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**The effects of a structured patient education program on  
adaptation to cancer**

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**The University of Arizona, 1987**

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THE EFFECTS OF A STRUCTURED PATIENT EDUCATION  
PROGRAM ON ADAPTATION TO CANCER

by

Lee Lucia Westfall

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A Thesis Submitted to the Faculty of the  
COLLEGE OF NURSING  
In Partial Fulfillment of the Requirements  
for the Degree of  
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In the Graduate College  
THE UNIVERSITY OF ARIZONA

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## ABSTRACT

This study examined changes in adult learning, adaptation, and anxiety that occurred as the result of the adult cancer education program "I Can Cope." The study utilized a repeated measures descriptive design. A volunteer sample of 19 subjects participated in this study. Changes in each person's pre-mid-post-test scores were measured against their pre-mid-post-test scores on three instruments: a) Course Inquiry Test; b) Purpose in Life Test; and c) A-State Anxiety Inventory. A comparison of scores measured whether any short-term adult learning, adaptation and change in anxiety occurred as a result of the "I Can Cope" Program. The study did demonstrate that an organized adult patient education program could foster and enhance adult learning and adaptation as well as influence anxiety of participants.

## CHAPTER 1

### INTRODUCTION

Cancer is a significantly complex chronic disease which has a profound impact on the lifestyle of the individual. The disease process makes demands on patients and family members because of its elusive nature and the resultant stresses. This fosters the development of new coping strategies to facilitate changes in lifestyle as patients and families live with and adapt to this chronic illness. The way in which patients with cancer, their families and/or significant others adapt to the disease often will ultimately affect perceptions of the perceived quality of life. This study explored the effects of a structured education program designed to facilitate learning by the participants to specific aspects of the disease and increase adaptation to selected ramifications of the disease.

#### Delineation of Problem

##### Prevalence

During 1985, approximately 910,000 persons in the United States were expected to be newly diagnosed with cancer (American Cancer Society, 1985). In 1986 the State of Arizona, population 2,962,300 (University of Arizona, 1985), is expected to have approximately 10,000 newly diagnosed cases of cancer (American Cancer Society, 1985).

The survival rates for cancer are improving. This appreciable improvement of survival rates among cancer patients is attributed to early detection and better treatment of some of the various forms of cancer. The American Cancer Society reports that one in three persons will survive five years after diagnosis and treatment, compared with one in five in the 1930's, and one in four in the 1940's (Statistical Bulletin, 1981, p. 11-13).

### Economics

The economic realities of cancer are due to direct and indirect costs. A major cause of distress for the cancer patient and family is the financial burdens associated with cancer (Baird, 1981). Baird (1981) reported that numerous studies document the cost of cancer treatments at \$15 billion annually and that an individual's cancer treatment cost may vary from \$5,000 to \$35,000 annually. In addition to the direct costs are the indirect costs such as temporary or permanent loss of income. The indirect costs are enormous for persons with cancer. According to Baird (1981), these indirect costs are nearly twice as high for cancer as for other chronic diseases.

Nurses can assume an active role in the containment of direct costs. Nurses also have an opportunity to be instrumental in the promotion of cancer prevention, education of the public about the improved and improving survival rates of cancer, and the adaptation of people to living with cancer. Nurses could influence the indirect and direct cost of cancer with the utilization of all of these activities.

The scientific and medical understanding of cancer has increased significantly in the past decade as well as strides made in the understanding of the emotional impact of cancer to enable patients and their families to cope more effectively. This understanding helps patients and their significant others refocus their energy to move from dwelling on internal anxieties to concentrating on opportunities which could enhance their quality of life (American Cancer Society (1983b).

Redman (1976), Johnson (1979), and Johnson and Green (1981) contend that the threat of illness and its diagnosis precipitates a series of redefinitions of self. This adjustment of self to changes in physical health and one's psychosocial being is essential in living and adapting to life with cancer. Persons adapt to illness based upon their psychological nature and social behavior (Roy, 1981) and modify their behavior to meet the limits imposed upon them by the disease. The way in which a person adapts to their disease often determines the difference between optimum recovery or psychological invalidism (Lipowski, 1970; Johnson, 1979).

#### Patient Education

Salzer (1975) proposed that persons affected directly or indirectly by chronic illnesses are entitled to as much information as they can accept about the illness in order to adapt to the disease and care for themselves. Acquired knowledge, attitudes, and behaviors which influence the maintenance and promotion of health are one goal of health education (Roberts, 1976). Another goal of health education

is to provide persons and their significant others with information that will assist them in adapting to achieving and maintaining an optimum state of health (Johnson, 1979). Baldonado and Stahl (1982) contend that a multidisciplinary health care team, client and family should be involved in a structured health teaching plan. That plan needs to relate to the disease, the treatment and disabilities that might ensue from the disease and/or treatment process.

Even with the scientific knowledge and sophisticated equipment for diagnosis and treatment, health care professionals cannot expect effective results without the help, cooperation, and understanding of the patients. Health care would be enhanced if it were supported by informed, involved persons who realize they have an active role, responsibility and a unique contribution to make toward their individual and collective state(s) of well-being. Patient education, that branch of health education designed for those who are affected by an illness, is a means of satisfying this educational need (Johnson, 1979).

Patient education is not a new concept in the health care system. However, in the past decade, the concept of patient education has changed substantially (Johnson & Green, 1981). There has been a shift from basically unplanned, fragmented, incidental and spontaneous experiences to programs that are purposefully designed, systematically applied, and comprehensive in scope (Brown, 1976).

Today, patient education is designed for inpatients and outpatients; implemented on a one-to-one basis or in groups; delivered

in a variety of settings; and conducted by a multidisciplinary team which may include physicians, nurses, social workers, and dieticians (Breckon, 1976). Ulrich (1976) noted that there is one element central to all patient education programs, which is the necessity of gearing it to the specific needs of the persons or the group for whom it is intended (Johnson & Green, 1981).

Support and justification for patient education comes from a variety of sources; e.g., the Health Maintenance Organization Act of 1973 (Public Law 93-222, 1973) and the Joint Commission on Accreditation of Hospitals (1979). Other factors supporting patient education are the emergence and increase of chronic disease (Simonds, 1974; Archer & Fleshman, 1979), and the increased survival rate of cancer patients (American College of Surgeons, 1982).

Patient education has increasingly become a component of cancer nursing practice. The "Outcome Standards for Cancer Nursing Practice" (1979) of the Oncology Nursing Society and the American Nurses' Association, provide a set of standards and criteria for the practice of oncology nursing. Patient education is identified as an outcome criteria for the majority of the 12 standards.

The chronicity of each stage of cancer has significant ramifications on the lifestyle of individuals with cancer and their families. The question of how an educational program could contribute to the process of adaptation of a person affected by a chronic disease was central to this study.

### "I Can Cope" Program

"I Can Cope" is an educational program for adult cancer patients, their families and friends which is co-sponsored by the ACS and local community facilitators. The American Cancer Society I Can Cope Facilitators Manual (1983b) states that the goal of the "I Can Cope" program is to provide an organized educational program about cancer for adults with cancer, their families, their friends and/or significant others which will assist the patient et al. to cope more effectively with all facets and ramifications of the disease. The effects of this structured educational program were studied to determine whether the program enhanced learning and adaptive changes in adult cancer patients and their families and/or significant others.

### Significance

Narrow (1979) proposed that the nurse can be viewed as the primary health teacher because of the nurse's: a) Knowledge of matters related to health, b) opportunity to teach, c) ability to individualize the teaching and make relevant to clients, and d) liability. Dodd and Mood (1981) demonstrated that subjects have inadequate knowledge about their disease and treatment. Their study did find that subjects having chemotherapy explained to them by a nurse, after the physician had obtained informed consent, showed greater accuracy of information recall than control subjects and noninformative visits by the nurse. Due to the significant number of patients admitted to hospitals, the shortened length of stay, and the legal responsibility of nurses to provide patient education, cancer

education by nurses needs to be met in a variety of ways. Nurses at the bedside need to meet daily teaching needs of the cancer patient and family. Johnson (1979) demonstrated that post-hospitalization education taught by nurses in conjunction with other members of the multidisciplinary health care teaching team was effective in helping adults to learn and to acquire information, attitudes and behaviors that will improve their ability to adapt to living with a chronic disease. The major health care goal, by a multidisciplinary staff, is to intervene with the client and/or significant others in order to help the client et al. to cope and sustain maximum functioning with living. Spinetta (1972) contended that when cancer exists within a family, the health care team must firmly believe that the quality of life is enhanced by maximum efforts devoted toward living. Living with cancer is maintaining a full and normal quality to life as possible within the physical limitation imposed by the disease.

#### Purpose of Study

This study was conducted to measure the effects of a structured educational program on participants' perceptions of specific aspects of their disease as measured by changes in adult learning, adaptation and anxiety. The underlying assumption of this study was that the process of adaptation could be accelerated by facilitating the participants' learning, i.e., change or reorganization of insights, knowledge, skills, attitudes, values or expectation to the latest health care practices in the treatment of the disease.

Specifically, the research questions posed for this study were:

1. Will adult learning as measured by the Course Inquiry Test increase over time for participants of the "I Can Cope" program?
2. Will adaptation as measured by the Purpose in Life Test increase over time for participants of the "I Can Cope" program?
3. Will Anxiety as measured by the State Anxiety Inventory decrease over time for participants of the "I Can Cope" program?
4. Is there a positive (+) relationship between the Course Inquiry Test and the Purpose in Life Test at the end of an "I Can Cope" program?
5. Is there a negative (-) relationship between The Purpose in Life Test and A-State Anxiety Scale of the end of the "I Can Cope" program?
6. What is the relationship between Adult Learning and Anxiety at the end of an "I Can Cope" program?

#### Summary

Cancer is a complex chronic disease which has a profound impact on the lifestyle of the individual and/or his significant others. The disease makes demands on patients and families due to its elusive nature and resultant stressors. This study explored the effect of a structured patient education designed to foster learning

of specific aspects of the disease and increase adaptation by the program participants to selected ramifications of the disease. The question of how an educational program could contribute to the process of adaptation of program participants was central to this study.

## CHAPTER 2

### CONCEPTUAL FRAMEWORK

This chapter presents the conceptual framework for this study and Figure 1 represents the conceptual model to be used. The concepts and relationships found in the model are defined and discussed.

All of the vertical linkages in the conceptual model are signed positively (+) to indicate a hierarchical relationship between the concepts at the higher level and the operational variables at the lower level. No causality is depicted in the conceptual model, but rather positive predictive correlations (+), negative predictive correlations (-), and inconsistent associations (?) are predicted at the horizontal levels.

First, the construct of patient education is presented followed by the presentation of cancer patient education at the concept level and the operational level is then indexed by the "I Can Cope" Program presentation. The construct of adult learning is presented next followed by the concept of learning about cancer and the Course Inquiry Test at the operational level. Adaptation is the third construct discussed followed by meaningfulness in life at the concept level and was indexed at the operational level by the Purpose in Life Test.

Next the construct of anxiety is presented followed by the concept of A-State Anxiety which is indexed at the operational level

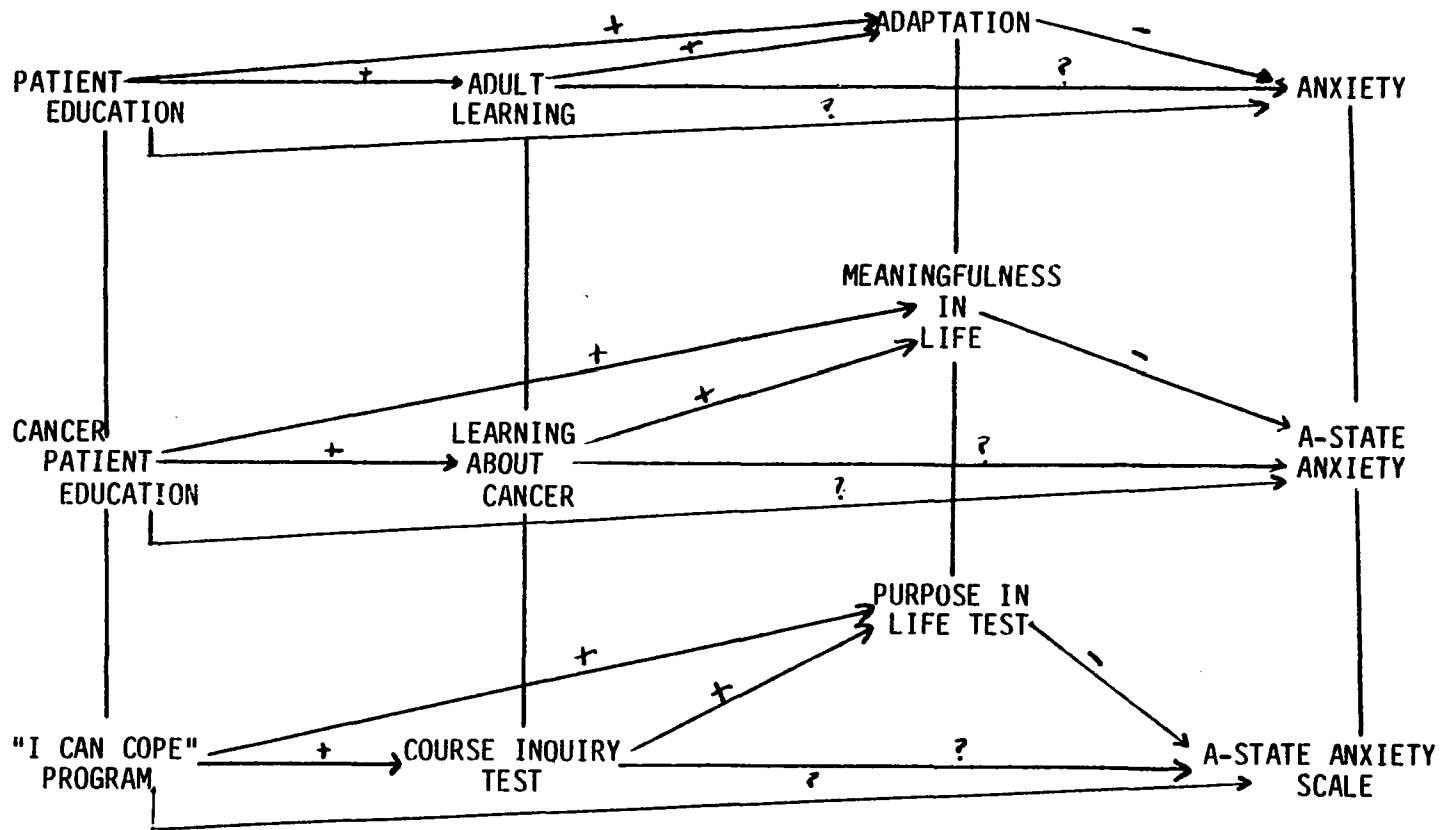


Figure 1. Conceptual Model

by the A-State Anxiety Scale (Form Y) (STAI). Lastly, the relationships between the constructs are presented and discussed.

