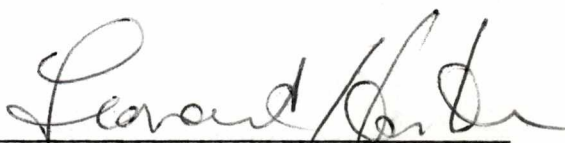
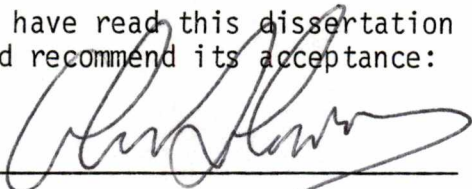


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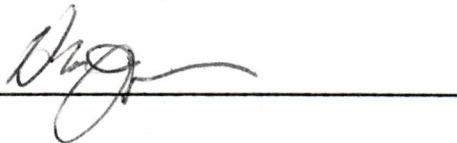
I am submitting herewith a dissertation written by Karl W. Buddenhagen entitled "The Worlds of Cancer Patients." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.


Leonard Handler, Major Professor

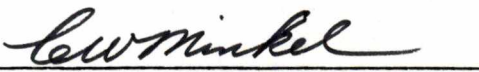
We have read this dissertation
and recommend its acceptance:







Accepted for the Council:


The Graduate School

4

THE WORLDS OF CANCER PATIENTS

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Karl W. Buddenhagen

March 1984

To Ernie

Crystal

Dudie

Bob

John

Norma

With many thanks

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ABSTRACT

"The Worlds of Cancer Patients" reports a phenomenological study of the experienced worlds of six cancer patients. In four to ten hours of interviewing with each patient each person's unique experiences of cancer were explored. Data analysis was accomplished using a phenomenological reduction procedure which abstracted essential statements from recorded interview data while retaining verbatim the language of each subject. This procedure followed a paradigm established by Keen, Giorgi, Colaizzi and others. Direct statements about the subjects' experience of cancer were collected from the interview material. The resulting protocols were reduced to their essential elements by eliminating repetition and choosing the best statement in a group of closely related statements. The remaining statements were grouped into theme areas and the themes organized into superordinate groups to facilitate comparison of the six subjects' protocols.

Results were discussed first in terms of the shared perceptions of all six patients of the experience of cancer. Their statements were organized into three superordinate categories: Being, Doing and Being-with-Others. Patients described their relationship with cancer in terms of limitations on their lives and the painfulness of the disease and the treatments. They stated that they "don't dwell on" their illness and don't often think about being a "cancer patient." Perhaps the single most important finding of the study was that each patient, no matter how many or few close family or

friends he or she had, described vividly the importance of these relationships in coping with having cancer. Each superordinate category was composed of two thematic elements which are detailed in the results section. These six shared themes were used to develop the Cancer Experience Questionnaire, a small number of questions of value to clinicians and researchers for both psychosocial screening and more detailed interviews with cancer patients. The questionnaire can be used as a tool to quickly discover significant issues and areas of concern for patients. The protocols were also discussed in terms of each subject's unique experience of cancer as well as theme areas of partial agreement: themes which were significant for more than one but not all of the subjects. The discussion section described the value of phenomenological research as a "human science," described the relationship of this study to previous research, covered methodological concerns and suggested areas for further research.

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CHAPTER I

THE CANCER PERSONALITY

This introductory chapter will describe in detail the psychological literature on the personal functioning of cancer patients. While personality is flexible, it is in most cases not changed markedly by even such a disaster as cancer (Bacon, Renneker and Cutler, 1952). It is the lifelong pattern of behavior of cancer patients and some description of the reaction of patients to their illness which we will attempt to delineate in this section.

Surface Personality

In my work on the Oncology Unit at East Tennessee Baptist Hospital last year I often heard the staff remark that patients on the unit were "very nice people." This description is more than just the usual sort of compliment and it was a remark that I heard repeatedly from almost every staff member. The psychological research bears out this common perception: cancer patients are friendly, agreeable, compliant and submissive (Appelbaum, 1981). They report feeling content rather than depressed (Dattore, Shontz and Coyne, 1980) and are hesitant to complain (Kissen, Brown and Kissen, 1969). They are responsible, hard-working people for the most part who are conscientious in their work and family obligations (Greene, 1966). Cancer patients are not wont to express negative feelings and they seem equally hesitant about positive feelings. This friendly but reserved and repressed personality style is universally

described in the literature. Some authors (Greer and Morris, 1975) have noted a small subpopulation of particularly vituperative cancer patients. They are similar to other cancer patients in their responsible and basically cooperative nature, but they are as unusually emotionally expressive as most other cancer patients are emotionally repressed. Both "types" of patients are similar in their insistence on independence and self-control which at times can make their treatment quite difficult (Booth, 1969). They want to know what is being done to them and they do not enjoy the feeling of not being in control of their lives. This style makes the subgroup of feisty patients a particularly difficult group to treat. Their mild-mannered peers tend to suffer silently and fight against treatment indirectly, by missing appointments and by other "passive-aggressive" means.

The niceness of cancer patients has been described as due to a hesitancy to express negative feelings or to feel that other people are hostile or unfriendly (Bahnson and Bahnson, 1966). They feel that other people are more important than they are. LeShan (1966) describes a common pattern he noted in his research and therapy with cancer patients:

They were good to others and gave far more than they ever felt they received, but the one-way street nature of their perceived relationships seemed only justified to them They found it difficult to express or defend their own wishes . . . (and only) in the interest of their group or of (a) relationship could they act very strongly (p. 786).

Cancer patients are also often seen as being usually rather superficial in most social relationships and they are generally

seen as not being very heavily invested in most of their relationships (Kissen, et al., 1969). While they conform socially, cancer patients seem to have only a few close relationships which are of real importance to them. Even in these contacts there is a sense in which cancer patients feel put out, in that they feel that they put more energy into their relationships than do the people with whom they are close. Their "significant others" do not share this perception, which evidences the difficult time these patients appear to have with close relationships.

Psychodynamics of the Cancer Personality

The outward niceness of cancer patients appears to cover some hidden, disturbing feelings. Their thoughtful, gentle natures appear to be a way for these individuals to attempt to win love and affection which they feel they have never received (Pelletier, 1977). Underneath their pleasant facade, such people feel unworthy and have little self-love. Bacon, et al., (1952) studied 40 breast cancer patients and saw a facade of easy sociability. Their evaluative data revealed women who were masochistic, inhibited sexually and unable to express anger, aggressiveness, or hostility. This kind of repression and inhibition is probably the most marked behavioral expression of cancer patients. Again and again it turns up in the literature: "the cancer group showed greater repressive tendencies . . ." (Dattore, et al., 1980); "Thus the hypothesis of inhibited aggression set forth by others receives

additional support here . . ." (Appelbaum, 1981); ". . . repressive ego defenses are the most outstanding and characteristic features . . ." (Bahnson and Bahnson, 1969); ". . . an inability to consciously accept and express disturbing elements . . . less able to discharge emotion . . ." (Kissen, et al., 1969); ". . . repression of hostility and guilt are as important aspects in the cancer personality as is overt depression . . ." (Bahnson and Bahnson, 1966). Some researchers also report that cancer patients do not project undesirable emotions onto others (Bahnson and Bahnson, 1966), and they deny that they are depressed more frequently than do non-cancer controls (Dattore, et al., 1980). They are unaware of unpleasantness in themselves or in the world, which leads to their blandly friendly manner and a Pollyanna outlook on life (Bahnson and Bahnson, 1969).

Booth (1965) administered the Rorschach inkblot test to 93 patients with cancer and 82 patients with tuberculosis. He found that despite their facade, cancer patients ". . . strive for independent self-expression and to avoid emotional involvements on the level of equality (p. 44)." Unlike tuberculosis patients, cancer patients rarely formed dependent relationships with their physicians although they did follow their recommendations for treatment. They put a great deal of emphasis on self-control and they also demanded control in their interpersonal relationships. They depended a great deal on one or two other people or on a job role to feel good about themselves. These important other people were guarded and controlled carefully because they are so essential

to the patient (Booth, 1979; Kissen, 1966). The control they exert is of a subtle kind, because these people hesitate to speak up about what they want. Despite this their control loses none of its power for its quietness.

A final important dynamic aspect of the cancer personality speaks to this issue: cancer patients often appear uninvolved in their own lives, while they are actually grimly struggling to hold on to a job role or a relationship which they experience as being necessary to life itself. This seems related to the pervasive, though deeply repressed feeling of the cancer patient that ". . . no matter what he achieved, his basic feelings of failure predominated (LeShan, 1966)." The "social selves" of cancer patients (the surface personality) are indeed "false selves" which are removed from any of the patient's emotional realities, due to the extent of the patient's repressive defenses (Bahnson and Bahnson, 1966). They follow bleak, repetitive routines in their life-styles and are, in the words of Kierkegaard, "in despair of being themselves (LeShan, 1966)."

Childhood Development

In classical psychodynamic thought, the basis for adult personality is believed to be laid down in early childhood. We are fortunate in having remarkably clear experimental evidence of this in the cancer personality. Carol Thomas (Thomas, Duszynski and Shaffer, 1979) began the Precursors Study in 1948 at Johns Hopkins University in order to study personality/lifestyle effects

on essential hypertension and coronary heart disease. Thomas did wide enough data collection, however, so that her study has become a classic in the areas of suicide and of the cancer personality. The subjects were 913 white male physicians, who were graduated from Johns Hopkins University in the years 1948-1964. One of the psychological tests administered was the Family Attitudes Questionnaire, measuring medical students' feelings about their parents and siblings. The subjects who were to develop cancer (40 subjects so far) indicated a lack of closeness to parents as compared to the other subjects. In fact, in their expressed distance from their parents, the cancer group was very similar to the group of subjects who were later to commit suicide. These findings are similar to the observations of cancer patients made by Carl and Stephanie Simonton who note that cancer patients feel rejected by either one or both of their parents (Simonton and Simonton, 1975). In addition, this feeling of a lack of closeness appears to be accurate: the families of cancer patients are noted for a lack of open expression of emotion and closeness between parents and children (Booth, 1979). Thomas' study confirmed this finding and also generated some evidence that the families of these patients tended to be dominated by the mother.

Other researchers (LeShan, 1966; Pelletier, 1977; Bacon, et. al., 1952) agree with Booth (1979) that the early childhood of cancer patients was marked by "traumatic frustration in the mother relationship." The nature of this frustration is not explored in the cancer literature but will be discussed later in this chapter.

This frustration leads to conflict with the mother, which is never adequately resolved (Bacon, et al., 1952; Booth, 1979). Feelings of anger, anxiety and rejection then ensue. It is this repressed conflict which is crucial in the adult cancer personality.

Lawrence LeShan studied the life histories of 450 cancer patients in a 12-year study. He summarized his findings as follows:

Early in life, during the first 7 years, damage was done to the child's developing ability to relate (to others). Often this was accentuated by a physical event, such as a loss of a parent, the death of a sibling or something of this sort. From his experience at this time, the child learned to feel that emotional relationships brought pain and desertion. Loneliness was his doom. In the usual manner of children, this was attributed to some fault of his own rather than to the result of accidental forces. Guilt and self-condemnation were the inevitable response . . . (LeShan, 1966, p. 781).

Because of this sense of failure in early family relationships, the child attempted to overcompensate by trying to win the affection of others by pleasing them (Pelletier, 1977). Underneath this facade are feelings of anger, loneliness, hopelessness and self-hatred so threatening that they are deeply repressed. In this way the future cancer patient shuts himself off from emotional contact with others, and because of the depth of repression, is shut off from his own feelings.

The Issue of Separation and Loss

LeShan (1959) postulates a loss-depression syndrome of cancer causation. He describes the patient before cancer diagnosis as we have described him: very superficially pleasant but repressed and depressed, holding on tightly and possessively to a job role and/or to a few essential relationships. He functions adequately but

superficially in other relationships or life tasks. Then, according to LeShan:

. . . for reasons beyond the individual's control, the relationship was lost. This occurred through such events as the death of a spouse, children growing up and moving away, retirement from a job and others. Attempts to find substitute relationships failed, and the patient underwent a period of intense despair which was later repressed. Within a period of 6 months to 8 years after the loss of the relationship, the first signs of malignancy were noted (1959, p.9).

Greene (1966), in studying over 100 leukemia and lymphoma cases, found that these cases "developed in a setting in which the patient was also dealing with a number of losses or separations (p.800)." Green and Swisher (1969) studied three sets of male identical twins, in which one twin had leukemia and the other did not. The leukemia was found to occur in a setting that was quite stressful for the entire family, but especially so for the patient who developed cancer. In all three cases, a loss of some kind was sustained, and two of the cases would fit LeShan's paradigm. In contrast, Muslin, Kalman and Pieper (1966), in a very well-designed and conducted double-blind study found that in 37 matched pairs of individuals with cancerous versus benign tumor growth, there was no difference in separation experience, either early in development or recently in life. It is possible that the outcome would vary with healthy controls rather than controls with benign tumors. However, the claim made by LeShan that loss is nearly the universal proximal cause of cancer has not been consistently supported by the main body of the literature.

Toward a Unified Theory of "Cancer Personality"

One of the most striking elements in research on the cancer personality is the lack of a unifying conception. Dattore, et. al. (1980) describe two of the more popular theories: LeShan's theory of loss leading to depression and Bahnson's (and others) of the role of ego defense mechanisms. Both these conceptions are too limited to provide a complete understanding of the cancer personality style. Still, they are both helpful pieces of the larger puzzle.

Depression is a key factor in the two main theories of cancer personality. This appears to be an underlying theme in the research literature as well. Greer and Morris (1975) found that 35% of their 69 breast cancer patients had suffered from a depressive illness for which they had received medical treatment some time in the five years prior to their cancer diagnosis. Their discovery that 36% of their benign breast tumor controls had also been treated for depression obscured their finding, but it might be best explained by a similarity in patients who have benign and those who have cancerous tumors. Goldfarb, Driesen and Cole (1967) treated three patients with advanced cancer and "concomitant depression" with electro-convulsive therapy, with improvement both in the depression and the cancer. Stoll (1979a) states that ". . . depression is the most common mental disorder found in cancer patients, and significant depression . . . is found in at least one-quarter of cancer patients."

This evidence prompted a search of the literature on depression, particularly on the depressive personality, and there the image of

the cancer personality is filled in with rich detail.

Friedman (1974) describes Schmale's subtypes of depressive personality. One type is our previously described interpersonally controlling cancer patient: ". . . who relate to few other people but who depend on those people for their narcissistic identification. They are described as 'sticky, demanding and pessimistic'." Schmale describes these individuals as defending against a "high helplessness predisposition." The other type of person, defending against a "high hopelessness predisposition," is overly responsible, believing that salvation resides in hard work, regardless of the results. These people are often described as "masochistic" or "pseudo-independent." Edith Jacobsen (1953) describes depressive personalities as warm, companionable and apparently mature, but with a crucial specific ego weakness. Again, the control of relationships recurs: ". . . they require a constant supply of love and moral support from a highly valued love-object . . . (p. 67)."

It is important to note that depressive personalities often do not appear to be depressed or sad, nor is their personality style the same as the emotion of depression, which almost everyone experiences from time to time (Friedman, 1974). The kind of chronic depressive personality we are describing has a life-long pattern of experiencing and interacting with the world which is superficial; such people shy away from close interpersonal relationships unless the other person is perceived as someone who will meet their needs while not putting demands on them. Basic trust in oneself is not established and these people have an underlying feeling of worthlessness.

They expect to fail and to be rejected by others and so they experience a feeling of futility in trying to be successful or to please others, despite their extreme efforts and outward success. Becker (1974) and Chodoff (1974) both further delineate the dependency of these people on others, their need to be loved and nurtured. Chodoff describes their manipulations, submission, coercion, piteousness, demands or placation, used to maintain their needy ties to others. Rado (1928) describes the change which takes place in depressives when they have become secure in this relationship:

They accept the devoted love of the beloved person with the sublime nonchalance, as a matter of course, and become more and more domineering and autocratic, displaying an increasingly unbridled egoism, until their attitude becomes one of full-blown tyranny. They cling to their objects (other people) like leeches and feed upon them, as though it were their intention to devour them altogether . . . (p.422-23).

In all other relationships, they remain friendly but superficial, and to all appearances, meek.

According to Fast (1967), development of the depressive personality begins in childhood. The pre-depressive child does not develop firm boundaries between himself and others. Without a secure sense of self, the infant's feelings are highly dependent on the feeling-state of the mother. If she is gratifying then all is well in the world; if she is rejecting everything is terrible. This all-good/all-bad thinking is called "splitting," and is a defense mechanism which acts to safeguard good objects, permitting the infant to rely on them (Klein, 1945). This primitive defense is needed because the infant is not confident in the self's ability to overcome bad

states: anger or destructive rage. The "all-bad" side is split-off and repressed, however, making for intensely ambivalent interpersonal relationships. While the depressed person is mostly unaware of bad feelings, this affects his ability to love, limiting it greatly. Abraham (1924) describes this pattern: "The child had felt that he was his mother's favorite and had been certain of her love. He had then suffered a disappointment at her hands . . . later on, he had had fresh experiences of the same sort which had made him feel that his loss was an irreparable one . . . (p. 459)."

