1995

The lived experience of cancer patients using unconventional therapies.

Audna Agustsdottir
University of Alabama at Birmingham

Recommended Citation

Agustsdottir, Audna, "The lived experience of cancer patients using unconventional therapies." (1995). *All ETDs from UAB*. 5882.
https://digitalcommons.library.uab.edu/etd-collection/5882

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

THE LIVED EXPERIENCE OF CANCER PATIENTS USING UNCONVENTIONAL THERAPIES

by

AUDNA AGUSTSDOTTIR

A DISSERTATION

Submitted in partial fulfillment of the requirements for
the degree of Doctor of Science in Nursing
in the School of Nursing in the Graduate School,
The University of Alabama at Birmingham

BIRMINGHAM, ALABAMA

1995

UMI Number: 9537108

UMI
300 North Zeeb Road
Ann Arbor, MI 48103

ABSTRACT OF DISSERTATION
GRADUATE SCHOOL, UNIVERSITY OF ALABAMA AT BIRMINGHAM

Degree Doctor of Science in Nursing Major Subject Adult Health

Name of Candidate Audna Agustsdottir

Title The Lived Experience of Cancer Patients Using Unconventional Therapies

The phenomenological study presented here was conducted to explore the experience of cancer patients using unconventional therapies and the meaning of the experience for them. For the purpose of this study unconventional therapies are defined as a self-care activity practiced by a cancer patient or a therapy given to the patient to supplement or replace mainstream medical treatment but is not considered a conventional therapy for cancer.

Ten participants who had cancer and used unconventional therapies were interviewed after a pilot study of two cancer patients. The telephone interviews were recorded, transcribed, and analyzed according to steps from van Manen (1990) and Colaizzi (1978). Credibility and applicability were evaluated by a cancer patient who was not a participant in the study, and auditability was evaluated by a doctorally prepared nurse.

From the data emerged a trajectory consisting of four themes. The first theme, Given the Meaning of Cancer, described the meaning that cancer held for the participants, how the meaning is influenced initially by external forces and is later reshaped by the participants. The second theme, Searching for Something Else, represents the urge to search for something, conventional or unconventional, to treat the cancer. The search is motivated by the desire to live healthfully. The third theme, Making Sense, is the decision-making process in which the participants make sense of what they are learning and apply to themselves that which is congruent with their belief systems. The fourth theme, Commitment, is the participants' commitment to use the chosen method. They feel they can have some input into what happens to them by using methods that affect their whole being and that are guided by their own philosophy.

The nurse who is conscious of the meaning of using unconventional therapies can enter the reality of cancer patients and assist them in exploring their belief systems to realize how they want to proceed with their lives.

Abstract Approved by: Committee Chairman Judy Holcombe

Program Director Carol J. Dashiff

Date 7/6/95 Dean of Graduate School John K. [illegible]

ACKNOWLEDGMENTS

Completion of the dissertation was facilitated with the support of committee: Dr. Judith Holcombe, Chairperson; Dr. Kathleen Brown; Dr. Ann Clark; Dr. Peggy Harrison; and Dr. Cecelia Pierce. All members added their own special expertise and cheerful guidance, which was appreciated during all phases of the dissertation. Special appreciation is extended to Dr. Judith Holcombe for continuous encouragement, support, and guidance through tides and waves.

At times, the dissertation process seemed long but was shortened with the love and help of family and friends. I am truly grateful for their encouragement and endless support during this time. My deepest gratitude is extended to the anonymous cancer patients who shared their experience with me and to Kate Presti who evaluated my analysis of the data.

TABLE OF CONTENTS

TABLE OF CONTENTS (Continued)

Page

CHAPTER

CHAPTER I

Introduction

New cancer cases in the year 1994 affected an estimated 1,208,000 individuals (Boring, Squires, Tong, & Montgomery, 1994). Most cancer patients will receive one or more conventional treatments for their cancer and approximately half of the patients can expect to live five years or more. The most common conventional therapies for cancer are surgery, chemotherapy, radiation, hormonal therapy, and immuno-therapy (Office of Technology Assessment (OTA), 1990).

The road to possible recovery is often viewed with dread as conventional cancer treatments may mutilate patients physically and psychologically. Nausea, vomiting, alopecia, impaired functioning, and burned skin are well known to people as common side effects of these conventional treatments (Porth, 1986). Some individuals choose unconventional therapies to treat their cancer or to enhance their well-being. Surveys show that 6 to 54 percent of cancer patients use some form of unconventional therapy during the course of their illness (Cassileth, Lusk, Strouse, & Bodenheimer, 1984; Lerner & Kennedy, 1992). A wide variety of unconventional therapies is available in the United States today. The most common unconventional therapies used by cancer patients in the United States are metabolic therapy, diet therapy, mega-doses of vitamins, 'immune' therapy ("interferon", autogenous vaccines, fetal tissue, and other "immune support" agents), imagery, and spiritual therapy (Cassileth, & Berlyne, 1989; Cassileth et al., 1984). These and other unconventional therapies differ from each other in their invasiveness, theoretical background, and expected outcomes. Different expressions are used for the wide variety of unconventional therapies available, often depending on the speaker's attitude toward the issue.

Unconventional Therapies

Unconventional therapies is a term used here for a wide range of therapies used to supplement or replace mainstream medical treatment for cancer. These unconventional therapies are at varying distances from mainstream medical research and practice, from supportive psychological approaches and vitamins to practices that reject the norms of conventional medicine (OTA, 1990). Some of the unconventional therapies may be used along with conventional therapies whereas others exclude mainstream medical treatment. The expected outcome from the therapy may be cure of the disease, control of the disease, temporary relief of symptoms, or generally increased well-being. The legality of unconventional therapies ranges from being within rules and ethical assumptions of society to therapies that are illegal according to U.S. laws (OTA, 1990).

Thousands of cancer patients turn to unconventional methods to supplement or replace conventional treatment. Cassileth and Berlyne (1989) state that more than one half of all patients diagnosed with cancer will try "an unorthodox method at some point during their illness" (p. 29). Cassileth and colleagues (1984) reported that 54 percent of cancer patients in a U.S. clinic used unconventional therapies along with traditional medical treatment, and 40 percent of them left traditional care to receive unconventional therapy only. These figures of 54 percent of cancer patients using unconventional therapies are, however, the highest ones reported. Other surveys show the prevalence of use of unconventional therapies to be 7 to 24 percent among cancer patients (Eidinger & Schapira, 1984; Eisenberg et al., 1993; Faw, Ballentine, Ballentine, & vanEys, 1977; Harris and

Associates, 1987; Lerner & Kennedy, 1992; Mooney, 1985). A recent survey by Lerner and Kennedy (1992) found that 9 percent of over 5,000 cancer patients used one or more unconventional therapies. The cancer patient using unconventional therapies was usually well off financially and better educated than a non-user (Cassileth & Berlyne, 1989; Lerner & Kennedy, 1992). More than one half of the patients turned to unconventional therapies while their disease was still local or regional (Cassileth & Berlyne, 1989). Few patients went to foreign countries to get unconventional therapies; most of them used local unconventional practitioners (Lerner & Kennedy, 1992). Of 166 unconventional practitioners in Cassileth and Berlyne's study (1989) 51 percent were medical doctors.

The main reasons reported by cancer patients for using unconventional or questionable therapies are the hope of cure or control of the cancer, absence of toxicity accompanying these therapies, and the active role patients take in their own therapy (Cassileth & Berlyne, 1989). Danielson and colleagues identified the main risk involved in unconventional therapies as patients delaying or not receiving "effective conventional therapies" (Danielson, Stewart, & Lippert, 1988; Hiratzka, 1985). Among other risks identified are harmful side effects from drugs and inadequate nutrition (Danielson et al., 1988). While none of the unconventional therapies have been proven effective scientifically to control cancer, 59 percent of 452 cancer patients using such therapies considered them to be somewhat to very effective (Lerner & Kennedy, 1992). However, only 16 percent of physicians interviewed in Lerner and Kennedy's study reported that their patients had benefitted from an unconventional therapy. It can be speculated that cancer patients perceive that they are experiencing benefits from unconventional therapies that their physicians and possibly other health care professionals do not know about or understand. Lerner and Kennedy (1992) do not discuss what these perceived benefits of cancer patients using unconventional therapies could be, although other surveys have reached similar results (Faw et al., 1977; Harris and Associates, 1987). No study has been done in the United States to learn what cancer patients are experiencing when using unconventional therapies and what the experience means to them.

There is a lack of consensus in the health care literature on what is an unconventional therapy. In a few of the articles on unconventional therapies the authors list what they consider unconventional (Brown, 1987; Miller & Howard-Ruben, 1983; Murray & Rubel, 1992; OTA, 1990; Sikora, 1989), but in most articles there is only a general discussion or definition of unconventional therapies. Sikora (1989) lists "complementary treatments used for cancer" (p. 1286) including relaxation, counselling, and massage that by some authors would probably be called "middle ground treatments" according to OTA (1990, p. 11). Murray and Rubel (1992) include licensed chiropractors and acupuncturists as "healers" (p. 61). Miller and Howard-Ruben (1983) list 110 "unproven methods for diagnosis or treatment of cancer" (p. 49) including mega-doses of vitamins, and olive oil but do not mention acupuncturists. Differences in what is considered unconventional therapies could be caused by different perceptions of individual authors and the focus of their disciplines. Medicine is more oriented toward treating symptoms, controlling, and curing whereas nursing is focused more on holistic caring and respecting self-determination of the client (Munhall & Oiler, 1986). Medicine may, therefore, focus more on unconventional therapies that aim to cure while nursing also considers methods to enhance the patient's well-being.

Medical Perspective

At first glance, general articles, surveys, and reviews of unconventional therapies are centered around medicine as a science. The unconventional therapies most discussed in medical journals are those claiming possibilities of cure when conventional treatment fails. Emphasis is on the lack of scientific evidence of efficacy of these therapies and on possible dangerous side effects. The approach to unconventional therapies as only curative is supported by the definition of unconventional therapies by Lerner and Kennedy (1992) as "scientifically unproven treatments of cancer and cancer remedies" (p. 181). The American Cancer Society defines questionable methods for cancer treatment as "those diagnostic tests or therapeutic modalities which are promoted for general use in cancer prevention, diagnosis, or treatment and which are, on the basis of careful review by scientists and/or clinicians, not deemed proven nor recommended for current use" (McGinnis, 1991, p. 1789). Dr. Cassileth also defines unconventional therapies as those meant to cure cancer, and excludes from her studies patients who use therapies for psychological benefits only (Cassileth et al., 1984).

Other sources have a broader definition. A report from OTA (1990) states

> They [unconventional methods] are defined in this report not by what they are, but by what they are not; they are not part of mainstream, conventional medicine in the United States. Because of this variety, the treatments described do not easily lend themselves to simple characterizations (p. 9).

According to this statement, unconventional therapies include those meant to enhance overall well-being rather than only directly affecting the cancer. And 'treatment' does not necessarily imply intentions to medically cure but to care for the cancer patients in other ways.

Nursing Perspective

As medicine focuses on cure and control, nursing focuses on care and choice. Treatment in nursing refers to nursing actions or interventions, not medical cure. "The aims of nursing actions are to ameliorate, improve, or correct conditions to which those practices are directed, to prevent illness, and to promote health" (American Nurses' Association (ANA), 1980, p. 12).

> Nurses are guided by a humanistic philosophy having caring coupled with understanding and purpose as its central features. Nurses have the highest regard for self-determination, independence, and choice in decision making in matters of health (ANA, 1980, p. 18).

Any definition or evaluation of unconventional therapies from a nursing perspective would likely include caring, the main characteristic of nursing, rather than the medical aspect of cure.

Literature in nursing regarding unconventional therapies is scant, but in most cases differs from the medical literature. Both general articles and a few studies have been published in nursing concerning unconventional therapies as a nursing intervention for symptom control, to decrease pain and stress, and to increase relaxation and rest, to name a few (Heidt, 1991; Mast, 1986; Newshan, 1989; Zimmerman, Pozehl, Duncan, & Schmitz, 1989). Nursing interventions such as progressive muscle relaxation to decrease nausea and vomiting (Cotanch, 1983), music to decrease cancer pain (Zimmerman et al., 1989), and therapeutic touch to help patients to rest (Heidt, 1991) are not labeled as unconventional therapies but rather referred to as behavioral techniques, non-invasive methods, and in some cases controversial. All of these nursing interventions aim to assist the patient to improved well-being, but not to cure.

However, increased well-being and decreased stress may have health-related consequences. Psychoneuroimmunology (PNI), the study of the relationship between stress, the immune system, and health, has its roots in ancient beliefs. Studies have shown that the immune system is negatively affected by stress and depression (Hillhouse & Adler, 1991). Other studies have found that some unconventional therapies positively affect the immune system (Lane, 1991; Newshan, 1989; Vines, 1988). The mind-body relationship is central in some unconventional therapies such as guided imagery, hypnosis, and relaxation (Cotanch, 1983; Cotanch, Hockenberry, & Herman, 1985; Mast, 1986; Weinrich & Weinrich, 1990) but has been controversial with health care professionals. These therapies are now being subjected to empirical testing, both in animal and human studies (Hillhouse & Adler, 1991). Results from such studies will undoubtedly affect nursing interventions, both conventional and unconventional. "Nursing theoretical frameworks strongly support mind and body integration, and standards of practice emphasize recognition and active intervention in all aspects of a person's experience with health and illness" (Zahourek, 1987, p. 16).

In summary, unconventional therapies span a wide range of therapies, approached and used in different ways by each individual. Although some distinction has been made between care and cure, this is not a basis for categorization of unconventional therapies. The same therapy may be intended to cure by one practitioner and to enhance well-being (care) by another practitioner. Guided imagery as used by Simonton is meant to cure cancer (American Cancer Society, 1982), but in pediatric care is used to reduce pain during diagnostic procedures (Goldsmith, 1992). Clients using unconventional therapies also may have different expectations although most of them enter unconventional therapy with hope of receiving some benefit (Lerner & Kennedy, 1992). A distinction between conventional and unconventional therapies is not clear either. No decisions are found in the literature regarding when a normal use of vitamin supplements ends and therapy with mega-doses of vitamins begins. The same can be said about many other unconventional therapies that are relatively close to the practices of mainstream medicine or everyday life.

Statement of the Problem

Various studies indicate that from 6 to 54 percent of cancer patients in the United States use unconventional therapies contrary to the advice of the conventional medical system and the American Cancer Society (Cassileth & Berlyne, 1989; McGinnis, 1991).

Professional health care literature states that it is necessary to learn about these unconventional therapies to be able to give "informed and persuasive advice" (Cassileth & Berlyne, 1989, p. 29) against what medical professions perceive as a dangerous practice. Patients, however, claim they benefit from the unconventional therapies although it is not specifically known how (Lerner & Kennedy, 1992). The limited research conducted in the United States regarding patient use of unconventional therapies does not satisfactorily answer the question, "What are patients experiencing when they use unconventional therapies and what does their experience mean to them?". The literature does not indicate that health care professionals have an understanding of the experience of a cancer patient using unconventional therapies.

Statement of Purpose

The purpose of this study is to explore the experience of cancer patients using unconventional therapies and the meaning of the experience for them. The research question guiding the study is as follows: What is the lived experience of adult cancer patients who have used or are using unconventional therapies?

Specific aims are to:

1. Obtain descriptions of cancer patients' experience of using unconventional therapies.
2. Analyze and present these descriptions using phenomenological methods (Colaizzi, 1978; van Manen, 1990).
3. Interpret the text to describe the meaning of using unconventional therapies for cancer patients.

Conceptual Framework

The theoretical framework for this study is human science. Wilhelm Dilthey is often credited for the distinction of natural science (naturwissenschaften) versus human science (geisteswissenschaften) (van Manen, 1990). Natural science studies the objects of nature, things, and observable behavior of objects (van Manen, 1990). The method preferred to study natural science "has been detached observation, controlled experiment, and mathematical or quantitative measurement" (van Manen, 1990, p. 4). In natural sciences, the values of the researcher are expected to be separate from the observable "facts" existing in a "real world" (Anderson, 1991). Human science studies the human world of feelings, thoughts, values, emotions, and purposes. Human science uses methods of description, analysis, and interpretation to study subjective, inner world experiences. The human science researcher is a scholar whose research questions come from interest in life (van Manen, 1990). The researcher and the question can not be detached from each other (Bergum, 1991). Nature is explained, but human life must be understood (van Manen, 1990).

Human science allows the study of human perception of experience and its meaning in context since human phenomena are difficult to study in isolation. Human experience is perceived in a personal and cultural domain of meanings and thoughts. Experience and its meaning is not static, but changes continuously through recollection and reflection. As experience is expressed to other individuals it affects them and is in turn affected by their expression. Human experience interacts with the environment in an open system where new experiences and meanings emerge (Polkinghorne, 1988).

