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PERSONAL GROWTH FOLLOWING THE DIAGNOSIS OF CANCER: INTERVIEWS WITH MASTECTOMY PATIENTS

by

Nancy L. Mahoney

A Thesis Submitted to the Faculty of the Graduate School of Loyola University of Chicago in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

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VITA

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CHAPTER I

INTRODUCTION

The existentialists, among others, believe that each of us must come to terms with the inevitability of our own death if we are to live well in the fullest sense. Many of us are seemingly unable to do this, however. We either consider death to be unspeakable, even unthinkable, and thereby deny its reality; or else we become so preoccupied with it that fear greatly diminishes our lives. At its very best, death is generally regarded as something hateful but unavoidable.

Although death is rarely thought of as a positive thing, there are some who say that it is. In presenting the existential position of death and death anxiety, Yalom (1980) reviews themes found in great literature and conclusions drawn by philosophers down through the ages, namely that without death life would lose much of its meaning. The knowledge that life will someday end makes possible the appreciation of each day until the final one comes. Yalom further describes actual personal growth which occurred in individuals confronted by death. During his years of clinical practice, he observed that terminally ill cancer patients frequently reported the following inner changes:

A rearrangement of life's priorities; a trivializing of the trivial

A sense of liberation; being able to choose not to do those things that they do not wish to do

An enhanced sense of living in the immediate present, rather than postponing life until retirement or some other point in the future

A vivid appreciation of the elemental facts of life; the changing seasons, the wind, falling leaves, the last Christmas, and so forth

Deeper communication with loved ones than before the crisis

Fewer interpersonal fears, less concern about rejection, greater willingness to take risks, than before the crisis (p. 35).

It is perhaps remarkable that people can actually achieve personal growth not only because of, but in spite of, an illness such as cancer. To better appreciate this fact, one should know something about the disease itself.

Cancer has always had a strong emotional component. Historically the very word, "cancer", has evoked feelings of fear and dread. Shame and a desire for secrecy were not uncommon reactions of patients and their families upon hearing of the diagnosis. Before the advent of effective treatment, cancer invariably brought about prolonged and painful death which was often looked upon as punishment from God for some wrong-doing, real or imagined. Weight loss and other effects of the disease usually produced a wasted appearance which reminded friends and relatives of death and caused them to avoid the patient whenever possible. Patients themselves were ashamed of their appearance and often hid from the outside world. In addition, many people believed that cancer was a contagious disease and therefore a threat to others. And so added to the already heavy burden was the reality of social stigma. Unfortunately, these attitudes and beliefs

persist in some people even today and continue to compound the problems of the cancer patient.

Through the years, cancer research has produced some very effective treatment regimens and also many screening techniques designed to detect cancer in its early stages. Both have greatly increased the chances for cure or long term tumor control. And if cure or control are not options for the patient, methods for providing a substantial degree of comfort are now available. However, in spite of the vast amount of productive research currently being done, cancer continues to be among this nation's major health problems, second only to cardiovascular disease as the leading cause of death. The American Cancer Society reported that over 805,000 people were diagnosed with cancer in 1981, and predicts that one in every four persons now living will be diagnosed with cancer in the future. About two thirds of these people will probably die of their disease (Rubin, 1983).

While any illness almost invariably requires a certain amount of adjustment on the part of all concerned, the adjustments associated with a diagnosis of cancer can be disruptive in the extreme as the cancer patient is faced with the many changes taking place because of the disease. These changes are illustrated by the tasks which the patient is expected to accomplish during the period of adjustment. There are tasks of both an illness-related and a general nature. Illness-related tasks include: dealing with pain and incapacitation; dealing with the hospital environment and special treatment procedures; and developing adequate relationships with professional staff. General tasks include: preserving a reasonable emotional

balance; preserving a satisfactory self-image; preserving relationships with family and friends; and preparing for an uncertain future (Blumberg, Flaherty, and Lewis, 1980).

These tasks are obviously interrelated. How well they are carried out is also dependent upon the nature of the disease, the personal characteristics of the patient, and the milieu. This is particularly true of the final task on the list, that of preparing for an uncertain future. Yalom (1980) writes, "Life and death are interdependent; they exist simultaneously, not consecutively; death whirs continuously beneath the membrane of life and exerts a vast influence upon experience and conduct" (p. 29). Yalom's message has particular significance for the cancer patients even though modern technology has greatly increased their chances for survival. For the patient who is considered cured, the cancer can perhaps be likened to the near miss of a potentially fatal accident. For the patient with active disease, the reality of death is more tangible. For both, a significant new dimension has been added to the total life experience.

Importance of the Study

Inquiries into the experiences of cancer patients have significant value because of the great numbers of people affected by the disease. Added to the one in four who will eventually be diagnosed with cancer are the family members and others who are close to the patient. Most of the research into the physical and emotional impact of cancer deals with the distressing elements of the illness and its treatment. There is evidence to suggest, however, that along with the obvious and threatening aspects of cancer, there may be some

positive changes which occur in patients as they learn to live with the disease. The number of references to these positive changes is somewhat limited and further research into this area cannot help but broaden understanding of the total cancer experience.

In addition, we need to acknowledge and accept our own finitude if we are to realize our potential as human beings. Therefore, the documentation of personal growth in cancer patients who have gained a heightened awareness of their own mortality can be integrated into anyone's philosophy of life, thereby enriching it.

Purpose of the Study

The cancer patient is expected to adjust to all sorts of changes related to both the disease process, and to the treatment which often causes very distressing side effects. In addition, cancer is most decidedly a life-threatening disease. How successfully the patient will cope with all of this is determined not only by the nature and the severity of the disease and by environmental factors, but also by the individual's own inner strength and resourcefulness. In fact, there is evidence to suggest that for some patients, coming to terms with the life-threatening aspects of the disease brings about a degree of personal growth. The purpose of this study was to explore positive as well as negative changes which may take place in cancer patients and to further document evidence of personal growth associated with a life-threatening situation such as cancer.

Limitations

The degree to which this study may be generalized is limited by the following conditions:

- 1. Only patients considered to be psychologically stable were initially approached. Of these, only patients who agreed to be interviewed participated. Patients who consented to help the investigator might be more giving in nature and thus more prone to personal growth.
- 2. None of the patients were below the age of 37, and all were white and middle class. Younger groups and other racial and socio-economic groups were not represented.
- 3. All the participants were female breast cancer patients. The data obtained from these patients may not be generalizable to men or to patients with other types of cancer.
- 4. The questionnaire responses regarding feelings and actions before the onset of the cancer were dependent upon the memory of the respondents.
- 5. The personal growth questionnaire was not administered to a control group in order to rule out the possibility of personal growth occurring as a result of the passage of time.
- 6. The sample size of 30 might not represent all possible response patterns.

Definition of Terms

Adjuvant therapy

A treatment that is added to a primary modality to enhance its effectiveness.

Cancer

A large group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled or checked, it results in death.

Chemotherapy

Treatment of disease by chemical agents. Generally used to denote those drugs

which kill tumor cells or interfere with their reproduction.

Lumpectomy Surgical removal of a tumor mass together with a small amount of

surrounding tissue.

Mammography Radiologic procedure used to detect

breast tumors in their very early

stages.

Mastectomy Surgical removal of the breast.

Metastasis

The invasion of cancer cells into neighboring tissue or organs either by direct extension of the growth or by

becoming detached and carried through the lymph or blood systems to other

parts of the body.

Oncology The study of tumors. Generally used in

reference to the medical specialty dealing with malignant tumors.

Personal growth A general term meaning positive changes

in attitude about life, and usually characterized by an increased awareness of the meaning and purpose in one's

life.

Breast prosthesis An artificial breast form worn inside

the bra or adhered to the skin.

Radiation therapy Treatment using high energy radiation

from x-ray machines, Cobalt, Radium or

other sources.

Reconstructive Mammaplasty Surgical reconstruction of the breast

through implant or tissue relocation.

Summary

Life becomes more precious when we understand and accept the fact that it must someday end for us. This was demonstrated by Yalom in his work with terminally ill cancer patients who experienced personal growth as a result of their life-threatening illness. Because there are so many physical and emotional problems associated with cancer, it

is of particular significance that the disease can be related to positive as well as negative life changes.

Initially, three patients who had undergone mastectomies for breast cancer participated in a pilot study to explore the possibility of personal growth occurring. Following this, an additional 30 breast cancer patients were interviewed and asked seven open-ended questions about their experiences with cancer. They were also asked to complete questionnaires designed to measure personal growth over time for periods before and after the onset of the cancer. These scores were analyzed using the matched-paired t-test. The results of the questionnaires and the interviews are presented here as the substance of this study which describes the life changes experienced by these breast cancer patients as they learned to live with their cancer and with their uncertain future.

Chapter 2 has a review of related literature including a very brief overview of the Kubler-Ross Staging controversy. With an emphasis on malignant breast tumors, a general description of the physical changes associated with cancer and its treatment is given. Following this, the emotional impact of the disease is discussed. The evidence of personal growth related to cancer and other life-threatening situations is then presented.

Chapter 3 describes the methodology including design, subject selection, instrumentation, procedural details, and treatment of the data from both the interviews and questionnaires. Chapter 4 presents the results of the study in terms of personal growth as measured by both the questionnaire scores and the interview responses. A

summarization of the results follows in Chapter 5 which also includes a discussion of implications for counseling and for further research.

It must be emphasized here that it is not the intention of the investigator to in any way minimize the physical or psychological distress which the cancer patient experiences. It is rather an attempt to learn how these patients can and do use the experience to somehow bring greater meaning and purpose into their lives.