The developmental precursors for this personality style are quite clear. The mother, and probably both parents of the pre-depressive child offer little affection to the child. Negative and aversive messages are used to train the child, who is rarely rewarded for his behavior. Without affection and encouragement the child never learns that he is worthwhile. He never becomes able to be adequately self-motivated or able to give affection freely to others. Depression is the child's bungled attempt to cope with sadness and loss prior to the establishment of a solid sense of self-worth. This leaves the child feeling lost, alone, and frightened (Friedman, 1974). The child (and this carries over into adulthood) feels that he has caused the mother to hate him. The key conflict then is the child's guilt because of his misguided notion that it is his own fault that he has lost the love of others: that by his aggressiveness he has destroyed them.

That early separation from the mother causes depression has been seen again and again and it has been borne out as well in

studies of monkey mother-child pairs (McKinney, Suomi and Harlow, 1973). Perhaps the clearest description of the development of the depressive personality in humans is found in the work of Margaret Mahler and her colleagues (Mahler, Pine and Bergman, 1975).

Mahler describes the process of separation and individuation in infants and toddlers from birth through roughly three years of age. The crucial stage for the depressive personality is the third subphase of the separation-individuation process, the rapprochement period. The crisis at this stage, theoretically unresolved in cancer patients, is the fear of losing the love of the parent and is manifest in oversensitivity to the approval and disapproval of others. Life becomes then a careful walk on a narrow path with loneliness on one side and loss of self on the other. Without the consolidation of a solid sense of self, each step is a shaky one.

It seems clear from this discussion that the "cancer personality" described in the cancer literature is synonymous with the "depressive personality" of the classical literature on depression. While this is an impressive finding which links these bodies of research, it leaves unanswered the question of a causal link between personality and cancer. LeShan (1966) and the Simontons (1975) among others argue for such a relationship, describing the theoretical impact of depressive emotions on the immune system. This is a new area in medical research, but already some studies have developed evidence supporting this position (Bartrop, Luckhurst, Lazarus, Kiloh and Penry, 1977). Unfortunately, the fields of psychophysiology in general and neuroendocrinology in particular are in their infancy in these areas.

This is particularly true when it comes to clearly demonstrated links between specific emotional states, such as depression, and specific physiological states (Nossal, 1976). Selye (1976) and others have demonstrated strong correlations between personality styles and physical illness, but only at a very generalized level. The fact remains that not all Type-A personalities suffer from high blood pressure or heart disease nor do all "depressive personalities" develop cancer (Greer and Morris, 1975). The best that can be said at this time is that the depressive personality style is quite common, though not universal, in people who develop cancer. A more direct and specific relationship between personality and cancer is currently only theoretical and speculative.

This chapter has described the views of psychologists who work with cancer patients. In the next chapter we will present the views of cancer patients themselves as they have appeared in the literature.

CHAPTER II

A PHENOMENOLOGICAL APPROACH TO THE STUDY OF CANCER

Research and Self-Report Material

A representative portion of the increasingly large body of research on the "psychosocial aspects of cancer" (American Cancer Society, 1980) was discussed in Chapter 1. The subtypes of this literature include studies of cancer patients, their families and the meaning of cancer; practical descriptions of therapy and programs; discussion of death, dying and bereavement with patients and families; and perhaps the most rapidly expanding area, home health care through hospice and other programs, that emphasize the use of lay volunteers for a variety of services.

The present research project represents the mutual efforts of the researcher and six cancer patients in an attempt to map the territories of their lives which the "weather of cancer" has marked. This chapter will review prior work designed to illuminate the experience of being a cancer patient and will present a description of phenomenological research methodology.

Myra Bluebond-Langner conducted a painfully beautiful study of a small group of young children, aged three through nine, dying of acute lymphocytic leukemia. These results are reported in her book, The Private Lives of Dying Children (1978). Bluebond-Langner used a non-intrusive technique based on a form of modified play therapy. She spent a great deal of time with the child patients while she had more limited interaction with staff and parents. For the most

part she saw the children alone, when their parents were absent. She also saw the children in groups in the outpatient waiting area and together with their parent(s) in the child's hospital room. She rarely asked direct questions and then only after some contact with the child, during which time they would often watch T.V. or play together. She originally was a distanced observer, but found this to be much less true to the data than her eventual interactive approach, which she described in Sullivanian terms as "participant observation." From a clinical perspective, she worked as a psychotherapist to and with these children. She developed excellent rapport by being cooperative, interacting and emphasizing understanding rather than questioning and "treatment." It is not clear from Dying Children exactly what types of data Bluebond-Langner used, but from the results she reports she appears to split the difference between validation/theory construction and a more impressionistic/descriptive approach, in what appears to be an adequate phenomenological discussion of the data.

Her results are reported in three sections. The first is a report of her experiences with the children in the form of a five-act play. It is divided into acts based on the stages of learning about serious illness and death through which she postulates that the children inevitably pass. The second section details these stages and uses descriptive examples. In the third section she becomes more explicitly value-laden, advocating "open awareness" and discussion of death rather than the more typical "mutual pretense." This is particularly interesting in that she did not see any advantage for those who were openly aware other than the parents' report that

their own awareness helped them to cope better with their child's prognosis. Staff often avoided children who practiced open awareness. Parents had the additional burden of what to tell their children and were ostracized by other parents for being "bad parents" for not protecting their children from bad news. In most other concrete ways, there was very little difference in the two styles. Bluebond-Langner emphasizes that openness is not the panacea that some writers claim it to be. Like Kubler-Ross' (1969) fifth stage of acceptance, it is easy to imagine a "return to the garden." Bluebond-Langner demonstrates her perceptiveness in expressing so clearly that life's problems go on no matter how well we learn to cope with them.

The five stages of understanding of the illness begin shortly after the initial diagnosis. First the children find out that they have a serious illness, not just measles or the flu, although they have little idea yet just how profoundly ill they are. The next stage consists of concrete learning about the operation of the hospital, the names of procedures (bone marrow, x-rays, scans and so on), drugs and drug side effects. Then gradually, through interaction with other children and the piecing together of parents' and physicians' statements (or, in rare instances, direct communications from them), the children learn the purposes of the treatments. The fourth stage begins after the first relapse following initial remission. The children come to understand their illness as a series of relapses ('bad times') and remissions ("good times"). Finally, in the fifth stage, through the experience of the death of another child,

the children learn that eventually they will not gain remission and that they too will die. Their awareness of the deaths of other children was often uncanny, considering the lengths that some parents would go in attempting to protect their children from this knowledge. In every child their own awareness of death occurred immediately after the first death they experienced once having reached stage four.

It is clear in this descriptive study, and in her personal account of the work in the appendix, that Bluebond-Langner was able to allow her subjects, these leukemic children, to show her their worlds. She vividly describes in her somewhat labored prose, her guilt, anger and, more subtly, her despair about the difficulty of this work. Our cultural denial of death makes it easy for the researcher to maintain distance from dying subjects (Becker, 1973). Bluebond-Langner mentions several occasions in which she, like the childrens' parents, needed to imagine that this time the statistics were wrong and this child would live. The painfulness of the experience of cancer makes this sort of phenomenological research quite difficult.

Norman Cousins (1979) described his experiences with ankylosing spondylitis--a fatal collagen disease--in his popular book The Anatomy of an Illness. He discovered his disease in 1964 when gravel-like nodules appeared under his skin. He was hospitalized, tests were conducted and numerous specialists were called to examine him. Cousins was infuriated by hospital routines, particularly the repetitive (and, he felt, unnecessary) tests, daily blood sampling and various intrusions on sleep and privacy. He is a

rare patient in that he complained aloud, enlisted his physician's aid, and became his physician's partner in treatment planning. He familiarized himself with the medical research on his illness and devised a treatment plan at variance with usual medical practice, but with the support of his physician. He checked out of the hospital into a motel room so he could have more privacy, he hired a private nurse and began megadose vitamin C therapy, eventually taking 25 grams per day. Instead of pain-killing drugs he watched movies of "Candid Camera" provided by his friend Alan Funt and had his nurse read to him from a "trove" of humor books. He found that laughter relieved his pain to the point that more often than not he could sleep without pain for two hours at a time or more. Gradually his pain decreased, his fever subsided and by the eighth day his nodules appeared to shrink. At the end of three weeks he was well enough to go on a vacation to Puerto Rico. It took 11 years for him to become completely free of pain when exercising, but he has not yet had a relapse and appears to be one of the only 1 in 500 patients with this disease who are cured.

Cousins concluded that "the will to live" had an important role in his recovery. He is not adverse to the conclusion that the placebo effect accounts for his recovery and quotes Ana Aslan, a Rumanian endocrinologist, who feels that creativity (an aspect of the will to live, in Cousin's opinion) triggers the endocrine system. His total involvement in his cure and his physician's willingness to let Cousins be a "respected partner" in his treatment

were also important in the cure according to Cousins. He attributed his ability to withstand pain to his firm belief that he would recover. When told by specialists that his disease was incurable he did not accept this judgement and was neither afraid nor depressed. He describes himself as being aware of the seriousness of his illness but never losing his feeling that he had a good chance of recovery. He is an advocate of holistic medicine, an approach which believes that emotional states have a great impact on physical health. His world view was not changed by his illness, but perhaps his belief in his ability to overcome illness was strengthened with the disease acting as a catalyst.

Neil Fiore (1979) is a California psychotherapist who discovered in 1974 that he had an embryonal carcinoma. In many ways his case is similar to that of Cousins. This is particularly so in that Fiore and Cousins both survived against very long odds. This makes them both a part of a very valuable, but positively skewed sample. Fiore was familiar with the research on the placebo effect and the importance of the immunological system in fighting cancer. He also quickly familiarized himself with the medical research on his type of cancer. In contrast to Cousins, he underwent orthodox medical treatment: chemotherapy with adriamycin, bleomycin and velban. Nonetheless, like Cousins he was a pushy patient, ready to fight for his opinion and to push for his case to be seen in review by the tumor board at the hospital where he was treated. His relationships with his physicians were also excellent, so much

so that he was asked to make a videotape for other patients telling them how he dealt with having cancer and the side effects of cancer therapy. Also, like Cousins, he speaks only in passing of his feelings about cancer and his changed perception of the world. The only exception is his report of his reflection during a fever-caused hospital stay about halfway through his treatment. He realized that he had an unspoken wish to end his "toxic" chemotherapy. Although he was initially eager to take the drugs, he gradually slipped into feeling that he was taking them only for his oncologist and "the integrity of the research project."

Fiore describes the feelings of hopelessness that surround a diagnosis of cancer because of our societal belief that cancer is equivalent to death. In addition, the advanced medical armamentarium of cancer treatments (radiation, chemotherapy, advanced surgical techniques, immunotherapy) leaves the patient not feeling responsible to make treatment decisions and usually feeling that there is little he can do to aid in his treatment.

Fiore and Cousins are both advocates of greater attention to the emotions and psychosocial needs of patients, particularly the needs of cancer patients. Fiore's approach differs from Cousins' approach only in a greater emphasis on psychosocial intervention, which makes sense because he is himself a psychotherapist. Still, their reports of their experiences are one step or more removed from their view of their own world and in this way they are shy of the standard for good phenomenological research. I would next like to discuss how a good phenomenological study should be carried out and

then describe some particular techniques that seem effective in phenomenological work.

Phenomenological Methodology

The goal of phenomenological research is to let the person to be studied "speak for him or herself." This approach is described by Heidegger (1962) in a rather more convoluted manner, but one which aids in the point we are making: ". . . to let that which shows itself be seen from itself in the very way in which it shows itself from itself (p. 58)." It is a basic tenet of phenomenological philosophy that every individual has a point of view through which perceptions are attained. Despite any attempted justification to the contrary, there is no such state as "objectivity"; only variations of subjectivity. Since the source of all of our knowledge is our experience of the world, knowledge at best is intersubjective (verified by the observations of others). The role of the scientist, then, is to take off as many pairs of glasses as possible, examine them carefully, and thereby understand as much of his own perspective as possible. Through this understanding of his own perspectivity the scientist can approach the data with a less jaundiced eye (Merleau-Ponty, 1962). The phenomenologist attempts to abandon theory at the beginning of an investigation so as to get back to the phenomenon as experienced and describe it as accurately as possible. It is by definition not possible to be theory-free, but major scientific gains have occurred when new kinds of observation have lead to a new paradigm of awareness (Kuhn, 1962). The ability of a scientist to be "free from

theory" allows the scientist to observe events with a fresh perspective, in an attempt to see that which is before him. In describing the "what" of experience, he is able to identify the subject of investigation; this is the crucial first step in phenomenological research (Colaizzi, 1978). This is in strong contrast to traditional science which determines the "what" to be studied from a theoretical perspective, thereby determining what is to be seen before looking in the first place.

It is the fact that psychologists study people which makes phenomenology so applicable to psychological research. Colaizzi (1978) makes this point in his description of the paradox inherent in the study of human experience using "objective" means:

If only observable, duplicable and measurable definitions have psychological validity, then a crucial dimension of the content of human psychological existence, namely, experience, is eliminated from the study of human psychology--and this is done in the name of objectivity. How could the word 'hunger' have ever conveyed any meaning whatsoever to us if we did not ourselves undergo, that is, experience, hunger? In other words, according to this queer notion of objectivity, to be objective means to eliminate and deny what is really there (p. 51).

The first element of this approach is that we are not, as in traditional science, wise researchers studying subjects who are ignorant of our purposes. In our paradigm, subjects are co-researchers (Keen, 1977). Rather than utilize more traditional methods of enlistment such as monetary rewards, extra credit or blind voluntarism, subjects participate in a phenomenological study in order to learn more about themselves. Subjects become involved in the study and committed to its ends. This research is inherently ethical; it can

only be properly conducted with full disclosure of the purposes and methods of the study by the researcher and with the full understanding and cooperation of the subject/co-researcher (Keen, 1977).

Further description of methodology must be preceded by the caution that there is no set pattern for this kind of research, in the sense that there is for traditional kinds of psychological research. What identifies the phenomenological approach is not a technique, but an attitude toward whatever investigation one pursues. Every question and every researcher require different techniques so as to remain true to the object of study (Keen, 1975). Several researchers have developed a canon of sorts which details rough steps in the pursuit of phenomenological research, which are basically the same for any project, although they are always open for amendment. It is this guiding outline, based on the work of Keen (1975; 1977) that will be briefly presented here and followed in the more detailed discussion in Chapter III.

Phenomenological research is seen as consisting of four phases. The first stage is one of deciding what is to be studied, and of describing the investigator's initial impressions of what he is seeing. A description of the investigator's initial conceptions about the area he/she will study is seen as an essential element of the research itself because these initial conceptions will influence what the investigator observes. This phase is often accomplished using a pilot study. The researcher enlists prospective subjects to describe their impressions and to assist the researcher in finding the best way to elicit impressions from other subjects in the future.

The second step is to obtain the personal reactions of subjects in the research study itself. This "data" can be collected in a variety of ways, including written accounts or interviews at all levels of structure. In traditional nomenclature, this phase is one of "data collection" but differs from standard psychological research in that it involves the active cooperation of the subject(s) in determining what the data are and how they are to be presented.

The third stage of phenomenological research involves a review by the researcher and each subject or each subject's perceptions. This combination of different viewpoints clarifies the original description and often adds newly discovered elements from both points of view. In an interview study this can be accomplished as an ongoing part of the interview process or separately from initial interviews in a second interview or phase of interviews. In the fourth stage the researcher attempts to structure all the impressions of the experience being studied, in this way defining it. This is a phase of the research involving great care in bringing together diverse perceptions into a meaningful whole.

This phenomenological research methodology is new in the field of psychology and is one which is tailored to both subject and researcher in each new study. In this phase of the development of a body of phenomenological research, each study adds a great deal to the body of experience in this kind of research. This study follows the general canons described above but by necessity also has some unique aspects required by subject selection and subject matter. For these reasons further discussion of methodology will

be both necessary and quite valuable. A very detailed description of the method and process of this study will be presented in the next chapter.

CHAPTER III

METHOD AND SUBJECT

"The Worlds of Cancer Patients" focuses on the phenomenological description of the experience of cancer patients. While the crisis of cancer has increasingly been a topic for psychological research, the primary method of study has been anecdotal description with a theoretical explanation of observations of the researcher. In this, a collaborative study, subjects acted as co-researcher. In this, a collaborative study, subjects acted as co-researchers. The researcher observed the patients' words and behaviors but he continually verified his descriptions of their experiences by sharing them with the patients. This allowed for continued interaction and discussion throughout the entire study, promoting a rich and complex description of how the patients experienced their lived worlds.

The primary goal of the study was to describe the experienced world of six different cancer patients. In examining the variety and richness of these descriptions, our understanding of cancer and of its effects on people ought to be widened. In summing up the commonalities of experience of these people, the research has tapped experience shared by every cancer patient. In addition the researcher developed a small group of questions based on areas of shared experience of the subjects. These questions speak to the common areas of patients' experience of cancer and should be very useful in both research and clinical settings.