Language is the tool that enables human beings to express their world as meaningful to others. The interaction between meaning and its expression in language has posed problems in Western philosophy (Polkinghorne, 1988). Language has been seen as a transparent tool for individuals to convey their experience or as a distorting screen which affects the experience. Merleau-Ponty posed the third possibility that "language may be the lens whose flexibility makes reality appear in sharp focus before experience" (Polkinghorne, 1988, p. 26). Creative language does not determine what is said but enables words to be understood in new connections and in new meanings (Polkinghorne, 1988).

"Human science is rationalistic in that it operates on the assumption that human life may be made intelligible, accessible to human logos or reason, in a broad or full embodied sense" (van Manen, 1990, p. 16). Believing that human experience can be made understandable to others means to believe a person's reality or world can be shared. Human science, however, also assumes that human experience is too complex ever to be understood from a single description as there are always elements of experience that are inexpressible (van Manen, 1990). Human science may often seem to result in vague or ambiguous texts, however, texts that are more recognizable as life than results of natural science fixed in forms of scientific method unable to convey the meaning of life (van Manen, 1990).

Human science has its own criteria for precision, exactness, and rigor. Precision and exactness are met when interpretive descriptions show fullness and completeness of detail, and the phenomenon is explored to a degree of perfection. Human science shows its rigor in a moral and spirited sense. "A strong and rigorous human science text distinguishes itself by its courage to stand up for the uniqueness and significance of the notion to which it has dedicated itself" (van Manen, 1990, p. 18). This study was conducted within the framework of human science as it would allow exploration of a complicated human phenomena.

Definition of Terms

For the purpose of this study, unconventional therapy is defined as a self-care activity practiced by or a therapy given to a cancer patient to supplement or replace mainstream medical cancer treatment but is not considered a conventional treatment for cancer. A self-care activity in this definition refers to an unconventional therapy carried out by the patient rather than by a practitioner.

Assumptions of the Research

Burns (1989) states that the researcher should identify personal assumptions, preconceptions, and presuppositions regarding the phenomenon. The assumptions of this researcher are as follows:

1. There exists a structure that governs the phenomenon of seeking and using unconventional therapy for treatment of cancer and the side effects of the disease.

2. Coping with serious illness encourages some people to search for information regarding the disease and its treatment in order to be an active and responsible participant in promoting one's own health (Cassileth et al., 1984).

3. People are as honest as they choose to be in any given situation.

4. Although empirical studies do not consistently support the effectiveness of unconventional therapies, many clients get some unknown benefits from the therapy (Lerner, & Kennedy, 1992).

5. A strong bias exists in the United States against unconventional therapies.

Significance

A gap has been identified in nursing knowledge regarding the meaning of using unconventional therapies for cancer patients. As usage of unconventional therapies may be a common human response to cope with cancer; the experience for the patient is of interest to oncology nurses. A phenomenological approach is a logical first step toward developing further knowledge regarding the issue. Better understanding of the experience of cancer patients using unconventional therapies may guide traditional health care providers in incorporating some of the important and helpful features found in unconventional therapies.

Utilization of unconventional therapies among cancer patients is a fact. Most of the health care literature in the United States portrays a negative attitude toward unconventional therapies, and warns patients not to use them. The practitioners of unconventional therapies are often accused of intentionally misleading the patient, and thereby delaying or interfering with "appropriate treatment" (Miller & Howard-Ruben, 1983, p. 47). However, some authors suspect that unconventional therapies may offer patients something the traditional health care system does not but should offer, possibly more attention, a personal atmosphere, and hope (Danielson, et al., 1988). Less discussed is the fact that nurses and other health care professionals are already using unconventional therapies within the health care system, in a search for non-invasive therapies and methods consistent with holistic view of nursing to relieve symptoms and increase well-being (Heidt, 1990, 1991; Mast, 1986; Newshan, 1989; Zimmerman et al., 1989). With an understanding of the experience of cancer patients using unconventional therapies, nurses can further study nursing interventions to assist cancer patients. Further studies in this area may form a foundation for different education of cancer patients regarding their disease and therapeutic options. Nurses may be the health professionals to bridge the gap between patients' needs for unconventional therapies and the medical model of the current health care system.

CHAPTER II

Review of Literature

The main purpose of the literature review for this study is to determine the current state of research on unconventional therapies for cancer patients. It is generally accepted that literature reviews must not be exhaustive prior to conducting qualitative studies in order to avoid the development of preconceptions of the phenomenon. However, a systematic search of the literature is necessary to determine the questions that remain unanswered about the phenomenon. The documentation of background knowledge assists the researcher to identify personal assumptions prior to the study (Swanson-Kauffman & Schonwald, 1988). An additional purpose of the literature review is to become familiar with phenomenology in nursing.

The search for literature took place mainly through the use of computerized databases; Medline and PsychLit. Keywords used were alternative, complementary, unorthodox, unconventional, quackery, questionable, unproven, interventions, cancer, nursing, and several specific therapies such as acupuncture, therapeutic touch, hypnosis, and macrobiotic diet. Phenomenology, qualitative, nursing, and methodology were words used to search for data on phenomenology in nursing.

Literature of the health care professionals in the United States quoted in this literature review is often strongly biased against unconventional therapies. The review of literature does not include studies published outside the United States or the lay literature on different therapies.

Results of the literature review are presented in the following sections of 1) studies of unconventional therapies in general, 2) reviews of unconventional therapies, and 3) phenomenology in nursing.

Studies of Unconventional Therapies

Several studies have been conducted to examine the prevalence of use of unconventional therapies among cancer patients (Cassileth et al., 1984; Cassileth, 1986; Eidinger & Schapira, 1984; Faw et al., 1977; Harris and Associates, 1987; Lerner & Kennedy, 1992; Mooney, 1985). Few studies regarding effects of conventional therapies in general are discussed (Bagenal, Easton, Harris, Chilvers,

& McElwain, 1990; Cassileth et al., 1991) but studies focusing on the effects of individual therapies are not included in this review.

Cassileth and colleagues (1984) conducted the first extensive study of cancer patients' use of unconventional therapies. A total of 304 cancer center inpatients and 356 cancer patients cared for by unconventional practitioners were interviewed in order to "identify popular alternative therapies" (p. 105) and those who offer these therapies. Cassileth and colleagues (1984) defined alternative or unorthodox therapies as "treatments that are both used specifically to cure cancer, and are not part of anti-cancer therapies used by the medical establishment" (p. 105). Of the 304 cancer center patients, 13 percent had used unconventional therapy. Since more than half of the total sample was obtained through contacts with unconventional practitioners, the majority of patients used unconventional therapies either as the only treatment (8%) or with conventional treatment (54%). Open-ended questions were used in interviews conducted by research assistants either in the patients' homes or over the telephone.

Race and education of those using unconventional therapies differed significantly from non-users. Cancer patients using unconventional therapies tended to be white and better educated than non-users (Cassileth et al. 1984). Forty-two percent of the patients using unconventional therapies had localized disease or no evidence of cancer at the time they started the therapy and 43 percent had distant spread of their cancer. The most common unconventional therapies used were metabolic therapy (43%), diet therapies (35%), megadoses of vitamins (24%), mental imagery (24%), spiritual healing (19%), and "immune" therapy (15%).

Cassileth and colleagues (1984) found that 60 percent of 138 practitioners of unconventional therapies were M.D.s while the remaining 40 percent were chiropractors, osteopaths, naturopaths, nutritionists, or spiritual/religious leaders. The majority of the cancer patients using metabolic or immune therapy (65% and 53%, respectively) received their care from M.D.s whereas a number of patients in other therapy groups practiced self-care (imagery 46%, spiritual 27%, diet 24%). Thirty-six percent of patients using mega-doses of vitamins received their care from M.D.s while 32 percent of patients treated themselves.

Most patients had started the use of unconventional therapy hoping it would control their disease but these expectations were not fully realized. The majority of patients on metabolic regimens and immune therapy believed the therapy was effective whereas 22 percent of patients using imagery and 43 percent of those on mega-doses of vitamins found their therapy effective in curing or controlling the disease. The natural, non-toxic qualities of unconventional therapies was the most frequent reason for patients to adopt the therapy (Cassileth et al., 1984).

Cassileth and colleagues (1984) found that patients using unconventional therapies held different beliefs regarding the disease and treatment than did non-users. The majority of users of unconventional therapies believed that their cancer could have been prevented. Most users of unconventional therapies told their physicians about their other treatments but in general did not have as good relationship with their physician as did non-users.

Cassileth (1986) extended her previous study to include 1,000 cancer patients; 504 from an inpatient cancer center and 496 patients recruited from unconventional practitioners and groups utilizing unconventional therapies (Cassileth, 1986, Cassileth & Berlyne, 1989). Results of this extended study are similar to those in the previous report. From this extended study, Cassileth and Berlyne

(1989) concluded "that up to half of all patients in any conventional cancer treatment setting . . . will use unorthodox therapies at some time during their illness" (p. 32). This estimate is higher than other surveys show and may be biased by having almost half of the sample recruited from unconventional therapists rather than the cancer patient population at large.

An earlier survey of use of unconventional cancer remedies in pediatric outpatients conducted by Faw and colleagues (1977) showed lower incidence than that of Cassileth and colleagues (1984) and Cassileth (1986). In a sample of 69 patients or their parents, 6 (8.7%) had tried one or more unconventional therapies, 4 (5.8%) had considered trying an unconventional therapy, and 17 (24.6%) patients had received recommendations to seek unconventional therapies (Faw et al., 1977). A similar incidence of use was reported in a Canadian study conducted by Eidinger and Schapira (1984). Three hundred and fifteen cancer patients were asked whether unconventional therapies such as laetrile, megadoses of vitamins, and special diets could cure cancer. About 40 percent of the patients were unsure and one third claimed they were ineffective. However, 70 percent were ready to try such therapies if they were available even though only 7 percent of the patients used some unconventional therapy.

A survey regarding use of unconventional cancer treatments was conducted by Mooney (1985). Seventy-one cancer patients in Utah were interviewed about their knowledge of cancer, use of unproven treatments, and their relationship with health care providers. Thirteen of 71 (18%) participants in the study used some unconventional treatment. Ten of the patients treated themselves with vitamins, herbs, teas, enemas, diet, laetrile, and DMSO, whereas three were treated by a practitioner. Self-care among users of unconventional therapies was higher in Mooney's study (1985) than Cassileth and colleagues (1984) reported. This difference may be a result of different sampling methods. No significant difference was found on biological, social, or disease-related factors between users of unconventional treatments and non-users in the study nor was there a significant difference in purpose in life, anxiety level, social support, knowledge about cancer, and health behavior prior to the diagnosis of cancer. Like Cassileth and colleagues (1984), Mooney found that users of unconventional treatments were less positive about their physician, used more information sources, and took a more active role in their treatment than did non-users. Mooney (1985) suggests that users of unconventional treatments stay active in preserving their quality of life and in control of their life by involvement in treatment-related activities such as preparing food and administering treatments. This need for active involvement in their own treatment could be met in a conventional treatment program rather than be fulfilled in unconventional therapies (Mooney, 1985).

Hiratzka (1985) asked 125 cancer outpatients to complete a questionnaire regarding locus of control, and knowledge and attitudes toward unconventional therapies. A majority of patients had heard of several unconventional therapies, most often laetrile, Greek cure, diets, and detoxification. Patients with a higher internal locus of control had more a positive attitude toward use of unconventional therapies ($r = 0.25$).

The U.S. Department of Health and Human Services contracted with Louis Harris and Associates to conduct a survey of public use of "questionable treatments" (Harris and Associates, 1987). The purpose of the study was to "estimate the extent, pattern, and consequences of public use of unproven treatments in selected areas"

(Harris and Associates, 1987, p. i). An advisory group classified reported treatments as either scientifically acceptable or questionable. A random telephone dialing nationwide provided a sample of 1,514 adults, including 249 arthritis patients and 58 cancer patients. The sample of these subgroups was increased to 297 arthritis patients and 207 cancer patients for further analysis. Of the general sample, 26.6 percent had used one or more unconventional therapies, most of them within a year prior to the survey. Harris and Associates did not find an association between income or race and use of unconventional therapies. Most users were in good health but use of unconventional therapies was more frequent among those in fair or poor health.

Within the subgroup of 207 cancer patients in the Harris and Associates (1987) survey, 15 percent used unconventional therapies and about 33 percent of those found it somewhat or very likely that the therapy would cure their disease. Like Cassileth and colleagues (1984), Harris and Associates, found that cancer patients who used unconventional therapies were better educated and had less faith in traditional medicine than non-users. Cancer patients in the study used various types of diets, vitamin therapy, and mental imagery most often. Metabolic diet, interferon, bile capsules, DMSO, and teas were used less often (Harris and Associates, 1987).

Lerner and Kennedy (1992) did a nationwide survey for the American Cancer Society. "The goal of the survey was to gather information about various types of questionable methods, the extent of their use, the nature of patients who use such methods, the types of methods used, and the effects on patients" (p.182). Random telephone dialing to 36,000 households nationwide by a professional polling agency identified 3,272 living cancer patients and 1,775 cancer patients who had died within 2 years prior to the study, a total of 5,047 cancer patients. This nationwide sample showed the prevalence of use of unconventional therapies to be 9 percent among cancer patients, somewhat lower than reported by Harris and Associates (1987) and Mooney (1985), and much lower than Cassileth's report (1986). Consistent with the study conducted by Cassileth and colleagues (1984), Lerner and Kennedy (1992) found that users of unconventional therapies were better educated than non-users. Users tended to be better off financially than non-users and more women (9.2%) than men (8.7%) used unconventional therapies. Lerner and Kennedy (1992) found that use of unconventional therapies varied by cancer site. More than 20 percent of patients with cancer of the brain, central nervous system, spine, and spinal cord used unconventional therapies. Patients with ovarian cancer, lymphomas, leukemias, and cancer of the mouth also had a high percentage of use of unconventional therapies (12-16%).

Use of unconventional therapies was highest among cancer patients in the West and New England (13-15%) and lowest in the South (6-7%). Sixty-five percent of the patients had told their physician about the use of unconventional therapy, a similar portion as in the study by Cassileth and colleagues (1984). The survey asked whether the patients had used any of the 39 "questionable methods of cancer management known to be in use at the time of the survey" (Lerner & Kennedy, 1992, p. 185) but no list is presented in the report of findings. The most commonly reported unconventional therapies were mind therapies (including imagery, hypnosis, and psychic therapy) (49 %), diets (38%), and drugs or other methods (33%). Few questionable methods were begun in the absence of hope of achieving a benefit. Fifty-nine percent of the patients considered the therapy somewhat or very effective, which is similar to the findings of Cassileth and colleagues (1984).

According to a survey on the prevalence, costs, and patterns of use of unconventional therapies in the United States, in 1990 one in every three (34%) respondents used unconventional therapy (Eisenberg et al., 1993). Random-digit dialing resulted in 1539 completed telephone interviews with English-speaking adults who were physically and cognitively able to be interviewed. The majority of those interviewed reported having one or more medical conditions in the year prior to the survey. Use of unconventional therapies was found in all socio-demographic groups considered, but significantly more so among non-black, college educated, well-off people in the age group 25 to 49 years. Frequency of use of unconventional therapies was 24% among people with cancer or tumors, compared to 36% for people with back-problems, 28% for people with anxiety, and 27% for people with headaches. Groups of people with other medical conditions such as diabetes, urinary problems, and pulmonary problems were less likely to use unconventional therapies (2%-11%) than those previously named. Most of the users of unconventional therapies (72%) did not inform their conventional medical doctor about their use of those therapies (Eisenberg et al., 1993).

Studies on survival of cancer patients using unconventional therapies show inconclusive results (Bagenal et al., 1990, Cassileth et al., 1991). Bagenal and colleagues (1990) compared survival of breast cancer patients receiving unconventional therapy only in the Bristol Cancer Help Center in the United Kingdom with control groups receiving traditional care. Women receiving unconventional therapy only had a shorter survival than did women in the control groups. Cassileth and colleagues (1991) compared survival and quality of life of cancer patients using unconventional therapies and traditional treatment to patients on traditional treatment only. No differences were found in survival between the two groups but patients on traditional treatment only had higher scores for quality of life (Cassileth et al., 1991). Studies on the effects of individual unconventional therapies for various patient groups are numerous but summaries of results most often are inconclusive (Murray & Rubel, 1992).

