To the Graduate Council:

I am submitting herewith a dissertation written by Richard James Fitzpatrick entitled "Emotional Distress, Locus of Control and Information Preferences among 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.

Kenneth Newton, Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted for the Council:

Vice Chancellor
Graduate Studies and Research

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EMOTIONAL DISTRESS, LOCUS OF CONTROL AND INFORMATION PREFERENCES AMONG CANCER PATIENTS

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Richard James Fitzpatrick

June 1983

118831

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DEDICATED TO

Alice, my mother, and Amy, my wife,

who have loved me in times

of joy and pain.

ACKNOWLEDGMENTS

This dissertation was the focal point, hopefully a catalyst, in a project that is much more important. That is, the establishment of a thriving Psychosocial Clinic in the Hematology-Oncology Consultation Service of the University of Tennessee Memorial Hospital. This service has provided me with both academic and professional training that I know will be invaluable in my career ahead of me. More importantly, it has given me an opportunity to listen to and learn from many people intensely alive in their struggle with dying. I can think of no other experience which would have challenged me more to feel and think and grow. Ken Newton, Ph.D., my major professor, supervisor, dissertation chairman and friend, is responsible for allowing me to have this experience. I am grateful. Along with Co-director Joyce Robinson-Diftler M.S.W., I wish you the very best in making the Psychosocial Clinic a "Wellness Center" for years to come.

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ABSTRACT

One hundred and nine cancer patients were evaluated with psychological tests which included the Inventory of Current Concerns, Profile of Mood States, Index of Vulnerability Rating Scale, Multidimensional Health Locus of Control Inventory and Information Styles Questionnaire. The purpose of the study was to examine the pattern of relationships between emotional distress, locus of control and information preferences among cancer patients. Patients with high health internal locus of control scores were expected to have less distress and greater information preferences.

The sample of patients in the present study was found to have more concerns, mood disturbance, vulnerability, physical symptoms and wider extent of illness compared to the sample from Weisman and Worden's Omega Project (1977). The present sample was also shown to have less information and participation preferences compared to Cassileth's (1980) survey. The present sample was found to have higher health external, and lower health internal, scores compared to patients with other chronic illnesses, or healthy adults.

Reported physical symptoms was the best predictor of emotional distress among medical variables. Medical data predicted less than one-third of the variance in distress.

Patients with more aggressive cancers were found to be more distressed. Distress was high at initial diagnosis and then decreased, confirming Weisman and Worden's (1976) findings, but rose again

before the end of the first year postdiagnosis suggesting the "existential crisis" returns for many.

Results indicated that health locus of control and information styles are not significant factors in determining the amount of emotional distress that the cancer patient reports. However, consistent trends and occasional significance showed health internals to have less concerns, mood disturbance, vulnerability, or overall distress, and greater information preferences. High chance patients had greater concerns, vulnerability, composite distress, and lower information preferences.

Elderly patients reported the least information preferences and internal locus of control. The overall pattern of results suggested that health locus of control beliefs may become altered in situations of life-threatening illness; that denial becomes significant, especially among the elderly; and that effectiveness in coping needs to be assessed along with reported distress.

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Death as a dialogue between
The spirit and the dust.
"Dissolve," says Death. The Spirit, "Sir,
I have another trust."

Emily Dickinson

CHAPTER I

LITERATURE REVIEW

Psychosocial Oncology: The Early Years

The early literature concerning the psychologic aspects of cancer generally paralleled developments in the field of psychosomatic medicine in the 1950's and 1960's. Research during these years typically focused on the attempt to uncover specific personality traits which were associated with the cancer patient. This work was pursued in a spirit of observed consistencies about the personality of cancer patients noted as far back as Galen (LeShan, 1959). Cancer patients were described as relying heavily on denial and repression as defense mechanisms (Bahnson & Bahnson, 1966, 1969, 1971, 1975); having impaired self-awareness and introspective capacity (Valadares, 1969; Jacobs, 1954; Abse et al., 1972); having poor outlets for emotional discharge (Kissen, 1963, 1964, 1967; Cutler, 1954; Blumberg, 1954); showing little expression of aggression (LeShan, 1966; Nemeth & Mezic, 1964; and Stavrasky et al., 1968); as being self-sacrificing and self-blaming (Booth, 1965; Schmale & Iken, 1966); as being rigid and conventional (Bahnson, 1969; LeShan, 1966); as having a "reality" and practical orientation (Jacobs, 1954; Abse et al., 1972; Blumberg, 1954); as having meagre, but deeply felt object cathexes (Booth, 1965; LeShan, 1966) and as having a predisposition for experiencing hopelessness (Kowal, 1955; Greene, 1966). Despite these apparent consistencies

across studies, it is clear that the vast majority were poorly designed. They were retrospective, poorly controlled, often consisting of interviews at the time of diagnosis and were carried out without a hypothesis or theoretical construct to guide the study. Fox (1978) criticizes these studies for being woefully inept in methodology.

Although interest in exploring the psychogenic etiology of neoplasms has waned in the last decade, studies continue to be published which are better designed, but which are also showing equivocal results. In a series of prospective analyses, Thomas (1973, 1974, 1975, 1976, 1977) describes a difference between cancer patients and controls on a closeness-to-parents scale, with cancer patients showing lack of warm relationship to parents as well as pathological Rorscharch responses. Harrower et al. (1975) compared the Draw-a-Person tests of 20 medical students who later developed cancer with matched controls and found significant differences. Keehn et al. (1974) did a prospective study of causes of death among enlisted men discharged for psychoneuroses in 1944. The number who later died from cancer was no different from controls, although they did show excess mortality. Watson and Schuld (1977) found the performance of psychiatric patients on the MMPI who later developed cancer were not different from matched controls. Dattore et al. (1980) compared the MMPI scores of veterans who later developed cancer with matched controls and found the cancer patients were significantly higher in repression, particularly in repression of depressed content and affect.

The cancer prone personality remains an interesting and potentially fruitful field of continuing research. However, the actual stresses of

the disease require that mental health professionals who work with cancer patients address issues pertaining to psychosocial adaption and coping (Brown, 1966; Monat & Lazarus, 1977; Worden & Sobel, 1978). Until recently, few papers have described psychotherapy or other interventions with cancer patients. In general, few researchers went beyond attempting to describe the psychological makings of the cancer patients. In the early years of psychosocial oncology little effort was devoted to describing the psychological impact of living with cancer or of psychological factors associated with effective coping with cancer and recovery from disease or of research on appropriate therapeutic interventions (Holland, 1979; Freidenbergs et al., 1982).

Prognosis and Personality: Psychosocial Factors Related to Recovery and Longevity

Closely related to the study of the psychogenic aspects of cancer is the question of the role of psychological factors in the course and outcome of the disease. Derogates et al (1979) found that women receiving treatment for metastic breast cancer lived significantly longer if they were able to externalize their negative feelings and communicate distress. Those who expressed a strong will to live survived longer. than those with more conservative reactions. Rogentine et al. (1978) discovered that patients with melanoma who reported less psychological distress in managing their illness were significantly more likely to

have a recurrence of the disease than those patients who reported higher levels of distress.

Stavraky (1968) administered the MMPI, WAIS verbal scale and the Differential Diagnostic Technique to 204 cancer patients and found that patients with above average IQ and strong, aggressive drives which were controlled had more favorable outcomes of their disease. Archerberg et al. (1977) found poor prognosis significantly related to denial, expressing dependency on others and viewing one's body as having little ability to fight disease. Ikemi et al. (1975) expressed the finding that faith, especially religiosity, was a strong factor in the spontaneous regression of cancer seen in several patients.

Weisman and Worden (1975) assessed terminal patients and used regression analysis to compare expected survival times with actual survival outcome. They found that those with shorter survival times were more alienated, depressed, felt deprived, and had destructive relationships with others while the longer survivors maintained good relationships with others.

Cancer and Its Impact on Mood

This area of research has attempted to answer the question: Are cancer patients, as a group, depressed and/or mood disturbed? Craig and Abeloff (1974) found 20 of 40 leukemic and lymphoma patients to be depressed while 12 were anxious. Roberts et al. (1972) also found 50% of breast cancer patients either significantly anxious or depressed. Plumb and Holland (1977) using the Beck Depression Scale

found only 25% of cancer patients to be significantly depressed. Worden and Weisman (1977) found 20% of breast cancer patients to be depressed. Leiber et al. (1975) found women to be more depressed as cancer patients than their husbands, male patients, or spouses of male patients. Comparing cancer patients to surgery patients, healthy persons or psychiatric patients have produced unclear results. The trend seems to indicate that as a group cancer patients are less distressed than patients hospitalized for depression and suicidality and not more depressed than their next of kin (Koenig et al., 1967).

Comparing radiation, surgery and chemotherapy and their effects on mood disturbance has not been well studied. Davis and Beumont (1973) found patients requiring laryngectomy to be very highly anxious and depressed at the time of surgery. Unfortunately, follow-up interviews were not completed. Myerowitz, Sparks and Spears (1979) interviewed 50 women receiving chemotherapy for breast cancer. They found 88% described a decrease in activities; 54% had increased financial burdens and 41% had family life affected in a negative way. Also, in this study, side effects from chemotherapy did not account for the overall levels of distress. Forester, Kornfeld, and Fleiss (1978) followed 200 radiotherapy patients over time using the schedule for Affective Disorders and found them to be depressed and anxious, but less so than a psychiatric comparison group. Peck (1972) interviewed 50 patients undergoing radiation and found 98% were anxious and 75% depressed.

Problems of Living with Cancer

Relatively fewer research efforts have been devoted to exploring problems the cancer patient has with activities of daily living (McCollum, 1978). Lehman et al. (1978) interviewed 805 cancer patients in an effort to document specific rehabilitation problems with different cancer sites. They concluded that problems were many and were frequently poorly managed because of inadequate identification of problems by caretakers and lack of appropriate referrals for rehabilitation. Gorden et al. (1977) found the areas of daily functioning most frequently problematic for the cancer patient independent of site were dissatisfaction with medical treatment, difficulties in social relations and family problems. They also found one-third of their patients had some form of vocational difficulty. Feldman (1978) also found cancer patients with work problems: 13% were denied work for having cancer; 35% reported on-the-job discrimination; 11% lost health insurance or had benefits reduced.

Few studies have explored the impact of cancer on family life. Krant and Johnston (1977) found communication among family members during the terminal phase of cancer was often very poor. Weisman and Hackett (1961) suggest that family members withdraw more from a chronically ill than for an acutely ill patient. Sheldon et al. (1970) estimated that 12 of 16 families they studied with a cancer patient were coping poorly. However, cancer patients coped better with family involvement than when living alone.

Lieber et al. (1976) found desire for sexual intercourse decreased in 37% of the 36 advanced stage cancer patients he studied; whereas desire for nonsexual physical closeness increased in half the patients. Female patients and wives of patients were more likely to have their needs met than male patients or husbands of patients. Wellisch et al. (1977) found husbands of mastectomy patients frequently had somatic symptoms, work problems, and difficulty concentrating. Freidenbergs et al. (1982) in an excellent review of the literature concludes:

> the impact of cancer on diverse aspects of daily functioning (including work, social interactions, sex, family relations, personal care) is an important area of investigation about which all too little is known. (page 310)

Psychosocial Changes during the Course of the Disease

Are there stages through which the cancer patient typically proceeds during the course of his or her illness? Gullo et al. (1974) cautions that changes over time must be studied in the context of the extent of disease at the time of diagnosis. The available evidence seems to suggest that psychosocial adaption improves during the course of illness. Wiesmann and Worden (1976) point out that the first 100 days is typically the peak vulnerability during what they term the "existential crisis" of the illness. They also noted that distress is influenced by the site of cancer, extent of disease, symptoms, medical treatment and its side effects.