Subjects

Subjects were six cancer patients from the University of California, Davis Medical Center located in Sacramento, California. Colaizzi (1979) states the simple requirements for subjects in a phenomenological study: "Experience with the investigated topic and articulateness . . . (are the basic) . . . criteria for selecting subjects (p. 58)." With this in mind, the criteria for subject selection were as follows:

(1) Since the subjects in the project were to be asked about their experience of cancer, they were required to have been diagnosed for approximately three months or longer. Three months was considered enough time for the initial shock of diagnosis to subside and for patients to begin to adjust to living with cancer. In addition, it was felt that interviewing more newly diagnosed patients would be extremely stressful for these patients.

(2) Subjects had to be willing to donate a substantial portion of time (described as 6 to 10 hours in the consent form) to the research.

(3) Finally, it was hoped that subjects could be obtained who would have a prognosis of six months of life or longer so that subjects could interact with the researcher in the process of data analysis. Unfortunately, it was not possible to find many subjects who fit both the first two and this last criterion. It is often difficult to determine the life expectancy of cancer patients, but an effort was made to exclude patients who appeared to be

in imminent danger of dying. Unfortunately, because of the length of the study, three of the subjects died in the interim between the completion of their interviewing and this writing.

Subjects were obtained in consultation with the physicians in the Hematology/Oncology Department at the Medical Center. To obtain the six eventual participants, fifteen cancer patients were contacted. Six of these patients either declined to participate immediately after hearing a brief summary of the project or after having given it some thought for a few days prior to making a decision. The other three patients dropped out of the study after they had been interviewed for between one and three hours. One of these patients found the discussion of cancer to be too stressful. Another had a downturn in her medical condition for a number of weeks so that she felt too tired to be interviewed. She was afraid that she would not improve enough to be able to interview later. Under those circumstances, both the researcher and the subject agreed that she should withdraw from the study. The final patient who dropped out of the study experienced several life crises unrelated to her cancer shortly after the initial interview. She decided that she would be unable to complete the research. It is certainly true that subjects were both selected by physicians as being likely subjects and were then also highly self-selected; this sort of selection factor, however, was unavoidable in this research. The implications of this non-random selection will be addressed in the discussion section.

There were no demographic requirements for subjects in the study; it was hoped that as wide a range of subjects could be interviewed as possible in terms of diagnosis, sex, age and life circumstances. More by luck than by design this hoped-for variety of patients was achieved. Table 1 briefly outlines some of the demographic data on the subjects.

Table 1. Subject and Interview Data

	Type of cancer	Age	Date of Diagnosis	Date of Interviews	Hours of Interviews
Crystal ^a	lung	39	2-83	4-83	8
Ernie	colon	74	3-82	3-83	10
Dudie	undifferentiated ^c	40	9-82	4,5-83	7
John ^b	esophageal	59	7-81	5-83	4
Bob ^a	acute monocytic leukemia	34	12-82	4-83	5
Norma	cholangiocarcinoma ^d	52	10-82	7-83	4

^a Died in 6-83.

^b Died in 5-83.

^c Either extra-gonadal germ cell or large-cell undifferentiated lung cancer (HCG positive).

^d Cancer of the common bile duct.

Methodology

This research project followed the general format described in the phenomenological literature and reported previously on pages 21 to 24. Phenomenological research is not "scientific" in the sense that it does not follow the canons of natural science such as random sampling, treatment and control groups, statistical analysis of results and so on (Pollio, 1983). Traditional scientific methods, however, are difficult to apply to the personal, subjective consciousness of unique individuals, which is the subject matter of this study and a large body of human psychological research. So while phenomenological research is not "good" science in the technical sense of the canons mentioned above, it is a "human science" (Giorgi, 1975) able to find things out about human experience which are (at least) currently beyond the bounds of ordinary scientific research. The phenomenological methodology of this study is more analogous to a mathematical proof than to natural science in that it involves a stepwise process which follows canons of rigor and order (Pollio, 1983). At its best, it provides for a rich description and comparison of the lived worlds of the research subjects. This section will further detail the individual steps and processes of data collection and analysis used in this study. The design of the research follows closely an outline presented by Colaizzi (1978, pp. 57-62).

To begin the process of studying the experience of cancer patients, the researcher examined his presuppositions about the feelings of cancer patients toward their illness. In addition,

the researcher asked many cancer patients, members of his dissertation committee, colleagues and friends to describe what they felt to be salient aspects of the experience of having cancer. Combining these impressions with his own, he developed the five-section questionnaire used for the study, presented in Appendix A. For the purpose of organization of the large number of questions, they were grouped into Van den Berg's (1972) four phenomenological categories: "world," "others," "time" and "self" (with "self" having two subdivisions: emotions and physical body).

The pilot study consisted of interviewing the first subject, Ernie, and of an initial effort at reducing and organizing interview material. The pilot study was also intended to fine tune the questionnaire. However, it was discovered that Ernie responded with richer, more detailed descriptions when he followed his own lead in describing his experience of cancer. The researcher then resolved to follow that approach with the other subjects in this study, presenting them with the questionnaire to read (or not) as they pleased and to respond to (or not) as they chose. The researcher opened the initial session with each subject by asking the subject to describe his or her experience of cancer. In this dialogical interview procedure the conversation followed the direction chosen by each subject while the researcher asked specifying or expanding questions about the material presented. This procedure was designed to encourage subjects to speak about their experiences with cancer in their own highly personal styles. This flexible style of interviewing, allowing each subject to speak about anything that he or

she chose was crucial to the success of the study. While it is never possible to eliminate the demand characteristics of an interview situation, the researcher's effort to let each subject speak his or her mind in his or her own way was essential in collecting valid data. This decision of each subject about what the data were to be, that is, what they would focus on in their experience of cancer, is a crucial way in which the subjects acted as coresearchers. Interviews were tape recorded.

Data selection. The decision to use recorded interviews as a way to collect the experiences of cancer patients is only the beginning of the very complex process of data selection: the choice of what the researcher will see as valuable data and how he will attend to this data. An important value of phenomenological research is the close attention it demands of the researcher to this process of choice and the requirement to make the reasons for the choice clear to other scientists as well as to himself.

If phenomenological research in psychology is to be valuable it must attempt to retain more of the richness of the raw data in the final report of the research and describe more specifically the data to which the researcher is both attending and not attending than do other kinds of psychological research (Kruger, 1981). It is this process of data selection and selection of the way we will attend to the data which we will now detail further.

For all of the positive value of phenomenological research, it does not eliminate the scientific need to reduce the volume of raw data and to somehow organize it in order to clarify its meaning.

As with other kinds of research, phenomenological research eliminates large quantities of data as they are refined through analysis. In addition, the live richness of human interaction in an interview can easily be lost when it is thus analyzed and reduced. However we choose to attend to these interviews and report them, we drastically reduce the amount and richness of the raw data. This is unavoidable for a number of reasons. Every researcher must have a tolerance for ambiguity and an ability to handle complex issues (Colaizzi, 1978) but even the finest researcher has limitations in this regard. So, too, the limitedness of time makes its own demand to curtail the variety of data which can be analyzed. Due to these factors, many aspects of the interview data we collected have been given little consideration. For example, by audiotaping rather than videotaping we have lost some potentially interesting data, including body movement, gestures and dress. The gain in terms of lack of intrusiveness of audiotape versus videotape was deemed valuable, but does not replace this "lost data." The next "loss" of data occurred in the reduction of the data from 40 hours of audiotaped interviews to 72 pages of selected transcripts. The choices involved in this process and the reasoning behind them are crucial to the study.

In order to work with the data and present it to other investigators, it had to be transferred to print form in some manner. Ideally, the 40 hours of interviews would have been carefully and completely transcribed. Even if this were possible, another vast body of data would be lost in the process: voice inflection,

phrasing of speech, voice quality, accent, pacing and the live interaction between the researcher and each subject. It was an active choice of the researcher not to attend to these varieties of data because of the difficulties involved in interweaving such data with verbal material. This loss of data was mitigated somewhat in that the researcher chose to use only the verbatim language of each subject without changing it in any way, unlike virtually all other psychological research, phenomenological or otherwise (Keen, 1977; Giorgi, 1975). In this way, the researcher attempted to remain faithful not only to the content, but also to the style of speech of each subject. The requirement of using the exact words of each subject is one of the chief assets of phenomenological research in comparison to standard psychological research. Indeed, this faithfulness to the original style of speech is more often associated with artistic endeavors, particularly writing for the stage or screen, than it is with science. Bluebond-Langner (1978) went even further toward presenting the style of her subjects by presenting her findings in a five-act play, among other kinds of reporting. This researcher chose not to fictionalize the data in this manner, making a composite drawing, as it were, of all the subjects. Rather, each individual was allowed to speak in his or her own words. This retention of the rich, individual language of each subject was chosen by this researcher as more valuable than the dialogical, extended reporting style used by Bluebond-Langner. Scientific precision was chosen over less precise but more artful methods at this point in the data selection.

Other sorts of data loss also occurred in this step of the data selection. Ideally the data analysis would have begun with careful transcription of the raw data, nearly 40 hours of taped interviews. Because of the prohibitive amount of time required to transcribe all this material, such transcription of the raw data was not attempted. Instead, the tape recorded interviews were transcribed by extremely careful listening to the tapes leading to the extraction of "significant statements" (Colaizzi, 1978, p. 59); that is, statements which described each person's experience of having cancer. From an estimated equivalent of 480 pages of recorded material, this reductive process produced 72 pages of data.

This choice of methodology further limited the data used in this study. The major loss was of the huge volume of conversation in the interviews in which the subjects did not speak directly about their experience of cancer. This material took up between 25 and 80 per cent of the interview time, depending on the subject. This is a very sweeping loss of data, deeper than it originally appears. In choosing to attend only to statements which clearly and directly describe the subjects' experience of cancer, we eliminate less direct, metaphorical material. The advantages of this approach include increased consensual validation, ease of recording, simplicity in reporting (verbatim) and the very basic kind of validity that exists in precise, accurate reflection. The loss includes analysis of thematic areas which could validate or be discrepant with the subjects' direct statements.

In focusing exclusively on the direct statements of

subjects the researcher follows the experimental paradigm that has been used in nearly all prior phenomenological research in psychology (Keen, 1975; Kruger, 1981). This failure to explore aspects of human experience other than the exact level of factually-oriented interviews is a possible weakness of phenomenological research in psychology. That weakness in this research was addressed in several ways. First, the exact language of each subject was strictly adhered to in data recording. This included the retention of metaphors, descriptive speech and verbal style. In addition, information about the subjects which they provided and which had an impact on their experience of cancer was included in Appendix B. This information is an important counterpoint to what each subject has to say about his or her experience of cancer. The last way in which the problem of superficiality was addressed was by the open-ended, lengthy interview process itself. This situation encouraged subjects to speak openly and genuinely about their experience of having cancer.

Phenomenological reduction. Phenomenological analysis of interview protocols is a relatively new development in psychological research and the relatively small number of reports of such studies in the literature are often incomplete or unclear in their descriptions of the process of phenomenological reduction. Because of these factors we will describe the analysis of the interview protocols in this study in a step-by-step fashion and in great detail, beginning with a verbatim transcript from one of the research interviews. Figure 1 presents a transcript of one of the interviews with Bob.

Bob: At the same time my body seems to be recovering and we don't know how long my remission is going to last, maybe another remission if it doesn't, if it does . . . you just don't know. We're in the stone age with leukemia I think, and (Bob's physician) if you got him in a real sober moment would tell you the same thing.

Karl: I'm sure he would . . .

B: Yeah, how much more would you like to know about the disease of leukemia, there's so much . . . So we take it one day at a time. I don't make any long-range plans, we don't as a family. We make some for the children, school, uh, in the summer my son hopes to fish with some friends.

K: But you don't make any plans for yourself.

B: Oh no. I plan that if I'm here, I will.

K: So you do, indeed, like for this summer?

B: I make reservations. I'll say to myself, I'm going to do that if I'm here, but I don't get my hopes up. I don't make it so its going to be catastrophic, I'm going to have a breakdown if I end up in the hospital.

K: I think about people who write in pencil in their schedule books.

B: (Laughs) O.K., thats one way to do it too. No, I really don't have any plans for the summer. My wife and I hopefully are going to camp or something like that, but if we don't, she and I, so far God's given us the grace to adjust and, . . . Say we were in Viet Nam, say that we were infantry lieutenants, their longevity was very short. They didn't have leukemia, they had another disease . . . Some got through, one of my clients, Bob, got through it, got shot four times. So there's another group of people in their prime who for their country supposedly, ended up taking a potentially much shorter lifespan in exchange for uh, not a lot, when you think about it. At one time it was in weeks, average. I was in the service in the sixties, late sixties and seventies, so I got something also to consider, someone with a terminal disease, or potentially terminal disease, suffers basically the same fate or can look at it with the same outlook as people who are going to war too. They knew the facts when they went over there, the facts were that they probably wouldn't come back, and if they made it a year they would be way above average. That's just something to think about, that I've thought about. I'm shooting for a year, I'm going for it. It'd be nice if it came.

K: (Mentions a cancer patient of his acquaintance who survived for twenty years.)

B: Oh, really? And I also hope . . . I've read a lot about people with chronic diseases who recover . . . and I hope

Figure 1. Verbatim Interview Transcript.

- (B:) that during my remissions that they make some breakthrough, research pays off and that I'm not too far along to have some attempts like that on me.
- K: You would take an experimental procedure?
- B: My procedure right now is experimental. The protocol and the speed at which I got it are not standard and I signed papers to that effect. I'm here. I'd have been dead if I'd have waited a few more days to even go to the hospital, I realize that right now.
- K: You were that close?
- B: Oh yeah. I had a white count of 225,000 when I got to the hospital. There's a fellow in the hospital right now named Mike, in the room next to mine, room 668 or something like that, I don't know if you visit him or not, but he is a little older than myself, with acute leukemia, I don't know if its myelocytic or not and he had a white count of 50 or 60,000, he was passing out, blurred vision, and I had never had any of those symptoms, none of them, but those were all symptoms that he was experiencing. It was at a dangerous point that he came to the hospital. He had been diagnosed but he was also having these severe symptoms, things that lead to like heart failure because of increased viscosity of the blood, is really the thing that causes the blurred vision. I had a white cell count many times his, so my blood viscosity was higher than his yet I didn't have any of those (symptoms). Yet they said if it would have been two or three more days I would have had a failure of some kind. All I had was a soreness, two sores in my mouth at the time.
- K: The only thing that told you something was wrong?
- B: No, I had weakness, general lethargy. I didn't feel right. I felt strange enough to apply for more life insurance. (laughs) There's a big legal battle right now.
- K: Is there? How long did you apply for it before you . . .
- B: A couple months. I was seeing a physician at the time for this infection. I disclosed it.
- K: This infection of unknown . . .
- B: Unknown origin. And how long I'd had it. It was a sore in my mouth and everything. There's nothing we didn't disclose to them. They paid the commission to the agent, took my money, approved the policy, sent their medics out, I passed my physical. And 8 days later from the conclusion of all this I was diagnosed with leukemia. They kept my money, gave the agent his commission but they haven't delivered my policy and its five or six months ago. The attorney is working, he's a Christian man, a good friends of ours, an older man. Our arrangement is that he will work on it for a per centage of the damages, he doesn't want any of the face

(B:) amount of the policy. It was a (omitted) dollar policy, (\$) to my business, (the rest) to my wife. So I applied for that, you're always getting insurance men coming to sell you insurance.

K: So someone came up to you . . .

B: I was solicited. Absolutely amazing.

K: They don't have a leg to stand on.

B: That's what they told the agent. The attorney has not pressed it. They also haven't returned my money. So that in itself is a major consideration. We even have a sheet from the agent himself showing my policy as being approved, that they sent him, called him with the approval.

K: Strange. (pause) That's very unscrupulous.

B: Yeah, its also very unusual, the whole thing.

K: The timing of it? Have you had any thoughts about that? Feel like it's a premonition?

B: No, I feel it was the hand of God, meeting my needs like he always has. Another way of meeting the needs of my family in the event that things go swiftly for me and that I fail, physically. Its very uncanny, so much so that the insurance company just doesn't believe it. And they've contacted all the doctors I've dealt with at the Medical Center and my local doctor.

K: And your doctor had no notion . . .

B: None of us did.

Figure 1 (continued)

We will follow this brief sample protocol through all the steps of the phenomenological analysis used in this study in order to clearly demonstrate our methodology.

The first part of the analysis, as described above, is the reductive transcription of the raw data. Statements about each subject's experience of cancer were recorded verbatim while other statements were very briefly summarized. In this first phase of the data analysis three simultaneous but different types of initial reduction were used. The first step: very briefly summarizing conversations not related to the study we will label "A." The second type of reduction (B) shortened long vignettes to their essentials. The last reduction (C) was applied to statements that repeated earlier statements. They were recorded in a very brief, summary fashion, retaining the spoken words of the subject. These three types of reduction of the recorded interview data comprise the first stage of the phenomenological analysis. The result of this first stage in the reduction process as applied to the sample transcript is reported in Figure 2.