### Patient Education

Patient education has undergone many changes during the last decade. To understand the trends specific to adult cancer patient education, one must first examine patient education and, from that generalized area of theory and practice, draw what is specific and useful for adults with cancer.

A composite definition of patient education is a series of structured or unstructured experiences designed to help patients and their significant others to cope voluntarily with the immediate crisis of the diagnosis, with long-term adjustment, and with symptoms; gain needed information about sources of prevention, diagnosis, and care; and to develop skills, knowledge, and attitudes needed to maintain or to regain health (Deeds, Herbert, & Wolle, 1979; Green et al., 1980; Simonds, 1974; Blumberg et al., 1983).

Patient education accomplishes these goals by working with patients and their families to plan strategies for change; interpret and integrate the information needed to achieve desired attitudes or behaviors; and meet patients' specific learning needs, interests, and capabilities (Rankin & Duffy, 1983). Patient education may be thought of as a field of practice, as an intervention, and as an evolving body of theory and concepts. Although still developing, patient education is widely accepted in most fields of health care and represents a monumental philosophical shift from a previous era in which patients

were told nothing. Patient education is central to the philosophy of nursing practice (Redman, 1985).

Patient education is not a new concept in the health care system. For years, physicians and nurses, in the course of normal patient contact, have explained to patients certain aspects of their illness and their consequences. However, their educational endeavors were often done sporadically and without consistency (Breckon, 1976).

References to patient education first began to appear in the 1950's. One of the primary factors responsible at that time for increased attention to patient education was the development of prepaid health care plans. Prepaid health organizations contended that prevention and informed self-care could reduce long range patient care costs (Shapiro, 1960).

In 1964, the American Hospital Association, at a conference on health education, took the position that the Association should act as the nationwide agency for stimulating the development of patient education programs. Assumption of this advocacy role served as a milestone in the recognition of patient education within the health care system. Patient education was recommended as an integral part of patient care (Johnson, 1979).

In 1955, the Russell Sage Foundation published three monographs entitled Newer Dimensions of Patient Care. These documents further added to the acceptance of patient education as a relevant aspect of patient care and are still being used today as points of reference.

Another step in policy making occurred when Congress passed the Health Maintenance Organization Act of 1973 which required health maintenance organizations to provide health education for their members. The government's Medicare Program also has moved to provide coverage for the cost of patient education as an integral part of medical services provided to Medicare recipients.

There are several key factors in addition to policy making that may be viewed as part of the development of patient education. The future direction of patient education may be influenced by the following factors:

1. As the population of elderly persons in this country increases, so will the number of individuals increase who have chronic diseases and disabilities. The emergence of chronic illness as a major health problem has provided stimulus for the development of patient education services (Simonds, 1974; Strauss, 1975).
2. The consumer rights' movement also impacts on the development of patient education. "A Patient's Bill of Rights," adopted by the American Hospital Association (AHA) outlined the patients' right to know (1973).
3. Medical practice itself is changing. Prepaid health care plans are on the increase. National health insurance is being proposed by the federal government. Due to the advent of diagnostic related groups (DRGs) and similar concepts from

third party payers, there has been a decrease in the length of hospital stays.

4. A further element that has set the stage for expansion of patient education has been legal actions and judicial decisions. The policies of "informed consent" and "informed discharge" have altered the health care system. Medical malpractice suits are on the increase. Improved patient communication has been shown to reduce malpractice litigation (Johnson, 1979).

In the past decade the concept of patient education has changed. There has been a shift from primarily unplanned fragmented, incidental, and spontaneous experiences to programs that are purposefully designed, systematically applied, and comprehensive in scope (Brown, 1976; Johnson, 1979). Today patient education is: a) Designed for inpatients and outpatients; b) implemented on a one-to-one basis or in groups; c) delivered in a variety of settings; and d) conducted by a multidisciplinary team often consisting of physicians, nurses, social workers, physical and occupational therapists (Breckon, 1976). The one element central to all patient education programs is the necessity of gearing it to the specific needs of the persons or group for whom it is intended (Ulrich, 1976).

Patient education has been significantly influenced by the health care profession, institutions, foundations, presidential committees, Congress, private and government reports and conferences.

Therefore, patient education has been influenced by social, political, and economic conditions.

Patient education is an important component in medical and nursing care of the chronically ill persons and their families. It can help patients and their significant others not only be more informed about the nature of the chronic illness but also to adapt behaviors in accordance with treatment regimen and their inherent ramifications (Knudson et al., 1981).

The patient has the right to know about his disease, and an informed patient is better equipped to deal with the various stages of the disease process. Issues relating to loss of control and fear of death, have been related to "the dark cloud of unknowing" (Lane, 1980). Patient anxieties are often alleviated when they have knowledge about the disease, the disease process, and its treatments as well as their ramifications.

#### Cancer Patient Education

Green (1984) noted that, in the broader concept of patient education, cancer has lagged behind other diseases in the attention that health educators and others have devoted to the subject. Within the area of cancer education, patient education has been overshadowed by prevention and public education about cancer (Green, 1984).

Cancer patient education has been defined by Rimer et al. (1985) as a series of structured or unstructured experiences

designed to assist patients to cope voluntarily with the immediate crisis response to their diagnosis, with long-term adjustments, and with symptoms, to gain needed information

about sources of prevention, diagnosis, and care, and to develop needed skills, knowledge, and attitudes to maintain or regain their health status" (p. 802)

The National Cancer Institute has identified several issues that are unique to cancer patient education. Most notably, cancer is many diseases, each imposing different educational requirements. Cancer can often result in social isolation and is often associated with pain and death. Cancer may produce a sense of loss of control, impose a severe financial strain and its treatment may cause life-threatening side effects (Rimer et al., 1985).

When cancer is diagnosed, patients may potentially undergo a variety of psychological and emotional changes that challenge their previously accepted life-style and self-concept/self-esteem (Blumberg et al., 1983). Cancer patient education can respond to this complex changing environment of the cancer patient by providing information, resources and support in an organized manner.

Both the National Cancer Institute's patient education goals and the Oncology Nursing Society's Standards for Cancer Nursing Practice (Outcome Standards for Cancer Nursing Practice, 1979) identify a number of tasks for cancer patient education. These include helping patients and their families to adjust to the disease, participate in treatment, carry out regimens, manage stress, recognize and control side effects, prevent social isolation and to strengthen relationships with significant others, mobilize and manage resources and "to adapt to a life of uncertainty" (Rimer et al., 1985, p. 802).

Patient education has increasingly become a component of cancer nursing practice. In the Outcome Standards for Cancer Nursing Practice (1979), a set of standards and criteria for the practice of oncology nursing is outlined. Patient education is identified as an outcome criteria for the majority of the 12 standards. This demonstrates that there is a growing interest in providing substantial services in the area of educational support for people experiencing cancer. Cancer patients feel a strong concern about their health and its effect on their future.

Patients who have cancer must deal not only with physical problems but also with anxiety. One of the best ways to become able to deal with every aspect of being ill is through learning. Andragogy is a self-directed approach to adult education. It is a design for teaching that aims at providing learners with what they need and value in relation to an identified need or problem. A belief in Andragogy is related to a set of beliefs about the learner as the director of his or her own life. In Andragogy, Knowles (1984) applies four assumptions to the adult learner. First, a person becomes an adult when he achieves self-direction. Second, one utilizes his previous life experiences in learning and third, social needs, or the need to fill a social role are necessary. Fourth, adults are motivated to learn subjects or skills that will help them to overcome a perceived problem (Knowles, 1984).

Johnson stated "the literature is clear, teaching people about various aspects of their conditions in an organized systematic manner,

is an effective method for improving quality of care" (Johnson, 1980, p. 63). Persons affected by cancer need to be taught how to modify and adapt their behavior to adjust to the ramifications of cancer, as well as the treatment modalities of the disease (Marino, 1981). Cancer patients are saying that they want to make decisions about their lives. In order to make appropriate decisions they need information. Cancer patients are saying they want some control (Johnson & Flaherty, 1980). Information which allows patients to make decisions in turn provides them that control. Oncology patients and their significant others view educational programs as a commitment on the part of the professional, to them. This commitment, to help persons to live with cancer and its treatment allows self-respect (Johnson & Flaherty, 1980). Thus patient educational programs are designed to foster patient and family learning of specific aspects of the disease and treatments and increase adaptation to specific ramifications of the disease.

#### "I Can Cope" Program

The "I Can Cope" Program is a structured patient education course of the American Cancer Society about living with cancer. Topic content of the course was developed from interviews of cancer clients and their family members and a variety of professional persons residing in Minneapolis-St. Paul, Minnesota (Johnson, 1979). Johnson (1979) stated that: a) There was a need for an education program for persons with cancer to assist them in adapting to cancer; and b) a formal educational program did not exist for persons with a chronic

illness, except for the diabetic person. In response Johnson (1979) designed a course with classes taught by multidisciplinary cancer educators. Individuals who know more about their disease can make informed decisions and become partners in the treatment team. The "I Can Cope" Program is designed to clarify facts and myths for people living with cancer. It helps patients and their families cope with the problems of living with the chronic disease of cancer (American Cancer Society, 1983b).

"I Can Cope" is an educational program for adult cancer patients, their families and friends which is co-sponsored by the American Cancer Society and local community facilitators. It is a structured program that meets for eight weekly two hour sessions.

The course starts with specific information about normal anatomy and physiology, and progresses to explain a variety of facts about cancer. The information is designed to clarify misinformation and decrease anxiety (American Cancer Society, 1983b). The curriculum then explains the psychosocial aspects of cancer. The emotional impact of the disease on the patient and family, enhancing self-esteem, using community resources, improving physical fitness, and working for increased control over uncontrollable situations are discussed.

The American Cancer Society "I Can Cope" Facilitators Manual (1983b) states that the goal of the "I Can Cope" Program is to provide an organized educational program about cancer for adults with cancer, their families, their friends, and/or significant others which will

assist the patients et al. to cope more effectively with all facets of the disease.

The "I Can Cope" Program has the following objectives:

1. To provide the opportunity to learn about cancer, its cause, diagnosis, treatment and rehabilitation.
2. To understand the medical problems that may arise from the disease or its treatment, and to teach the individual ways of dealing with these problems.
3. To learn the importance of communicating effectively with health care professionals, family and friends.
4. To provide a better understanding of the psychosocial aspects of cancer and how to cope with them.
5. To recognize the importance of maintaining physical fitness during treatment.
6. To identify and use physical, social, psychological, rehabilitation, financial, legal, spiritual, and other resources within the community.
7. To provide a climate of understanding with others by sharing common needs and experiences.
8. To provide an opportunity for interaction between health care professionals and cancer patients.

The "I Can Cope" Program does not:

1. Interfere with the physician/patient relationship.
2. Provide a support group or professional care setting.

3. Attempt to be an ultimate authority on all aspects of cancer information.
4. Replace the individual's ability to seek other sources of cancer information.

The American Cancer Society provides patient education as one of its basic Service and Rehabilitation Programs. The "I Can Cope" Program was adopted in 1979 as a National Service and Rehabilitation structured patient education program.

Thus, the underlying assumption of the "I Can Cope" course is that with a structured educational course, the person affected directly or indirectly by cancer can adapt to chronic illness and the ramifications of that illness. Adaptation is facilitated by the clients' learning about the: a) Disease, b) current treatment of the disease, and c) living with cancer (American Cancer Society, 1983b).

#### Adult Learning

Learning is an "enduring change" (Bigge, 1982, p. 274) in an individual in which genetic inheritance is not a predisposing factor. It may be considered a change in "insights, behavior, perception, or motivation, or a combination of these" (Bigge, 1982, p. 274). Thus, learning is a change or "reorganization of insights, knowledge, skills, attitudes, values, or expectations and may or may not be closely related to some change in overt behavior" (Bigge, 1982, p. 274).

A learning theory can be defined as a

systematically integrated concept of process whereby people relate to their environments in such a way as to enhance their ability to use both themselves and their environments more effectively (Bigge, 1982, p. 3).

Learning theory which has been particularly useful in adult education has emerged from several differing points of view.

One viewpoint of scholars in the field of adult education is to adapt childhood instructional theories to the adult. Houle (1974) noted that the components of the educational process remain the same for all ages and the basic design for learning is identical--this is the basis for the pedagogical model of learning (Knowles, 1984).

A second viewpoint of adult learning is that of andragogy which was first popularized by Knowles. Andragogy is a theory of adult learning that takes into account experience and research about the unique characteristics of adult learners.

The Andragogical model is based on several assumptions that are different from those of the pedagogical model (Knowles, 1984). The assumptions of this theory are that, as people mature:

1. There is a need to know. Adults need to know why they need to learn something before applying oneself to learn it. Tough (1971) found that when adults commit to learn something on their own they will invest considerable energy in understanding the benefits they will gain from learning. As a result of this, one of the first tasks of the facilitator is to help the "learners become aware of the need to know" (Knowles, 1984, p. 55). Adults learn when shown that they will be able to apply the learning to real life.

2. They have a self-concept of being responsible. According to Knowles (1984), adults have a self-concept of being responsible for their own decisions, for their own lives. Once they have arrived at that self-concept they develop a deep psychological need to be seen and to be treated by others as being capable of self-direction.

3. They acquire and retain a variety of experiences. Adults come into an educational activity with both a great volume and a different kind of experience from youths (Knowles, 1984). This quantity and quality of experience has several consequences for adult education.

In any group of adults there will be a wider range of individual differences than is the case with a group of youths. Knowles (1984) noted that any group of adults will be more "heterogeneous--in terms of background, learning style, motivation, needs, interests and goals" (Knowles, 1984, p. 57).

For many kinds of learning the richest resources for learning reside in the adult learners themselves. Hence, the greater emphasis in adult education on experimental techniques.

But in fact the greater experience also has some potentially negative effects. As we accumulate experience, we tend to develop "mental habits, biases, and presuppositions that tend to cause us to close our minds to new ideas, fresh perceptions, and alternative ways of thinking" (Knowles, 1984, p. 58).

4. There is readiness to learn. Adults become ready to learn those things they need to know and be able to do in order to cope more

effectively with their real-life situations. An especially "rich source for readiness to learn is the developmental task associated with moving from one developmental stage to the next" (Knowles, 1984, p. 58). The critical implication of this assumption is the importance of timing learning experiences to coincide with those developmental tasks (Knowles, 1984).

5. Their orientation to learning changes. Adults are life-centered (task-centered or problem-centered) in their orientation to learning. Adults devote energy to learn something to the extent they perceive that it will help them perform tasks or deal with problems that they confront in their life situations. "They learn new knowledge, understandings, skills, values, and attitudes most effectively when they are presented in the context of real-life situations" (Knowles, 1984, p. 59).

