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Health locus of control and perceived quality of life in patients with cancer

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with cancer**

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San Jose State University, 1992

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HEALTH LOCUS OF CONTROL AND PERCEIVED
QUALITY OF LIFE IN PATIENTS WITH CANCER

A Thesis

Presented to

The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By

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August, 1992

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ABSTRACT

HEALTH LOCUS OF CONTROL AND PERCEIVED QUALITY OF LIFE IN PATIENTS WITH CANCER

by Cathy Brzezinski Linehan

This descriptive study addressed the effect of an individual's perception of control over his or her health on his or her perceived quality of life while living with cancer. Research questions addressed relationships among specific types of health locus of control orientation and quality of life, and whether internal health locus of control facilitated more optimal quality of life. Patients receiving radiation therapy were studied ($N = 70$).

Instruments utilized were the Cancer Health Locus of Control Scale, the Quality of Life Index and a Demographic Data Form. Data were analyzed using descriptive statistics, the Pearson Product Moment Correlation Coefficient and Analysis of Variance.

A statistically significant, positive correlation was demonstrated between powerful other ($r = .35$, $p = .010$) and internal ($r = .47$, $p = .001$) health locus of control orientations and quality of life. Respondents reported either a powerful other or internal health locus of control orientation. However, both of these groups reported similar high quality of life scores. It was concluded that both internal and powerful other health locus of control orientations supported optimal quality of life.

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To my husband, Con,
for his unfailing support
and encouragement —
and to the patients who gave
so generously of themselves.

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Chapter 1

INTRODUCTION

Quality of life is a phrase meant to convey that which makes life worth living. The phrase quality of life has been part of the American vocabulary since the period following World War II. Quality of life issues have become important concerns in planning, choosing, implementing and evaluating policies in both the health care and social arenas (Ferrans & Powers, 1985, pp. 15-16).

In this study, quality of life was defined as the satisfaction of needs. Measurement of a person's quality of life assessed variables across a broad spectrum of life experiences relevant to the person. The individual's degree of satisfaction with these variables as well as the importance of the variable to the person was considered (Ferrans & Powers, 1985, pp. 15-19). One variable that may have influenced quality of life for an individual was that of illness. In the presence of a serious life threatening illness, such as cancer, quality of life was influenced by the illness and should be considered. Germino (1987) stated, "Cancer, cancer treatment symptoms, and symptom distress represent variations in health that may impose changes on the patient in many areas, so that an individual's criteria for good quality of life may vary" (p. 299).

Another variable that may have influenced quality of life was an individual's perception of the degree of control the individual had over his or her life and health. The concept of control over life was first pioneered by Julian Rotter in the 1950's (Rotter, 1975, p. 56). Since the 1970's, researchers have broadened the meaning of the concept of control. The concept of control in relation to situations of health/illness was then defined as a separate psychological construct known as health locus of control (Wallston, Wallston, Kaplan & Maides, 1976, p. 580). Health locus of control referred to the degree to which an individual perceived that the reinforcements specific to health/illness situations were due to the individual's behavior and actions, to chance or fate, or to control by a powerful other (Wallston, Wallston & DeVellis, 1978, pp. 161-162).

This research study was developed from the author's observation that the cancer patients who appeared to experience high quality of life, while living with cancer, also appeared to have higher perceptions of being in control of their cancer and of their life. This research study was an attempt to validate the observation that perception of control influenced perception of quality of life for individuals living with a chronic and potentially life threatening disease.

Problem

Various past studies associated health locus of control orientation with variables such as adaptation, adjustment and coping skills (Dodd, 1984; Marks, Richardson, Graham & Levine, 1986; Padilla & Grant, 1985; and Taylor, Lichtman & Wood, 1984), and self-worth/self-esteem (Lewis, 1982; Power & Craven, 1983; Shillinger, 1983). It was believed that adaptation, adjustment, coping skills and self-worth/self-esteem directly and indirectly influenced the individual's perception of his or her quality of life.

This study questioned the appropriateness of viewing health locus of control orientation as an indirect influence on perception of quality of life, especially for persons with cancer. The nature of cancer and the effects of treatment available for cancer often affected how people felt both about their ability to achieve a good quality of life and about their ability to remain in control of their life and health.

Health locus of control and quality of life were associated in prior research studies (Burckhardt, 1985; Lewis, 1982; Padilla & Grant, 1985). In each of these studies, health locus of control was viewed as one of several variables thought to influence perceived quality of life.

In this research study the effect of health locus of control on perceived quality of life was examined to determine: (a) if there was a significant relationship between health locus of control orientation and perceived quality of life, and (b) if a specific health locus of control orientation (internal, chance, or powerful other) was associated with a higher degree of perceived quality of life.

Purpose and Need

Optimal quality of life has become a goal in health care. In the field of oncology, quality of life has assumed a special significance. With cancer, cure was not always a reality. Nurses and health care professionals instead focused on optimizing the patient's quality of life within the context of a shortened life span and/or physical disability. Research that clarified what factors contributed to optimal quality of life could assist nurses to enable clients' achievement of an optimal quality of life.

One purpose of this study was to expand knowledge regarding the validity of health locus of control as a contributor to quality of life. Health locus of control was defined through the Cancer Health Locus of Control Scale (Dickson, Dodd, Carrieri & Levenson, 1985, pp. 49-54).

Through this instrument, the effect of cancer on patients' frame of reference in regard to health was acknowledged.

A second purpose of this study was to determine if an internal orientation toward health was associated with a higher degree of perceived quality of life. A correlation between internal health locus of control orientation and optimal quality of life could be a stepping stone towards further research. Clients could be taught behaviors that enhance internal control and thus enhance quality of life.

A third purpose of this study was to familiarize nurses with the concept of health locus of control. Insight into a patient's orientation on the internal-external control continuum could guide nurses in their understanding of patient health care behaviors. This insight could also be used to guide nurses' approaches to patient care based on familiarity with a conceptual framework which takes control into account as a determinant of health behaviors and actions (Shillinger, 1983, p. 61).

Actualization of this concept would need to be achieved through education of nurses. Eventually, nurses could administer health locus of control orientation tests to patients and utilize the findings in planning care.

Definitions of Terms

For the purposes of this study, the following definitions were utilized:

1. Quality of life was the subjective reporting by a person of his or her sense of well being, happiness and satisfaction of needs in four general areas of life called domains (health and functioning domain, socioeconomic status domain, psychological/spiritual domain and family domain) (Ferrans, 1990, p. 16). Both satisfaction with each domain and measurement of the importance of the domain to the person were considered. Quality of life was measured in this study by the instrument known as the Quality of Life Index (QLI) (Ferrans & Powers, 1985).

2. Cancer was a malignant disease characterized by: (a) abnormal, increased cell proliferation, (b) loss of cell control mechanisms, (c) loss of ability to differentiate cell morphology, (d) altered biochemical properties, (e) chromosomal instability, and (f) the capacity to spread (metastasize) beyond the point of origin (Donehower, 1985, p. 2). In this study malignancies of four histological types were included: (a) carcinomas (arising from epithelial cells), (b) sarcomas (arising from muscle, bone, fat and other connective tissues), (c) lymphomas (arising from lymphoid tissues), and (d) leukemias (cancers of the hematological system).

3. Optimal was the most desirable or satisfactory (Webster's Ninth New College Dictionary, 1983, p. 829). In

this study, optimal was used to describe a degree of quality of life to be achieved.

4. Health locus of control was a concept which referred to the degree to which an individual perceived that reinforcements and conditions specific to health/illness situations were a result of his or her own behavior, control by chance or fate, or control by powerful others (Wallston et al., 1978, pp. 161-162).

5. Internal health locus of control was the degree to which an individual perceived reinforcements and conditions related to health/illness situations to be contingent upon his or her own behavior (Wallston et al., 1978, pp. 161-162).

6. Chance health locus of control was the degree to which an individual perceived reinforcements and conditions related to health/illness situations to be contingent upon chance, luck or fate (Wallston et al., 1978, pp. 161-162).

7. Powerful other health locus of control was the degree to which an individual perceived reinforcements and conditions related to health/illness situations to be contingent upon a powerful other (Wallston et al., 1978, pp. 161-162).

8. Cancer patient was defined by the researcher as a person receiving health care services for cancer.

9. Perception was awareness of the elements of environment through physical sensation or intuitive cognition (Webster's Ninth New College Dictionary, 1983, p. 873).

Research Questions

For this study the following research questions were proposed:

1. Was there a statistically significant correlation between the perception of health locus of control orientation and the perception of quality of life in persons with cancer?

2. Did cancer patients who exhibited a high internal health locus of control score also report more optimal quality of life than cancer patients who exhibited high chance locus of control or high powerful other health locus of control scores?

These questions were studied by measuring health locus of control orientation of participants and comparing this orientation to self-reported perception of the participant's quality of life.

Research Design

This study utilized a descriptive, correlational research design. The objective was to examine the relationship between the three different types of health locus of control orientation and quality of life, if any,

and to quantify the magnitude and the direction of the relationship (LoBiondo-Wood, Haber & Kovner, 1986, p. 131).

A convenience sample of cancer patients who received radiation therapy at a local community hospital radiation therapy department was used as the sample. Written consent was obtained from each participant. The participants then filled out three separate questionnaires. The questionnaires used in this study were: (a) Cancer Health Locus of Control Scale (CHLC) (Dickson et al., 1985), (b) Quality of Life Index (QLI) (Ferrans & Powers, 1985), and (c) Demographic Data Form (DDF).

Protection of human subjects was ensured by obtaining written permission to conduct the study from the local hospital administrator, the department head of the hospital based radiation therapy department, and the San Jose State University Human Subjects Committee. Individual participants gave written permission to participate in the study. Confidentiality was maintained for study participants by ensuring that only the researcher had access to participants' names and that the data were coded by number when submitted for analysis. In addition, the findings of the study were presented in aggregate form, rather than by individual subjects.

Scope and Limitations

The scope of this study was limited. It was viewed as a descriptive study of one patient population at one point in time and not over a period of time. The results were not generalizeable beyond the study participants and setting.

The limitations of the study included:

1. The study sample was one of convenience. The sample was not randomly selected. It was not representative of the cancer patient population as a whole, or of all cancer patients undergoing radiation therapy.

2. The health locus of control orientation inherent in each subject prior to the cancer diagnosis was unknown. Orientation towards health locus of control may have changed with the diagnosis of the cancer. This study examined the health locus of control after the diagnosis of cancer was made. The researcher had no documentation or knowledge of the prior orientation towards health locus of control.

