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THE ONCOLOGY PATIENT'S PERCEPTION OF SUPPORT FOR THE USE OF
ALTERNATIVE THERAPIES BY THEIR HEALTH CARE PROVIDER

By

Michelle Lynn Witkop

A THESIS

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ABSTRACT

THE ONCOLOGY PATIENT'S PERCEPTION OF SUPPORT FOR THE USE OF ALTERNATIVE THERAPIES BY THEIR HEALTH CARE PROVIDER

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Michelle Lynn Witkop

The purpose of this descriptive study was to determine if patients with cancer communicated their use of alternative therapies to their health care providers, to identify factors that influenced their decision to share (or not to share) this information with the health care provider, to describe the types of alternative therapy they were using, to identify where information on the chosen alternative therapy was obtained, and to discuss the factors that influenced their use of an alternative therapy. A convenience sample of 29 subjects from five oncology practices in northwestern lower Michigan responded to questionnaires assessing their use of alternative therapy.

Descriptive statistics along with t-test, correlation coefficients, and chi-square were used to analyze the data. The survey determined that cancer patients who are younger, with a higher education and higher income tend to use more types of alternative therapies. The surveyed group tends to supplement their traditional treatments with alternative therapy more frequently than nationally published reports, receive their alternative therapy information from the lay press, and share this information more often with a health care provider than previously published reports.

This is dedicated to my mother-in-law, Louise C. Witkop, who passed away on May 10, 1997. Through her illness I gained an appreciation for life and faith in the unknown. Life will not be the same without her.

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Table of Contents

List of Tables.....	vii
List of Appendices.....	viii
Chapter	
1 INTRODUCTION.....	1
Purpose.....	4
Significance.....	5
2 CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW.....	6
Conceptual Framework.....	6
Literature Review.....	12
3 METHODOLOGY.....	22
Study Design.....	22
Limitations of Design.....	22
Sample and Setting.....	23
Instrument.....	24
Procedure for Data Collection.....	24
Risks to Subjects.....	25
Approval Process.....	25
4 DATA ANALYSIS.....	27
Techniques.....	27
Research Questions.....	27
Results.....	28

5	DISCUSSIONS AND IMPLICATIONS.....	40
	Discussion.....	40
	Limitations.....	47
	Recommendations.....	47
	Conclusions.....	48
	APPENDICES.....	49
	REFERENCES.....	56

List of Tables

TABLE	PAGE
1. Respondents Income Levels.....	29
2. Types of Alternative Therapy Used.....	30
3. Categories of Alternative Therapies.....	32
4. Compressed Income Data.....	34
5. Compressed Education Data.....	35
6. Percentage of Health Care Providers Informed of Alternative Therapy Usage.....	36

List of Appendices

APPENDIX	PAGE
A. A Conceptual Framework for Nursing: Dynamic Interacting Systems.....	49
B. Alternative Therapy Survey.....	50
C. Alternative Therapy Consent.....	55

Chapter 1

Introduction

The American Cancer Society (1997) estimates that 1.4 million people will be diagnosed with cancer in the United States in 1997. Approximately 50% of individuals diagnosed with cancer will become long term survivors. For the person with cancer these statistics are so frightening that many are turning to alternative forms of therapy to supplement or replace traditional treatment regimes. Cassileth et al. (1984) define alternative therapies as “treatments that are both used specifically to cure cancer, and are not part of anti-cancer therapies used by the medical establishment” (pg. 105). Many people who have used alternative therapies believe that conventional treatments actually weaken the body’s reserves, inhibit the capacity for cure, and mistakenly address the symptom (cancer) rather than the underlying systemic disorder. To better evaluate the effects of alternative therapies Congress, in 1992, instructed the National Institutes of Health to establish the Office of Alternative Medicine to support studies of alternative therapies (Mahaney, 1992). According to Youngkin and Israel (1996), the lay press

publishes many articles about the benefits of alternative therapies.

Regretfully, clinical trials determining the efficacy of the alternative treatments are rare and the benefits being reported are determined through anecdotal reports, which not only can be harmful but fatal in some cases.

To further complicate treatment planning, the Food and Drug Administration does not regulate herbs as long as they are marketed as a health food product with no claims of efficacy as a drug (Young and Israel, 1996). With no governmental standards in place to verify the quality of herbal products in the United States, manufacturers have little to no incentive to perform the expensive assays necessary to determine the purity and concentration of their particular product.

A review of the literature reveals a wide variation in the estimation of the extent of use of alternative therapies. Researchers report that 9-83% of people with cancer use some form of alternative therapy (Lerner and Kennedy, 1992; Montbriand, 1993). Montbriand's research reveals that most alternative therapies are initiated by non-medical people and are categorized into three areas: spiritual, physical, and psychological. The participants receive information on the chosen alternative therapies from the lay press which is often biased in favor of the manufacturer and does not include information on possible toxicities or drug interactions.

In 1993, Eisenberg et al. found that 83% of people who use alternative therapies for serious medical conditions do not inform their physicians of their use. People who use alternative therapies for cancer treatment are more educated and in a higher income bracket than the people who do not use them (Cassileth et al., 1991; Lerner & Kennedy, 1992). Their dissatisfaction in conventional cancer treatment stems from several factors including the lack of improvement in the rates of cure over the years, the lack of new or improved treatment regimes despite decades of efforts, and the toxic effects of conventional treatments. Montbriand (1995) developed a decision tree model to determine how a participant makes the decision to use an alternative form of therapy. In developing the decision tree it was noted that 62% of alternative therapies users do not share their decisions with their physicians. Nor do these patterns of decision making include discussion with nursing professionals or other health care practitioners.

This information is important to the nursing profession and all health care providers. Many of the physical forms of alternative therapies may interact with conventional medications taken by the client and traditional treatment modalities used to treat cancer. There are ways nursing professionals can support clients in the use of alternative therapies while keeping them safe by limiting the risk of untoward drug reactions and educating the client

regarding potential toxicities. If toxicities are observed they can be attributed to the correct source and not falsely attributed to the traditional treatment.

Many clients are willing to discuss their innermost feelings with nurses. This offers nurses the unique opportunity to inquire about the use of alternative therapies. Education can then be initiated on the latest research and information on the chosen alternative therapy.

Imogene King's Theory of Goal Attainment will be used to guide this descriptive study. King (1981) focuses on the interactions between the nurse and the client. These interactions are influenced by perceptions, past experiences, and the knowledge base of both of the participants. King maintains that mutual goal setting with the client requires the interaction be based in "perceptual accuracy". In order for perceptual accuracy to occur, both participants of the interaction need to be open, honest, and non-judgmental with each other. Only then can mutual goal setting be accomplished and effective outcomes obtained.

Purpose

The purpose of this descriptive study is to determine if clients with cancer communicate their use of alternative therapies to health care providers, to identify factors that influence their decision to share (or not to share) this information with the health care provider, to describe the type of alternative

therapy they are using, to identify where information on the alternative therapy was obtained, and to discuss the factors that influenced their use of an alternative therapy.

Significance

The use of alternative therapies is important data that is critical in developing a plan of care. Health care providers must be aware of any alternative therapies used by patients in order to assess the potential toxicities, educate the client, and differentiate between toxicities caused by the traditional therapy and the alternative therapy. Alternative therapies have the potential of mimicking, potentiating, or masking the toxicities of chemotherapeutic drugs. Without prior knowledge of the alternative therapy, the toxicities may be incorrectly attributed to the traditional treatment modality being used, resulting in possible dose modifications or treatment cessation.