Now we will examine this first attempt at reducing the transcript material in more detail (Figure 2). This initial reduction contains Bob's verbatim statements, grouped into topic segments which follow the pattern of his conversation. Numbering, coding and transposition of material comes later in the process. For the purpose of exposition, all the segments in Figure 2 are numbered so that they can be referred to easily in this discussion.

- 1 My body seems to be recovering, we don't know how long my remission is going to last. So we take it one day at a time. I don't make any long-range plans, we don't as a family, we make some for the children. I make reservations. I plan that if I'm here I will. I'll say to myself, I'm going to do that if I'm here, but I don't get my hopes up.
- 2 Someone with a terminal disease, or potentially terminal disease can suffer basically the same fate or can look at it with the same outlook as people going to war . . . I'm shooting for a year. I'm going for it. It'd be nice if it came.
- 3 Treatment, white count, increased viscosity, would have been dead in another few days.
- 4 I had weakness, general lethargy. I didn't feel right. I felt strange enough to apply for more life insurance.
- 5 Difficulty with the insurance company. Helpful lawyer.
- 6 I feel it was the hand of God, meeting my needs like he always has (insurance timing).

Figure 2. First Reduction. (Recorded interview to: verbatim themes (A), summary statements of non-study themes (B) and brief summary of previously mentioned themes (C)).

The first type of reduction (A) was applied to items three and five: items which did not directly refer to Bob's reactions to having cancer and were, therefore, very briefly summarized. The second type of reduction (B), still in the first step of the reduction process, was applied to items one, two, four and six. These longer discussions were shortened to the key statements, recorded verbatim from the longer recorded discussion. This transcript was from an early part of the initial interview, so the final type of reduction (C) does not apply.

A second reduction of themes was undertaken in order to

eliminate previously summarized items which did not bear on the experience of cancer. This step served to eliminate items three and five in Figure 2.

A third approach to the material provided by the interview also takes place in three simultaneous but independent modes. The first part of this, the third reduction, is what Giorgi (1975) described as determining "natural meaning units" in the protocol. This is done by grouping ideas together into the numbered areas, that is, into groups of statements that seem to concern the same general theme. These tend to collect in groups in natural speech, as can be seen by comparing Figures 1 and 2. The second, analogous type of reduction (B) is to eliminate repetitions within theme areas and to pare down the resulting descriptions to essential elements. In the third part of this reductive process (C) "one tries to state as simply as possible the theme that dominates the natural unit with the same attitude that defined the units (Giorgi, 1975, p.87)." Figure 3 presents this third step in the reductive process. The theme of each "natural meaning unit" is underlined.

In our sample transcript the natural meaning units (A) are conveniently grouped together. When dealing with the entire transcript, further grouping occurred because of a repetition of themes. For the most part, however, the subjects spoke about their experiences of cancer in thematic units, with a duration of between thirty seconds and roughly 15 minutes. Changes to a new theme area were readily apparent. The main difficulty to this part of the analysis was the determination of whether a theme was repeating a previous theme (B).

- 1 We don't know how long my remission is going to last, so we take it one day at a time. I don't make any long-range plans, we don't as a family, we make some for the children. I plan that if I'm here I will do things.
- 2 Someone with a terminal disease, or potentially terminal disease, can look at it with the same outlook as people who are going to war. I'm shooting for a year. It'd be nice if it came.
- 3 I feel it was the hand of God, meeting my needs like he always has.

Figure 3. Third Reduction (finding "natural meaning units" (A); eliminating repetition/reducing to essential elements (B) and locating themes (C)).

At this level of the reduction when there was any question about statements having appeared earlier in the transcript the statement was recorded in its entirety. For an example of (B) we see that the statements "My body seems to be recovering"; "I make reservations"; and "I'll say to myself, I'm going to do that if I'm here, but I don't get my hopes up" have been eliminated from theme 1. In the opinion of the researcher, these statements that were removed did not detract from or lessen the meaning of the "natural meaning unit." The third phase of this reduction (C) is seen in the table as the underscoring of the vital theme in each meaning unit. At this point, although each meaning unit has a central theme, any further reduction would seem to remove a great deal of the individuality of the protocol. The themes are used to compare protocols and to create a grand schema that will encompass all of the subjects. This process will be detailed in the next section of this paper.

The reduction approach as we have described it was applied to the complete protocols produced by all six subjects. The final product of this process was six pages, one per subject, of statements ranging in length from a few words to three or four sentences. These statements were meant to contain in a summary fashion but in each subjects' own words all the direct statements made by each subject about their experiences of cancer. As a check on the inclusiveness and validity of this process each person's one page reduction was referred back to their original (reduced) transcript. No omission of themes was found and every theme in the reduced protocols was present in the original transcript. An example of the data as it looks at this point is given in Figure 4. The data consist of a list of the themes which Bob spoke about during our interviews, in the order in which he initially spoke about them. The phrases are summaries of longer statements which were reduced through the process we have described, retaining Bob's original language. This data for each subject is both a complete statement of the experience of cancer for each patient and the raw data we will use in order to compare the six subjects' experience of cancer. It is at this point that the phenomenological method becomes more individualistic but also displays its richness as a research approach.

If I dwell on it, not being a husband and a father, it makes me sad. I don't dwell on it.

We don't know how long my remission is going to last, so we take it one day at a time. I don't make any long-range plans, we don't as a family, we make some for the children. I plan that if I'm here I will (do things).

Someone with a terminal disease, or potentially terminal disease can look at it with the same outlook as people who are going to war. I'm shooting for a year. It'd be nice if it came.

Knowing the future makes it easier, known through faith and study (of the Bible).

I feel it was the hand of God, meeting my needs like he always has.

The medical treatment is violent on body and mind. The doctors and nurses make an effort not to make it so, but it still is.

Just prior to having cancer I gave up good exercise and calm for no exercise and a lot of stress, working 12 hours a day, 6 days a week. I wanted very much to change things in my life, I was praying very hard about it. I felt trapped.

I feel less tense generally since having cancer.

People really came through, sending cash, paying our utility bill, stocking the pantry. People from our church and people from the town where I work. A tremendous outpouring.

Now, for the first time I have been able to accept blessings, the help of others. Before it was always easiest for me to give to others.

I have overall muscular weakness, feeling of exhaustion, general soreness, aches and pains. One day I went in just to say "hi" to the people at work and the whole next day I had to lay in bed to recuperate.

Figure 4. Sample of Complete Reduced Protocol (Unthematized): Bob.

Clustering of themes. The next step of the phenomenological method was to organize each of the six protocols into larger, more meaningful wholes. This process, the "clustering of themes" (Colaizzi, 1978), is an extremely productive but problematic area in this sort of research. Colaizzi describes this process:

Particularly in this step is the phenomenological researcher engaged in something which cannot be precisely delineated, for here he is involved in that ineffable thing known as creative insight; he must leap from what his subjects say to what they mean. This is a precarious step because, while moving beyond the protocol statements, the meanings he arrives at and formulates should never sever all connection with the original protocols; his formulations must discover and illuminate those meanings hidden in the various contexts and horizons of the investigated phenomenon which are announced in the original protocols
Contextual . . . meanings are given with the protocol but are not in it; so the researcher must go beyond what is given in the original data and at the same time, stay with it (1978, p. 59).

It is this portion of the research which is the most personal and the least "scientific." This "ineffable thing known as creative insight" is analogous to such nebulous processes as "clinical intuition" or "clinical judgement." Concretely, the clustering of themes is a grouping together of protocol statements which seem to go together in the studied opinion of the researcher. This judgement occurs as a result of careful, repeated reviewing of the themes. Various organizational patterns are attempted until one particular pattern appears to give the best "fit" for all of the subjects' protocols. What the researcher thus contributes is an organization of the raw protocols into a form in which they can be more easily conceptualized individually and compared as a group. This whole process was informed

by a determination not to add anything to, or subtract anything from, the protocols. As in the previous reduction process the researcher retained the words of each subject.

The first step of this organizational process involved seeking statements of different subjects which were roughly comparable as well as sorting out those statements which characterized each individual or subgroup. Agreement on an issue was not a consideration. That is, what was important in reviewing the protocols was simply the mention of a certain kind of experience as being significant in each person's experience of cancer. Several examples may well be helpful at this point. Figure 5 illustrates one issue about which each subject speaks: the experience of reflecting on having cancer. On the surface there is great dissimilarity in the statements but with persistent rereading and careful consideration two main themes appear in each of the six subjects' statements. These themes (using the words of the subjects) are: "I don't think in terms of 'I have cancer'" (or "I don't dwell on having cancer.") and "you gotta learn to live with some things." In this example there is basic agreement on both of the themes, but this need not be the case. So, too, all subjects may mention a thematic area in the experience of cancer which is significant for them yet each may have a different opinion about the issue. For example, all of the subjects mentioned thinking about the relationship of cancer to death, but each thought about it in a different way. Crystal says "(Since having cancer) I'm (just) happy to wake up in the morning and see the sun shine"; Ernie is convinced that he'll

I don't think in terms of "I have cancer." Cancer is just like any other terminal illness. My chances are slim, but you can't live without hope. (Norma)

I can feel the pain, the progression, eating. The initial pain goes away after a while. Its hard to go through and remain relatively sane. (Crystal)

Cancer can get you down, let you lose your spirit. Its been a fight not to let down. I never think of having cancer; if you really thought of it, it would drive you buggy. You gotta learn to live with some things. (Ernie)

People dwell on cancer to the point it drives them nuts. I haven't figured out why I haven't gone crazy yet, I guess I can cope more than other people. I'm a survivor. (Dudie)

If I dwell on it, not being a husband, a father it makes me sad. I don't dwell on it. I'm shooting for a year. (Bob)

I don't think about it too much, I block it out except when someone like you wants me to talk about it. I may be in agony from pain. If I am there's nothing I can do about it. (John)

Summary I don't think in terms of "I have cancer." I don't dwell on it. You gotta learn to live with some things.

Figure 5. Sample Theme Area (Thinking about having cancer).

"get it whooped, all right"; Norma says directly "I'm not afraid of dying" and so on. This is recorded as an area of thematic agreement in that, despite the variety of views, each patient has reflected on death in the context of his or her larger experience of having cancer. Finally, some themes were only mentioned by some of the subjects. Such statements were recorded as thematic areas of only partial agreement since only a subgroup of subjects mentioned

certain themes as being significant for them. This process of clustering resulted in six major theme areas which were significant for all subjects. An additional seven theme areas of partial agreement were discovered. These themes are listed and detailed in the results section (Chapter IV).

The final step of this clustering process is the determination of whether the themes can be sorted into superordinate categories. This is analogous to the initial clustering of themes in that various schema can be attempted until the one which best fits the data is discovered. In the dissertation proposal it was planned that Van den Berg's four phenomenological categories of "world," "others," "time," and "self" would be used in this categorization. When this organizational scheme was applied to the data, however, it was discovered that it did not fit the themes as optimally as did the more inductive scheme eventually arrived at from an analysis of the protocols. It is important to note at this point that this final categorization is less important than the initial clustering of themes and that the actual final grouping together of themes is more important than whatever labels we choose to place on the groups so constituted. Three superordinate categories were developed out of the process of reviewing the 13 theme areas and are intended only to group themes into comprehensible bundles, not to interpret any sort of final meaning in the clusters. The categories were derived from the theme areas and seemed to fit the theme areas together in a way which remained true to the way the subjects presented their experiences.

A note on control groups. Despite the fact that this is both a case study and a pilot project, some discussion of what sorts of experimental controls apply in this study might be helpful at this point. Phenomenological research does not use control groups per se, but the construction of the research does provide for several "natural control groups" which will be elaborated here (Pollio, 1983). Composed within the experiences of each subject is the first sort of control process: experiences pre- and post-cancer. Since each subject has experienced both not-having and having cancer, each subject is his or her own experimental group and control group. This is the within-subject component of experimental control. In speaking about how they have experienced cancer the subjects speak using their pre-cancer life experience as ground and their post-cancer lives as figure. Their descriptions of having cancer, then, are actually their own observation of the changes in their experience of the world since they found out they had cancer.

A second kind of experimental control applies as we compare the experiences of all of the subjects. Each subject acts as a control on the other subjects as themes are pooled to examine similarities and differences. Theme areas experienced by all of the subjects would appear to have a good chance of being themes in the experience of every person who has cancer.

Finally, a third sort of control group is contained in the vast dissimilarity in age, background, diagnosis, severity of current symptoms and life circumstances of the subjects. Because

of their different experiences of life, both pre- and post-cancer, it would seem that similarities in their experience of the world, post-cancer, would likely come from their shared humanity and the universality of the human experience of cancer.

CHAPTER IV

RESULTS

Results will be reported in a number of different formats to present as complete a picture of the data as possible. In addition to the data derived from the phenomenological analysis (as described in the previous chapter) one other type of data will also be reported. An additional kind of data was present in the transcripts that the researcher felt was important to present in some form in this report. This material falls under the categories of personal information, personal or clinical impressions of the researcher and some added medical and treatment data culled from medical charts. A brief presentation of this information for each subject comprises Appendix B. This information, while not part of the study proper, reflects many of the life experiences of the subjects which enrich and enliven our understanding of each person's experience of cancer.

Our reporting will begin with the protocols of each subject: reduced, thematized and the themes clustered as described in Chapter III. Each sentence or small group of sentences is the condensation of an essential theme. The sentences are clustered into three paragraphs which comprise the superordinate themes. Figures 6 to 11 present each patient's individual protocol. The protocols are presented in each subject's own words with only occasional intervention by the researcher to smooth transitions between themes (sentences) within the clusters

Cancer is not natural to the body, that is scary. Its a foreign substance in me, almost like its alive. I don't think in terms of "I have cancer." Cancer is just like any other terminal illness. My chances are slim, but you can't live without hope. If you're consumed with the fear of dying you can't get the most out of each day. I don't feed on false hopes but as long as I'm alive there's hope. I take each day as it comes. I plan for next year but not ten years in the future. I have felt a serenity almost from the beginning, a kind of peacefulness, sort of a sense of relief. It's probably from knowing your destiny, something you don't have any way of knowing usually. I'm not afraid of dying as I am very strong in my faith. I'm a Mormon and have a very strong testimony of life after death. Death is just another part of a complete program, just another step, but for right now I'd prefer to live.

I really hate pain but I carry my share. I fear undying pain and I pray that I die before I'm incoherent, but other than that I have no fears. I'm not resentful, but disappointed and frustrated by not being able to do what I once did, socially or in the house. I feel that quality of life is more important than quantity, which is why I quit chemotherapy. If you cease to give to people who you get from emotionally, feel like you don't care if you see anyone, I didn't really care if I lived or died.

The giving of my family reduces my pain and eases the fact that I have cancer. Knowing that I'm loved so much, the thought of being without my family makes me feel lonely. Its easy for people to turn away, acting like you're contagious, not knowing what to say. I feel that. We have three couples who have been good friends and there's no change in our relationship. Without that kind of support from family and friends I would see where people would have a very tough time living with cancer.

Figure 6. Subject's Reduced Protocols: Norma.

I had a strong feeling when I was in kindergarten or before that I'd never live to be forty. It almost seems like it's pre-ordained, with so many factors correlating together. Its like the game Pac-Man, the cancer going through my body. I can feel the pain, the progression, eating. The initial pain goes away after a while. Its hard to go through and remain relatively sane. Crying is helpful although it doesn't solve any problems. Before when I was assaulted by difficulties I've always bounced back. Now I don't know which way to go. I did want to slip over the edge but my mother wouldn't let me. I wish I could beat this cancer, I'd love it. Dying isn't frightening, I'm not frightened to have peace. I feel almost calm and happy almost, a very strange contentment. When I say this to people in my family or in the hospital, they think I'm off the wall. I am happy to wake up in the morning and see the sun shine.

I used to be hyper, with lots of energy. Now its hard to walk to the bathroom. Pain is frightening, dying isn't. I'd rather go for quality than quantity, that why I decided not to have chemotherapy.

Some people avoid me because they're afraid my cancer is contagious. I've met people who won't have anything to do with me. Having cancer I can feel isolated. My oldest son is so frightened, he tries to avoid me. Still, I have expanded my realm of knowing people since I've had cancer. I don't want in my time left to smother my children, I just want to put my arms around them and hold them. I don't want to be taken away from them.

Figure 7. Subject's Reduced Protocols: Crystal.

Cancer can get you down, let you lose your spirit. Its been a fight not to let down. I never think of having cancer, if you really thought of it, it could drive you buggy. Its not good to dwell on your illness, you get sicker if you put your mind on yourself. You gotta learn to live with some things. I live one day at a time. Either you get better or you die and I'm not gonna die until I want to. I'll get it whooped all right.

The idea of cancer isn't upsetting, but pain and needles are. I just get quiet, my wife knows when I'm in pain. I try to screen it out. I lost 22 pounds in the hospital and even though I eat good I can't gain it back. It's harder to get around since I got cancer.