3. Study participants may have had additional health problems or other problems that affected their orientation toward health locus of control. This effect was minimized by utilization of instruments that instructed participants to respond from the frame of reference of living with cancer.

4. The researcher was also employed as a patient educator in the radiation therapy department study setting.

Investigator bias was possible as the researcher had both prior and concurrent contact with the participants in another capacity.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF THE LITERATURE

This chapter examines the concepts of health locus of control and quality of life and the conceptual framework underlying these concepts for purpose of this study. A general review of the literature is also presented.

Conceptual Framework

The study was based on material drawn from Burckhardt's 1985 study exploring the impact of arthritis on quality of life. In Burckhardt's review of the literature it was noted that the broad domains that appeared to constitute general quality of life were similar for persons both with and without physical disabilities or chronic illnesses. Burckhardt reviewed studies that correlated specific disease related variables (such as pain or dyspnea) with diminished quality of life. These specific symptoms or disease related sequelae were thought to have a direct effect on perception of quality of life. Burckhardt developed a causal model to demonstrate that the impact of the disease, with its individual symptoms and sequelae, was not as direct as theorized. Burckhardt noted numerous studies which demonstrated that different psychological factors were present in many cases that may have had more of an impact on the quality of life of chronically ill people than the disease or disability itself. Among the different

psychological factors proposed was that of personal control over health (Burckhardt, 1985, p. 12).

The causal model was based on a cognitive framework developed by Lazarus and Cohen (cited in Burckhardt, 1985). Lazarus and Cohen proposed that the impact of environmental variables (called inputs) on any personal outcome was mediated by psychological factors. Inputs were defined as variables that included: (a) the physical environment necessary to support human life, (b) the social environment, (c) demographic characteristics, and (d) particular adaptive problems. Adaptive problems included both major life changes that were of an acute or cataclysmic nature and those of a stable, repetitive, chronic nature, such as chronic illness. Mediators were the intervening processes operating in persons assisting them to understand the importance of environmental inputs to the person. The results of this environment-person transaction were defined as success or failure based on value judgments held by the individual and society (Burckhardt, 1985, p. 12).

Using this framework, Burckhardt selected inputs and mediators theorized to impact upon each other and on the quality of life of persons with the chronic illness of arthritis. One of the mediators Burckhardt chose was that of internal control over health. The other mediators chosen

were: (a) perceived support, (b) negative attitude, and (c) self-esteem.

Burckhardt's findings demonstrated that all of the prechosen mediators listed contributed to the total explained variance in quality of life. Self-esteem and internal control over health were the mediators that affected quality of life most (Burckhardt, 1985, pp. 14-15). Burckhardt's findings showed that five variables accounted for the majority of total explained variance in quality of life. Of these five variables, four were the prechosen mediators, one of these being internal control over health (Burckhardt, 1985, p. 16).

Burckhardt's study illustrated that psychological factors, including a sense of personal control, played a major role in determining the quality of life of persons with arthritis. These psychological factors or mediators were what either buffered or enhanced the effect of disease related symptoms on perceived quality of life, not the symptoms experienced by the individual. Burckhardt recommended further research into nursing strategies that affected both the environmental inputs and the mediators as a means of enhancing quality of life (Burckhardt, 1985, p. 16).

This study utilized Burckhardt's recommendation to examine the effect of the individual parts of the causal

model on the outcome goal of quality of life. Increasing the knowledge base of what contributed to optimal quality of life for patients would assist nurses to choose appropriate interventions and develop realistic goals with patients to enhance their quality of life.

Although this study did not replicate Burckhardt's study, it extended the general concepts presented in Burckhardt's work. In this study, the chronic illness was cancer. The outcome was quality of life. The outcome was mediated by the psychological factor known as health locus of control. The concepts of health locus of control and quality of life for persons with cancer as they relate to the tenants of this study are presented.

Health Locus of Control

Health locus of control was derived from a more general psychological concept known as locus of control. Locus of control addressed individuals' expectations about the outcomes of their actions. Health locus of control was the same concept as locus of control, but it specifically addressed individuals' expectations about the outcomes of health-related actions (Dickson, Dodd, Carrieri & Levenson, 1985, p. 49).

Health locus of control suggested that the likelihood of a health-related behavior occurring was a function of both the expectancy that a behavior would lead to a specific

outcome and the reward value assigned to that outcome by the individual (Rotter, 1975, p. 56). Health locus of control was a generalized expectancy developed over time that occurred when individuals learned that health related events were contingent or noncontingent on their behaviors (Dickson et al., 1985, p. 49). Through individual health experiences, people developed a generalized belief system, which was the basis of their health locus of control orientation, as to whether or not health events and outcomes were under their control or were largely influenced by forces external to them.

Three separate dimensions were identified under health locus of control orientation. The internal dimension referred to the degree to which individuals perceived the health events that happened to them as being dependent upon their own behavior. The chance dimension referred to the degree to which individuals perceived the health events that happened to them as a result of chance, luck or fate and beyond their personal control. The powerful other dimension referred to the degree to which individuals perceived health events that happened to them as primarily under the control of a powerful other or others, such as a physician or nurse (Dickson et al., 1985, p. 49).

Quality of Life

The work of Ferrans guided the definition of quality of life for this study. Quality of life was defined as, "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (Ferrans, 1990, p. 15). This definition accounted for differences in individual's values. It also evaluated the importance of a value to an individual. This definition of quality of life evaluated the subjective experience of life rather than the conditions that influenced the experience of life. Quality of life was conceptualized as a multidimensional concept consisting of four broad areas known as domains. The domains were: (a) health and functioning domain, (b) socioeconomic status domain, (c) psychological/spiritual domain, and (d) family domain (Ferrans, 1990, p. 15). The domains reflected areas that impacted all individuals.

Related Literature

The review of related literature presented here encompasses studies that examined health locus of control orientation as it affects quality of life, or a specific domain of quality of life.

Hallal (1982) examined differences in the health beliefs, health locus of control and self-concept of women who practiced breast self-exam as compared to women who did

not. Her findings showed that women who practiced breast self-exam demonstrated higher levels of health beliefs and higher self-concept levels. The practice of breast self-exam was not significantly correlated with a higher score on the internal subscale of the Multidimensional Health Locus of Control Scale used to determine health locus of control. This finding was unusual in view of a number of prior study results that showed "internals" were more likely to engage in behaviors that facilitated physical well-being. Hallal did not specifically relate health locus of control to quality of life. The findings were relevant in that they suggested a relationship between health beliefs, self-concept and the practice of breast self-exam. Health beliefs and self-concept were concepts related to health locus of control and quality of life.

Lewis (1982) conducted a study which examined the association between experienced personal control and quality of life for late stage cancer patients. The study sample was comprised of 57 adults with cancer. Late stage cancer patients were defined as those diagnosed as terminal, with care directed towards palliative goals only. These criteria produced a study sample different in nature from that of the sample population in this research study. Quality of life was conceptualized as a measure of self-esteem, degree of anxiety and perceived meaningfulness. It was hypothesized

that greater control would be associated with higher quality of life as measured by the chosen indicators (Lewis, 1982, p. 114).

The study results demonstrated evidence of two potentially distinguishable aspects of personal control in late stage cancer patients, personal control over one's life and personal control over one's health. The results demonstrated that the experience of personal control over one's life was a more significant predictor of quality of life, than the narrower viewpoint of personal control over one's health was to perceived quality of life. The measure of experienced personal control over life significantly correlated with scores on the Self-Esteem Scale, the Purpose-In-Life Test, and the Parsell Anxiety Scale (Lewis, 1982, p. 113). Personal control over one's health was measured using the Health Locus of Control Scale and the separate personal control subscale of the HLC Scale. Contrary to Lewis' expectations, scores on the Health Locus of Control Scale were associated only with scores on the Purpose-In-Life Test (Lewis, 1982, p. 113).

Lewis' study demonstrated that the concept of personal control over health (high internality) was not predictive of better quality of life in cancer patients. Lewis specifically noted problems associated with the use of the HLC Scale with chronically ill subjects in terms of the

vocabulary used in the HLC Scale not being sensitive enough to reflect the illness experience of the subject. Lewis also noted the need to examine the concept of perceived control over one's life and one's health within a framework that includes other concepts which mediate the relationship between perceived personal control and quality of life (Lewis, 1982, pp. 117-118). These factors may have accounted for the lack of support for the hypothesis that increased personal control over health would be related to better quality of life for cancer patients.

Young and Longman (1983) investigated variables associated with quality of life in patients with melanoma. Variables chosen for their study were: (a) symptom distress, (b) social dependency, (c) behavior-morale, and (d) life change. Three hypotheses were postulated and all were supported. The first hypothesis found symptom distress was inversely associated with quality of life. The second hypothesis found social dependency was inversely associated with quality of life. The third hypothesis found behavior-morale was positively associated with quality of life (Young & Longman, 1983, pp. 222-224). Lower degrees of symptom distress and social dependency, and higher degrees of behavior-morale were associated with better quality of life. The conceptual framework and model of this study was

similar to Burckhardt's description of the impact of the variables on quality of life.

Burckhardt's causal model was the conceptual framework on which this thesis was based. Young and Longman's model was less specific in its presentation of inputs, utilizing the entire disease experience of melanoma to correspond with the input section of Burckhardt's causal model. The variables thought to mediate the disease experience differed from those in Burckhardt's study. Young and Longman's findings added credence to the conceptual framework utilized in this study.

Padilla and Grant (1985) developed a multidimensional instrument for measuring quality of life in cancer patients. In addition, they offered a model that described how quality of life functioned as an outcome variable. Using this model, predictions were made as to how nursing interventions might directly or indirectly impact quality of life. The initial testing demonstrated specifically how personal control acted as a mediator of self-worth, which then impacted on dimensions of quality of life.

Padilla and Grant's model was based on Burckhardt's (1985) causal model. Personal control was measured with the Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978) Padilla and Grant found that increased perceived control over health was correlated with

increased psychological well-being. They stated that the chance locus of control score supported this expectation. As feeling of control by chance or fate as a perceived cause of wellness or illness diminished, control and physical well-being increased (Padilla & Grant, 1985, p. 55).

Dickson, Dodd, Carrieri and Levenson (1985) developed a Cancer Health Locus of Control (CHLC) Scale. The CHLC Scale was based on the Multidimensional Health Locus of Control Scale (Wallston et al., 1978) and was compared to it for reliability and validity determinations. Development of the CHLC Scale was anticipated to be of use in increasing the researcher's ability to predict health behaviors in cancer patient populations and to better understand the diversity among cancer patients' health behaviors.