6. They respond to a variety of motivational factors. While adults respond to external stimuli/motivators (better job, promotions, higher salaries and the like) the most potent motivators are internal pressures--the desire for increased job satisfaction, self-esteem, quality of life and the like.

The andragogical model is not an ideology; it is a system of alternative assumptions. And Knowles (1984) noted that this leads to one critical difference between the pedagogical and andragogical models of learning. The pedagogical model is an "ideological model which excludes the andragogical assumptions. Whereas the andragogical

model is a system of assumptions which includes the pedagogical assumptions" (Knowles, 1984, p. 62).

From this overview of adult learning the next consideration is of its application to patient education more specifically, learning about cancer.

### Learning about Cancer

The consumers' rights movement has had an impact as demonstrated by "A Patient's Bill of Rights" developed by the American Hospital Association (AHA) (1973). This document states that a patient shall a) receive information about diagnosis, treatment, and prognosis, and b) give consent for a procedure only after being informed about the procedure and possible consequences. Hospitals are now required by the federal government to demonstrate proof of patient education and discharge planning before they receive federal funds (Long, 1984).

Society has an increased awareness of human rights. Long (1984) stated that "in order for a patient to achieve the highest potential for quality of life once a chronic disease, such as cancer has developed, new knowledge, understanding, and new skills for self care are necessary" (p. 584). A person's inability to provide adequately for himself burdens society in general by the loss of that person's actual and potential contributions as well as the increased cost of providing care.

When cancer is diagnosed, patients may potentially undergo a variety of psychological and emotional changes that challenge their

previously accepted life-style and self-concept/self-esteem (Blumberg et al., 1983). Cancer patient education can respond to this complex changing environment of the person affected by cancer by providing information, resources and support in an organized manner which has the potential to facilitate learning about cancer (Johnson & Flaherty, 1980).

Persons who are affected by cancer must deal not only with the physical problems but also with anxiety. One of the best ways to become able to deal with every aspect of being ill is through learning (Long, 1984).

Johnson stated "the literature is clear, teaching people about the various aspects of their condition in an organized systematic manner, is an effective method for improving quality of care" (Johnson & Flaherty, 1980, p. 63). Patients with cancer and their significant others need to be taught how to modify and adapt their behavior to adjust to the ramifications of cancer, as well as the treatment modalities of the disease (Marino, 1981). Cancer patients are saying they want to make decisions about their lives. In order to make appropriate decisions they need information as brought about through learning about cancer.

Recent literature supports that education can help in reaching positive treatment outcomes. Learning is one such outcome of education. Learning is any change in "insights, behaviors, perceptions, attitudes, skills, values, knowledge, or expectations and may or may not be closely associated with any change in over behavior"

(Bigge, 1982, p. 274). A 1980 study of 50 patients receiving radiation therapy revealed that 88% of those surveyed wanted to participate in decisions regarding their treatment (Smith, 1981). Schain (1980) noted that women are demonstrating their knowledge, their competence, and their responsibility by actively making informed decisions about their medical treatment and quality of their life. Therefore, learning about cancer is a significant component of total patient care of persons affected by cancer.

#### Course Inquiry Test

For this study, the "I Can Cope" Program, the construct of adult learning and the concept of learning about cancer was indexed by the Course Inquiry Test (CIT). The Course Inquiry Test is presented and discussed in more detail in the next chapter.

#### Adaptation

The onset of a chronic illness often causes individuals to alter their life-style. Adaptation, conceptually analyzed is viewed as a time related process for maintaining dynamic equilibrium (Guzzetta, 1979) which is influenced by change or stressors. The capacity to adapt to the constant change(s) of illness is dependent upon the person's physical, intellectual, and emotional abilities as they interrelate with illness. Guzzetta (1979) wrote that: "the ability to adapt depends on the intensity, frequency, and duration of the stressor. It is also guided and modified by emotions, perceptions, and learning ability" (p. 37).

External stressors commonly influencing a cancer patient's ability to adapt are: a) perspectives of chronological age and emotional stability; b) family relationships; c) economic security; d) sociocultural beliefs; e) coping patterns; and f) locus of control for self and others (Bouchard-Kurtz & Speese-Owens, 1981). The external and internal stressors which occur because of the impact of cancer on persons affect the adaptation of a person to cancer and learning to live with cancer.

The original diagnosis of cancer presents the patient and family with a life crisis, a situation for which their usual patterns of problem solving are inadequate. The initial stage of adaptation is generally described as a period of disorganization and disequilibrium. The patient and family experience fluctuating feelings of shock, disbelief, sadness, anger, guilt and anxiety as awareness of the implication of the diagnosis of cancer grows (Kodadek, 1985). While it may be difficult for patients et al. to process information during the stage, they need access to information in terms that they can understand in order to begin to learn to deal with the illness (Kodadek, 1985). Individuals move toward a second major stage of adaptation, that of reorganization, as the individuals gradually learn ways to adjust to the illness and its impact, and they begin to regain some of the equilibrium in their lives. During this second stage, information appears to become important as it fosters understanding of diagnosis and treatment. Ways to manage the illness that enables the patient and family to live as normally as possible within the

limitations posed by the illness are significant in the second stage of adaptation (Kodadek, 1985). Finally, the stage of resolution occurs in which losses are acknowledged and a new definition of individual, and family identity incorporating the illness with all its inherent ramifications is accepted.

According to Kodadek (1985), "these stages are not meant to be discrete, linear, time-limited phenomena; rather they are dynamic and often overlap" (p. 46). For example, the chronically ill individual and family may experience feelings of fear again and again as they face the issues that emerge as the realities of living with a chronic illness unfold.

Current theories of chronicity are helpful in providing a framework for understanding the process of adaptation. Moss and Tsu (1976) identified three major determinants which influence the adaptation process: a) Background and personal characteristics, such as age, cognitive development, and spiritual beliefs; b) illness related factors, such as the type, severity and duration, extent of management requirement; and c) physical and social environmental factors such as structural barriers in home/work environment, and the support system available and utilized by the family.

The individual and his family move through a process of continual adjustment to changes in a chronic disease towards a goal of adaptation. Throughout the process of adaptation, the individual undergoes a gradual identity change and transition (Craig & Edwards, 1983). The threat of a chronic illness, its confirmation and

resultant changes in life-style precipitate a series of redefinitions of self (Redman, 1984). Often during this transition period, people experience strong feelings of panic, vulnerability, powerlessness, and apathy. These feelings make it hard for people to maintain a sense of identity and self worth.

The way in which patients adapt to their disease often determines the differences between optimum recovery or psychological invalidism (Lipowski, 1970). Adaptation in response to illness is twofold: a) Coping with the illness and its resultant problems; and b) coping with life's tasks and goals as they are altered by illness (Lazarus, 1974).

#### Meaningfulness in Life

The onset of a chronic illness often generates a change in life-style for the individuals involved. This, in turn, modifies or causes loss of the sense of meaning and purpose that has been their source on actualization and energy in the past (Johnson, 1979). New values must be explored for meaning which can fulfill the same identity or create new ones. Meaning and purpose in life comes from finding a place where one is needed and useful (Crumbaugh, 1973).

Frankl (1968) proposed that the strongest motive in an individual is the "will to meaning." According to Adler (1973) the individual is primarily motivated by the need for mastery (Johnson, 1979).

Frankl gave substance to the "will to meaning"; for people's primary need is to find a purpose in their personal existence and a

sense of significance in their total life experience that mark them as unique individuals. When people lack this purpose, they feel hopeless, powerless, and frustrated in spite of whatever else they might have (Crumbaugh, 1973).

There are basically two potential causes creating a sense of powerlessness and meaninglessness within a person: Loss of control and lack of knowledge (Johnson, 1967). Loss of control implies loss over one's self, one's behavior, one's environment. Lack of knowledge refers to one's illness and the implication it has on one's sense of self, one's family and one's future.

Illness forces people to relinquish control of their lives, at least temporarily, to the control of their physicians. Feelings of powerlessness and frustration are caused by loss of control over such things as medical procedures, appointments, and hospital routines. A lack of information about the disease further heightens people's sense of powerlessness and loss of personal control over what is happening to their bodies and their lives (Johnson, 1967).

According to Lynch (1965), hopelessness is noted in structures of thought, feeling, and action that are rigid and inflexible. It involves a number of powerful human feelings and arouses a sense of the impossible--what a person wants to do is beyond his reach. There is no goal, no reason for being. The sense of purpose in life is lost (Johnson, 1979).

The factors influencing a patient's perception of hope and sense of meaning in life fall into two categories. A first group of

factors threatening the internal resources of patients include their illness and their ability to cope. A second group of factors includes the patient's perceptions of the external resources such as their environment and persons within that environment who can help them (Crumbaugh, 1973). The goal of a chronically ill person is not just to stay alive or keep symptoms under control, but to live as normally as possible despite the symptoms of the disease (Anderson & Bauwens, 1981). Anderson and Bauwens (1981) contend that the goal of care for persons with a chronic disease is not only to treat the disease and to achieve compliance to the treatment, but to foster self-respect in the person and to minimize despair, frustration, bitterness, and grief. Strauss (1975) contended that the chronically ill person has multiple problems of daily living. Some of these problems are: a) The carrying out of or management of prescribed regimen; b) the prevention of, or living with, social isolation caused by lessened contact with others; c) the adjustment to changes in the course of the disease, whether downward or into remission; and d) the attempts at normalizing both interaction with others and their style of life (Strauss, 1975).

Developing disease affects the diseased person's view of self and affects social relationships (Strauss, 1975). Strauss (1975) contends that as the disease progresses, the person with a chronic illness will encounter increased isolation unless attempts are made by family, friends and health care professionals to intervene.

The onset of a chronic illness often causes persons to alter their lifestyle. The change in lifestyle modifies or causes loss of

the sense of meaning and purpose of life. Johnson (1967) noted that a person's sense of meaninglessness and powerlessness is caused by a loss of control over their personhood. The person affect by cancer may feel this loss of control over his/her life at various stages the of disease process. Thus, the meaning of life is threatened. In order to regain a sense of meaning and purpose for living, new values and goals have to be defined (Jonnsn, 1979).

Fisher (1981) noted that the issue to be faced by a person with cancer may not be beating cancer, but identifying what quality a person with cancer can put into living. Redefining of life goals and expectations enhances adaptation and normalization of living with cancer. The adaptation and normalization of the person affected by cancer to living within personal limits will enhance meaningfulness to life and influence the quality of this person's life. Spinetta (1982) contends that it should be the goal of all health care workers to help the person with cancer and family members adjust to the presence of cancer and to believe that the quality of life is enhanced by maximal efforts devoted to living with cancer.

Illness and psychological aspects of a person's affective state are interrelated. The following studies in the field of psychosocial health field give evidence to support the notion that a sense of meaning in life appears to be related to how a person functions in the face of illness (Johnson, 1979). O'Neill (1975) found that feelings of hopelessness and loss of control were very real for persons dealing with a life threatening disease. Another study

showed that patients who held a strong negative feeling about their illness had less hope, were more anxious, and had little faith in the competence of their physician (Schwab, Clemmons, & Marder, 1966). Crumbaugh (1973) reported that, when people must yield to an altered lifestyle, they experience a loss in a sense of meaning and purpose in life which in turn affects their sense of actualization. New values and reasons for living must be explored or otherwise people will lapse into a state of hopelessness and despair (Johnson, 1979).

In summary, these studies show that chronic illness often elicits a sense of helplessness in patients. Their meaning in life is threatened. In order to regain a sense of meaning and purpose for living, new values and goals have to be defined. Educational programming can offer patients assistance in redefining their life goals and expectations. This in turn can enhance patients' adaptation to living with their chronic illness and its ramifications.

#### Purpose in Life Test

For this study, the concept meaningfulness in life was indexed at the operational level by the Purpose in Life Test (PLT) which is presented and discussed in more detail in Chapter 3.

#### Anxiety

Anxiety is probably the most common emotional reaction people experience when becoming ill or when family members become ill (Johnson, 1979). This reaction may be manifested in many ways and may

vary in degree, but it frequently leads to confusion and limits a person's coping ability (Johnson, 1979).

Anxiety is a complex, multidimensional emotional reaction (Izard, 1972). The emotional reactives generated can be a result of stress produced by external (environmental) or internal stimuli (Lipowski, 1970). These reactions generally are characterized by an increased alertness and responsiveness to stimuli resulting in various bodily manifestations such as tension and/or nervousness which may result from autonomic nervous system reactions to stressful stimuli.

Freud (1936) regarded anxiety as "something felt," an unpleasant affective state of an individual. He described anxiety state as being: a) A specific unpleasurable quality; b) efferent or discharge phenomena; and c) the perception of these. Anxiety has a unique combination of experiential and physiological qualities that distinguishes it from other unpleasant affective states such as anger or guilt (Johnson, 1979). Freud defined the experiential qualities as feelings of apprehension, tension, or dread while the physiological qualities were seen in such symptoms as increased heart rate, disturbances in respiration, and profuse diaphoresis (Spielberger, 1966).

Cattell and Scherer (1961) mentioned several other varieties of anxiety. In comparing "realistic situational" and "characterological" anxiety, they proposed that the former is realistic, periodic and a response to immediate external threats. Characterological anxiety is relatively permanent and stable in

nature. By identifying and labeling these dual concepts of anxiety, Cattell and Scherer refuted the concept of anxiety as a single entity within itself.

Combs and Taylor (1952) indicated that even with the mildest threats to the self, performance is impaired. The degree of threat is determined by the: a) Importance of the threatened concept of self; b) immediacy of the threat; c) clarity of perception(s) of danger, fear, and anxiety; and d) the degree of threat as a function of personal adequacy challenge, and threat.

People have personal ways of viewing their world. Combs' significant contribution to the study of anxiety was: a) That people's conception of anxiety is a function of their perceptions, and b) that anxiety affects the self-concept and consequently performance (Johnson, 1979).

A general finding of a number of studies is that there is a substantial linear relationship between self-concept and anxiety. A study by Schwabb, Harmeling and McGinnis (1966) dealt with the interaction of "triangular associations" between anxiety, self-concept, and body image. Persons with this syndrome tended to distort the severity of a chronic illness. DiBartalo (1969) concluded from his study that anxiety level and body image perception were significant factors for success in the rehabilitation program for persons with cancer of the head and neck.

The word cancer elicits immediate fears associated with vulnerability, helplessness, death and the unknown (Hefez, 1982).

Cancer also evokes anxiety because cancer usually does not follow a clear course and therefore is unpredictable. Compromise becomes an important issue as many patients have a difficult time doing only part of their normal routine. Due to cancer-imposed physical restraints, sometimes patients are not able to use activities which helped to relieve anxiety in the past. Due to this and other complex factors, the family roles and responsibilities often change with cancer. For the family then, the heightened responsibilities may heighten anxiety (Welch-McCaffrey, 1985).