Reviews

Reviews of topics of interest are probably often the first literature consulted among health care professionals as reviews give a quick overview and references to more detailed articles. Reviews in medical and nursing literature carry an air of caution against unconventional therapies for cancer and give advice to health care professionals on how to help patients make decisions regarding cancer treatment (Brown, 1987; Danielson et al., 1988; Filicetti, 1987; Howard-Ruben & Miller, 1984; McGinnis, 1991; Miller & Howard-Ruben, 1983; Murray & Rubel, 1992).

In reviews, the history of unconventional therapies is often discussed as an introduction to today's unconventional cancer treatments and sometimes includes a statement that a few conventional treatments stem from experiments with unconventional therapies. Some authors discuss also the legislative history of unconventional therapies (Brown, 1987; Filicetti, 1987; Howard-Ruben & Miller, 1984; McGinnis, 1991; Miller & Howard-Ruben, 1983; OTA, 1990). Statistics regarding use of unconventional cancer therapies and demographic characteristics of cancer patients using them are usually cited in various reports by Cassileth and colleagues. Only two reviews mentioned the survey conducted by Harris and Associates (1987) for the U.S. Department of Health and Human Services (Lerner & Kennedy, 1992; OTA, 1990). A majority of the reviews categorize and discuss the most common types of unconventional cancer therapies (Brown, 1987; Danielson et al., 1988; Filicetti, 1987; Howard-Ruben & Miller, 1984; Miller & Howard-Ruben, 1983; Murray & Rubel, 1992; OTA, 1990). The cost of unconventional therapies is discussed in many of the reviews. McGinnis (1991) estimated that as much as 10 billion dollars are being spent nationally each year on unconventional therapies.

Reasons cancer patients seek and use unconventional therapies are speculated more often than empirically cited. Authors of the reviews discuss reasons such as a bad prognosis of cancer, a need for hope, helplessness, a need for control, fear of the disease, impatience, a bad relationship with medical professions, cost and side effects of traditional treatments, pressure from relatives and friends to try unconventional therapies, and a search for miracles (Brown, 1987; Danielson et al., 1988; Filicetti, 1987; Howard-Ruben & Miller, 1984; McGinnis, 1991; Miller & Howard-Ruben, 1983; Murray & Rubel, 1992; OTA, 1990). Risks or possible harm from use of unconventional therapies discussed include delay in seeking conventional treatment, toxic effects, cost, and societal harm as groups associated with unconventional therapies sometimes advocate mistrust of medical institutions (Brown, 1987; Danielson et al., 1988;

Filicetti, 1987; Howard-Ruben & Miller, 1984; McGinnis, 1991; Miller & Howard-Ruben, 1983; Murray & Rubel, 1992). Murray and Rubel (1992) discuss real and potential advantages of unconventional therapies as often being harmless, inexpensive, renewing hope, and occasionally leading to effective treatments.

Advice to health care professionals on how to "help patients make the best decision about their treatment" (Danielson et al., 1988, p. 1005) stresses open and frank discussions with the patient about all aspects of the disease and treatments, including unconventional therapies. Understanding of the patient's point of view also is emphasized. Most authors suggest a tolerant approach to patients who wish to incorporate unconventional therapies into their conventional treatment or go for unconventional therapies only. Murray and Ruben (1992), however, expect that in situations including harmful therapies or a possible lawsuit it "may be necessary to press the patient to choose between conventional and alternative treatments" (p.63).

OTA (1990) is a very thorough report on unconventional cancer treatments, including a review of current mainstream treatments and controversies surrounding traditional treatments. Different forms of evaluation of unconventional therapies are discussed and suggestions offered that traditional empirical methodology may not always be an appropriate way to investigate these therapies. Recommendations for research include further studies on the motivation and characteristics of cancer patients using unconventional therapies.

Phenomenology in Nursing

During the past 30 years, nursing has rapidly increased its knowledge base. The traditional scientific method has been the research method most used to develop knowledge in nursing and was basically the only method used until 1976 (Allen, 1985; Munhall, 1989; Omery, 1983). One of the assumptions underlying the scientific method is that human beings and their environment operate in a structure that can be identified, predicted, and controlled. Through nursing research, relationships between variables have been identified and interventions tested to predict and control human responses. Not all human behavior, however, can be measured and understood under controlled experimental conditions. As nurses described the discipline with holistic and humanistic philosophy, some nurse researchers found the reduction of human beings into small testable units incongruent with a human science (Allen, 1985; Munhall, 1989; Omery, 1983).

In 1976, nurse researchers and theorists began exploring alternative methodologies to empiricism that would enable understanding of nursing phenomena not possible to measure or observe (Munhall, 1989). These alternative methodologies have been called qualitative to contrast them with quantitative methods of the empirical view. One of these alternative qualitative methods is phenomenology (Munhall, 1989; Omery, 1983).

Nursing views the individual as holistic, unique, and self-determined. The focus of nursing humanistic philosophy is "caring coupled with understanding and purpose" (ANA, 1980, p. 12). Phenomenological methods share this view. A growing group of nurse researchers uses phenomenological methods to establish what Oiler (1986) calls a phenomenological baseline in nursing.

> The phenomenological baseline in nursing is the real world of living and experiencing of the patient, family, and nurse. In nursing research and theory, it is a thorough description of our nursing world as it is experienced by the participants. A phenomenological baseline, when established, would provide fully developed nursing concepts that are faithful to the real world of lived nursing experience (Oiler, 1986, p. 58).

A phenomenological study on the lived experience of cancer patients using unconventional therapies would add to the baseline of oncology nursing. One grounded theory study by Heidt (1990) was identified but no phenomenological study was found.

Summary

This review of the literature was conducted to examine the current state of research on unconventional therapies for cancer patients but is not meant to be exhaustive. This review revealed that cancer patients use unconventional therapies to replace or compliment their traditional treatment. Although unconventional therapies have not been proven scientifically to be effective against cancer, many patients claim they benefit from using them. No study was found that explored the cancer patients' experience of using unconventional therapies.

CHAPTER III

Methodology

The purpose of this study is to explore the phenomenon of unconventional therapies as experienced by cancer patients and the meaning of the experience for them. The methodology for achieving this purpose is described in this chapter.

The Phenomenological Method

The phenomenological method is concerned with phenomena of life. "Phenomenology is the study of the lifeworld - the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it" (van Manen, 1990, p. 9). It questions the facts about the world in order to understand and attempts to describe the experience as it is lived (Munhall & Oiler, 1986). Phenomenology takes interest in the human world as it finds it (van Manen, 1990) and accepts all data as they appear. Phenomenological research is a caring act as it sets out to learn what is the most essential to being. Phenomenology as human science aims to assist people to become more thoughtful and respectful of the existence of freedom in human life (van Manen, 1990).

The methodological approach of phenomenology "aims at being presuppositionless" (van Manen, 1990, p. 29) and yet have a certain method. There are paths that lead toward clarification of a phenomenon but there are no fixed signposts (van Manen, 1990). Van Manen (1990, p. 30) explains phenomenological research as a "dynamic interplay among six research activities." The first one is the commitment to the phenomenon that seriously interests the researcher. The second activity is investigating the experience to seek the practical wisdom in the original experience. The third activity is reflecting on the essential themes which characterize the phenomenon where a thoughtful, reflective grasping of the special meaning of the experience takes place. The fourth activity is the art of bringing the experience to life through writing or speech. The fifth activity is to maintain a strong relation oriented to the phenomenon. The sixth and final activity is to balance the research context by looking at the whole and the parts of the research (van Manen, 1990).

The first research activity is for the researcher to explore the interest of the phenomenon that preoccupies his/her mind and commit to that phenomenon. The researcher's orientation to the world guides this particular interest in a human experience. Then the researcher considers personal experience, what examples would illustrate the phenomenon, and what certain words mean in the context of the phenomenon. Formulating the phenomenological question is to ask what something is really like and "become" this question (van Manen, 1990). The researcher needs to be constantly oriented to this original question as he/she keeps opening up to the possibilities of the question.

Van Manen (1990) believes that bracketing is impossible to accomplish but uses the technical term "reduction" to describe the phenomenological device that enables the researcher to discover the lived experience of others. Reduction is a process that involves several steps. This first step of reduction enables the investigator to be open and receptive to every experience. The second step is to overcome one's subjective feelings, preferences, and expectations. This is parallel to the process other phenomenological approaches have named bracketing; that is, suspending one's assumptions and pre-understandings. Van Manen (1990), however, states that putting aside assumptions and knowledge regarding the phenomenon will not successfully eliminate preconceptions. Van Manen (1990) suggests that the investigator makes his/her understandings, assumptions, beliefs, and biases explicit so they can be recognized and challenged. The third step is to clear away theoretical conceptions and temporizations related to the phenomenon in order to be able to experience the phenomenon in a non-abstracting manner. The fourth step is to look beyond the particularity of the lived experience and see the essence of the phenomenon. Reduction is not an end in itself but rather a means to return to the living world for a deeper understanding (van Manen, 1990).

The meaning of the phenomenon needs to be found in the lived experience of the phenomenon. To investigate the lived experience is the second research activity and the researcher can use various methods: personal experience, trace the origin and meaning of words and phrases used for the phenomenon, get others to tell their experience or write it down, observe the phenomenon, or analyze descriptions in the literature and biographies (van Manen, 1990). The researcher, however, has to remember that all these collections of experiences are already transformations of the lived experience moment captured in a certain form of expression.

The third research activity occurs when the structures of experience or themes of the lived experience are determined. "The purpose of phenomenological reflection is to try to grasp the essential meaning of something" (van Manen, 1990, p. 76). The multi-dimensional and multi-layered essence is not grasped in a single definition and requires an organized text or a prose. Theme is more than a categorical statement; it is "seeing" meaning in the text (van Manen, 1990, p. 79) as the researcher tries to capture the phenomenon. In isolating thematic statements, the researcher can approach the text as a whole and make sense of it all, unveil selected phrases that seem particularly essential to the phenomenon, or check every sentence for what it reveals about the phenomenon. The thematic process is driven by the desire to make sense of the experience and to characterize the phenomenon.

The fourth research activity is to write and rewrite the phenomenological text. Human science research is a form of writing, and requires the researcher to be "sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak" (van Manen, 1990, p. 111). The researcher tries to make the experience explicit through the processes of writing and reflection; to see the hidden meaning or experience. By writing, the researcher creates a dialogue between what is known and what is unknown. Writing enables the researcher to discover the structures of experience by giving the researcher certain distance from the text. By writing, the researcher moves from the text into a more universal sphere and to a higher level of abstraction, which facilitates understanding (van Manen, 1990).

The fifth research activity is to maintain a strong and oriented relationship between the research writing and the focus of the research. The researcher cannot wander aimlessly or settle for a superficial description of the phenomenon, but needs to be fully devoted to the study. The text needs to be strong and clear about the phenomenon, and rich and deep. The researcher's knowledge about the lived experience is used to strengthen the relation between knowledge and action, influence the basis for practical action, clarify principles guiding the practice, and use the description of the lived experience as a form of thoughtful learning (van Manen, 1990).

The final research activity is to balance the research context by considering the parts and the whole. The researcher must be able to do both: closely describe the trees and give an overall picture of the forest. The significance of the parts must fit the overall design rather than get disproportional in their contribution to the textual structure. The researcher therefore steps back from the writing and assures that the study is properly grounded in the question (van Manen, 1990).

Data Collection

The method of sampling and data collection underwent some changes. Initially participants were to be sought from the Southeastern parts of the United States in order to be able to conduct face-to-face interviews within a reasonable distance from the researcher's hometown. This plan changed to one of nationwide telephone interviews once the pilot interviews had been conducted.

Sampling

In order to protect the rights of human subjects, the Institutional Review Board (IRB) of the University of Alabama at Birmingham reviewed and approved the research proposal (Appendix A). A flyer (Appendix B) was prepared and distributed locally in approximately 15 health food stores selling vitamins and supplements. These health food stores allowed the flyer to be on display where customers could see it.

An introductory letter (Appendix C) and a flyer were mailed to 66 unconventional health care practitioners such as chiropractors and acupuncturists whose names and businesses were found in the yellow pages of the telephone directory for the area. The researcher called the offices of the unconventional practitioners a week later to ask whether they would put the flyers on display in their waiting area or in some other way make the flyers accessible to cancer patients in their client group.

Out of the 66 unconventional practitioners who were mailed a letter, 27 gave permission to display the flyer. The researcher went to most of the offices of the practitioners to give them additional flyers and meet with them. This visit was meant to create a personal interaction so the practitioners could connect an image to the researcher's name on the flyers. Seventeen unconventional practitioners were reached who responded negatively to the request. Some said they had no cancer patients coming to their practice and others said they were unable to help the researcher at this point. Twenty-two unconventional practitioners were not reached.

From this initial attempt to reach cancer patients using unconventional therapies the researcher received two phone calls in a 2 month time period. The first cancer patient called because her unconventional therapist encouraged her to do so. The second person called several weeks later and did not reveal where she had received information about the study. These two cancer patients lived close enough to be interviewed face-to-face and became the participants for the pilot study.

Both of the pilot participants showed signs of distress resulting from the personal encounter necessary for a face-to-face interview. The first participant chose to come to the researcher's home for the interview and brought a female relative along with her. This can be interpreted as a logical precaution when meeting with an unknown person under unusual circumstances. The second pilot participant was interviewed at her business location where she could ensure privacy. She expressed concerns that her clients would find out about her use of unconventional therapies and asked for specific procedures to hide her identity.

Because the response to the locally distributed flyers was limited and the two pilot participants were concerned with the interview arrangements, the idea of telephone interviews emerged. The telephone interviews accomplished two things: (1) Participants could be reached anywhere in the United States and (2) they could conceal their identity if they so wished. A permission for change in sampling was obtained from the dissertation committee. New flyers were made and a toll-free telephone line opened.

Various means were used to reach possible participants nationwide. A mail-order company distributing vitamins and other supplies was willing to enclose a flyer in the orders mailed out to cancer patients. Friends near and far who either knew of cancer patients or unconventional therapists gave names and phone numbers to the researcher. An abridged version of the flyer was put on a medical bulletin board on an on-line computer system.

The most extensive search was done with mailings to unconventional therapists and clinics. A list of unconventional therapists and clinics nationwide was obtained through a book on various unconventional therapies for cancer patients. The previous letter to local practitioners was revised and mailed with an abstract of the proposed research and a flyer to 45 unconventional therapists and clinics. A week later the researcher started trying to reach these clinics by phone to learn whether the clinics' personnel would be willing to put the flyer on display. Fourteen of the clinics could not be reached and 7 were not able or willing to help. Twenty-four clinics gave a positive answer and were either mailed additional flyers or planned to photocopy the one sent to them. One unconventional practitioner asked to be faxed a copy of the researcher's nursing license and IRB permission.

Before the data collection method was changed to telephone interviews, a request to display flyers was sent to two local conventional cancer outpatient clinics affiliated with large hospitals. The director of nursing and the head nurse for one of the outpatient clinics gave permission after reviewing the proposal and IRB approval. The other clinic gave a temporary permission but wanted the proposal to go before their own Institutional Review Board which was scheduled to meet soon. The IRB discussed the proposal and requested that a statement be added to the flyer indicating the institution neither condoned nor condemned unconventional therapies. Later, when the interviews were to be recorded by telephone, the secretary of the Institutional Review Board did not approve the change in the proposal. No further attempt was made to gain permission at the clinic.

Procedure

Equipment needed for tape-recording was borrowed and tested in a mock interview with a friend in a long distance phone call. Each person who called to inquire about the study, or was called, was given further information (Appendix D) and asked general questions about his/her cancer diagnosis and treatments. Once the person had given a verbal consent to participate and for the interview to be recorded, and the researcher had clarified that the person met the criteria for participation, the recorder was turned on and the consent form was read to the participant.

Demographic data (Appendix E) were gathered first followed by open-ended questions in the interview (Appendix F). More direct questions were asked for clarification. The level of communication differed among the participants as did their experience, education, and mastery of the language. Several participants had a philosophical world view that enabled them to communicate their experience at a different level than others and thereby give a different perspective on the phenomenon. The researcher also changed as the number of interviews grew; becoming more comfortable with limited responses and silences and more sharing at the end of the interviews.

The researcher prepared herself to handle the ethical responsibilities of a nurse clinician in case she interviewed a person who, to the researcher's best judgment, was using life-threatening or otherwise dangerous therapies. This preparation turned out to be irrelevant as the people who responded had used their unconventional therapies safely for awhile and they assumed total responsibility for their actions. It therefore became evident that the researcher's notion of people using unconventional therapies in a self-destructive manner was one of her biases in preparing this study.

Pilot Study

A pilot study was done to assist the researcher to refine the research questions. The researcher met with two cancer patients using unconventional therapies who were willing to share their experiences in tape-recorded, face-to-face interviews.