Marks, Richardson, Graham and Levine (1986) examined the effects of health locus of control beliefs and expectations of treatment efficacy on short-term psychological adjustment in a sample of newly diagnosed cancer patients. The role of these health beliefs and expectations in moderating the relationship between disease severity and depression was also explored. Their findings demonstrated that the relationship between perceptions of disease severity and depression was much less for those patients who believed they could control their health personally and for those who held positive expectations

about the effects of compliance with medical treatment. The authors proposed that this finding indicated that beliefs and expectations about the role self plays in controlling one's own health could have functional value for a person with a serious illness (Marks et al., 1986, p. 448).

Hickson, Housley and Boyle (1988) examined locus of control in relation to life satisfaction, death anxiety, age and gender in the elderly. Gender was found to affect life satisfaction, as women reported lower life satisfaction. The higher the degree to which the individual perceived he or she had control of reinforcing events was also a main factor that affected the degree of life satisfaction among the elderly.

The study demonstrated that locus of control orientation could have significant effects on life satisfaction for the elderly. The concept of life satisfaction was parallel to the general concept of satisfaction of needs used to define quality of life in this study. Further research was indicated to examine the role of life span development perspective in both general and health locus of control orientation.

Summary

These studies demonstrated that health locus of control was related to quality of life from a variety of viewpoints, both directly and indirectly. These study findings

supported the need for further investigation of health locus of control in cancer patients.

Chapter 3

RESEARCH DESIGN AND METHODOLOGY

This chapter presents the methodology of the research study. It describes the population, setting, instruments, and manner in which data were collected and analyzed.

Setting

The setting for this study was the radiation therapy department of a 176 bed community hospital. The majority of patients were treated on an outpatient basis, although patients who required inpatient care were also treated in the department. Of the 70 study participants, one person completed the questionnaires while an inpatient. The remaining patients completed the questionnaires as outpatients.

A written proposal was submitted outlining the purpose, background, methodology, setting and use of human subjects to the San Jose State University Human Subjects Committee who granted permission and approval to conduct the study. Permission to use human subjects was granted from the hospital administrator. The head of the hospital based radiation therapy department gave written permission for the nurse researcher to approach patients in the department and invite them to participate in the study.

Sample

A convenience sample of 70 cancer patients receiving external beam radiation therapy was studied. All patients who met the designated criteria who presented themselves during the data collection time were eligible to be included in the study sample.

The desired sample of 70 was determined based upon Haber's (1986) recommendation that a sample size of 30 be chosen for each subset of the data (p. 216). The study had two major data subsets: (a) health locus of control, and (b) quality of life. The sample size was actually 35 for each subset.

Patients were required to meet the following criteria to be eligible for participation. The patient was eligible if he/she:

1. Was a legal adult, 18 years of age or older. A minor was considered a legal adult if: (a) he/she had entered into a legal marriage, whether or not the marriage was terminated by dissolution; (b) he/she was on active duty with any of the armed forces of the United States; or (c) he/she had received a declaration of emancipation pursuant to Civil Code Section 64 (Civil Code Sections 25 and 62) (California Association of Hospitals and Health Systems Consent Manual, 1991, p. 15).

2. Was diagnosed with one of four types of cancer:
(a) carcinomas, (b) sarcomas, (c) lymphomas, or
(d) leukemias. The cancer had to be actively proliferating at the time of the patient's participation in the study and not in a state of remission.

3. Had completed a minimum of five radiation therapy treatments. Patients would have had time to adjust to the surroundings and routine of the treatments. The researcher did not want to cause anxiety by asking individuals to participate when they were possibly still adjusting to the treatment regime.

4. Was able to read, write and speak English.

5. Was willing to respond to the questionnaire independently. The researcher read the questionnaires to the participants or marked their stated responses for them if they were physically unable. Spouses, family or friends were not allowed to assist in data collection to reduce bias.

Protection of Human Subjects

Approval of the study design, ethics and protection of patients' rights were ensured by the following means. The research study was approved by the San Jose State University Committee on Protection of Human Subjects (Appendix A). The proposal was submitted in writing and met the requirements set forth by San Jose State University. Written permission

was obtained from the hospital and the radiation therapy department head (Appendix B and Appendix C).

The study participants were asked to read and sign a written consent form (Appendix D). This form consisted of statements about the purpose of the study, form of involvement required and time commitment required. The possible risk of the study, emotional distress related to thinking about serious topics related to life, was presented. Participants were advised that if they felt any distress while participating they could return the questionnaires and state they had changed their mind about participating. There would be no adverse repercussions and no questions would be asked. It was anticipated that if any patients did become distressed, the nurse researcher would be available to offer emotional support as a first line response. The mental health services of the hospital were available if the patient required further counselling and/or support. The services of the nurse and of the mental health department were not required during the course of this study. The possible benefit, that the knowledge gained from the study would improve nursing care, was also stated. The guidelines of voluntary participation, which could be terminated at any time were stated. A copy of this consent letter was given to each participant.

Data Collection

A total of 76 patients were approached and invited to participate in the research study. Six declined to participate. All six patients who declined to participate gave a similar reason--they did not want to confront anything that might be emotionally risky or negative in content for fear of upsetting themselves. Data collection took place over a period of 16 weeks. The study participants took an average of 30-45 minutes to complete the questionnaires. Most participants had at least one to two questions about format and/or wording of the questions. Eight weeks had been allotted to collect data. However, more researcher involvement was required than had been anticipated, leading to the longer data collection period.

The researcher approached patients receiving external beam radiation therapy while they were in the department for treatment. Participation was invited through face to face contact only. The researcher explained the general purpose of the study, the form of involvement required, and the time commitment required. If the patient agreed to participate, written consent was obtained. The patient was given the research study packet with instructions on how to complete the packet. The research packet was collected when complete and reviewed briefly for completeness before the patient left the department. If an answer to a question had been

omitted, this was pointed out to the participant and he/she was asked to complete the missing question.

The researcher maintained a confidential master list of all patients asked to participate, along with their response. This prevented asking the same patient to participate more than once. The names of patients who agreed to participate were listed on a separate, confidential master list. Each name was assigned a code number which corresponded to the same number on each sheet of the research packet they completed. The coding ensured accurate assembly of the packet during and after data analysis. The coding also ensured the patient's name was not made known to the statistician during data analysis.

Instruments

Three self-report inventories, two scales and one questionnaire, were employed as the data collection instruments in this study. These instruments were chosen because they simplified responses to complex and sometimes difficult material for the respondent, while presenting the material in a structured and orderly format. The format also allowed respondents to express their personal feelings in an anonymous and confidential manner (Grey, 1986, p. 162). The three instruments used in this study were: (a) Cancer Health Locus of Control Scale (CHLC), (b) Quality of Life Index (QLI), and (c) Demographic Data Form (DDF).

Cancer Health Locus of Control Scale

The CHLC Scale was utilized to measure the patient's health locus of control. The CHLC Scale measured beliefs that a person's source of reinforcement regarding health beliefs related to living with cancer was either under internal control, a matter of chance, or under the control of a powerful other. The CHLC Scale consisted of three subscales: (a) Internal Health Locus of Control, (b) Chance Health Locus of Control, and (c) Powerful Other Health Locus of Control (Dickson, Dodd, Carrieri & Levenson, 1985, p. 51).

The CHLC Scale consisted of 18 items, grouped into 3 subscales. Each subscale consisted of six items. The items were rated on a 6-point Likert-type scale. The written instructions on the first page of the scale informed the patients that the statements which followed were belief statements with which they might agree or disagree. The patients were directed to express their cancer health locus of control beliefs in writing by completing the scale beside each statement. The patients were directed to rank the extent to which they agreed or disagreed with the cancer health belief statement by circling a number.

The Likert-type scale range was: strongly disagree (1), moderately disagree (2), slightly disagree (3), slightly agree (4), moderately agree (5) and

strongly agree (6). The patients were also instructed to circle only one response per item and to respond to each item independently in accordance with their personal beliefs and feelings at that time. The patients were asked to take into account the impact of their cancer diagnosis, if any, on their health belief system and to answer from that frame of reference. The researcher also emphasized this point verbally in giving the participant directions. In this manner, the illness experience of living with cancer was taken into account in determining health locus of control (Dickson et al., 1985, pp. 49-50).

The separate subscales of the CHLC scale each consisted of six similar item statements. The subscale statements were phrased to determine what the source of the patients' reinforcement of their beliefs regarding health locus of control were. The six internal subscale item statements were worded to determine if the source of reinforcement for health beliefs came as a result of the patients feeling that they controlled their health. The six chance subscale item statements were worded to determine if the source of reinforcement for health beliefs came as a result of the patients feeling that chance, luck, or fate was the primary determinant of their health beliefs and actions. The six powerful other subscale item statements were worded to determine if the source of reinforcement for health beliefs

came as a result of the patients feeling that a powerful other or others were the primary determinants of their health beliefs and actions. (Dickson et al., 1985, p. 51).

The item statements of each subscale were randomly scattered throughout the CHLC Scale. Upon completion of the entire 18-item CHLC Scale, the researcher utilized a key to identify the questions belonging to each individual subscale. The score for that individual subscale was computed by summing the value circled for each item statement of the subscale. The range of scores for each subscale extended from the lowest score of 6 to the highest score of 36. The subscale with the highest score noted indicated the patients' most dominant health locus of control orientation (personal communication, Angie Dickson, 10/22/88).

The content validity of the CHLC Scale was established "by having a panel of experts in oncology and attitude scales critique the instrument" (Dickson et al., 1985, p. 51). A pilot study was conducted with five patients to determine clarity of the instructions and items. The CHLC Scale was compared to a similar scale known as the Multidimensional Health Locus of Control (MHLC) Scale (Wallston, Wallston & Devellis, 1978) to establish reliability and validity. A comparative cross-over design with a non-randomized convenience sample of 30 patients with

cancer was utilized. Reliability coefficients for each subscale on the two scales were estimated by Cronbach's alpha. The alpha reliabilities of the MHLC Scales were from .65 to .75, while the internal consistency estimates for the CHLC subscales were all lower than for the MHLC Scales (CHLC Internal = .63, CHLC Chance = .62, CHLC Powerful Other = .48).

The validity of the relevant subscales of the MHLC and the CHLC Scales was estimated through Pearson Product Moment Correlation Coefficients. The Internal and Powerful Other subscales from the MHLC and the CHLC Scales correlated significantly ($p = .005$). The Chance subscales for the two scales were not significantly correlated, suggesting that the CHLC Chance subscale was measuring a different concept than that of the more general health oriented MHLC Scale's Chance subscale (Dickson et al., 1985, pp. 49, 52). Permission to utilize the instrument was obtained from the authors (Appendix E).