Lucente (1972) stated that cancer patients are generally more anxious than other patients. Pattison (1977) stated that when the certainty of the death trajectory is interrupted, ambiguity escalates and persistent high levels of anxiety are promoted.

Weisman (1979) noted that two to three months following the initial diagnosis of cancer represents the time of most intense anxiety. Cumulative anxiety may result from much and diverse stimuli such as multiple diagnostic procedures, surgical intervention and the follow-up for the treatment.

Derogatis (1983) in his random evaluation of 250 new admissions to three cancer centers, found that 47% of the patients received formal psychological diagnoses of anxiety and depression. Craig and Abelhoff (1974) evaluated 30 patients consecutively admitted to an oncology research unit and found 30% of the patients had more than minimal levels of anxiety. Peck (1972) noted that anxiety is the most common response in patients about to start radiation therapy.

Chronic anxiety is often seen in cancer patients in the state of remission. Chronic anxiety parallels remission (Welch-McCaffrey, 1985). In breast cancer patients following simple mastectomy with adjuvant chemotherapy, Hughson (1980) found symptoms of depression and anxiety persisting for more than one year--these were patients with no evidence of active disease.

Welch-McCaffrey (1985) presented Wroblewski's concept that anxiety in the cancer experience is often related to a misunderstanding about the illness and/or its treatment(s). "Educating patients plays an important role in anxiety reduction" (Welch-McCaffrey, 1985, p. 156).

Anxiety is a complex, multidimensional emotional reaction (Izard, 1972). The emotional reaction generated can be a result of stress, produced by external (environmental) or internal stimuli (Lipowski, 1970). The stimuli initiate the arousal of anxiety states involving a sequence of events. Spielberger, Gorsuch, and Lushene (1970), make a distinction between anxiety as a relatively stable personality trait (A-Trait) and as a transitory state (A-State). Spielberger's (1966) State-Trait theory will be presented in the next section in the concept level discussion.

#### A-State Anxiety

Anxiety is a complex, multidimensional emotional reaction (Izard, 1972). The emotional reactions generated can be a result of stress, produced by external (environmental) or internal stimuli (Lipowski, 1970). The stimuli initiate the arousal of anxiety states.

Spielberger, Gorsuch, and Lushene (1970), make the distinction between anxiety as a relatively stable personality trait (A-Trait) and as a transition state (A-State).

There are two distinct anxiety concepts: State anxiety and trait anxiety. Trait anxiety refers to an individual's anxiety proneness or the probability that he will develop the anxiety state in response to a stimulus. Anxiety trait is unaffected by situational stress and is relatively stable over time (Spielberger et al., 1970). Therefore, A-Trait was not operationalized in this study.

State Anxiety (A-State) may be conceptualized as a transitory emotional state or condition that varies in intensity and fluctuates over time (Spielberger et al., 1970) as a result of the stresses perceived by the individual. Recognizing the presence of an anxiety state, the individual may try to alter his appraisal of the situation. Behaviors most frequently utilized were those which previously had reduced or eliminated the unpleasantness of anxiety state reaction (Spielberger, 1972). An individual's state anxiety would be high in circumstances that are perceived as threatening regardless of the objective danger. State anxiety would be low in non-stressful situations or in circumstances in which the existing danger is no longer perceived as threatening. The level of anxiety also tends to increase with prolonged duration and increased severity of threat (Spielberger, 1972).

### The A-State Anxiety Scale (STAI)

For the purpose of this study, the concept A-State Anxiety was indexed at the operational level by the A-State Anxiety Scale (STAI). The STAI is presented in more detail in the next chapter.

### Relationship between Patient Education and Adult Learning

The construct of patient education and adult learning have been presented in previous sections. The following section establishes relationships between the two constructs and their conceptual components.

Recent literature supports that education can help in reaching positive treatment outcomes. All studies cited utilized adult learners. Carefully planned and executed patient education programs have shown increased patient understanding, thus promoting compliance (Rickel, 1981). A 1980 study of 50 patients receiving radiation therapy revealed 88% of those surveyed wanted to participate in decisions regarding their treatment (Smith, 1981). Schain (1980) noted that women are demonstrating their knowledge, their competence, and their responsibility by actively making informed decisions about their medical treatment and quality of their life. Therefore, it is essential to educate patients to recognize the value of their participation. Such collaborative endeavors could result in increased patient satisfaction, and preserve the patient's feelings of individuality, anatomy, and sense of personal dignity (Schain, 1980).

Linde and Janz (1979) conducted a study of 55 subjects who had coronary bypass or valve repair. Their purpose was to examine the effects of a comprehensive inpatient postoperative teaching program on learning by assessing patient knowledge and compliance. An individualized and structured comprehensive patient education program using a variety of teaching materials was utilized for all subjects. The program content included information on the disease process, surgical intervention, activity progression, medications, and dietary regimes. Five to six sessions were required to complete the program. Learning as indexed by knowledge was examined. A measurement of knowledge was obtained preoperatively and at the time of discharge and during the first two postoperative visits. Results of the knowledge test showed a significant increase in knowledge scores from the preoperative to the discharge tests, and stability in most patient scores from discharge to both postoperative visits. Thereby, this demonstrated that learning did occur in this adult population.

Rahe, Scalzi, and Shine (1975) published a methodological paper on the construction of a questionnaire to evaluate the learning by patients with coronary heart disease to six areas of post myocardial infarction management. Questions covered the areas of: nature of the disease, emergency treatment, physical activity, diet and smoking, psychological factors, and return to home and work. The questionnaire was first administered after the patient had been medically stabilized--usually between the fourth and seventh day after the myocardial infarction (MI). These data served as baseline

estimates of patient knowledge. A prepared booklet which covered the six major problem areas was then given to the subjects. Several nurse-patient sessions took place over the next few days with the same nurse reviewing various sections in the booklet with the patient. Shortly after discharge, the questionnaire was readministered. A statistically significant increase in total number of correct responses for the entire questionnaire was seen.

Owens, McCann, and Hutelmyer (1978) investigated the effectiveness of patient education on 36 hospitalized cardiac patients in a group setting. This study demonstrated that the patients were able to learn in a group setting. Learning was indexed operationally by knowledge in the Owens et al. (1978) study. Results of a pre-posttest showed a marked increase in the general level of knowledge. Furthermore, a follow-up study utilizing the same pretest showed that patients continued to gain knowledge after conclusion of the group patient educational sessions.

A third study supported group patient education was that of Vignos, Parker, and Thompson (1976). They developed a group education program for patients with rheumatoid arthritis. Results from a multiple choice pre-posttest showed an improvement in both short and long-term retention of knowledge, therefore, demonstrating the occurrence of learning.

### Relationship between Patient Education and Adaptation

The constructs of patient education and adaptation have been discussed in previous paragraphs. This section establishes a relationship between the two constructs.

Johnson (1982) presented experimental evidence concerning the use of a structured educational program for persons whose lives are impacted by cancer. The 52 subjects were randomly selected from a group aged 18 and older, who had been diagnosed or rediagnosed within 12 months as having cancer. Each participant was measured on three dependent variables: Anxiety, meaningfulness in life, and knowledge about cancer. Meaningfulness in life is presented in this section. The groups were paired by cluster analysis and found to be homogeneous. There was random assignment of each pair to either treatment or control group. The treatment group attended eight structured educational sessions in a four week period. Each session had goals, learning objectives and study assignments. The two groups were compared with respect to their pre-post change scores on the dependent variables. Thus, patient education was correlated to adaptation to life with cancer at the  $p = .001$  level with the Hotelling's  $T^2$  test.

Fortin and Kirovac (1976) in their study of 69 elective surgery patients found structured teaching had a beneficial effect on physical comfort and analgesia requirements. They concluded that a structured educational program was effective in recovery of patients.

Levine and Britten (1973) reported that a structured educational program resulted in a reduction of absenteeism and a reduction of days spent in the hospital for 45 hemophilia patients. Leving et al. (1979) demonstrated that small group sessions had the strongest impact on blood pressure control in a population of 400 hypertensive patients.

Educators can help adults recognize the type of adjustments they are likely to confront (Johnson, 1979). Participation in an educational activity can facilitate adults in increasing their understanding and competence for dealing with changes that have already occurred as well as increasing both their awareness and understanding of possible future changes (Knowles, 1976). The response to cancer is not a single one, but a continually changing adaptation based on the demands of the disease.

These studies investigated the effect of patient education programs on a person's ability to cope with illness, and suggest that educational programs for patients influence adaptation to the illness.

#### Relationship between Patient Education and Anxiety

Adaptive behavior involves the simultaneous management of at least three variables: Securing adequate information, maintaining satisfactory internal conditions and keeping some degree of autonomy (White, 1974). The need for information about a stressful situation can be related to the basic needs of safety and security. Even though the stressor may not be eliminated by the acquisition of information,

the person may feel less anxious. There is a need to validate the assumption that health and patient teaching alters the degree of anxiety experienced during illness. The inference of this assumption is that a reduced anxiety level enhances adaptive behavior.

Wallace and Wallace (1977) hypothesized that patients who received post myocardial infarction education in group settings would be found to have made a better psychological adjustment to their post infarction state than patients who did not receive special group education. Subjects were in two groups: Group A consisted of 60 patients; some of whom had received planned education, and Group B consisted of 23 patients who all received formal post myocardial infarction (MI) instruction. All subjects were given the Eysenck Personality Inventory (EPI), and the Institute for Personality and Ability Testing Anxiety scale (IPAT), and an investigator-designed questionnaire relating specifically to variables which might be expected to affect post MI psychological status. Those in group B received the IPAT while hospitalized and four months after discharge. Those in group A were given the IPAT only once--about 10 months after discharge. Contrary to the expected, the IPAT scores demonstrated higher anxiety levels among those subjects who had taken part in the group education. Higher anxiety levels were also demonstrated by some subjects in group A who had received patient teaching. Within group B, the IPAT scores did not reflect a significant increase between the test performed during hospitalization and that recorded after discharge. Results of the IPAT raised the question of whether the

education groups were poorly conducted or whether they were conducive to anxiety by stressing the responsibility for self-care. The raw scores of the EPI showed no difference between the two groups.

Koch (1971) investigated the effects of structured teaching done by operating room nurses on the anxiety levels in 14 patients. Subjects were randomly assigned to one of two groups. The experimental group received structured instruction from the investigator the evening prior to surgery, while the control group received the usual instruction from a regularly assigned staff nurse. Results of the IPAT anxiety scale administered on the second or third post operative day did not demonstrate a lower postoperative anxiety level of those who had received the structured preoperative teaching as anticipated by the investigator.

Johnson (1982) presented experimental evidence concerning the use of a structured patient education program for persons whose lives are impacted by cancer. The 52 subjects were randomly selected from a group aged 18 years and older, who had been diagnosed or rediagnosed within 12 months as having cancer. Each participant was measured on three dependent variables: Anxiety, meaningfulness in life and knowledge about cancer. Anxiety is the variable addressed in this section. The groups were paired by cluster analysis and found to be homogeneous. There was random assignment of each pair to either treatment or control group. The treatment group attended eight structured educational sessions over a four week period. Each session had goals, learning objectives, and study assignments. The two groups

were compared with respect to their prepost change scores on the dependent variables. The patient education course was found to have a significant effect on the participants' scores. Thus, patient education was correlated to anxiety at the  $p = .001$  level with the Hotelling's  $T^2$  test.

Jacobs et al. (1983) conducted two prospective, controlled studies to determine whether psychological and social functioning could be enhanced in patients with Hodgkin's disease by either education or participation in a peer support therapy group. Eighty-two patients were evaluated with the Cancer Patient Behavior Scale prior to and following intervention. Following education, patients experienced significant improvement in the frequency of anxiety, treatment problems. At the completion of the study, the education group had a significant reduction in anxiety ( $p = 0.02$ ) and treatment problems ( $p = 0.009$ ). Thus, education does appear to alter psychological and social functioning of patients with Hodgkin's disease.

Small et al. (1983) noted that for the most part, increased knowledge and understanding is sought by persons affected by illness as it promotes a sense of control in their life with resultant decreased anxiety. Wayne (1981) described a formal patient education program provided to end stage renal failure patients to reduce anxiety and fear as well as to allow the patient dignity and freedom of choice. Wayne notes the effectiveness of educational programs on reducing anxiety in patients with end stage renal disease.

Felton et al. (1976) found that semistructured teaching was effective in reducing anxiety in 62 surgical patients. Emotional support and information was demonstrated to be most effective in reducing postoperative anxiety by Fassler (1980) in 45 children undergoing minor surgical procedures. Because the evidence is conflicting, a question mark has been placed in the theoretical model to indicate that the direction is not hypothesized.

#### Relationship between Adult Learning and Adaptation

Adaptation, conceptually analyzed, is viewed as a time-related process for maintaining dynamic equilibrium (Guzzetta, 1979) which is influenced by change or stressors. The ability to "adapt depends on the intensity, frequency and duration of the stressor and is guided by emotions, perceptions and learning ability" (Guzzetta, 1979, p. 37). Thus, learning which occurs through an education process may abet adaptation.

The capacity to adapt to the constant change of illness is dependent upon the person's physical, intellectual, and emotional abilities as they interrelate with illness. Guzzetta (1979) wrote that: ". . . the ability to adapt depends on the intensity, frequency and duration of the stressor. It is also guided and modified by emotions, perceptions, and learning ability" (p. 37). External stressors commonly influencing cancer person's ability to adapt are: a) Perspectives of chronological age and emotional stability, b) family relationships, c) economic security, d) sociocultural beliefs, e) coping patterns, and f) locus of control for self and others

(Bouchard-Kurtz & Speese-Owens, 1981). These external and internal stressors which occur because of the impact of cancer on persons affect the adaptation of a person to cancer and the learning to live with cancer.

As defined by Bigge (1982), learning is a change in an individual "in which genetic inheritance is not a predisposing factor" (p. 274). Learning may be considered a change in insights, behaviors, perceptions, or motivations, or a combination of these. Thus, learning is a change or "reorganization of insights, knowledge, skills, attitudes, perception, values, or expectations and may or may not be closely associated with any change in overt behavior" (Bigge, 1982, p. 274).

Long (1984) defined teaching as "any activity or effort that is undertaken for the purpose of bringing about learning" (p. 583). According to Long (1984) learning is a change in knowledge attitude or abilities. "Planned teaching does not always result in learning and learning may take place in the absence of teaching" (Long, 1984, p. 583).