The first pilot participant, Anna (pseudonym) picked up the flyer from her therapist. Anna was diagnosed with lung cancer a year and a half before the interview and had received chemotherapy and radiotherapy. At the time of the interview she was using mega-doses of vitamins and other supplements from a health food store. Anna came to the home of the researcher with a female relative as a companion. After Anna became comfortable with the setting, she opened up about many of her life experiences regarding her cancer and other aspects of her life, such as caring for her sick mother, children, and now raising her grandchildren. Because this was a pilot interview, the researcher felt it was necessary to allow Anna to express whatever she needed to in order to learn everything Anna was willing to share regarding her experiences.

Marie (pseudonym of the second pilot participant) did not reveal where she had learned about my study and asked to be interviewed in her business office. Marie was diagnosed with cancer in her head and neck area more than 10 years ago and her life expectancy was said to be less than a year at the time of diagnosis. She refused to have surgery as was recommended to her and sought unconventional treatments. Marie used herbs, vitamins, a special diet, and other treatments she was not willing to describe. Her cancer had neither spread nor disappeared during those 10 years. Marie was anxious that her identity was in no way revealed and that none of her clients would come to learn about her treatments of the past 10 years. She also expressed a need to shield the identity of her therapist and the methods that were used. She was very focused and articulate as she told me her story. The events of the last decade were etched into her memory and she had often reflected on her experience.

The pilot interviews were transcribed, and transcription verified against the tape recording and critiqued for interview technique. The researcher learned from the pilot interviews to modify responses to the participants regarding the therapies they used and to help them to keep focused on the subject of cancer and unconventional methods. Phrasing of questions was also modified as asking about feelings regarding unconventional therapies turned out to be confusing. The modifications in the interview guide were helpful for the interviews that followed.

Conclusions from the two pilot interviews supported the idea of collecting data in telephone interviews. Both pilot participants showed concern about meeting with the researcher face-to-face. Anna made special arrangements for safety reasons when meeting with a strange person in an unknown place, and Marie was concerned about her identity being revealed. Telephone interviews would serve the purpose of reaching more cancer patients from all over the United States and also enable participants to control information given to the researcher about their identity.

Data Analysis

Ten interviews were taped, transcribed, and included in analysis for description of the phenomenon. The average interview lasted 30 minutes, ranging from 15 minutes to 90 minutes. When each interview was completed, the tape was transcribed by the researcher. Participants were given pseudonyms and no information about the participants, places, or practitioners was transcribed that could possibly lead to their identification. The transcript of each interview was verified against the tape and corrected. The transcripts ranged from 8 to 55 pages in length on a single-spaced page with 1" margins. The following steps derived from van Manen (1990) and Colaizzi (1978) guided the data analysis:

1. Become embedded in the lived experience by reading and rereading transcripts of the data.
2. Isolate thematic statements by identifying phrases that seem particularly essential to the phenomenon.
3. Look for commonalties in themes.
4. Differentiate between essential themes and themes that are incidentally related to the phenomenon.
5. Describe the meaning of the lived experience of cancer patients using unconventional therapies.
6. Validate description of the phenomenon and its meaning.

Throughout the process of data collection and analysis the researcher used the reduction process suggested by van Manen to enable the researcher to discover the lived experience of others. The steps of the reduction process include being open to every experience, making assumptions and biases explicit in order to recognize and challenge them, clearing away theoretical conceptions related to the phenomenon, and looking for the essence of the phenomenon beyond the particularity of the lived experience. This proved to be important in the data analysis. By accepting all data as they appeared, the researcher discovered themes not previously described in the literature related to the use of unconventional therapies.

The interviews were read for overall impression, and then re-read several times. The researcher also listened to the tapes in a "walkman" tapeplayer on daily walking tours and thereby became submerged in the data. As the first seven interviews were transcribed and read, an image of a path arose in the researcher´s mind; an image of a path that the participants traveled from the diagnosis of cancer to the use of unconventional therapies. This path, later named trajectory, consisted of four themes reflecting the diagnosis of cancer, the dissatisfaction with treatment or treatment options, the process of making a decision regarding treatment, and the commitment to the chosen treatment. To follow the data analysis steps proposed, thematic statements that seemed essential to the phenomenon were isolated from the text. The statements were words, phrases, sentences, and/or paragraphs that described how the participant experienced being a cancer patient and using unconventional therapies. Working with the thematic statements, the researcher looked for commonalities and 16 categories were formed. In an attempt to collapse some of the categories together, the four themes of the path described earlier emerged again. All but two of the categories fell distinctively into one of the four themes named: Given the meaning of cancer, Searching for something else, Making sense, and Commitment.

Three additional interviews were conducted, transcribed, and analyzed. No new ideas or experiences were evident in the additional interviews and analyses confirmed the previously discovered description of the phenomenon. One of the last participants interviewed has 16 years of battling cancer, receiving every possible chemotherapy, and exploring many unconventional therapies. She was very articulate and had a deep understanding of the phenomenon. Without a clue from the researcher, she described the four themes in a nutshell. That was an important confirmation of the analysis for the researcher.

Validity and Reliability

Evaluation of reliability and validity in qualitative research is different from the evaluation in quantitative studies, as are the purposes and approaches. Sandelowski (1986) has defined the evaluation criteria selected for use in this study. The evaluation criteria consist of four factors related to tests of rigor in qualitative research. They are 1) truth value, 2) applicability, 3) consistency, and 4) neutrality.

Truth value is evaluated by the credibility of the qualitative study whereas the quantitative study uses internal validity. A qualitative study is credible when descriptions of its phenomenon and meaning are immediately recognized by people who have experienced the same phenomenon (Sandelowski, 1986).

Applicability is termed fittingness in qualitative research rather than external validity as in quantitative research. The criterion of fittingness is met in a qualitative study "when its findings can 'fit' into context outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experience" (Sandelowski, 1986, p. 32).

Consistency is reflected in the criterion of auditability. A clear decision trail described by the researcher that can be followed by another investigator meets the criterion of auditability. The outside investigator should arrive at similar conclusions given the researcher's data and situation (Sandelowski, 1986).

"Neutrality refers to the freedom from bias in the research process and product" (Sandelowski, 1986, p. 33). Confirmability is the criterion of neutrality and is achieved when truth value, auditability, and applicability are present (Sandelowski, 1986).

To assess credibility and fittingness of the findings of this study, a cancer patient who had used unconventional therapy, but was not a participant in the study, was asked to read and comment on the credibility of the final description of the phenomenon and its meaning. A member check was considered to establish the credibility of the study, but Sandelowski (1993) discussed the complexity and possible threat to validity of using member validation and an outside audience member. The reader stated that she related to the description of the phenomenon and found it fit with her experience. There were occasional issues she did not know from personal experience, such as physicians giving her a bleak outlook on her prognosis. She felt the description was truthful and that she had not learned anything new from reading a draft of the dissertation.

An outside reviewer was asked to assess the auditability. The reviewer is a faculty member at Adelphi University and is familiar with the methodology of the study and the phenomenon of using unconventional therapies. The reviewer read two interviews (Chris and Hannah) and the first four chapters of the dissertation. She commented that the trajectory represented the core themes that emerged in the interviews she read. The reviewer asked for clarification regarding the idea of commitment and whether there are different levels of commitment since Chris's commitment was less whole-hearted than Hannah's. She also suggested that the first theme (then labelled "the meaning of cancer") should be renamed to show that the meaning of cancer came from external forces into the patients' lives.

Limitations

The following limitations are identified for this research:

1. The quality of data is directly dependent on the researcher's ability to ask questions that allow the participants to describe the meaning of using unconventional therapies, to listen, and to respond to participants.

2. The conduct of a phenomenological study is dependent on the researcher's ability to identify own assumptions, preconceptions, and presuppositions regarding the phenomenon in the process of reduction.

3. The quality of data is dependent on the participants' willingness to share their experience with the researcher and their ability to express themselves.

4. As the researcher is an outsider in the community of cancer patients using unconventional therapies, the description of the phenomenon is limited to the researcher's best ability to understand and glean a meaning from the reality of the participants.

Summary

The phenomenological method was used to gather data to describe the lived experience of cancer patients using unconventional therapies. A pilot study with two participants was used to refine the interview guide and go through the steps of data analysis. Then telephone interviews with 10 participants were conducted and analyzed. Data were reviewed repeatedly until themes emerged. Four themes forming a trajectory emerged from the data; Given the meaning of cancer, Searching for something else, Making sense, and Commitment. The analysis process and themes were shared with an outside reviewer and a cancer patient with the experience of using unconventional therapies to establish credibility, fittingness, and auditability.

CHAPTER IV

Findings

The intent of this chapter is to describe the phenomenon of using unconventional therapies from cancer patients' perspective and to explore the meaning of the phenomenon for cancer patients. Data collection, data analysis, and interpretation were guided by phenomenological philosophy and methodology. Included in this chapter are a profile of the participants, a description of the trajectory and its four phases, and discussion of the meaning of the experience.

Participants

Nine women and one man, age 26 to 75 years, participated in the study. All the participants were white and had finished high school. They were of different religious backgrounds and income varied from below $10,000/year to over $100,000/year. The following is a profile of the participants under their pseudonyms including their diagnosis, prognosis as stated by the participants, conventional as well as unconventional treatment, and what each especially contributed to the description of the phenomenon.

Fanny was 67 and had picked up my flyer at her doctor's office. She had a history of various health problems such as arthritis, kidney stones, and heart disease in addition to being diagnosed with breast cancer 17 years ago. Fanny had a mastectomy with positive lymph nodes. She quit chemotherapy after 10 months of treatment and refused to have radiation therapy. Her unconventional methods included guided imagery with a prayer (a method she designed herself) and megadoses of vitamins. Fanny believed that malnutrition in adolescence had something to do with the onset of her cancer. She believed that mind has power over matter, and she thanked her positive attitude and will-power to fight for her cure. She felt that her religious beliefs and support from her husband also made a difference in the process of her cure. Fanny said that if she ever got cancer again she would not use chemotherapy or radiation but would search for other methods.

Bobbie was encouraged to call the researcher by a woman with whom they both were acquainted. However, when she called she said she had very little time to talk but still wanted to participate in the study. This interview was therefore limited in length and depth. The researcher put it aside thinking it would not meet the needs of the study, but as the analysis of the data began to unfold, this limited interview turned out to be a confirmation of the analysis. Bobbie was 75 years old and was diagnosed with breast cancer that had metastasized to her lymph nodes. She was treated with surgery and chemotherapy. Bobbie did not say when she was diagnosed or what her prognosis was at the time of the diagnosis. She used a macrobiotic diet and megadoses of vitamins, expecting that a change in lifestyle would halt the cancer growth. Bobbie talked very matter-of-factly about her cancer experience and her choice of unconventional therapy as the most logical for her.

Chris, a 38-year-old female, was recruited through a physician at an unconventional clinic. She was diagnosed in 1986 with breast cancer that had metastasized to her lungs and bones. A node in her breast was removed and later she had a mastectomy. She received five months of chemotherapy, suffered severe side effects, and quit the chemotherapy when she started using other therapy. The unconventional therapy consisted of a diet, vitamins, fever therapy, and intravenous vitamin C treatment. Chris also had a few acupuncture treatments. Chris provided an insight into what it is like to have a husband and young children while fighting cancer. She was disappointed that the disease and the experience related to it did not pull the family together as she had expected. She had hoped that they would become close and treasure the time they had together but instead, life carried on as usual once the initial crisis was over.

Ester was 55 years old and newly diagnosed with breast cancer when she was interviewed. Her prognosis was good and her conventional treatment was a mastectomy and the hormone, Tamoxifen. Her unconventional therapies consisted of changes in her diet, megadoses of vitamins, and other supplements. Ester had recently lost several family members to cancer and other chronic diseases and she felt that her grief may have caused the cancer. She felt a lot of uncertainty about her future and her treatments, both conventional and unconventional. She asked herself how anyone could know what was the right amount of medicine or vitamins for her body as everyone had different needs.

Jim, 65 years old and single, was the only male in the study. The researcher was referred to him by a mutual acquaintance. Jim was diagnosed with metastatic colon cancer three years prior to the interview. He did not tolerate chemotherapy because of side effects and was given 6 to 12 months to live. He searched diligently for unconventional therapies and decided on one consisting of special diet, drugs (not FDA approved), and supplements. He later added other therapies such as laetrile, Hoxely tonic, and shark cartilage. Jim emphasized that he did not choose unconventional over conventional treatment. Searching for unconventional therapies was, in the beginning, a desperate attempt to stay alive, but later became a lifestyle to feel as good as possible with the spreading disease. Jim was a very articulate participant and discussed how humiliating the battle with death can be.

Kristin, 50 years old, was diagnosed with breast cancer three years earlier. She had a lumpectomy, radiotherapy, and 3 courses of the recommended 6-course chemotherapy. Kristin indicated that the cancer in her body could have been associated with increasing restlessness and a need to change her lifestyle in the years prior to the diagnosis. Kristin and her husband did an extensive search of therapies, both conventional and unconventional. She felt the urge to do something to help heal the cancer and turned to an unconventional therapy that included a special diet, huge amounts of supplements, enemas, and baths. Kristin had doubts about the therapy in the beginning, but was committed to her choice regardless of the work involved and the cost. She is convinced that the mind has power over matter and it is the patient's faith and commitment rather than the therapy that works the wonders.

Molly was a 73-year-old lady who picked up the flyer for the study at her doctor's office. She was diagnosed a year earlier with multiple myeloma with lesions in several places. Her conventional therapy consisted of oral chemotherapy and radiotherapy. She searched for additional knowledge through reading health magazines, and talking to sales representatives in health food stores and other cancer patients in her circle. Molly's unconventional therapies consisted of megadoses of vitamins and other supplements, exercises, changes in nutrition, and prayers. Her attitude was like that of so many other participants: that whatever one believed in would be beneficial to that person.

Ruth was 52 years old and one of the last participants to be interviewed. She had picked up the flyer at the office of her unconventional therapist. She was diagnosed 7 years earlier with oral cancer, had major facial surgery, and was fitted with a prosthesis. She also received radiotherapy to her head. A few years later the disease spread to her lungs and chemotherapy was suggested to her. Ruth decided to turn down chemotherapy and started searching for information on unconventional therapies. Her unconventional therapy is a regimen of special diet, supplements, and enemas. Ruth is convinced that her unconventional therapy has helped her to survive and felt she had to participate in spreading her knowledge.

Sarah was the youngest participant, 26 years old. She was diagnosed with lymphoma 5 years earlier and was originally treated with oral chemotherapy. She and her family felt that the chemotherapy was inadequate and started searching for unconventional therapies. During the next 3 to 4 years she tried serum injection in a foreign country, herbs, vitamins, wheatgrass juice, and a liquid mixture called CANCELL. The conventional therapies were changed to intravenous chemotherapy, and she finally was treated with a bone marrow transplant. Sarah now seems to be disease free. Conflicts with physicians who did not approve of her unconventional therapies affected Sarah in a negative way and were a part of her resentment toward the medical profession. However, when asked what she would recommend for the researcher to do in case of cancer, Sarah suggested a visit to the only conventional physician who was understanding of her unconventional therapies.

Hannah was 42 years old and the last participant in the study. She was diagnosed with Hodgkin's disease 17 years earlier and had used a wide variety of both conventional and unconventional therapies through the years. By the time she was interviewed for this study, the conventional medical world had exhausted chemotherapy options for her and she was receiving a homeopathic therapy in a foreign country. Hannah was self-educated in unconventional therapies and spiritual searching after these 17 years and often discussed spiritual issues that were beyond the understanding of the researcher, so some information may have been lost as result of the knowledge gap between the participant and the researcher.

The Trajectory

The description that emerged from the interviews with the participants in this study was one of a journey following an unknown path or a trajectory. The American Heritage Dictionary (1983) defines trajectory as "the path of a moving particle or body" (p. 717). The Funk and Wagnall's New Comprehensive International Dictionary of English Language (1980) has a similar definition: "The path described by an object or body moving in space" (p. 1332). According to Webster (1987) it means "the curve that a body describes in space" (p. 1251). This applies well to cancer patients using unconventional therapies as they are forced to make their journey on an unknown path toward an unknown destination.

The course of cancer patients' lives is being decided by both external and internal forces over which most of them feel they have little or no control. They feel as though the cancer in their body is an invasion of an external force, but yet they must acknowledge that the cancer is derived from their own cells. The medical team giving treatment to cancer patients, well-meaning family members and friends, toxic chemotherapy, and radiation therapy are important external forces that shape the reality of the cancer patients' experience. Internal forces are the attitudes and belief systems that the patients bring to the situation, knowledge development that takes place through the course of the disease, and biopsychosocial changes that are inevitable part of the journey.

One participant in the study pictured her life with cancer and unconventional therapies as a journey, one of change and growth.