Nurses must compile a complete record of therapies used by clients in order to participate in mutual goal setting. The nurses role is critical in educating the clients on potential toxicities and interactions between alternative and traditional therapies. When toxicities are noted, they can be attributed to the correct cause and not incorrectly alter traditional treatments.

Chapter 2

Conceptual Framework and Literature Review

Conceptual Framework

Imogene King's Theory of Goal Attainment is the framework for this study. King first introduced her conceptual framework for nursing in 1971, and later refined the concept for presentation in her book A Theory For Nursing (King, 1981). Her model (Appendix A) of a conceptual system shows that the care of human beings is the focus of nursing with the goal being health. This model incorporates three open systems: individuals as personal systems, groups as interpersonal systems, and society as social systems. King (1981) bases this open systems model on the assumption that "the focus of nursing is human beings interacting with their environment leading to a state of health for individuals, which is an ability to function in social roles" (p. 143).

Personal systems are individuals. An individual nurse as a person and an individual client as a person are each a total system (King, 1981). King

identifies several kinds of interpersonal systems where two or more persons are interacting. A dyad involves two interacting individuals, whereas three interacting individuals are called a triad. In nursing, the interpersonal system usually involves the nurse and the patient but the family or other supportive persons may also be included. Larger groups with special interests and goals form organizations, which make up a community or society and are called social systems. Examples of social systems where nurses and clients interact are religious or belief systems, family systems, work systems, or educational systems.

King's Theory of Goal Attainment is derived from the interpersonal systems concept. Using the nurse and the client as a dyad, King describes the dynamics of this theory: "nurses purposefully interact with clients to mutually establish goals and to explore and agree on means to achieve goals" (King, 1981, p. 142). During that interaction, information is gathered and shared, observations are made, questions are asked, and both participate in the process to set goals. Goals are defined as "events that one values, wants, or desires" with the results of attained goals being measurable outcomes (p. 145). The attainment of the goal completes the transaction.

The major concepts of the theory of goal attainment include interaction, perception, communication, transaction, self, role, stress, growth and

development, and time and space (King, 1981). Use of these concepts related to the clients willingness to divulge their use of alternative therapies to their healthcare provider will provide structure for this study.

King (1981) defines interaction as “a process of perception and communication between person and environment and between person and person, represented by verbal and non-verbal behaviors that are goal-directed” (p. 145). Each participating person influences the interaction with their different needs, goals, knowledge, perceptions, and past experiences. According to King’s theory, the patient and the nurse come together in a clinical situation, perceive each other, make judgments about each other and react based on the significance they attribute to the situation or their perception (King, 1981). “Interactions are directly observable behaviors..” (p. 146). Patients interact daily with health care providers in multiple settings including offices, hospitals, and out-patients clinics.

Each person’s representation of reality constitutes perception (King, 1981). Perception is an awareness of persons, objects, and events. Past experiences, self concept, socioeconomic groups, genetics, and educational background all contribute to one’s perceptual process. “Perception is each person’s subjective world of experience” (p. 146). Perception of the situation and each other is the first step in the nurse-client interaction process. How

patients perceive an interaction with their health care provider will determine their willingness to discuss their use of alternative therapies.

“Communication is defined as a process whereby information is given from one person to another either directly in face-to-face meetings or indirectly through telephone, television, or the written word” (King, 1981, p. 146). Information is shared via verbal and non-verbal communication which express the goals of the communicants. “Control can be exerted in the process of communication” (Norris, 1992, p. 80). Information allows others to participate in making decisions and choices regarding their health. Communication is critical to both the patient and the health care provider in terms of informed consent and decision making in the use of alternative therapies.

Goal attainment is achieved through transaction when the value of the situation is exchanged between participants. King (1981) defines transaction as “observable behaviors of human beings interacting with their environment” (p. 147). Along with mutual goal setting comes an exchange of the frame of reference for a given situation, the identification of commonalties between the nurse and the client, bargaining, and negotiating. Goals are attained when the nurse and the client complete a transaction. The use of alternative therapies should be included in the mutual goal setting

transaction between the nurse and the client.

The role of professional nursing is based on values of the nursing profession, skills, and knowledge. Role is defined by King (1981) as “a set of behaviors expected of persons occupying a position in a social system; rules that define rights and obligations in a position; a relationship with one or more individuals interacting in specific situations for a purpose” (p. 147). Role conflict can occur when the expectations of one group (employer, client, or other health care professionals) differ from the expectations of the involved nurse. King encourages nurses to increase achievement of goal attainment by understanding their role in a given situation and interpreting it for all others involved thereby decreasing role conflict, confusion, and stress. Nurses should actively increase their role in determining the patients use of alternative therapies by clearly informing the patient of their reasons for investigating this and the need for accurate information. This would help with role clarification as well as decreasing the patients level of stress.

“Stress is defined as a dynamic state whereby a human being interacts with the environment to maintain balance for growth, development, and performance” (King, 1981, p. 147). Client stress may be increased by sensory overload from a new diagnosis, thereby narrowing their perceptual field and decreasing the rationality of their decision making abilities. King

expresses concern that nursing care, goal setting, and interactions in general may be adversely effected by increased stress, ultimately interfering with the clients developmental tasks. Stress can be decreased by increasing communication regarding the use of alternative therapies between the nurse and the patient.

Stress may also interfere with the patients growth and development. Growth and development are defined by King (1981) as “continuous changes in individuals at the cellular, molecular, and behavioral levels of activities” (p. 148). Genetics are key elements as are an environment that enables the client to move towards maturity and experiences that are satisfying and meaningful to the client. The processes a client experiences in life allows movement over time to occur from potential capacity for achievement to self actualization.

Time is defined by King (1981) as “a sequence of events moving onward to the future. Time is a continuous flow of events in successive order that implies change, a past, and a future” (p. 148). The relationship of events to each other in space as experienced by each unique individual also constitutes time.

King (1981) defined space as “existing in all directions and is the same everywhere” (p. 148). Individuals define their personal space or territory by

their postures, gestures and visible boundaries. Individuals behavior in certain situations are influenced by their perception of space as well as their cultures perception and meaning of space.

Literature Review

A review of the literature reveals multiple news clips in the lay press on alternative therapies. Limited studies have been reported in the professional literature. Due to the increased use of alternative therapies and the medical communities concerns about client safety, in 1992 Congress appropriated 2 million dollars to create the Office of Alternative Medicine (Mahaney, 1992). This National Institutes of Health (NIH) Office answers directly to the NIH and Congress. The primary purpose of the new office is to determine which alternative therapies may be effective, which are not, and to provide information regarding the various alternative therapies to patients and practitioners. Medical researchers are demanding that alternative therapy data undergo rigorous testing. There is no central database for alternative therapies at this time plus the traditional medical community resists publishing data presented by alternative therapy practitioners in the traditional peer-reviewed journals.

Seaward (1994) feels that the appropriation of money to the Office of Alternative Medicine for the study of alternative therapies is indicative of a

transition in the mechanistic model previously used by conventional medical practices of Western based medicine. A new paradigm of whole systems will incorporate a more comprehensive system that combines alternative therapies and traditional medicine to accomplish a new holistic medicine that will unite the body, mind, and spirit for optimal health.