CHAPTER II

REVIEW OF RELATED LITERATURE

Death and Dying

When Kubler-Ross (1969) first wrote of her interviews with dying patients, she opened up an area of inquiry previously avoided by most everyone. She identified and described five psychological stages through which the terminally ill person passes along the dying trajectory. The stages are: denial, anger, bargaining, depression and acceptance. Some investigators dispute the rigidity of the staging concept, although Kubler-Ross did not propose that all terminally ill patients pass through these stages, nor that the ones who do pass through them do so in an orderly or inflexible manner. There is also controversy over whether or not these stages really do exist. Metzger (1980), using Q-Methodology, found no evidence of the staging in two breast cancer patients or their spouses. Wasow (1984) credits Kubler-Ross with the healthy influence she has had on all those who work with the dying, but questions the acceptance of her theories in the absence of systematic testing.

While Weisman (1979) acknowledges the validity of the stages, he believes that they can be found in persons suffering any type of loss and that all five stages can sometimes be identified in the same person during a single interview. For some, the stages provide a framework for interpreting behavior. Mauksch (1975) writes:

These stages provide a very useful guide to understanding the different phases that dying patients may go through. They are not absolute; not everyone goes through every stage in this exact sequence, at some predictable pace. But this paradigm can, if used in a flexible, insight producing way, be a valuable tool in understanding why a patient may be behaving as he does (p. 10).

The Physical Impact of Cancer on the Individual

The following discussion of the physical impact of cancer on the individual is a very general one, designed to give the reader a basic understanding of the patient's potential for physical distress.

Levels of physical comfort or discomfort cannot help but influence coping behaviors and general psychological status.

Cancer has been defined as a large group of diseases (American Cancer Society, 1983). As the cancer cells multiply, the physical effects can vary considerably among individuals according to the site of the cancer and what body systems are being affected. How much the cancer interferes with the function of the affected organ and its effect on the nervous system can determine the amount of pain and discomfort. The number of symptoms which can be attributed to cancer is exceedingly large as the list of problems it can cause is exhaustive. This is because of the multiple variations of the disease. For example, many diseases can mimic cancer and conversely, cancer can be the underlying cause of many other diseases. Some of the early symptoms are found listed among Cancer's Seven Warning Signals:

Change in bowel or bladder habits

A sore that does not heal

Unusual bleeding or discharge

Thickening or lump in breast or elsewhere

Indigestion or difficulty in swallowing

Obvious change in wart or mole

Nagging cough or hoarseness

Source: American Cancer Society: Cancer Facts and Figures.
New York: American Cancer Society, 1983.

Sometimes the diagnosis of cancer is made before symptoms begin to become noticeable. This may occur when it is found during a routine physical examination or cancer screening program. At other times, it is the effects of the metastatic process which leads to the diagnosis. It may happen that the primary tumor is never found.

In addition to the physical changes which occur as a direct result of the cancer, there are also changes which are produced by the treatment. Standard treatment modalities include surgery, chemotherapy, radiation therapy, or a combination of these (Cancer Source Book, 1981). There are also experimental treatments in limited use such as immunotherapy, which makes use of the body's own defense system to fight the cancer cells (Mielnicki, 1984). For some patients, the side effects of these treatments are minimal to moderate; for others, they are very severe and disruptive.

Cancer surgery is often more extensive than other types and, as in the case of mastectomy, the results may be disfiguring. In addition to the loss of the body part, there may be residual swelling of the arm, a stiffness of the arm and shoulder, and some numbness of the chest wall (National Cancer Institute, 1980). Following the mastectomy, a prosthesis is usually worn to conceal the loss of the

breast, and some modification of clothing is often necessary. As a result of these secondary problems related to the mastectomy, the patient is continually being reminded of the cancer and of the altered body image (Meyerowicz, 1981). For this reason, many women who are free of apparent metastatic disease choose to undergo reconstructive surgery.

Although the mastectomy is the surgical treatment most frequently recommended and used at this time, an alternate procedure, the lumpectomy, has been available for the past few years. For breast cancer in its early stages, this treatment includes the lumpectomy together with radiation therapy. In the case of advanced disease, and depending upon the individual situation, various combinations of lumpectomy, radiation and chemotherapies may be used (Keyes, Bakemeier, and Savlov, 1983).

In a discussion of treatment side effects, Blumberg, Flaherty, and Lewis (1980) explain that because chemotherapy affects healthy cells as well as the tumor cells, it often produces a variety of unpleasant side effects. Depending upon the drug or combination of drugs used; loss of hair, loss of appetite, nausea and vomiting, fatigue and weakness and a decreased resistance to infection may occur. Radiation side effects are dependent upon the area being treated and the dosage of the radiation being given. Because these treatments also effect healthy tissue, they may also produce appetite loss, nausea and vomiting, swallowing difficulties, fatigue and weakness, hair loss, lack of resistance to infection and irritation of skin and mucus membrane.

The Emotional Impact of Cancer on the Individual

Emotional impact begins with the awareness that the cancer exists. For some, this awareness is gradual, growing with the suspicion that cancer may be the cause of their symptoms. For others, awareness comes suddenly, when they are informed of the results of diagnostic or screening procedures. The way in which the patient is actually told of the diagnosis is very important. If the disclosure is made with compassion and hope, the patient is better able to utilize the internal resources which are present (Cancer Source Book, 1981). In general, however, individual coping styles are dependent upon how problems have been handled in the past, the perception of the present situation, whether the attitude about life is essentially optimistic or pessimistic, and the degree of personal flexibility or rigidity (Ostchega and Jacob. 1984).

Weisman (1979) describes seven areas of concern for the cancer patient. They are: health concerns (physical problems), self-appraisal concerns (self-esteem), work and financial concerns, family and significant relationships, religion, friends and associates, and existential concerns. These areas of concern wax and wane according to the patient's situation at the time, but most all patients agree that during any given period; existential, work, self-appraisal and health concerns take precedence over religion, family and friends. Weisman also states, "At critical moments, which come at any time, existential and self-appraisal concerns always predominate, as if we are abruptly prodded into thinking about who we are and where we are going" (p. 80).

Mastectomy patients are well represented in the literature describing the psychosocial problems associated with cancer. The reason for this may be due to the fact that breast cancer is so greatly feared. Although it is curable if detected and treated in its early stages, the fear is justified. According to Keyes, Bakemeier, and Savlov (1983), it is the most common malignancy found in women and its incidence is increasing. In addition, there is no known means of prevention, the course of the disease is unpredictable, and the possibility of metastasis remains for many years. Breast cancer is also a complex disease. As Meyerowicz (1981) comments, the majority of these patients face a three-fold problem: that of undergoing a major surgical procedure, of losing a breast, and of having cancer.

In reviewing the literature, Lewis and Bloom (1979) found that breast cancer is often associated with death and the fear of disfigurement. Mastectomy may be seen as a threat to femininity, and so many patients fear losing their sexual attractiveness. Some women also fear becoming a burden on others. Additional reactions may include anxiety, depression, anger, guilt, denial and fear. These feelings are not unlike the stages described by Kubler-Ross (1969) in her work with dying patients, and provides additional evidence that these stages can be found in people suffering other types of loss (Weisman, 1979). The National Cancer Institute (1980) reports that the most common fears among breast cancer patients are: the fear of death, of pain, and of living with uncertainty. The uncertainty of the future for these patients is stressed by Taylor (1982) who interviewed 78 breast cancer patients and found that many considered

their cancer to be a continuing threat, affecting them for perhaps the rest of their lives.

Although the future may be perceived as uncertain and even threatening by many patients, the majority seem to have resources to help them adjust. Bloom, Cook, Holland, and Muenz (1984) compared data obtained within a month following surgery from mastectomy patients, benign breast biopsy patients and cholecystectomy (gall bladder) patients. The investigators found that although the breast cancer patients, particularly those with more advanced disease, had more anxiety, negative attitudes, concerns about physical problems, role strain and interpersonal difficulties; their levels of psychological distress were significantly reduced within a year. There is also likely to be an improvement in the level of psychological comfort when the treatment regimen has been completed and the patient is able to return to a more normal lifestyle (Meyerowicz, Watkins, and Sparks, 1983).

A major theme found in the breast cancer literature is the altered self-image, the loss of a body part associated with femininity and sexuality. How well a patient adjusts to the mastectomy is largely dependent upon her level of self-esteem before the surgery and also the degree to which she defined her femininity and self worth in terms of her breasts (National Cancer Institute, 1980). Metzger, Rogers, and Bauman (1983) interviewed 652 breast cancer patients one year following mastectomy and found that only 54 percent reported concerns about disfigurement or sexuality. The women who did have these concerns tended to be under 50 years of age. In the under 50

age group, the women who were unmarried were more concerned with disfigurement than the married. However, in the over 50 age group, the married women were more concerned than the unmarried.

Romsaas, Malec, Trump, and Wolberg (1984) assessed sexual function in women with breast masses both before and after biopsy, and in patients with known breast cancer before and after mastectomy. Upon the initial assessment, they found that the patients who knew of their cancer had a poorer self image than those women whose breast lesions were questionable. While both of these groups reported a poorer self image, decreased femininity, and sexual function when compared to a normal group, an assessment four months later showed no difference between the mastectomy patients and those who underwent biopsies for benign lesions. Both of these groups remained different from the normal control group, however.

It has also been demonstrated that gynecologic cancer patients have more problems with body image disruption than mastectomy patients, although both groups showed a decrease in sexual function when compared to healthy controls (Anderson and Jochimsen, 1985). It is also interesting to note that Cohen, Wellisch, Christiansen, and Guiliano (1984) found no significant differences in mood, functional impairment, self concept and marital satisfaction between patients treated with mastectomies and those who had undergone lumpectomies. It was also found that the lumpectomy patients believed the lumpectomy more effective in treating breast cancer than the mastectomy, and the mastectomy patients believed the mastectomy to be the superior treatment. This led the investigators to conclude that the belief in

the effectiveness of a treatment influences coping more than the treatment's cosmetic result.