Internal consistency reliability estimates were run on the CHLC subscales with this study's data. The alpha reliabilities for the data were: (a) Internal subscale = .78, (b) Chance subscale = .69, and (c) Powerful Other subscale = .77. These figures compared favorably to the internal consistency reliability estimates done for the

CHLC subscales in the original research done to develop the CHLC Scale (Dickson et al., 1985, p. 52).

Quality of Life Index

This study utilized the Quality of Life (QLI) Index developed by Ferrans and Powers (1985). The QLI based the definition of quality of life on the framework of satisfaction of needs. Satisfaction was defined as "the perceived discrepancy between aspirations and achievement, ranging from the perception of fulfillment to that of deprivation; need was defined as the amount of a particular reward that a person may require" (Ferrans & Powers, 1985, p. 17).

Two separate subscales were developed:

(a) Satisfaction, and (b) Importance. In the Satisfaction subscale individuals rated their degree of satisfaction with different areas reflective of overall quality of life. In the Importance subscale individuals rated the importance of different areas reflective of overall quality of life to themselves (Ferrans & Powers, 1985, p. 17). Permission was obtained from the authors to use the tool (Appendix E).

Each of the two subscales consisted of 35 items that assessed overall quality of life as well as items reflective of the specific illness of cancer. These items were chosen from a review of the literature as probable determinants of quality of life. The 35 items were grouped into similar

categories. The categories reflected four broad areas, also known as domains, which were felt to represent quality of life aspects that concerned all people. These domains were called: (a) health and functioning domain, (b) socioeconomic status domain, (c) psychological/spiritual domain, and (d) family domain (Ferrans & Powers, 1985, pp. 16-17).

For each item of the scale, participants responded by ranking their degree of either satisfaction or importance with the specific item in question. A 6-point Likert-type scale was used to rank the degree of satisfaction or importance. The range of the scale was: very unimportant/very dissatisfied (1), moderately unimportant/dissatisfied (2), slightly unimportant/dissatisfied (3), slightly important/satisfied (4), moderately important/satisfied (5), and very important/satisfied (6).

The final Quality of Life Index score was determined, via a specially designed computer program, by adjusting the satisfaction responses by the importance responses of each question. The responses were able to be looked at individually, question by question, or grouped together under domains. A total, overall Quality of Life Index score was also obtained. The final score considered not only the respondent's satisfaction with the different aspects that make up individual quality of life, but also how much the

individual valued each aspect of quality of life. A more accurate reflection of the subject's quality of life was thus obtained. Satisfaction responses for each item were recoded and multiplied with the importance response for that item to produce an adjusted score. Raw satisfaction responses were recoded to make zero the midpoint to produce this adjustment. Adjusted item scores were totaled to produce domain subscale scores and overall quality of life scores (Ferrans & Powers, 1985, p. 18).

The psychometric properties of the QLI were demonstrated through review of content validity, criterion-related validity, stability reliability and internal consistency reliability. Content validity was supported by choosing items based on review of the literature related to quality of life and on patient reports regarding the effect of illness and treatment on their quality of life (Ferrans & Powers, 1985, p. 18).

Criterion-related validity was evaluated by comparing the QLI to another instrument with known reliability and validity. The QLI was compared to an overall satisfaction with life question. Correlations between scores from the QLI and life satisfaction question for healthy persons were .75; for ill persons it was .65. A high correlation was demonstrated, supporting the validity of the QLI (Ferrans & Powers, 1985, p. 19).

Stability reliability was demonstrated by the test-retest method. Quality of life had been demonstrated to be relatively stable over a period of a few weeks. For both well and ill test group persons high test-retest correlations were present, supporting the stability reliability of the QLI (Ferrans & Powers, 1985, p. 19).

Internal consistency reliability was evaluated using Cronbach's alpha. The higher the alpha, the greater the internal consistency reliability. Internal consistency reliability of the QLI was supported by Cronbach's alphas of .93 (healthy persons) and .90 (ill persons) (Ferrans & Powers, 1985, pp. 19-20).

Internal consistency reliability estimates were run on each domain of the QLI with this study's data. The alpha reliabilities for the data were: (a) health and functioning domain--satisfaction responses = .91, importance responses = .61, (b) psychological/spiritual domain--satisfaction responses = .91, importance responses = .49, and (c) family domain--satisfaction responses = .61, importance responses = .72. The fourth domain of the QLI was the socioeconomic status domain. Accurate internal consistency reliability estimates were not able to be determined for this domain. Two of the items relevant to this domain sought information on participant's feelings about either being employed or being unemployed. Since

respondents answered either one or the other of the questions, the sample size for each question was smaller and contributed to a significant amount of missing data when attempting to calculate an alpha reliability. The alpha reliability obtainable was not accurate. The overall mean of the alphas available for this study's data was .71.

Demographic Data Form

Demographic data were collected to describe the patient population characteristics and define the nature of the study population. Knowledge about the types of participants was helpful in data interpretation and analysis (Haber, 1986, p. 218). The Demographic Data Form was formulated by the researcher based upon a review of the literature on quality of life. The researcher chose demographic variables which were believed to be descriptive of the population, easily obtained, and which could help interpret the basic questions posed in this study.

The demographics requested of each participant were: (a) age, (b) sex, (c) highest grade level of school completed, (d) primary site of the cancer, (e) when the cancer was diagnosed, (f) when the present course of radiation therapy was begun, (g) religious affiliation, (h) race, and (i) income level. The information was solicited in writing. Participants were assured in writing

and verbally by the research that all information was confidential.

Analysis of the Data

The demographic data were analyzed in the following ways. The mean and standard deviation were calculated for the demographic variable of age. Tabulation of numbers and quantitative reporting of results were done for the demographic variables of: (a) sex, (b) grade level of school completed, (c) primary site of cancer, (d) religious affiliation, (e) race, and (f) income level. The remaining demographic variables: (g) date of cancer diagnosis, and (h) date current course of radiation therapy treatment was started, were reported in terms of range of time.

The mean and standard deviation were calculated for each item of the CHLC Scale, subscales of the CHLC Scale (Internal, Chance and Powerful Other), and the QLI. An overall Quality of Life Index score was calculated for each respondent using the author's instructions. A Pearson Product Moment Correlation Coefficient was done to determine relationships between the CHLC subscales (Internal, Chance and Powerful Other) and overall Quality of Life Index scores. A Pearson Product Moment Correlation Coefficient was calculated to analyze the relationship between those respondents with a specific predominant health locus of control orientation, as determined by the CHLC Scale and

that groups' Quality of Life Index score. The purpose was to determine if one type of health locus of control orientation led to a higher Quality of Life Index score. The correlations presented the relationships between the concepts.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

This study described the relationship between health locus of control and quality of life in a sample of patients with cancer. It examined the relationships between the different types of health locus of control and quality of life. It also examined the relationship between the specific subscale of internal health locus of control and perception of quality of life in cancer patients.

Description of the Sample

Table 1 described the demographic variables of the sample: (a) sex, (b) age, (c) highest grade level of school completed, (d) religious affiliation, (e) race, and (f) income level. The demographic data revealed that over one-half of the study participants were male ($n = 41$, 58.6%), while the remainder were female ($n = 29$, 41.4%). These figures corresponded to both the state of California and the nationwide statistics for cancer incidence by sex, in that males had a higher incidence of cancer than did females (Schiller, McKendry, Wright, Perkins & Young, 1988, p. 1). The sample population ages were between 61-70 years old ($n = 31$, 44.3%) and 71-80 years old ($n = 17$, 24.3%). The mean age of the total sample population was 65.5 years. Cancer incidence was known to

Table 1

Demographic Data

	<u>n</u>	<u>%</u>		<u>n</u>	<u>%</u>
<u>Sex</u>			<u>Religious Affiliation</u>		
Male	41	58.60	Protestant	40	57.10
Female	29	41.40	Catholic	19	27.10
<u>Total</u>	<u>70</u>	<u>100.00</u>	Jewish	01	01.40
<u>Age</u>			Buddhist	01	01.40
21-30 years	00		Other	09	12.90
31-40 years	03	04.30	<u>Total</u>	<u>70</u>	<u>100.00</u>
41-50 years	05	07.10	<u>Race</u>		
51-60 years	09	12.90	Caucasian	63	90.00
61-70 years	31	44.30	Black	03	04.30
71-80 years	17	24.30	Hispanic	01	01.40
81-90 years	05	07.10	Asian	02	02.90
<u>Total</u>	<u>70</u>	<u>100.00</u>	Other	01	01.40
			<u>Total</u>	<u>70</u>	<u>100.00</u>
M = 65.60 years			<u>Income Level</u>		
SD = 11.01 years			Less than \$15,000/yr	06	08.60
			\$15,000-\$25,000/yr	08	11.40
<u>Highest Grade Level of School Completed</u>			\$26,000-\$35,000/yr	24	34.40
Elementary	04	05.70	\$36,000-\$45,000/yr	09	12.90
High School	19	27.10	\$46,000-\$55,000/yr	07	10.00
Bachelors Degree	30	42.90	More than \$55,000/yr	15	21.40
Masters Degree	13	18.60	<u>Total</u>	<u>70</u>	<u>100.00</u>
Doctoral Degree	04	05.70			
<u>Total</u>	<u>70</u>	<u>100.00</u>			

increase with age; this data correlated as expected (Schiller et al., 1988, p. 8).

The data revealed a well-educated sample. Forty-seven of the participants were educated at the college level or beyond (67.2%).

Over one-half of the participants were of the Protestant faith ($\underline{n}$ = 40, 57.1%). The second most frequently reported religious affiliation was Catholic ($\underline{n}$ = 19, 27.1%).

The sample population was predominantly Caucasian ($\underline{n}$ = 63, 90%). The next most frequently reported ethnicity was Black ($\underline{n}$ = 3, 4.3%), followed by Asian ($\underline{n}$ = 2, 2.9%), Hispanic ($\underline{n}$ = 1, 1.4%), and Other ($\underline{n}$ = 1, 1.4%). This data did not follow the racial composition of the geographic area from which the study sample was drawn. This area was composed of Caucasian (58.9%), Hispanic (29.7%), and Other (11.4%). Over one-half of the persons in the Other category were Asian, followed by Black, then by American Indian (Bay Area Cancer Registry Report, 1991). The ethnic population breakdown was for the general population, not specifically for cancer patients. The study data for race did not correlate with nationwide racial composition either. According to 1980 census data, Caucasian was the nation's predominant race, followed by Hispanic, Black, Asian and

Pacific Islander, and American Indian (United States Department of Commerce, Bureau of the Census, 1980).