Currently, there exists a growing interest to support educational programs for persons experiencing cancer. Miller and Nygren (1978) evaluated behavioral changes in persons with cancer based upon an educational program. The results of this study described the positive changes that persons affected either directly or indirectly by cancer expressed toward coping with cancer and their adaptive feelings and reflections on living with cancer. The Johnson

(1979) study had an "underlying assumption that adaptation can be accelerated by increasing patient's knowledge of the latest health care practices encompassing their diseases" (p. 2). The results of Johnson's (1979) study indicate

the study results give experimental evidence concerning the advisability of using a structured educational course as part of the rehabilitation program for persons who must adapt to living with a chronic disease (p. 79).

Small et al. (1983) in their study of patients with gynecological cancer, found that increased knowledge and understanding promotes a sense of control in a patient's life, i.e., a sense of power rather than powerlessness. Thus, adult learning fosters and enhances one's sense of meaningfulness in life and self esteem thus hastening the adaptation process.

Educational programs assist subjects in adjusting to living with cancer, especially in coping strategies and adaptation to changes (Miller & Nygren, 1978). Johnson's (1979) study supported the conclusion that the patient's ability to adapt and cope with the chronic disease of cancer was improved as a result of a structured educational experience. Narrow (1979) contended that clients have the right to acquire knowledge and skills which will enable them to function at their optimum level. One of the primary functions of a structured educational course is the learning of accurate information which will facilitate adaptive behaviors. This adaptive behavior will then help the cancer patients, their families and/or significant others address the many psychosocial problems associated with cancer that often interfere with the individual's quality of life.

### Relationship between Adult Learning and Anxiety

The constructs of adult learning and anxiety have been presented previously. This section discusses the relationship between these two constructs.

Johnson (1982) presented experimental evidence concerning the use of a structured patient education program for cancer patients and/or their significant others. The subjects (N = 52) were randomly selected from a group aged 18 years or older, who had been diagnosed or rediagnosed within 12 months as having cancer. Each participant was measured on three dependent variables: Anxiety, meaningfulness in life and knowledge about cancer. The groups were paired by cluster analysis and found to be homogeneous. There was random assignment of each pair to either treatment or control group. The treatment group attended eight structured educational sessions over a four week period. Each session had goals, learning objectives, and study assignments. The two groups were compared with respect to prepost change scores on the dependent variables. The patient education course had a significant effect on the participant's knowledge scores, therefore, adult learning was demonstrated. The course and resultant increased knowledge was found to have a significant effect on the participants' anxiety. Thus, patient education and the resultant increase in learning were correlated to anxiety at the  $p = .001$  level with the Hotelling's  $T^2$  test.

Small et al. (1983) noted that increased knowledge and understanding is sought by patients. This is due to the fact that it

promotes a sense of control in a patient with resultant decreased anxiety. Jacobs et al. (1983) examined adult learning and noted that a structured patient education program with resultant increased knowledge was more effective in reducing anxiety of patients with Hodgkins disease than was a formalized peer support group. Scientific evidence is uncertain concerning the relationship between adult learning and anxiety, as multiple factors influence anxiety. Thus the specific relationship between adult learning and anxiety is uncertain.

#### Relationship between Adaptation and Anxiety

The constructs of adaptation and anxiety have been presented previously. This section establishes a relationship between the two constructs.

This study was conducted to measure the effects of a structured patient education program on participants' perceptions of specific aspects of and ramifications of their disease process. The underlying assumption of this study was that the process of adaptation would be accelerated by facilitating the participants' learning. The question of how an educational program could contribute to the process of adaptation was central to this study. Therefore, studies cited herein have patient education as a major component due to the effects of patient education on both adaptation and anxiety.

Welch-McCaffrey (1985) noted that for the most part increased knowledge and understanding is sought by patients with cancer as it promotes a sense of control in the individual's life with a resultant decrease in anxiety.

Miller and Nygren (1978) evaluated behavioral changes in persons with cancer based upon an educational program. A convenience sample of 10 subjects participated in this study. The participants' ages ranged from 35-72 years and they had been diagnosed or re-diagnosed as having cancer within the past year. The subjects voluntarily attended a structured cancer education program. The results of this study described the positive changes expressed by the participants toward coping with cancer and their adaptive feelings. The subjects in this study revealed a greater appreciation of life and a more positive attitude toward living.

Small et al. (1983) in their discussion of patients with gynecological cancer found that increased knowledge and understanding promotes a sense of control in a patient's life, i.e., a sense of power rather than powerlessness. They reported enhancement in the sense of meaningfulness in life and self-esteem thus facilitating the adaptation process with resultant decreased anxiety.

Jacobs et al. (1983) conducted two prospective, controlled studies to determine if psychological and social functioning could be enhanced in patients with Hodgkin's disease by either education or participation in a peer support group. Eighty-one patients were evaluated with the Cancer Patient Behavior Scale prior to and following intervention. The results of their study demonstrated that increased knowledge facilitated adaptation by increased meaningfulness in life and was more effective in reducing the anxiety of patients with Hodgkin's disease than was a formalized peer support group.

These research studies investigated the effects of patient education programs on a person's ability to cope with illness, and suggest that educational programs for patients influence adaptation to illness with a resultant decrease in anxiety.

#### Summary

Investigations have demonstrated that the diagnosis of cancer and/or the resultant therapy/treatments have a profound impact on the lifestyle of cancer patients, their families and/or significant others. A heightened state of anxiety, and an alteration in meaningfulness in life have been documented in relation to the diagnosis of cancer. Patient education, specifically cancer patient education, is a vehicle to enhance the process of ongoing adaptation to cancer. Adult learning as a result of cancer patient education has been demonstrated to enhance adaptation to cancer.

This study explored the effects of a structured education program designed to facilitate learning by the cancer patients and their families and/or support groups to specific aspects of their disease and enhance adaptation to selected ramifications of the disease.

## CHAPTER 3

### METHODOLOGY

This study was conducted to measure the effects of a structured education program on learning about specific aspects of cancer. The purpose of this study was to determine whether the structured "I Can Cope" Program created learning and adaptive changes in adult cancer patients and/or significant others.

The research questions posed for this study were:

1. Will adult learning as measured by the Course Inquiry Test increase over time for participants in the "I Can Cope" Program?
2. Will adaptation as measured by the Purpose in Life Test increase over time for participants in the "I Can Cope" Program?
3. Will Anxiety decrease over time for participants of the "I Can Cope" Program?
4. Is there a positive (+) relationship between the Course Inquiry Test and Purpose in Life at the end of an "I Can Cope" Program?
5. Is there a negative (-) relationship between the Purpose in Life Test and A-State Anxiety Scale at the end of the "I Can Cope" Program?

6. What is the relationship between adult learning and Anxiety at the end of an "I Can Cope" Program?

This chapter describes the methodology used in this study. The study's design, setting, sample, protection of the rights of subjects, data collection, measurements and procedure as well as the plan for data analysis are described.

#### Design

This study utilized a repeated measures descriptive design. The study examined changes in adult learning, adaptation to living, and anxiety that occurs as a result of the cancer education course "I Can Cope." All subjects were participants in the cancer patient education course "I Can Cope." Changes in each person's pre-mid-post test scores were measured against their pre-test and post-test scores on three instruments: a) Course Inquiry Test; b) Purpose in Life Test; and c) A-State Anxiety Scale. A comparison of scores measured whether any significant short-term adaptation and adult learning occurred as a result of the "I Can Cope" course.

#### Sample and Setting

The sample for this study was a volunteer sample of 19 subjects. Subjects were any adult person who wished to participate in the course "I Can Cope." Both cancer patients and their significant others may register in the "I Can Cope" Program and were included in the sample. The American Cancer Society (ACS) limits the size of each "I Can Cope" Program to no more than 35 and for the purpose of

analysis of data in this study, a minimum number of 15 participants was acceptable. The subjects participated in the course on a voluntary basis and were not required to have a physician's prescription to attend. Subjects were made aware of the course from brochures placed in physicians' offices, clinics, hospitals, and through the media. The brochures briefly described the course content and information on the course enrollment process. Thus, participants voluntarily attended a course to learn about cancer, disease ramifications, and adapting to living with cancer.

The sample was composed of those persons from the population who met the following criteria:

1. adults aged 18 years or older;
2. participants in the "I Can Cope" course selected for study;
3. able to speak, read, and understand English.

All participants were assumed to have received informal, unstructured, individualized teaching through contact with physicians, nurses, and other health professionals throughout the course of care for themselves or their significant others whether as inpatients or as outpatients. Subjects meeting the above criteria were given an explanation by a course facilitator to the nature and purpose of this study. These participants were informed what their participation would entail, and that their participation would in no way affect their health care. Subjects agreeing to participate were given the four part self-completion questionnaire containing the three measurement tools. A disclaimer was used for subject consent.

Confidentiality was assured by assigning a number to each subject and explaining that the data would be coded for analysis.

The study took place in a southwestern community where the "I Can Cope" courses are offered on an outpatient basis at local public and private health care institutions. The health care facilities are located in a county with an estimated population of 1,837,956 (University of Arizona, 1985). The classes are offered in comfortable, relaxed class and/or meeting room settings.

#### Protection of Human Rights

The proposal for this study was reviewed and approved by the Ethical Review Committee of the College of Nursing, University of Arizona. The purpose of this study was explained to the "I Can Cope" course participants and a disclaimer form was given to participants to read prior to participating in the study (Appendix B). Any questions the participants had at these times were answered by a course facilitator. Confidentiality of the information was assured to the participants by assigning each subject a number.

#### Operational Measures

##### "I Can Cope" Program

A structured cancer educational course consisting of eight sessions, "I Can Cope," was led by trained facilitators and other health care professionals. Each program session, approximately two hours in length, had learning objectives and appropriate supportive

educational materials. The course outline for each session is in Appendix C.

The underlying assumption of this course is that the adaptation of a person whose life is affected by cancer shall be enhanced by learning about cancer and how to adapt to the many physiological and psychosocial ramifications of this chronic disease.

#### Measurement Tools

Four measurement tools were used in this study: Course Inquiry Test (CIT) (Appendix D); Purpose in Life Test (PLT) (Appendix E); the A-State anxiety Scale from the State-Trait Anxiety Inventory (STAI) (Appendix F); and the Demographic Individual Participant Data Sheet (Appendix G). The instruments measure the variables of a) learning about cancer; b) meaningfulness in life, and c) perceived State anxiety. Each instrument was administered to each volunteer participant attending the "I Can Cope" course at the beginning of the course, at the midpoint of the course (week four) and again at the close of the course.

The Course Inquiry Test was developed by Johnson (1979) and is designed to measure the subjects' knowledge about cancer, its related treatments, and other ramifications of the disease process. Twenty-four items were developed to measure participant knowledge acquisition. The participants could give one of three responses: Agree, disagree, or uncertain. Directions suggested that the subjects circle uncertain if they are unsure of an answer. This was done in order to reduce the chance of variation through guessing. Uncertain

responses were scored as incorrect answers. Maximum score on the CIT is 24 points.

The content validity of the CIT was assessed by having the CIT examined by several health care professionals who were viewed as experts on the course content. In order to assess for readability the test was administered to several patients prior to its use in the study. In this manner, the Course Inquiry Test was judged for its content validity. Content validity between "I Can Cope" course groups may vary due to the course presenters and the composition of the group-participants.

The reliability procedure for the Court Inquiry Test was estimated from the internal consistency of the 24 items within it. The split-half reliability was obtained by using the Spearman-Brown formula which resulted in an  $r$  value of .73. The reliability of the instrument may be affected by the short spans of time between pre-test, mid-test, and post-test.

The Purpose in Life Test (PLT) is an attitude scale designed to measure the degree to which the subjects experience a sense of meaning and purpose in life. The PLT has three parts. Only part A, was used in this study. It consists of 20 items that are rated on a seven-point scale whose dimensions are bounded by descriptive bi-polar adjectives. A score is calculated by adding across all items of the scale points selected by the subjects. The higher the score, the higher the degree of meaning and purpose in life. A participant's

score is the sum of the numerical values circled and can theoretically range from 20 to 40.

Both construct and criterion validity of the PLT has been assessed. Crumbaugh (1969) predicted correctly from the standpoint of construct validity, the order of the means of four "normal" populations. The combined results of these groups showed  $M = 112.42$ ,  $N = 805$ ,  $S.D. = 14.07$ . Criterion validity of the instruments has been evaluated by two measures. For a group of 138 outpatient neurotics, a correlation of .50 was found between PLT scores and therapist ratings of degree of purpose and meaning exhibited by the patient. Likewise, with a group of 120 Protestant parishioners, a correlation of .47 was found with ministers' ratings (Crumbaugh & Makolick, 1969). The Spearman and Brown split-half reliabilities have been demonstrated to be adequate in two separate studies (.90 and .92) (Crumbaugh, 1969).

The third measurement tool is the A-State Anxiety Scale (Form Y-1) entitled "Self-Evaluation Questionnaire." The STAI was developed by Spielberger, Gorsuch, and Lushene (1970) and revised in 1980 to provide reliable and objective measures of both State and Trait anxiety using two easily administered, self-report scales. The STAI is composed of two 20-item scales, one each to measure State and Trait anxiety. Only the A-State Anxiety Scale was used in this study. Permission for use and reproduction of the STAI was obtained (Appendix H). The directions for the STAI are written on the scale. The range of possible scores is from a minimum score of 20 to a maximum score of 80, with the higher scores indicating higher anxiety levels.

According to the STAI Manual, "instructions may be modified to evaluate the level of A-State intensity for any situation or time interval that is of interest to an experimenter" (Spielberger, 1983, p. 4). Since the State anxiety is a transitory State, the A-State Anxiety Scale asks the participant how he feels at a particular moment in time. For the purpose of this study, the instructions for the A-State Anxiety Scale were not changed. Therefore, the A-State Anxiety Scale scores obtained from this study will reflect the degree of anxiety experienced by the participants at the time the scale was administered.

In the STAI Manual, Spielberger (1983), noted that the test-retest reliability of the STAI is relatively high for the A-Trait Scale. The A-State Anxiety Scale, however, tends to have a lower test-retest reliability due possibly to environmental and/or situational factors present at the time of the retesting.

Spielberger (1983) noted a high degree of internal consistency which was demonstrated for both the A-State and A-Trait Anxiety Scales. Both of the item-remainder correlation coefficient (median  $r^2 = 6.3$ ) and alpha reliability coefficient (median = .92) tend to be higher for the A-State Anxiety Scale when given under stressful situations.

Other tools to measure trait anxiety such as Taylor (1953) Manifest Anxiety Scale, the Institute for Personality and Ability Testing (IPAT) Anxiety Scale (Cattell-Scherer, 1961), and the A-Trait Anxiety Scale of the STAI correlate highly with one another ( $r = .80$ ,

$r = .75$ , respectively) (Spielberger, 1972). Moderate correlations have been established between the STAI and the Zuckerman (1960) Affect Adjustment Checklist in two separate studies. One study involved college students, and the other neuro-psychiatric patients ( $r = .52$ ) (Spielberg et al., 1970).