While Seaward feels the Office of Alternative Medicine is indicative of the winds of change for Americans, Ullman (1993) expresses concern that the United States is “significantly behind Europe in its exploration of alternative therapies” (p. 26). He points out that the small country of Switzerland has appropriated \$4 million to study the practice of alternative therapies, who uses alternative therapies, and why. German medical students are tested on their knowledge of alternative therapies on their medical board exams. The Germans spent over \$3 billion for herbs in 1988, surpassing the amount spent by any Western country.

Cassileth et al. (1991) compared the quality of life and length of survival between two groups of patients. One group received treatment at an unorthodox cancer clinic in San Diego while the other group received conventional treatment in an academic setting. They found the treatment regimes were similar in efficacy with the length of survival not differing between the two groups. The quality of life in the conventional treatment

group was consistently better than the unorthodox treatment group from enrollment to death. This study refutes the perception that the use of alternative therapies are associated with a better quality of life.

Eisenberg et al. (1993) found that more than one-third of adult Americans partake in some form of alternative therapy, usually at their own expense. Among those who used alternative therapies for serious medical conditions in conjunction with traditional medicine, 73% did not inform their medical physician of the alternative therapy use.

Lerner & Kennedy (1992) did an extensive survey of cancer patients, their families and physicians regarding their experience with alternative therapies. They found that the use of alternative therapies increased with higher income, higher education, prolonged illness, and certain types of cancers. Eighty percent of the patients who had used alternative therapies had also used some form of conventional therapy. Although the majority of reported alternative therapies were cheap, not harmful, and did not compete with conventional treatment there were some that were extremely costly and had major side effects. They also found a wide discrepancy between the physicians' and the patients' perception of alternative therapies use. Physicians disapprove of alternative therapies, do not condone their use, and felt toxicities were common. Their patients felt that their physicians condoned the use of

alternative therapies in the majority of cases, often directed them to specific alternative therapies, and felt the toxicities were rare. These vast differences in perceptions were attributed to the way physicians and patients communicate and perceive communication. The authors stressed the need of open communication between the physician and the patient so the alternative therapies could be thoroughly evaluated in relationship to the conventional therapy and the toxicities of each attributed to the rightful cause.

Downer et al. (1994) found that hope was an important issue to cancer patients who used alternative therapies and encouraged clinicians not to underestimate its value in patient management. Regretfully, they also found that over 50% of the patients interviewed stated their physicians did not know of their alternative therapy use. They encouraged an open discussion of the issues in an open minded, well informed, collaborative manner. By doing so, the clinician can assist the patient in making an informed choice, minimize the risks of alternative therapies, and maximize the benefits.

One of the earliest comprehensive studies on alternative therapies, the people who used them, and the practitioners who prescribed them was published by Cassileth et al. in 1984. An extensive survey of 660 patients determined that most users of alternative therapies were caucasian, well educated, frequently asymptomatic, and in the early stages of their disease

process. Those who did not use alternative therapies had a better relationship with their physician than the patients who did use alternative therapies.

Seventy-five percent of alternative therapy users informed their physician, with 42% of those physicians being either supportive or neutral about the alternative therapy use. The authors concluded with the belief that the use of alternative therapies will not be readily discarded as long as its emphasis is on nutrition, purification (with its religious and moral overtones), pollution, and health as a personal responsibility.

The need for the patient and the health care provider to communicate openly and honestly is expressed by multiple authors (Cassileth et al., 1984; Guzley, 1992; Zaloznik, 1994). Previous studies show a great discrepancy between the patients' and the physicians' perception of alternative therapies use (Cassileth et al., 1984; Lerner & Kennedy, 1992; McGinnis, 1991; Zaloznik, 1994). Physicians expressed disapproval of alternative therapies and rarely supported their use, while patients often stated that the alternative therapy was introduced to them by their physician and the physician was supportive of it. Perhaps the major discrepancy in the literature is in the actual usage of alternative therapies, which ranges from 9% reported by the American Cancer Society (1992) to 83% reported by Montbriand (1993).

A major nursing researcher of alternative therapies has been Muriel Montbriand, RN, Ph.D. (Montbriand, 1991; Montbriand, 1993; Montbriand, 1994; Montbriand, 1995A; Montbriand, 1995B). Using the theme of desire of control over an uncontrollable situation such as a chronic disease, Montbriand (1991) felt that patients did not view their use of alternative therapies as noncompliant behavior but as a right of theirs to control their health in a free society. The nursing model maintains a holistic approach towards the patients' use of alternative therapies by encouraging professional discussion directed at social and behavioral factors affecting the patient. The medical model approach is more paternalistic, viewing any deviation from the prescribed medical regime as noncompliance on the part of the patient. This view forces the assumption of a covert role by the patient in seeking control over their health care via the use of alternative therapies, even if this decision is considered wrong by the physician. Montbriand defines the three categories of alternative therapies as physical, psychological, and spiritual.

Physical alternative therapies are tangible and cause physiological changes in the body. Physical alternative therapies include: physical substances, physical manipulations, and physical objects. Examples are herbs, vitamins, diet, ingestible materials, massage, manipulation, reflexology, or physical objects such as talismans (Montbriand, 1991; Montbriand, 1993). Spiritual

alternative therapies evoke “a cosmic source to cure the illness or help the patient to cope. The cosmic source was often God or a saint.” (Montbriand, 1991, p. 327). Examples would be prayer, laying on of hands, and novenas to saints (Montbriand, 1993). Psychological alternative therapies use the mind to assist the body to heal. Examples are visualization (imagery) and distraction.

In 1993 Montbriand elaborated on her previous research by identifying the types of alternative therapies chosen by patients, some of the perceived benefits and known risks of selected physical alternative therapies, the methods used to obtain information on the chosen alternative therapy, and the perception of freedom of choice. A total of 300 patients with selected cancers were interviewed in a Canadian city. Several factors were determined to influence a patients decision to participate in an alternative therapy. These factors included a social group’s influence on the patient, anger at the medical system, fear (of disease, treatment, and death), stress from the lived experience of the cancer, and desire for control of the health situation.

Information on alternative therapies was usually obtained from friends and relatives, the lay press, or by lay persons affiliated on the “fringes” of the alternative therapy movement (health food industry or holistic health

providers). Those patients who searched the professional literature had great difficulty in both finding information on specific alternative therapies and understanding the medical language.

This led Montbriand to question if patients were truly making informed choices in their alternative therapy decisions. The lay literature stressed freedom of choice and the patient's right to choose. Yet Montbriand challenged that concept by suggesting that patients who received only biased information were not actually giving informed consent and did not have true freedom of choice. Full information from both sides of the issue would be necessary for the patient to make a truly informed decision. Montbriand suggested that nurses were in a perfect position to assist patients in their decision making by delivering accurate, nonbiased, and scientific information in a respectful, nonjudgmental fashion. Trust and sensitivity were identified as key issues.

In 1994 Montbriand continued her discourse regarding alternative therapies by concentrating on the specific alternative therapies chosen by patients. Her purpose was to show the health care professionals that not all alternative therapies were benign. Psychic surgery is classified as a spiritual alternative therapy and considered very unethical. The visualization described as a psychological alternative therapy could put the burden of cure

on the patient and evoke guilt feelings if the intervention is not successful.

Montbriand found that 75% of the 300 patients interviewed did not share the use of the alternative therapy with their physician. Specific nursing strategies are given to assess the patients use of alternative therapies and interventions suggested. Nursing has a unique opportunity to assess, intervene, and communicate accurate, nonbiased information to assist the patient in making truly informed decisions.