Depression is a very natural and understandable reaction in people who learn they have cancer. In fact, when treatment is unpleasant and survival questionable, it is difficult to imagine under what circumstances a degree of depression would not occur. Nevertheless, many patients seem to be able to overcome this. Silberfarb, Maurer, and Crouthamel (1980) studied 146 breast cancer patients and found a low incidence of depression, and also self-esteem levels which were intact. This was found even in those patients with progressive disease. In another study of 413 female cancer patients including 159 with breast cancer, Lansky et al. (1984) found that only 5.8 percent of the patients showed signs of clinical depression, and that the majority of these had strong family histories of depression and had showed signs of depression before the onset of the cancer. This supports the conclusion that cancer patients tend to handle cancer related problems in the same way that they dealt with other problems in the past.

In general, the literature describing the psychosocial aspects of cancer gives a fairly consistent account of the cancer patient's early reactions to the diagnosis. Fear, anger, denial and depression are among common responses and are certainly understandable. The breast cancer patient faces the additional problem of probable alteration in body image, adding greater potential for distress. The literature also suggests, however, that levels of emotional distress tend to decrease over time.

The Potential for Personal Growth

The preceding citations described some of the many problems associated with the diagnosis of cancer. There was some emphasis placed upon the patient's own ability to adjust to this crisis, to cope well. Some additional literature also suggests that many cancer patients not only continue to find satisfaction in their lives, they actually achieve a degree of personal growth as a result of their experience with a life threatening illness. Dunkel-Schetter (1982) interviewed 79 cancer patients to assess their social support systems and the impact of the cancer on their lives. In addition to their problems and concerns, some of the patients also mentioned positive changes in attitudes about life.

Yalom (1980) administered a 17-item personal growth questionnaire to 70 patients with metastatic breast cancer in a medical setting. While most of the patients reported no changes for periods before and after the onset of the cancer, those who did, indicated a change in the direction of personal growth. (Yalom's study is the basis for the investigation presented here.)

Spiegel and Yalom (1978) also described such changes in their account of group work done with terminally ill patients:

During the course of the group, the members came to feel less like passive victims of a disease process and more like experts on living. They discovered, often to their surprise, that they had something to teach others, both those who had more recently discovered that they had cancer and also people who had not yet confronted death. For many group members, the increased awareness of the passage of time brought about by the diagnosis of cancer seemed to accelerate the process of personal growth (p. 240).

The personal growth described in these studies seems to be more

closely linked to the issue of an increased awareness of one's mortality rather than to the cancer itself. In support of this, positive life changes have been associated with other kinds of life-threatening experiences. Noyes and Sylmen (1979) surveyed 189 victims of near-fatal accidents and found that 60% of those who believed that they were about to die described positive changes in their attitudes about life following the experience. Also, in an analysis of the experiences of 102 near-death survivors of accidents, serious illness, and suicide attempts, Ring (1980) found that the majority reported positive changes in attitude about life, a sense of renewal and purpose in life, an increase in inner strength, and a more positive attitude toward others.

In summary, the literature reflected rather well the problems associated with cancer. There was also a representation of the issues related specifically to breast cancer, the diagnosis of the participants in this study. The inner strength and resourcefulness of the individual was also evidenced by the fact that so many cancer patients adapt to their situations and cope effectively. In addition, there was substantial evidence that some patients not only adjust to this crisis, but somehow use it to their advantage, facilitating the process of personal growth.

CHAPTER III

METHODOLOGY

The question of personal growth following the diagnosis of a life-threatening illness such as cancer was approached by investigating the life changes experienced by 30 women after they had been diagnosed with breast cancer. Both negative and positive changes were explored by means of interview and questionnaire. The advantages of this design were twofold; while there was a degree of group homogeneity with control for sex and site of primary lesion, the severity of the disease and its metastatic effects were varied. This allowed for a more comprehensive review of cancer related problems, including the issues of altered body image and disfigurement. In addition, interview and questionnaire responses provided both quantitative and qualitative data for analysis.

In preparation, a pilot study was done in order to explore the possibility of personal growth in relation to cancer (see Appendix A). Three women who had been treated for breast cancer were interviewed and asked to complete personal growth questionnaires. Major themes were identified and the efficacy of the interview questions was assessed.

Subjects

Initially, the investigator approached three medical oncologists, explained the proposed study, and received permission to interview

their breast cancer patients. One oncologist referred a single patient; the other two oncologists were in joint practice and referred the remaining 29. All the patients had been screened by the physicians for mental stability. Of the joint- practice group, 35 patients were originally approached by the office nurse-clinician and told that the investigator was doing research for a thesis and wanted to interview cancer patients. They were also told that if they agreed, they would be telephoned by the investigator to arrange for a personal interview. Of the 35 patients who were approached by the nurse, 29 agreed to participate. An additional patient indicated that she would telephone the investigator to arrange for the interview, but she did not call.

The participants were the 30 women who agreed to be interviewed. They were between the ages of 37 and 71 and were either currently receiving chemotherapy or had received it in the past. Twenty-seven of the women had undergone mastectomies, and three had been treated with lumpectomies because of widespread metastasis found at the time of diagnosis. Ten of the women had metastases to the lymph nodes only; 20 had metastic disease in the bones and/or other organs. The elapsed time since the initial diagnosis had been made ranged from three months to 18 years. All the women were white, middle to upper-middle class, and resided in Chicago or surrounding areas. Nineteen of the women were married; eleven were either single, widowed or divorced.

Instruments

Instruments included a standard audio-tape recorder, a consent

form which the participants were asked to sign (see Appendix B), an interview guide (Appendix C), and a modified form of a questionnaire constructed by the investigator (Appendix D) from the description of an instrument developed and used by Irvin D. Yalom of Stanford University.

The interview guide is essentially the one used in the pilot study, although Question 5 was modified for the sake of clarity, and the order of the questions was slightly adjusted (examples of both interview guides are also found in Appendix A).

The questions were open-ended in order to elicit spontaneous ideas from the participants rather than their comments on more rigidly defined areas. Question 1 (How did you learn of your diagnosis?) was included because some studies have shown that the way in which a patient is told or learns of the diagnosis has bearing on future coping ability. Question 2 (What were your feelings at the time?) is not only related to the first question, but also serves as a baseline for future change. Question 3 (Have these feelings changed over time and if so, how?) relates to Yalom's personal growth questions and also to the Kubler-Ross staging concept.

Question 4 (How has your life changed since you learned of your cancer?) is more action-oriented and is targeted at physical limitations and possible personal growth. Question 5 (What has caused you the most distress since the diagnosis and what have you done to cope?) was designed to reveal the most problematic area for each particular patient and to generate talk of death-related fears and concerns. In addition, knowledge of individual coping strategies has

implications for counseling. Question 6 (What have you found to be the most helpful?) was included to differentiate between internal resources and external support. This question also has specific counseling implications, as does Question 7 (What advice would you give to other cancer patients to help them?). Each patient was then asked if there had been anything else important at that time that we had not talked about. This was done in order to gain any additional information that had not been covered.

Yalom (1980) constructed a 17-item questionnaire to measure positive change in cancer patients. The patients were asked to rate on a five point scale their feelings and attitudes about life for two periods in time, before the onset of the cancer and now. The questionnaire which was constructed from Yalom's description was used in the pilot study with Dr. Yalom's permission (Appendix E). For this present study, the following questionnaire revisions were made: the five point scale was expanded to a seven point scale in order to increase the sensitivity to subtle change; eight of the 17 items were worded in reverse order to increase the validity of the instrument. The modifications were discussed with Dr. Yalom during a telephone conversation and his consent was given.

Procedure

The patients who had agreed to participate in the study were telephoned by the investigator. Each patient was thanked for her help and told that participation would consist of answering some questions about her experience with cancer, and that she would also be asked to complete a questionnaire. The appointment for the interview was then

made. Each interview began with a brief period of general conversation followed by the investigator's request for permission to tape record (all the patients agreed). The patient was then asked to sign the consent form after being assured that she could stop the interview at any time if she wished (none did). The seven open-ended questions were then asked, and if the patient responded by asking for clarification of a particular question, the question was repeated and she was told to say whatever came to mind. Following the interview, the patient was given the questionnaire to complete. Here again, if the patient asked for clarification of a particular question, she was told to respond in a way that was meaningful to her. As the interviews progressed it became evident that some patients found that thinking about two time periods for questions which were worded in reverse order was difficult and confusing for them. The majority of the participants were told therefore, "keep in mind that if you agree with the statement, the number tends to be larger, and if you disagree the number tends to be smaller." This clarification seemed to be helpful. At the conclusion of the interview each participant was again thanked and a follow-up note of appreciation was sent.

These interviews took place during a seven month period from early May through the early part of December, 1985. Twenty-seven were conducted in the patients' homes; two were done in the home of the investigator; one was done at the patient's place of employment. Each location was selected by the patient, and every interview was conducted by the investigator.

Analysis of Data

Personal Growth Questionnaires

Following completion of the data collection, questionnaire reliability was assessed by the internal consistency method using Cronbach's coefficient alpha.

The matched pair <u>t</u>-test was used to analyze differences in before and after scores, both total and per item. <u>T</u> scores were also calculated for before and after differences (total and per item) according to age and marital status. Cancer education or support group attendance was also noted.

Interviews

The interviews were tape-recorded and then transcribed.

Responses to each of the seven questions were coded according to negative or positive life changes. Major themes were abstracted for discussion and varying coping behaviors compared. Also noted was any evidence of Kubler-Ross' staging (i.e. denial, anger, bargaining, depression, and acceptance).

CHAPTER IV

RESULTS

The purpose of the study, to explore life changes and to document evidence of personal growth in people following life-threatening situations was approached by interviewing 30 breast cancer patients. Differences in attitude about life for two periods in time, before the onset of the cancer and now, were measured by means of a personal growth quesionnaire. The reliability of the questionnaire was assessed using Cronbach's coefficient alpha. The participants were also asked seven open ended questions about their experience with cancer. Results of the questionnaire and interview responses are given below.

Personal Growth Questionnaires

The Cronbach coefficient alpha value for the <u>before</u> onset scores was .71, and .69 for the <u>now</u> scores. Results of the matched paired <u>t</u> tests indicated significant differences, in the direction of personal growth, between the total <u>before</u> and <u>now</u> scores as well as between the <u>before</u> and <u>now</u> scores for four of the 17 items. The means, standard deviations and <u>t</u> scores for differences on each of the 17 items as well as for the total score differences are found in Table 1.