> . . . illness, at least for me, has been a journey of change, of interchange. I personally believe that everything that happens to us is, is like we are in a school on this earth and we are, and we choose or we contract for certain life experiences before we are actually born even to learn lessons that we think we need to learn. Now, that of course is a belief system and, so that's what it has been for me. A real journey of discovery and change and, and that the decisions I make at one time using logic, using what sounds good, using whatever uh, uhm, sometimes using even things that is like an intuition will change over the years . . . so and for me it has also been a journey in, in overturning all your concepts a lot of the times (Hannah).

The journey with cancer begins when the person is diagnosed, but in a way it started much earlier. Previous life experiences, belief systems, health care habits, or habits endangering health are closely knitted into the journey with cancer. Therefore, life before the diagnosis also affects the journey on the path with cancer. The first theme of the trajectory, named Given the Meaning of Cancer, is realizing what cancer means to the individual, and how the diagnosis mirrors the meaning of life and death. What cancer means to the person recently diagnosed is influenced by many things and events in one's life such as previous encounters with cancer, the expressions of medical professionals, friends, and family at the time of the diagnosis, and the person's coping mechanisms throughout life.

The second theme, called Searching for Something Else, is the search for something else to cure the patient or enhance well-being. Conventional medical treatment may have been unavailable, unsatisfactory, unconvincing, unappealing, too toxic, or the patient felt that additional treatment would help. The patient begins a search, sometimes haphazardly, sometimes systematically in order to learn about other options that may be available. The focus is on the person's desire to live and the belief that conventional medical treatment does not promise a cure. Some people search for methods that cure, but others look for methods to enhance their well-being.

The third theme, called Making Sense, is the decision-making process by which the cancer patients sort through the information gathered and decide what treatment they will use. This phase is often a confusing journey on a rocky road for many of the patients, especially in the beginning, but it becomes a little easier as their method of sorting out things has been established. The decision-making process leads to a conclusion and commitment to the method chosen.

The last theme is Commitment, when the patient decides to use the chosen method for his or her own benefit and believes it will work, especially for the power of the mind over body. The commitment phase is a natural one after a carefully thought out decision. In this phase, patients look for manifestations that the treatment is working, or providing a benefit. These manifestations may be both internal, as patients feel in their own body that the treatments are working, or external, with comments from medical professionals or family and friends.

The path of the trajectory is a like a double helix spiraling up toward growth, light, hope, and life. One helix represents the cancer patient and the internal forces that shape the upward spiraling of the helix. Some of the internal forces are the fear of the power of cancer, the urge to live, the hope for a cure, and the faith that a healing modality exists. There are many other forces that affect the spiraling path and they can be different for each person.

The other helix represents the external forces that are always present and affect the cancer patient. Examples of external forces are people in the medical profession, medical research, books on unconventional therapies, information from other cancer patients, and television talk shows on cancer and healing. Each segment of the double helix includes the four themes of the trajectory woven together like threads in a weave. New threads are woven in to add thickness and color or to replace old and worn out threads. As the cancer patient travels the spiraling path, knowledge and experience from previous steps are carried into the next segment of the spiral.

Connecting the two spirals are the issues that are addressed within each theme and each segment of the helix. For example, some of the issues that connect the two spirals in the first theme of the trajectory are fear of death, reactions of others toward the cancer patient, and mourning of lost hopes and dreams. The issues can originate in either spiral of the double helix but will affect the other spiral in a connecting interaction between the internal and external forces. The issues form a cluster-like connection between the spirals and are addressed as such rather than in a sequence.

Some of the issues appear more often than others throughout the repeated segments of the helix. There are certainly more issues involved than are described here. As these spirals are intertwined with the issues on the path of a chronic disease, the two shape each other constantly as reality of the cancer patients using unconventional therapies is formed.

> This whole subject is so much bigger than one person . . . and it is very, very hard, and you just have to get as much information as you can at the beginning and then make a decision. You don't feel like it, you have to make a decision at some point. And go for it. Make the decision and once you have made the decision put your whole heart into it. And if it doesn't work, get on the horse again, get more information and make another decision (Hannah).

Given the Meaning of Cancer

The first theme of the trajectory is when the person learns about the diagnosis of cancer. The person is suddenly thrown into space on a journey with an unknown destination. A previously healthy person is now labeled a patient, one with a chronic disease that is ill-treatable and often fatal. Bushkin (1993) described this as starting a journey in a landscape of insurmountable odds.

The journey starts at this shocking moment when the person learns about the disease. Fear, anger, shock, and desperation are feelings commonly described by the participants as they shared what it meant to them to have cancer.

> Well, I was (short silence) well, you know, when you, when you're, when you receive that kind of news that you have cancer and you may not live a full life, it's really devastating (Chris).
>
> Frightened (short silence). Very frightened. Well, I tried to be brave but my emotions just kind of overtook me (Ester).
>
> I was angry, I was real angry when I was first diagnosed with the fact that I had cancer (Sarah).

Fear often represented what cancer meant to the patients. It was the fear of pain, suffering, and death. Knowledge of cancer stemmed from what the patients had observed with people in their environment, either family or neighbors, who had cancer. As people grow older, their contact with others with cancer increases and they hear more stories about the disease and it's treatment. Closely linked to the image of a cancer patient are the concepts of pain, humiliation, suffering, and death.

> So there I was, you know, within a matter of days, knowing that I had a, a malignancy and facing surgery and I thought I was going to die. So that was very scary (Ruth).

> At the time it happened I was expecting a brother to pass away from prostate cancer. And, I guess death was on my mind and watching him suffering. I was afraid of suffering, I guess. That is the big thing and afraid of leaving your family. I'm, I don't think I'm so much afraid of death (Ester).

Molly did not express the fear others did. She believed in God and had much support from the members of her church. Another factor in her view could be that her husband had passed away the year before and she missed him very much.

> But of course cancer has not, does not hold the horror, you know, for me as it does some people 'cause its a disease. It is treatable. And just like anything else. But I did read that it was terminal, but it didn't bother me. Because when you, I feel like, I don't know, I have a lot of faith (Molly).

The diagnosis of a possibly fatal disease means that dreams and hopes may not come true. The patients feel they have lost the certainty of a future with their loved ones. Their entire future is now dominated by the cancer.

> When I found out I was devastated. Uhm, I thought I would never live to see my son, you know, go to school, ride a dirt-bike, or you know (Chris).

Responses of physicians often reaffirmed the fear and the bleak outlook on life that intensified every moment in the cancer patient's mind. What to a health professional may be a dissemination of realistic information gives the patient an impersonal feeling; feeling that he is more of a "math problem" than a person who will either live or die.

> Yeah I guess that my initial feeling when I found out I had cancer was just total terror. And, every feedback I got back from my standard doctors just made me feel more terror. And I think the reason for that is, you know, you go into a standard oncologist and they right away tell you what your chances are of dying. I mean they don't offer you any hope . . . . So, so, so they, they, they, the whole thing is wrapped up in a whole

> bunch of negativity from them and I, I found it really hard to deal with all of these people and I think they do great disservice to their patients to continually emphasize death and de-emphasize hope (Kristin).

> So, ah, anyway. They told me that I had about six months of good nothing (short silence) to live and, and that I would be in pain . . . . So at home I was, you know, every time I got the death sentence and the doctors said, it put me down, I mean it had effect on me. Negative effect, you know. Well, it put you in a kind of depression, you know (Jim).

Others in the patient's environment also confirmed the image of cancer as being a terminal disease. People surrounding the cancer patient often had difficulty coming to terms with the diagnosis, and frequently cancer held the same fearful meaning for them that it did for the patient. People would not talk about the disease with the patient, felt they were in the presence of a dying person, or felt uneasy about this change in a loved one; one who was a healthy, strong person was now a vulnerable cancer patient.

> . . . and right away when I came home I tried to talk about my cancer at a party and cleared the room. I thought I had a

> contagious disease . . . but I know a lot of people just, the minute you say cancer they think you are dead (Fanny).
>
> . . . and people's reactions to cancer patients is really, really tough. I mean it is tough on the people you are dealing with because you become a person without a future. Although you have a future, you know (Jim).

The life experiences before the diagnosis of cancer affected how the cancer patients dealt with the challenge they faced. The effectiveness of their previous problem-solving methods often influenced how they dealt with the initial phase of their journey with cancer. Several participants leaned on their faith in God and expressed that their beliefs made it easier to face death. In addition to her faith in God, one participant had a lifelong experience of dealing with grief, difficulties, and diseases, and she knew that God helped those who helped themselves. Their coping mechanisms were different, but an important tool in the beginning of the journey.

> Well, I try to be realistic and say I am no different from anybody else in this world who has cancer and the cells move fast, ah, and if that happens to me, then I don't want to have

> myself so built up that I will be so disappointed that I'll say: 'Oh, I thought I had done everything' (Ester).
>
> I am a Christian so I didn't go into a tailspin over it, ah, because I know where I am going in the hereafter. But still it was, needless to say, very shocking (Ruth).
>
> Well, I'm a very positive, opinionated, determined person. Ah (short silence) I, at that time made up my mind I was going to do everything I could to fight it, and if I couldn't, then I made up my mind that I wasn't going to be the type that sat around crying and burden and things. That I would just take every day at a time. I'm a very religious person and I, ah, I made up my mind that the good Lord is the only one that could help, providing that I helped myself, which I was trying to do and I kept a very positive attitude (Fanny).
>
> I have a lot of faith. I live each day. I don't worry about tomorrow and I'm not worrying about yesterday. I, I try and live each day (Molly).

Some of the participants speculated why they and other people get cancer. One expressed responsibility and blame for getting her cancer. Several of other participants felt they might have contributed to developing cancer by having unsolved grief and self-destructive behavior but they did not feel guilty as these were lessons in the school of life.

> That was the big problem. I knew when I had, when I was diagnosed with cancer I knew why I had cancer. I had cancer because I abused my body. Plain and simple (short silence) . . . You know, no one had to tell me that. You see when I, uhm when I, when I was 45 in 1987 I had discovered the cancer. I related it immediately to my guilt and called it that. And I never blamed anybody but me so really this was my own doing and if I was to die I had nobody to blame but me. But I didn't want to die (Ruth).

> And also we have to examine whether we really want to get well. What are we getting from being ill? And if we don't deal with that, nothing will work . . . . That, that, that we need to deal with to heal. There's, they are very individual because in one person's case might be emphasis on one thing. Like for another person, like for one person, it might be primarily emotional, you were very depressed and they depressed their immune system or something. Another person, it might be

> they had very bad living habits and so we have to kind of, illness is, people realize that illness is a message for change. And they really have to examine themselves and see, I don't mean blame, look at yourself if there are things that need to be changed; and in a loving way to yourself change that (Hannah).

As this first theme of the trajectory is revisited in later segments of the double helix, the meaning of cancer changes. The initial shock has passed, the reaction of others toward them may have been modified, and for the patient the concept of cancer has changed. The meaning is then not as much from an external force but more formed within the cancer patient. The meaning of death for the participants changed over the course of their illness. In the beginning, death was a part of the fear that the cancer diagnosis evoked, but later, when this phase of the meaning of cancer was revisited, the face of death had changed.

> I'm not as afraid of death as I used to be. It did make me look at death differently too. And I think that was good. Because, you know, I see death now as an, as an extension, it is just a part of living, it is a part of every one's life (Chris).

> And, and I'm not afraid to die, I'm clean and I've had a beautiful life (Jim).

Searching for Something Else

The second theme of the trajectory is framed by the words "something else" that many participants used when they described their drive to explore unconventional therapeutic options. These words represent an uneasy feeling of not being whole.

> But I wanted to do something for myself . . . . But I still felt I had to do something for myself and I didn't know what else to do (Kristin).

This theme is characterized by confusion, conflicts, and dissatisfaction. Most prevalent are the conflicts with physicians who have lost their image as god-like guides on this journey and are now seen as narrow-minded servants of classical science. Another issue on this phase of the trajectory is the failure rate and difficult side effects of traditional treatments. Lack of the guarantee for a cure or at least some relief of side effects is difficult to tolerate. Some participants found the conventional treatment in conflict with their basic belief system and felt that this toxic treatment was based on illogical thinking.

The participants started their search for something else at different times on the journey. Some of them had used unconventional treatments for other illness or to promote health before they were diagnosed with cancer and it was logical to them to search this avenue for help with their cancer. Others were unfamiliar with unconventional treatments in the beginning, but were open to ideas of different treatment options as they heard of them.

> From the very beginning I started looking into alternative cancer therapies (Kristin).

Two participants did not consider unconventional treatments until they had had cancer for years and metastasis had appeared.

Information was gathered in a systematic, scientific way by some participants, and others took what was handed to them by friends, relatives, and strangers. Many informational sources were used by most of the participants; other cancer patients, systematic reading of research materials, self-help books, magazines, and unconventional therapists. All but one were in some contact with other cancer patients who had used unconventional therapies and these contacts were vital to the participants as they trusted these fellow cancer patients more than most other sources. These were patients who had survived and found something that worked for them. They were living proof that it was possible to get relief from unconventional therapies. Several of the participants did thorough research, using medical libraries, public libraries, conferences, and offices that specialize in providing information for cancer patients.

Gathering information and assimilating that information took a long time for some participants; for others, the search was shorter. All of the participants except one, who was the most recently diagnosed, had revisited this theme of the trajectory. As the participants learned more, their belief systems changed and their needs for different information emerged. Being in contact with providers and users of unconventional therapies also exposed them to an increasing amount of information and discussions on the topic. All changes in the disease and conventional treatment influenced their search for something else. If the patients were feeling better, they had a tendency to relax on their unconventional therapy regimen, but if symptoms worsened, it sent them plunging ahead for additional options.

> But after a while I got worse again and I was looking for something else to do and I found, there is somebody who I had known for, uh, some years (Hannah).

> But I started then, I started to really to feel bad, started to come down and was tired and down physically. Then I started the shark cartilage treatment (Jim).

A few of the participants said that the search for unconventional therapies was driven by a desperate desire to live. They acknowledged that they were looking for a therapy that would cure their cancer and make them able to live a healthy life. Others indicated that their expectation of unconventional therapies was to find something that could keep the disease at bay for a little while longer and make them feel better during the final phase of life. The fear experienced in the first phase of the trajectory was often the driving force in searching for unconventional therapies.

> You see, it is, alternative therapy is only a means in fact in the beginning a desperate mean to, to attempt to keep yourself alive. Because regular medicine has failed you . . . . You learn very fast when it means your life (Jim).

> I, I knew enough about standard breast cancer therapy to know that if I was in really bad shape it wouldn't really save my life. That I had to do something else (Kristin).

> But here in (state) I couldn't find anybody to really help me as far as cure. And so I was willing to try anything (Sarah).

> . . . and I realize psychologically that lot of times when we are scared we feel like we have to do everything (Hannah).

The disappointment and conflicts with physicians were dominant parts of this phase. All of the participants seemed to have trusted the physicians in the beginning and some never lost faith in them. But most had one or more negative encounters with the physician who attended them. Sometimes these conflicts arose out of the patient's search for or use of unconventional therapies, but at other times the patient felt the physician was incompetent in interpersonal skills and had no "bedside manner".

> A few days after I chose this (chemotherapy) my surgeon came in and requested for a radiologist to come in and I refused and he was very argumentative and so was my daughter who is a nurse (Fanny).

> And some, the first doctor would try to use a scare tactic, you know, with me . . . once he had actually had the bash to tell me that I wouldn't be alive at Christmas time (Sarah).
>
> And of course the doctor tried to persuade me to come down there and then he, you know, he never told me it was a chemotherapy . . . . Well he just told me well you've got nothing to, this here alternative medicine won't work, so why don't you come down here and talk to me (Jim).
>
> Well I just don't understand why doctors call vitamin treatment unconventional. I just, seems like to me that should be conventional. I just don't understand why they are so adamant against it and if, and if they really are they need to be educating the public about it (Ester).

A few of the participants were very aware of the amount of money that is contributed to cancer research and perceived the results as minimal.

> How come they are so unsuccessful for 50 years and they are still prevailing? It is cancer I'm talking about, you know. It is the same thing I know my mother died of, the same thing I die of, or am dying with and she, this is 40 years ago and they

> were in New York, in Sloan-Kettering, so it was a nice hospital. They said they'd try to keep her alive for another year, right around the corner something is going to come. This was 40 years ago. The same talk was given to me (Jim).

> As a matter of fact it makes me very angry that all the research money for cancer goes into chemotherapy. It has been obvious for 15 years that chemotherapy doesn't work. I think they ought, I think the medical establishment ought to get behind something new (Kristin).

The personal attitude that the physician displays is important for the patient's perception of what is going on, how sensitive and sympathetic the physician is. It is not easy for an outsider to detect this from the stories told. Only the patient can describe how messages are conveyed. Ruth tells stories of two physicians who both gave her blunt messages but they sounded entirely different to her.