Maguire et al. (1978) followed breast cancer patients for five years and found distress was also highest during the first year of

illness. Gorden et al. (1979) found at the time of diagnosis adjustment issues focused on worry about the disease. Upon discharge the issue became coping with "negative affect." By three and six month follow-up interviews, patients were struggling with the broader issues of mobility, financial concerns, family and social problems, body image problems, anger with treatment and health care services in general. In a cross sectional study, Mages and Mendelsohn (1979) found patients to experience marked changes in self image, values and capacities over time. Patients reported little change in levels of negative affect, but did report increased distraction and difficulty in concentration. They became less involved with the world outside, more involved with home, family and close friends. Interestingly, these authors also found that women maintained more or less even levels of self-esteem over three years, whereas the men experienced a decrease in their self-esteem over time. These researchers also point out the influence of age on distress in disrupting normal life span developmental stages. For young adults cancer impedes the development of autonomy and the establishment of adult roles. For middle age persons, cancer disrupts ongoing roles and interferes with life tasks that are yet to be carried out. In older persons, cancer is said to accelerate the aging process, resulting in withdrawal from work and social activities as well as increased dependency on others.

Individual Differences and Psychosocial Distress

Which patients are most vulnerable to psychosocial distress? Craig and Abeloff (1974) found that young, upper-middle class, white

females with physical impairment and poor prognosis were the most likely configuration of variables related to high distress. Morris et al. (1977) found poor adjustment to mastectomy was accounted for by depression (high scores on the Hamilton Rating Scale) and emotional lability (high scores on Neuroticism Scale of the Eysenck Personality Inventory) prior to surgery. Menopausal status, previous hysterectomy, and radiation treatment could not account for postoperative distress. Schonfield (1972) studied factors related to return to work among cancer patients and found that age, education, sex, initial severity of disease, and treatment, could not predict likelihood of return to work, while ratings of anxiety and low scores on the Morale Loss scales of the MMPI did predict return to work.

The extent to which distress is mediated by medical variables is unclear in the literature. Weisman and Worden (1977) suggest that 40 to 60% of the variance six months postdiagnosis was accounted for by symptoms, extent of disease and prognosis. This is in contrast to the findings of Schonfield (1972) and Morris (1977) cited above. Meyerowitz et al. (1979) also noted that distress in breast cancer patients could not be correlated with side effects from chemotherapy. Gorden et al. (1969) reported only 12% of the variance was accounted for by medical data in determing distress in patients. This study relied on patient self report, however, while Weisman's study used examiner ratings (Freidenbergs et al., 1982).

The Good Coper

What attitudes, styles, strategies and personality characteristics have been associated with successful coping with cancer? The early literature of West et al. (1952), Blumberg et al. (1956) and Klopfer (1957) suggest that those who were unusually able to manage the course of their illness were emotionally resilient, physically active, had flexible beliefs, strong self-concept and social autonomy.

Cobliner (1977) interviewed 300 women with gynecological or breast cancer and reported that the best copers were individuals with strong self image, positive views of themselves as women, regard for doctors and treatment, reliance on others to confide worries, good relationships with significant others, active social and/or work lives, a sense of having achieved life expectations and successful resolution of problems in the past.

Gorden et al. (1980) found the best copers were also those best able to use psychological intervention from mental health professionals in the effort to reduce levels of anxiety and hostility, aid patients in the return to work, increase active time usage, and to develop a more realistic outlook on life. They noted poor copers used intervention less well, were more passive, anxious, angry, unrealistic and tended to be older, less educated and with an observed high external locus of control.

Siminton and Siminton (1975, 1976, 1978, 1979) consistently describe the good copers with cancer as ones who are able to confront his or her own personal belief systems and take responsibility for

their contribution to causing their disease as well as becoming an active participant in their recovery. Thus, the good copers examine the role they have played in the development of the disease and the secondary gains they have received from their illness. The good coper is active, involved, informed and motivated to get well.

During the past ten years Weisman and Worden at the Omega project and Massachusetts General Hospital have made a thorough study of the process of coping with cancer. On the basis of a three-year descriptive study (1980) they describe the effective, successful coper with cancer:

> Patients who could call upon a wider number of strategies were more resourceful. Those who revised and substituted one strategy for another were considered more flexible. Patients who anticipated change for the better used their optimism in coming to grips with future problems. (page 8)
>
> Coping is defined as what one does or chooses not to do when contending with a problem in order to bring about resolution, relief, reward, quiescence and equilibrium. Defending means primarily to fend off, or avoidance. While coping also uses strategies which avoid, it is primarily concerned with active contending or problem solving . . . Coping contains many strategies . . . all requiring some degree of initiative. (page 10)
>
> Our concept of coping puts emphasis on first confronting or clarifying a problem, then urging consideration of alternative behavior . . . Morale is low (when) personal control is enfeebled. . . . Patients can be helped to take steps on their own behalf. (page 21)
>
> . . . This belief is within the spirit of rehabilitation and our growing awareness of the link between health and responsibility (Weisman & Sobel, 1979, page 22). . . . problems are not adequately resolved because patients assume too passive a stance. Direct confrontation of problems is encouraged (page 25). . . . The aim of short-term consultation . . . is to reinforce the reality of personal choice, control and competence. . . . By emphasizing the control that patients do have emotional stress can be relieved (page 25). . . . The value of conscious control over tension and debilitating emotions is unquestioned and strongly advocated (page 28). . . . The objective is to strengthen

> internal controls, choice in goals, personal resourcefulness (page 27).
>
> Patients who profited least from intervention were more depressed, pessimistic persons who tended to externalize their locus of control (examiner judgement). They were screened with higher scores and reported more work-finance, family, existential, and self-esteem concerns. Following interventions, they continued to project their pessimistic outlook onto their recovery, and displaced their anger to the inadequate support they received from family members and doctors. They also consistently reported more symptoms and poorer resolution of problems. Not surprisingly, patients profiting most from intervention internalized their locus of control, and generally had a more optimistic outlook on their problems, family support, medical care and recovery. These patients experienced lower distress levels and better resolution of their problems. (page 69, Weisman, Worden & Sobel, 1980)
>
> It is natural to like patients who are in need, are optimistic about getting help and have a stronger internal locus of control, meaning a belief that their attitudes contribute to distress, but can be changed for the better (page 71). . . . No psychosocial intervention can be considered unless it makes provision for strengthening a patient's autonomy. (page 81)

Weisman (1976) notes that good copers are optimistic and confidently comply with doctors' recommendations, while poor copers use "suppression, passivity and stoic submission" (page 193).

This review of the good cancer copers outlines the widely-held assumption that successful coping and internal locus of control, which we shall examine more closely in the next section, are closely related. The general opinion suggests that the involved and informed cancer patient who takes responsibility for actively participating in the process of managing the problems posed by their illness is the one best equipped to cope with the stresses of the disease. This is an assumption which has yet to be put to an empirical test.

Locus of Control and Successful Coping with Health Related Problems

What does the concept of Health Locus of Control actually mean and what relevance does it have to coping with illness?

In 1964 Norman Cousins, a former editor of the Saturday Review, was diagnosed as having ankylosing spondylitis—a collogen disease which destroys the connective tissue in the spine. He was told he had "one chance in five hundred" to recover. Years later, after his full recovery he wrote:

> Up to that time I had been more or less disposed to let the doctors worry about my condition. But now I felt a compulsion to get into the act. It seemed clear to me that if I was to be that one in five hundred I had better be something more than a passive observer. (Cousins, 1979, page 35).

Cousins went on to form a partnership with his physicians and helped develop his own treatment regimen. He behaved in accordance with his belief that he was largely responsible for his health. Other people, and many if not most physicians, behave as if doctors and perhaps nurses are primarily responsible for setting things right. Still others hold that no one is truly responsible for health. It is a matter of simple fortune, a stroke of luck or fate.

Locus of Control is a weary construct. Well over 1,000 published papers have attempted to outline individual differences in locus of control beliefs. Results have been equivocal through the years, but patterns seem to have emerged. In general, persons with internal as compared to external locus of control, appear to be more "potent,

competent, effective persons, likely to take responsibility for their actions and to take steps to change aversive life situations" (Wallston & Wallston, 1981, page 3; Phares, 1973, 1976; Rotter, 1966, 1975; Lefcort, 1966, 1976; Joe, 1971).

Norman Cousins had a generalized expectancy that the outcome of his illness was directly tied to his behavior. This is termed an internal locus of control orientation (Rotter, 1966). Social Learning Theory (Rotter, 1954) posits that

> The potential for a behavior to occur in any specific psychological situation is a function of the expectancy that the behavior will lead to a particular reinforcement in that situation and the value of that reinforcement. (Rotter, 1975, page 57)

Thus, the behavior of an individual is a function of their view of a situation, their expectancies of their own behavior and the value they place on the outcome of the situation in which they are behaving. Based on this conceptualization one could expect that the adjustment of a person with cancer is likely in some manner to be related to their view of their plight, and their expectancy of how their behavior can influence the outcome or course of their disease.

How is locus of control assessed with respect to health related phenomena? The first version of a health locus of control measure was the work of Kirscht (1972). The measure had nominal impact on the field since its theoretical validity was criticized for confounding expectancy and motivation. For example, one statement on his questionnaire was "I really work at it to stay in good health."

Wallston, Wallston, Kaplan and Maides (1976) developed their first Health Locus of Control Scales (HLC) consisting of 11 items

with a 6-point Likert response format. Two years later they developed a multidimensional version of these scales (Wallston, Wallston, & DeVellis, 1978) modelled after Levenson's I, P and C Scales (Levenson, 1973). The MHLC scales consist of three 6-item scales, also using a 6-point Likert response format. Levenson's contribution has been to split externality into two theoretically and statistically distinct components; that is, the notion that health is either controlled by powerful others such as doctors, or by fate or chance. The three dimensions tapped by the MHCL Scales developed by Wallston and Wallston (1981) have been shown to be more or less statistically independent. They are also more internally consistent than earlier scales.

Thus far, the MHLC Scales have been used as both an independent and dependent variable primarily to investigate the areas of information seeking, preventive health behaviors, weight reduction, smoking control, dental hygiene, adherence behaviors and chronic illness.

With respect to preventive health behaviors, results have been, at best, mixed. No significant relationships have been found between health locus of control and generalized health behavior across a variety of samples of individuals, i.e. clerical workers (Baughman, 1978), HMO clients (Lauvess, 1978), pregnant women (Lowenstein, 1979) and two national surveys (Stuart, 1979). In studies which have explored more specific health behavior Olbrisch (1975) found no difference between HLC internal and external patients with venereal disease with intention to take future precautions against the disease. McLusken and Morrow (1979) also found no difference between HLC scores and behaviors to prevent cancer. Carnaham (1979) found no relationship

between MHLC scores and a dental plaque index. Wallston and Wallston (1981) also could not correlate MHLC scores with self reports of brushing and flossing. There was no relationship for their children's immunization (Berger, 1980), vitamins (Gossler, 1980) or car seat usage (Guske, 1980).

Positive results were reported by Dishman et al. (1980) who found internal HLC persons were more likely to stay with physical activities. Saltzer (1979) also found internals more likely to complete a weight reduction management program. Kaplan and Cowles (1978) found HLC internals more likely to reduce and maintain lower cigarette consumption. Wildman et al. (1979) and Shipley (1980) also had similar findings. In general, however, health locus of control is not easily related to preventive health behaviors. Wallston and Wallston (1981) suggest that such behaviors are multidetermined and that it is unrealistic to expect HLC to account for significant variance.