Montbriand (1995) re-examined previous research information using control theories to analyze the use of alternative therapies by the patient as a means of controlling their health care. This reanalysis uncovered many ambiguities regarding the control behaviors used by cancer patients.

Previously it was stated that patients used alternative therapies as a control mechanism in an uncontrollable situation. The question is then raised if the responsibility of control was actually too much for the patient and alternative therapies were a way for the patient to give that control away.

Finally, in 1995, Montbriand examined the decision making patterns of patients using alternative therapies. A decision tree outlining these strategies was then developed. This decision tree assists nursing by providing a pattern of how choices are made. Nursing is thus enhanced by enabling patients to make an informed decision.

In summary, there is a wide discrepancy in the estimated use of alternative therapies between various authors. The majority of patients do not share the information of their alternative therapy use with their physician or other health care providers. Most alternative therapy users are caucasian, well educated, frequently asymptomatic, and in the early stages of their disease process. In general, the authors do not believe that the use of alternative therapies will be easily discarded as long as patients feel that health is a personal responsibility. Montbriand, the most extensively published nurse researcher on alternative therapies, has divided the various alternative therapies into three main groupings (physical, psychological, and spiritual). She warns the health care practitioner that not all alternative therapies are benign and awareness of the various therapies and their toxicities is necessary to assist the patient in making a truly informed decision.

Chapter 3

Methodology

Study Design

This study used a descriptive survey design to determine if clients with cancer communicated their use of alternative therapies to their health care provider. It also determined the factors that influenced their decision to share (or not to share) alternative therapy information. In addition, this survey examined the type of alternative therapy the client used, where they obtained the information on their chosen alternative therapy, and what factors influenced their choice.

Limitations of Design

External validity problems included the limited geographical area and the small convenience sample which restricted the generalizability of the data (Talbot, 1995). It was not known what percentage of the general population of northwestern lower Michigan had been diagnosed with cancer so it was not possible to determine what percentage of the cancer population was actually surveyed. How the patient was approached and how they physically

felt on the day they were approached also threatened the external validity of this study. As well as the possibility that those who use alternative therapies may be more inclined to fill out a survey on that topic.

Staff members of the oncology offices presented the survey to patients as they arrived for an appointment. How the receptionist greeted the person, handed them the consent, and answered questions inadvertently impacted how the person responded to the survey. If the patient was not feeling well s/he may not have put much thought into answering the questions or avoided the survey all together. Fear of lack of confidentiality could also have limited the patients willingness to participate in the survey. If the patient decided to mail the survey to confirm confidentiality, she or he may have forgotten to actually mail the survey thereby not participating.

The internal validity of this survey was threatened by the development of a new survey tool. This was partially controlled by having a panel of experts in the field of oncology and alternative therapy review the tool for completeness and understandability. Several patients who were known to use alternative therapies also reviewed the survey for their input.

Sample and Setting

Subjects were gathered from five oncology practices located in northwestern lower Michigan. The oncology practices were associated with a

368 bed, acute care medical center with an extensive cancer program that offered multiple services.

The data was collected from a convenience sample of patients who met the eligibility criteria. The eligibility criteria includes a cancer diagnosis of at least 2 months duration, literacy in the English language, age 18 or over, and consent to participation. A total of 110 surveys were distributed to the five oncology offices. The data was tabulated at the end of one month.

Instrument

The survey instrument was developed based on information found in the literature. Demographic information was gathered to describe the sample. See Appendix B for an example of the questionnaire. Content validity was ascertained by having the survey reviewed by a group of five oncology nurses (each with at least 10 years oncology nursing experience), two oncology pharmacists, a clinical research associate, and one doctoral prepared educator. The survey was then presented to two oncology patients who were known to be actively using alternative therapies for their suggestions.

Procedure for Data Collection

This study obtained participants from five oncology practices located in northern lower Michigan. The participants were offered the survey by trained staff located in each office. A letter was given to the patient

informing them of the purpose of the study, methodology, risks, potential benefits, voluntary participation, and the right to withdraw at anytime.

Consent to participate was assumed by the completion of the survey. See Appendix C for a sample of the consent. The patient had the option of returning the survey in a sealed envelope to the staff member or mailing it directly in a stamped self addressed envelope to the researcher.

Risks to Subjects

Risks of participation by the patients were minimal. They might not have been feeling well when they entered the office and became anxious with the thought of another task to perform, the questions may have evoked anxiety, or they may have been concerned regarding potential confidentiality leaks. Patients were free to decline participation at any time prior to returning the survey (after they returned the survey it was not possible to determine which survey belonged to them) Informed consent was implied by completion of the survey.

Approval Process

Before data collection began, the proposal was submitted to the Grand Valley Human Research Review Committee for approval. The expected risks to the subjects in this study were outlined. Psychological or emotional anxiety may have occurred as a result of self assessment and self-disclosure.

A possible benefit of participation may have been the subject's heightened awareness of their alternative therapy use.

Chapter 4

Data Analysis

Techniques

This study used a descriptive design. Using descriptive statistics the percentages, means, and medians were determined for each survey question. The relationship between the number of alternative therapies used and age, education, and income were examined using correlation coefficients. The alternative therapies were then divided into three groups (physical, psychological, and spiritual).

Research Questions

1. What types of alternative therapies are patients using?
2. Do cancer patients communicate their use of alternative therapies to their health care providers?
3. Where do the patients obtain information on their chosen alternative therapy?
4. What factors influence patients decisions to share or not to share this information with the health care provider?

5. What factors influenced patients decisions to use alternative therapies?

Results

Surveys were distributed to patients in five oncology offices located in northwestern Michigan from March 10, 1997 to April 9, 1997. A total of 29 patients between the ages of 18 and 80 (mean age of 54 with standard deviation of 14.6) responded over a 4 week period. Seventy-nine percent of the respondents were female and 17% were male with one respondent not identifying gender. Sixty-five percent of the respondents were married; 20% were single; 10% were divorced; and 3% were widowed.

All of the respondents had insurance. Private insurance (such as Blue Cross/Blue Shield) was used by 69% of the respondents. The remaining coverage was split equally by managed care , Medicaid , and Medicare (17% each).

Twenty seven respondents provided a date of diagnosis with the earliest being February of 1986 and the most recent being November of 1996. The most frequent site of cancer for the respondents was breast cancer (37%) with lung cancer being the next most common site (14%). Sixty-two percent of the respondents had completed high school, 21% had attended college, 10% had attended graduate school, and 7% had attended post-graduate school. Sixty-two percent of the respondents made more than \$20,000 per

year. Only 7% made between \$80,000 and \$99,000 per year (See Table 1).

Table 1

Respondents Income Levels

INCOME	n	PERCENTAGE
\$0 - \$19,999	8	28%
\$20 - \$39,999	10	34%
\$40 - \$59,999	4	14%
\$60 - \$79,999	2	7%
\$80 - 99,999	2	7%
NO RESPONSE	3	10%
TOTAL		100%

Eighty-six percent of the respondents had received chemotherapy as a treatment modality for their cancer. Fifty-five percent had undergone surgery, 52% had received radiation, and 28% had used hormones during some phase of their traditional treatment.