I don't tell most people I have cancer, its none of their business. Most of our close friends are dead. We stay in close touch with our foster daughter. My younger sister came to the hospital to visit the last time I was in.

Figure 8. Subject's Reduced Protocols: Ernie.

People dwell on cancer to the point it drives them nuts. I haven't figured out why I haven't gone crazy yet, I guess I can cope more than other people. I can laugh at myself, and its important for others to laugh, too. It's things like that where you can overcome your cancer. You have the power in yourself, if you wish yourself dead, you'll eventually die. I believe in God, I'm a firm believer and I've prayed about it. I knew I was going to be healed of this cancer. When I die, I'll be dying of old age.

It was the hardest thing for me in the world to clean out my locker at work. I was gonna retire on that job, but they can't use me anymore so I've got to move on to something else. Before it was easy for me to put new head gaskets on the car, now I just can't do it. Mowing the lawn or getting screws out of the tape player, I ask for help on those. I'm gonna get my arm going again, I've been working on it for months and its getting better.

Though they sometimes can drive me up the wall, I love my boys, and my family comes first. We've all four done a lot of adjusting and we gotta see what we can do to make things smooth again. I came from a family where no one asked for help. Its hard to realize at times that there's always someone there you have to share your space with, you have to have help.

Figure 9. Subject's Reduced Protocols: Dudie.

Just prior to having cancer I gave up good exercise and calm for no exercise and a lot of stress, working twelve hours a day, six days a week. I wanted very much to change things in my life, I was praying very hard about it. I felt trapped. I don't dwell on having cancer. If I dwell on it, not being a husband and father, it makes me sad. Someone with a terminal disease, or potentially terminal disease, can look at it with the same outlook as people who are going to war. I'm shooting for a year. It'd be nice if it came. We don't know how long the remission is going to last, so we take it one day at a time. I don't make any long-range plans, we don't as a family, we make some for the children. I plan that if I'm here I will do things. I do feel less tense generally since having cancer and do not fear death. Knowing the future through faith and study of the Bible make it easier.

I do have a fear of pain and the process of treatment. I have overall muscular weakness, a feeling of exhaustion, general soreness, aches and pains. One day I went in just to say "hi" to the people at work and the whole next day I had to lay in bed to recuperate. The medical treatment is violent on body and mind. The doctors and nurses make an effort not to make it so, but it still is.

Now, for the first time I have been able to accept the blessings, the help of others. Before it was always easiest for me to give to others. People really came through, sending cash, paying our utility bill, stocking the pantry. People from our church and people from the town where I work, a tremendous outpouring. I feel it was the hand of God, meeting my needs like he always has.

Figure 10. Subject's Reduced Protocols: Bob.

I may be in agony from pain. If I am there's nothing I can do about it. Most people are afraid of death and pain; I'm not. Life is like a long distance run. There's lots of pain but you have to force yourself to endure. Sometimes you have to stop running and walk, but you must keep going. You must accept the things you cannot change. I had no feeling that something bad might happen before I got cancer. I don't think about it too much, I block it out except when someone like you wants me to talk about it.

Before last month I could lift 50 pound bales of hay. Its just the way I am, I've never liked to stop. I could walk seven days ago. I'd been independent all my life, then all of a sudden my legs began to become paralyzed. They got worse, just like that. I lay here and beat my legs, but they won't move. I can't control my bowel or bladder, its very upsetting. I don't think about it. The treatments have also been very hard.

I'm to the point now where all I want to do is go ahead and die. I can't feel good about living without my wife. She was like an old pair of shoes, stretched and worn out, but they sure feel good. I was never able to sleep well from the time that she got sick and I've never gotten over her death. I couldn't do anything about it, I just had to sit back and watch her die. Anyone would be bothered by a thing like that.

Figure 11. Subject's Reduced Protocols: John.

(paragraphs). Except for these very minor changes the protocols are presented in each patient's own words. The seemingly declamatory style of the protocols is a result of combining many short summary statements (themes), culled from many hours of less declarative dialog. In our discussion of the individual protocols we will emphasize the unique aspects of each of the protocols. In this way we will first examine the ways in which the experience of cancer was different for each subject in the study. Later in the chapter we will present the results of the later steps of the analysis which describe the shared experience of all the subjects.

Individual Protocols

Norma's protocol is presented in Figure 6. Norma was the only subject who specifically described her feeling that her cancer was "not natural to the body," that it was a "foreign substance." She made a clear differentiation, separating the cancer from her body. She also was the only subject who described a reason for her frequent feeling of "serenity" and "peacefulness" since discovering she had cancer: "Its probably from knowing your destiny, something you don't have any way of knowing usually." Two other subjects (Bob and Crystal) noted this feeling but neither presented a rationale for their newfound sense of calm. Norma also focused on the limitation imposed on her by cancer in a unique way. She emphasized her need to continue to "give to people who you get from emotionally." Because of the additional burden of chemotherapy she was for a time not only in great pain but depressed that she

could not give to others: "I didn't really care if I lived or died." The chemotherapy would at best only have extended her life for a short time, so she made the choice of "quality(over) . . . quantity" and "quit chemotherapy." Norma's statement on the importance of her family and friends in her effort to live with cancer is the clearest of all the subjects: "Without that kind of support from family and friends I would see where people would have a very tough time living with cancer." Even being hospitalized and jaundiced, she was the strong center of her family, who came often to see her. She helped them all to face her illness and they responded with sensitivity and protectiveness when she wasn't feeling well.

Crystal's protocol is presented in Figure 7. Crystal was the only subject who felt that there was something "pre-ordained" about her having cancer, as she reflected on her life. She didn't know where from, but she "had a strong feeling when I was in kindergarten or before that I'd never live to be forty." Other things which "correlated" were her difficult life experiences in the previous 3 or 4 years, including having her house burn down. Her experience of her cancer as "Pac-man . . . the progression, eating," was the only clear visualization expressed by any of the subjects. She also had a sense of calm very soon after her diagnosis which seemed unusual to doctors, nurses and her family. She could not explain this very well to anyone but the researcher found it to be quite genuine. For example, throughout the course of her illness, despite bouts of intense pain she was often relieved by long, peaceful sleeps which were frequently followed by many waking hours free

of pain. Thus, it seems that she had a rare ability to be quietly and peacefully content with herself.

Crystal was very active and energetic before she had cancer and felt badly physically limited by her illness. It was the suddenness of the limitation and the emphasis she had always placed on activity which apparently led to her experience of cancer as being so severely limiting. Because of her physical frailty at the time of her diagnosis and her poor prognosis even with chemotherapy she, like Norma, chose not to have chemotherapy. Death of itself wasn't frightening for Crystal but she was very sad to leave the job of raising her boys undone. It was thinking of leaving them that would bring her to tears. Crystal's eldest son's reaction to his impending loss, to try to avoid her, was very hard for her. It was her attachment to people which kept her from "slipping over the edge."

Ernie's protocol is presented in Figure 8. Ernie's health was substantially poorer than any of the other subjects but perhaps paradoxically, his experience of cancer was mild compared to the other subjects. His treatments were as "severe" as most of the subjects and his type of cancer is generally quite painful. His side-reactions to treatment were minimal as was his experience of pain. He explained this as due to a tough constitution, two heart attacks which had inured him to the idea of his own death and great effort on his part not to "think of having cancer. Its not good to dwell on your illness, you get sicker if you put your mind on yourself." He frequently commented that he felt he would

survive his cancer to die of old age but there was always a tongue-in-cheek flavor to these pronouncements that seemed to put them in the category of things he did to keep his spirits up. His secretiveness about having cancer seemed to stem from this same source and to reveal the essential quality of Ernie's pride: to be helpless, to receive pity was for him not really to be alive.

Dudie's protocol is presented in Figure 9. In contrast to Ernie's seemingly joking statements about recovering from cancer, Dudie appeared to be very serious in his belief that he was on the road to complete recovery. His certainty, "I knew I was going to be healed of this cancer," was related to his religious faith. He was the only subject who expressed this sort of conviction. Perhaps this enabled him to take a light-hearted view of having cancer. He repeatedly stated how important this was for him; to allow his boys to tease him about losing his hair (from the chemotherapy) was more than he had permitted them before. This sort of casually friendly teasing about his difficulties, even to the extent of his limited use of his left arm, was one of the most unique experiences reported by any of the subjects. So, too, Dudie was the only subject to express his frustration with not working, though none of the subjects were working at the time of their interviews. There was a sense that Dudie missed both the camaraderie of his friends at the plant as well as the enjoyment of his competence in doing his job. One might hazard that the subjects who were thrown out of work by cancer may well not have been as able to openly express that particular sense of loss. Dudie was in many

ways, amidst what would at least at first appear to be denial, able to experience clearly and express frankly the devastating effect that cancer had on his life.

Bob's protocol is presented in Figure 10. Bob stopped short of blaming himself for having cancer but felt that his ill-advised effort to start a computer business of his own had had a bearing somehow on his illness. He was "working twelve hours a day, six days a week," spending little time with his family and he "felt trapped. I really wanted to change things in my life, I was praying very hard about it." This realization seems to fit very well with his factual approach to his prognosis: "I'm shooting for a year." Indeed, in the sense of the word which has been developed out of the work of Kübler-Ross (1969) Bob "accepted" his illness more fully than did any of the other subjects. His strong religious faith seemed to be the foundation for this. Bob considered worries about his prognosis and about the future of his family to be "temptations." To have faith in God was to trust Him to provide. Bob was "sad" when he thought about "not being a husband and father" but had only worried to the point of becoming upset a few times. He found that he was able to accept "blessings" (of God) through the gifts of others that he had always been too self-reliant to accept in the past. His faith certainly enabled him to live in the present, spending time with his family and planning their future without the fear one would expect about his personal future.

John's protocol is presented in Figure 11. He was more

alone than any of the subjects and also the nearest to death at the time of the interviews although no one was certain of that at the time. He had an indefatigable spirit and only very near death would say, "I'm to the point now where all I want to do is go ahead and die." The death of his wife left him unable to sleep well, nor was he able to cry. She was his only intimate friend. He spoke of how crucial the loss was to him: "She was like an old pair of socks, stretched and worn out, but they sure feel good." It was the loss of the use of his legs and the loss of control of his bowels and bladder which were too much to bear. It was the suddenness of these severe limitations on his ability to function which apparently made them so difficult: "Before last month I could lift 50 pound bales of hay . . . I could walk seven days ago." It almost seemed that the suddenly enforced stillness on this always active, extremely efficient man caused him to concede the long battle.

This concludes the discussion of the individual protocols. In sum, the individual reduced protocols speak very strongly for themselves, and fluently for each individual. John's acute despair is sadly, clearly evident as is his iron-willed reluctance to give up: the ambivalence of "all I want to do is go ahead and die/you must keep going." Crystal's imagery about a devouring cancer is portrayed as is her quality of calm acceptance, strongest in her of any of the subjects. Dudie's intense feeling of loss over being forced to leave his job because of his cancer and his belief that he had been healed are shown clearly. Now we will move on to discuss the many similarities in our subjects' experience of cancer.

Shared Theme Areas

Figures 12 and 13 are the overall result of the phenomenological analysis of the protocols. Figure 12 presents the six theme areas which were mentioned by all of the six subjects as significant in their experience of cancer. The superordinate categories (Being, Doing and Being-with-Others) serve to divide the themes into three pairs which are thematically similar. The themes themselves are the closest to the experience of the subjects ("most valid") in that they use the words of the subjects. The organizational pattern itself was derived through the process of clustering. This grouping process is one step removed from the protocols. Finally, the labels for the clusters are least close to the subjects' experience, applied by the researcher in an attempt to describe the content of the three clustered theme areas. Figure 13 follows the same basic format but presents the seven theme areas which were agreed on by between two and four of the subjects. These theme areas represent a section of second-order results. We will next discuss each of the six theme areas in Figure 12 (areas of agreement of all the subjects) in detail.

Theme areas of agreement. The first theme, which we will refer to as "Being-A" ("I don't think in terms of 'I have cancer,'" etc. . .), was agreed upon by all the subjects. Not only was the theme area "thinking about cancer" an important one for each of the subjects but they all also agreed that they rarely reflected on having cancer. It is a simultaneous affirmation of having cancer and a profound statement about how difficult it is to allow death

- | | |
|-----------------------|---|
| Being | <p>A I don't think in terms of "I have cancer." I don't dwell on it. You gotta learn to live with some things.</p> <p>B I live one day at a time. I hope <u>or</u> I will survive cancer.</p> |
| Doing | <p>A Cancer and cancer therapy is painful and frightening. I can handle my share of pain.</p> <p>B My activities are more limited than before I got cancer and my overall energy level is poorer.</p> |
| Being-with-
Others | <p>A Closeness to family and friends is very, very important.</p> <p>B Some people turn away, feeling cancer might be contagious.</p> |

Figure 12. Thematic Areas of Agreement.

- | | |
|-----------------------|--|
| Being | <p>C I had premonitions of having cancer or another serious illness prior to my diagnosis (Crystal, Bob).</p> <p>D I experienced a sense of relief or calm at some period after my diagnosis (Norma, Bob, Crystal).</p> <p>E Cancer is easier to face because of my religious faith (Bob, Dudie, Norma, Crystal).</p> <p>F If you did dwell on your cancer it would drive you buggy (Ernie, Dudie, Crystal).</p> <p>G I have an image of my cancer (Crystal, Norma).</p> |
| Doing | <p>C Quality of life is more important than quantity (Crystal, Norma).</p> |
| Being-with-
others | <p>C I have been able to accept help from others since I've had cancer whereas I couldn't in the past (Dudie, Bob).</p> |

Figure 13. Thematic Areas of Partial Agreement. (Names of subjects who agreed or commented on the issue).

to be figural while one is living. The statement "you gotta learn to live with some things," or as John said, "you must accept the things you cannot change," is an expression of the clear, aware acceptance of the cruel fact of having cancer. The elements which demark this theme, then, are the resigned acknowledgement of cancer along with a determination to avoid thinking about it whenever its possible to do so.

"I live one day at a time," (Being-B) has become such a cliché that it carries questionable validity as a statement of feeling. Nonetheless, there is a sense in which every subject had a glimmer of knowledge of an ending to their lives that they had not had prior to cancer and a heightened sense of living in the present moment. All of the subjects expressed a hope that they would recover from cancer. Norma's statement that "you can't live without hope" seems literally, poignantly true. This seems to echo "the will to live" of which Norman Cousins (1979) speaks. Two of the subjects, Ernie and Dudie went beyond hope into what many writers (LeShan, 1966) would label "denial": "I knew I was going to be healed of this cancer (Dudie)." In this context it seems to make sense to speak of an exaggeration of hope rather than denial, or perhaps, in addition to denial. For all that we may say about denial, both Ernie and Dudie had a good response to treatment. It seems that the conviction that one will get well, which can be interpreted as denial, does relate at least for these two patients, with a good response to treatment.

Doing-A and B are clear and unequivocal. All the subjects spoke of the experience of the pain of cancer and cancer therapy as well as some degree of limitation of action caused by illness or treatment. The range was quite wide, from Ernie who experienced minimal ill effects from his cancer or treatments (colostomy and chemotherapy) in the context of declining health over many years to Crystal, who went from being very physically active and healthy to being so weak and ill that she could barely make it to the bathroom. All of the subjects focused on these issues, issues of doing rather than being, as the central problem in living with cancer. One is tempted to infer displacement of fear from the unknowable (death) to the knowable (physical pain and limitation) as suggested by Bobby Aguilar, a former cancer patient who is quoted in the first question in Appendix A. This is an inference with which Becker (1973) would certainly have agreed:

In other words, the fear of death must be present behind all our normal functioning, in order for the organism to be armed toward self-preservation. But the fear of death cannot be presently constant in one's mental functioning, else the organism could not function. (p. 16)

Whether or not this speculation is accurate, the patients all agreed that they don't dwell on the fact of their being cancer patients but frequently live with the fear of pain and the limitations imposed by cancer in a very concretely felt way.

The statement, "I can handle my share of pain" (Doing-A) is both the expression of stoicism on the part of all the patients and an unstated fear: what happens if/when I am given more than my share? Norma, as she so often did, made this explicit: "I fear undying

pain and I pray that I die before I'm incoherent." The limitation of activity (Doing-B) was an area agreed upon by all the subjects. The distinction between the limits caused by cancer and those caused by their treatments, for those who had treatments, were often blurred. It certainly was easy for patients to complain about some aspect (at least) of their care. John, for instance, said "I lost 22 pounds in the hospital and even though I eat good I can't gain it back." That was a frequently repeated statement. Dudie mentioned the need for help on tasks that were once easy for him, even buttoning his shirt because of the weakness and immobility of his arm. Crystal and John both focused on the difficulties of severely limited mobility. This seemed the area of the greatest emotional pain for all the subjects. Through the ways it reduced the subjects' energy and free movement cancer seemed most real, present and painful for them.