Over one third of the population ($\underline{n} = 24$, 34.3%) had an income level between \$26,000-\$35,000 per year. The second most frequently reported income level was greater than \$55,000 per year ($\underline{n} = 15$, 21.4%).

Table 2 displayed the oncology related demographic characteristics of the sample. The primary sites of the respondents' cancer were: (a) prostate ($\underline{n} = 20$, 28.6%), (b) breast ($\underline{n} = 15$, 21.4%), (c) lung ($\underline{n} = 9$, 12.9%), and (d) head/neck tumors ($\underline{n} = 7$, 10.0%). These statistics corresponded to regional, state and nationwide data with one exception. In the geographic region from which the study sample was drawn, as well as in the state of California and the nation, the four most common cancer sites were found to be: (a) prostate, (b) female breast, (c) lung, and (d) colorectal. These sites were for both genders and not listed in descending order of frequency. The study sample had a higher incidence of head/neck cancers than of colorectal cancers.

The study data were collected between June, 1989 and October, 1989. In 1989, over one half of the sample population ($\underline{n} = 46$, 65.7%) was diagnosed with the cancer and began a course of radiation therapy. Another group of respondents ($\underline{n} = 10$, 14.2%) had been diagnosed with cancer in 1988. Over three fourths of the study sample ($\underline{n} = 56$, 79.9%) had been living with the diagnosed cancer

Table 2

Oncology Demographic Data

Month/Year of Cancer Diagnosis	<u>n</u>	<u>%</u>
<hr/>		
July-Dec/1989	15	21.42
Jan-June/1989	31	44.28
1988	10	14.28
1987	03	04.29
1986	03	04.29
1985	02	02.80
1984	01	01.40
1981	02	02.80
1979	01	01.40
1978	01	01.40
<u>Unknown</u>	<u>01</u>	<u>01.40</u>
Total	70	100.00

Primary Site of the Cancer

Prostate	20	28.60
Breast	15	21.40
Lung	09	12.90
Head/Neck	07	10.00
Lymphoma	03	04.30
Colon	02	02.90
Stomach	02	02.90
Rectum/Anus	01	01.40
Hodgkin's	01	01.40
Bladder	01	01.40
Ovary	01	01.40
Cervix	01	01.40
<u>Other</u>	<u>07</u>	<u>10.00</u>
Total	70	100.00

for a period of 22 months or less at the time the data were gathered.

Quality of Life Index

The Quality of Life Index (QLI) consisted of two separate subscales: (a) Satisfaction subscale, and (b) Importance subscale. Each item ranking was reported by mean and standard deviation (Appendix F). The raw data were analyzed by how satisfied the respondents were with the subscale items and by how important the subscale items were to the respondents.

Satisfaction Subscale

The purpose of the Satisfaction subscale of the QLI was to determine the degree of satisfaction of different items thought to contribute to quality of life for all individuals. An initial analysis of the Satisfaction subscale items' mean rank scores demonstrated that very few responses were ranked as dissatisfied under the Likert-type scale utilized. Three of the 35 satisfaction items had a mean rank score between 3 (slightly dissatisfied) and 4 (slightly satisfied). Twelve of the 35 satisfaction items had a mean rank score between 4 (slightly satisfied) and 5 (moderately satisfied). The remaining 20 of the 35 satisfaction items had a mean rank score between 5 (moderately satisfied) and 6 (very satisfied) on the Likert-type scale utilized.

Analysis of this data revealed that the sample population was more satisfied than dissatisfied with quality of life as measured by this instrument. When analyzed in the context of living with and being treated for cancer, this finding of overall satisfaction was surprising. In a sample of this size, it was unlikely that all 70 participants were functioning without any problems related to the disease. Both cancer and the radiation therapy treatments caused symptoms and side effects. When the satisfaction items were analyzed for content, the areas of disease related symptoms and treatment related side effects were covered in a very limited manner. These omissions led to questions regarding the sensitivity of the instrument in measuring quality of life in cancer patients accurately and comprehensively. However, the participants could have been satisfied and perceived that they were living optimally within their limitations.

Importance Subscale

Initial analysis of the Importance subscale items' mean rank scores indicated that the majority of the importance items were ranked between 4 (slightly important) and 6 (very important) to the participants. The study population ranked 32 of the 35 importance items presented in the tool as representative of quality of life to be of importance to them more so than as being unimportant. The concepts that

ranked highest were related to family, health and functioning abilities and psychological aspects such as control, happiness, satisfaction, peace of mind and usefulness. This applied to 32 of the 35 importance items.

Three of the 35 importance items were ranked as unimportant to the participants. The items ranked as unimportant related to: (a) sex life, (b) having a reasonable amount of stress and worries, and (c) having a job again, if the respondent was currently unemployed, disabled or retired. Two of these three items, (a) sex life, and (b) having a reasonable amount of stress or worries, had a importance ranking of $\bar{M} = 3.81$ and $\bar{M} = 3.96$, respectively.

Considering the sample population was living with and being treated for cancer, the ranking of a reasonable amount of stress or worry as unimportant was unclear. The wording of this item regarding amount of stress or worry needed frequent clarification during the administration of the tool. It was legitimate to assume that having a reasonable amount of stress or worry at such a time would be of greater importance to individuals than the results indicated. The item could be reworded in future applications of the tool to improve the ease of interpretation. The low importance of sex and employment was clearer considering the mean age of the respondents was 65.5 years. A portion of the

respondents were retired and sexual drive could be affected by both age and the disease process of cancer or by the radiation therapy treatments.

Quality of Life Domains

Each of the Satisfaction and Importance subscale items was also be grouped together under one of four domains. A domain was an area that addressed a broad range of aspects of life that were similar in nature. The domains were: (a) family, (b) psychological/spiritual, (c) socioeconomic status, and (d) health and functioning (Ferrans, 1990, p. 16). When related items were grouped together for comparison other findings emerged.

Family Domain

The family domain included four items on: (a) family happiness, (b) children, (c) spouse, and (d) family health. In the family domain, all items were ranked between 5 (moderately satisfied) and 6 (very satisfied). Respondents were most satisfied with spouse/significant others ($\bar{M} = 5.72$) and with children ($\bar{M} = 5.84$). The data showed that participants were satisfied with their families and parameters associated with their families. In the family domain, all four items were ranked between $\bar{M} = 5.87$ and $\bar{M} = 5.90$ on importance on the Likert-type scale used. The participants felt family and family related factors were very important and were satisfied with them.

Psychological/Spiritual Domain

The psychological/spiritual domain grouped together eight items related to: (a) life satisfaction, (b) happiness, (c) self, (d) goals, (e) peace of mind, (f) personal appearance, (g) faith in God, and (h) control over life. In this domain all items were ranked between 4 (slightly satisfied) and 6 (very satisfied). Participants ranked as highest their satisfaction with: (a) their faith ($\bar{M} = 5.37$), (b) their happiness in general ($\bar{M} = 5.29$), and (c) their life in general ($\bar{M} = 5.21$). Respondents ranked as lowest in this domain their satisfaction with: (a) their personal appearance ($\bar{M} = 4.84$), (b) the amount of control over their life ($\bar{M} = 4.86$), and (c) their achievement of personal goals ($\bar{M} = 4.89$). It is significant to note that the items ranked as lowest in the psychological/spiritual domain were all still ranked between slightly and very satisfied, with most clustered around the moderately satisfied rank. Respondents were not as satisfied with those aspects of their lives, but still gave them a relatively high ranking.

When the satisfaction responses were compared to the importance responses of the eight items in the psychological/spiritual domain a pattern was noted. In seven of the eight items, the mean rank of the satisfaction response was lower than the mean rank of the importance

response for each item. Participants rated the importance of items in this domain between 5 (moderately important) and 6 (very important) on the Likert-type scale used. The participants felt these items were important, yet their satisfaction level was lower. It was concluded that there was still room for improvement related to quality of life in these areas.

The item related to control over one's life was of special interest to note, since it was one of the basic concepts of this study. At first examination, there was support for the premise that control over one's life enhanced quality of life, since the item received a ranking near moderate satisfaction. However, when compared to similar items in that domain, it was one of the lower ranked items. There was also a considerable discrepancy between the satisfaction score of the control item ($\bar{M} = 4.86$) and the importance score of the control item ($\bar{M} = 5.81$). Respondents felt control over their life was very important but were only moderately satisfied at the amount of control they had over their lives at that time. This may have been caused by the necessity to give over, or at least share control, with health care personnel during the treatment phase for cancer.

Socioeconomic Status Domain

The socioeconomic status domain grouped together 11 items related to: (a) standard of living, (b) financial independence, (c) home, (d) job), (e) unemployment, (f) neighborhood, (g) conditions in United States, (h) friends, (j) emotional support, (k) education, and (i) influence in government. In the socioeconomic status domain, the score of 9 of the 11 items were between $\bar{M} = 4.99$ and $\bar{M} = 5.76$. On the Likert-type scale used a rank of five indicated moderate satisfaction. Participants reported highest satisfaction with: (a) degree of emotional support ($\bar{M} = 5.76$), (b) friends ($\bar{M} = 5.57$), (c) neighborhood ($\bar{M} = 5.56$), and (d) home ($\bar{M} = 5.54$). Participants reported lowest satisfaction with: (a) financial independence ($\bar{M} = 4.99$), and (b) education level ($\bar{M} = 5.00$). The lowest mean rank, however, was still at a level of moderate satisfaction. Again, the data continued to demonstrate that even when respondents indicated a degree of lesser satisfaction they still assigned a relatively high ranking to these items.

The socioeconomic status domain contained two of the lowest ranked items in the tool. These items were related to satisfaction with: (a) overall conditions in the United States ($\bar{M} = 3.81$), and (b) degree of influence on government ($\bar{M} = 3.81$). The responses indicated that the respondents

were more dissatisfied with the conditions in the United States and in government than they were with their own lives, even when they were living with a diagnosis of cancer. Given that the respondents were living with and being treated for cancer, this finding was unclear. The relevance of such questions in a tool measuring quality of life in cancer patients was also unclear.

When the satisfaction responses and importance responses of the 11 items in the socioeconomic status domain were compared, the responses were similar. The participants found the items important, and simultaneously, were satisfied with the majority of the items addressed. The highest degree of discrepancy was found between satisfaction and importance in the items related to: (a) financial independence, (b) conditions in the United States, and (c) influence on government. Participants thought these areas were important, but were considerably less satisfied with these areas as they related to their quality of life.