Instances of life changes in a negative direction are also noted.

Table 1

Differences Between Now and Before Scores on Personal Growth Questionnaires

| Item | <u>N</u> | <u>M</u> | SD | <u>t</u> | <u>Item</u> | <u>N</u> | <u>M</u> | SD | <u>t</u> |
|--|-----------------|----------|-----|----------|--|----------|----------|-----|----------|
| Communicating openly with a husband | 21 ^a | 0.2 | 1.0 | 0.85 | Doing only those things one wants to do | 30 | 0.2 | 1.0 | 0.93 |
| Having a sense of personal freedom | 30 | 0.1 | 1.2 | -0.44 | Communicating openly with friends | 30 | 0.2 | 8.0 | 1.15 |
| Living in the present rather than in the past or future | 30 | 0.4 | 1.3 | 1.68 | Appreciating the beauty of nature | 30 | 0.2 | 0.4 | 2.41* |
| Communicating openly with children | 23 | 0.2 | 0.6 | 1.74 | Having moments of deep serenity | 30 | 0.6 | 1.3 | 2.67* |
| Believing that being liked by everyone is unimportant | 30 | 0.0 | 0.7 | 0.25 | Believing that one has something of value to teach others about life | 30 | 0.4 | 0.8 | 2.63* |
| Obtaining much pleasure from life | 30 | 0.0 | 0.6 | -0.33 | Being able to choose what | 30 | 0.2 | 0.6 | 1.54 |
| Communicating honestly and frankly | 30 | 0.0 | 0.5 | 0.00 | Believing that one's life has meaning and purpose | 30 | 0.2 | 0.5 | 2.26* |
| Standing up for personal rights | 30 | 0.4 | 1.0 | 1.94 | Having significant reli- gious-spiritual beliefs | 30 | 0.1 | 0.7 | -0.49 |
| Having a sense of psycho- logical well-being | 30 | 0.2 | 1.2 | -1.10 | | 30 | 2.5 | 6.1 | 2.28* |

Note: Negative t values indicate negative life changes $\overline{^{a}}$ One separated and one divorced patient also responded to this question.

The patients were also grouped according to age and marital status. Table 2 lists the means, standard deviations and \underline{t} values for total before and now differences according to age. In addition to the positive change reported by the 46-55 age group, there was also a significant per-item difference in this group for item number 14, believing that they had something of value to teach others about life $(\underline{M} = 0.8, \underline{SD} = .07)$ \underline{t} (7) = 3.0 p < 0.5. In addition, item number 13, having moments of deep serenity, was significant for positive personal change in the 56-65 group $(\underline{M} = 1.4, \underline{SD} = 1.8 \underline{t}$ (9) = 2.41 p < 0.5.

Table 2

Differences Between Now and Before Scores on Personal Growth

Questionnaires According to Age

| Age Group | N | <u>M</u> | SD | <u>t</u> |
|-----------|----|----------|------|----------|
| 35 - 45 | 4 | 2.0 | 3.2 | 1.26 |
| 46 - 55 | 8 | 3.5 | 2.1 | 4.78** |
| 56 - 65 | 10 | 3.6 | 10.0 | 1.14 |
| > 65 | 8 | 0.5 | 3.2 | 0.45 |

^{**}p < .01

There were no significant differences in the total scores of the women grouped according to marital status. However, for item number 13, having moments of deep serenity, the married women showed a significant degree of positive change (M = .8, SD = 1.3 t (18) =

2.62, p < 0.5.

Only two of the 30 patients had attended a cancer education or support group. Their difference scores of one and two respectively are somewhat below the total difference mean of 2.5.

Interviews

The interview responses clearly illustrated, not only the common characteristics shared by these breast cancer patients, but also their uniqueness as individuals. Because the interview questions were open ended, some responses were more closely related to questions other than the one being asked at the time. Response patterns along with selected material quoted from the interview transcripts are presented here. It is hoped that the generous use of quotations will help the reader better understand the patients as living people rather than responses summarized in the data. In addition, feelings are so often very complex and seem to suffer somewhat in the translation by another.

When asked how they had learned of their diagnoses, the majority of women responded by explaining how the lump had first been detected.

A summary of these responses together with their frequencies are listed in Table 3.

Upon learning that the lesions were malignant, initial reactions varied considerably, although almost one third of the respondents reported relatively little difficulty. The responses to this question are summarized in Table 4. A 48 year old women who had been diagnosed three years before stated, "It was not a shock, although it was not the most pleasant news. But I think one looks at it as a part of

Table 3

Question 1 (How did you learn of your diagnosis?)

Means of Tumor Discovery in Breast Cancer Patients

| How Discovered | Frequency |
|--|-----------|
| Found by the patient | 17 |
| Found by a physician during an office visit either for a routine check-up or for problems unrelated to the eventual cancer diagnosis | 7 |
| Found by a physician during an office visit for symptoms related to what was later | |
| determined to be metastatic disease | 3 |
| Found during mammography screening | 2 |
| Found by a sex partner | 1 |

N = 30

Table 4

Question 2 (What were your feelings at the time?)

Initial Reactions of Breast Cancer Patients to Their Diagnosis

| Initial Reaction | Frequency |
|------------------|-----------|
| Acceptance | 9 |
| Shock | 9 |
| Fear | 9 |
| Denial | 3 |
| Depression | 3 |
| Anger | 3 |

N = 30

Note: Some patients mentioned more than one feeling in response to this question.

life. I couldn't change what I had and I think I just decided it was time to roll with the punches." Another woman, 54 years old who had been diagnosed within the past year, said, "I've always been kind of an 'up' person. I guess you have to look at the bright side of something. It didn't bother me that much because I figured they would get it." This woman had initially believed her lump to be benign and later on in the interview described rather poignantly her first awareness of the cancer:

I went in for the biopsy and of course he said it was benign and they would send me home. I was an outpatient. When I was lying in the recovery room there was a girl, a young girl, and they told her that everything was fine and she was going to go home, and she was crying. And they didn't tell me that, so I knew that it was more than we thought it was.

Three of the women said that their initial reactions to the cancer were feelings of anger. One woman, 67 years old and diagnosed four years before, described her anger mixed with disbelief, "It seemed like I was kind of angry and yet not wanting to believe it, you know, and like it just couldn't be." Three others remembered a kind of resigned depression. A 68 year old woman with advanced disease who had been diagnosed 11 years earlier said:

Right after Christmas I told him (her husband). I was pretty depressed about it when I first heard the news. But when I went into the hospital, I was resigned. My roommate asked me what I was in for and I told her I was going to have a mastectomy, not that I was there to find out if I needed a mastectomy. I just

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seemed to adjust to the fact that was what was going to happen.

Shock was the initial reaction mentioned by almost one third of the women. A 44 year old patient with advanced disease (the effects of the metastases had originally brought her to the physician) described her feelings very graphically: "When the doctor came to tell me it was cancerous, it was a shock. It was an extreme shock. The face felt like all the nerve endings were right there, not anyplace else. Just like somebody put a poker in your face." Another 48 year old woman, upon hearing that her biopsy had proved to be malignant, went into shock quite literally and spent three days in the intensive care unit before she was stable enough to have the mastectomy. It was later learned that she had tumors in both breasts and they were eventually removed.

Fear was named as the initial reaction by almost one third of the women. A 57 year old patient diagnosed within the past year talked of her feelings at the time, "Well, cancer is a bad word, like everyone gets frightened of it. And you think you're going to die and you get frightened." Others felt shock and fear. A 50 year old woman with metastatic disease diagnosed two years before said:

Well, I was very surprised. This was something that happens to other people. And I was always very happy. I never got sick. I played tennis both days before I went in for the biopsy. So it was a real shock. And of course with a lot of things you have a lot of fear of the worst. You think you're going to die. You think the worst. And each time the doctor came in I thought, well here goes.

The fear of disfigurement was the primary issue with one of the respondents, a 54 year old woman who had been diagnosed during the past year. She had been confident that her cancer would be cured but in remembering her thoughts before the mastectomy said: "Oh, I didn't want to have it done, you know. I always thought that it was the worst thing that could happen to a woman. I read about other women having this done and I thought, Oh God, it's so disfiguring." This woman came to accept her situation by making arrangements for reconstructive surgery. This decision was also influenced very much by the reaction of her husband to the mastectomy, "My husband has had a hard time with it. He doesn't want to look at it and has had more trouble accepting it than I have." On the subject of disfigurement, another 54 year old patient diagnosed at age 47 and now with metastatic disease commented:

I'm basically a very self-confident person. I've had a full life and a very supportive family. I did not feel that I had gone through half a life depending upon a breast. I want to live, but if my personality hinged on having one or two breasts, I would be in very bad shape.

Sixty percent of the women reported some positive change in their feelings over time, even though many of them have progressive disease. These changes and their frequencies are listed in Table 5. Forty percent of the women reported little or no change in feelings over time. An example of positive change is found in the 44 year old woman mentioned earlier who described her shock in such detail. She went on to explain her later feelings:

Table 5

Question 3 (Have these feelings changed over time and if so, how?")

Positive Changes Over Time in the Feelings of Breast Cancer Patients

| Change | Frequency |
|----------------------|-----------|
| Increased acceptance | 16 |
| Decreased shock | 9 |
| Decreased fear | 7 |
| Decreased anger | 2 |
| Decreased denial | 1 |
| Decreased depression | 1 |

N = 30

Note: Varying combinations of these changes were described by the patients in response to this question and/or during other parts of the interview.

The impact of the first day was hard, but the following day it was much easier for me. Basically I didn't feel sorry for myself because why not me? I am a statistic in life. If you're afraid of the word, cancer, you're afraid of reality; and if you can't face it, you're not going to fight it. I am not afraid of death, I never have been. I was born in Europe and I've seen people dead on the streets, being shot, being killed. I'm not afraid to die. I love to live, and I fight, and nobody said that this is going to

be a Garden of Eden. But yet, the world is so beautiful.