Research question #1

Of the 29 respondents, only one did not use any type of alternative therapy. The mean number of alternative therapies used by 97% of respondents was 5 (standard deviation of 3.5). The maximum number of therapies used by one respondent was fourteen. See Table 2 for a breakdown of types of alternative therapies used.

Table 2

Types of Alternative Therapy Used

<u>ALTERNATIVE THEARPY</u>	<u>n</u>	<u>PERCENTAGE</u>
Prayer	25	86%
Vitamins	22	76%
Herbs/enzymes	13	45%
Teas	12	41%
Nutritional changes	11	38%
Visualization	11	38%
Support/self help groups	9	31%
Shark cartilage	8	28%
Meditation	5	17%
Counseling	4	14%

Table 2 continued

Types of Alternative Therapy Used

<u>ALTERNATIVE THERAPY</u>	<u>n</u>	<u>PERCENTAGE</u>
Healing touch	3	10%
Massage	3	10%
Yoga	3	10%
Music therapy	2	7%
Art therapy	2	7%
Faith healing/healer	2	7%
Biofeedback	2	7%
Alternative treatment clinics	2	7%
Hydrogen peroxide/hydrogen sulfate	1	3%
Other	1	3%
No alternative therapy used	1	3%

The alternative therapies were divided into the three categories defined by Montbriand(1991)(1993). These categories are physical (tangible and cause physiological changes in the body), spiritual (evoke a cosmic source to cure the illness or help the patient to cope), and psychological (use the mind to

assist the body to heal)(See Table 3).

Table 3

Categories of Alternative Therapies

Physical	Psychological	Spiritual
Vitamins	Music therapy	Healing touch
Nutritional changes	Art therapy	Prayer
Shark cartilage	Support groups	Faith healing/healer
Herbs/enzymes	Biofeedback	Meditation
Teas	Visualization	
Hydrogen peroxide	Counseling	
Hydrazine sulfate		
Massage		
Yoga		
Alternative Therapy Clinics		

The most frequently used category of alternative therapy was the spiritual category which was used by 90% of the respondents. The second most frequent category, used by 86% of the respondents, was the physical category. The psychological category was used by 49% of the respondents.

The respondents were divided into two equal groups based on the number of alternative therapies used. Group #1 used 0-4 alternative therapies. Group #2 used 5 or more alternative therapies. There were 14 respondents in Group #1 for a total of 48% of the total respondents. There were 15 respondents in Group #2 for a total of 52% of the total respondents

The ages of the respondents in each group was analyzed using a t-test. The mean age of respondents in Group #1 (0-4 alternative therapies used) was 62. The mean age of the respondents in Group #2 (5 or more alternative therapies used) was 47. There was a statistically significant difference between the age of those who use less alternative therapies versus those who use more alternative therapies ($t=2.95$; $d.f.=24$; $p=.007$).

A Pearson R correlation was used to analyze the relationship between age and the total number of alternative therapies used. There was a weak inverse relationship between age and the total number of alternative therapies used, but it was not statistically significant. This does support the previous findings that as age increases, the number of alternative therapies used decreases.

Next, the marital status, income, and education level of each group was analyzed using a Chi-Square. There was no statistically significant difference between marital status, income, or education level of each group.

The income data was then compressed from five groups into three groups. The new income groups were \$0-\$19,999, \$20-\$39,999, and \$40,000 and above. It was found that those in the \$40,000 and above income tended to use a greater number of alternative therapies than those who had an income less than \$40,000 ($\chi^2 = 5.98$; d.f. = 2; $p = .05$).

A Spearman correlation was used to analyze income and total number of alternative therapies used. There was a weak positive relationship, which is statistically significant ($r = .39$; $p = .05$). This supports the previous findings that as income increases, the total number of alternative therapies used increases (See Table 4)

Table 4

Compressed Income Data

NEW INCOME	GROUP 1	GROUP 2
\$0 - \$19,000	4	4
\$20,000 - 39,000	7	3
\$40,000 and above	1	7

Note. Group 1 used 0-4 different types of alternative therapies

Group 2 used 5 or more different types of alternative therapies

The education data was also compressed from four groups into two groups and analyzed using a Chi-Square. The new education groups were high school education and any college education. Although there was no statistically significant difference between the two groups, the group with a high school education tended to use less alternative therapies than the group with a college education (See Table 5).

Table 5

Compressed Education Data

Education	Group 1 (n)	Group 2 (n)
High School	11	7
College	3	8

Note. Group 1 used 0-4 different types of alternative therapies

Group 2 used 5 or more different types of alternative therapies

Research question #2

The data was analyzed to determine with whom the respondent shared the information of the use of alternative therapies. Only 2 respondents (7%) did not share this information with anyone. The majority of respondents (93%) told family members and 83% told friends. In regards to health care providers, 62% of the respondents did inform their oncologists and/or a nurse

of their use of an alternative therapy, while only 42% informed their family care practitioner, 17% informed a pharmacist, 14% informed a nurse practitioner, and 7% informed a dentist.

The respondents were again divided into two groups, based on the number of alternative therapies used, to determine if there was a difference in how they communicated with their health care providers. In general, Group 1 (0-4 alternative therapies used) shared the use of an alternative therapy with health care providers less often than Group 2 (See Table 6).

Table 6

Percentage of Health Care Providers Informed of Alternative Therapy Usage

Informed Provider	Group 1	Group 2
	n (%)	n (%)
Oncologist	8 (57%)	10 (67%)
Nurse	4 (29%)	14 (93%)
Primary Care Provider	4 (29%)	8 (53%)
Nurse Practitioner	0 (0%)	4 (28%)

Note. Group 1 used 0-4 different types of alternative therapies

Group 2 used 5 or more different types of alternative therapies

The majority of respondents (83%) felt the person they shared their decisions with were supportive while 62% received help in obtaining information about various alternative therapies from those with whom they shared this information. 17% of the respondents felt the person with whom they shared this information with was undecided about their feelings while 14% didn't care, 7% tried to change the respondents mind about using the alternative therapy, and 3% were angry about the use of an alternative therapy. When the respondent shared information of an alternative therapy, 62% of the people had some knowledge of the alternative therapy used.

Research question #3

The data was next analyzed to determine where the respondents were receiving their information on the various alternative therapies. Friends and family provided information 69% of the time. The respondents next turned to books (65%), other cancer patients (48%), health food stores (31%), television (31%), magazines and journals (28%), nurses (21%), the Internet (14%), an oncologist or a primary care provider (3%)

Research question #4

The question of what factors influenced the respondent to share the use of an alternative therapy with their health care provider was then examined.

The most frequent reasons for sharing this information was that the

respondent felt the health care provider would be supportive and they told this person everything (38% each). Information seeking was the next most important reason (31%), followed by concerns regarding side effects (28%), and finally the respondent was concerned that the health care provider would be angry if they weren't informed (3%).

The factors that influenced the respondent to **not tell** the health care provider that they were using an alternative therapy were also examined. The respondents were evenly split in their main reasons for withholding this information. They included fear of disapproval, privacy, embarrassment, and fear that the health care provider would tell them to stop taking the alternative therapy (7% each). Less frequently the respondent expressed concern that the health care provider would not continue to provide services to the respondent and that the issue was just not relevant to their care (4% each).