Is there a meaningful relationship between physical illnesses, chronic health conditions and health locus of control? Wallston and Wallston (1981) write "Health locus of control beliefs should influence one's response to symptoms and to chronic illness" (page 22). Strickland (1978) writes:

> Any impending or disabling disorder, whether chronic or temporary, has a varying degree of influence on the response of the person faced with the handicap. The severity of the disorder, the time of onset, the current status of the patient, the support he or she receives, and so on, all interact with what is probably a complex set of cognitions about the disorder. When an individual is more helpless than he or she once was . . . beliefs about locus of control would be expected to be related to reactions to the disorder. (page 1198)

Empirical support for these points of view about the theorized relationship between health locus of control and chronic illness are limited. Eggland (1973) and Goldstein (1976) found that chronically handicapped children were more external than healthy children. DeVallis et al. (1980) found an increased powerful-other locus of control with epileptics. Tolor (1978) found for women, but not for men, external HLC beliefs correlated with a history of childhood illnesses and accidents. Binik and Devins (1979) reported that patients on renal dialysis were highly external. Interestingly, patients on home dialysis did not have a more internal or less external orientation than inpatients. Comparing all reported data, the least internal locus of control group are chemotherapy outpatients (Wallston, 1979). This group also shows high chance beliefs, as might be expected. Hypertensives are the most chance external group (Nagy, 1979). Diabetics are the most powerful other external group (Nagy, 1979).

Wallston and Wallston (1981) in a review of the literature in this area conclude:

> Across a variety of chronic patient samples beliefs in chance health locus of control and in powerful others health locus of control are relatively high, while beliefs in internal health locus of control are similar to those of healthy adults. Such divisions are relatively consistent across diverse conditions, including cancer, diabetes, epilepsy, and respiratory disease. (page 23)

It appears that chronically ill persons are more likely to believe that they did not bring about their illness, but rather see it more as a function of chance. Also, they are more likely to realize

their dependence on family, friends, doctors and others to help them in managing their disease. This apparently occurs while beliefs in internal locus of control remain high. These findings lend support to the view that health locus of control is, at least in part, a situational variable. Beliefs appear to be influenced by the illness experience.

It also appears that beliefs are modifiable. Diller et al. (1979) followed cancer patients with the HLC scale at admission, three months after, and six months after, discharge. An experimental group received a brief psychosocial intervention while inpatient. Results showed that the control group increased in externality at three months while the intervention group remained the same. At six months there was no difference. In a similar study Bloom (1979) compared mastectomy patients who received psychosocial intervention postsurgery. At two months postsurgery these women had not increased in externality, while those patients who did not receive intervention had increased. He concluded "the effect of intervention was to cancel out what would have been a more fatalistic attitude on the part of the treatment group subjects" (page 638).

Wallston and Wallston (1981) report no evidence to suggest a relationship between age and health locus of control in the literature. They suggest some indications that higher education is inversely related to externality, but this has not been partialled out from lower socioeconomic status. They also write "sex differences have not been found on health locus of control scales" (page 218).

In a study not reviewed by Wallston and Wallston, Leigh, Ungener and Percaspio (1979) looked at cancer patients using the traditional locus of control inventory (Rotter, 1975). They found significant differences between the sexes. Men expressed higher internal beliefs and this increased as radiation therapy progressed. Interestingly, men were also more likely to characterize their illness as not very serious and to deny knowledge of their diagnoses or details of their treatment. They concluded that sexual differences in coping mechanisms may be accentuated by malignancy, with men actively denying their diagnoses and its implications. These findings seemed to contradict the conclusions of Wiseman, Worden and others reviewed earlier. That is, according to them, internal locus of control should have been inversely related to denial and avoidance of information about one's illness. Also, these findings challenge the assumption that internal locus of control is necessarily associated with good coping with a disease such as cancer. Unfortunately, this is the only study reported in the literature which begins to assess empirically the relationship of locus of control to coping with cancer. Its findings are surprising and perhaps represent a response set on the part of men to appear "in control" of their illnesses. In addition, the more global rating of locus of control using a different scale may have also affected results. Moreover, there was no attempt to empirically assess coping among subjects. Information preferences and denial were judged without test instruments. For these reasons it seems safe to conclude that this study legitimately raises important questions; but because of design flaws, however, does not provide supportable answers.

Information Preferences, Coping and Locus of Control

This literature review thus far crystallizes the question: Does there appear to be a relationship between locus of control, preferences for information about one's illness and ultimate ability to cope with the stresses of that illness? Wallston and Wallston (1981) write, "Another aspect of behaving responsibly (internal locus of control) is to be informed and knowledgable about all aspects of health and illness, including the health care systems" (page 14).

Wallston and Wallston (1981) found a significant inverse relationship between powerful others on the MHCL scales and desire for behavioral involvement, self care and active participation on the Krantz Health Opinion Survey. Dunn (1980) also found powerful others negatively correlated with attitude toward self care as assessed by Linn and Lewis' method (1979). Wallston et al. (1976) found internals were more willing to read hypertension related information than externals. In another study (Wallston et al., 1976) college students' role playing newly diagnosed hypertensive patients were split into two groups, high internal and powerful others with low chance, and high chance with low internal and powerful others. The first group was found to be more likely to ask questions about the disease when given the opportunity to do so. Interestingly, high internals were no more likely to choose more hypertension-related pamphlets than low internals whereas, high powerful others, low chance locus of control subjects did choose more pamphlets than their counterparts. Wallston et al. concluded that it was more salient to be low chance external than high internal in believing

that one's own behavior influences their health. They also reported that they were unable to generalize these findings using similar designs to other medical conditions.

Sproles (1977) reported that HLC internal patients on renal dialysis knew more about their condition, desired to know even more and were more willing to attend patient education classes than HLC externals.

In a national study of persons with epilepsy (DeVellis et al., 1980B) Wallston et al. (1971) included a measure of information seeking. High powerful other scores were the single best predictor of willingness to receive information about epilepsy. They concluded that it was not necessary to hold exclusively internal health locus of control beliefs in order to seek health relevant information. No studies, however, have supported high chance scores with information preferences.

In a detailed study of information preferences among cancer patients Cassileth et al. (1980) reported that those who sought detailed information were younger, better educated and more recently diagnosed. Younger, better educated patients also indicated that they were more willing to participate in decisions about their medical treatment. These researchers also reported a strong majority (80+%) of their sample population preferred active participation and detailed information. Weisman (1979) reported that only 10% of his newly-diagnosed cancer patients were reluctant to hear facts about their illness, and were satisfied to depend on the physicians' discretion for further information. As Cassileth points out, however,

> these settings may have encouraged preferences for information, and patients who seek treatment in large

> medical centers may differ from those who go elsewhere. Therefore, the extent to which data can be generalized to patients in non-academic or community hospitals is unknown. (page 835)

Using the Beck Hopelessness Scale, Cassileth et al. (1980) also found those who preferred active involvement in their own care to be more hopeful. Patients who wanted as much information as possible, good and bad, were more hopeful than those who preferred minimal or only good information. These statistical significance levels were sustained when medical status was held constant. Other than this measure of hopefulness no attempts were made to assess the relationship of coping to information preferences. Nor was an attempt made to assess locus of control with respect to information preferences among these patients. Their findings suggest though, that to the extent hopefulness is a signal of effective coping, cancer patients with hope are more likely actively to seek information and cope better.

In contrast to this implication, Cohen and Lazarus (1973) investigated the relationship between recovery from surgery and avoidance or vigilance toward seeking information about their medical condition and surgery, as measured in a preoperative interview. The results showed that those who sought the most information and control (the vigilant) had the slowest and most complicated recovery from surgery. This finding was replicated in a subsequent study (Cohen, 1975). Cohen and Lazarus concluded that the coping strategy of actively trying to "master" the world by seeking information may at times be maladaptive. In contrast to Weisman and Worden's conclusions, they

seem to suggest that an internal locus of control may not be most appropriate or most effective as a coping strategy in all situations. Kornfield et al. (1974) express a similar view in explaining why patients who were dominant and self-assured had a greater incidence of delirium after open heart surgery. Hackett and Cassem (1968) also suggest that denial and avoidance can be adaptive in the coronary care unit. Cohen and Lazarus (1973) suggest that avoidant-denial forms of coping may be more effective than active-vigilant strategies in certain stressful situations. Indeed, as Stone (1979) writes in conclusion of his review of the relevant literature "many patients and health professionals believe that 'ignorance is bliss'" (page 244).

Schnaper (1977), an experienced clinician with cancer patients, writes about a surgeon who believed that patients should be directly and fully informed about their illness and trained his residents in this approach. This man later developed a carcinoma, and his own surgeon, a former resident of his, being very well trained, told him "the facts" and that he had better make his arrangements. The doctor-turned-patient spent the next year trying to have his surgeon thrown off the medical staff. Schnaper concludes "denial is hope, and as such, it is as important to cancer patients as are the narcotics they need for pain" (page 1153).

This review of literature suggests two independent lines of thinking. It seems that either actively seeking information and taking responsibility for involvement in one's own "arrangements," or avoiding such information and responsibility for managing one's illness,

have been justified as the better coping strategy. Weisman, a firm supporter of encouraging an internal locus of control, full disclosure and participation, contradicts his own findings when he reports that he could find no relationship between denial and increased vulnerability (1979). He concluded "Theoretically, a patient with high denial should score highly on vulnerability" (page 191). The relationship between one's preferences for information, locus of control beliefs and ability to cope with their illness is one that remains confused and unclear.

Statement of the Problem

Several investigators and clinicians suggest that having an internal locus of control is better when it comes to coping successfully with the stresses of having cancer. Indeed, intervention programs appear almost universally designed to enhance one's sense of control, participation and knowledge. While it has been assumed that there ought to be a relationship between internal health locus of control and good coping, this has not been tested empirically. In the one study published which does measure locus of control and coping among cancer patients, internals surprisingly were found to be the most avoidant. This was in spite of the fact that inadequate design limited proper assessment of coping, information preferences or locus of control. At this point we simply do not know what relationship, if any, exists between coping with cancer and locus of control, coping with cancer and information preferences, or between locus of control and

information preferences among cancer patients. Previous work suggests contradictory results, expectations and assumptions. The present research is designed to look more directly and more closely at what empirically described relationships might exist between information preferences, locus of control, and one's success in coping with cancer.

Hypotheses

Main Hypotheses

1. Although the relationship of emotional distress and coping to health locus of control among cancer patients appears complex, the research literature and theory would expect that internals would cope better and thereby experience less distress. Chance and powerful other externals, should experience somewhat more distress.

2. The relationship of health locus of control and information preferences among cancer patients has also not been tested before. However, previous research and theory suggest that internals should have higher participation and information preferences than chance or powerful other externals.

3. The relationship of emotional distress and information preferences among cancer patients has not been tested before. However, since internals should take more responsibility for being well informed, and since internals should also cope better, patients who seek out information should also experience less distress. Conversely, more distressed patients should have less information preferences and less

desire to participate with doctors in decisions regarding their medical treatment.

Secondary Hypotheses

4. The findings of Weisman and Worden would suggest that distress is mediated to some extent by the specific cancer diagnosis. Patients with more aggressive cancers should experience more distress than patients with less aggressive cancers.

5. Distress is also mediated by time since diagnosis according to Weisman and Worden. The peak distress should be within the first three months since diagnosis, then rapidly decline for most patients.

6. Gorden et al. (1980) found patients to have more emotional upheaval and worry early in diagnosis and more pragmatic concerns as time wore on. Weisman and Worden (1980) found very different results. Pragmatic concerns were initially very high and dropped off rapidly, whereas mood disturbance and distress dropped off only slightly over time. Since we are using Weisman and Worden's instruments we would expect similar findings.