Being-with-Others is essential to all of the subjects, and in some cases (Dudie and Bob) cancer was even an event that was followed by an increased ability to accept things from others. Perhaps the most important aspect of being with others to this group of subjects was continued closeness to family and friends. It was in speaking of family that subjects most often expressed their emotions strongly: feelings of love, sadness and loss. In many ways this is the most important finding of the study. It is a very strong statement in that each patient, no matter how many or few close family and friends they had, described so vividly the importance of these relationships. Perhaps this is due to

the increased isolation, something Crystal often described herself as feeling, and perhaps it is also due to the increased realization of the importance of emotional bonds that occurs in times of great upheaval. The experience of having others, even relative strangers, "turn away" (Being-with-Others-B) seems very powerfully evocative and saddening for all the subjects. The impact of the experience of rejection seconds the need to be with others expressed by all of the subjects.

Thematic areas of partial agreement. Figure 13 (page 67) lists the themes that were agreed on by more than one subject but not by all of the subjects. The themes are organized into the same three clusters as the six areas of thematic agreement in Figure 12 (page 67). These themes are a sort of second-order result of this study. They both help to characterize the variety of the the protocols and detail further issues in the agreed-upon theme areas. Since this is a pilot study these themes may also at some time prove to be more universal than they currently appear.

The first theme, "I had premonitions of having cancer or another serious illness prior to my diagnosis (Being-C)" was mentioned by Bob and Crystal. For Crystal, it seemed to fit patterns in her life ranging from her belief as a child that she'd never live to be forty (a not uncommon one) to a growing sense of something seriously wrong in the months before her 39th birthday. For Bob it was more a feeling of stress, nagging infections and dissatisfaction with his life. He was worried enough about himself that when he was offered a life insurance policy he took it. Norma was aware that she

was ill: she felt low in energy but only felt it was working too hard combined with perhaps an ulcer. Several of the subjects firmly denied any such fore-knowledge with vehemence. It seemed that they felt that an awareness of cancer prior to diagnosis might imply responsibility on their part, either for the cancer itself or for not seeking treatment sooner. None of the subjects spoke about this issue. Whether or not this speculation is accurate the subjects who had a strong premonition of serious illness seemed to be those who were most factually aware of having cancer at the time of the interviews.

The group that said "I experienced a sense of relief or calm at some period after my diagnosis" (Being-D, spoken by Norma, Bob and Crystal) was about the same as the group who mentioned Being-C. The two notions seem to fit together in that subjects who seem more aware of having cancer also seem to be those who are able, at least at times, to react to that knowledge calmly. More than equanimity, it seems in some ways a coming to terms with the notion of one's own death. Norma mentioned this sense of knowing: "I have felt a serenity almost from the beginning, a kind of peacefulness, sort of a sense of relief. Its probably from knowing your destiny, something you don't have any way of knowing usually." Bluebond-Langner (1978) spoke of "open awareness" of cancer, and that concept seems to apply here. She saw little to recommend this open awareness other than the report of the leukemic children's parents that the parents felt that this openness helped them to cope better with

their childrens' prognoses. The sense of relief reported by our subjects allows us to be more specific about what this "coping" might be. Perhaps this "open awareness" in some of our subjects allowed them to develop this sense of calm, a profound self-calming which seemed to make the course of their illness easier for them. This may be similar as well to Kübler-Ross' (1969) concept of "acceptance."

Four subjects (Bob, Dudie, Norma and Crystal) stated that "cancer is easier to face because of my religious faith." Ernie felt that religion was bunk and spoke of heaven and hell as existing in the present, depending on one's life circumstances. He railed at the "preachers" but also described some spiritual or mystical experiences he'd had, related to the deaths of family members. John was the only subject who didn't mention religion or some notion of the hereafter in our interviews, so this was a nearly unanimous theme. Religion was found to be a comfort for different reasons for the different subjects. Dudie believed that his faith would help him recover. Bob and Norma both mentioned being reunited with family after after death while Crystal found strength in her feeling of a strong personal relationship with God.

Craziness was a surprisingly infrequent topic of conversation considering that the researcher was a psychology intern, but three subjects (Ernie, Dudie and Crystal) did say "if you did dwell on your cancer it would drive you buggy (Being-F).'" This theme has been discussed earlier in relation to Being-A: "I don't think in terms of 'I have cancer.'" It seems that the subjects who didn't comment

directly on this issue hinted at the disorganizing fear one would experience if the fact of having cancer were always figural for patients. Each of the three who commented on this issue directly described ways in which they managed to remain relatively calm and stable. Dudie felt that laughter and not taking himself too seriously helped him to survive. Ernie was stolid in refusing to allow cancer to impinge too much on him. He considered his cancer-caused problems with digestion to be digestive problems, not cancer. Crystal combined a delight in conversation and the company of others with time by herself late at night thinking and watching television. All were somehow surprised at their ability to cope with their vastly changed lives.

Only Crystal and Norma mentioned specific images of their cancer (Being-G). Crystal felt the lumps of metastases and had pain in many parts of her body. She described her image of the cancer: "Its like the game Pac-Man, the cancer going through my body. I can feel the pain, the progression, eating." Norma's image was more diffuse. She saw her cancer as a foreign substance, foreign to her body. Bob had a sense of his leukemia as an absence of crucial blood cells, but never expressed any further imagery. Ernie outright refused to think of it, while John didn't mention it. Dudie had surgery on his shoulder and experienced his cancer as the necrotic tissue which occasionally came out of the wound. It seemed that John's experience of cancer was of his physical symptoms: difficulty breathing and increasing paralysis. The issue of a visual image of cancer also seems linked to Being-A.

Some of the not-thinking about having cancer appears to manifest for many of the patients in either not thinking about or at least not speaking about their imagery about their illness.

Again, Crystal and Norma were the subjects who clearly stated that "quality of life is more important than quantity (Doing-C)." Norma decided not to continue her chemotherapy regimen and Crystal decided not to take chemotherapy at all. Neither encountered much resistance from their physicians since both had cancers for which, as yet, no highly effective chemotherapeutic agents have been developed. The issue of quality versus quantity, which is a frequently mentioned topic in the psychosocial literature on cancer, was not mentioned by the other subjects.

Dudie and Bob each mentioned that "I have been able to accept help from others since I've had cancer whereas I couldn't in the past (Being-with-Others-C)." Other subjects spoke a great deal about the importance of other people in their lives, particularly family and close friends, but not about this issue of a particular change in their relationships with others. It seems a mixed blessing for these two men who were always strong and self-reliant to learn that they can accept and appreciate the help of others. Dudie seemed to have more difficulty with this than did Bob, but the physical handicap of his weak and inflexible left arm gave him a great deal of difficulty in doing everyday tasks.

Reliability Study

The researcher had some hesitation about the reliability of the process of phenomenological reduction of the data in the early stages of the project. Having completed this process it seemed a remarkably effective tool for evaluating interview transcripts. In order to test this intuition in a more scientific manner a reliability study was undertaken.

The reliability study used the reduced transcripts of one of the patients, John, as the raw data. The reduced transcripts were roughly six single-spaced pages of verbatim statements made by the subject. The study was conducted on the main reduction process: reducing the six pages of transcripts to an approximately one page reduced protocol. The complete reduced protocol contains all of the themes mentioned by the subject without repetitions and is refined down to a minimum number of statements without eliminating any essential material.

The reliability reviewer was familiar with the theoretical model of phenomenological reduction but had only little knowledge of the process used in this study. In addition, she was also quite doubtful of the scientific validity or usefulness of this research methodology. Her sole previous contact with the manuscript occurred when she proof-read some portions of the rough draft of the manuscript roughly four months prior to the reliability study. She was given rather brief, simple instructions to first choose every direct statement about cancer made by the subject in the reduced transcript. From the researcher's experience on performing the reduction he noted that

most of the patients' direct statements about cancer included an emotional component. As an aid to the reviewer this fact was included in the instructions. The reviewer was instructed that once all the direct statements were chosen the reviewer should eliminate repetition by choosing the "best" statement on any given theme but not eliminate statements which included unique information. This process of refining the data should continue to the point at which the reviewer felt no more statements could be eliminated without losing essential data. The reviewer prepared her version of the reduced protocol without any further instruction or intervention on the part of the researcher. The two versions of John's reduced protocol are presented in Figures 14 and 15. Figure 14 presents the reduction performed by the researcher; Figure 15 presents the reduction performed by the reliability reviewer.

The protocol contained in Figure 14 includes several more sentences than the one presented in Figure 15 although both protocols include seventeen statement areas; these statement areas consist of one or more sentences on the same theme occurring together in the reduced transcript. Of these areas, 11 were precisely the same for an exact agreement value of 65 per cent. These statements have been labeled with the single letters A through K. In addition, four other pairs of statements in the two versions of the protocol were clearly statements about extremely similar or identical theme areas. These pairs are labeled with double letters LL through OO. If these areas are counted, the agreement value between the two versions of the protocol increases to 88 per cent. Finally, four statements

- A (I had) no feeling that something bad might happen before I got cancer.
- B (You) must accept things you can't change (cancer and paralysis).
- C I'm to the point now where all I want to do is go ahead and die.
- D Can't control bowel or bladder . . . its very upsetting.
- E Before (the) last 8 months (I) could lift 50 pound bales of hay.
- F Most people are afraid of death and pain. I'm not.
- G (I) don't want to think about it too much (having cancer).
- H (You) have to force yourself to endure.
- I I may be in agony from pain, if I am I am, there's nothing I can do about it.
- J (I'm) very frustrated by the paralysis of my legs.
- K (I've been) independent all my life, then all of a sudden . . . I lay here and beat my legs but they won't move.
- LL Can't feel good about living without my wife. (I) never got over it (her death). Never been able to sleep well from the time that she got sick. I couldn't do anything about it, just had to sit back and watch her die. Anyone would be bothered by a thing like that.
- MM (I) block out illness except when someone like you wants me to talk about it.
- NN Treatment is very hard.
- OO I could walk seven days ago. It got worse just like that.
- P (My wife was) like an old pair of shoes, stretched and worn out but they sure feel good.
- Q Life is a long distance run. There's lots of pain, sometimes (you have to) stop running and walk, but you must keep going.

Figure 14. Complete Reduced Protocol (Unthematized): John
as Prepared by the Researcher.

- A (I had) no feeling that something bad might happen before I got cancer.
- B (You) must accept things you can't change (cancer and paralysis)
- C I'm to the point now where all I want to do is go ahead and die.
- D Can't control bowel or bladder . . . its very upsetting.
- E Before (the) last 8 months (I) could lift 50 pound bales of hay.
- F Most people are afraid of death and pain. I'm not.
- G (I) don't want to think about it too much (having cancer).
- H (You) have to force yourself to endure.
- I I may be in agony from pain, if I am I am, there's nothing I can do about it.
- J (I'm) very frustrated by the paralysis of my legs.
- K (I've been) independent all my life, then all of a sudden . . . I lay here and beat my legs but they won't move.
- LL (My) wife and I ill at the same time.
- MM Not interested if cancer has metastasized to (my) brain.
- NN (You) gotta realize you hurt sometimes.
- OO Life isn't worth living this way (being unable to walk or control excretion). Of course its depressing.
- R (I'm) tired, (I) can't eat much.
- S Before (the) last six months (I was) able to do hard physical work.

Figure 15. Complete Reduced Protocol (Unthematized): John
as Prepared by the Reliability Reviewer.

occur, two in each protocol, which do not occur in the other protocol. These are labeled separately P through S. Each of these four themes except R is closely related to a theme area already mentioned in both of the protocols. Overall, considering the nearly 12 to 1 reduction in material (John's reduced protocol is roughly one-half of a single-spaced page), this study suggests that the reliability of the reduction process is comparable to the reliability of most psychological research.

CHAPTER V

DISCUSSION

We will begin our discussion of the results by reviewing the major findings of the study. Next we will discuss the relationship of this study to the previous psychological research on cancer as described in Chapters I and II. Methodological issues including the advantages and disadvantages of the phenomenological approach and the reliability and validity of the findings will then be detailed. The Cancer Experience Questionnaire will then be presented. The Questionnaire covers the six theme areas which were significant for all subjects. Suggestions for further research and a discussion of the value of "human science" conclude the chapter.

Significant Findings

The major findings of this study were concisely presented in Figure 12, page 67. The six theme areas were the ones endorsed by every subject as issues which were figural in their experience of cancer. In Figure 12 each theme is presented in the words of the subjects. In the following discussion we will focus on the themes as they are paired together in the categories of Being, Doing and Being-with-Others.

The themes in the superordinate category of Being are:

I don't think in terms of "I have cancer." I don't dwell on it. You gotta learn to live with some things (A).

and

I live one day at a time. I hope or I will survive cancer (B).

The first theme (A) seems to express the subjects' resigned acknowledge-

ment of cancer along with a determination not to allow their concern about cancer to overwhelm them and make their daily lives unlivable. This is not Kubler-Ross' (1969) "denial" but a practical matter of how to continue living. It is the sort of "denial of death" which Becker (1973) describes as a necessary underpinning for life in any society. All of us will eventually die and can never know for certain how long we will live. A constantly experienced dread of the possibility of death, however, would make everyday life extremely painful and difficult. The second theme (B) deals directly with the issue of daily life implied in theme A: living each day is impossible without hope. This hope seems the stuff of which Norman Cousins (1979) speaks in his description of "the will to live." Without this stance and the ability to allow cancer to be in the background there seems to be no point in continuing to live. In summary, the subjects were hopeful and avoided despair by continuing their lives as normally as they could rather than living in constant dread of having cancer.

The themes in the superordinate category of Doing are:

Cancer and cancer therapy is painful and frightening. I
can handle my share of pain (A).

and

My activities are more limited than before I got cancer
and my overall energy level is poorer (B).

The first theme (A) speaks of the pain of cancer and of cancer therapy which frequently became indistinguishable for the subjects. The subjects described thinking about being cancer patients most often either when they were in pain or while they were actually receiving treatment. Theme B seemed the area of the greatest

emotional pain for the subjects: in the ways it reduced the subjects' energy and free movement cancer seemed most real and painful. In describing their experience of cancer the subjects focused on the concrete experience of pain and limitation rather than on the prospect of death or the actuality of being a "cancer patient." It was in this way that cancer made its impact as a physical and emotional reality for the subjects.

Themes in the superordinate category of Being-with-Others are:

Closeness to family and friends is very very important (A).
and

Some people turn away, feeling cancer might be contagious (B). It was in speaking of their families (theme A) that subjects most often expressed strong emotions: feelings of love, sadness and loss. The experience of having even relative strangers turn away from them (theme B) was emotionally evocative and saddening for the subjects. This emphasizes the great importance which our subjects placed on their relationships with others. In many ways this is the single most important finding of this study: each patient, no matter how many or few close family and friends he or she had, described vividly the importance of these relationships in coping with having cancer.

Relationship of this Study to Previous Research

It is difficult to define the relationship of this study and previous psychological research on cancer because of the uniqueness of this study. We did not investigate any of the findings reported in

Chapter I. Some observations based on various data collected in this study can be applied to one of the psychological theories of cancer presented in Chapter I.

Personal history data on our subjects provides primarily negative findings related to LeShan's (1959) theory of loss/depression as causative in cancer. LeShan states that most people who develop cancer sustain a major personal loss 6 months to 8 years prior to the onset of cancer: death of a spouse, loss of an important job role (or retirement), children growing up and moving away and other such losses. Essential to this theory is the failure of the person to find substitute relationships in the face of this loss. None of our subjects fit this paradigm but three subjects were somewhat closer to this pattern while the other three were relatively less close.

Crystal, Norma and Dudie sustained major losses prior to having cancer but they were not the same sort of losses that LeShan described. Norma's husband had a stroke several years before she discovered she had cancer but he fortunately survived. He was forced to retire and Norma returned to work, which she found rather stressful. In addition, Norma's mother died just a few days after she was diagnosed with cancer. Norma does not fit LeShan's theory because she didn't sustain a loss of the type LeShan describes prior to having cancer. Crystal's and Dudie's (seperate) homes burned down several years before they each discovered that they had cancer. While having one's house burn down is a major loss it is not the sort of loss described by LeShan.

Bob's, Ernie's and John's experience fit even less with LeShan's paradigm. Bob had no essential losses although he had taken on a different, more stressful job two years prior to finding out he had cancer. Ernie had a number of losses, the major ones being retirement and progressive weakness in his legs. Both of these occurred more than 8 years before he discovered he had cancer. John retired shortly prior to discovering he had cancer but worked all the harder on the farm where he and his wife had lived for many years. Six months after he found out he had cancer John found out that his wife had cancer. Her course was rapid and she died a year prior to John's death. Her death sapped much of his desire to go on. The chronology doesn't follow LeShan's pattern but John did sustain several major losses around the time of discovering he had cancer and thereafter. In sum, this study can offer little support for LeShan's loss/depression theory of cancer causation. It is an interesting observation, however, that other major losses are closely linked in time with cancer for most of our subjects. LeShan's theory does not explain this phenomenon.