> So I (short silence) I asked a second opinion, and unfortunately I was referred to a colleague in the hospital association that (short silence) of this oncology department and this doctor was the meanest doctor I have ever been to in my life. He ah,

> (short silence) I have really to this day can not understand how an oncologist can talk to a patient the way he talked to me in the first time I met him . . . . And he came back in the room, had an intern with him and the first words he said to me were: 'Mrs. (her name) (short silence) you have cancer and you are going to die from it' (Ruth).
>
> And I went to a wonderful oncologist who examined me (for third opinion) and talked to me and he, I guess, confirmed what they had told me. That the only option was chemotherapy (short silence) ah and yes there were side effects, ah, but the way he put it to me, ah, he said: "If you do not have chemotherapy you will die a very unpleasant death" (short silence). So, but he was very nice. And, so I was there saying all right, that's all there is, that's all there is (Ruth).

Dissatisfaction with conventional treatment and the fear of side effects were important reasons for searching for unconventional therapies for most of the patients. Some expressed a mild uncertainty about whether the chemotherapy was adequate but others had felt strongly that the conventional treatment would kill them sooner than the cancer.

. . . but I'm afraid of that (vitamins) because I don't know what a proper dosage is for me. That is just like I'm afraid of the Tamoxifen. Well, how do they know that 10 milligrams is good for everybody? (Ester).

And I was very much against it (radiation). So I did not allow him (radiologist) to come in. Uh, I was also against chemotherapy to tell you the truth, but I did consent to it . . . But the radiation. I had, I had seen so many people and I had a nurses book I once read and it showed me what it did to people and I just couldn't, I wouldn't consent to it (Fanny).

But right away I was very allergic to the chemo. I had, I got, (short silence) shingles on the, on the face and I almost lost my eyesight. And then the white blood cells went down to almost nothing. So I walked away from it and the following week when the doctor was able to study the record he said I did the right thing. So my instincts are pretty good on that stuff, you know (Jim).

My mind was just completely empty. And it took a long time for me to, for my brain to get to functioning at the speed I was

> accustomed to. They told me the radiation would not affect my brain, but (short silence) I'm telling you it did (Ruth).

The search for information regarding unconventional therapies took on many forms. Almost all the participants had contact with other cancer patients in order to get information about the kind of unconventional therapies they were using and found these sources were very valuable to them. Not only did they feel that there was proof that unconventional therapies could affect survivorship but they expressed the need to talk to people in a similar situation because cancer-free people were unable to understand completely what they were going through.

> I first of all I went to the uhm, (short silence) the Cancer Control Society, I joined that. Went to conventions on the west coast they have another one in Sept, in the early part of September . . . . I went to two of those conventions, . . . and you talk to people that have lived. See my, my program from the very beginning was that, all kinds of people want to give you advice . . . . It is always someone that their relative died. Now they got the answer. I wouldn't listen to those people. The only ones I would listen to were people that were living.

> (laughs) I, I said to them, 'what are you doing?' (laughing) and, and most of them were on (X's) therapy (Jim).
>
> I started talking to this woman (cancer patient) about every two or three weeks on the telephone . . . . And she told me about this Dr. (X) . . . and she told, she had gotten a tremendous amount of information about Dr. (X). She had, as a matter of fact she had talked to several of his patients and she had heard some really wonderful things about him (Kristin)
>
> Well, you know, people talk, you know, if you have cancer and you talk to each other and you discuss what you do and how you are approaching it (Molly).

Books and magazines were a common source for information for all the participants. Most of them read anything they could find and identified the material they wanted to examine further.

> Well, I can't recall if I read it. I, I read an awful lot, but as far this concentration of me and the cancer in my body I read it or I heard it some place that mind over matter . . . . I read of people who went through cancer without any chemo or radiation (Fanny).

> Well everything I read or what I'm reading says that it is the nutrients that we need, ah, to fight the free radicals in our system (Ester).
>
> I read a ton of research. My husband and I spent months going over medical research and everything (Kristin).
>
> Well from reading, you know, there is accounts of people who have had cancer and what they had done, and how it affected them. (short silence) I read a lot of magazines, Hippocrates, Prevention, Longevity, and I try and read anything medical that I can find or anything on cancer or anything about nutrition (Molly).

Friends, family, and strangers were also an information source. Some of the participants found their advice a little too pushy, but most of them explored to some degree the options that were suggested.

> Well I have a cousin who is really big into natural healing or what ever you call it . . . she is really pushing, you know, this kind of thing and she sent me a lot of information (Chris).
>
> My psychiatrist was trying to get me to think about doing some other things. He wasn't trying to get me to quit chemotherapy

> but he kept bringing up the idea, yeah gently pushing me, I guess you could say, into doing something else (Kristin).

Several of the participants were asked what kind of expectations they had for the results of unconventional therapies when they started searching.

> I was hoping and what I was expecting to happen, I was, what I was wanting to happen was to be able to maintain, not get any worse, stop the tumors that I had, be able to keep them under control . . . . That's what I wanted to happen. I (short silence) just so as long as I could control and maintain them and not let them get any worse (Chris).

> There is a category that is considered cancer free and my aim and my goal is to get down to that (Kristin).

> I hope that it will, that I will be a survivor of cancer (Molly).

Making Sense

This third theme of the trajectory is characterized by the decision-making process. In the previous theme, the cancer patients had gathered information from different resources. In this theme it is time to synthesize the information and make a decision. This is often a confusing process in the beginning as the patients sort through a huge amount of material, both intellectually and emotionally. This theme is revisited because the patients are usually continually gathering information and working through it, although the amount is somewhat more constant and manageable as time goes on.

Cancer patients try to use logical reasoning as they go through the information they have gathered and make a decision. The belief that the unconventional therapy is harmless even if it is not effective gave the patients a bottom line; that is, they would not be worse off for trying it.

> The vitamins, I was certain it couldn't hurt me. I was once in (drug store) selling and they had vitamins that were very good and I had taken them to a doctor and he was very pleased with them (Fanny).
>
> I, I don't know. I guess I look at the pros and the cons of them. I think, can this hurt me? . . . . And I thought, as long as it don't hurt me, it can only try and help me, I might as well try. Because I don't want to be one of those people who say 'I wish I would have done this' (Sarah).

Applying the information they have obtained in a logical way gave some of the participants a method with which to work.

> There are so many variables, how do you know that your body, I don't feel like my body is getting the proper feeding, the cells are getting the proper feeding it, as often as it should. So that's why I take extra (Ester).

> Well, I know when I had the cancer and I was taking the chemo I wasn't eating properly. And I felt this was to augment what vitamins, or what I wasn't eating (Fanny).

Decisions are not based on logical reasoning only. Emotions, insights, and intuition were a part of the process toward making a choice that led to a commitment. The uneasy feeling created by the urge to do something had to be satisfied and, therefore, played a part in the decision. In the same way patients were influenced to seek something else because of conflicts with the conventional medical world, so were their decisions influenced by the attitude they encountered at the unconventional clinics.

> And at the time, you know, my mother and I and my husband, we thought it was kind of a silly just waiting around for it to

> act up, so I went to (country A) for some treatment and the center is called (X) (Sarah).
>
> I don't know, suddenly I walked home and I thought, 'I've got to quit chemotherapy.' I've just got to quit. It is going to kill me and I know it that the chances of helping me are like infinitesimal so why am I doing this to myself? (Kristin).
>
> and once I had visited the clinic in (city A) I really liked the atmosphere there. And I liked the people there, and I liked the way that I was treated (Chris).

What is available or feasible was an important influence on the decision-making process, especially for those who had conducted a less extensive search for information.

> The man who I first talked to, he had taken some different kinds of therapy and I would not have minded trying them because it sounded like they would have been beneficial also, but they were not available here (Chris).
>
> It was easy to do it because there was a macrobiotic center here in town. I could go to one of the counselors and get information about it. So it was easy to get information in the library about macrobiotics (Bobbie).

In the same way therapies were chosen based on their appeal to the participants, therapies were excluded because of how unappealing or illogical they were. This exclusion criterion was an important step in selecting a therapy and often crystallized the beliefs underlying the decision.

> The whole idea behind cancer therapy is that they try to kill your cancer without killing you. It doesn't make any sense to me that you can cure somebody's cancer by destroying their immune system, breaking down their body. There is something just illogical about it. Chemotherapy and radiation (Kristin).

> Well, just I've heard lots of quackery type stuff, I guess they are, referred to as far out alternatives such as flushing your system and ah (short silence) things like that. But my, my philosophy on that is that if you eat the proper fruit and vegetables, you don't need weird treatments (short silence) to flush you out or whatever (Ester).

Making sense was the underlying theme of the whole decision-making process. Making sense meant that things had both logical reasoning and a feeling of completeness; something that was agreeable both to the mind and soul. It was like "being in the flow"; feeling in harmony with inner and outer forces.

> Well, everything, I found some things to read about him and just everything he just did made total sense to me (Kristin).
>
> And like I said I went with the treatment that made sense to me. Something that I could understand. Uh, uh (short silence) even with all its complexity, because it certainly has a lot of complexity, I could understand the principle (Ruth).
>
> Well it is like things make a certain kind of logical sense but I don't think we realize that logic is based on premise. That our premises are like beliefs, they can change. And, uhm, so if you have a certain premise, you can make a beautiful logic about it (Hannah).

The decision-making phase of making sense is revisited when additional information has been gathered, or the underlying premise for using a therapy changes.

> Well, making a decision, I think a person can only do what they are capable of doing at that time. I would have made a very different decision at the beginning if I knew what I knew now

> and I would say that in 10 years I might have made still different (Hannah).

Ruth summarized the theme of decision-making:

> And so I started reading. And ah, (short silence) and I got royally confused for a while. And, you know, it gradually sorted it self out. Uhm, but I read about the (Y) treatment, and then uhm, the (Z) treatment and uhm, I then think other macrobiotic treatments, uh, various ones but I kept coming back to the intrigue of Dr. (X) treatment. And that's what I finally settled on because to me that made sense (Ruth).
>
> Researcher: Can you tell me anything more about this process of gradually sorting things out, what happens?
>
> Ruth: Well, I imagine that is different from person to person. I am analytical by nature and I, and I want to know as much as I can about the subject, but I do get tired after a certain length of time. Uh, I don't go to the ends of the earth to exhaust the subject like I am sure a scientist would do. Uh, but I am pretty consistent and so I did read, uh, about all of these treatments from the information that was given to me, but I read through it like you would a novel, you know, and it was, it was

information overload and, and it was confusing and so I had to go back and go through it a little more slowly and then, of course, I went for some books, there was one book, Cancer Survivors and how they did it, uh, was especially good. It was probably the best book that I read . . . . Well, I search for the truth. I (short silence) I don't want to be deluded. (short silence) That's a concern that I have.

Researcher: . . . how do you know that this therapy you chose is the right one?

Ruth: (short silence) Well it seems complete. No mysterious parts.

Commitment

A decision regarding use of unconventional therapy that makes sense to the cancer patient leads to a commitment to the unconventional therapy chosen, even if it may not seem effective in the beginning or turns out to be no more pleasant than chemotherapy. The cancer patients look within themselves for manifestations of the effectiveness of the therapy. They look for signs such as increased well-being, that they have outlived their prognosis, or that they are able to lead what they consider a normal life regardless of the cancer. Manifestations of the effectiveness of the unconventional therapy also come from the environment in the form of x-rays, blood-tests, and reactions of physicians and other therapists to their status.

Support from others plays an important role in the commitment. Many of the patients are dependent on others to assist them in carrying out the procedures of the unconventional therapy. Lack of support from others or conflict with others calls for additional commitment from the patients as they have to carry more of the burden by themselves. To continue the commitment even if there is conflict with friends, family, and medical professionals demonstrates that cancer patients have made their decision regarding treatment for their cancer.

For most of the participants the commitment is total, physical, financial, emotional, and spiritual. The two participants who had young children in their family did not fully follow their therapy regarding diet. They were, however, aware of the importance of total commitment to their regimen.

> I bought the machines and all the stuff that went with it . . . . But I had to, what I had to do was, was I, I sold my other house

> and bought, actually I was renting a border house, so that I had my freezer and machines and the tables to do all the juicing. So I built my, my, my whole life around my therapy. You have to make that kind of commitment . . . and then I hired some help to do that, help me with the meals and that kind of stuff and that was the only way I really stay on the program (Jim).

In response to the researcher's question: "How does one know what's gonna work?" Chris answered:

> Well you don't. (laughs) Really I don't think you do. I don't think you know what's going to work. I think you can believe and you can dedicate yourself to one kind of therapy and I think dedicating yourself to it has a lot to do with whether or not it does help you because I do believe that your mind and the frame of mind that you are in has a lot to do with it . . . . There is a big routine (we laugh). But it takes time to shop. It takes time to do those infinitive different things and like every hour you are stopping to do something. Since I started the (X) program my company has been letting me work at home. I have also cut down to three quarters job. I need to get back to work pretty soon. Actually that is probably coming to an end.

> It would be absolutely impossible to do this and hold down a regular job . . . . Well, I just, I need to have an income. And between the fact that I am only working three quarter time and the fact that my, the expense of this program. It is very expensive. It is about 600 dollars a month in supplements and everything. I, you know, my income is, between those two things and I actually have, you know, less than half the income that I used to have, and so, my insurance does not cover any of this. Plus, I have the expense of going to (state) twice a year to see Dr. (X) and that is expensive too (Kristin).

Committing to a therapy often requires a total change in lifestyle and prohibits the patient from many activities he/she previously enjoyed. The social isolation the participants felt was due to a variety of reasons: fatigue from the disease and the therapy, strict diets that are not served in restaurants, lack of time to socialize because of the treatment, and last but not least, avoidance of people who do not support the patients in their use of unconventional therapies.

> Well, there are so many that are skeptical. If you talked about things like that (mind over matter) they thought you were crazy (Fanny).
>
> Yeah it definitely does isolate you. There is no doubt about that . . . . I'm at home now and because I spend so much time doing all this stuff I, you, you really are a bit cut off. So in a way you are kind of off by yourself because I guess that generally people feel that if there were a cancer therapy around that worked all doctors would be doing it (laughs), you know . . . . Oh they (family and friends) don't, they don't voice it like that cause they are trying to be very positive about it. (Kristin).
>
> Well, it takes a lot of effort to do the cooking and be careful about eating out (Bobbie).

The participants expressed their need for physical and emotional support. Family, friends, and therapists played an important role in providing support for the participants during this time. The participants were grateful for the support they received and found it extremely valuable.

> Oh, I think a cooperative husband is very important and I have one (Fanny).
>
> That (fever therapy) treated me, that made me, that was really the same way that the chemotherapy had done me. But the main difference was the people that surrounded me and that took care of me while I was going through the therapy (Chris).
>
> I was lucky to have a cousin who went with me to (city for unconventional therapy) . . . but I knew that I had to have some kind of help (Chris).

Evidence that the therapy is working toward a cure or at least better health is an important motivator. This evidence is often a subjective assessment of how the patient feels but may also be provided by physicians who show some signs of approval of the unconventional therapy, or blood tests or x-rays which show improvement.

> Those doctors have called my daughter (who is an RN) from back here and stated that if it wasn't for my positive attitude and my vitamins I would be dead (Fanny).
>
> When I left work to begin treatment I was quite weak and could barely walk. By April 8 all the time my body was a real

chore to carry along. My tissues were swelled and bloated. My joints hurt and sleeping was uncomfortable. My mind was not sharp. I troubled over every decision. My husband, off work for the time, helped me for the first two months in seven and a half hours daily spent in meal preparation, detoxification, around the clock supplements, and related tasks were struggles. I had various temporary illnesses but by October 1992 I begin to feel a little better under the treatment program. Very gradually I improved, being alternately ill and well day to day. It wasn't easy. Since May of 93 I have had longer and longer periods of well being. Today I feel like a different person . . . . I know how I felt in July of 1992 and I know how I feel today and if somebody is depending on the bloodtest column how I feel, they are not going to find that out (From a letter Ruth wrote to Congress regarding unconventional therapies).

Well, the last check that I had was good. Since I had the, started having the therapy, now even since I had the chemotherapy there has been no new growths by the tests that

> have been done . . . There has been no new growth and that's what counts to me (Chris).

Several of the participants were asked what they would recommend the researcher do if she became a cancer patient. It was evident through their answers that they have not subscribed to a certain method or "a cult" they think will work for everyone, but that they believe in the power of a person's mind to affect his or her body. The faith in the power of mind over matter consistently appears. Sometimes it is rooted in fundamental religion, and for other participants it is a part of metaphysical faith, faith in the evidence of things that are unseen. Therefore, their suggestion to the researcher was to follow the trajectory of realizing what cancer means, searching for methods that were compatible with the person's belief system, making logically and emotionally sound decisions, and committing to that therapy.