7. The amount of emotional distress accounted for by medical factors has also been an area of much disagreement. However, we would expect that physical symptoms, extent of illness and Karnovsky performance status should account for a significant amount of the distress experienced by cancer patients.

8. Cassileth's (1980) most impressive findings were that participation and information preferences dropped off significantly with increasing age. We would expect to replicate these findings.

9. Wallston and Wallston (1981) write that, theoretically, locus of control is not mediated by age. However, given the sample population of patients being treated for cancer, and the findings of Cassileth (1980) that older patients have much less investment in getting information, we would hypothesize that older patients would also be less likely to be internals and more likely to be chance and powerful other externals.

10. Wallston and Wallston (1981) specifically hypothesize that in a population of chronically ill patients those who are emotionally depressed should have higher chance health locus of control scores.

11. Although Leigh et al. (1980) found men more likely to be internals and to report less distress, Wallston and Wallston (1981) write that, theoretically, there should be no differences between the sexes on locus of control. Since the bulk of locus of control research reports no differences in this area we would expect to find the same.

CHAPTER II

METHODS AND PROCEDURES

Subjects

The experimental subjects were all private patients of the Hematology-Oncology Consultation Service of the University of Tennessee Memorial Research Center and Hospital. Subjects included both inpatients and outpatients. Patients were referred to the Hematology-Oncology Consultation Service by other internists, surgeons, and primary care physicians who initially diagnosed a carcinoma and were looking for evaluation of the possible use of chemotherapy. Nearly all patients had been told of their diagnosis by the time referral to the service was made.

Subjects were selected for psychosocial screening if they were new patients on the service or old patients who had not yet been screened. Every effort was made to screen each consecutive admission from October 1980 through June 1981. Each referral for psychosocial evaluation was specifically referred by one of three physicians working on the service who introduced the screening battery as a routine clinical and research procedure. Quite often the physicians directly introduced the individual doing the evaluation to the patient.

The patient was selected to be in the study if physicians judged the patient to be sufficiently sound to participate. Patients had to be 18 years or older, physically well enough to participate, without

neurological deficits, and able to read. Patients thus referred met with a psychosocial screener who introduced the evaluation in more detail, provided a letter of introduction and answered whatever questions the patient might have. If there was interest, informed consent was obtained and testing proceeded. (See the Appendix for a copy of this form.)

A total of 120 patients were referred for screening. Refusals and incomplete testings resulted in a total of 109 patients who were fully tested. These consisted of 60 inpatients and 49 outpatients. It was intended that 100 evaluations be completed as an arbitrary cutoff target after which the clinical usefulness of the screening battery would be assessed and necessary improvements and streamlining implemented. This figure was also chosen to maximize statistical power.

No other restrictions were placed on patient selection regarding type of diagnosis, extent of illness, performance status, time since diagnosis or kind of treatment.

Instruments

A semistructured interview, symptom checklist and five psychological instruments were presented to each person examined in a single session which typically lasted ninety minutes.

The interview was given to obtain biographic and demographic information and was designed by the staff of the University of Tennessee Hospital's Psychosocial Clinic to assess in a more global and

open-ended fashion the person's experience with cancer. The interview is an integration of the most useful aspects of similar interviews developed by Cassileth (1980), Weisman, Worden, and Sobel (1980) and Harrison (1979). Subjects were asked to describe how they first discovered their cancer and how they and their family reacted. They were asked in some detail about their emotional reactions, typical moods, changes in feelings and areas of most worry. Subjects were also asked how and with whom they discussed their illness, how activities changed and their perceptions about role changes in their lives. The interview concluded with questions about the anticipated future, sources of strengh and support, and means of relaxation.

An assessment of physical status and symptoms was recorded from medical chart data by the supervising Oncology Coordinator, a former Head Nurse of the Service and one well trained for determining the specific naming, staging and extent of disease, Karnovsky rating of performance status, and duration and intensity of a wide range of debilitating symptoms. The rating of symptoms was determined by following a scale developed by Weisman, Worden and Sobel (1980). (See Appendix.) A measure of the extent to which the disease had impaired the ability to function with normal physical routines was assessed using Karnovsky's procedures (1948).

The five specific psychological instruments used in the present study included the Inventory of Current Concerns (ICC), the Profile of Mood States (POMS), the Index of Vulnerability Rating Scale (VUL), the Multidimensional Health Locus of Control Inventory (MHLC) and the Informational Styles Questionnaire (ISQ).

1. The Inventory of Current Concerns (ICC) (Weisman and Worden, 1977) is a standard checklist of 72 problems commonly found among medical and surgical patients. It is typically given as a paper and pencil task which is self-administered, but in this study was orally administered for efficiency, convenience, reliability and accuracy of scoring. All tests were administered orally. Each problem was presented in a statement form using a forced choice scale of true, somewhat true, or not true. The ICC areas are subsumed under seven psychosocial categories: health, work/finance, religion, family, friends, self-appraisal, and existential concerns. Cronbach's (1951) alpha coefficient for estimating internal reliability revealed the following consistencies: health (.75), work/finance (.69), religion (.81), family (.76), friends (.71), self-appraisal (.86), and existential (.73). The alpha coefficient, which estimates the proportion of test variance due to all common factors, has been shown to be a stable reliability index in that it represents a mean of all split half coefficients resulting from all possible ways of dividing the test. In the present study, the subscale scores for all the categories were combined and averaged according to the method of Weisman et al. (1977) to produce a rating of total current concerns.

2. The next test which was administered was the Profile of Mood States (POMS) (McNair et al., 1971). This is a 65-item adjective checklist which was read aloud to subjects. The test yields scores on the mood states of tension, anger, fatigue, depression, confusion and vigor. Total mood disturbance (TMD) is the sum of the first five mood

states with the vigor score subtracted from that sum. The TMD score was used as a global measure of dysphoric mood in the present study. Adequate reliability and validity testing of the POMS has been reported by McNair and his associates. Specific norms for cancer patients were developed based on data collected by Weisman et al. at the Massachusetts General Hospital and on the data collected in the present study.

3. Next administered was the Multidimensional Health Locus of Control Inventory (MHLC) (Wallston and Wallston, 1973). The instrument is a health-specific indicator of generalized expectancy of locus of control reinforcement based on Rotter's social learning theory (1972). This self-report test represents a reconceptualization of the original Health Locus of Control scale developed by Wallston, Wallston, Kaplan and Maides (1976) based on the work of Levenson (1973, 1974, 1975) which suggested that understanding and prediction of locus of control could be improved by splitting externality into the dimensions of chance expectations and expectations of external control by powerful others. The alpha reliabilities for the MHLC Scales (6-item forms) ranged in validation studies from .67 to .77. When forms A and B were combined into 12-item scales the alpha reliabilities ranged from .83 to .86. Form A was used in the present study. Wallston and Wallston (1981) report that the three dimensions have proven to be statistically independent, especially the IHLC (internal) and PHLC (powerful others) Scales. The IHLC and CHLC (Chance) Scales are negatively correlated (but share less than 10% common variance), and

the CHLC and PHLC Scales are modestly correlated (+.20). Only the CHLC Scale correlated with the shortened version of the Marlowe-Crowne Social Desirability Scale (R = -.24).

Concurrent and discriminant validity of the MHLC Scales were adequately established by Wallston et al. (1981) with appropriate empirical correlations with the theoretical counterparts among the Levenson's I, P and C Scales. The designation of items into IHLC, PHLC, and CHLC Scales was supported by a factor analysis which reproduced the three dimensions without error.

4. Administered next, and last, was the Informational Styles Questionnaire (ISQ) (Cassileth et al., 1980). This self-report test was designed by researchers at the University of Pennsylvanic Cancer Center to elicit data on cancer patients' preferences for information about their illness and their desire to participate in their treatment. Patients were asked to describe their information preferences on a five-point scale ranging from 1 (no more details needed) to 5 (as many details as possible). Patients were also asked to select the statement that best described their point of view from the following alternatives: "I prefer to leave decisions about my medical care and treatment up to my doctor," or "I prefer to participate in decisions about my medical care and treatment." Patients were further asked to choose whether they want "only the information needed to care for myself properly," "additional information only if it is good news," or "as much information as possible, good and bad." A list of 12 items determined the type of information desired by patients and whether they "absolutely need,"

"would like to have," or "do not want" this information. This questionnaire evolved from a sequence of pilot tests, was tested on a pool of 300 subjects, and has been shown by Cassileth (1980) to use wording that patients found meaningful and comprehensible and to discriminate among patients' viewpoints.

5. The Index of Vulnerability Rating Scale (VUL) (Weisman, 1976) was designed by researchers at the Omega Project of Massachusetts General Hospital as a clinical rating scale for obtaining information on the type of degree of patient distress. The rating scale was completed by the examiner clinician who administered the interview and other instruments and was included as a means to provide an external rating of patient coping and distress other than self-report. This index measures 13 observed emotional states: hopelessness, turmoil, frustration, depression, powerlessness, anxiety, exhaustion, worthlessness, abandonment, denial, truculance, repudiation of significant others, and time perspective. Each variable is scored on a 1-4 point scale. Total vulnerability scores range from a low of 13 to a high of 52. A principal components factor analysis with varimax rotation disclosed four primary clusters on the VUL: annihilation, alienation, denial and dysphoria.

Reliability Check

Interrater reliability ratings from the Omega Project on the 13 VUL scales ranged from a low of .64 (powerlessness) to a high of .92 (truculence). The reliability of the overall scale was .95. Although Sobel and Worden (1979) considered these ratings sufficiently high

to use in group research, Tinsley and Weiss (1975) recommend that interrater reliability be recalculated for every new set of rating data and raters that use such an instrument. This recalculation was carried out with the raters used in the present study. After multiple training sessions to be described in a later section, each rater viewed two videotapes which were recordings of a complete psychosocial screening with different patients and were administered by the present writer in one case and the senior psychosocial clinic staff member in the other case. In addition, all raters listened once per week for five weeks to audio tapes of screening interviews administered by different examiners each week. VUL rating forms were completed by all for each of the seven sessions. Kendall's coefficient of concordance (Kendall's W) was used to measure the degree of similarity among the sets of ranks provided by the raters. The resultant reliability coefficient was .85. Using Cronbach's coefficient ALPHA as an alternate statistic for interrater reliability check a coefficient of .97 was computed. Each figure represents a high overall consistency among examiners with respect to the total VUL scale rating and is considered adequate for the present group research.

Scoring

Each examiner was responsible for scoring each of the tests following the screening. Procedures for scoring were explained and practiced during the training sessions. Only the VUL required scoring reliability assessment. The other tests were patient self-report

and were scored according to instruction in the test manuals. All test protocols were reviewed again for accuracy by two undergraduates in psychology who then recorded test results onto coded data sheets.

Examiners

The psychosocial screeners, as they were called, came from a variety of backgrounds. Besides the present writer and the senior staff at the psychosocial clinic, there were twelve screeners. One was a third year graduate student and one a first year graduate student in clinical psychology. Two were upper level undergraduates in Human Services. Two were doctoral students in medical ethics. Six were women volunteers who came from a variety of experienced backgrounds.

Training

Training for all examiners was extensive, not only to assure accuracy in the administration of the test battery, but to insure that each contact made with a patient would be a therapeutic one. Following initial interviews by senior staff to screen examiners who were not appropriate for the role, an initial training period of four, two-hour sessions began. Testing procedures were reviewed and interviewing techniques were taught. Dyads were formed for applying skills in role played situations while third observers provided feedback for improvement. Videotapes of interviews were discussed, dyads met between sessions for further practice, and finally scoring of tests was taught. Weisman's book Coping with Cancer (1979) was used as a guidebook for developing

the necessary knowledge of relevant theory, research and clinical findings. William Worden, Ph.D, coprincipal investigator of the Omega Project at Massachusetts General Hospital was also brought in to provide a two-day workshop on interviewing, screening and counseling cancer patients.