Another 59 year old woman diagnosed eight years before and now with advanced metastatic disease said, "I have a firm faith in God and I kind of accept things. My feelings about this have become stronger with time." A 67 year old woman, diagnosed 10 years previously and who has had two reoccurances told the investigator:

It's serious, it's very serious now. In the beginning I felt real, real bad. But then I felt, well, take it one day at a time and it'll work out for me. And I have a positive feeling about this and maybe things will work out. How much time I've got, who knows. I don't know.

The majority of the women who reported little or no change in feelings over time described acceptance and hope as their initial responses. There were some negative feelings that lingered, however. A 71 year old woman diagnosed three years ago and who now has extensive metastatic disease said:

I was mad, disgusted. Why did it happen? I gave up smoking 21 years ago and I eat the proper food. I worked hard and got my

proper rest. I exercised. But I've had a good life up to now.

I've traveled all over, I've been fortunate. I've never been sick and I just couldn't believe that it happened. I was hoping they were wrong. Well, I just have to live with it. I go to the doctor's office and I see all those people just like me who are never sick and that happens. So I'm living with it, but I'm still mad, you know!

A few other patients described feelings which vacillated. A 42 year old woman who had been diagnosed three years previously, said of her initial reaction upon learning of her cancer, "I was very frightened. What came to mind immediately was that I was going to die, and what was going to happen to my family?" Of her struggle with her feelings over time, she said:

I think that now, almost three years later, I'm handling things better than I did then. I find myself talking to myself more about it. I find myself getting down about it once in awhile but not as badly. And I think as time goes on, especially if I don't have any more reoccurances, I'll feel better mentally. I think the hardest thing; because I don't feel sick, I feel good; is the mental part of it. What it does to you mentally. It's crazy, and I think that's what makes me depressed sometimes. All of a sudden it will just pop into my mind: Oh God, am I dying, am I sick again, do I have to go for more treatments? But now that's not as often as it was before.

There were varied responses to the question about life changes since the diagnosis had been made. Some of the changes were positive

and others were negative. Seven of the women said that their lives were essentially unchanged. The life changes mentioned by the other 23 women are found in Table 6. Frequencies indicate the number of respondents who named a particular change. The majority of women who mentioned change talked about both positive and negative change. A 51 year old woman who had had a reoccurance said:

I've grown in the four years since surgery. I've grown more independent and more appreciative of my children as adults. But, as you get a little bit older you always wonder how you are going to die, and somehow or other, this vision comes to you that now I have this disease, I know how I'm going to die. You don't know, but you know.

Another patient, a 68 year old woman who had been diagnosed 10 years before, said:

My life didn't change much after the mastectomy, but it's changed more now with the metastasis because there seems to be no checking it now. It goes from one thing to another. My husband is very understanding, which helps, a tremendous plus, I think. There may be marriages that suffer, but ours has only grown stronger.

A 44 year old woman with a favorable prognosis talked about the changes in her life:

I can't really say it's changed a great deal other than the fact that I think more people need to be educated to the fact that other people have cancer. I have run into a few situations where people are afraid that I'm a different person and don't know how to act toward me. They think that maybe it's catching and they

Table 6

Question 4 (How has your life changed since you learned of your cancer?)

Life Changes Since Learning of the Diagnosis as Reported by Breast Cancer Patients

| Positive | Positive Negative | | |
|-------------------------|-------------------|------------------------------------|-----------|
| Change | Frequency | Change | Frequency |
| Greater appreciation | | Decrease in activity | |
| of life | 5 | tolerance | 8 |
| Reorganization of | | Altered body image | 4 |
| priorities | 4 | Prosthesis | 3 |
| Increased responsibilit | :v | | • |
| for own health | 2 | Changes in the attitudes of others | 2 |
| Change in values | 2 | Delegation 1 | • |
| Increased need to help | | Rejection by a mate | 2 |
| others | 2 | Clothing restrictions | 1 |
| Increase in awareness | | | |
| of the concern of | | | |
| others | 1, | | |
| Increase in the | | | |
| strength of the | | | |
| marriage | 1 | | |
| Increased patience and | | | |
| tolerance | 1 | | |
| Greater appreciation | | | |
| of children | 1 | | |
| Increase in personal | | | |
| strength | 1 | | |

N = 23

Note: Some patients mentioned more than one change in response to this question.

don't know what to say as if they're going to hurt my feelings.

Or maybe they think that I'm not feeling well and they may not

want to include me. But I want to make that decision for myself

and not have them make it for me. I think one of the biggest

things is educating people more.

This particular woman wrote a letter which she circulated among her friends to promote greater understanding of the needs of cancer patients (see Appendix F). Social stigma is also illustrated in the following comments made by a woman who worked with other cancer patients in a mutual support organization:

There is a tremendous amount of prejudice as far as people with cancer. There is a tremendous amount of ignorance. I can tell you a case where people were invited to somebody's home to have coffee with a group. You as a cancer patient will be handed a paper cup. It's not unusual. It's not unusual to hear comments that if you were a good friend you wouldn't associate with these people because they could catch this from you. It's a crazy world out there and cancer is synonymous with death. There's no way you can get around it, the minute people hear the word, you are automatically dead.

Another patient had been severely wounded by the reaction of another person. A woman with advanced disease, she had been initially diagnosed 18 years before at the age of 44. Following her mastectomy, her husband rejected her, they were divorced, and she made two suicide attempts. These many years later, in reflecting upon the many changes which have taken place in her life, she emphasized the positive ones,

"Oh, it's (her life) improved a 100 percent. I have become a better person. I was always very into myself. Helping others is important now; material values are less important."

Another participant talked of many terrible events which had taken place in her life: parental neglect and abuse when she was a child, abuse and eventual desertion by a husband, the kidnapping of a child whom she did not see again for many years, a business failure, and the rejection of her fiancee following her mastectomy. She is now 49 years old and has advanced metastatic disease. Of life changes since learning of the cancer, she said:

As far as the cancer goes in my life, no way. Really, I would say my love life has changed, that's the only thing. But as far as life goes, if anything, it has made me stronger. It's made me appreciate life more. It made me ... well, I always did like to get up in the morning and think what a beautiful day it was, the birds and the trees. I think it's made me appreciate life more. I do more valuable things with my life, more things that are important to help other people and things like that. Although I've never been a slouch in that respect. I love animals, I love people, I have all my life. If anything, it's screwed up my love life. That's it. But as far as life goes, I grab every breath I can, I live every moment!

In talking about the changes in her life, a 47 year old woman with a favorable prognosis said:

I wake up in the morning and I'm going to enjoy every minute of the day, every minute. And it's been like this since the end of the chemo; well, maybe a month after the end of the chemo, when I was coming out of the after effects. And then I got to the point when I could get up in the morning and feel good, then it never has turned back. I've enjoyed every single day... The illness made me want to go home and that was the thing that I accomplished. I went home (to Scotland). I felt that I had to see everyone again and renew the contact because it had been 12 years. I had lots and lots of things to do, places to see, memories to run away and look at. And I retraced my whole life; I finished everything that I had to finish.

Another woman, 71 years old and with metastatic disease, also talked about the need to accomplish things, "I seem to appreciate the littlest things a lot more, accomplishing things I have wanted to do. For instance, I'm making a christening blanket for my granddaughter and she's not even married."

The women were all asked what had caused them the most distress since the diagnosis and what they had done to cope. Their responses were summarized and can be found in Table 7. The frequency indicates the number of respondents who mentioned a particular effect or strategy. While the treatment side effects was the most frequently mentioned item, the majority of women perceived the treatment as helpful. One woman described the experience:

I'm not real fond of chemotherapy. It does make you pretty sick and you can get pretty sick of having your head in the toilet. I keep telling myself that if that's what is keeping me alive, well damn, I'll do it! Life has to go on, so don't give up, God, don't

Table 7

Question 5 (What has caused you the most distress and what have you done to cope?)

Distressing Effects of Breast Cancer and Coping Strategies Employed

by Patients

| Effect | Frequency |
|--|----------------|
| Treatment side effects | 11 |
| Anxiety due to metastasis or a reoccurance | 5 |
| Disfigurement | 4. |
| Discomfort due to the prosthesis | 3 |
| Fatigue due to the illness | 3 |
| Physical problems unrelated to the cancer | 3 |
| Fear of reoccurance | 2 |
| Negative reactions of friends | 2 |
| Rejection by mate | - 2 |

| Coping Strategy | Frequency |
|------------------------------------|-----------|
| Having a positive attitude | 15 |
| Helping others | 5 |
| Getting information | 3 |
| Talking with others about feelings | 3 |
| Trying not to think about it | 3 |
| Keeping busy | 2 |
| Praying | 1. |
| Crying alone when upset | 1 |
| | |

N = 30

Note: Some patients mentioned more than one effect and/or strategy.

give up.

Another 37 year old patient, who had been diagnosed within the year talked about losing her hair:

The treatments, the chemotherapy, brought more frustration.

Nausea wasn't a big problem but the thinning of the hair was.

Some people will say to me that it is not noticeable, but they're not the ones who are sweeping it up every morning and every night, and so I see it. The loss of the breast became more important as time went on. The body is so beautiful, so balanced the way it is, and this isn't very balanced. The coping mechanism is the attitude, and being able to see the gifted side of it. I see that as a blessing and that has somehow helped. I have reprioritized a lot and some of the things that I would have thought were so important before just aren't. And I see that as a real good thing, almost like a gifted side to this whole thing.

For one woman the effects of a double mastectomy were very severe. She was 65 years old and had her breasts removed 24 years before:

I don't look at myself too much, you know, more so now than years ago. When I take a shower, when I dry myself. And then with him (her husband) I never let him see me at all until just about the last year when I went to the doctor's office because I had a heart attack. I'm not driving and he takes me and then he came into the doctor's office because he wants to be sure I tell the doctor everything. And so now he has seen me. Because it, it's a horrible sight.