The STAI Manual lists many studies which document the construct validity of the STAI for high school and college students, and for patient populations. Research studies utilize patients include those of Auerbach (1973), DeLong (1971), Edwards (1970), Florell (1971), Gentry, Foster and Henry (1972), Lucas (1972), Newmark (1972), Parrino (1977), and Spinetta (1972), Gentry and Williams (1975). These studies further attest to the construct validity of the STAI.

#### Data Collection Procedure

The participants were given the following instructions for filling out the forms.

1. The purpose of this study was explained to the "I Can Cope" Program participants and a disclaimer form was given to the participants to read prior to participating in this study. Completion of the questionnaires did reflect both informed consent and voluntary participation in this study.
2. Individual Participant Data Sheet--participants were advised that questions asked on this form would provide data on age, sex, diagnosis, and treatments of persons taking the course.

3. Three measurement tools--the instructions for each of these was read aloud and the participants' questions were clarified. Participants were instructed that there was no right or wrong answers on the Self-Evaluation Questionnaire or the Purpose in Life Test. It was stressed to the participants that they were to think about how they feel right now; today, as a person whose life is being influenced by cancer.

The same three instruments (CIT, PLT, A-State) were given again to all voluntary participants during the fourth week of the course (mid-test) and at the last course session (post-test). Instructions for test taking was the same for these tests as it was for the pre-test. Due to time constraints, the participants were requested to complete their questionnaire packet at home and mail it to the investigator in the self-addressed, stamped envelope provided. This method was utilized for each of the three times data were collected.

#### Data Analysis Plan

The first phase of the data analysis focused on the demographic questionnaire to determine general descriptors of the participants. This descriptive analysis included: male to female ratio; age of participants; educational level attained; primary cancer site; number of participants receiving chemotherapy vs. radiation treatment.

One-group repeated measures of analysis of variance was used to answer the first three questions of this study:

1. Will adult learning as measured by the Course Inquiry Test increase over time for patients who are taking the "I Can Cope" Program?
2. Will adaptation as measured by the Purpose in Life Test increase over time for patients who are taking the "I Can Cope" Program?
3. Will A-State Anxiety decrease over time for patients who are taking the "I Can Cope" Program?

Pre-test, mid-test and post-test scores comprised the longitudinal measures for analysis. The critical significance level of  $p \leq .05$  was established.

Pearson-product moment correlations were used to examine data related to the last three questions of this study:

4. Is there a positive (+) relationship between the Course Inquiry Test and Purpose in Life Test at the end of an "I Can Cope" Program?
5. Is there a negative (-) relationship between the Purpose in Life Test and A-State Anxiety Scale at the end of the program?
6. What is the relationship between adult learning and anxiety at the end of an "I Can Cope" Program?

All inferential analyses used a critical significance level of probability at  $p \leq .05$ .

## CHAPTER 4

### PRESENTATION AND DATA ANALYSIS

The results of this study were based on 19 "I Can Cope" course participants. The following pages include the demographic data followed by a presentation of the questionnaire data and statistical tests.

#### Sample Characteristics

Out of 32 class participants, 25 persons responded initially with 19 participants completing the data collection procedure at each of the three times. Therefore, 19 participants comprised the sample for this study. Initially, demographic data were evaluated for the total group and the two subgroups comprising this total group. The first subgroup is persons with cancer who are participants of the "I Can Cope" course ( $n = 14$ ). The second subgroup is that of significant others of persons with cancer ( $n = 5$ ) and the total group consisted of all persons with cancer and significant others of persons with cancer who were participants in the "I Can Cope" course ( $n = 19$ ).

Demographic data on age revealed that the mean age in the cancer patient group ( $n = 14$ ) was 48.6 years with a range from 25-71 years. The average age of the significant other group ( $n = 5$ ) was 49.8 with an age range of 31-64 years. The total sample mean age was 48.9 years with an age range from 25-71 years.

Demographic data on gender revealed that of the cancer patient group there were six times as many females as males, whereas, the significant other group had three males and two female participants. Total group (n = 19) demographic data revealed that there were twice as many female participants as male participants (Table 1).

The marital status data indicated that for the cancer patient group (n = 14) three times as many participants were married as separated while in the significant other group (n = 5) four times as many participants were married as divorced. The total group data on marital status indicated that over one-half of the group (68.4%) were married and 15.8% were separated (Table 1).

Demographic data representing education level demonstrated that of the 14 persons in the cancer patient group, four persons had some post-graduate preparation, while three persons reported some college preparation and three persons were college graduates. In the significant other group, two out of five group members reported they were college graduates while one person reported college preparation and one person had some post-graduate preparation. In regards to the total group data (n = 19), five persons reported they were college graduates and five persons reported some post-graduate preparation while four persons reported some college preparation (Table 1).

Demographic data specifically addressing ethnic background is presented in Table 1. The data for the cancer patient group (n = 14) indicated that nine categorized themselves as Caucasian while three

Table 1. Sample Characteristics

Characteristics	Cancer Patient Group	Significant Other Group	Total Group
<b>Gender</b>			
Male	2 (14.3%)	3 (60%)	5 (26.3%)
Female	12 (85.7%)	2 (40%)	14 (73.7%)
<b>Marital Status</b>			
Single	1 ( 7.2%)	---	1 ( 5.3%)
Married	9 (64.3%)	4 (80%)	13 (68.4%)
Widowed	1 ( 7.2%)	---	1 ( 5.3%)
Divorced	---	1 (20%)	1 ( 5.3%)
Separated	3 (21.4%)	---	3 (15.8%)
<b>Educational Level</b>			
Less than High School	---	---	---
High Schl or GED	2 (14.3%)	---	2 (10.5%)
Some College	3 (21.4%)	1 (20%)	4 (21.0%)
College Grad	3 (21.4%)	2 (40%)	5 (26.3%)
Some Post-Grad	4 (28.6%)	1 (20%)	5 (26.3%)
Post-Grad Degree	1 ( 7.1%)	---	1 ( 5.3%)
Technical Schl	---	---	---
Other	1 ( 7.1%)	1 (20%)	2 (10.5%)
<b>Ethnic Background</b>			
Asian	1 ( 7.1%)	---	1 ( 5.3%)
Black	---	---	---
Hispanic	1 ( 7.1%)	---	1 ( 5.3%)
Native Amer.	3 (21.4%)	1 (20%)	4 (21.0%)
Caucasian	9 (64.3%)	4 (80%)	13 (68.4%)

were Native Americans. In the significant other group (n = 5) four categorized themselves as Caucasian while one person categorized himself as Native American. In the total group (n = 19) data on ethnic background, 13 persons categorized themselves as Caucasian while 4 persons categorized themselves as Native Americans.

Sample characteristics related to cancer are presented in Table 2. The characteristics represented the data obtained for the cancer patient group only as these characteristics specifically address aspects of cancer.

Demographic data specifically addressing Cancer Type are presented in Table 2. The patient group data demonstrated breast cancer for 57% while 14.3% reported ovarian cancer and 7.2% for each: larynx, colon, lymphoma, throat-tongue-neck, respectively.

Data representing time since original diagnosis and participation in the "I Can Cope" course are presented in Table 2. In the patient group (n = 14) five persons were in the 13-18 month category, while three persons reported 25-30 months from original diagnosis to participation in the "I Can Cope" course.

Treatment types reported by the patient group are in Table 2. In the cancer patient group (n = 14), eight persons reported surgery and chemotherapy as treatment received while two persons reported surgery and radiation and surgery-radiation-chemotherapy as treatment types received respectively.

Table 2 also represents the perceived state of control of cancer. As reported by the cancer patient group (n = 14), nine

Table 2. Sample Characteristics Related to Cancer for Cancer Group

Characteristics	Cancer Patient Group (n = 14)
<b>Cancer Type</b>	
Breast	8 (57%)
Ovarian	2 (14.3%)
Larynx	1 (7.2%)
Colon	1 (7.2%)
Lymphoma	1 (7.2%)
Throat-Tongue-Neck	1 (7.2%)
<b>Time Since Original Diagnosis and Participation in Course</b>	
1-6 Months	1 (7.1%)
7-12 Months	2 (14.3%)
13-18 Months	5 (35.7%)
19-24 Months	1 (7.1%)
25-30 Months	3 (21.4%)
10 Years	2 (14.3%)
<b>Treatment (Types)</b>	
Surgery	1 (7.1%)
Chemotherapy	1 (7.1%)
Radiation	---
Surgery-Radiation	2 (14.3%)
Surgery-Chemotherapy	8 (57.1%)
Surgery-Radiation-Chemotherapy	2 (14.3%)
<b>Perceived State of Control of Cancer</b>	
Cured	3 (21.4%)
Being Controlled	9 (64.3%)
Not Controlled	---
Missing Data	2 (14.3%)

persons reported their cancer as being controlled while three persons reported their cancer as cured and three persons did not respond to this item.

Demographic data addressing previous involvement in support or education groups for the two subgroups and total group are presented in Table 3. Of the total group ( $n = 19$ ), 16 participants had no previous exposure to educational and/or support groups while 78.6% of the cancer patient group ( $n = 14$ ) and five of the significant other group ( $n = 5$ ) had no previous exposure to educational or support groups. The cancer patient group ( $n = 14$ ), three participants reported previous involvement with educational and/or support groups.

To summarize the sample characteristics, the majority of the total patient group were female with an average age of 48.9 years, were college graduates or had some post-graduate preparation. The average participant was married with an ethnic background of Caucasian who had breast cancer for 13-18 months prior to participation in the "I Can Cope" course. The average respondent had received surgery and chemotherapy for treatment of their disease and viewed their cancer as being controlled and had had no previous involvement with educational and/or support groups prior to participating in the "I Can Cope" course.

#### Reliability Coefficients for the Instruments

Split-half reliability coefficients for the three instruments for all three testings combined are displayed in Table 4. The

Table 3. Frequencies of Previous Educational and/or Support Groups

Previous Involvement	Cancer Patient Group (n = 14)	Significant Other Group (n = 5)	Total Group (n = 19)
Yes	3 (21.4%)	---	3 (15.8%)
No	11 (78.6%)	5 (100%)	16 (84.2%)

Table 4. Split-Half Reliability Coefficients for Instruments

Instrument	r
A-State Anxiety Inventory (STAI)	.77
Course Inquiry Test (CIT)	.76
Purpose in Life Test (PLT)	.69

criterion level of .70 was set for the reliability coefficients (Polit & Hungler, 1983).

The STAI had a reliability coefficient of .77, thus was accepted at the .70 criterion level. The Course Inquiry (CIT) had a reliability coefficient of .76 which was acceptable in terms of the .70 criterion level previously established. The PLT had a split-half reliability coefficient of .69. This reliability coefficient does not meet minimum acceptability of criteria.

The reliability of the instruments across time is presented in Table 5. Split-half reliability coefficients for each instrument at each time interval is presented and later addressed. The criterion level of .70 was established.

There are a few interesting observations regarding the change in the reliability coefficient across time for each instrument. In general all scores did change across time--each instrument had both positive and negative numerical fluctuations.

Results of the split-half reliability coefficient for the instruments demonstrated changes across time. Addressing the STAI, there was a decrease in the reliability coefficient from time 1 to time 2 and time 3. Likewise, the results of the reliability coefficient for the PLT demonstrated a decrease across time--from time 1 to time 2 and time 3. There were similar results of the reliability coefficient for the CIT. The CIT demonstrated changes across time from time 1 to time 2 and time 3.

Table 5. Split-Half Reliability Coefficients for Instruments  
across Time

Instrument	Time 1	Time 2	Time 3
A-State Anxiety Inventory (STAI)	.88	.84	.77
Course Inquiry Test (CIT)	.45	.15	.76
Purpose in Life Test (PLT)	.72	.71	.69

The inconsistencies of the reliability coefficient for the Course Inquiry Test (CIT) denotes questionable reliability for this instrument at times 1 and 2. This causes one to inquire how much error of measurement there is in the instrument. Kerlinger (1973) addresses random or error variance as "self-compensating: Scores tend to lean this way, now that way. Errors of measurement are random errors" (p. 443). These errors are the sum or product of numerous causes: Temporary or momentary fatigue, fluctuations of memory or moods, "fortuitous conditions at a particular time that temporarily affect the object measured or the measuring instrument" (Kerlinger, 1973, p. 443). According to Kerlinger (1973), "reliability can be defined as the relative absence of error of measurement in a measuring instrument" (p. 443). In essence there is questionable reliability of the Course Inquiry Test at times 1 and 2, while the reliability coefficient of .76 for time 3 did meet the minimally acceptable criterion for Cronbach's alpha of .70.

#### Research Findings Related to Research Questions

One group repeated measures analysis of variance was used to answer the first three research questions in this study.

1. Will adult learning increase over time participants of the "I Can Cope" course?
2. Will meaningfulness in life as indexed by the Purpose in Life Test Increase over time for participants of the "I Can Cope" course?

3. Will A-State Anxiety decrease over time for participants of the "I Can Cope" course?

Pre-test, mid-test and post-test scores comprised the longitudinal measures of analysis.

Initial results of the one group repeated measures of analysis revealed no significant differences between the three subgroups. The subgroups were previously defined as persons with cancer who were participants of the "I Can Cope" course known as the cancer patient group (n = 14). The significant other group (n = 5) is defined as significant others of persons with cancer who participated in the "I Can Cope" Program. And the total group (n = 19) is composed of both the significant other group (n = 5) and the cancer patient group (n = 14). Therefore, all data presented for the one group repeated measures analysis of variance and the correlational coefficients addressing the final three questions shall be based upon total group data.

Wilks' lambda ( $\lambda$ ) was the statistical index utilized in this one group repeated measures analysis of variance. The Wilks' lambda utilizes F scores and significance of F as its parameters for interpretation. The minimum accepted criterion level was .05.

The first research question stated, "Will adult learning increase over time for participants of the "I Can Cope" course? The Wilks' lambda significance of F indicated that there were changes in the scores over time with a significant F value of .001 (Table 6). The mean scores for the Course Inquiry Test over time (Table 7)

Table 6. One-group Repeated Measures Analysis of Variance across Time

Dependent Variable	Wilk's Lambda	Exact F	Hypoth. DF	Error DF	Significance of F
Adult Learning	.3941	11.5278	2.0	15.0	.001
Adaptation	.4719	8.3929	2.0	15.0	.004
Anxiety	.2102	28.1811	2.0	15.0	.000

Table 7. Means and Standard Deviations across Time

	Time 1		Time 2		Time 3	
	Mean	S.D.	Mean	S.D.	Mean	S.D.
CIT	14.58	2.93	14.05	2.35	18.42	4.01
PLT	112.05	11.50	113.89	10.05	120.21	13.01
STAI	38.26	8.76	44.10	7.41	33.47	7.56

demonstrated a decrease from time 1 to time 2 with an increase from time 2 to time 3 and an increase from time 1 to time 3. This demonstrated an increase in adult learning from the beginning of the program to the end of the course.