Each examiner's first administration of the battery to a cancer patient was observed by a member of the core staff of the psychosocial clinic and feedback provided. After this, screeners followed up several referrals in pairs taking turns administering and observing. Less experienced interviewers continued in pairs for multiple referrals. Soon each "graduated" to following up referrals independently. They were each assigned a particular day and time to be "on call" for referrals.

In addition to the above procedures, the examiners attended weekly meetings, ninety minutes in length, throughout the remainder of the nine month data collection period. These meetings were used to review and improve administration and scoring procedures, conduct interrater reliability assessment for the VUL and most importantly, to discuss and process the experiences one had in getting to know intimate aspects of a person facing the emotional and physical catastrophe of having cancer. Any patients who were recognized as having a pressing need for clinical intervention were also discussed and attempts were made, often on the part of the examiners, to follow up on these needs. The research project thus became a springboard for clinical assessment and intervention by a staff of well-trained and caring counselors.

Screening Procedure

All patients were first referred by their Oncologist. All newly-diagnosed patients were routinely referred following initial assessment by the physician. These patients were typically screened on the inpatient service. Patients who had known of their diagnosis for some time were screened as part of their follow-up visits to the outpatient clinic. Frequently these patients were receiving chemotherapy. On occasion patients rescheduled or asked to complete screening at a more convenient time. Patients were interviewed in their hospital room, in an office near the outpatient clinic, or in the psychosocial clinic office. Nurses were asked to help not allow interruptions during screening. Family and friends of patients were asked to leave the room during screening. After introductions, each patient was told that the screener was gathering information concerning their emotional reactions to their having cancer in order to determine whether they might need or desire psychosocial intervention and support. The clauses of the Informed Consent were discussed with all subjects at the outset. Both the service aspects and the research related aspects of the procedure were explained. Each of the questionnaires were introduced and any and all questions addressed. Participation was encouraged, but was completely voluntary. It was emphasized that the patient could discontinue at any point and that he or she was free not to respond to any particular question. Patients who refused screening were told they would not be prejudiced in their medical treatment or in the opportunity to use the services of the Psychosocial

Clinic in the future. It was also explained that the patients identity and results of screening were confidential and would be protected. Patients were also told that they were welcome and encouraged to discuss with a member of the Psychosocial Clinic staff the results and findings of their screening.

CHAPTER III

RESULTS

Demographic Findings

Of the 120 cancer patients referred for psychological screening, 109 were fully tested. Eleven patients were either too sick to complete testing or, in a few cases, refused testing. The final sample consisted of 60 inpatients and 49 outpatients. Patients ranged in age from 18 to 86 years with a median age of 57 years. Fifty-eight patients were females and 51 were males. There was a nearly even distribution of education levels ranging from grade school only (N = 26), through high school (N = 38), and through college and graduate school (N = 48). The vast majority were married and had children. Nearly all were privately insured.

Among the types of cancer diagnoses in the sample there was also a fairly wide and even distribution. All gastrointestinal cancers were combined and this formed the largest subgroup (N = 23). The next largest subgroups were lung cancer (N = 21) followed by lymphoma and leukemia (N = 20). Other groups were breast cancer (N = 17), skin and melanoma (N = 8) and reproductive (N = 3). All other cancers were listed as other carcinoma (N = 17).

Patients were tested in a wide range of time since diagnosis. Those diagnosed less than two weeks from time of diagnosis comprised 7.4% of the sample, more than two weeks but less than three months

comprised 25% of the sample, more than three months but less than one year 21.3%, between one and three years 25%, and more than three years, 21.3%. The service from which patients were referred was medical oncology. Thus, the vast majority of patients in the sample were receiving, had received, or were about to receive, chemotherapy ($\underline{N}$ = 50). A large proportion of the patients, however, also had surgery and/or radiation ($\underline{N}$ = 36). Sixteen of the 109 patients were not receiving any treatment at the time of screening.

There was an even distribution of extent of illness among the patient sample. Forty-six had disease that could be characterized as locally invasive, 21 had cancer spread to nearby organs and 31 had widely disseminated cancers. All ratings as to extent of illness were made by the nurse oncology coordinator from the patients' medical records.

The majority of patients were able to carry on normal activities and work (52%). These patients had Karnovsky Performance Status ratings of 80-100. Patients scoring in the middle range on the Karnovsky scale (50-70) comprised 34% of the sample. These patients were unable to work. They were able to live at home and care for most of their personal needs, but needed some assistance. Patients rated 0-40 on the Karnovsky scale were 14.2% of the sample. This group was disabled, requiring the equivalent of institutional or hospital care. Most of these patients were in the terminal phase of their illness.

The most common symptoms patients experienced were pain, fatigue, loss of weight and difficulty in sleeping (see Table 1). A rating of total symptoms for each patient was made by assigning weights to

Table 1

Relative Frequency of Symptom Intensity among Patient Sample during Month Prior to Screening (N = 109)

Symptom	Not at All	Some	A Great Deal
Pain	51.4%	36.4%	12.1%
Tiredness and Loss of Energy	36.1%	48.1%	15.7%
Los of Weight	61.3%	27.4%	11.3%
Trouble Sleeping	52.8%	34.3%	13.0%
Swelling, Irritation, Lumps, Poor Healing	80.2%	13.2%	6.6%
Trouble with Vision or Hearing	76.6%	19.6%	3.7%
Difficulty Walking or Keeping Balance	76.6%	20.6%	2.8%
Nausea, Vomiting or Trouble Eating	77.4%	17.0%	5.7%
Diarrhea, Constipation, or Cramps	86.0%	11.2%	2.8%
Difficulty Urinating	95.3%	3.7%	0.9%
Cough or Shortness of Breath	75.7%	15.0%	9.3%
Heart Problems	85.8%	12.3%	1.9%
Feeling Depressed, Worried or Tearful	38.9%	40.7%	20.4%
Speech Difficulty	95.4%	3.7%	0.9%
Hair Loss	78.5%	13.1%	8.4%
Bleeding	97.2%	2.8%	0.0%

specific symptom intensity. A patient received a score of one for each symptom that he or she was rated as not having, two if he or she had reported the symptom at least once and a weight of three if the patient reported the symptom on more than two occasions. Scores were summed and total symptoms ranged from 16-33 with a median symptom total of 20.2 and a standard deviation of 4.0.

Normative and Comparative Findings

The number of subjects tested in the present study was smaller (N = 109) than the sample at Massachusetts General Hospital's Omega project (Weisman and Worden) (N = 246), or the sample at the University of Pennsylvania Hospital (Cassileth) (N = 256). The distribution of subjects by sex was very similar. In all these studies there were somewhat more women than men tested.

Similarly, the age groupings among the three groups were comparable. Nearly half the patients were 40-59 years of age in all samples. The next largest group were over 60 years of age and the smallest group were between 18 and 39 years (see Table 2).

The present sample and the Omega Project sample show a distinct difference on results from the Inventory of Current Concerns (see Table 3). Among all subgroups the present sample shows a greater number of concerns. The largest difference by far was on religious concerns where the present sample had a much greater number of such concerns than the sample at Massachusetts General. The smallest difference was on existential concerns. This category had the highest

Table 2

Comparison of Age Distribution between Present Sample, Omega Project and Pennsylvania Findings

Present Study			Omega Project			Pennsylvania Study		
18-39	40-59	60+	18-39	40-59	60+	18-39	40-59	60+
14%	51%	35%	24%	46%	29%	21%	41%	38%

Table 3

Comparison of Frequencies of Current Concerns between Current Patient Sample ($\underline{N}$ = 109) and Omega Project Sample ($\underline{N}$ = 246)

Concerns	Current Sample Percent	Omega Project Percent
Health Concerns	28.2	19.1
Religious Concerns	28.8	13.8
Work/Finance Concerns	30.1	22.1
Family Concerns	17.8	10.5
Existential Concerns	35.0	31.6
Friend Concerns	18.6	11.0
Social Activity Concerns	25.1	18.5
Total Concerns	26.2	26.2

percentage of concerns for both samples, but was relatively less significant among the present sample than among the Omega Project where it was by far the most highly scored subgroup. The percent of total current concerns among the present sample was 8.1% higher than in the Omega Project sample.

The Profile of Mood States also shows the present sample to be more distressed than the Omega Project sample. (See Table 4.) On all subscales the present sample shows more tension, anger, depression, fatigue, confusion, less vigor; it also shows more total mood disturbance. The standard deviations produced by the present sample are also larger suggesting wider range and variation of scores among the present sample as well.

Table 4

Comparison of Means and Standard Deviations of Profile of Mood States between Current Sample (N = 109) and Omega Project Sample (N = 246)

	Current Sample		Omega Project	
Mood	T-Score Means	Standard Deviations	T-Score Means	Standard Deviations
Tension	39.5	7.9	37.6	5.9
Anger	42.2	5.8	40.9	4.7
Depression	38.9	5.6	37.2	4.4
Vigor	56.2	9.6	58.9	9.3
Fatigue	47.2	8.9	45.2	7.2
Confusion	41.9	7.1	38.3	5.6
Total Mood Disturbance	153.5	35.0	140.5	30.1

The present sample shows itself to be consistently more distressed than the Omega Project sample in that clinical ratings from the Index of Vulnerability Scale are also higher. These scores suggest the present sample experienced more feelings of endangerment, alienation, isolation and annihilation. (See Table 5.)

Converting total weighted symptoms to the same scale used by the Omega Project also shows the present sample as having more physical symptoms (see Table 6). Comparing extent of disease between the two samples shows the present sample to have considerably more patients with widely disseminated cancers while the Omega Project sample has a relatively larger proportion of patients with regionally invasive tumors (see Table 7).

In sum, the present sample appears to be generally older with more advanced disease, more physical symptoms, more concerns, more mood disturbance and is rated with higher vulnerability than the sample from the Omega Project.

Comparing scores from the Multidimensional Health Locus of Control Inventory (see Table 8) shows the current sample to be close to the mean scores of patients from a variety of chronic illness backgrounds (dialysis patients, diabetics, hypertensives). The present sample is somewhat lower than other chronic patient groups on internal beliefs. They are somewhat higher on chance beliefs as well as on powerful other beliefs. Comparing the present sample with chemotherapy outpatients (Burrish et al., 1979) shows the present sample to have higher internal beliefs and lower chance beliefs. However, the Burrish sample tested

Table 5

Comparison of Index of Vulnerability Ratings between Present Sample and Omega Project

Study	N	Mean Total Vulnerability	SD
Present Study	109	22.77	6.09
Omega Project	152	20.23	5.69

Table 6

Comparison of Weighted Total Symptoms between Present Sample and Omega Findings

Study	N	Mean Total Weighted Symptoms
Present Study	109	5.4
Omega Project	246	5.2

Table 7

Comparison of Frequencies of Extent of Disease between Present Sample (N = 109) and Omega Project (N = 246)

Study	Localized Tumors	Regionally Disseminated Tumors	Distantly Disseminated Tumors
Present Study	47%	21%	32%
Omega Project	38%	44%	18%

only 29 patients. A comparison of the present sample of cancer patients to healthy adults (N = 1,287) shows cancer patients to have distinctly higher scores on chance and powerful others beliefs while internal beliefs remain high and only slightly lower than healthy adults.