Coping strategies varied among the respondents, however maintaining a positive attitude was most frequently named. A 69 year old woman with metastic disease diagnosed within the past year said:

Have a good attitude about it. Be optimistic no matter how bad it looks. You have to put your faith in God and pray, pray a lot.

Keep looking on the brighter side, you have to laugh about it or else you're going to cry. Try to be optimistic because nobody really knows and everybody is trying, and guessing, and doing the best they can.

While some patients tried not to think about it, others found comfort in information. A 68 year old woman with advanced disease and diagnosed nine years before said:

Coping is something within your own personality. You can either do it or you can't. I feel confidence in the doctors. They answer all my questions, they explain and don't 'double talk'. That has been the biggest help outside the family. But I go to the library and look it all up anyway. I think maybe the fact that I read about it and know about it and know the team is doing what is recommended makes me feel confident.

Another patient advises:

Find someone you can talk to, share feelings with. When I'm frightened about it, I cry. A closet crier, I call it. Because sometimes you talk about it to people, even though I have a need to talk, it depresses them so they don't want to see me that way. So I just try to get it out of my system one way or another, and it passes.

Those factors listed by the respondents as being most helpful to them are listed in Table 8. Frequencies indicate the number of respondents who mentioned a particular factor. Some of the women mentioned more than one type of help. A 57 year old woman diagnosed a few months before said:

The first time I saw myself I really cried, but my husband said I was still the same person to him, and that I haven't changed.

Leading a normal life again has helped the most. Life goes on and you have to accept it. I was worried about the people at work, was afraid that they would feel sorry for me ... but people forget very fast, you know. I'm one of them again.

Another woman named several things about her situation which has helped her:

Possibly the most helpful is my own ability to bounce back. It's something I've always had. My family and my husband, they are sensational. I can say anything and they don't panic. I've gone through metastasis on a couple of occasions and if I think of something I want to say, no one is going to freak out and nobody is going to tell me not to talk that way or that they don't want to hear it. If my kids or my husband have a question, they have the same freedom.

When asked what advice they would give other cancer patients to help them cope, most of the patients talked about the things which had helped them the most or the things which they had mentioned earlier when asked about their own coping strategies. Their advice and the frequency of each suggestion are listed in Table 9. Many of the women

Table 8

Question 6 (What have you found to be the most helpful to you?)

Factors Named by Breast Cancer Patients as Being the Most Helpful
to Them

| Factor | Frequency |
|---|-----------|
| Family support | 11 |
| Ability to keep busy and/or go back to work | 7 |
| Physicians and/or nurse clinician | 6 |
| Information and knowledge about the disease | 5 |
| Satisfaction with self and own attitude | 5 |
| Faith in God | 4 |
| Ability to keep from thinking about it | 2 |
| Prosthetic device | 1 |
| Increased freedom since the end of therapy | 1 |

N = 30

Note: Some patients mentioned more than one factor as being the most helpful.

Table 9

Question 7 (What advice would you give to help them?)

Advice Breast Cancer Patients Would Give to Other Cancer Patients

| Advice | Frequency |
|--|-----------|
| Have a positive attitude, be optimistic | 8 |
| Don't give up hope | 7 |
| Trust your physician and follow his/her advice | 6 |
| Have faith in God | 4 |
| Share your feelings with others | 4 |
| Get information about your illness | 4 |
| Avoid self-pity | 3 |
| Take each day as it comes | 3 |
| Don't let people bury you | 2 |
| Help others | 2 |
| Keep busy | 2 |
| Understand yourself, make peace with yourself | 1 |
| Learn to accept | 1 |

N = 30

Note: Most patients offered more than one suggestion.

offered more than one suggestion, and some mentioned several.

One of the participants was 46 years old and had been diagnosed two years before. She now had extensive metastatic disease and appeared very weak and ill. When she was asked the advice question she replied. "Well you know, I guess the worst thing we all do is start to feel sorry for ourselves. If we can just get beyond that.... She went on to say, "Don't give up hope, there is always hope! I've gone through a couple of reoccurances and yet I feel that when the doctors tell me that I've got six months to live, I tell them I've got a year. Don't give up on it, just fight it!" When she was able, this woman had worked with other cancer patients that she had encountered in her job and in the neighborhood. She can no longer do this because she is too ill. But she thinks about them all. "It's a little heartbreaking right now ... I don't see them, but I hear about them." In reflecting about a particular friend she said, "Even though it could be any day, he's ready and you know, I guess he's suffered enough. There's no hope any more, and that's it. We all have our day coming and when you can accept it, fine, that's it."

At the close of the interview, each participant was asked if there was anything she considered important that had not been covered. Most had nothing new to add, either saying that there was nothing else or reviewing things that had been covered earlier. Many expressed love and concern for their families. The patient who had been mistreated as a child and who had suffered many hardships as an adult talked about her concern for her 16 year old daughter:

Well I've slowly been working my way mainly for her comfort

because I know I'm not going to live forever. We all hope for a cure someday and if it should come, beautiful. But if not, at least now I know that she'll be secure and have things. She probably was my main determining factor in regard to what I was doing with my life right now. I'm planning it mainly for her. I'm almost 50 years old. I've had my life. It's been rough, but it's been a good life. Now I don't want to make it too easy for her because you learn by your mistakes. But at least she won't be stranded and she's got a roof over her head. What she does with it, that's going to be up to her, but at least I got her set in a halfway decent situation.

Another patient with advanced disease asked for her tape and transcript to give to her family. Of course her request was granted. In response to the final question she talked about her children and her grandchildren and how she looks forward to the future, "There might be a wedding one of these days and I'm going to be there....

I'm not going to give up ... I don't know if I'll get better but every day is a new day and if I don't feel too good, maybe tomorrow I'll feel better. This is the way we have to do it."

The stages which Kubler-Ross found in so many of her cancer patients were represented in many of the preceding quotations.

Denial, anger, depression and acceptance have all been illustrated.

Bargaining was clearly stated by only one of the participants, the 65 year old woman whose husband had not seen her mastectomy scars until more than 20 years later. She recalled, "Well, I prayed a lot and what I prayed for was to see P (her son) graduated from high school.

My prayers were answered. Now of course, I'm asking for more time to see that he is settled."

The two major themes found in the interviews were: hope and the desire to get on with one's life. The 50 year old woman who had spent three days in the intensive care unit after learning that her breast lesion was malignant, talked of her life since that time:

The first year I had a lot of hope. I was so glad that I was alive and I really had a lot of hope. I felt that everything was going to be alright. But when I went in March of this year and found out it had gone to the bones, I started noticing a bigger change. As far as losing the breasts, I think I handled that better than I thought. I put on my prostheses and forgot about it. I was just happy to be alive and I felt normal. But I don't think you should ever give up hope. Even if its bad, you have to have that hope. I do see other cancer patients and a lot of them are suffering. That day might come for me because I have bone cancer and I know what could happen. And that scares me a little bit, the fear of the unknown, that anxiety. Anxiety is hard to cope with. But for me, I feel good so I just go on with my life.

CHAPTER V

DISCUSSION

Summary

Life becomes more precious when we understand and accept the fact that it must someday end for us. This was demonstrated by Yalom in his work with terminally ill cancer patients who experienced personal growth as a result of their life-threatening illness. Because there are so many physical and emotional problems associated with cancer, it is of particular significance that the disease can be related to positive as well as negative life changes.

The present study describes the life changes experienced by 30 breast cancer patients as they learned to live with their cancer and with their uncertain future. The review of related literature includes a brief overview of the Kubler-Ross staging controversy. With emphasis on malignant breast tumors, a general description of the physical changes associated with cancer and its treatment is also given, followed by a discussion of the emotional impact of the disease. The evidence for personal growth related to cancer and other life-threatening situations is then presented. There is a description of the methodology including design, subject selection, instrumentation, procedural details and treatment of data from both interviews and questionnaires. The results of these interviews and questionnaires follow, and an interpretation is given below.

Conclusions

The questionnaire responses indicated a significant degree of positive change over time in the participants. While the coefficient alpha values for instrument reliability were not impressive at .71 and .69, the recommended value of .80 for widely used scales does not necessarily apply in all cases and may be too costly, in terms of time and money, to achieve (Carmines and Zeller, 1979). In addition, the patients whose questionnaire responses indicated positive change over time invariably were the ones who described positive change during the interviews. An exception was the score differences of the participant who had grown up in Europe during the war and had witnessed scenes of violent death. This woman's scores reflected no change probably because her 'before' scores were so high; it is very likely that her previous experience with death had taught her the value of life.

In addition to the significant total score differences, there were also differences on four of the 17 items which were significant for positive change. Appreciating the beauty of nature, having moments of deep serenity, believing that one's life has meaning and purpose, and believing that one has something of value to teach other's about life are essentially the same items that Yalom (1980) found significantly changed in his study of breast cancer patients.

Four items showed negative changes, although none of these differences were significant. Yalom (1980) also found negative change for the item, "having a sense of personal freedom." He attributed this to the physical restrictions imposed by the cancer. This might also explain the additional negative change for the items, obtaining

much pleasure from life and having a sense of psychological well being, found in the present study. The negative change for the item, having significant religious/spiritual beliefs, may have reflected either disappointment in God or else a tendency to look more to the self or other people for strength and support.

The women in the 46-55 age group reported significant positive change as reflected in their total score differences. The reason for this is unclear as there is no particular relationship between this age group and the variables of marital status or severity of the illness as defined by the presence or absence of metastases to other organs. In fact, one might expect negative rather than positive change in this menopausal age group. However, it is possible that personal change is more influenced by a life-threatening situation and unknown variables than by menopause. There was also significant change in this age group associated with an increase in the belief that they had something of value to teach others about life. It is possible that women in general, perhaps all people at this time in their lives, tend to think about what they would like to pass on to others, and this life-threatening situation enhances the effect.