Health and Functioning Domain

The health and functioning domain grouped together 12 items related to: (a) usefulness to others, (b) physical independence, (c) responsibilities, (d) own health, (e) stress, (f) leisure activities, (g) retirement, (h) travel, (i) long life, (j) sex life, (k) health care, and (l) discomfort/pain. In the health and functioning

domain the mean score of the 11 satisfaction items remained at 4 (slightly satisfied) or above. Participants were most satisfied with: (a) the health care they were receiving ($\bar{M} = 5.72$), (b) their ability to meet family responsibilities ($\bar{M} = 5.09$), and (c) leisure time activities ($\bar{M} = 5.00$). Participants were least satisfied with: (a) their health ($\bar{M} = 3.93$), (b) sex life ($\bar{M} = 4.03$), and (c) freedom from pain/discomfort ($\bar{M} = 4.31$). The respondents again demonstrated by their responses that they were still more satisfied than dissatisfied with their basic level of health and ability to function, even during active treatment for cancer.

The mean rank scores for 9 of the 12 importance items in the health and functioning domain were between 5 (moderately important) and 6 (very important) on the Likert-type scale utilized. Respondents ranked items related to health and their ability to function effectively as important to their quality of life. There were considerable differences in the respondents' ranking of their satisfaction with these areas, with satisfaction consistently ranking less. In the three items that were ranked lowest in importance to the participants, their level of satisfaction was either greater or about equal to the corresponding item's level of importance.

Domain Analysis

When the satisfaction responses from the QLI were analyzed by domain, the mean scores were highest on the items in the: (a) family domain, (b) psychological/spiritual domain, and (c) socioeconomic status domain. The mean satisfaction scores were lowest on the items in the (d) health and functioning domain. A common finding in the analysis of all four domains was that the items respondents were less satisfied with still received a ranking of at least slight to moderate satisfaction. Respondents rarely indicated outright dissatisfaction with an item.

When the importance responses were analyzed by domain, the mean scores were consistently high in all the domains. The health and functioning domain held the lowest ranked items of importance in the instrument, but only three items were considered lower in importance. The health and functioning domain also produced lower satisfaction scores. Participants appeared to demonstrate a lower degree of satisfaction with quality of life concerns related to health and functioning as measured by this instrument.

Cancer Health Locus of Control Scale

The mean and standard deviation scores for the individual items of the CHLC Scale were reported in Appendix G. Results were for the entire sample population of 70. When grouped into subscales, the scores from highest

to lowest are: (a) Powerful Other subscale, ($\bar{M}$ = 27.19), (b) Internal subscale, ($\bar{M}$ = 24.83), and (c) Chance subscale, ($\bar{M}$ = 16.31). These results were logical, when the characteristics of the sample were considered. Cancer was a disease that required the patient to turn over significant degrees of control to medical personnel. It was expected that perceptions of others being in control would be present. In addition, the patient was involved in decisions affecting treatment and undergoing treatment, which accounted for the close proximity of scores for perception of internal control.

Correlation of the CHLC Scales and QLI Scores

The first research question posed in this study was: Was there a statistically significant correlation between the perception of health locus of control orientation and the perception of quality of life in persons with cancer? Table 3 displayed the correlations of the individual CHLC subscale scores with the QLI scores for the total study population. Quality of Life Index scores significantly correlated with the Internal Health Locus of Control subscale scores (r = .47, p = .001), and with the Powerful Other Health Locus of Control subscale scores (r = .35, p = .010). In this study, Chance Health Locus of Control subscale scores were not significantly correlated with Quality of Life Index scores.

Table 3

Correlations of Internal, Powerful Other and Chance
Subscales with Quality of Life Index Scores, (N = 70)

Subscale	QLI Correlation	p
Internal	.47	.001
Powerful Other	.35	.010
Chance	.09	NS

In this study there was a statistically significant correlation between internal health locus of control orientation and powerful other health locus of control orientation and quality of life. This correlation implied that there was a direct relationship between the two components, as one increased, so did the other. The results were again consistent with the nature of cancer and cancer treatment, where a combination of internal resources and trust in others was necessary to bring success with treatment. Future research could concentrate on identifying behaviors and interventions that strengthened internal and powerful other health locus of control orientations, which could in turn influence perception of quality of life.

The second research question in this study was: Did cancer patients who exhibited a high internal health locus of control score also report a more optimal quality of life

than cancer patients who exhibited high chance locus of control or high powerful other locus of control scores? The second research question was answered by first categorizing the subscales according to cancer health locus of control orientation.

The QLI scores ranged from a high of $\bar{M} = 28.25$ to a low of $\bar{M} = 11.85$ for the entire study sample. The average QLI score for the sample was $\bar{M} = 23.17$. The higher the QLI score, the more optimal the perception of quality of life was for the individual, for purposes of this study.

The sample population was divided into groups according to each respondent's predominant subscale score on the CHLC Scale. The highest subscale score for each respondent determined the cancer health locus of control orientation for that respondent. Twenty of the respondents had the highest score on the Internal subscale of the CHLC scale. For these 20 respondents, the average QLI score was $\bar{M} = 22.84$. Next, 46 respondents demonstrated their highest score on the Powerful Others subscale of the CHLC scale. For these 46 respondents, the average QLI score was $\bar{M} = 23.21$. For the Chance subscale, no analysis was possible since the number of respondents with a predominant chance health locus of control orientation was not greater than one.

An analysis of variance was done to determine if there was a difference in mean QLI scores between the group with high Internal subscale scores and the group with high Powerful Other subscale scores. There was no statistically significant difference in mean QLI scores between the two groups. Therefore, the mean QLI scores for respondents with high scores on the Internal subscale and high scores on the Powerful Other subscale were considered virtually identical.

In answer to the second research question, there was no difference demonstrated in perceived quality of life for respondents with predominant internal health locus of control orientation when compared to respondents with predominant powerful other health locus of control. Both of these health locus of control orientations correlated significantly with high perceived quality of life. No comparison was possible with chance health locus of control orientation, as no study participants demonstrated a predominant chance health locus of control orientation.

Summary

Analysis of the study data demonstrated that participants were satisfied overall with their quality of life. Very few items were reported as dissatisfied. The findings were unexpected considering the respondents had cancer and were undergoing treatment for cancer. The sensitivity of the Quality of Life Index in reflecting the

true experience of living with cancer was felt to be a factor in the demonstrated results. The QLI omitted addressing specific, negative aspects of cancer that could have strongly influenced perception of quality of life. Participants should at least have had the opportunity to document the effect of such aspects on their perceived quality of life.

Participants demonstrated that the items presented in the QLI were important concerns related to their quality of life by consistently assigning high importance rankings. It was of interest to note that the areas that were perceived to be of less importance were also questionable as to their relevance to quality of life issues.

Internal and powerful other health locus of control orientations were correlated significantly with perceived quality of life for the study participants. Chance health locus of control orientation was not correlated significantly with quality of life.

The study participants with a predominant internal orientation did not report a higher quality of life by comparison to participants with a predominant powerful other or chance health locus of control orientation. It was demonstrated that for this study population, quality of life scores were similar for the participants with predominantly internal and powerful other health locus of control

orientations. Although this finding was not in accordance with the underlying premise of this study, it was not considered to be out of context. Patients with cancer and undergoing treatment for their disease could require characteristics of both orientations to experience optimal quality of life.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents conclusions drawn from the data presented in this study. Recommendations for further research, patient care recommendations and nursing recommendations are also given.

Discussion of Findings

This study sample was described as older, well educated, Caucasian, middle class, and from common religious affiliations. The study sample was representative of the community it was drawn from in these areas. The study sample was not representative of the community which it was drawn from in the areas of primary cancer site occurrence and race at the time the data was gathered. These discrepancies could have reflected temporary fluctuations in the department's normal census. The purpose of the demographics used was to describe the sample. Future research in this arena might benefit from more detailed exploration of the effects of age, gender, income level and education level on variations in health locus of control orientation and perceived quality of life.

Quality of Life Index

The study respondents were consistently satisfied with their perceived quality of life in the majority of the areas surveyed. The mean score ranked as dissatisfied in only

three areas. This finding was surprising given the nature of the disease of cancer and the fact that the respondents were undergoing treatment for cancer.

Several explanations for the study findings were possible. First, 65.71% of the sample population had been diagnosed with cancer within the year. It might have been that the chronicity of living with cancer had not yet made a significant impact on the lives of the respondents.

Secondly, 69 of the 70 respondents were receiving radiation therapy treatment as outpatients. The respondents were able to remain in their own environments and carry on with their lives with some degree of normalcy. The objective indicators such as home, neighborhood, family, and other factors that influenced the experience of quality of life for the individual were still present.

A third explanation for the findings related to the overall sensitivity of the Quality of Life Index in capturing the experience of living with cancer. The QLI was developed initially using a sample of graduate nursing students, then tailored to reflect the experience of illness by adapting it to a population of hemodialysis patients (Ferrans & Powers, 1985, pp. 18-19). Ferrans and Powers then adapted the QLI to the cancer patient population by the addition of the following three items to the generic QLI

instrument: (a) physical discomfort, (b) control over one's life, and (c) influence on government (Ferrell, 1990, p.20).

In a critique of the QLI Ferrell specifically questioned the relevance of the item related to influence on government to the quality of life for patients with cancer. Ferrell also noted the lack of items related to common symptoms of cancer and cancer treatment, such as fatigue, nausea and immobility (Ferrell, 1990, p. 20).

Overall, the sensitivity of the QLI instrument in reflecting the experience of living with cancer was felt to be inadequate for purposes of this study. Another instrument specific to cancer and treatment for cancer or an option such as a semistructured interview designed to pick up individual interpretations may have been a better choice.

Several additional explanations for the high satisfaction responses were possible. First, the timing of data collection during the course of radiation therapy could have influenced participants' responses. Radiation therapy was generally given over a period of four to six weeks. Side effects were nonexistent or minimal for the first few weeks. Some symptoms, such as pain, may have improved after one to two weeks. No attempt was made to document where the respondent was in his or her course of therapy when he or she participated in the study. If the questionnaires were completed in the first one to two weeks of the therapy

course versus the fifth or sixth week, the responses may have been significantly different. It would be interesting to note whether symptom occurrence and length of time under treatment affected participants' feelings regarding both their health locus of control orientation and their perceived quality of life. This would entail a longitudinal study during a course of therapy to assess if there was any change over time.