Table 8

Comparison of Mean Raw Scores from Various Samples on the Multidimensional Health Locus of Control Inventory

Samples	N	Internal	Chance	Powerful Others
Healthy Adults (Wallston and Wallston, 1981)	1,287	25.5	16.2	19.2
Chronic Illness Patients (Wallston and Wallston, 1981)	609	25.8	17.6	22.5
Chemotherapy Patients (Burrish et al., 1979)	29	21.8	19.3	23.9
Cancer Patients (Present Study)	109	24.5	18.6	23.5

Comparing the present sample with the sample from the University of Pennsylvania Cancer Center (Cassileth) on Information Styles (see Table 9) shows both samples prefer to have a great deal of information about their illness. The present sample was somewhat less interested in getting details about their illness. Slightly more patients were content with getting no more information and some 8% fewer patients in

Table 9

Comparison of Frequencies of Information Styles and Participation Preferences between Present Sample (N = 109) and Pennsylvania Study (N = 256)

Study	Want No More Details	Want a Few More Details	Want Some More Details	Want Many More Details	Want as Many Details as Possible	Leave Decisions about Treatment to Doctor	Prefer to Participate in Decisions about Treatment	I Need No Other Information	I Need Further Information	No Friends Know	Only Intimate Friends Know	Most Friends and Neighbors Know	Want Minimal Information	Want Information Only if Good News	Want Information Good and Bad
Present Study	17.5%	6.8%	9.7%	7.8%	58.3%	41.7%	58.3%	72.7%	27.3%	9.7%	15.5%	74.8%	12.7%	8.8%	78.4%
Pennsylvania Study	15.2%	8.2%	8.2%	2.0%	66.4%	36.7%	62.9%	75.0%	24.9%	16.0%	32.0%	52.0%	12.5%	4.5%	82.8%

the present sample reported they wanted as many more details as possible compared to Cassileth's sample. In the present sample 5% more patients preferred to leave decisions about their medical treatment up to their physician (see Table 9), while in Cassileth's sample more patients preferred to participate in such decisions. Both samples had a majority of patients preferring to participate in treatment decisions. Between the two samples the percent of patients who report they need further information about their illness was similar. Three-fourths of both groups report no need for further specific information (see Table 9).

The present sample reports that most friends and neighbors know of their diagnoses (75%) compared to significantly fewer patients in Cassileth's group (52%) (Table 9). Cassileth's patients were generally more likely to tell only intimate friends or no friends at all. Patients in both samples want information that provides both good and bad news about their illness (80%). The present sample was somewhat more likely to admit only wanting information if it was "good news." In sum, while the present sample of cancer patients appeared more likely to tell friends and neighbors of their diagnoses, they generally did not seem to need as many details about their illness as the patients in the Cassileth sample. The present sample of patients also seemed more willing to leave medical decisions about their treatment up to their physicians.

Relationships among Measures of Distress

For the three tests of emotional distress (Inventory of Current Concerns, Profile of Mood States, Index of Vulnerability Rating Scale) three indices were chosen to represent each one; an average percent of the total current concerns from the ICC, total mood disturbance from the POMS, and total vulnerability rating from the VUL. Pearson product correlations among these measures show moderate positive correlations ranging from .44 to .56.

Chi Square analyses compared the upper and lower one-third scores on the emotional distress and physical symptom measures with each other (see Table 10). On each measure high scores on one distress measure were associated with high scores on the next and low scores were associated with low scores. The weakest relationship among the various distress measures was between vulnerability ratings and total symptoms with a chi square of 3.9 which is significant at the .05 confidence level. Chi Squares computed on the relationships between all the other distress measures range from 11.1 to 29.0, each significant beyond the 0.001 level.

A number of *t*-tests comparing lower and upper one-third scores on total symptoms with mean scores on emotional distress measures showed that patients with more physical symptoms had more current concerns (*P*-value .003), more mood disturbance (*P*-value .001) and somewhat higher vulnerability ratings (*P*-value .07) (see Table 11).

Several *t*-tests comparing mean differences of lower and upper one-third scores on emotional distress measures with each other

Table 10

Chi Square Contingency Tables of Upper and Lower One-Third Extreme Scores on Distress Measures

Measures	Low ICC	High ICC	Total	χ^2	Significance
Low Symptoms	17	3	20	14.1	.00
High Symptoms	6	16	22		
Total	23	19	42		
	Low TMD	High TMD			
Low Symptoms	16	3	19	11.1	.00
High Symptoms	8	16	14		
Total	24	19	43		
	Low VUL	High VUL			
Low Symptoms	13	5	18	3.9	.05
High Symptoms	9	13	22		
Total	22	18	40		
	Low TMD	High TMD			
Low ICC	20	0	20	29.0	.00
High ICC	6	22	28		
Total	26	22	48		
	Low VUL	High VUL			
Low ICC	23	3	26	27.8	.00
High ICC	4	22	26		
Total	27	25	52		

Table 10 (Cont'd)

Measures	Low VUL	High VUL	Total	χ^2	Significance
Low TMD	16	7	23	18.6	.00
High TMD	2	22	24		
Total	18	29	47		

showed patients having high scores on any emotional distress measure most likely to have high scores on any other distress measure (P-value .001). It was somewhat more likely for high current concerns to be associated with many symptoms (P-value .001) than for high mood disturbance to be associated with many symptoms (P-value .01). High scores on both of these distress measures were more likely to be associated with many symptoms than vulnerability ratings (P-value .025). (See Tables 12, 13, and 14.)

Table 11

Two Tailed t-tests Comparing Total Symptoms Extreme Scores with Other Distress Measures

Symptoms	Current Concerns Means	SD	t	P
Low Symptoms	18.1	15.0	-3.04	.00
High Symptoms	30.4	16.6		
	Total Mood Disturbance			
Low Symptoms	5.1	25.3	-3.68	.00
High Symptoms	33.4	32.2		
	Vulnerability Means			
Low Symptoms	20.7	5.2	-1.83	.07
High Symptoms	23.6	6.8		

Measures of physical symptoms and distress (Extent of Illness, Karnovsky Performance Status Ratings, Total Symptoms) revealed that only total symptoms showed consistent low to moderate positive

Table 12

Two Tailed t-tests Comparing Current Concern Extremes Scores by Other Distress Measures

Symptoms	Total Symptom Means	SD	t	P
Low Concerns	19.7	2.9	-3.50	.00
High Concerns	22.9	4.5		
	Total Mood Disturbance Means			
Low Concerns	2.6	13.8	-4.30	.00
High Concerns	40.9	48.5		
	Vulnerability Means			
Low Concerns	18.5	3.8	-7.29	.00
High Concerns	27.1	5.5		

Table 13

Two Tail t-tests Comparing Total Mood Disturbance Extreme Scores by Other Distress Measures

Mood	Total Symptom Means	SD	t	P
Low TMD	20.4	4.0	-2.41	-.01
High TMD	22.8	4.2		
	Current Concern Means			
Low TMD	19.5	16.9	-12.00	.00
High TMD	35.8	13.9		
	Vulnerability Means			
Low TMD	20.5	5.3	-4.60	.00
High TMD	27.4	6.3		

Table 14

Two Tail t-tests Comparing Index of Vulnerability Extreme Ratings by Other Distress Measures

Vulnerability	Total Symptom Means	SD	t	P
Low Vulnerability	20.4	3.5	-2.29	.02
High Vulnerability	22.6	4.7		
	Current Concern Means			
Low Vulnerability	16.4	11.0	-5.60	.00
High Vulnerability	35.2	16.7		
	Total Mood Disturbance Means			
Low Vulnerability	7.1	15.0	-4.16	.00
High Vulnerability	39.9	42.1		

correlations with the emotional distress measures (.15 to .28). (See Table 15.) Comparing the physical status measures with each other showed a -.32 correlation between symptoms and Karnovsky status; the more symptoms one had the less likely were patients to be ambulatory. Symptoms reported were slightly more frequent in patients with wider extent of illness (.11) and Karnovsky Status ratings were worse in patients with wider extent of illness (-.23).

Table 15

Correlation Matrix of Measures of Distress among Cancer Patients in the Current Sample (N = 94)

Measures	TMD	ICC	VUL	Symptoms	Karnovsky	Extent
Inventory of Concerns Total (ICC)	.49	-	-	-	-	-
Index of Vulnerability Total (VUL)	.44	.56	-	-	-	-
Symptoms Total (Symptoms)	.22	.28	.15	-	-	-
Karnovsky Status (Karnovsky)	-.13	.11	-.09	-.32	-	-
Extent of Disease (Extent)	.10	.10	.01	.11	-.23	-

Discriminant function analysis was performed to explore whether or not there was a pattern among the measures of physical symptomatology (total physical symptoms, Karnovsky performance status ratings, extent

of illness ratings) which could be used to differentiate the patients who were considered to be highly emotionally distressed from all other patients. A patient was placed in the high emotional distress group if he or she scored in the upper one-third of scores on any one of the three measures of emotional distress (ICC, TMD, VUL). All patients not scoring in the highest one-third on any distress measures were placed in the lower distress group. Results (see Table 16) show that standardized canonical discriminant function coefficients were able to demonstrate that the total physical symptoms measure (1.05) was twice as important in predicting membership in the distressed group as were Karnovsky ratings of performance status (0.52). Ratings of extent of illness did not prove to be powerful enought to complete the canonical discriminant functions. The classification results demonstrate that the discriminant function analysis fit the high distressed group better than it fit the less distressed group in that 70% of patients who were highly emotionally distressed could be predicted to fall into this group by account of their physical symptomatology.

Table 16

Discriminant Function Analysis of Physical Symptomatology Measures Predicting Composite Emotional Distress Measures ($\underline{N}$ = 105)

Distress	$\underline{N}$	Predicted Lower Distress	Predicted High Distress
Lower Distress	49	55.1%	44.9%
High Distress	56	30.4%	69.6%

Percent of cases correctly classified: 62.8%.

Emotional Distress and Locus of Control

The presumed relationship between health locus of control and measures of distress among cancer patients is not apparent from simple Pearson product-moment correlations which were uniformly low (see Table 17). The highest correlations suggest that as vulnerability ratings increase, scores on chance locus of control also increase (.25), and as physical symptoms increase, scores on powerful others tend to decrease (-.26). These correlations are significant at less than the .01 level. Even though these correlations are significantly different from a zero correlation, meaningfully, they account for very little variance. Other correlations are not noteworthy, ranging from -.13 to .19.

Table 17

Pearson Correlation Coefficients of Distress Measures with Measures of Health Locus of Control (N = 109)

Measures	Internal	Chance	Power
ICC	.06	.13	-.06
TMD	-.07	-.02	-.11
VUL	-.05	.25	-.01
Symptoms	-.03	-.13	-.26
Karnovsky	.14	.19	.11
Extent	-.12	-.11	-.10

Multiple regression analyses were performed to examine the pattern of variables which predicts distress in cancer patients. Using

continuous scores and the full spread of values over the 109 cases, eleven variables were placed in the stepwise equation. The six variables which accounted for the most variance in a distress measure are presented in table form. Independent variables include age, in or outpatient, time since diagnosis, extent of illness, internal, chance, powerful others, power-internal, internal-chance, and total health locus of control, information preferences, participation in treatment decisions preferences, and total information preferences.

With Inventory of Current Concerns scores as the dependent variable, the best six predictor variables were able to account for only .13 of the total variance (see Table 18). Age was the best predictor. The simple correlation of -.18 suggests that as age increases current concerns tend to decrease. The next best predictor was chance scores which increase as current concerns tend to increase (.13) adding .02 to the R-square. The next four variables were power, time since diagnosis, total information and participation in decisions preference adding .08 to the R-square. The F-ratios of all variables were not large enough to reject the null hypothesis at the .05 level of significance.