Research question #5

Finally, the respondents were asked what factors influenced their decision to use an alternative therapy. The most frequently cited reason for deciding to use an alternative therapy was that it would make the respondent feel better (65%). Next the respondents felt it would give them hope (59%) followed by giving them control over their health care (55%) and help them control their cancer (55%). Some respondents were afraid of the cancer, the

traditional cancer treatment, or of dying (17%). Family or friends talked 17% of the respondents into using an alternative therapy. Only 3% of the respondents resorted to the use of an alternative therapy due to anger at the medical system.

Chapter 5

Discussion and Implications

Discussion

The literature states that the average user of an alternative therapy was caucasian, well educated and with a higher income than average (Cassileth et al., 1984)(Lerner & Kennedy, 1992). In 1984 Cassileth determined that 75% of patients informed their physicians of their alternative therapy use.

However, Eisenberg in 1993 determined that over 1/3 of the patients he surveyed used some form of alternative therapy and 73% of them did not inform their physician. If King's theory of goal attainment was used by the health care profession, communication would focus on mutually establishing goals and the means to achieve those goals. If the patient were interested in using an alternative therapy it would be important for the health care provider to facilitate interactions regarding the chosen alternative therapy , validate the perceptions of the dyad (patient and health care provider), and set goals that are mutually agreed upon. In such a situation, with open communication, the percentage of patients using an alternative therapy without informing their

health care would be lower.

The data from this study supports Lerner & Kennedy's study (1992) that those who use alternative therapies are well educated. In this study, 100% of the respondents completed high school, 38% completed college courses, and 7% had engaged in graduate education or higher.

Lerner & Kennedy (1992) also found that households with higher incomes used alternative therapies more than households with lower incomes. This study supports those findings. Twenty-eight percent of the respondents had an income of under \$19,999, 34% had an income in the \$20,000 to \$40,000 range, and 28% of the respondents had an income over \$40,000 per year.

The data was further compressed into two groups based on the number of alternative therapies used. The first group (Group 1) used 0-4 different forms of alternative therapies while the second group (Group 2) used 5 or more. Group 2's statistics fit very well with Lerner & Kennedy's (1992) statistics on alternative therapy users. They had high incomes and were well educated.

Reports in the literature vary widely on the percentage of people who use some form of alternative therapy. Researchers report that 9-83% of people with cancer use some form of alternative therapy (Lerner and Kennedy, 1992; Montbriand, 1993). This study found that 97% of the respondents used some form of alternative therapy which is significantly higher than published

studies.

Eisenberg (1993) found that 73% of the surveyed patients did not inform their physician of their use of an alternative therapy. There are no studies that queried patients about whether they shared this information with a nurse or other health care professional. This study queried the patient on whether they communicated their use of alternative therapies with any of their health care providers. It was determined that the Group 2 (5 or more alternative therapies) had a tendency to share this information more with their health care providers. A full 93% shared their use of an alternative therapy with a nurse while only 67% shared this information with their oncologist and 53% shared this information with their family physician.

Group 1(0-4 alternative therapies total) were significantly different in their sharing of this information. Overall they were much more private about their use of an alternative therapy. Only 57% of them shared this information with their oncologist while only 29% told a nurse or their family physician. This information does not support Eisenberg's (1993) study.

The people in this study tended to share the information of their use of an alternative therapy more than other reported studies. Those who use 5 or more types of alternative therapies were more open with this information with all of their health care providers than those who used a lesser number of

alternative therapies.

Again, this raises the question of why one group communicates more freely with a health care provider. Does a person with a higher education or higher income, such as the patients in Group 2, have greater self-esteem thereby giving them more confidence in broaching the subject of alternative therapy with a health care provider? Do they have a higher concept of communication which allows them to negotiate their health care and feel comfortable in goal setting that someone with a lesser education or lower income does not have? Or are health care providers making assumptions of people with less education and lower incomes and not making the effort to communicate effectively or attempt mutual goal setting?

King's theory would imply that the interaction portion of mutual goal setting between the patient and health care provider is occurring. It appears though that the perception and transaction portions of her theory are missing in these interactions. As Lerner & Kennedy (1992) discovered, the perceptions by the patients and physicians of their interactions often did not agree. If the transaction is when the value of the situation is exchanged between participants and a frame of reference is established, then goals cannot be set if the perceptions of the two parties (dyad) do not agree.

This study also examined the factors that influenced patients in their decision to share or not to share alternative therapy information with their health care provider. The most frequently cited reason to share this information was that they tell their health care provider everything and felt the provider would be supportive. Regretfully, only 39% of the respondents felt this way. The next most common reasons to share this information was because the respondent was seeking information on the chosen alternative therapy (32%) and concern regarding side effects (28%).

There were no clear cut factors that influenced the respondents in not sharing the information of their alternative therapy use with their health care provider. The responses were equally divided between fear of disapproval, desire to keep the information private, embarrassment, and concern that the health care provider would tell them to stop taking their chosen alternative therapy. Most patients could not clearly explain why they would not share information with their health care provider on an alternative therapy that they hoped would cure them of a disease. This offers the health care professional a perfect opportunity to establish mutual goal setting. If health care professionals understand their role in communicating, clarifying the issues, and providing accurate, nonjudgmental information, they can reduce role conflict, confusion, and stress for all involved.

The alternative therapy users in northwestern lower Michigan used spiritual alternative therapies such as prayer more often than physical alternative therapies such as vitamins or herbs. The use of psychological alternative therapies were not as commonly used.

The respondents decision to use an alternative therapy often revolved around the hope that the therapy would make them feel better. The next most frequent reasons were the offering of hope in general plus control over their health care and their cancer. Fear of dying was a factor for over 30% of the respondents.

As Montbriand (1993) discovered, patients received most of their information regarding alternative therapies from non-medical sources such as friends, family, books, other cancer patients, health food stores, television, and magazines. Only 20% of them received information from nursing. This was eighth on the list of information sources. This definitely demonstrates a lost opportunity for nursing to support the patient in their search for goal attainment. If information allows patients to participate in making decisions and choices regarding their health care, nurses should be seizing this opportunity to communicate with their patients. They should be discussing alternative therapy usage and offering comprehensive, unbiased information. By providing this service to their patients they will be participating in

mutually directed goal setting that will be effective in the treatment plan.

By dividing the total number of respondents into the two groups (based on the number of alternative therapies used) a number of interesting differences were noted. Group 1 (0-4 alternative therapies used) had a mean age of 62, 72% were married, 79% had a high school education, and 79% had an income of \$40,000 or less (29% had less than \$19,999). Group 2 (5 or more alternative therapies used) were younger with a mean age of 47 (15 years younger than Group 1). They were similar in their marital status (60% married). They were more highly educated with 53% of them having a college education compared with only 21% in Group 1. While 47% of Group 1 had an income of \$40,000 or less, 47% of Group 2 had an income greater than \$40,000.

These statistics demonstrate two things. First, a weak inverse relationship exists between age and the total number of alternative therapies used that is not statistically significant. Although this does support previous findings that as age increases, the number of alternative therapies used decreases. Secondly, there is a weak positive relationship, which is statistically significant, between the income level and the total number of alternative therapies used. As the income increases, the total number of alternative therapies used also increases.

Limitations

There are several limitations to this study. First, the geographical area is limited to northwestern lower Michigan, thus very small, quite rural, and caucasian. The results of this descriptive study could not be extrapolated to a larger geographic area, an urban population, or a multicultural population.

Secondly, the surveyed population was small at 29 patients. The results could not be generalized to a larger population. Finally, the time frame for distributing the survey was short at only 4 weeks.