A second explanation that might account for the high satisfaction response noted by participants might be their own understanding of the intent of treatment--curative or palliative. This would be a difficult aspect to determine. Many physicians would be reluctant to clearly state the intent of treatment for fear of taking away hope or will to live. Patients may often realize their condition is terminal, but need to believe that something can help prolong their life. If the respondents in this study believed their disease was curable, their overall satisfaction with life might remain high. No effort was made in the course of this study to determine the impact of this factor. A patient response with a favorable prognosis might differ greatly as compared to a patient with a less favorable prognosis.

A third explanation might be that this particular group of participants may have had a high degree of satisfaction

with their quality of life at the time of the study. The participants have simply been glad to be alive and may have had genuine hope and reason to believe they could be cured. Replication of the study with different groups would be necessary to determine if these satisfaction results were noted consistently.

Cancer Health Locus of Control Scales

The respondents reported the highest scores on the Powerful Other subscale, followed by the Internal subscale, and finally the Chance subscale. The largest number of respondents had as their primary health locus of control orientation that of powerful other, followed by internal orientation. This finding was reasonable considering the nature of cancer and the cancer treatment experience. Internal resources and internal belief systems were necessary during crisis situations. However, with a life threatening illness, reliance solely on internal resources would be detrimental to a patient. The ability to accept the expertise and care of a powerful other would also become necessary. There could be value in identifying what interventions, behaviors and attitudes were inherent in chance locus of control orientation. Research could assist in delineating how to eliminate the more negative aspects related to this locus of control orientation, as well as turn the more positive related aspects into useful behaviors

and attitudes that would help patients cope with cancer and treatment.

Correlations Between QLI and CHLC Scales

One question addressed in this study sought to determine whether a predominant internal health locus of control orientation promoted a more optimal perception of quality of life. The underlying assumption was that there existed a definitive health locus of control orientation to have or achieve in order for an individual to experience optimal quality of life. Correlations demonstrated that powerful other and internal health locus of control orientations had virtually the same degree of influence on perceived quality of life and were correlated with high satisfaction with perceived quality of life. The importance of the items related to quality of life as measured by the QLI instrument used was found to be high. The Importance subscale of the QLI instrument was otherwise not examined separately in relation to health locus of control orientation.

These findings indicated that both a powerful other as well as an internal orientation could be necessary for optimal quality of life to occur during a time of illness and treatment. Rather than trying to categorize health locus of control orientation and focus on promoting one over the other, it could be more beneficial to research the

positive aspects of all types of orientations and apply these to patient care.

Comparison of Findings to Literature

The conceptual framework for this research study was based on Burckhardt's work related to the impact of arthritis on quality of life. Burckhardt's causal model theorized that the impact of environmental variables (or inputs) on any personal outcome was mediated by psychological factors. One of the mediators chosen by Burckhardt was that of internal control over health. In Burckhardt's study, internal control over health was found to contribute directly to higher perceived quality of life (Burckhardt, 1985, pp. 14-16).

Burckhardt recommended that the effect of the mediators on the outcome goal of quality of life be examined on an individual basis (Burckhardt, 1985, p. 16). The results of this research study demonstrated a significant correlation between both internal and powerful other health locus of control orientations and perceived quality of life. These results supported Burckhardt's findings, although they did not duplicate them exactly.

In a separate study, Lewis (1982) hypothesized that greater experienced personal control would be associated with higher quality of life (p. 114). Lewis' study demonstrated evidence of two potentially distinguishable

aspects of personal control, personal control over one's life and personal control over one's health. The experience of personal control over one's life was a more significant predictor of quality of life than the experience of personal control over one's health.

In this research study, internal and powerful other health locus of control orientations were found to correlate with higher perceptions of quality of life in a more heterogeneous sample of cancer patients. The conclusion was drawn that these health locus of control orientations affected perceived quality of life. However, this study also recommended that the sample population's perception of the intent of treatment, curative or palliative, be determined.

This factor could serve in future research to further define differences in how the concept of health locus of control orientation affects perceived quality of life based on where the patient is in their illness trajectory. If perceived quality of life differed based on where a patient perceived he or she was in terms of the disease, this finding could support Lewis' results. Such a finding could also be used to direct future research efforts. Separate approaches to patient care could be indicated. Patients who were newly diagnosed or with a good prognosis may find it more important to try and maintain control over both their

life in general and their health. The findings of the current research study appeared to support this perspective, since the majority of patients indicated internal or powerful other health locus of control orientations. Patients who were terminal or with guarded prognoses may be ready to relinquish physical control over their health and concentrate their energies on other life matters that continued to contribute to their general quality of life (Lewis, 1982, p. 188).

Limitations

The limitations of the study noted in Chapter 1 had some effect on the study and its findings. The convenience sample using only radiation therapy patients was a factor. Broadening the population base to include chemotherapy, surgery or immunotherapy patients would have increased the generalizeability of the results and may have changed the findings considerably.

The possibility that health locus of control orientation was different in each subject prior to the diagnosis of the cancer was noted. The study findings indicated that serial measurement of health locus of control orientation, as patients progress through cancer diagnosis and treatment, could yield more pertinent data than knowing the respondent's prior health locus of control orientation.

Recommendations

More research was felt to be warranted on health locus of control and quality of life. One recommendation for future research was to use another quality of life tool that more accurately reflected the nature of the cancer experience and the effects of cancer treatment. The QLI did not reflect the effects of treatment on quality of life.

The study should also be replicated with different groups of patients such as those receiving chemotherapy or surgery, and in different settings, such as in the home, and in the hospital. If health locus control orientations differed based on treatment or setting, nursing care and nursing interventions would need to be individualized.

Longitudinal research should also be conducted to assess for changes in health locus of control orientation and perceived quality of life over time. As treatment side effects occurred and resolved, perceptions may have changed. In addition, as the disease progressed, and the goal of treatment changed from cure to palliation, perceptions of health locus of control orientation may have changed. Comparison of the results could yield valuable information regarding health locus of control and perceived quality of life.

There are recommendations for patient care that emerged as a result of this study. First, in order to utilize

nursing interventions based on knowledge of health locus of control orientation, such orientation would need to be determined. Patients would require education regarding health locus of control orientation and would need to consent to fill out a questionnaire. A questionnaire would be necessary to determine health locus of control orientation. Some patients would not be willing to fill out a questionnaire, some would not be able to do so. Determination of the health locus of control orientation may need to be done repeatedly. The benefits might not be worth the amount of patient energy and research time required.

Another recommendation for patient care focused on developing nursing care delivery systems that enhanced health locus of control orientation and quality of life, rather than placing the focus on repeated patient testing. A care delivery system that allowed for flexible delivery of care could improve quality of life for patients while they were receiving medical care. Such a system would allow patients to assume responsibility for care, medications, and other therapies when they were able and desired to do so. Nursing staff would be available to deliver care when expertise was required or the patient chose to relinquish control.

There were also recommendations for nursing research and practice that emerged from this study. Health locus of

control was felt to be an important concept for nurses to explore. Nurses would need more education concerning the effect of health locus of control on perceived quality of life. More research would be needed before this could be integrated into nursing education. It has been demonstrated that health locus of control orientation is correlated with quality of life. If health locus of control was found to definitely determine higher perceived quality of life, this knowledge could then be used to guide the nursing approach to patient care. Increased understanding of these concepts could lead to nursing interventions to improve patient quality of life.

However, it could be discovered that health locus of control is too global of a concept. Health locus of control was noted to have many facets. For example, could a person maintain control? Does an individual want to be in control? There would be educational aspects necessary to understanding the concept of health locus of control. There would be benefits to maintaining control and there would be benefits to allowing someone or something else to assume control. There could be other means found that were easier to determine and operationalize that could give similar information to nurses about control, quality of life, and methods to enhance quality of life for patients.

Summary

Health locus of control orientation is felt to be an inherent phenomena developed over time in each individual. It influences health actions, behaviors and choices. The saying goes, "When you have your health, you have everything." As such then, what affects health affects quality of life. The development of nursing theory related to health locus of control orientation and quality of life is in its beginning stages. With quality of life issues becoming more important concerns in health care and in society, health locus of control orientation research and quality of life research will need to develop and expand.

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APPENDIX A
Human Subjects Consent Letter

SAN JOSE STATE UNIVERSITY
GRADUATE STUDIES AND RESEARCH

HUMAN SUBJECTS INSTITUTIONAL REVIEW BOARD
PROJECT PROPOSAL REVIEW

Regular Review ☐

Expedited Review ☒

Deadline Date _____

I, the undersigned member of the San Jose State University Human Subjects Institutional Review Board, have reviewed the following proposal submitted to the Board on 4/11/89 by:

PRINCIPAL INVESTIGATOR: Cathy L. Brzezinski

PROTOCOL #: 7490

DEPT: Nursing

PROJECT TITLE: THE EFFECT OF HEALTH LOCUS OF CONTROL ORIENTATION ON
PERCEPTION OF QUALITY OF LIFE IN CANCER PATIENTS

I recommend the following action (Indicate one):

1. Approved for clearance as involving minimal risk to Human Subjects. ☒

2. Approved for clearance with risk to Human Subjects. ☐

3. Approval depends upon the satisfactory completion of the following conditions: ☒

It this investigator provides a consent form that includes Serena Stanford's name
title and phone number in her group to be
contacted.

I DON'T NEED TO SEE THIS AGAIN IF THIS CONDITION IS MET

4. I have serious concerns about this protocol and it should go before the full committee to review. ☐

Signature of IRB-HS member

Date

5. Not Approved. ☐

Approved. ☒

OFFICIALS SIGNING FOR INSTITUTION

Joni Campbell 5/1/89
Chair, Human Subjects Institutional Review Board

Date

Serena N. Stanford
Serena Stanford, Ph.D.
AAVP for Graduate Studies & Research

Date

Please return to: San Jose State University Foundation, One Washington Square, San Jose, CA 95192-0139
(408) 924-1438

APPENDIX B
Facility Consent Letter

Community Hospital of the Monterey Peninsula

Department of Nursing
San Jose State University
San Jose, CA 95192

February 24, 1989

Cathy L. Brzezinski, R. N., a graduate student at San Jose State University School of Nursing, has my permission to contact patients at the Radiation Therapy Department, Community Hospital of the Monterey Peninsula, to request their participation in her study exploring the relationship between health locus of control and quality of life.

I understand that participation in the research study is completely voluntary, that the anonymity of the facility and the patients will be maintained, and that we may have access to the results of the research study on request.