Using Total Mood Disturbance as the dependent variable (see Table 19) the best six independent variables were able to account for .20 of the total variance. Total information was the best predictor accounting for .08 of the variance. The simple correlation of -.28 suggests that patients with more mood disturbance tended to want less information about their disease. Time since diagnosis was the next

Table 18

Multiple Regression Analysis of Total Current Concerns (N = 109)

Concerns	Multiple R	R Square	Simple R	Beta	F-Test	Probability Values
Age	.18	.03	-.18	-.21	3.31	NS*
Chance	.23	.05	.13	-.28	4.61	NS
Power	.26	.07	-.06	-.19	2.15	NS
Time Since Diagnosis	.29	.08	.07	.15	1.75	NS
Total Information	.32	.11	-.09	-.19	2.49	NS
Viewpoint	.36	.13	-.07	0.16	1.87	NS

*NS: Not Significant

Table 19

Multiple Regression Analysis of Total Mood Disturbance (N = 109)

Factor	Multiple R	R Square	Simple R	Beta	F-Test	Probability Values
Information Total	.29	.08	-.28	-.37	10.87	.01
Time Since Diagnosis	.34	.11	.16	.29	6.39	.01
In or Out-patient	.37	.13	.08	-.17	2.32	.05
Power and Internal	.40	.16	.13	0.29	3.92	.05
Internal and Chance	.43	.19	.05	.25	2.67	.05
Viewpoint	.44	.20	-.01	-.11	0.94	.05

best predictor of mood disturbance; a partial correlation of .16, it accounted for another .03 suggesting that mood disturbances tend to increase with time since diagnosis. Both of these variables have F-ratios strong enough to reject the null hypothesis at the .01 level of significance, but they account for relatively little variance. The next two predictors suggested that inpatients were slightly more mood disturbed than outpatients, high scores on power and internal locus of control were somewhat less mood disturbed. These added .05 to R-square. The next two predictors, internal plus chance, and viewpoint, added .01 to the R-square.

When Index of Vulnerability ratings are placed as the dependent variable in the regression analysis (see Table 20) the best six independent variables are able to account for only .13 of the variance in this measure. The best predictor was chance health locus of control accounting for .06 of the variance. The simple correlation of .24 suggests that vulnerability tends to increase as chance scores increase. The next best predictor was participation in treatment decisions preferences which added .03 to R-square. The simple correlation of 0.20 suggests that as vulnerability increases patients are somewhat more likely to want to leave decisions about their medical care and treatment up to their physicians rather than participate in such decisions. The F-ratios of these two variables are large enough to reject the null hypothesis at the .05 level of significance. The next four variables to be placed in the equation were power, total

information, information preference and extent of illness. These accounted for another .04 of the variance.

Table 20

Multiple Regression Analysis of Index of Vulnerability (N = 109)

Factor	Multiple R	R Square	Simple R	Beta	F-Test	Probability Value
Chance	.25	.06	.24	.33	6.70	.05
Viewpoint	.31	.09	-.20	-.19	2.63	.05
Power	.33	.11	-.02	-.14	1.27	.05
Information Total	.34	.12	.04	0.13	1.11	.05
Information Preference	.36	.13	-.13	0.11	0.77	NS*
Extent	.36	.13	.01	.05	0.24	NS

NS: Not Significant

The best six predictor variables account for .14 of the total variance of total physical symptoms when it was considered as the dependent variable. (See Table 21.) The best predictor of symptoms was powerful others health locus of control which accounted for only .07 R-square. The simple correlation of -.26 suggests that as physical symptoms increase scores on powerful others tend to decrease. The next best predictor was Information Preferences. The correlation of -.13 suggests that as symptoms increase patients tend not to want as much detailed information about the illness. The next best predictor was total information preferences and the partial correlation of -.11 also suggests that information preferences slightly decrease with increasing physical symptoms. The F-ratios of these

three variables are high enough to reject the null hypothesis at the .05 level of significance. The next three variables in the equation are time since diagnosis, age and participation preferences accounting for another .04 of the variance.

Table 21

Multiple Regression Analysis of Total Symptoms (N = 109)

Factor	Multiple R	R Square	Simple R	Beta	F-test	Probability Value
Power	.26	.07	-.26	-.27	5.74	.05
Information Preference	.28	.08	-.13	-.21	2.88	.05
Information Total	.31	.10	-.11	-.15	1.55	.05
Time Since Diagnosis	.34	.12	.06	.13	1.33	NS*
Age	.35	.13	-.09	.15	1.68	NS
Viewpoint	.38	.14	-.08	.14	1.37	NS

*NS: Not Significant

When Karnovsky Performance Status ratings is the dependent variable (see Table 22) in the regression analysis the first six independent variables account for .24 of the total variance. The best predictor was age accounting for .12 R-square. The simple correlation of -.35 suggests that with increasing age patients are less likely to be carrying on normal activities and be ambulatory and the more likely they are to need special care for their personal

needs. The next best predictor was chance locus of control adding .04 to R-square. Participation preferences, information preferences, extent of illness and in or outpatient status were the next best predictors adding .08 to R-square.

Table 22

Multiple Regression Analysis of Karnovsky Performance Status Ratings (N = 109)

Factor	Multiple R	R Square	Simple R	Beta	F-test	Probability Value
Age	.35	.12	-.35	-.37	11.03	.01
Chance	.40	.16	.19	.18	3.30	.01
Viewpoint	.44	.19	-.09	-.21	3.65	.01
Information Preference	.47	.22	.12	.16	2.21	.01
Extent	.48	.24	-.23	-.13	1.42	.01
In or Out-patient	.49	.24	-.13	-.07	0.45	.01

The hypothesized relationship between locus of control and emotional distress is not apparent in the multiple regression analysis except where chance locus of control positively predicted current concerns, and powerful others was negatively related; chance locus of control positively predicted vulnerability ratings; powerful others locus of control was negatively correlated with physical symptoms; and chance locus of control positively predicted Karnovsky ratings. In no regression analysis did internal health locus of control emerge as a predictor of any measure of distress.

Using continuous scores was unable to clearly outline the hypothesized relationships. However, these patterns may be disguised by the large number of patients scoring in the middle ranges. By transforming distress and locus of control variables from interval to nominal measurements, eliminating the middle-most scorers, and comparing independent samples of patients who score only in the top one-third or lowest one-third on each measure, the hypothesized relationships are given a greater likelihood to emerge.

Chi square analyses compared patients who were high and low scorers on Current Concerns with patients who were high and low scorers on the health locus of control variables. The frequencies obtained cannot be considered different from what would be expected from chance variation alone.

Comparing patients who were high and low scorers on Total Mood Disturbance with patients who were high and low scorers on health locus of control using Chi square analysis (see Table 23) shows that low and high scorers on TMD are distributed significantly differently across low and high internal locus of control (P-value .04). This justifies the inference that patients with low mood disturbance are more likely to be high internals; mood disturbed patients are more likely to be low on internal health locus of control.

Chi square analyses comparing low and high scorers on Vulnerability ratings with patients who were low and high scorers on the health locus of control variables failed to differentiate obtained frequencies from

Table 23

Chi Square Contingency Tables of Upper and Lower One-Third Extreme Scores on Total Mood Disturbance by Locus of Control

Mood	Low Internal	High Internal	Total	χ^2	Significance
Low TMD	5	16	21	4.3	.04
High TMD	13	11	24		
Total	18	27	45		
	Low Chance	High Chance			
Low TMD	10	16	26	.47	NS
High TMD	12	13	25		
Total	22	29	51		
	Low Powerful Others	High Powerful Others			
Low TMD	11	13	24	.86	NS
High TMD	17	12	29		
Total	28	25	53		
	Low Power Internal	High Power Internal			
Low TMD	11	16	27	2.12	NS
High TMD	13	8	21		
Total	24	24	48		

what would be expected by chance. Low or high vulnerability ratings do not appear related to locus of control scores using this statistic.

While there are no significantly different distributions from chance comparing patients low and high on physical symptoms with locus of control low and high scorers (see Table 24), several trends are apparent. Patients with a high number of physical symptoms tended to be low on powerful others and chance locus of control (P-value .11) and patients high on chance and powerful others locus of control tended to have low symptoms (P-value .11). While these are only trends they would be in the direction opposite to the hypothesized direction. Another trend showed patients high on powerful others plus internal to have lower symptoms and patients with high symptoms to be low on powerful others plus internal (P-value .08). This trend conforms to the hypothesized direction.

Two tailed t-tests were also performed to compare the means on health locus of control variables with the lower and upper one-third scorers on the various measures of distress. Comparison of mean differences yielded no statistical significance in comparing physical symptoms with locus of control variables. Two tailed t-tests comparing mean differences of locus of control variables on patients who were low and high scorers on the emotional distress measure of Current Concerns were also unable to yield statistical significance.

Comparing patients low and high on Total Mood Disturbance with means of patients locus of control scores shows the largest difference of means to be on health internals who were somewhat more likely to have

Table 24

Chi Square Contingency Tables of Upper and Lower One-Third Extreme Scores on Total Symptoms by Locus of Control

	Low Internal	High Internal	Total	χ^2	Significance
Low Symptoms	7	13	20	.67	NS
High Symptoms	10	11	21		
Total	17	24	41		
	Low Chance	High Chance			
Low Symptoms	6	15	21	2.53	.11
High Symptoms	12	11	23		
Total	18	26	44		
	Low Powerful Others	High Powerful Others			
Low Symptoms	6	12	18	2.53	.11
High Symptoms	15	11	26		
Total	21	23	44		
	Low Power Internal	High Power Internal			
Low Symptoms	7	13	20	2.96	.08
High Symptoms	13	8	21		
Total	20	21	41		

low scores on TMD. Patients with high mood disturbance scores had somewhat lower internal means (P-value .18). However, comparisons of TMD with means on the locus of control variables yielded no statistically significant differences. Using two tailed t-tests to compare high and low vulnerability ratings with means on locus of control variables also yielded no statistically significant differences.

As a final statistic comparing the relationship of health locus of control to emotional distress, the three measures of emotional distress (ICC, TMD, VUL) were combined into a composite global distress measure by the method described earlier. Using two tailed t-tests to compare mean differences on locus of control variables with the high and low distress group membership yielded no statistically significant relationships.

In order to test the specific hypothesis that patients who score high on chance health locus of control ought to be more depressed, a composite depression indice was created by including in the high depression group any patient who scored in the highest one-third of scores on the hopelessness or depression subscales of the Index of Vulnerability Rating Scale, or who scored in the top one-third on the depression subscale of the Profile of Mood States. Any patient who did not score in the upper one-third on any one of these scales was classified as low depression. A two tailed t-test shows the mean differences on chance locus of control between the depression groups was insignificant.

Emotional Distress and Information Styles

A clear relationship between information and participation preferences and emotional distress among cancer patients was not apparent from Pearson product-moment correlations which were generally low and inconsistent. (See Table 25.) Weak negative relationships between current concerns and the information styles questions suggested that information preferences tended to decrease with increasing concerns. This pattern was replicated by correlations between vulnerability ratings and information styles. As vulnerability ratings increased, patients were slightly less likely to want to participate in decisions about their medical care and treatment (-.20). They were less likely to have told most of their friends and neighbors what their diagnosis was (-.35) and they were more likely to prefer having only information needed to care for themselves, rather than as much information as was possible, good and bad (-.21). These correlations were generally significantly different from a zero correlation at the .02 level of significance.

