process? What constitutes a trusting relationship in health care?

Summary and Conclusions

The process people go through in making the decision to go to Mexico for cancer treatment is multifaceted. It involves cognitive, rational processes. However, it

also involves social networks and personal values. These are strongly influenced by interpersonal and emotional experiences and processes.

It is appropriate that patients and the people closest to them be as involved as possible in the cancer treatment decision-making process. Nurses who approach the discussion with an open-minded attitude are better positioned to participate constructively in the process people go through when choosing between care options.

The clinics in Mexico have a colorful history and provide a very wide variety of approaches to cancer. They provide many different alternatives to the conventional approach. They can do this because they are less strictly regulated than US or Canadian cancer treatment centers. However, because they are less regulated, there is also a greater risk of fraudulent or injurious procedures. People will be drawn to the caregivers whom they feel they can trust, and not necessarily to those who have credentials.

As the health care system grows and becomes more complex, people have more options and therefore more decisions. It is vital that they receive the best support possible to make the best decisions they can.

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Appendix I Questions will be open ended and interviews will be tape recorded, then transcribed.

Questions will include:

1. What is your health reason for seeking treatment? (Diagnosis)
2. How long have you had this condition?
3. How did you hear about the treatment being offered here?
4. Did you use or consider using any other treatments? What?
5. What, if any, conventional treatments are you receiving in the United States?
6. What led to your decision to come to Mexico?
7. Was anyone else involved in your decision? How?
8. Did the way you made your decision to come to Mexico differ in any way from the way you usually make decisions? How?
9. Have you had negative experiences with conventional US medicine that may have influenced your decision to come here?
10. Is there anything else that you feel it is important to know about your decision to come to Mexico?
11. Tell me a story that clearly demonstrates how you made the decision to come to Mexico for treatment.

Appendix II

CONSENT TO BE A RESEARCH SUBJECT

Purpose and Background

Ms Alicia Bright, a graduate student in the Nursing Department at Dominican University, is conducting a research study designed to explore and better understand the experience of United States Citizens who make the decision to travel to Mexico to receive nonconventional medical care. I am being asked to participate because I live in the United States and have chosen to receive nonconventional care in Mexico.

Procedures

If I agree to be a participant in this study, the following will happen:

1. I will participate in an interview, in which I will discuss my experience with cancer and the process by which I chose to travel to Mexico for treatment. The interview will take place at a site convenient to me while I am staying in Mexico for treatment.
2. I will be recorded during the interview. All personal references and identifying information will be eliminated when these recordings are transcribed, and all subjects will be identified by numerical code only, thereby ensuring confidentiality of the subjects responses. The master list for these codes will be kept in a locked file by MS. Bright, separate from the transcripts. Only the researcher and her faculty advisors will see the coded transcripts. One year after the completion of the research, all written and recorded materials will be destroyed.
3. If I am interested, I will be furnished with a written summary of the relevant findings and conclusions of this project, such results may not be available for three to six months.

Risks and/or discomforts:

1. I understand that my participation involves no physical risk, but may involve some psychological discomfort, given the nature of the process of reviewing what may have been a difficult process.
2. If at any point during the interview I become fatigued or otherwise indisposed to continue, I will state this to the interviewer. She will stop the interview process at that time. The subject may opt to continue the interview at a future time, or not to continue.
3. I will be discussing topics of a personal nature, and I may choose not to discuss any topic that causes me distress or seems like an invasion of my privacy. I may elect to stop the interview at any time and may refuse to participate before or after the study is started without any adverse effects.

Benefits:

There will be no direct benefit to me from participating in this study. The anticipated benefit of the study is a better understanding of the experience of choosing unconventional treatment options.

Questions

I have talked to Ms. Bright about this study and have had my questions answered. If I have further questions about the study, I may call her at (505) 385-6272 or her research supervisor, Dr. Barbara Ganley, MSN Program Director, Dominican University of California, at (415) 482-1829.

If I have any questions or comments about participation in this study, I should talk first with the researcher and the research supervisor. If for some reason I do not wish to do this, I may contact the Dominican University of California Institutional Review Board for the protection of human subjects (IRBPHS), which is concerned with the protection of volunteers in research projects. I may reach the IRBPHS Office by calling (415) 257-0168 and leaving a voicemail message, by FAX at (415) 458-37555 or by writing to the IRBPHS, Office of the Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA, 94901

Consent

I have been given a copy of this consent form, signed and dated, to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study or to withdraw my participation at any time without fear of adverse consequences.

My signature below indicates that I agree to participate in this study.

 Subject's Signature

 Date

 Signature of Researcher

 Date