Having moments of deep serenity was reported significantly more often in the 56-65 age group. Again, there was no apparent relationship between this age group and marital status or severity of the illness, although this may be the age in which people ordinarily become less concerned with practical issues in life and more concerned with philosophical ones.

Married women as a group reported significant increases in

moments of deep serenity. This finding is in accord with Metzger, Rogers and Bauman (1983) who determined that widowed breast cancer patients are more likely to be depressed than are married or single women with the disease. It is possible that married women tend to have more frequent moments of serenity because having a spouse, particularly during the time of illness and uncertainty, reduces stress sufficiently to allow for such moments.

While the questionnaire results provided evidence to suppport the conclusion that personal growth occurs in many people following the diagnosis of cancer, this personal growth was further demonstrated in the interview responses, often to a surprising degree. The patients talked frankly about their experiences and openly shared their feelings. Even the two patients who coped with their cancer by trying not to think about it not only consented to the interviews, but spoke freely about the impact it had made on their lives.

Most of the things mentioned by the patients reflected the issues discussed in the literature. The physical problems associated with both the disease and the treatment side effects were apparent, and the themes of the uncertain future (Taylor, 1982) and disfigurement emerged. Metzger, Rogers and Bauman (1983) found that 54 percent of mastectomy patients reported concerns relating to disfigurement. While only four of the participants in this study saw disfigurement as their greatest concern, a few additional patients talked about the altered body image, and it is possible that more might have named it as a concern if they had been specifically asked about personal

growth, and yet they clearly described it.

The internal resources that most patients have to help them cope as discussed by Bloom, Cook, Holland and Muenz (1980) were found in the majority of the participants, probably in all. The fact that of the 30 participants, only two had attended cancer education or support groups seem to indicate that internal resources are present regardless of outside influences. The seemingly low incidence of depression observed by the investigator supports the findings of Silberfarb, Maurer, and Crouthame (1980), and the improvement of psychological comfort over time found by Meyerowicz, Watkins and Sparks (1983) was also demonstrated by the participants. Evidence for the existence of Kubler-Ross staging is in accord with the conclusions of Weisman (1979) who found that two or more stages were likely to co-exist at the same time within the same patient.

The qualitative data obtained from the interviews correlate very well with the quantitative data found in the questionnaire responses. Both are in accord with the findings of Yalom (1980) and Spiegel and Yalom (1978) who described personal growth they had observed in cancer patients.

In addition, the personal growth found in this study is not unlike the change in attitude about life observed by Noyes and Slymen (1979) in people who had survived life-threatening accidents. It is also very similar to the positive changes in attitude about life, sense of renewal and purpose, increase in inner strength, and more positive attitude toward others which were found by Ring (1980) in people following near-death experiences.

This personal growth, then, seems to be related to the increased awareness of one's own mortality rather than to the cancer diagnosis itself. It is likely therefore, that it can be found in other people who, as Weisman (1979) observed of cancer patients during crisis, "are prodded into thinking about who they are and where they are going."

Implications for Counseling

A major implication for counseling is clearly illustrated by the fact that the majority of the patients stressed the importance of having a positive attitude. This positive attitude seems to be related not only to an acceptance of the situation but also to the preservation of hope, however the focus of the hope might change. A degree of hope should always be offered and reinforced; without hope, whether it is hope for a response to treatment or for one more good day, there is little left.

Getting involved with others and helping others with their problems were also considered to be important by a number of patients. This should also be encouraged and might be particularly helpful for people with limited family support.

Further implications for counseling are illustrated by the other conclusions drawn from this study: each patient is a unique individual, each patient has inner strength and resourcefulness, and each patient has the potential for personal growth. While it is true that many people who share the same illness tend to have some common reactions to that illness and some common needs which should be addressed; individual personalities, past experiences, and present situations are more likely to be remarkable for their differences.

The inner strength and resourcefulness of the patient can always be utilized and should never be underestimated, as many patients suffer incredible hardships and still prevail. For this reason, decisions to keep "the truth" from the patient are very rarely justifiable, if ever. Finally, there is a potential for personal growth which seems to be stimulated in people who are faced with existential crisis, and being diagnosed with cancer is just that. Facilitating this growth process might be a base for counseling not only cancer patients but other types of clients and ourselves as well.

Implications for Further Research

A study of personal growth following other types of serious illness would increase generalizability, as would a study of personal growth in male patients. Comparisons of men and women on personal growth achievement might prove interesting. Because it is very likely that some personal growth occurs over time as a result of the maturing process, a baseline study would be valuable as would studies comparing personal growth following other types of life events. Finally, it remains unclear why the respondents in the 46-55 age group reported greater personal growth in general and were more likely to feel they had something of value to teach others about life. This, as well as the fact that those in the 56-65 group were more likely to experience moments of deep serenity, could be investigated.

A discussion of results would be incomplete without a statement regarding the profound effect this study has had upon the investigator who prays that the lessons in successful living taught by the participants will never be forgotten.

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APPENDIX A

PERSONAL GROWTH FOLLOWING THE DIAGNOSIS OF CANCER:

INTERVIEWS WITH MASTECTOMY PATIENTS

A PILOT STUDY SUMMARY

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According to the Existentialists, if we are to truly savor life, we must first come to terms with the fact of our own mortality, a fact largely considered only by the philosophers until quite recently. During the past fifteen years, however, the area of death and dying has generated considerable interest and research. With the publication of Kubler-Ross' On Death and Dying, science has turned its attention to this ultimate of human experience.

Much of the research in the area has involved cancer patients because cancer has so long been associated with death. Even those who were fortunate enough to be cured did not escape the fear, the dread of the very word, "Cancer". And so reactions of the patient and his family to the diagnosis, reactions of the health professionals, varying support systems, treatment regimes, changes in lifestyle, coping strategies and counseling methods have all been investigated in an effort to help the cancer patient adjust to this crisis.

The fear of pain and death is only one dimension of the crisis, however. Hospice philosophy, a concept of care for the terminally ill is built upon the belief that although the patient is dying; most importantly, he is still living. It is the quality of that life remaining that deserves the greatest consideration. The dying itself takes but a moment, and so to live life as fully as possible is the goal of Hospice. It follows from this that as there is life, there is also the potential for growth. And it is this growth that is the other dimension of the crisis.

In Existential Psychotherapy, Yalom suggests that the diagnosis of cancer can bring about some changes in attitudes about life in

individuals facing this life-threatening illness. This potential for personal growth is the topic chosen for a thesis. It is the intention of the researcher to personally interview at least 30 mastectomy patients, asking eight open-ended questions dealing with the cancer experience. Following the interview, each subject will be given a "Personal Growth Questionnaire" to complete. The questionnaire was developed from Yalom's 17 personal growth questions published in Existential Psychotherapy. His written permission has been obtained. The sample will consist of women currently being treated by three medical oncologists. Interviews will be tape recorded whenever possible and transcribed.

The personal growth questionnaires will be scored, and interview responses reviewed and coded according to predominant themes which appear. Although Yalom found no evidence of Kubler-Ross' staging, indications of denial, anger, bargaining, depression and acceptance will also be noted. Stage of the illness and prognosis will also be considered. As the project is essentially qualitative, theory regarding personal growth will emerge from the interviews as well as questionnaire scores.

In preparation for the project, a small pilot study was done in order to test the hypothesis that personal growth may occur, to test the relevancy of the interview questions, and to develop sensitizing concepts for the codification of interview responses.

Method

Subjects

Participants were three women aged 40, 46 and 50 respectively who

had undergone mastectomies for the treatment of breast cancer. The eldest had been diagnosed 16 years previously and was currently being treated for metastatic disease. The others had been diagnosed about a year before and no evidence of metastatic disease had been found. All three were contacted by telephone after being made aware of the project by a Social Worker mutually known to us.

Apparatus

Apparatus consisted of a tape recorder, a 17 item personal growth questionnaire graded on a five point scale for periods both before and after the onset of the cancer, and a seven question interview guide.

Procedure

Participants were interviewed in their homes. They were told that their interviews were part of a pilot study being done to collect information for a thesis. Following the interview, the personal growth questionnaire was completed by each of the women. The interview tapes were later transcribed, reviewed and major elements abstracted. The questionnaires were reviewed and scores for each period in time were noted.

Results and Discussion

There was evidence for personal growth as shown by the scores of all three participants. One reported growth on all 17 questions, another on eight questions. The third reported growth on only one question, but her "Before" totals were considerably higher than those of the other two subjects. She may have achieved a great degree of personal growth before the onset of her cancer and thus had less room in which to grow. It is also possible that as she had become ill 16

years previously, she is no longer aware of a time when she perceived herself and her world in a different way. It is also interesting that she scored high for both "Before" and "After" on the item. "It is important to me to be liked by everyone." This is the one question stated in reverse and is not considered to be an indication of personal growth.

The interview questions generated a great deal of information about the subjects and their experiences. Sensitizing concepts and prevailing themes include:

Pre-existing physical problems vs. sudden awareness Relationship with the physician Degree of ongoing independence Need for stability Quality of the marital relationship, before and after Affect during the interview Fear Body image Femininity Personal values Spirituality Control over one's life Internal vs. external support Ambiva lence Identification with others (other's mastectomies, other's death)

There was no apparent evidence for Kubler-Ross' staging found in any of the three interviews, however the sample is very small. The interview questions were purposely structured in such a manner so as to elicit responses which would tap the feelings and concerns of the individual without leading her by suggestion. However, question #6, "What has been the least helpful?", has a high degree of ambiguity and will be changed to, "What has caused you the most distress since the diagnosis was made and what have you done to cope?" Also, the third

subject was asked at the end of the interview, "Is there anything that was very important to you at this point in time that we haven't covered?" This question generated significant information and so a modified version has been incorporated into the interview schedule.