> I think anyone who goes into any therapy knowing that it is going to work, I think believing that it is going to work (short silence) I think that it can, you know, if you, if you believe strongly enough and you dedicate yourself to whatever the doctors tell you, doctors and nurses tell you to do, I think

> sometimes mind over matters is where it is at . . . . Keeping the right attitude, yes, has a lot to do with it (Chris).

> I think whatever you do, whether it is traditional or non-traditional you should put your full faith in it. And in order to put your full faith in something you have to really be ready to be well (Hannah).

The spiral nature of the trajectory unfolds itself as the patients learn more and their condition changes. This leads to new decisions and sometimes changes in the therapy. That does not indicate the previous decision was wrong but that circumstances change and beliefs evolve. And although the participants get more familiar with the path and the methods to deal with issues that arise they are never walking the same path and do not know what is around the next curve.

In response to the researcher's question: " Can you tell me what it is like to be a person with cancer trying different kinds of treatments?" Sarah replied:

> It's like a stab in the dark (laughs). Like being blindfolded, like a pin-the-tail-on-the-donkey kind of thing. That's what I picture it as. Because you know, you never know what is

going to work for you. And if you find that one thing, then more power to you.

The Meaning of Using Unconventional Therapies

When a person is diagnosed with cancer his/her prospect of life is replaced in one instant with the prospect of death. Goals and priorities in life have changed as cancer represents uncertainty, lack of future. And the goal of life becomes to stay alive. The desire to live is the motivation to search for cure and thereby hope. In searching and making choices, the patient is forced to look at his/her own priorities and what belief system or life philosophy on which he/she bases decisions. Many cancer patients find conventional medical science agreeable to their belief system and commit to use conventional therapies.

Cancer patients using unconventional therapies in this study did not find that kind of faith in medical science and searched for something else to add to or replace their treatment. The participants found therapies that made sense to them to which they could commit. An important component of the therapy was to believe it would work. The philosophy that mind governs the body was common among the participants and the basis for the advice they gave the researcher to follow if she ever got cancer.

According to this philosophy the person with cancer has an opportunity to reform the reality of cancer as he/she uses his/her mind to govern his/her body. To the participants in this study, mind over matter is not all there is to using unconventional therapies. As they took the steps necessary to select and commit to a therapy, they cared for their whole existence, physical, mental, emotional, and spiritual. Exploring the literature; looking at their past, present, and future; and weighing the options and excluding all but one was not an easy task to do. However, they firmly believed that they were capable of knowing what was best for them and carry out the treatment. By doing so, they expressed love and care for themselves. They decided to love all of who they were.

Summary

The findings in this chapter are presented in the form of a trajectory; a path of a body hurtling through space. The cancer patient in this study traveled a path consisting of four themes that are repeatedly visited. The first theme, called Given the Meaning of Cancer, is realizing what cancer means to the person just diagnosed and how its meaning changes as the path is traveled. The meaning of cancer is mostly influenced by external factors such as reactions of others to the cancer patient but also internal factors such as beliefs and coping style.

The second theme, called Searching for Something Else, is the search for a treatment or philosophy that gives the possibility of cure or enhanced well-being. The motivation behind the search is the desire to live.

The third theme, Making Sense, is the process of decision-making. The decision to use a certain unconventional therapy was based on both intellectual and emotional processing. The therapy that participants chose had to appeal to them, make sense to them, and fit with their belief system.

The fourth theme, Commitment, represents the necessity of committing to the therapy they chose because it will work only if they are committed; if they live the therapy. If it does not work or the disease changes the patients keep on searching and make another decision and commitment.

As participants in the study were diagnosed with cancer, their purpose in life was replaced by the single goal to live.

Unconventional therapies became the means to restore certainty in their life in the form of possible cure. The belief that their commitment to the therapy was more important than the therapy itself indicates that the main element in using unconventional therapy is putting in practice the idea of mind over matter.

CHAPTER V

Discussion and Implications

Discussion

In this phenomenological study, aimed at describing the lived experience of cancer patients using unconventional therapies and the meaning of that experience, the researcher was for a brief moment allowed to enter the world of the participants. During that brief visit into the reality of cancer patients, the researcher was able to take a few snapshots of that world and put together a photo album afterward. This album can show neither the view behind the photographer's back nor the scenes that were not filmed, but only made a hazy imprint in the mind. However, the overall impression, the gestalt view, of the lived experience formed in the researcher's mind.

The finding that emerged from the interviews was a path or trajectory. From the interviews with the participants, their stories were found to be diverse and the unconventional methods they used different. It seemed as if they were going in different directions.

After transcribing the interviews and reading them multiple times, the researcher began to formulate a common path or a process. Despite the variety of unconventional therapies the participants used, they were all hurtling along on the same trajectory. They found their choice of unconventional therapy a significant factor in their well-being and hope to survive cancer. Megadoses of vitamins, prayers, shark cartilage, and Gerson's therapy were equally important therapies and the decision-making processes to use these therapies were very much alike.

The participants, however, had their own way of travelling the trajectory. Cancer had a significant meaning for them. Some were overcome by the diagnosis of cancer. Others like Molly decided that cancer didn't hold the horror for her. The search the participants did was different, but they were all seeking the missing piece to their treatment puzzle. Some did an extensive search and felt confident in what they were doing. Others did a less extensive search and what they found met their need for that something else. They believed that only they themselves could know what was best for them. The decision-making process was similar among them; the decision was both emotional and logical. Things had to appeal to them, to be available within their resources, make sense within their belief system, and have some logic to them. Once the decision was made, the patient committed to the therapy. The decision and the commitment showed respect for his/her mind as well as his/her body. He/she took the whole of his/her being into account as he/she carried out the treatment he/she believed was the right one.

The decisions the participants made regarding use of unconventional therapies were solid, but not necessarily final. Their search often continued as they kept on reading and talking to other cancer patients using unconventional therapies. When their understanding and meaning of the disease changed with the detection of a new metastasis or new information about their prognosis, they were motivated to fight harder, find new ways, make another decision, and commit again. This way they could reshape the meaning of cancer and gain hope while coping with what others thought of as a fatal disease.

The participants described a journey which they in the beginning were forced to take, but later they took charge of what happened on that path they travelled. After the experience of being a person without a future because of their cancer they became motivated to find another meaning of cancer and another way of dealing with their powerlessness. In other words, they found a different way of dealing with the cancer, and through that, found another meaning to cancer. They realized they could have some input into what happened to them by using methods that affected body and mind. They also felt confident that they could partially care for themselves and know what was best for them. Everything was dependent on their commitment to their beliefs and choices. Although some had to face the realization that the therapy they chose didn't cure their cancer, they steadfastly believed that trying the unconventional therapy had helped them feel better or to stay alive long enough to try another choice, be it conventional or unconventional.

In a paper delivered posthumously by her husband, Bushkin (1993) took her audience with her as tourists on "the unknown roads that stretch before anyone with a life-threatening diagnosis" (p. 869). She said: "It is designed to allow you to enter into another dimension of living and to glimpse the unique philosophy of survivorship. It will enable you to better prepare for future encounters in your personal and professional lives " (Bushkin, p. 869). This researcher hopes that the realities that the participants in this study shared with her will in a similar way increase the level of understanding of cancer patients' use of unconventional therapies among health care professionals.

Bushkin described the journey of the cancer patient once the diagnosis has been made. She made drawings of traffic signs that represented the many different aspects of the journey: options, feelings, support, isolation, and hope. The journey starts at the sign pointing to Insurmountable Odds. The options are to travel the road of courage or the road of hopelessness. The road of courage has a stop sign indicating that life has stopped and the medical diagnosis has taken over. Bushkin described in her presentation how the disease had become her, but later she learned to survive with the disease. There were times during the journey when a change in the disease filled her with fear and the meaning of cancer took over, but after a field trip on that path, the cancer patient knows how to get the upper hand again (Bushkin, 1993).

The medical system is pictured by Bushkin as a maze where the patients are powerless outsiders forced to travel and the health care professionals observe them like fish in a bowl. The patients' rage becomes the fuel they need to continue on the road of courage. There is, however, the fear that the bowl might break and none of the observers would pay attention. Some of the observers are capable of becoming supporters and travel companions for awhile, but only the cancer patient knows what it is really like to travel the path (Buskin, 1993).

The participants in this study described a journey similar to Bushkin's. The meaning of cancer was overwhelming at first but later they were able to change that meaning. Most of the participants found the medical system narrow-minded and negative, but were also dependent on the same system for care. They made a decision to follow the road of courage based on their belief system. They committed to major life-style changes and expensive treatments regardless of doubtful outcomes and conflicts with the conventional medical system.

Bushkin (1993) expressed the ambivalence between being forced to travel a road for which she had no map and yet being willing to take charge of the journey. When Bushkin chose to follow the road sign of courage rather than that of hopelessness, she made a decision much like the participants in this study did although she did not articulate how that decision was made. She was committed to follow that road sign whereever it took her; on rough roads with no shoulders, roller coasters, and endless waiting rooms; toward the light of hope.

Framework of Illness Trajectory

The findings of this study are supported by the illness trajectory framework described by Strauss and colleagues. "The trajectory framework is a conceptual model built around the idea that chronic conditions have a course that varies and changes over time" (Corbin and Strauss, 1991, p. 156). The framework has been developing over the last 30 years through a series of research studies of patients with chronic and terminal conditions. The purpose of the research is to determine the proper management of the illness trajectory.

"Trajectory" is the central concept in the framework, and represents the course of an illness that is shaped by the efforts of the patient, family, and health care workers. Corbin and Strauss (1991) describe eight phases of different status changes during the course of the illness and within each of those are subphases. As in the trajectory developed in this study, Corbin and Strauss point out that during each phase there may be conditions that characterize other phases. Therefore, the phases are intertwined and there is a constant interaction between the illness, the patient, and the environment. Other concepts in the framework are trajectory projection, trajectory scheme, conditions influencing management, trajectory management, biographical and every day living impact, and reciprocal impact.

"Trajectories are often uncertain. They can be graphed but only in retrospect" (Corbin & Strauss, 1991, p. 162). Trajectory projection is the vision of the illness course. Previous experiences, a meaning of the disease, symptoms, and time shape the vision. Others in contact with the patient have their projection and affect the patient's vision. Knowledge, beliefs, and experience regarding the illness are other factors that affect the vision of the trajectory. This vision may motivate the patient to take action as it motivated the participants in the study presented here. The meaning of cancer for most of the participants, fear of death and suffering, and dissatisfaction with their treatment options motivated them to search for other modalities. Corbin and Strauss' trajectory projection shows similarities with factors in the first two phases of the trajectory in this study, namely Given the Meaning of Cancer and Searching for Something Else.

In the trajectory framework, the trajectory scheme is the plan to handle disabilities, control symptoms, and shape the course of the illness. This scheme includes not only conventional treatment but also unconventional. As the illness and its trajectory is complex, so are there many conditions that can facilitate or hinder how the scheme is carried out. Support from the environment, interactions with conventional and unconventional medical providers, politics, money, past experience, motivation, setting of care, life-style, and beliefs are a few of these conditions (Corbin and Strauss, 1991). The third and fourth themes of the trajectory emerging from this study, Making Sense and Commitment, address many of these conditions. Making Sense was an internal process affected by beliefs, previous experience, life-style, and also external forces such as money, politics, and resources. Motivation to take action was the prime force behind the decision and commitment to an unconventional therapy.

Wiener and Dodd (1993) use the trajectory framework to describe work processes as a way to view coping with chronic illness. The illness trajectory refers to all of the related work in a course of an illness as well as to the impact on everyone involved. Wiener and Dodd (1993) use the word "process" to imply change over time rather than stages. Therefore, the trajectory is not a cycle that is repeated, but a change on a continuum toward growth. This understanding of the nature of a trajectory is similar to the researcher's.

The Literature and the Findings

A review of the literature revealed several nationwide studies on the prevalence of unconventional therapies, demographic descriptions of cancer patients using unconventional therapies, their reasons for using these therapies, and descriptions of unconventional therapists (Cassileth et al., 1984; Eisenberg et al., 1993; Lerner & Kennedy, 1992). Only one of these quantitative studies employed open-ended questions to collect data regarding issues like what expectations the patients had toward the unconventional therapies they were using, how they related to the physicians, and why they started using unconventional therapies (Cassileth, 1984; 1989). The reasons for cancer patients' use of unconventional therapies found by Cassileth through her interviews are in essence the same as those revealed by the participants in this study -- mainly the need to practice a treatment method that is consistent with their belief system and that gives them hope for cure. "Most patients find the internal logic and global, mind-body emphasis of this perspective intuitively correct and fundamentally appealing" (Cassileth, 1984, p. 110). Cassileth's view is, however, limited in the sense that it gives a stagnant picture of the patient's mind rather than capture the continuous change that takes place in interaction between the disease, the patient, and the environment. Some of the participants in this study used both conventional and unconventional therapies at the same time, and others went from conventional to unconventional and back to conventional as their disease and knowledge changed.

The Phenomenological Framework

The phenomenological framework that guided this study allowed for insight into the world of realities of cancer patients using unconventional therapies. The methodology allowed the description to come forward by using open-ended questions and in some cases letting the participants lead the interview. The experience of participating in the interviews was in all cases moving, sometimes humbling, and reminded the researcher of her own ignorance and lack of self-care. Interviews with the participants were open and honest. The reality of the lived experience was shaped as the participants told their story and articulated the experience. The researcher used the method of reduction to stay open and alert to new ideas and be constantly aware of her own reactions to the data.

Many of the interviews reached a level of honesty where the researcher was moved to view her own life and belief systems in the light of the experience of the participants. The effect of the data on the researcher's life was a verification that in-depth interviews in qualititve research are interactive, and the researcher is not a mere outside observer facilitating the flow of data. Being invited into the world of the participants made the researcher a partner in their temporary life. Reality was being shaped as the interview took place.

The phenomenological method allowed for the trajectory to emerge as the significant meaning of the lived experience. Without the in-depth interviews, the process that took place over the time of a life-threatening disease would not have surfaced. Only through sharing time with the participants on their "turf" could the researcher get glimpses of what their world was like.

Implications for Nursing

Practice

Nurses working with oncology patients and possibly other patient populations need to develop a consciousness of what using unconventional therapies means to the patients and care for them in the light of that consciousness. The trajectory as presented in this study offers an insight into the realities of the patients' world. By learning about the different phases of the trajectory and how patients travel the path, nurses and other health care workers will be able to understand the factors that are the basis for the use of unconventional therapies for the cancer patient.

The health care worker caring for a cancer patient using an unconventional therapy can use the trajectory to understand where the patient is on the path, where the patient has been, and how any changes in the disease may affect the path of the trajectory. Based on the trajectory, the nurse can care for the patient's needs to re-establish meaning and philosophy in life as well as their need for time to search for different methods and to find the congruency between their new philosophy of life and the treatment they chose. The nurse who is conscious of the meaning of using unconventional therapies can enter the reality of the patients and assist them through their belief systems to articulate what they want and how they wish to proceed with their treatment.

Education

The description of the lived experience of cancer patient using unconventional therapies and its meaning are of importance to health care workers as they have not been described previously. It is important for health care professionals to realize what cancer patients experience and how some of them come to use unconventional therapies. Students in health care need to understand the treatment of the cancer patient not only from the classical medical model, but also from the patients' perspective. The students need to gain insight into the reality of patients with chronic diseases and others who use unconventional therapies contrary to the beliefs of the conventional medical system.

It is interesting to observe that nurses are incorporating holistic health care into their nursing practice at hospitals and that courses on alternative nursing care such as therapeutic touch are being offered at nursing schools. Having increased opportunities to use unconventional methods within the health care system might make it easier for patients to explore different methods and for health care professionals to have open and honest dialogue about this aspect of health care.

Research

In light of the trajectory, it would be interesting to conduct a similar study with other patient populations who are known to use unconventional therapies, such as patient with arthritis or AIDS. Patient populations who have either more or less life-threatening illness may travel the path differently or a different path altogether. The effects of different cultures on the lived experience of cancer patients using unconventional therapies could be explored in international studies.

This study could be expanded to learn about the possible role of the health care workers with the patient using unconventional therapies. According to the findings from this study, the medical profession is often seen as having a biased attitude toward unconventional therapies and negative effects on patients who use these therapies. Nurses are hardly mentioned in the interviews conducted for this study. Since the patient is the focus of attention for the health care workers, it would be essential to know what meaningful role nurses could play in the lived experience of cancer for patient using unconventional therapies.