Recommendations

The purpose of this survey was to identify issues surrounding the use of alternative therapies in northwestern lower Michigan. To make it easier to generalize the findings to this rural population it would be recommended that the survey be conducted over a longer time frame and include a larger population. It would also be helpful to mail the surveys to all of the patients of the five oncologists that provide services in the specified geographic area. This would avoid any bias of having office personnel distribute the surveys. It would be interesting to explore the oncology nurses awareness and understanding of various alternative therapies that are being used by people with cancer.

Conclusions

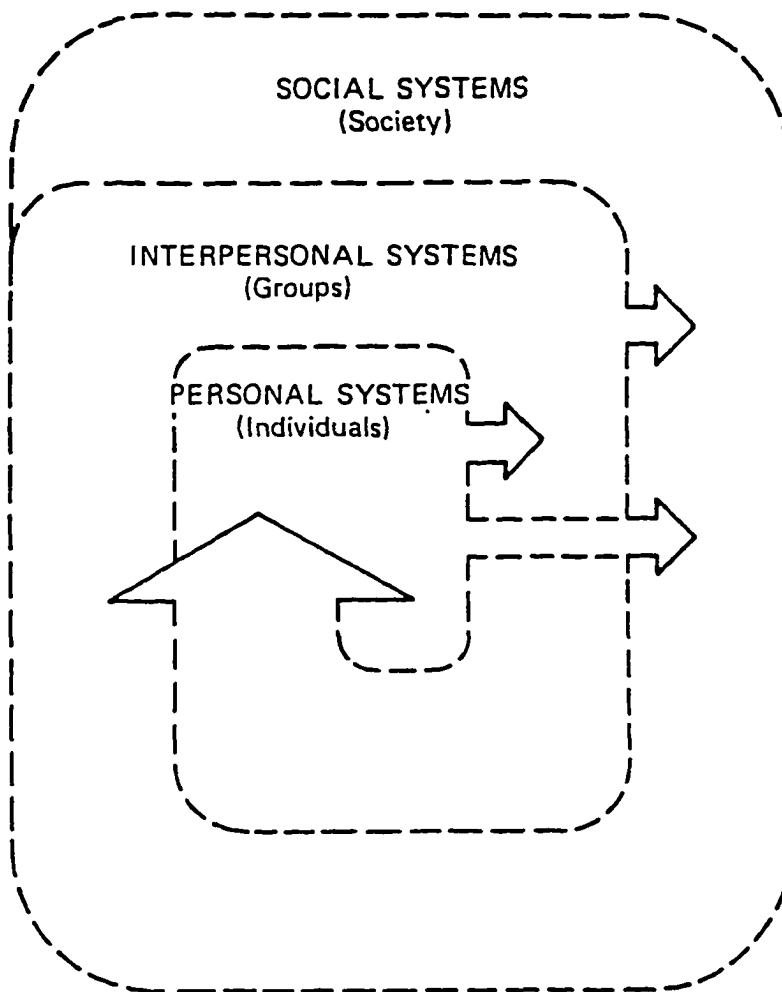
Overall this study demonstrates that in northwestern lower Michigan cancer patients who are younger, have a higher education, and a higher income tend to use more types of alternative therapies. The general cancer population of northwestern lower Michigan tends to use alternative therapy as a supplement to their traditional treatments more frequently than nationally published reports. Similar to the respondents in the published reports, this population receives their information about alternative therapy from the lay press and public rather than the medical profession. They also tend to share this information more often with a health care provider, mostly those of the nursing profession. This offers nursing many opportunities to assist their patients. By being aware of the various alternative therapies available the nurse can initiate communication, clarify perceptions, and establish mutual goal setting with their patients. If nurses understand their role in this situation they can increase achievement of goal attainment and interpret it for all others involved thereby decreasing role conflict, confusion, and stress for themselves and their patients.

Conclusions

Overall this study demonstrates that in northwestern lower Michigan cancer patients who are younger, have a higher education, and a higher income tend to use more types of alternative therapies. The general cancer population of northwestern lower Michigan tends to use alternative therapy as a supplement to their traditional treatments more frequently than nationally published reports. Similar to the respondents in the published reports, this population receives their information about alternative therapy from the lay press and public rather than the medical profession. They also tend to share this information more often with a health care provider, mostly those of the nursing profession. This offers nursing many opportunities to assist their patients. By being aware of the various alternative therapies available the nurse can initiate communication, clarify perceptions, and establish mutual goal setting with their patients. If nurses understand their role in this situation they can increase achievement of goal attainment and interpret it for all others involved thereby decreasing role conflict, confusion, and stress for themselves and their patients.

APPENDICES

Appendix A



A conceptual framework for nursing: dynamic interacting systems.

Source: A Theory For Nursing: Systems, concepts, process

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SURVEY

NO. _____

SEX 1. M ____ 2. F ____

AGE _____

MARITAL STATUS 1. S ____ 2. M ____ 3. D ____ 4. W ____

PRIMARY INSURANCE (check all that apply)

- ☐ 1. Private (BC/BS, Continental, etc.)
☐ 2. Managed Care (Includes HMO & PPO)
☐ 3. Medicaid
☐ 4. Medicare
☐ 5. Unknown
☐ 6. None

DATE OF DIAGNOSIS (month/year) _____

SITE OF CANCER (check original site)

- | | | | |
|----------------------------------------------|----------------------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> 1. Breast | <input type="checkbox"/> 2. Lung | <input type="checkbox"/> 3. Colon | <input type="checkbox"/> 4. Prostate |
| <input type="checkbox"/> 5. Stomach | <input type="checkbox"/> 6. Brain | <input type="checkbox"/> 7. Kidney | <input type="checkbox"/> 8. Ovarian |
| <input type="checkbox"/> 9. Head/Neck | <input type="checkbox"/> 10. Rectum | <input type="checkbox"/> 11. Melanoma | <input type="checkbox"/> 12. Cervical |
| <input type="checkbox"/> 13. Unknown Primary | <input type="checkbox"/> 14. Other (Specify) _____ | | |

EDUCATION (fill in highest grade completed)

- | | |
|------------------------------|------------------------------|
| 1. Elementary (Grade) _____ | 2. Junior High (Grade) _____ |
| 3. High School (Grade) _____ | 4. College (Grade) _____ |
| 5. Graduate School _____ | 6. Post Graduate _____ |

INCOME LEVEL (check one)

- | | | |
|---------------------------------------------|---------------------------------------------|--------------------------------------------------|
| <input type="checkbox"/> 1. 00000 - 19,999 | <input type="checkbox"/> 2. 20,000 - 39,999 | <input type="checkbox"/> 3. 40,000 - 59,999 |
| <input type="checkbox"/> 5. 60,000 - 79,999 | <input type="checkbox"/> 6. 80,000 - 99,999 | <input type="checkbox"/> 7. greater than 100,000 |

TRADITIONAL TREATMENTS RECEIVED FOR CANCER (check all that apply)

- | | |
|-------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <input type="checkbox"/> 1. Surgery (excluding biopsy) | <input type="checkbox"/> 2. Chemotherapy |
| <input type="checkbox"/> 3. Radiation | <input type="checkbox"/> 4. Hormones (ex: Tamoxifen, Arimedes,
Zolodex, Luperon) |
| <input type="checkbox"/> 5. Other (Please specify)
_____ | |

SURVEY

NO. _____

FOR ALL QUESTIONS CIRCLE Y FOR YES OR N FOR NO. PLEASE BE SURE TO RESPOND TO ALL OF THE OPTIONS.