In summary, the pilot study provided some interesting insights into the experience of the person who is faced with life-threatening illness. The fear of death seemed to be of less concern than was getting on with one's life. Each of the participants was quite open, supporting the prevailing opinion that people who have had such experiences are willing, even anxious to tell their stories. Of course, it must be recognized that such participants are self-selected and may differ considerably from those who decline participation in such a study. Nevertheless, it is very possible that information obtained from those willing to share their feelings and experiences will have counseling implications for those who cannot.

| | THICELATEM | nomper. | |
|---------------------------------|---------------|---------|------|
| | | | |
| AGE | | | |
| MARITAL STATUS | | | |
| WHEN DIAGNOSED | | | • |
| CANCER EDUCATION OR SUPPORT GRO | HIDS ATTENDED | | |

AN INVENTORY OF

PERSONAL FEELINGS AND BEHAVIORS BEFORE AND AFTER THE

ONSET OF CANCER

Please read each of the following statements about your feelings and actions both before the onset of your cancer and at the present time. Circle the number corresponding to the response that most accurately describes these feelings and actions for each period in time.

If the statements pertaining to husband or children are not appropriate for you, leave them blank.

| | Hardly ever | Sometimes | As often | _ | Freque | ently | <u>A</u> | ay | 3 | |
|-----|---|----------------|----------|-----|--------|-------|----------|-----|-----|----------|
| | 1 | 2 | 3 | | 4 | | | 5 | | |
| | | | | | | | | | | |
| | | | | BEF | ORE | | | N | OW | |
| 1. | I communicate oper husband. | aly with my | 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | ¥ 5 |
| 2. | I appreciate the nature. | beauty of | 1 | 2 3 | 4 5 | | 1 | 2 | 3 4 | 5 |
| 3. | I have a sense of freedom. | personal | 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | 5 |
| 4. | I try to communication with my children. | ate openly | 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | 5 |
| 5. | It is important to liked by everyone | | 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | 5 |
| 6. | I obtain much plealife. | asure from | 1 | 2 3 | 4 5 | | 1 | 2 | 3 4 | 5 |
| 7. | I communicate hone frankly. | estly and | 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | 5 |
| 8. | I do only those the want to do. | nings I really | r 1 | 2 3 | 4 5 | | 1 | 2 : | 3 4 | 5 |
| 9. | I live in the pres than in the past of | | 1 | 2 3 | 4 5 | | 1. | 2 | 3 4 | ¥ 5 |
| 10. | I have moments of | deep serenity | y. 1 | 2 3 | 4 5 | | 1 | 2 | 3 4 | 5 |

| I stand up for my own personal rights. | 1 2 3 4 5 | 1 2 3 4 5 |
|--|-----------|-----------|
| 12. I have a sense of psychological well-being. | 1 2 3 4 5 | 1 2 3 4 5 |
| 13. I communicate openly with my with my friends. | 1 2 3 4 5 | 1 2 3 4 5 |
| 14. I feel I have something of value to teach others about life. | 1 2 3 4 5 | 1 2 3 4 5 |
| 15. I am able to choose what I want to do. | 1 2 3 4 5 | 1 2 3 4 5 |
| 16. My life has meaning and purpose. | 1 2 3 4 5 | 1 2 3 4 5 |
| 17. Religious/spiritual beliefs | 1 2 3 4 5 | 1 2 3 4 5 |

INTERVIEW SCHEDULE

- 1. How did you learn of your diagnosis?
- 2. What were your feelings at the time?
- 3. Have these feelings changed over time and if so, how?
- 4. How has your life changed since you learned of your cancer?
- 5. What have you found to be most helpful to you?
- 6. What has been the least helpful?
- 7. What advice would you give to other cancer patients to help them cope with their illnesses?

INTERVIEW SCHEDULE (revised)

- 1. How did you learn of your diagnosis?
- 2. What were your feelings at the time?
- 3. Have these feelings changed over time and if so, how?
- 4. How has your life changed since you learned of your cancer?
- 5. What has caused you the most distress since the diagnosis and what have you done to cope?
- 6. What have you found to be the most helpful to you?
- 7. What advice would you give to other cancer patients to help them?

APPENDIX B

Personal Growth Following the Diagnosis of Cancer:

| Project Title Interviews with Mastecto | omy Patients |
|---|-----------------------------------|
| For the thesis, Loyola I | University of Chicago |
| (volunteer) years of age and that I wish to partic being conducted by Nancy L. Mahoney. | |
| I understand that my participation will the administration of a questionnaire, understanding of the feelings and expediagnosis of cancer. | , and that the purpose is to gain |
| For the purpose of accuracy, I also corecording of the interview. | onsent to the audio-tape |
| I acknowledge that I have been informed participation at any time without prejudich I may have concerning the process answered. | judice, and that any inquiries |
| I freely and voluntarily consent to my project. | participation in the research |
| | |
| (Investigator) | (Volunteer) |
| (Date) | (Date) |

APPENDIX C

INTERVIEW SCHEDULE (revised)

- 1. How did you learn of your diagnosis?
- 2. What were your feelings at the time?
- 3. Have these feelings changed over time and if so, how?
- 4. How has your life changed since you learned of your cancer?
- 5. What has caused you the most distress since the diagnosis, and what have you done to cope?
- 6. What have you found to be the most helpful to you?
- 7. What advice would you give to other cancer patients to help them?

APPENDIX D

AN INVENTORY OF

PERSONAL FEELINGS AND BEHAVIORS BEFORE AND AFTER THE ONSET OF CANCER

Please read carefully each of the following statements about your feelings and actions both before the onset of the cancer and at the present time. Circle the number corresponding to the response that most accurately describes these feelings and actions for each period in time.

If the statements pertaining to husband or children are not appropriate for you, leave them blank.

| Ne | | ver | Sometimes | As Of | ten Frequently not | | Almost always | | | Alway | | | ys | | | | |
|----|------------------------------|-------|---------------------|--------|--------------------|---|------------------|---|---|-------|----|-----|----|---|---|---|---|
| | 1 | 2 | 3 | | 4 | | | 5 | | | | | 7 | | | 7 | |
| | · | | | BEFORE | | | | | | NOW | | | | | | | |
| i. | I commun | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | I have a | | of personal | . 1 | 2 | 3 | 4 | 5 | 6 | 7. | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | I live if the pres | ather | _ | . 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 4. | I try to | | nicate children. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 5. | It is in to be li | - | t to me | 1 | 2 | 3 | 4 | 5 | 6 | 7 | .1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 6. | I obtain | | e pleasure | ì | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 7. | I have of communicated frame | ating | lty in honestly | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |
| 8. | I stand personal | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | . 2 | 3 | 4 | 5 | 6 | 7 |

| 9. | I have a sense of psychological well-being. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|-----|--|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 10. | I do things I really don't want to do. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. | Communication with friends is guarded rather than open. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. | I appreciate the beauty of nature. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. | I have moments of deep serenity. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. | I feel I have nothing of value to teach others about life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. | I am unable to choose what I want to do. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16. | My life has meaning and purpose. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17. | Religious/spiritual beliefs have much significance for me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

APPENDIX E





STANFORD, CALIFORNIA 94305 • (415) 497-6352

Irvin D. Yalom, M.D., Professor Department of Psychiatry

August 13, 1984

Nancy Mahoney 7471 W. Rosedale Chicago, Ill 60631

Dear Ms. Mahoney,

Yes, you have my permission to use my questions about personal growth in your research. My own experience is that Kubler-Ross' stages don't hold up very well when working with patients who have metastatic disease but sill may have months or years of life ahead of them. In fact, my experience was that many patients resented the idea of staging and one patient set about writing a book attempting to refute that very point. I've lost touch with her and don't know whether she ever finished the book but I did sympathize with her point of view.

Sincerely,

Irvin D. Yaldm, M.D.

Professor of Psychiatry

IDY:bm

APPENDIX F

Dear Anybody:

I am dying. But don't become alarmed, and please don't feel sorry for me. After all, we are ALL dying.

Two and 1/2 years ago I learned I have cancer. This news came at a crisis time in my life, but I am handling it.

In talking with others, would you believe, some people feel they have to move out of town to a new area, not because of the devastation of the disease, which can be controlled by drugs, but by the way a person is treated. We can all lead a normal life, taking part in activities and going to work full time, but there ARE people that have made our lives miserable. Some of the people I thought were my FRIENDS no longer call or want to associate with me. I have been treated like some sort of social outcast. I even lost my job, because a new manager found out I had cancer, making my life a living hell.

I changed my place of work. I no longer want or have negative people around me. I do work full time, I have many GOOD FRIENDS, and FAMILY, and I participate in the same activities I did before.

I know that this may not last forever, but right now, I look good, feel wonderful, and I have the great hope that I can lick this dreaded disease.

You are reading this letter because I want to educate you. There are many people in this world around just like me, and I/we need your help.

You can help by:

Treating me the same as you would any well person. Don't always ask me, "How is it going?"

Include me in your gatherings, and any other social or work related activities. I need friends too.

Don't always discuss funeral arrangements with me.

I forget I have any disease. My positive mental attitude is my life-saver.

Ask me out. Develop a friendship/relationship with me. YOU COULD EVEN MARRY ME, Remember I could outlive you or even some of my healthy friends.

Hire me. I am a productive person as well as a dedicated employee. I will live longer, be happier if I am productive. If I, or others like me are forced to go on welfare or disability, it will raise YOUR taxes.

Give to the American Cancer Society. They support research, educate and alert the public to cancer signs. And plan to get a check-up.

Treat me as you would want to be treated.

Enjoy me! Laugh and cry with me! Be my friend and LOVE ME! I HAVE A LOT OF LOVE TO GIVE.

Approval Sheet

The thesis submitted by Nancy L. Mahoney has been read and approved by the following committee:

Dr. Gloria J. Lewis, Director Associate Professor and Chairperson, Counseling Psychology and Higher Education, Loyola

Dr. Manuel S. Silverman Professor, Counseling Psychology and Higher Education, Loyola

The final copies have been examined by the director of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the Committee with reference to content and form.

The thesis is therefore accepted in partial fulfillment of the requirements for the degree of Master of Arts.

une 2, 1986 Sloria Director's Signa