REFERENCES

Allen, D. G. (1985). Nursing research and social control: Alternative models of science that emphasize understanding and emanicipation. Image, 17 (2), 58-64.

American Cancer Society (1982). Unproven methods of cancer management: O. Carl Simonton. CA-A Cancer Journal for Clinicians, 32, 58-61.

American Nurses' Association (1980). Nursing: A social policy statement. Kansas City, MO: ANA.

Anderson, J. M. (1991). The phenomenological perspective. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 25-38). Newbury Park, CA: Sage Publications.

Bagenal, F. S, Easton, D. F., Harris, E., Chilvers, C. E. D., & McElwain,T. J. (1990). Survival of patients with breast cancer attending Bristol Cancer Help Center. The Lancet, 336, 606-610.

Bergum, V. (1991). Being a phenomenological researcher. In J. M. Morse (Ed.), Qualitative nursing research. A contemporary dialogue (pp. 55-71). Newbury Park, California: Sage Publications.

Boring, C. C., Squires, T. S., Tong, T., & Montgomery, S. (1994). Cancer statistics, 1992. CA-A Cancer Journal for Clinicians, 44, 7-27.

Brown, H. G. (1987). The deadliest delusion: Unproven methods in the management of cancer. Women and Health, 11, 165-177.

Brown, M. I. (1986). Social theory in geriatric nursing research, In L.H. Nicoll (ed.), Perspectives on nursing theory (pp. 126-132). Glenview, Illinois: Scott, Foresman and Company.

Burns, N. (1989). Standards for qualitative research. Nursing Science Quarterly, 2 (1), 44-52.

Bushkin, E. (1993). Signposts of survivorship. Oncology Nursing Forum, 20, 869-875.

Cassileth, B. R. (1986). Unorthodox cancer medicine. Cancer Investigation, 4, 591-598.

Cassileth, B. R., & Berlyne, D. (1989). Counseling the cancer patient who wants to try unorthodox or questionable therapies. Oncology, 3 (4), 29-33.

Cassileth, B. R., Lusk, E., Strouse, T., & Bodenheimer, B. (1984). Contemporary unorthodox treatments in cancer medicine. Annals of Internal Medicine, 101, 105-112.

Cassileth, B. R., Lusk, E. J., Guerry, D., Blake, A. D., Walsh, W. P., Kascius, L., & Schultz, D. J. (1991). Survival and quality of life among patients receiving unproven as compared with conventional cancer therapy. The New England Journal of Medicine, 324, 1180-1185.

Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In R. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 48-71). New York: Oxford University Press.

Corbin, J. M., & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. Scholarly Inquiry for Nursing Practice: An International Journal, 5, 155-174.

Cotanch, P. H. (1983). Relaxation training for control of nausea and vomiting in patients receiving chemotherapy. Cancer Nursing, 6, 277-283.

Cotanch, P., Hockenberry, M., & Herman, S. (1985). Self-hypnosis as antiemetic therapy in children receiving chemotherapy. Oncology Nursing Forum, 12 (4), 41-46.

Danielson, K. J., Stewart, D. E., & Lippert, G. P. (1988). Unconventional cancer remedies. Canadian Medical Association Journal, 138, 1005-1011.

Eidinger, R. N., & Schapira, D. V. (1984). Cancer patients' insight into their treatment, prognosis, and unconventional therapies. Cancer, 53, 2736-2740.

Eisenberg, D. M., Kessler, R. C., Foster, C., Norlock, F. E., Calkins, D. R., & Delbanco, T. L. (1993). Unconventional medicine in the United States. Prevalence, costs, and patterns of use. The New England Journal of Medicine, 328, 246-52.

Faw, C., Ballentine, R., Ballentine, L., & vanEys, J. (1977). Unproved cancer remedies: A survey of use in pediatric outpatients. JAMA, 238, 1536-1538.

Filicetti, J. (1987). Unproven methods of cancer treatment. American Association of Occupational Health Nursing Journal, 35, 153-158.

Funk and Wagnall's New Comprehensive Internatinal Dictionary of the English Language (1980). New Ark, N. J: Publishers International Press.

Goldsmith, J. (1992). Lasting impressions: Sue P. Heiney. Sigma Theta Tau International Reflections, 18 (2), 4-5.

Harris and Associates (1987). Health, information and the use of questionable treatments: A study of the American public (Study No. 833015). Washington, D. C: U. S. Department of Health and Human Services.

Heidt, P. R. (1990). Openness: A qualitative analysis of nurses' and patients' experiences of therapeutic touch. Image, 22, 180-186.

Heidt, P. R. (1991). Helping patients to rest: Clinical studies in therapeutic touch. Holistic Nursing Practice, 5 (4), 57-66.

Hillhouse, J., & Adler, C. (1991). Stress, health, and immunity: A review of the literature and implications for the nursing profession. Holistic Nursing Practice, 5 (4), 22-31.

Hiratzka, S. (1985). Knowledge and attitudes of persons with cancer toward use of unproven treatment methods. Oncology Nursing Forum, 12 (1), 36-41.

Howard-Ruben, J., & Miller, N. J. (1984). Unproven methods of cancer management Part II. Current trends and implications for patient care. Oncology Nursing Forum, 11 (1), 67-73.

Lane, D. (1991). Music therapy: A gift beyond measure. Oncology Nursing Forum, 19, 863-867.

Lerner, I. J., & Kennedy, B. J. (1992). The prevalence of questionable methods of cancer treatment in the United States. CA-A Cancer Journal for Clinicians, 42, 181-191.

Mast, D. E. (1986). Effects of imagery. Image, 18, 118-120.

McGinnis, L. S. (1991). Alternative therapies, 1990. An overview. Cancer, 67 (6 suppl), 1788-1792.

Miller, N. J., & Howard-Ruben, J. (1983). Unproven methods of cancer management Part I: Background and historical perspectives. Oncology Nursing Forum, 10 (4), 46-52.

Mooney, B. K. H. (1985). Utilization of unproven methods of cancer treatment: An investigation of prevalence and relevant factors (Doctoral dissertation, University of Utah, 1985). Dissertation Abstracts International, 46 (4), page 903A.

Munhall, P. L. (1989). Philosophical ponderings on qualitative research methods in nursing. Nursing Science Quarterly, 2 (1), 20-28.

Munhall , P. L., & Oiler, C. J. (1986). Language and nursing research. In P. L. Munhall & C. J. Oiler (eds.), Nursing research: A qualitative perspective (pp. 3-26). Norwalk, Connecticut: Appelton-Century-Crofts.

Murray, R. H., & Rubel, A. J. (1992). Physicians and healers - Unwitting partners in health care. The New England Journal of Medicine, 326, 61-64.

Newshan, G. (1989). Therapeutic Touch for symptom control in persons with AIDS. Holistic Nursing Practice, 3 (4), 45-51.

Office of Technology Assessment (1990). Unconventional cancer treatment. Summary. Washington D. C.: Government Printing Office.

Oiler, C. J. (1986). Phenomenology: The method. In P. L. Munhall & C. J. Oiler (Eds.), Nursing research: A qualitative perspective (pp. 69-84). Norwalk, Connecticut: Appelton-Century-Crofts.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5 (2), 49-63.

Polkinghorne, D. E. (1988). Narrative knowing and the human sciences. Albany, N.Y.: State University of New York Press.

Porth, C. M. (1986). Pathophysiology: Concepts of altered health states. Philadelphia: J.B. Lippincott.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8 (3), 27-37.

Sikora, K. (1989). Complimentary medicine and cancer treatment. The Practitioner, 233, 1285-1286.

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. In B. Sarter (Ed.), Paths to knowledge: Innovative research methods for nursing (pp. 97-105). New York: National League for Nursing.

The American Heritage Dictionary (1983). Boston: Houghton Mifflin Company.

van Manen, M. (1990). Researching the lived experience. Human science for an action sensitive pedagogy. New York: The State University of New York Press.

Vines, S. W. (1988). The therapeutics of guided imagery. Holistic Nursing Practice, 2 (3), 34-44.

Webster's Ninth New Collegiate Dictionary. (1987). Springfield, MA: Merriam-Webster.

Weinrich, S. P., & Weinrich, M. C. (1990). The effect of massage on pain in cancer patients. Applied Nursing Research, 3, 140-145.

Wiener, C. L., & Dodd, M. J. (1993). Coping amid uncertaintly: An illness trajectory perspective. Scholarly Inquiry for Nursing Practice: An International Journal, 7, 17-31.

Zahourek, R. P. (1987). Clinical hypnosis in holistic nursing. Holistic Nursing Practice, 2 (1), 15-24.

Zimmerman, L., Pozehl, B., Duncan, K., & Schmitz, R. (1989). Effects of music in patients who had chronic cancer pain. Western Journal of Nursing Research, 11, 298-309.

APPENDIX A

Institutional Review Board Approval

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Office of the Institutional Review Board for Human Use

FORM 4: IDENTIFICATION AND CERTIFICATION OF
RESEARCH PROJECTS INVOLVING HUMAN SUBJECTS

THE INSTITUTIONAL REVIEW BOARD (IRB) MUST COMPLETE THIS FORM FOR ALL APPLICATIONS FOR RESEARCH AND TRAINING GRANTS, PROGRAM PROJECT AND CENTER GRANTS, DEMONSTRATION GRANTS, FELLOWSHIPS, TRAINEESHIPS, AWARDS, AND OTHER PROPOSALS WHICH MIGHT INVOLVE THE USE OF HUMAN RESEARCH SUBJECTS INDEPENDENT OF SOURCE OF FUNDING.

THIS FORM DOES NOT APPLY TO APPLICATIONS FOR GRANTS LIMITED TO THE SUPPORT OF CONSTRUCTION, ALTERATIONS AND RENOVATIONS, OR RESEARCH RESOURCES.

PRINCIPAL INVESTIGATOR: AUDNA AGUSTSDOTTIR

PROJECT TITLE: THE LIVED EXPERIENCE OF CANCER PATIENTS USING UNCONVENTIONAL THERAPIES

____ 1. THIS IS A TRAINING GRANT. EACH RESEARCH PROJECT INVOLVING HUMAN SUBJECTS PROPOSED BY TRAINEES MUST BE REVIEWED SEPARATELY BY THE INSTITUTIONAL REVIEW BOARD (IRB).

X 2. THIS APPLICATION INCLUDES RESEARCH INVOLVING HUMAN SUBJECTS. THE IRB HAS REVIEWED AND APPROVED THIS APPLICATION ON 4-1-94 IN ACCORDANCE WITH UAB'S ASSURANCE APPROVED BY THE UNITED STATES PUBLIC HEALTH SERVICE. THE PROJECT WILL BE SUBJECT TO ANNUAL CONTINUING REVIEW AS PROVIDED IN THAT ASSURANCE.

X THIS PROJECT RECEIVED EXPEDITED REVIEW.

____ THIS PROJECT RECEIVED FULL BOARD REVIEW.

____ 3. THIS APPLICATION MAY INCLUDE RESEARCH INVOLVING HUMAN SUBJECTS. REVIEW IS PENDING BY THE IRB AS PROVIDED BY UAB'S ASSURANCE. COMPLETION OF REVIEW WILL BE CERTIFIED BY ISSUANCE OF ANOTHER FORM 4 AS SOON AS POSSIBLE.

____ 4. EXEMPTION IS APPROVED BASED ON EXEMPTION CATEGORY NUMBER(S) ____

DATE: 4-1-94

RUSSELL CUNNINGHAM, M.D.
INTERIM CHAIRMAN OF THE
INSTITUTIONAL REVIEW BOARD

The University of Alabama at Birmingham
212 Mortimer Jordan Hall • 1825 University Boulevard
Birmingham, Alabama 35294-2010 • (205) 934-3789 • FAX (205) 975-5977

APR 6

APPENDIX B

Flyer

PERSONS WITH CANCER

I'm a cancer nurse and a doctoral student who is interested in meeting and talking with persons with cancer who are using or have used treatment methods to supplement those recommended by a medical physician. These other methods might include herbs, special diets, meditation, acupuncture, detoxification, and many more. Treatment methods usually recommended by physicians for cancer are surgery, chemotherapy, and radiation. The supplemental methods are often used with medical cancer treatment although some persons with cancer use these other therapies only.

I'm eager to learn from persons with cancer who use other than the usual medical therapies what their experiences are. My purpose is <u>not</u> to learn if particular therapies work or not but rather to learn how is it to be a person with cancer using the therapy.

If you have cancer and use or have used one or more supplemental therapies or therapies other than surgery, chemotherapy and radiation because of your cancer, please contact me to learn more about my study and possibly share your experience with me. You can either call me or send a me a letter.

Audna Agustsdottir
665 Idlewild Circle #B7
Birmingham, AL 35205
Tel: 1-800-262-0477 or
(205) 328-5113

If my answering machine is on, please just leave message when you plan to try reaching me again or if you wish leave a number where I can reach you.

#You will not be asked to give any names of physicians or practitioners.

#All information you give to me is confidential.

#Your regular health care will not be affected by talking to me.

APPENDIX C

Letter to Practitioners

University of Alabama School of Nursing
University of Alabama at Birmingham
1700 University Blvd
Birmingham, AL 35294

(Name)
(Address)

Dear (name):

I am a doctoral student at the University of Alabama School of Nursing and am now collecting data for my doctoral dissertation titled " The lived experience of cancer patients using unconventional therapies". The purpose of the study is <u>not</u> to learn if the unconventional therapies work or not, but rather to understand the experience and meaning for cancer patients who use them. An abstract of the proposal is attached.

My plan is to reach possible participants through flyers as those enclosed with this letter. I am asking if you would be willing to leave the flyers in the waiting room of your clinic or institute accessible to persons with cancer

I will call your office within a week from mailing this letter to answer any of your questions regarding the study and to learn if you are willing to leave the flyers in your waiting room. If you wish to contact me do not hesitate to call me at (205) 328-5113 or 1-800-262-0477.

Sincerely yours,

Audna Agustsdottir, MSN, RN

APPENDIX D

Consent Form

CONSENT FORM FOR TELEPHONE INTERVIEW

To be read to the participant

You will be a part of a study that focuses on the lived experience of cancer patients using unconventional therapies. The purpose of this study is to describe the experience of cancer patients who use unconventional therapies because of their cancer. Hopefully, this study will increase understanding among health care professionals of cancer patients who use unconventional therapies.

You will be asked questions about your experience of using unconventional therapies and what it means to you. You are not required to give any names of anyone assisting you with your treatment.

This interview is entirely voluntary and even after the intervie begins you can refuse to answer any specific questions or decide to terminate the interview at any point. The tape with the interview will be transcribed without any information that could identify you and the tape then destroyed. No reports of this study will never identify you in any way.

Your participation/nonparticipation or refusal to answer questions will have absolutely no effect on services that you or any member of your family may receive from the health or social service providers.

The results of this research will be given to you if you ask for them and you can contact me, Audna Agustsdottir, tel: (205)328-5113 or toll free 1-800-262-0477 if you have any questions about the study or your rights as a study participant. My mailing address is School of Nursing, University of Alabama at Birmingham, UAB Station, Birmingham, AL 35294.

APPENDIX E

Demographic Data Sheet

Demographic data

Age in years: ____________

Gender: Female __ Male ___

Race: ____________________________________

Education: ____________________________________

Religion: ____________________________________

Family income/year: $________________

APPENDIX F

Interview Guide

INTERVIEW GUIDE

In the interview I will have the following questions in mind although they may not all be necessary or appropriate. The questions indented would be used to stimulate or orient if the participant does not give these information in their response to the general question.

Tell me about your cancer.

- How was the cancer discovered?
- What does it mean to you to have cancer?
- What kind of therapies were recommended to you?
- I don't need any names, but can you tell me who talked to you about cancer therapies?

How did you decide on the therapy/therapies you are using now?

- What/Who helped you make that choice?
- What/Who supported you or stimulated you to make that choice?
- How did you come in touch with this/these therapy/therapies?

Tell me about the therapy.

- Explain the therapy to me.
- How do you understand the therapy works?

Tell me about your experience of using this therapy.

- What is it like for you to use this therapy?
- What kind of feelings do you have about using the therapy?
- How or what do you feel for example when you are getting ready to go to get the therapy or while your are receiving the treatment?

GRADUATE SCHOOL
UNIVERSITY OF ALABAMA AT BIRMINGHAM
DISSERTATION APPROVAL FORM

Name of Candidate Audna Agustsdottir

Major Subject Adult Health Nursing

Title of Dissertation The Lived Experience of Cancer Patients
Using Unconventional Therapies

Dissertation Committee:

Judy Holcombe, Chairman
Kathleen C Brown
Cecilia Pierce
Ann J Clark
Peggy C Harrison

Director of Graduate Program Carol J Dashiff

Dean, UAB Graduate School Joan F Lorden

Date 7/6/95

PS-1428