The second research question was, will meaningfulness in life as measured by the Purpose in Life Test increase over time for participants of the "I Can Cope" Program? The Wilk's lambda indicated that there were changes in the scores over time with a significant F value of .004 (Table 6). The mean score for the Purpose in Life Test over time (Table 7) demonstrated an increase from time 1 to time 2 and an increase from time 1 to time 3. This demonstrated that that meaningfulness in life increased from the beginning to the end of the "I Can Cope" Program.

The third research question addressed whether anxiety as measured by the A-State Anxiety Inventory will decrease over time for participants of the "I Can Cope" course. The Wilk's lambda demonstrated that anxiety did fluctuate as a function of time as demonstrated by the F value less than .001 (Table 6). The mean scores over time (Table 7) for the A-State Anxiety Inventory increased from time 1 to time 2 with a decrease from time 2 to time 3 and a decrease noted from time 1 to time 3. Therefore, this demonstrated that anxiety did decrease from the beginning of the course to the end of the program.

In answering the last three research questions, Pearson product moment correlations were utilized. Significance was judged at

the  $p \leq .05$  level. The Pearson product moment correlational coefficients are presented in Table 8.

Question 4 states, is there a positive (+) relationship between the Course Inquiry Test (CIT) and the Purpose in Life Test (PLT) at the end of an "I Can Cope" course? This question examined the relationship between adult learning and adaptation for participants of an "I Can Cope" Program. The correlation coefficient between adult learning (CIT) and adaptation (PLT) was  $r = .4743$ . The  $r$  value of  $r = .4743$  was significant at  $p \leq .05$  for this question. Therefore, there was a positive relationship between adult learning as measured by the CIT and adaptation as measured by the PLT at the end of an "I Can Cope" course.

Question 5, is there a negative (-) relationship between the Purpose in Life Test (PLT) and the A-State Anxiety Scale (STAI) at the end of the course? This question examined the relationship between adaptation and anxiety at the end of an "I Can Cope" course for the course participants. The correlation coefficient between adaptation (PLT) and anxiety (STAI) was  $r = -.3620$ . The  $r$  value of  $r = -.3620$  was not significant at  $p \leq .05$  for this question, although this correlation does suggest a moderate negative relationship between adaptation and anxiety.

The sixth question, what is the relationship between adult learning (CIT) and A-State Anxiety (STAI) at the end of an "I Can Cope" course? Pearson product-moment correlative coefficient for adult learning and anxiety was  $r = -.3745$ . The  $r$  value of  $r = -.3745$

Table 8. Pearson Product-Moment Correlational Coefficients

	Anxiety	Adult Learning	Adaptation
Anxiety	1.0000	-.3745	-.3620
Adult Learning	---	1.0000	.4743*
Adaptation	---	---	1.0000

\*Significant at  $p \leq .05$ .

was not significant at  $p < .05$  for this question. This correlation does suggest a moderate negative relationship between adult learning and anxiety.

#### Summary

The following conclusions are drawn from this study as a result of the statistical analysis:

1. There were changes in the scores for the CIT across time with a demonstrated increase in adult learning over time for "I Can Cope" course participants.
2. There were changes in the scores for the PLT across time with a demonstrated increase in meaningfulness in life over time for "I Can Cope" course participants.
3. There were changes in the scores for the STAI across time with a demonstrated decrease in anxiety from the beginning to the end of the program for course participants.
4. A positive relationship was demonstrated between adult learning and adaptation at the end of the "I Can Cope" Program.
5. There was no statistically significant relationship established between adaptation and anxiety at the end of an "I Can Cope" Program. However, the correlation did suggest a moderate negative relationship between adaptation and anxiety at the end of the course.
6. There was no statistically significant relationship established between adult learning and anxiety at the end of

an "I Can Cope" Program. However, the correlation suggested a moderate negative relationship between adult learning and anxiety at the end of the course.

## CHAPTER 5

### DISCUSSION OF RESULTS

#### Introduction

This study was conducted to measure the effects of a structured education program on participants' perceptions of specific aspects of their disease as measured by changes in adult learning, adaptation and anxiety. The underlying assumption of this study was that the process of adaptation could be accelerated by facilitating the participants' learning, i.e., change or reorganization of insights, knowledge, skills, attitudes, values or expectations to the latest health care practices in the treatment of the disease as well as psychosocial and spiritual aspects of living with cancer.

A repeated measures descriptive design was used to test the research questions posed in this study.

1. Will adult learning as measured by the Course Inquiry Test increase over time for participants in the "I Can Cope" Program?
2. Will adaptation as measured by the Purpose in Life Test increase over time for participants in the "I Can Cope" Program?
3. Will anxiety as measured by the A-State Anxiety Inventory decrease over time for participants of the "I Can Cope" Program?

4. Is there a positive (+) relationship between the Course Inquiry test and Purpose in Life Test at the end of an "I Can Cope" Program?
5. Is there a negative (-) relationship between the Purpose in Life Test and A-State Anxiety Scale at the end of an "I Can Cope" Program?
6. What is the relationship between adult learning and anxiety at the end of an "I Can Cope" Program?

This study examined changes in the dependent variables of adult learning, adaptation, and anxiety that occurs as a result of the independent variable the cancer education course "I Can Cope." This study used a volunteer sample of 19 participants of an "I Can Cope" Program. Changes in each person's pre-mid-post test scores were analyzed on the instruments: CIT, PLT, STAI. A comparison of scores measured whether there were any significant short-term adaptation, changes in anxiety and changes in adult learning as a result of the "I Can Cope" Program.

One-group repeated measures analysis of variance was used to answer the first three research questions posed in this study. Pre-test, mid-test, and post-test scores comprised the longitudinal measures for analysis. The critical significance level of  $p \leq .05$  was established.

Pearson product-moment correlations were used to examine the data related to the last three research questions. In this

inferential analysis, the critical significance level of  $p \leq .05$  was established.

A discussion of the results, as well as limitations of the study, implications for nursing and recommendations for further study are presented in this chapter.

#### Relationship of Findings to Conceptual Framework

This study was conducted to measure the effects of a structured patient education program on participants' perceptions of specific aspects of a disease process as measured by changes in adult learning, adaptation and anxiety. In response to the question of whether an educational program increase adult learning over time, there was not a gradual increase over time. However, when looking from the beginning of the program to the end of the program there was an increase in adult learning thus supporting the direction hypothesized in the conceptual framework. The data demonstrated that there was a decrease in adult learning from time 1 to time 2. This may have been due to the fact that the participants had not completed the course and therefore, had not received all the concepts and/or information at this point in the program. This lack of information may have impacted on the participants' anxiety level as well. Increased anxiety has been shown to negatively influence adult learning to a certain degree.

In answering the question of whether an educational program increase adaptation over time, there was a gradual increase in adaptation for participants of this study across time which supported

the direction hypothesized in the conceptual framework. The process of adaptation is influenced by self-concept and self-esteem. Actively engaging in a program aimed at facilitating learning and decreasing anxiety may positively influence a person's perception of self. One example is that active involvement or participation in such an activity may foster and enhance the control a person has and/or perceives as having in the context of their life situations. This sense of increased control enhances both self-esteem and the process of adaptation.

In response to the question of whether an educational program decrease anxiety over time, there was not a gradual decrease over time. There was an increase in anxiety from time 1 to time 2 which may have been the result of multiple factors influencing the participants' anxiety which were not taken into account in this study. One such factor is that the participants had not completed the course and therefore had not received all the information and incomplete information sets will influence anxiety. Another possible factor is that the course content stresses self-care and self-responsibility and without the needed information and application of content these concepts may have been threatening and negatively influence anxiety. When looking from the beginning of the program to the end of the program, there was a decrease in anxiety thus supporting the direction hypothesized in the conceptual framework.

In the conceptual framework a positive relationship between adult learning and adaptation was proposed. Actual data analysis in

terms of correlation coefficients demonstrated a significant positive relationship between adult learning and adaptation at the end of the "I Can Cope" program thus supporting the conceptual framework.

A negative relationship was proposed between adaptation and anxiety in the conceptual framework. The correlation coefficient between adaptation and anxiety was not significant, although the correlation did support the direction hypothesized and does suggest a moderate negative relationship between adaptation and anxiety. The interaction between adaptation and anxiety is multidimensional and complex. It is conceivable that adaptation and anxiety are closely associated. It was proposed that adaptation influences anxiety when in essence there is a likelihood that anxiety also influences adaptation, i.e., high levels of anxiety have an inhibitory effect on the process of adaptation, therefore, decreasing adaptation. Interventions aimed at facilitating adaptation may in turn decrease anxiety and this decreased anxiety may have a positive reinforcing influence on the process of adaptation.

A relationship between adult learning and anxiety at the end of an "I Can Cope" course was proposed in the conceptual framework. There was no direction hypothesized in this relationship due to inconsistencies demonstrated in both research and literature. The correlation coefficient for adult learning and anxiety was not significant. This correlation does suggest a moderate negative relationship between adult learning and anxiety at the end of an "I Can Cope" course.

There are a multitude of factors influencing adult learning, adaptation and anxiety on an ongoing basis. This study analyzed the effects of one such factor and did not take into consideration the other numerous factors influencing adult learning, adaptation and anxiety. The data do not overwhelmingly support the conceptual framework; neither do they completely refute it.

#### Sources of Error

In Chapter 4 discussion the reliability of the CIT was identified as a source of error impacting on the validity of this study. Other sources of error were divided into the following subsets: The instrument, the research design and the sample.

The Course Inquiry Test (CIT), developed by Johnson (1979), was designed to measure the subjects' knowledge about cancer, its related treatments, and other ramifications of the disease process. This is a multi-dimensional knowledge test measuring many different aspects of knowledge about cancer. Therefore, the type of reliability coefficient utilized for this study may be inappropriate. Split-half reliability looks at whether the two parts of the test are consistent. This may not be the case with the CIT as it is a multidimensional knowledge test. It is possible that the acceptable reliability coefficient at time 3 was due to the fact that by that point in time the participants had enough information that they were able to respond to things alike. It could be that test-retest and/or item analysis would be a more appropriate measure of reliability. Johnson (1979) noted that the reliability of the instrument may be affected by the

short span of time between pre-test, mid-test and post-test. Patient-participant opinion as well as the opinion of experts on adult learning were not solicited during tool development.

The research design was another source of error for this study. Participants were able to complete their questionnaires at home. Although encouraged to complete them in the class setting, many were unable to do so due to time constraints. Completing them elsewhere may have heightened some participants' misunderstanding as there was not someone present to answer questions.

Another potential source of error related to research design as the times for the completion of the pre-test, mid-test and post-test. Time 1 was during the first evening of the program while the mid-test was at Week 4 and the post-test at Week 8. This shortened time span is a questionable measure of longitudinality and causes one to question if this accurately provided appropriate time intervals to assess for changes across and as a result of time.

Sample size and selection in most studies needs careful consideration. In this study, there was a small sample size of 19 total group respondents comprised of 14 participants with cancer and only five participants who were significant others of persons with cancer. The 19 total group participants was a small sample from which to draw conclusions. In particular, certain characteristics may have affected this study. Stage or type of cancer was not controlled. In the future it may be wise to analyze the data from the significant other group, the cancer patient group, and the total group separately.

Another source of error in this study was the Hawthorne effect. The Hawthorne effect is a change in subjects' behavior due to knowledge of being included in a study (Polit & Hungler, 1983). This concept may also have had some effect on the course presenters as well as course facilitators due to the fact that they were all aware that the course was being evaluated. Thereby potentially influencing all individuals involved in this study.

#### Implications for Nursing

From this study some recommendations can be made for the oncology nurses working in the outpatient setting. Identification of the oncology nurse as a patient/family educator may provide an important resource for persons living with a chronic illness such as cancer.

Patients' and/or significant others' needs and expectations from the time of diagnosis and as they change with the disease process, need to be identified, individualized and outlined. Inherent in the outpatient education process is the necessity for a mutual approach to needs assessment, care goals and goals of living with cancer. These goals and expectations could be established through the development of a nursing care plan for outpatients and significant other utilizing nursing diagnosis. This approach would be a more systematic, individualized and thorough approach to the patient's nursing care and educational needs.

In the Johnson (1979) study, a multidisciplinary staff conducted an outpatient education program for cancer patients and/or

significant others. Nurses were an integral part of this multidisciplinary group of patient educators. The study demonstrated that outpatient education fostered adaptation to specific ramifications of cancer, enhanced learning and lowered anxiety for the course participants.

#### Recommendations for Future Research

Based on the findings from this study, recommendations for future research can be divided into the following areas: Instrument reliability and validity; issues of study design; and variations of the study.

One important source of error identified earlier was the questionable reliability of the CIT. There was a lack of participant involvement in the development of this instrument as well as no recent revision of the instrument to measure the changes in the program content due to new scientific, medical, psychosocial and spiritual information. This instrument needs to be revised to accurately assess the current course content. In the revision of the instrument, a panel of experts to include oncology specialists, adult educators as well as patients and/or significant others is proposed.

The research design did not include cultural aspects nor cultural bias. The same patient education course should be implemented with persons from other backgrounds, educational levels, and cultural groups. The course materials need to be examined for their readability and cultural bias.

This research considered neither the uniqueness of the individual instructors or the characteristics of the program setting. These could be crucial variables affecting the outcomes of the study. Replication of the study using a variety of other settings and staffing would help to define these possible limitations.

A longer time interval between pre-test, mid-test, and post-test is proposed to further assess the changes over time related to adaptation, anxiety and adult learning. It is questionable whether this would be feasible to do with a population of persons having cancer though it would be significant in terms of future study results.

#### Conclusion

The implications of this study, when combined with the previously reviewed research and literature suggest that patient education is a key factor in assisting people to develop realistic expectations and attitudes toward adjusting to changes created by illness. The "I Can Cope" course fulfills one of the fundamental functions of adult education: To keep the balance between people and circumstances. It is a learning activity that allows people to cope with and function in highly unpredictable situations in their adult lives. Educators can help adults increase their understanding of the multitude competences required for dealing with the changes imposed upon them. This study did demonstrate that an organized, adult patient educational program could foster and enhance adult learning

and enhance adaptation, which impacts on persons living with the chronic disease of cancer.