DATE 2-24-89

Signed

Jay M. Hudson

Title

Senior Vice President

APPENDIX C

Radiation Therapy Department
Consent Letter

Community Hospital of the Monterey Peninsula

2/28/89

Department of Nursing
San Jose State University
San Jose, Ca. 95192

To Whom It May Concern:

Cathy Brzezinski, R.N., student enrolled in the Graduate Nursing Program at San Jose State University is currently employed in my department and has requested permission to interview patients receiving radiation therapy to gather data for her Masters Thesis. I have reviewed the proposal and she has my permission to work with patients under treatment in the department. She has also received institutional permission from the hospital administration. It is my understanding that patients will participate on a voluntary basis and their identity will not be disclosed.

Sincerely,

David R. Holley, M.D., Director
Radiation Therapy Department

APPENDIX D
Participant Consent Letter

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: CATHY BRZEZINSKI

Dear Client,

I am asking you to participate in a research study that is investigating perceptions of quality of life and perceptions of control over health. Your participation would mean answering a personal data sheet and a research questionnaire. I will ask you to complete these items on your own and to do so here in the Radiation Therapy Department. I will need the data sheet and research questionnaire returned to me before you leave. Your time involvement will be about 30 minutes.

The possible benefits of this study are contributions to the improvement of nursing care for yourself and others. The study is a first step towards research to improve quality of life.

The questionnaires do have some items which may bring forth emotional responses, both positive and perhaps negative, related to the experience of living with cancer.

The results of the study as a whole may be published. Any information you contribute will be held in strict confidence. Your name will not be included in any data tabulation.

Your participation in this study is voluntary. You may withdraw at any time from the study. Withdrawing from the study will not affect your treatment or your relationship with the Radiation Therapy Department or with Community Hospital of the Monterey Peninsula.

Any questions or concerns about any part of this study may be addressed to:

Cathy Brzezinski, RN
Principal Researcher

Elizabeth O. Dietz, EdD., FNP
Associate Professor
San Jose State University

Serena Stanford, Ph.D.
Associate Academic Vice President
for Graduate Studies

Your signature below indicates your agreement to participate in this study.

Thank you.

Date

Participant's Signature

Cathy Brzezinski, RN
Cathy Brzezinski, R.N.

APPENDIX E
Author Consent Letters

Oct. 21, 1988

Kathy Brzezinski

Dear Kathy,

Congratulations on your research interest. I am happy to see the use of the Cancer-Specific Locus of Control (CHLC) Scale being used in the oncology population.

Enclosed is a copy of the CHLC for your use as well as scoring instructions.

Best wishes in your work! Please send me a copy of your results on the enclosed questionnaire.

Sincerely,

Angie

Angie Dickson

SCORING INSTRUCTIONS CHLC SCALES

The score on each subscale is the sum of the values circled for each item in that subscale.

INTERNAL ITEMS: 1, 6, 8, 12, 13, 17

CHANCE ITEMS: 2, 4, 9, 11, 15, 16

POWERFUL OTHERS ITEMS: 3, 5, 7, 10, 14, 18

THE
UNIVERSITY
OF
ILLINOIS
AT
CHICAGO

Department of Medical-Surgical Nursing (M/C 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612
(312) 996-7800

October 20, 1988

Ms. Kathy Brzezinski

Dear Ms. Brzezinski:

Thank you for your interest in the Quality of Life Index (QLI). I have enclosed the cancer version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, socioeconomic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate subscale scores and overall scores.

There is no charge for use of the QLI. However, in return for my permission to use the QLI, I would appreciate it if you would send me the raw data from the QLI and sociodemographic information on your sample. This data will be combined with other data and used for further reliability and validity assessments. The results of these assessments then will be made available to researchers like yourself.

If you do use the QLI for your research and publish an article(s) reporting the findings, I would be very grateful if you would send me a copy. If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN
Assistant Professor

APPENDIX F
QLI Scales Data

Satisfaction Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
1.	How satisfied are you with your health?	3.93	1.74
2.	How satisfied are you with the health care you are receiving?	5.72	0.68
3.	How satisfied are you with your freedom from physical discomfort or pain?	4.31	1.37
4.	How satisfied are you with your physical independence (ability to do things for yourself, get around)?	4.90	1.34
5.	How satisfied are you with the amount of control you have over your life?	4.86	1.24
6.	How satisfied are you with your potential to live a long time?	4.79	1.44
7.	How satisfied are you with your family's health?	5.20	1.00
8.	How satisfied are you with your children?	5.84	0.37
9.	How satisfied are you with your family's happiness?	5.49	0.74
10.	How satisfied are you with your relationship with your spouse/significant other?	5.72	0.64
11.	How satisfied are you with your sex life?	4.03	1.74
12.	How satisfied are you with your friends?	5.57	0.50

Likert scale key:

Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied
1	2	3	4
Moderately Satisfied	Very Satisfied		
5	6		

Satisfaction Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
13.	How satisfied are you with the emotional support you get from others?	5.75	0.60
14.	How satisfied are you with your ability to meet your family responsibilities (things you have to do for your family)?	5.09	1.25
15.	How satisfied are you with your usefulness to others?	4.73	1.30
16.	How satisfied are you with the amount of stress or worries in your life?	4.47	1.29
17.	How satisfied are you with your home (furniture, house or apartment)?	5.54	0.76
18.	How satisfied are you with your neighborhood?	5.56	0.61
19.	How satisfied are you with your standard of living?	5.49	0.85
20.	How satisfied are you with the overall conditions in the United States?	3.81	1.39
21.	How satisfied are you with your influence on local, state and national government?	3.81	1.37
22.	(If employed) how satisfied are you with your job?	5.10	0.91

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

Satisfaction Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
23.	(If unemployed, retired or disabled how satisfied are you with not having a job?	5.40	1.25
24.	How satisfied are you with your education?	5.00	1.25
25.	How satisfied are you with your financial independence?	4.99	1.12
26.	How satisfied are you with your leisure time activities?	5.00	1.15
27.	How satisfied are you with your ability to travel on vacations?	4.51	1.48
28.	How satisfied are you with your potential for a happy old age/retirement?	4.70	1.47
29.	How satisfied are you with your peace of mind?	5.00	1.47
30.	How satisfied are you with your personal faith in God?	5.37	1.14
31.	How satisfied are your achievement of personal goals?	4.89	1.27
32.	How satisfied are you with your happiness in general?	5.29	0.84
33.	How satisfied are you with your life in general?	5.21	0.85

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

Satisfaction Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
34.	How satisfied are you with your personal appearance?	4.84	1.06
35.	How satisfied are you with yourself in general?	5.01	1.10

Likert scale key:

Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied
1	2	3	4
Moderately Satisfied	Very Satisfied		
5	6		

Importance Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
1.	How important is your health to you?	5.81	0.67
2.	How important is health care to you?	5.87	0.38
3.	How important is it to you to be free of physical discomfort?	5.61	0.60
4.	How important is your physical independence to you (ability to do things for yourself, get around)?	5.93	0.26
5.	How important is it to you to have control over your life?	5.81	0.73
6.	How important is living a long time to you?	5.04	1.12
7.	How important is your family's health to you?	5.91	0.28
8.	How important are your children to you?	5.89	0.37
9.	How important is your family's happiness to you?	5.90	0.30
10.	How important is your relationship with your spouse/significant other to you?	5.87	0.45
11.	How important is your sex life to you?	3.81	1.58
12.	How important are your friends to you?	5.50	0.61
13.	How important is emotional support to you?	5.31	0.86

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

Importance Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
14.	How important is meeting family responsibilities to you (things you have to do for your family?)	5.66	0.68
15.	How important is being useful to you?	5.66	0.59
16.	How important is it to you to have a reasonable amount of stress or worries?	3.96	1.38
17.	How important is your home to you (furniture, house or apartment)?	5.36	0.70
18.	How important is your neighborhood to you?	5.11	0.79
19.	How important is a good standard of living to you?	5.44	0.79
20.	How important are the overall conditions in the United States to you?	5.04	0.94
21.	How important is it to you to have influence on local, state and national government?	4.39	1.20
22.	(If employed) how important is your job (or working) to you?	5.50	0.76
23.	(If employed, retired or disabled) how important would it be to you to have a job?	2.71	1.72
24.	How important is your education to you?	5.29	1.07

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

Importance Questionnaire of the Quality of Life Index -

Mean and Standard Deviation Per Item

		M	SD
25.	How important is your financial independence to you?	5.73	0.64
26.	How important are leisure time activities to you?	5.17	0.66
27.	How important is the ability to travel on vacations to you?	4.80	0.94
28.	How important is having a happy old age/retirement to you?	5.61	.071
29.	How important is peace of mind to you?	5.84	0.40
30.	How important is your personal faith in God?	5.30	1.26
31.	How important is achieving your personal goals to you?	5.49	0.65
32.	How important is happiness to you?	5.70	0.55
33.	How important is it to you to be satisfied with life?	5.21	0.78
34.	How important is your personal appearance to you?	5.70	0.46
35.	How important are you to yourself?	5.57	0.63

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

APPENDIX G
CHLC Scales Data

Cancer Health Locus of Control Questionnaire -

Mean and Standard Deviation Per Item

		M	SD
1.	It is my own behavior which determines how soon I get well again.	4.94	1.21
2.	No matter what I do, if I'm going to get worse, I'll get worse.	2.50	1.66
3.	Having regular contact with my physicians is the best way for me to avoid getting worse from this illness.	5.10	0.93
4.	Most things that affect my health now that I am ill, happen to me by accident.	2.39	1.55
5.	Whenever I don't feel well, I should consult a medically trained professional.	4.49	1.35
6.	I am in control of cancer.	3.86	1.70
7.	My family has a lot to do with how well I cope with this illness.	5.03	1.30
8.	I am to blame for getting this illness.	2.01	1.59
9.	Luck plays a big part in determining how soon I will recover.	2.21	1.51
10.	Health professionals control cancer.	3.86	1.68
11.	Improvement of this illness is a matter of good fortune.	2.69	1.66
12.	The main thing which affects my condition is what I do myself.	4.43	1.50

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

Cancer Health Locus of Control Questionnaire -

Mean and Standard Deviation Per Item

		M	SD
13.	If I take care of myself, I can avoid progression of my illness.	4.56	1.21
14.	When I get better from this illness, it's because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	4.90	1.25
15.	No matter what I do, it's likely that my illness will get worse.	1.99	1.48
16.	If it's meant to be, I will regain my health.	4.54	1.54
17.	If I take the right actions, this illness will be controlled.	5.03	1.08
18.	Regarding this illness, I can only do what my doctor tells me.	3.81	1.71

Likert scale key:

Very Dissatisfied 1	Moderately Dissatisfied 2	Slightly Dissatisfied 3	Slightly Satisfied 4
Moderately Satisfied 5	Very Satisfied 6		

APPENDIX H
Participant Questionnaires

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