This study does have a relationship to the cancer literature discussed in Chapter II. Cousins' (1979) concept of "the will to live" was echoed in two of the major thematic areas: the themes labeled Being-A and Being-B. This is evident in Cousins' description of himself as being aware of the seriousness of his illness but never losing his feeling that he had a good chance of recovery. We have also mentioned the relatedness of Bluebond-Langner's (1978) discussion of "open awareness." Several of the subjects in

this study who seemed more factually aware of their cancer also described themselves as being able to feel a sense of calm and profound relaxation at times. This was discussed as being a more specific delineation of the result of "open awareness" than Bluebond-Langner's description of generalized "better coping" in people who were more openly aware of cancer.

Reflections on Methodology

Having never before done a phenomenological reduction and having approached the process with some trepidation, the researcher has been very impressed by the authenticity of this methodology. The reduction process both retained the essential content and kept faith with the style of presentation of each subject in a very powerful and convincing way. Despite the difficulties with handling metaphorical and non-direct verbal material, the verbatim reduction process retained the flavor and much of the richness of the recorded interviews. In terms of measures of reliability, considerable further scientific work could be undertaken. The methodology could also be even more specified and further refined than it has been in this study. Overall, however, the pilot study appears to be both a reliable and valid piece of work.

Despite the apparent reliability of our methodology many issues limit the validity and generalizability of this study. First, this is a pilot study and as such the methodology is still being refined. A number of lessons were learned in the process of conducting the study. The interviewer became more adept at non-directive interviewing as the study progressed so that the later interviews

took much less time than the earlier interviews. Also, each subject made varied use of the questions provided by the researcher and this may well have had an effect on the data. Ernie, the pilot subject, was asked nearly all the questions directly by the interviewer while other subjects were not asked any of the questions unless they decided to respond to them of their own accord. Finally, an obvious difficulty in terms of the generalizability of the results is in the small subject group of just six.

The particularities of the subject group also cause difficulties in generalizability. The subjects were doubly selected: first by their physicians as being potentially "good" subjects and then self-selected. Fifteen subjects were contacted in order to obtain the six subjects who would eventually complete the study. The six subjects were self-selected in that they were willing and physically able to undertake a series of lengthy interviews. Their variety in age, diagnosis and life situation is encouraging in that it provided a rather heterogeneous subject pool, but any volunteer for such an arduous task as this research must have a special interest in sharing of him or herself with the researcher. There are as many motives as subjects, but we must keep in mind the selectivity of this small group. Finally, this subject group was composed of six people who all had poorer-than-average medical prognoses. This was a completely unintentional artifact but one which is statistically more likely with smaller subject groups such as this one. All of these factors combine to moderate the generalizability of our data, particularly the theme areas of partial agreement.

Cancer Experience Questionnaire

The six thematic areas of agreement present a good starting point for anyone wishing to assess the psychological impact of cancer. The next section will present a brief questionnaire based on the major findings of this research project. The questionnaire is intended to assess major or minor adjustment problems in terms of each patient's current experience of cancer.

The Cancer Experience Questionnaire is presented in Figure 16. The questions cover many important areas in patients' experience of cancer. The first question attempts to evaluate whether the fact of having cancer is figural or more in the background for the patient. If cancer continues to be figural for the non-hospitalized patient after the initial adjustment to his or her diagnosis and in the absence of a current life-threatening situation it may well be an indication of a difficult adjustment. Depending on the patient's medical status encouraging them to maintain their pre-cancer lifestyle as much as possible or to be as active as possible would be appropriate. Only one of our subjects was hospitalized during the interview process and was not in a life-threatening situation. From the researcher's experience with hospitalized patients, however, the second question in #1 ("Do you dwell on having cancer?") would probably be more appropriate for this group. The issue of how figural cancer is for a person is certainly a matter of clinical judgement. The act of encouraging patients to do as much as they can comfortably manage, however, is nearly always accepted.

The second question attempts to evaluate the hopefulness

1. How do you think you are doing in terms of living with cancer?
Do you dwell on having cancer?
2. Are you keeping your hopes up about getting better?
3. Can you tell me about the sorts of pain you've experienced?
4. In what ways has cancer affected your daily life?
5. Tell me about how your illness has affected your family
and your close friends.

Figure 16. Cancer Experience Questionnaire.

of patients. The answers to these first two questions will probably be closely related. Patients who don't dwell on having cancer will probably maintain hope of recovery and vice versa. It is very important, however, to make a special effort to reassure each patient that even though many people consider it irrational to feel hopeful that the patient should continue to do so. Hoping against the odds is not evidence that a patient is denying his or her illness: our six subjects varied a great deal in terms of "accepting" the fact of cancer but they all continued to hope.

The third question is particularly important for medical staff but along with question four is also the best way to evaluate how a patient is reacting emotionally to cancer. Asking about pain and limitation is a very delicate matter and should be approached with care. Patients should be encouraged to discuss any new pain they experience with their physicians because this sort of information is a very important aid in their treatment. It is frequently difficult for patients either to remember or to feel comfortable

about detailing their symptoms to physicians. The interviewer might aid in this process by writing down a list for the patient to present to their physician.

Finally, the last question asks for details of each patient's "support system" (American Cancer Society, 1980) in the community at large. This is an important area in which hospital treatment teams can be of help. Patients can be referred to community agencies which provide for physical and emotional needs of patients who have few family or friends in the area or make similar within-hospital referrals.

The questionnaire has a number of important clinical uses. It is a flexible instrument in that it can be discussed briefly in 10 to 15 minutes or can be used as an outline for a longer clinical interview. Its best use is as a first-interview tool either in an inpatient or outpatient setting. It is a handy brief screening device for hospitals that wish to make a psychosocial assessment of each new cancer patient. While there is no such thing as a non-intrusive questionnaire, the Cancer Experience Questionnaire would seem to approximate this ideal. As with all such instruments some initial friendly conversation with the patient helps to make the patient comfortable. In presenting the questionnaire it should be explained that the interviewer is simply interested in finding out how the patient is coping with having cancer and in finding any way in which he or she, the institution or other agency can be of help. If it is used with every new patient the mention of this fact will ease anxiety and increase the cooperativeness of most patients.

When used in such a context only the very rare patient will have difficulty with the questionnaire. Some patients remain visibly upset about having cancer for a long period of time and this questionnaire should not be used with them. With such patients, a technique similar to the interview style of this research project can be used. Simply bringing up the topic of cancer, talking with such patients and allowing them to direct the flow of conversation will generally produce at least short answers to all of the questionnaire items. The interviewer need only listen attentively while keeping the questions in mind.

The advantages of the questionnaire include its brevity, simplicity in use, ease in training staff to use and universality in application to cancer patients in most phases of their illness. The questionnaire is an evaluative instrument which is also simultaneously a supportive clinical intervention. The act of asking concerned, meaningful questions is in itself therapeutic and additional supportive interventions have been built into the questionnaire (as described in the initial discussion of the questionnaire). It could become an effective tool in the hands of doctors, nurses or hospice volunteers after only very brief training. The questionnaire allows a wide variety of professionals and volunteer workers to develop some familiarity and comfort in talking to cancer patients about significant psychosocial issues.

Suggestions for Further Research

The results of this study suggest a number of areas for future exploration. A study which comes easily to mind is an expanded study based on the methodology of the current study, using some sort of sampling procedure to insure a wide range of subjects. Another large project would involve interviewing cancer patients, one or more of each patient's significant others and one or more of each patient's medical caregivers. The study would examine each person's experience, the experience of each of the subject groups (patients, significant others and caregivers) and compare the experience of each patient/significant other/medical caregiver trio. Finally, a rather small-scale study could be conducted using the Cancer Experience Questionnaire to evaluate its usefulness in a clinical setting.

The Value of Phenomenological Research

Phenomenological research is not a "natural science" kind of research but a "human science" research which attempts to explore people's subjective experience in order better to describe the human experiences of aliveness and awareness. The language of phenomenological psychology is the natural language used by people and the types of organization employed are those used by people in their processes of self-reflection. Rather than applying labels to human experience human science strives to allow people to describe and make sense of experience in their own ways. As evidenced in this study, phenomenological research adds an important third voice to the medical and

psychological understandings of the human experience of cancer. The self-descriptions of patients would seem to add a crucial dimension to our understanding of cancer's impact on people's lives.

In sum, we have shown that vastly different people experience cancer in remarkably similar ways. They realize they are ill, but don't dwell on this fact, living each day as it comes. Despite the pain and limitation imposed by illness and treatment they are resolved to carry on, holding firmly to their relatedness to family and friends. Death, for these patients at least, must remain the ground of being, not one of its figural aspects.

We must not overlook the human situation of the subjects who participated in this study: a real loss has taken place. At the time of this writing four of the subjects have died. If we lose the sense of the reality of the lives and deaths of these people, if this is lost in methodological considerations and reportage, then this study has been pointless. I hope in this small way to show my love for my six coresearchers: may this attempt to understand their personal worlds grant each of them at least a small measure of that kind of immortality which resides in the grateful memory of the living.

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APPENDIXES

APPENDIX A
INTERVIEW QUESTIONNAIRE

Self (Mostly body or physical experience)

Bobby Aguilar, a former cancer patient at the Medical Center, writes "I thought that the greatest fear of mankind is fear of pain, disease and death. We fear the things we do not understand more than we fear the things of which we have full knowledge." What are your thoughts on this?

Did you have generally good or generally poor health before you found out that you had cancer? In what ways do you think this may have affected your response to finding out you had cancer and your adjustment to it?

Similarly, are you the kind of person who pays a lot of attention to your body or do you pretty much ignore it? Do you pay more or less attention when you are hurting? How do you usually handle illness and has cancer been different than other minor and major illnesses?

This is often difficult to do, but I'm wondering if you could describe your body, that is, how your body looks and feels to you. For instance, do you feel attractive? What are your good and bad features? What parts of your body do you like, what parts dislike? What parts feel good mostly, which bad? and so on . . .

Again, in this same direction, can you describe how cancer and your treatments affected you physically (and emotionally)? For instance: did you experience weight loss
hair loss
lessening or change in appetite
sleep changes
change in a sexual relationship
other unpleasant side-effects of
drugs, radiation treatments,
or surgery
bowel or bladder changes?

Can you describe the sorts of pain (if any) you have experienced from you cancer or treatments, its change over time and your attitudes toward your pain over time? How do you feel about pain medication, and what has been your physical reaction to such medications if you've taken them?

Do you feel physically disabled by cancer? Has this had personal or spiritual implications?

This may sound silly, but has having cancer changed the way you dress or your personal hygiene habits? Is the change a comfortable one, if you've experienced such a change?

Please describe your average sort of day before and after you developed cancer. If you will, focus on such items as work, exercise, hobbies and physical activities.

Do you feel more or less tense since you found out you have cancer? How do you handle this tension or stress now versus before?

Self (Mostly emotions and thoughts)

Cancer is often described as a major life crisis, and it seems that people who go through such crises often change a great deal in their lives, developing entirely new attitudes towards their lives and greatly changing their priorities. Have you experienced your illness as such a crisis? Whether or not you see cancer as a crisis, do you feel that your priorities have changed since you discovered you had cancer?

One element of stressful life events is their tendency to weigh on one's mind and seem entirely inescapable. For instance, when one has very little money it often seems that every waking minute is affected by worry over money matters. Is having cancer like this for you? If you are able to forget about it for awhile how do you manage to do this? Anything in particular that makes you think about having cancer?

Perhaps the most often talked about psychological issue in physical illness, is "acceptance" of one's illness: that is, the ability of a person to allow the fact of serious illness to really hit them emotionally. On the other hand, it has been observed that often people who deny their illness (pretend successfully that nothing, or at least only very little, is wrong with them) can do quite well. Do you feel that you accept or deny your illness? Will this change? How do you feel this has affected the course of your disease and your feelings about it?

Can you describe your initial reactions to your discovery that you had cancer? For example, did you suspect you had cancer before it was diagnosed? What sorts of feelings did you have initially (fear, anger, shock, numbness, nothing much) and how did those feelings change over time?

In your opinion, did you do anything before you got cancer that might be related to your illness now? Some examples of this might be smoking, drinking alcohol, exposure to asbestos or radiation, or perhaps stressful events in your life.

Finally, are there any ways that cancer has affected your experience of the passage of time which we haven't discussed? Please give this some thought and write down any questions that you think up that would be helpful for us to talk about.

The World

What sorts of places do you like to go? Has cancer affected the amount that you get around?

Can you talk a little bit about how you see the world? Is it a good place or a bad place, or somewhere in between? Do you find it pleasurable or painful, frightening or enjoyable? Has cancer changed your perception of the world?

People can be in the external world very intensely or can experience fantasy, reverie, memory, physical sensations or other states of mind which keep them at some remove from the external world. How would you describe yourself in this respect?

Which of the following adjectives would you use to describe the world as you see it: colorful, bright, cheerful, alive, depthful, meaningful, bland, gloomy, dark, dull, superficial, meaningless? Would you have used different adjectives before you found out that you had cancer?

Do you feel that you see the world pretty much the same as other people do? Has cancer changed this?

How do you usually get around? Do you drive yourself, are driven by someone else, walk, ride a motorcycle or bicycle?

Do you pay much attention to local, state, national and international events? Has cancer changed your interest in these events?

Do you feel that you have an important contribution to make to the world? Have you already made one? Has cancer changed your feeling about this?

Can you speak a little about your experience with hospitals? Most cancer patients spend at least a bit of time in the hospital. If you have done so since you were diagnosed, how has your latest experience in the hospital compared with previous ones?

Do you think cancer has helped or hindered you in facing the realities of your life? Have the things that you think are important been changed by your experience with cancer?

Do you have dreams or fantasies about your cancer? If you can, talk about what you think your cancer is like: part of yourself or separate, an invader, destructive, an internal eating away or something else?

Anger is an emotion often linked to catastrophic illness. Often a "Why me, Lord?" feeling is expressed by people who can't understand why such an awful event could happen. Your thoughts on this?

Has cancer affected your religious life or interest in religion?

Sometimes major catastrophes can cause people to really take stock of their lives. Has this happened to you? Do you feel any more or less honest with yourself since you found you had cancer?

Out of the work of Lawrence LeShan, and implicit in the work of O. Carl Simonton, is the theory that many people who get cancer have had a major emotional loss within two years of their diagnosis with cancer. These losses are said to be primarily of family members or very close friends, but could also include the loss of a job that is very important to a person or a role in life (i.e., a mother having her last child leave the home) to which they have become very accustomed. Does this fit for you?

Grief or sadness is another major feeling usually experienced at some point by people who have cancer. This is a very difficult, painful question, but could you talk about times when you have felt sad or frightened and how you handle these feelings when you have them?

In the same vein, has your mood, that is your general way of feeling about things (cheerful, grumpy, up and down, depends on what time it is) changed since you found out about having cancer? Can you describe the change(s)? Also, have your feelings intensified, weakened or stayed about the same since you discovered you had cancer?

Finally, are there any other ways that cancer has affected your body and you personally that we haven't talked about? Please think about this for awhile, and if you can think of anything, write some of your own questions for us to talk about.

Time

Since you found out that you have cancer, do you think differently about the past, about the present, about the future? Do you think more about time now than previously? Do you think that cancer has changed your view of time?

Has cancer changed the way you reflect on important events: for instance, your childhood, school days, first job, marriage, children (or grandchildren) and so on?

Do you still make long-range plans?

Since you discovered that you have cancer, do you think about the future of people close to you? The world in general?

Do you feel that your life was well-spent? Have you regrets, and what would you have done differently?

Can you think of any major historical events which have deeply affected your life?

Do you think more about dying or not being alive since you found out that you have cancer? What are your thoughts and feelings about death and dying?

How would you describe your youth? Are there any particular memories that really stick out for you?

In your early adulthood, were you married? What sort of work did you do? What were your hobbies? Who was important to you?

Time feels like it moves at different speeds at different times of day as well as in different segments of our lives. I am interested in how you experience time moving for you now since you discovered that you have cancer. Is it faster, slower or unchanged; are there differing shifts in how it seems to move now than before you found out about your cancer?

What comes to your mind when you think about time?

In your daily life now, when are you most and least aware of time? Any idea about why you are more or less aware at any given time?

Do you experience time differently when you're alone than when you're with other people? Has cancer changed this?

Do you think that you experience time in a way similar to or different from the way that others do? How can you tell? Do you think that cancer has changed this?

Many cancer patients with whom I have worked say that cancer has caused them to more fully experience the present and to be grateful for every minute they have to live. Do you feel this has been true of your experience with cancer?

Finally, are there any ways that cancer has affected your experience of the passage of time which we haven't discussed? Please give this some thought and write down any questions that you think up that would be helpful for us to talk about.

Other People

How has cancer affected your relationships with important people in your life, particularly friends and family?

What groups you belong to or are associated with? Has your diagnosis with cancer affected your relationships with these groups?

Describe your prejudices. Have they been affected by cancer?

Do you think that you have done things mostly to please other people or mainly to please yourself? Has cancer changed this?

Can you describe your general experience of other people? That is, are they helpful, needing your help, attractive, irritating, sources of approval, friends, enemies, acquaintances, people who you love? Which best describes the way you feel?