APPENDIX A

HUMAN SUBJECTS APPROVAL

**THE UNIVERSITY OF ARIZONA**

TUCSON, ARIZONA 85721

COLLEGE OF NURSING

## MEMORANDUM

TO: Lee Lucia Westfall, BSN  
Graduate Student  
College of Nursing

FROM: Ada Sue Hinshaw, PhD, RN <sup>ASH</sup> Linda R. Phillips, PhD, RN  
Director of Research Chairman, Research Committee

DATE: October 29, 1986

RE: Human Subjects Review: The Effects of a Structured Patient  
Education Program on Adaptation in Cancer

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Subcommittee of the Research Committee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH/fp

**APPENDIX B**

**SUBJECT DISCLAIMER FORM**

The Effect of Structured Patient Education Program  
on Adaptation in Cancer

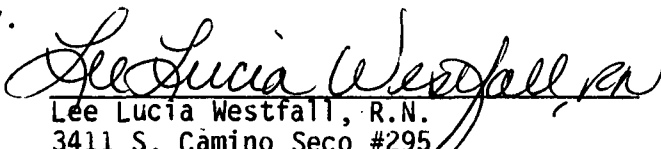
DISCLAIMER FOR SUBJECT'S INFORMED CONSENT

I am requesting your voluntary participation in a study to evaluate the effects of an educational program on persons with cancer and/or family/friends of cancer patients.

The purpose and objectives of this study are to determine participants' learning about cancer, evaluation how persons affected with cancer (directly or indirectly) feel, as well as to assess/measure anxiety levels of cancer patients, family and/or friends.

There will be no cost to you nor any potential or known risks. Participation in this study involves taking three pencil and paper questionnaires three times. At the beginning, in the middle and at the end of the course. You are free to ask any questions at any time or to withdraw from the study at any time. Your decision to participate, to not participate, or to change your mind about participating, will in no way influence the care which you are receiving.

If you decide to participate, please answer as many of the questions as you are able to answer with confidence. About 45 minutes of your time will be required for completion of this questionnaire packet and will indicate your informed consent as a willing participant in this study. All data received will be treated with anonymity and confidentiality.

  
Lee Lucia Westfall, R.N.  
3411 S. Camino Seco #295  
Tucson, Arizona  
721-1168

APPENDIX C  
COURSE OUTLINE

### COURSE OUTLINE

The course content for each of the classes includes:

#### Class I:

##### Class Purpose

The first class introduces the participants, the course facilitators and the course objectives. The education process begins with the first presentation on cancer, and through introduction to the educational material available from the Recourse Center. Participants should begin to think about what they can do personally to affect their lives in a positive manner.

##### Class Objectives

1. To introduce class participants and learn what they expect from the course.
2. To introduce the course, its purposes, objectives and format.
3. To introduce normal human anatomy and function in relation to cancer.
4. To discuss cancer, its causes, statistics and research.
5. To encourage participants to use resource materials and to develop a method of personal reflection.
6. To stimulate and continue communication between health professionals and participants.

#### Class II:

##### Class Purpose

The purpose of this class is to introduce cancer management, rehabilitation and unproven methods.

1. To review terms used by health professionals relevant to cancer.
2. To review the diagnostic, treatment and rehabilitation techniques used in cancer management.
3. To introduce the concept of unproven methods and give participants information to help them assess these remedies.
4. To further encourage personal reflection and relaxation as one tool for coping with cancer.

**Class III:****Class Purpose**

This class concentrates on the concrete health problems which may be troubling participants and the actions that they can take to help themselves. The importance of good nutrition is explored including the ways to maintain adequate nutritional status.

**Class Objectives**

1. To discuss the common health problems facing cancer patients and what can be done to lessen side effects.
2. To explain the role of good nutrition in maintaining health and to provide tips on diet during therapy.
3. To expand the participant's role in improving their health and feelings of well-being.

**Class IV:****Class Purpose**

The purpose of this class is to focus on the psychosocial aspects of cancer, and how to share feelings and communicate with family, friends, and health professionals.

**Class Objectives**

1. To discuss the emotional reactions often experienced by cancer patients and their families.
2. To emphasize the importance of recognizing and sharing feelings with family and friends.
3. To develop ways to communicate with family, friends and health professionals.

**Class V:****Class Purpose**

The purpose of this class is to introduce the changes in the ways cancer patients view themselves, to explore the broad concept of sexuality and to describe the ways a chronic disease like cancer may affect relationships emotionally and physically.

#### Class Objectives

1. To introduce the concept of sexuality as it relates to self-esteem, body image and sexual expression.
2. To discuss the effect which cancer can have on life roles and relationships.
3. To acknowledge the need for physical contact and to discuss ways of enhancing such contact.

#### Class VI:

##### Class Purpose

The purpose of this class is to introduce concepts of fitness and exercise and to describe ways to reduce stress for cancer patients, and their families and friends.

#### Class Objectives

1. To explain the ways to maintain fitness for persons with a chronic disease.
2. To learn methods for dealing with the activities of daily living.
3. To practice simple exercises.
4. To understand stress and the techniques to help lower stress.

#### Class VII:

##### Class Purpose

The purpose of this class is to discuss support networks, available community resources and legal issues.

#### Class Objectives

1. To encourage participants to understand and use support networks.
2. To provide information about community agencies available to assist cancer patients such as financial resources, home health care, Social Security, the American Cancer Society, support groups, etc.
3. To familiarize patients and their families with the law as it relates to taxes, health care, estate planning, wills and probate.

**Class VIII:****Class Purpose**

The purpose of this class is to answer remaining questions, to discuss the knowledge gained through the course and to celebrate graduation with a party.

**Class Objectives**

1. To provide an opportunity for participants to ask remaining questions of instructors.
2. To learn from participants their reactions about the course and their own self-growth.
3. To encourage continued personal reflection and self-appreciation through use of AMOR's.
4. To acknowledge course commitment through a graduation ceremony.
5. To celebrate being together and growing together.

APPENDIX D

COURSE INQUIRY TEST

QUESTIONS ABOUT COPING WITH CANCER

## PART I

Circle "agree" or "disagree" to each of the following questions, OR circle "uncertain" if you have not heard, or don't know the answer to a question.

Your answers will help us in deciding what to include in the future classes. Thank you.

- |    |                                                                                                                     |       |          |           |
|----|---------------------------------------------------------------------------------------------------------------------|-------|----------|-----------|
| 1. | Cancer is a chronic disease like diabetes.                                                                          | AGREE | DISAGREE | UNCERTAIN |
| 2. | Persons with cancer should not be expected to practice "physical fitness".                                          | AGREE | DISAGREE | UNCERTAIN |
| 3. | If a friend does not want to talk about what I want to talk about, maybe he/she is not really a friend.             | AGREE | DISAGREE | UNCERTAIN |
| 4. | Radiation treatment will sometimes cause a metallic taste in a person's mouth.                                      | AGREE | DISAGREE | UNCERTAIN |
| 5. | A person can expect that their cancer will affect their sexuality.                                                  | AGREE | DISAGREE | UNCERTAIN |
| 6. | I know how my cancer treatment will affect my body.                                                                 | AGREE | DISAGREE | UNCERTAIN |
| 7. | If a cancer drug should cause my hair to fall out, I can expect that it will start to grow back within a few weeks. | AGREE | DISAGREE | UNCERTAIN |
| 8. | The American Cancer Society provides equipment and dressings free of charge.                                        | AGREE | DISAGREE | UNCERTAIN |
| 9. | Performing daily tasks like bed making and bathing can be thought of as ways to exercise.                           | AGREE | DISAGREE | UNCERTAIN |

10.	Red blood cells are important, because they make my blood clot.	AGREE	DISAGREE	UNCERTAIN
11.	People can prepare for their own death by thinking about it.	AGREE	DISAGREE	UNCERTAIN
12.	When a person is eligible for Social Security Disability, he/she is eligible for Medicare at the same time.	AGREE	DISAGREE	UNCERTAIN
13.	The Lamaze program of exercise is being used to help control the pain caused by cancer.	AGREE	DISAGREE	UNCERTAIN
14.	People often use denial in coping with reports about their cancer.	AGREE	DISAGREE	UNCERTAIN
15.	I will have better relationships with my friends if I try and keep the conversation light and easy.	AGREE	DISAGREE	UNCERTAIN
16.	Lymph nodes act as a first line of defense against my cancer.	AGREE	DISAGREE	UNCERTAIN
17.	Sometimes it's OK not to say everything about what I am feeling.	AGREE	DISAGREE	UNCERTAIN
18.	There are special diets and foods that will cure cancer.	AGREE	DISAGREE	UNCERTAIN
19.	Eating cold foods will help to control nausea.	AGREE	DISAGREE	UNCERTAIN
20.	Touching someone else will make a person feel less lonely.	AGREE	DISAGREE	UNCERTAIN
21.	Exercise is important for cancer patients because it increases their ability to cope with stress.	AGREE	DISAGREE	UNCERTAIN
22.	Anger is a reaction to frustration.	AGREE	DISAGREE	UNCERTAIN
23.	People who care about me should know what I want without me telling them.	AGREE	DISAGREE	UNCERTAIN
24.	Each cancer drug has its side effects and everyone taking that particular drug can expect to have them all.	AGREE	DISAGREE	UNCERTAIN

APPENDIX E

PURPOSE IN LIFE TEST

## PART II

For each of the following statements, circle the number that would be most nearly true for you. Please note that the numbers always extend from one extreme feeling to its opposite kind of feeling. "Neutral" implies no judgement either way; try to use this rating as little as possible. Thank you.

1. I am usually:

1	2	3	4	5	6	7
completely bored			(neutral)			exuberant, enthusiastic

---

2. Life to me seems:

7	6	5	4	3	2	1
always exciting			(neutral)			completely routine

---

3. In life I have:

1	2	3	4	5	6	7
no goals or aims at all			(neutral)			very clear goals & aims

---

4. My personal existence is:

1	2	3	4	5	6	7
utterly meaningless without purpose			(neutral)			very purposeful and meaningful

---

5. Every day is:

7	6	5	4	3	2	1
constantly new			(neutral)			exactly the same

---

6. If I could choose, I would:

1	2	3	4	5	6	7
prefer never to have been born			(neutral)			like nine more lives just like this one

---

7. After retiring, I would

7	6	5	4	3	2	1
do some of the exciting things I have always wanted to do			(neutral)			loaf completely the rest of my life

---

8. In achieving life goals I have:

1	2	3	4	5	6	7
made no progress whatever			(neutral)	progressed to complete fulfillment		

---

9. My life is:

1	2	3	4	5	6	7
empty, filled only with despair			(neutral)	running over with exciting good things		

---

10. If I should die today, I would feel that my life has been:

7	6	5	4	3	2	1
very worthwhile			(neutral)	completely worthless		

---

11. In thinking of my life, I:

1	2	3	4	5	6	7
often wonder why I exist			(neutral)	always see a reason for my being here		

---

12. As I view the world in relation to my life, the world:

1	2	3	4	5	6	7
completely confuses me			(neutral)	fits meaningfully with my life		

---

13. I am a:

1	2	3	4	5	6	7
very irresponsible person			(neutral)	very responsible person		

---

14. Concerning man's freedom to make his own choices, I believe man is:

7	6	5	4	3	2	1
absolutely free to make all life choices			(neutral)	completely bound by limitations of heredity and environment		

---

15. With regard to death, I am:

7	6	5	4	3	2	1
prepared and unafraid			(neutral)	unprepared and frightened		

---

16. With regard to suicide, I have:

1	2	3	4	5	6	7
thought of it seriously as a way out			(neutral)	never given it a second thought		

---

17. I regard my ability to find a meaning, purpose, or mission in life as:

7	6	5	4	3	2	1
very great			(neutral)	practically none		

---

18. My life is:

7	6	5	4	3	2	1
in my hands and I am in control of it			(neutral)	out of my hands and controlled by external factors		

---

19. Facing my daily tasks is:

7	6	5	4	3	2	1
a source of pleasure and satisfaction			(neutral)	a painful and boring experience		

---

20. I have discovered:

1	2	3	4	5	6	7
no mission or purpose in life			(neutral)	clear-cut goals and a satisfying life purpose		

---

Thank you very much for taking the time to fill out this evaluation. Please know that I appreciate all the time and consideration you put into filling it out. Thank you again.

**APPENDIX F**

**SELF-EVALUATION QUESTIONNAIRE**

## SELF-EVALUATION QUESTIONNAIRE

## Directions:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your feelings best.

	Not at all	Somewhat	Moderately so	Very much so.
1. I feel calm . . . . .	1	2	3	4
2. I feel secure . . . . .	1	2	3	4
3. I am tense . . . . .	1	2	3	4
4. I feel strained . . . . .	1	2	3	4
5. I feel at ease . . . . .	1	2	3	4
6. I feel upset . . . . .	1	2	3	4
7. I am presently worrying over possible misfortunes . . . . .	1	2	3	4
8. I feel satisfied . . . . .	1	2	3	4
9. I feel frightened . . . . .	1	2	3	4
10. I feel comfortable . . . . .	1	2	3	4
11. I feel self-confident . . . . .	1	2	3	4
12. I feel nervous . . . . .	1	2	3	4
13. I am jittery . . . . .	1	2	3	4
14. I feel indecisive . . . . .	1	2	3	4
15. I am relaxed . . . . .	1	2	3	4
16. I feel content . . . . .	1	2	3	4
17. I am worried . . . . .	1	2	3	4
18. I feel confused . . . . .	1	2	3	4
19. I feel steady . . . . .	1	2	3	4
20. I feel pleasant . . . . .	1	2	3	4

APPENDIX G

PARTICIPANT DATA SHEET

## INDIVIDUAL PARTICIPANT DATA SHEET

Sex \_\_\_\_\_ Age \_\_\_\_\_ Marital Status (Circle) S M W D Sep

Occupation \_\_\_\_\_

Ethnic background (optional)

Asian	_____
Black	_____
Hispanic	_____
Native American	_____
Other	_____

Education: Less than 12 yrs in school \_\_\_\_\_

High school graduate \_\_\_\_\_

Some college \_\_\_\_\_

College graduate \_\_\_\_\_

Some Post graduate \_\_\_\_\_

Post graduate degree \_\_\_\_\_

Technical School \_\_\_\_\_

Other \_\_\_\_\_

Your type of cancer is: \_\_\_\_\_

Your cancer was first diagnosed in: Month \_\_\_\_\_ Year \_\_\_\_\_

Check the kind of treatment(s) you have had for your cancer:

\_\_\_\_\_ Surgery (state kind) \_\_\_\_\_

\_\_\_\_\_ Radiation (state site) \_\_\_\_\_

\_\_\_\_\_ Drugs (state kind/s) \_\_\_\_\_

Circle the word that best describes the state of your cancer:

Cured

Being Controlled

Not Controlled

Have you previously been involved in any support group or cancer education course? Yes \_\_\_ No \_\_\_ If so, please describe the group or course in the space provided below.

APPENDIX H  
PERMISSION TO REPRODUCE  
A-STATE ANXIETY INVENTORY SCALE

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