1. WHICH OF THE FOLLOWING ALTERNATIVE THERAPIES HAVE YOU USED?

1. Y / N vitamins (more than a multivitamin)
2. Y / N nutritional changes (ex: macrobiotics, juicing, etc.)
3. Y / N shark cartilage
4. Y / N herbs or enzymes
5. Y / N teas (ex: mushroom, Essiac, Pau D'Arco, green)
6. Y / N hydrogen peroxide or hydrazine sulfate
7. Y / N healing touch
8. Y / N music therapy
9. Y / N art therapy
10. Y / N massage
11. Y / N yoga
12. Y / N prayer
13. Y / N faith healing/healer
14. Y / N support groups/self help groups
15. Y / N meditation
16. Y / N biofeedback
17. Y / N visualization
18. Y / N counseling (individual or group)
19. Y / N alternative therapy clinics (ex: Mexico, Livingston-Wheeler Clinic, etc)
20. Y / N none (stop survey now) Thank you for participating
21. Y / N other (please specify) _____
22. Y / N other (please specify) _____

Comments:

2. WITH WHOM HAVE YOU SHARED INFORMATION REGARDING YOUR USE OF THESE THERAPIES?

- | | |
|------------------------------------|---------------------------------|
| 1. Y / N No one (go to question 5) | 2. Y / N Family doctor |
| 3. Y / N Family | 4. Y / N Nurse Practitioner |
| 5. Y / N Friends | 6. Y / N Dentist |
| 7. Y / N Oncologist | 8. Y / N Pharmacist |
| 9. Y / N Nurse | 10. Y / N Other (specify) _____ |

Comments:

3. WHEN YOU SHARED INFORMATION ABOUT USING AN ALTERNATIVE THERAPY, HOW DID THE PERSON REACT?

- | | |
|---------------------------------------|--------------------------------------------|
| 1. Y / N They were undecided | 2. Y / N They were angry |
| 3. Y / N They didn't care or comment | 4. Y / N They were supportive |
| 5. Y / N They tried to change my mind | 6. Y / N They helped me obtain information |
| 7. Y/N Other (Please specify) _____ | |

Comments:

4. WHEN YOU SHARED INFORMATION ABOUT USING AN ALTERNATIVE THERAPY, DID THE PERSON HAVE ANY KNOWLEDGE OF YOUR CHOSEN THERAPY?

- ___ 1. Yes ___ 2. No ___ 3. Don't know

Comments:

5. WHERE DID YOU RECEIVE INFORMATION ON YOUR CHOSEN ALTERNATIVE THERAPY?

- | | |
|---------------------------|----------------------------------------|
| 1. Y / N Friends | 2. Y / N Other cancer patients |
| 3. Y / N Family | 4. Y / N Television |
| 5. Y / N Books | 6. Y / N Video tapes |
| 7. Y / N Internet | 8. Y / N Health food store |
| 9. Y / N Magazine/Journal | 10. Y / N Primary care provider |
| 11. Y / N Oncologist | 12. Y / N Nurse |
| 13. Y / N Pharmacist | 14. Y / N Other (Please specify) _____ |

Comments:

6. IF YOU TOLD YOUR HEALTH CARE PROVIDER, WHAT FACTORS MADE YOU DECIDE TO SHARE THIS INFORMATION?

1. Y / N Information seeking
2. Y / N Concern about side effects
3. Y / N I tell him/her everything
4. Y / N I thought he/she would be supportive
5. Y / N Concern that he/she would be angry if I didn't share
6. Y / N Other (Please specify) _____

Comments:

7. IF YOU DID NOT TELL YOUR HEALTH CARE PROVIDER, WHAT FACTORS MADE YOU DECIDE NOT TO SHARE THIS INFORMATION?

1. Y / N Fear of disapproval
2. Y / N Wanted to keep it private
3. Y / N Embarrassment
4. Y / N Fear s/he would not continue to be my health care provider
5. Y / N Fear s/he would tell me to stop using it
6. Y / N Other (Please specify) _____

Comments:

8. WHAT MADE YOU DECIDE TO USE AN ALTERNATIVE THERAPY?

1. Y / N I believed it would make me feel better
2. Y / N I felt it would give me more control of my health care
3. Y / N I believed it would give me hope
4. Y / N I felt it would help control my cancer
5. Y / N I was angry at the medical system
6. Y / N I was afraid of the cancer, the treatment, or of dying
7. Y / N My family or friends talked me into it
8. Y / N Other

Comments:

SURVEY

NO. _____

THANK YOU FOR FILLING OUT THIS CONFIDENTIAL SURVEY.

PLEASE REVIEW THE FORM CAREFULLY TO MAKE SURE YOU'VE
ANSWERED EVERYTHING. IT IS IMPORTANT THAT THIS SURVEY BE AS
COMPLETE AS POSSIBLE. **PLEASE PLACE THE COMPLETED SURVEY IN
THE ENVELOPE PROVIDED, SEAL IT, AND RETURN IT TO THE
RECEPTIONIST. IF YOU PREFER, YOU MAY REQUEST A STAMPED
ENVELOPE AND MAIL IT AS SOON AS POSSIBLE.**

INFORMATION & CONSENT

Research Study Title: The oncology patient's perception of support for the use of alternative therapies by their health care provider.

Michelle L. Witkop, BSN, OCN.
Grand Valley State University
Kirkhoff School of Nursing
1-616-941-4608 (H)
1-616-935-6919 (W)

I am a graduate student in nursing at Grand Valley State University Kirkhoff School of Nursing, as well as the Oncology Research Coordinator at Munson Medical Center. I am conducting this research study as part of the requirements for the Master's in Nursing Program. This study will be used to determine the patients perception of support for the use of alternative therapies by their health care provider. Alternative therapies are defined as anything not ordered by your oncologist or family doctor. You will be asked to complete a questionnaire which should take 10 minutes and includes questions on your use of alternative therapies and your perception of support offered by your health care provider. The survey will also include demographic information which we will use to compare our region with demographic information from the nation.

All information will remain confidential. Once you complete the questionnaire put it in the attached envelope and seal it. You may give it to the office staff or mail it to me in a stamped envelope the staff will provide for you. No one will be able to identify you as a participant. Participation is voluntary. The only risk to participation is the time it takes to complete the study. The benefits of participation is your contribution to nursing science and that health care providers may better understand patients reasons for using alternative therapies. You may decide not to participate without consequences. Completion of this questionnaire will imply consent to participate. If you have any questions please contact me at the numbers listed above or you may contact Dr. Paul Huizenga, Chairman of Human Research Review, at 1-616-895-2472. Thank you for your participation.

Sincerely,

Michelle L. Witkop, BSN, OCN.

GRAND VALLEY STATE UNIVERSITY
KIRKHOF SCHOOL OF NURSING

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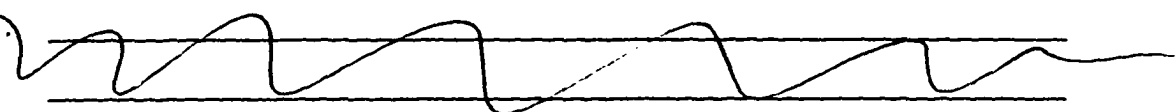
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~~the Grand Valley State University, Kirkhof School of Nursing,~~

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