What sorts of things do you enjoy talking about? What are your interests and how have they been affected by cancer?

Has cancer affected the level of your involvement with other people?

If you have experienced pain, how has this affected your relationships? Similarly, has cancer affected your desire to be with people? How about your efforts to be with people?

Have some people become more important and others less so, since you found out that you have cancer?

Do you feel that others are avoiding you since you found out you have cancer? If so, how has this affected you? Do others avoid talking about your illness? How do you feel about this?

Have you told other people that you have cancer? What have their reactions been like? What did you expect?

Do you feel that you've been treated fairly by others? Has this changed since your cancer diagnosis?

Would you be willing to discuss the death of someone important to you right now? If not, perhaps later. Do you think about the possibility of your own death?

APPENDIX B

SUBJECTS' PERSONAL INFORMATION

Crystal

Crystal was a 39-year-old divorced woman at the time of our interviews. Her 5'2" frame was emaciated from her illness, hospitalization and severe digestive difficulties; she repeatedly quoted her weight, 87 pounds, in awe and disbelief. She lived in Sacramento with her two teen-aged sons and had a close, non-sexual relationship with a man who acted as a surrogate father to her sons. Prior to her illness Crystal worked full time in a jewelry store.

Crystal remembered that as a little girl, perhaps in kindergarten or even earlier, she had a strong feeling that she'd never live to be 40 years old. On her thirty-ninth birthday, November 5, 1982, she experienced a strong sense of impending doom. The very next day she had pain and a great deal of trouble breathing, so much so that she went in to the hospital. Her trouble at that time was diagnosed as an asthma attack. She didn't return to the hospital until February 9, when she experienced difficulty in breathing and increased pain. At the hospital they found her left lung half full of fluid. That evening she was told that "abnormal cells" had been found and that they were likely to be cancer cells. She was angry with the doctor who brought her this news but in a few days appeared to be completely accommodated to her inoperable lung cancer, which had metastasized to the lining of her lungs and to her pancreas. Her acceptance was so complete and calm that the medical staff had difficulty believing the honesty of her feeling. Crystal herself pondered her quick acceptance, wondering if she had perhaps given up or if there was an altogether too morbid side to her personality. She firmly believed, after much thought, that she had not given up hope nor was she suicidal. She often felt deeply sad to leave her sons, especially her younger son, when they had always had "my mouth" around to rely on. She had days of difficult pain but was always able to eventually sleep soundly for 12 hours or more, awakening refreshed.

After nearly a month of hesitation, Crystal refused chemotherapy, which at best offered a brief extension of life at the cost of considerable suffering. Even without chemotherapy Crystal had extreme difficulty with digestion, having frequent vomiting, diarrhea and constipation. Just the odor of food cooking made her physically ill.

Crystal's marriage was a bitterly unhappy one. She was married at 18, already pregnant with their older son. The marriage went gradually downhill, her husband having affairs, hitting her and the children, drinking heavily and taking drugs. They were finally divorced in 1975. She has worked very hard to make a

good life for herself and for the boys, and by all appearances has done a very good job, but feels, "Any time I'm responsible it doesn't seem to work out too well." Other major events since her divorce include her uncle's death in 1977 and the destruction of her home by fire.

She had a dream during the research project, which moved her so much that she detailed it in one of the interviews. She was a member of a family she'd never met before in which a close relative, a collector of fine antiques and jewelry, had died. Despite a condition in the will that all relatives be present at its reading, the person's possessions were distributed in Crystal's absence. She angrily told them it was not fair and took some items from each of the other relatives. It felt really good, although she did not have the thing that she really wanted most. The dream ended before she got that, some sheet music. On awakening it reminded her of the music she has from her grandmother, passed to her through her mother.

I grew very close to Crystal in the process of our conversations for the research and later as her hospice worker. She was often irritable and demanding but generally was able to overcome her pain in time. At those times she could feel pleased with her close relationships with family and many friends. She attained at such times a sense of inner peace that has been very rare in my work with dying cancer patients. Crystal died in late June, 1983, in the Medical Center, with her family and closest friends by her side.

Ernie

Ernie is a 73-year-old man who lives in the Sacramento area with his wife of 38 years. Ernie has been married twice previously, but has no children. However, the couple have a "foster child" who spent many summers of her youth with them, still visits frequently and has two sons. Ernie is retired from a rice mill, where he was shop steward for his union as well as "head piler" of 100-pound rice sacks.

Generally speaking, Ernie feels that he's been a healthy person throughout his life; he has had few illnesses, either minor or major until his retirement in 1969 at the age of 60. He has always been a moderate to heavy drinker and has smoked since about age 7 but doesn't feel that either of these has adversely affected his health. After a life of heavy physical labor, Ernie began to have difficulty controlling his legs. In 1969 tests were performed at Stanford, and the problem was located in his spinal cord. He retired on disability. In 1971 Ernie had a very serious heart attack and in 1977 had another, minor one. In March, 1982 Ernie had several weeks of relatively severe stomach pains and cramping. He was diagnosed on 3-11-82 with an adenocarcinoma (colon primary), as well as adenocarcinoma of the prostate, metastatic to the

retroperitoneal space. It was also noted that the L-1 and L-2 vertebra had collapsed due to "degenerative joint disease of the lower spine." A colorectal resection with a colostomy and Hartman pouch was performed. In addition Ernie received 16 chemotherapy treatments (5-FU) between 3-82 and 2-83 to combat lung metastases.

His recovery from surgery was good and the course of his illness since that time has been almost unbelievably easy. His only pain has been from obstructions, which have so far been handled by a regular irrigation regimen. His reaction to chemotherapy treatments has also been remarkably mild.

Since his retirement, much of Ernie's story is one of personal losses. He has gradually lost the strength in and the use of his legs. His best friends have almost all died and one of his sisters died three years ago. His pet poodles, who were the joy of his retirement, also died. The things that concern him now are people: his immediate family and his "foster-family", his foster daughter and her children.

Ernie is a crotchety old man who insisted on telling things his own way in our interviews. I am grateful to him for his important help in determining that less structured interviewing produced the best picture of his private world. Our friendship grew with the progression of the interviews and we've kept in touch since they were completed.

Dudie

Dudie is a forty-year-old married man who lives with his wife and their two young adolescent boys in a small town in the foothills of the Sierra Mountains. He was previously married to a woman who ran off with their furniture, their bank account and their young daughter when the marriage didn't work out. Dudie was a forklift truck operator and had worked for 8 years for the same company prior to being diagnosed with cancer. In two more years his retirement would have been vested.

Having had pain in his armpit and shoulder, Dudie was diagnosed as having an "undifferentiated carcinoma" on 9-20-82. The records report "an extensive lesion of the left upper arm, into the axilla to the thoracic outlet." They saw "necrotic tissue in the wall of a large hepatoma." Cytology revealed an epithelial tumor diagnosed as either an extragonadal germ cell tumor (the beta HCG was positive) or large cell undifferentiated carcinoma of lung origin. The latter is more likely as regards tumor site and Dudie's history of lung problems. Between 10-1 and 10-7-82, 2000 rads were delivered to the lesion. Twice weekly followup chemotherapy was continued times 10 (Adriamycin and Vincristine) from 12-82 to 5-83 at which time it was discontinued. Dudie's left arm now has very limited movement and strength, though he faithfully practices his daily physical therapy regimen. His progress is steady but slow.

The Medical Center was able to cover the cost of his

treatments but in every other way the system has failed Dudie. His state disability benefits didn't amount to much and they ran out in June. As of our last contact, Social Security was still considering his second appeal for disability benefits, already having turned him down twice.

Dudie was born in Montreal and moved to Los Angeles as a child where he grew up in Watts, a rather tough neighborhood. He was a rough kid and began working as a shoeshine boy when he was nine. His relationships with his parents were never particularly good, and that hasn't changed over the years. At 18 he joined the Air Force where he was a refrigeration technician in the Titan missile program. When he got out he worked as a welder, burner and refrigerator repairman in Los Angeles. Eventually he learned dry-walling and worked construction on high rise buildings. He moved to the foothills because of lung problems but also to escape the hustle of Los Angeles and to have a better environment in which to raise his children.

The latest episode in his contentious first marriage was his daughter's recent demand to be officially adopted by her step-father. Dudie signed the papers reluctantly and with much protest: "She's still my daughter." The second major disaster of his life occurred on December 4, 1981, when his house burned to the ground. No lives were lost but nothing else was saved. These days Dudie constructs doll house furniture out of balsa wood. Right after his diagnosis he made the end tables in their living room with the use of only barely more than one arm. He feels he has been cured of his cancer and cites a dream which later came true in support of his belief. In the dream he was reaching in through his armpit and taking out lumps of the cancer. He was terrified by the dream. Later, after surgery the wound didn't heal well and he went home with a dressing on it. Several times that week he removed hunks of cancer ("necrotic tissue") roughly the size of silver dollars. After that, the wound healed properly.

Dudie repeatedly described himself as being cynical, tough and very private about his affairs but I found him gentle, amiable and generous. Our conversations have continued during his visits to the outpatient clinic. So far there is no evidence of a recurrence of his cancer.

Norma

Norma is a 52-year-old woman who lives in Sacramento with her husband. They are practicing Mormons and raised four devout children who are now all married. They also were surrogate parents to one of their nieces in her high school years and to Norma's younger brother, who lived with them for several years as a young adult. She had worked full time at a "store like Lumberjack's" prior to her diagnosis with cancer.

Prior to discovering that she had cancer, Norma had many months of physical and mental exhaustion and was afraid that she

had an ulcer. In 10-82 she was diagnosed as having a cholangiocarcinoma (biliary duct cancer), with metastasis to the liver. The day she was diagnosed with cancer, Norma's mother was found dead of a heart attack in her home. Norma was released from the hospital and her surgery postponed so that she could attend the funeral. Surgery had the expected result: the cancer was too widespread for removal. From 12-82 to 5-83 she underwent several courses of chemotherapy, taking 5-FU, Adriamycin and Mutamycin. Because of nausea, fatigability and resultant depression she decided not to continue with chemotherapy. Our interviews were all completed at the Medical Center (the only subject with whom that occurred) where her jaundice, due to the blockage of her common hepatic duct by cancer, was being treated.

Norma's father died when she was nine, a very traumatic event for her whole family and especially for Norma who felt especially close to him. Her mother seemed to Norma overwhelmed by the difficulty of working and raising four children by herself. Norma never felt that she could be as close to her mother as she wanted to be as well as feeling she could never do enough to please her. She resolved to be very independent and to always be there for her children in ways that she felt her mother was unavailable for her.

Norma's adult life was relatively unmarked by tragedy until August 1980, when her husband had a major heart attack and stroke. He was in intensive care until October and thereafter paralyzed on his right side. Fortunately, with physical therapy he recovered nearly complete function, though he walks with a limp. He is well enough recovered that he is able to play golf. With her husband unable to do chores, they found maintenance on their home to be too much of a burden and moved into a mobile home. For financial reasons Norma began working. She worked, by her own description, "too hard" and would arrive home utterly exhausted at the end of the day.

Norma was superhumanly understanding of the time pressure on the researcher and gave graciously of her time to complete the interview within the week. She was by far the most businesslike of the subjects and also was the most psychologically-minded. Her love and caring concern make her the focal point of a large, closely-knit extended family. In other words, we could all do worse for a mother than Norma, who is, to borrow the words of Charles Schultz, "a rare gem."

Bob

Bob was a 34-year-old man at the time of our interviews who lived with his wife and their five children (aged 2 to 14) in a town in the hills of northern California. For the two years prior to his cancer diagnosis he was the head of his own computer hardware and consulting firm. Prior to that he was managing partner in the

local Honda dealership.

Bob had several different strange, intractable infections and mild general malaise prior to his diagnosis. A routine blood test by his local doctor who was treating the infections revealed a phenomenal white count and Bob drove to UCDMC with his wife that evening on the advice of his physician and the specialist he consulted at the Medical Center. It was December, 1982 and Bob was diagnosed as having acute monocytic leukemia, type Fab-M4. After hydroxyurea and leukapheresis he was treated with ARA-C, 6-Thioguanine and Daunorubicin. A bone marrow on December 17 showed 40% cellularity and 20% blasts and a consolidation dose of chemotherapy was administered. A bone marrow on 1-3-83 showed less than 5% cellularity and shortly thereafter he appeared to be in remission and was released. He returned to the hospital on January 24 having felt only gradually weaker since his release. Tests showed that he had not attained remission and by luck a large perirectal abscess was discovered and handled surgically. He was given high-dose ARA-C and L-Asparaginase over two days. Following a very difficult hospital stay, including the fear of a bacterial infection and another round of chemotherapy, Bob was finally released from the hospital on March 18. He had been in the hospital for nearly two months, and nearly four months with only a ten-day respite in early January. He had lost a total of 55 pounds since December.

Bob was a very strong Christian who believed that his religious beliefs and principles should illuminate and guide his daily life. He and his family belong to a non-denominational, non-hierarchical church which is a pastoral outreach of the Calvary Chapel in Costa Mesa, California. The members of his church responded dramatically to his illness by coming to the aid of the family with money, services and the sort of help that a family needs when both parents are going through stressful times at a distance of one hundred miles from home.

Perhaps more than any of the subjects, Bob seemed forcibly yanked out of the ongoing stream of his life. His faith was a great comfort to him but the sadness of leaving a wife and young children seems nearly beyond bearing. On the afternoons I interviewed Bob I was a dinner guest in their home. It was a family that was very comfortable together and one which welcomed even a guest associated with the worst news they had ever heard. Bob did have the time he hoped for, though not as much. He died early in June, but not until he had taken the camping trip with his family which he had so much wanted to take.

John

John was a 59-year-old widower at the time of our interview and was living with his father and a female cousin who acted as his caretaker. He had been married to the same woman for 35 years before her death and had worked as a machinist for the same firm

for 31 years before his recent retirement. John and his wife had had a farm in rural northern California, ten acres on which they'd had a garden, horses, cows, dogs, cats and 400 chickens, "the smartest animals on the farm."

Prior to being diagnosed with cancer, John had been spitting up blood regularly about every other day. He was thoroughly checked by his physician who apparently diagnosed his problem as related to a heavy lifetime of smoking, including a period during which John would smoke and inhale fifteen to thirty cigars a day. He had had increasing chest pain and in 1-81 was diagnosed as having esophageal adenocarcinoma. In a surgical procedure "an extensive lesion at the hilum was cleanly removed" and a left pneumonectomy (removal of the lung) was performed. He received 4000 rads in 2- and 3-81, sustaining serious radiation burns, particularly on his back from the radiation therapy. During this time he was receiving monthly dilatations "to maintain good swallowing." In 8-81 a Celestin tube was installed (to pass food from his mouth to his stomach). By 5-6-83 the diagnosis had been changed to squamous large cell carcinoma (of the lung), which was metastatic to the ribs. Since the installation of the Celestin tube, John had lost 100 pounds.

While John's wife was nursing him, it was discovered (in late 1981) that she, too was suffering from cancer. Her course was very rapid: she died on May 4, 1982. This was a disaster for John because he and his wife were so close and because they had had no intimate friends other than each other. As he said so clearly, John was never able to sleep soundly again, nor was he able to cry. Never was he able to get over the death of his wife.

John spoke of a wide variety of experiences, fishing and hunting with his father, being in the army during World War II, being an amateur fighter as a young man. He had been a sales supervisor at one time as a relatively young man and regaled me with the lessons he used to teach the new young salesmen. He was always very stoical, except about the rapid paralysis and loss of control over his lower body which occurred in his last weeks of life.

John was a difficult subject because talking about cancer and his wife upset him so. We had a discussion about halfway through the interview process, hassling out what should happen. I agreed to just "come over and chat" with the tape recorder on and this seemed to free John to speak with less anxiety and pain, switching to topics other than cancer when he became uncomfortable. It was particularly valuable to have John as a part of the study because he shares this feeling of intense anxiety about talking about cancer with people who either dropped out or would not participate in the study. This anxiety seemed linked to the rigidity and driven quality of his statements: life is painful, but you must go on or die. John died in late May, 1983, just two days after our last interview.

VITA

Karl Buddenhagen was born in Waukegan, Illinois on February 10, 1957. As a child he studied bicycle riding, trombone and solo basketball on snowy winter evenings. He graduated from Waukegan High School in 1974. That fall he began his studies at Augustana College in Rock Island, Illinois, majoring in Psychology and Philosophy. He graduated cum laude in 1978 and was also elected to membership in Phi Beta Kappa.

He began his studies toward a Ph.D. in Clinical Psychology at The University of Tennessee, Knoxville, in 1978. He completed his internship at the University of California, Davis Medical Center in Sacramento, California, in June, 1983, and received his Ph.D. degree in December, 1983.

The author is the eldest of five children of Jerold and Dorothy Buddenhagen and was married to Gay Cooper of Knoxville, on August 8, 1983. The couple resides in Oakland, California where Karl is completing a post-doctoral internship at the Kaiser-Permanente Medical Center in Walnut Creek, California, and Gay is pursuing a professional acting career.