Table 25

Pearson Correlation Coefficients of Distress Measures with Information Styles (N = 109)

	Info. Pref.	Viewpoint	Friends	Attitude	Total Info.
ICC	-.05	-.08	-.10	.05	-.09
TMD	.21	.01	.07	.16	.29
VUL	-.13	-.20	-.35	-.21	.04
Symptoms	-.13	.03	.00	-.24	-.11
Karnovsky	.12	-.09	-.16	.06	.05
Extent	-.06	.11	.00	-.10	-.08

Relationships between mood disturbance and information styles showed low positive correlations. The strongest of these suggests that with increasing mood disturbance patients tended to want more details about their illness (R = .21; P-value .02) and to have greater total information preferences (R = .29; P-value .02). Correlations between medical status (i.e., symptoms, Karnovsky, Extent of Illness) and information preferences were also most unclear, but tended to be negative correlations implying that sicker patients have somewhat fewer information preferences. The strongest relationship was between total physical symptoms and attitude toward illness (R = .24; P-value .01) suggesting that sicker patients wanted just the information needed to care for themselves and not as much good and bad information as was possible.

Two tailed t-tests were computed to compare the means of information styles variables for differences among the lower and upper one-third scorers on the various measures of distress. Comparing physical symptom extremes with information styles yields no statistically significant differences. Comparing patients who were low and high on Current Concerns with means of patients information styles also failed to yield statistical significance.

Using two tailed t-tests to compare high and low mood disturbance scores with information styles (see Table 26) revealed that patients with high mood disturbance scores were more likely to want as many more details as was possible about their illness, while patients with low mood disturbance were more likely to be content with fewer details

Table 26

Two Tailed t-tests Comparing Total Mood Disturbance with Information Styles

Mood	Information Preferences Means	SD	t	P
Low TMD	3.26	1.79	-2.10	.04
High TMD	4.09	1.42		
	Viewpoint Means			
Low TMD	1.59	.50	0.00	NS
High TMD	1.59	.50		
	Other Information Means			
Low TMD	1.76	.43	1.49	.14
High TMD	1.59	.50		
	Friends Means			
Low TMD	1.65	.60	0.52	NS
High TMD	2.56	.77		
	Attitude Means			
Low TMD	2.47	.79	-1.85	.07
High TMD	2.79	.60		

(P-value .04). This finding was supported by the relationship between TMD and attitude toward illness which suggested that patients who reported higher mood disturbance were more likely to want as much information as possible, good and bad. Patients reporting low mood disturbance preferred only the information needed to care for themselves (P-value .07).

Comparing vulnerability ratings of patients who scored in the upper and lower one-third on this measure with mean scores of patients information styles (see Table 27) indicated a pattern of decreasing preferences for patients who were judged to be more vulnerable. Patients with low vulnerability ratings were slightly more likely to want as many more details about their illness as possible. They also preferred to participate in decisions about their medical treatment (P-value .05). Patients rated with high vulnerability would choose to leave such decisions up to their physicians. Low vulnerable patients were more likely to indicate they had a desire for specific other information (P-value .02) and they were more likely to report having told most of their friends and neighbors of their diagnoses (P-value .02). Patients with high vulnerability on the other hand were content with fewer details, were less likely to seek other information and preferred to keep knowledge of their diagnoses private. In addition, patients with high vulnerability tended to want only enough information to care for themselves properly and not as much good and bad information as possible.

One-way analysis of variance was computed comparing Karnovsky Performance Status ratings with mean differences on information styles.

Table 27

Two Tail t-tests Comparing Vulnerability Ratings with Information Styles

Vulnerability	Information Preferences Means	SD	t	P
Low Vulnerability	3.83	1.6	1.06	NS
High Vulnerability	3.39	1.7		
	Viewpoint Means			
Low Vulnerability	1.71	.45	1.96	.05
High Vulnerability	1.48	.50		
	Friends Means			
Low Vulnerability	2.77	.42	2.31	.02
High Vulnerability	2.39	.86		
	Attitude Means			
Low Vulnerability	2.71	.66	1.19	NS
High Vulnerability	2.50	.80		

While no statistically significant relationships were uncovered, trends suggested that patients who were able to carry on normal activities, or were ambulatory with help, had somewhat greater total information preferences compared to patients who were unable to care for themselves.

Health Locus of Control and Information Styles

The theorized and presumed relationship between Multidimensional Health Locus of Control and Information preferences emerges as expected in weak but consistent Pearson Product-Moment Correlations. (See Table 28.) Patients with internal health locus of control beliefs tended to say they wanted as many more details about their illness as was possible. This was significantly different from a zero correlation at less than the .005 level. They tended to want to participate in treatment decisions with their physicians (P-value .003) and preferred having as much information as possible, even if it is bad news. Those patients with a chance health locus of control orientation tended to be content with fewer details, to prefer to leave treatment decisions up to their doctors, and to keep their diagnoses private. No pattern of relationship was apparent between powerful others health locus of control beliefs and information styles.

Using two tailed t-tests to compare those patients who scored in the lower and upper one-third ranges on internal health locus of control with their mean scores on information styles questions (see Table 29) revealed that high internals appeared to want as many more details about their illness as possible, while low internals were content with

Table 28

Pearson Product Moment Correlations Comparing Multidimensional Health Locus of Control with Information Styles

	Information Preference	Participation Preference	Need Other Information	Told Friends	Information Both Good Information
Internal	.26	.27	-.04	-.03	.10
Chance	-.09	-.10	.00	-.15	-.04
Powerful Others	.04	-.04	.14	.03	.11

Table 29

Two Tailed t-tests Comparing Health Internal Locus of Control to Information Styles

	Information Preferences Means	SD	t	P
Low Internal	3.41	1.7	-1.91	.06
High Internal	4.12	1.4		
	Viewpoint Means	SD		
Low Internal	1.35	.48	-3.60	.00
High Internal	1.74	.44		
	Other Information Means			
Low Internal	1.78	.42	1.28	NS
High Internal	1.64	.48		
	Friends Means			
Low Internal	1.78	.53	1.07	NS
High Internal	1.64	.66		
	Attitude Means			
Low Internal	2.56	.78	-0.77	NS
High Internal	2.69	.69		
	Information Total Means			
Low Internal	19.88	5.4	0.29	NS
High Internal	19.52	4.8		

fewer details (P-value .06). High internals also preferred to participate in decisions regarding their medical care and treatment while low internals tended to prefer leaving such decisions up to their doctors (P-value .001).

Using two tailed t-tests to compare low and high chance health locus of control patients with mean differences on information styles questions (see Table 30) suggested a pattern consistent with expectations. Patients with high chance beliefs tended to want to leave treatment decisions up to their physicians and to keep knowledge of their diagnoses private. They also tended to have less total information preferences (P-value .05). Patients scoring low and high on the Powerful Others Health Locus of Control dimension showed no statistically significant mean differences on information styles questions.

Age, Emotional Distress, Information Styles and Locus of Control

As expected, a one-way analysis of variance shows that older patients were significantly more likely to have a poor Karnovsky performance status rating. (See Table 31.) The oldest group of cancer patients were unable to care for themselves and generally required the equivalent of hospital care. Patients who were ambulatory, but could not work were an average ten years younger. Patients who were able to carry on normal activities were significantly likely to be younger still. This pattern was significant beyond the .000 level of probability. Patients who fell into the composite high emotional

Table 30

Two Tailed t-tests Comparing Chance Health Locus of Control with Information Styles

Chance	Information Preferences Means	SD	t	P
Low Chance	3.85	1.67	0.23	NS
High Chance	3.76	1.60		
	Viewpoint Means			
Low Chance	1.62	.49	1.00	NS
High Chance	1.50	.50		
	Other Information Means			
Low Chance	1.84	.37	0.63	NS
High Chance	1.78	.42		
	Friends Means			
Low Chance	2.79	.48	1.30	NS
High Chance	2.60	.71		
	Attitude Means			
Low Chance	2.65	.69	-0.07	NS
High Chance	2.66	.71		
	Information Total Means			
Low Chance	19.5	4.4	-2.03	.05
High Chance	17.5	5.2		

distress group were likely to be younger (P-value .04). (See Table 32.) Older patients were more likely to fall into the lower emotional distress group.

Table 31

One-Way Analysis of Variance of Karnovsky Performance Status by Age

Karnovsky Rating	N	Mean Age		F-Ratio	F-Probability
Unable to Care for Self	15	66.5	13.0	7.0	.00
Ambulatory, Cannot Work	35	56.9	14.7		
Normal Activities	55	50.9	14.0		

Table 32

Two Tailed t-test Comparing Composite High and Lower Distress Measures with Age

	Mean Age	SD	t	P
Lower Distress	58.4	12.6	2.01	.04
High Distress	52.7	16.2		

Examining the separate emotional distress measures showed that on each measure older patients had lower distress scores (see Table 33). The group of patients with low current concerns was an average of

seven years older (P-value .07), patients reporting low total mood disturbance were five years older (P-value .13) and patients with low vulnerability ratings were an average of three years older.

Table 33

Two Tailed t-tests Comparing Separate Distress Measures with Age

	Mean Age	SD	t	P
Low Concerns	58.2	13.4	1.85	.07
High Concerns	51.4	16.9		
Low TMD	57.5	13.3	1.51	.13
High TMD	52.0	16.4		
Low Vulnerability	57.1	15.6	0.91	NS
High Vulnerability	53.9	13.9		

Using the composite high depression measure described earlier also showed that older patients were more likely to fall into the lower depression group (P-value .02) (see Table 34). In sum, older patients reported that they were less distressed and depressed, had fewer concerns, less mood disturbance and lower vulnerability ratings, despite requiring more care for their personal needs and being less ambulatory.

Based on the results of Cassileth's study at the University of Pennsylvania, it was expected that older patients would generally have less information and participation preferences. These expectations were

confirmed. In the present study younger patients clearly preferred to participate with physicians in decisions about their treatment by a majority of 80%. Patients in the oldest group did not report this attitude, but by a small majority preferred to leave decisions about treatment up to their doctors. These results parallel Cassileth's findings with a slight tendency for the present group to be even more willing to leave decisions up to the doctor.

Table 34

Two Tailed t-test Comparing Composite High and Lower Depression Measures with Age

	Mean Age	SD	t	P
Lower Depression	58.2	14.1	2.33	.02
High Depression	51.6	15.2		

When asked whether they wanted all information about their illness whether it was good or bad news, the youngest group of patients almost always responded in the affirmative. The oldest patients, however, were generally less convicted. Twenty-four percent more of the older patients reported they were content with minimal or only good information. This trend was even more apparent in the present study than in Cassileth's findings.

This pattern was confirmed by results from asking patients whether or not they wanted the maximum amount of details about their illness.

(See Table 35.) The younger patients typically did, while the older patients were split. Half of the oldest patients were content with less than maximum details. Again these findings corroborate Cassileth's, with the present sample of patients again appearing somewhat more content with fewer details of their illness than patients at the Pennsylvania Cancer Center.

Regarding the relationship of age to health locus of control (see Table 36) patients in the three age groups showed little differences on powerful others and chance health locus of control expectancies. Younger patients seemed to show a tendency to have higher chance beliefs with 67% of patients in this group falling into this category. However, the more striking finding was with Internal health locus of control beliefs. Eighty percent of the youngest group of patients subscribed to high internal beliefs. The pattern was reversed for the oldest group of patients. They were more likely to subscribe to low internal beliefs.

Sex, Emotional Distress and Locus of Control

Differences between male and female patients were not apparent on measures of physical symptoms, current concerns, or on total mood disturbance. (See Table 37.) A slight trend on TMD suggests that men reported somewhat less mood disturbance than women. Men also were rated as somewhat less vulnerable. Health locus of control scores did not differ between males and females on the present sample (see Table 38). There was a slight trend for women to report higher scores

Table 35

Comparison of Participation and Information Preferences by Age Group between Present Sample and University of Pennsylvania Findings

	Percent of Patients in Age Group Selecting Response					
	18-30		40-59		60+	
Preference	Present Study	Penn.	Present Study	Penn.	Present Study	Penn.
Participate in Decisions	80	87	60	62	46	51
Leave Decisions to Doctor	20	13	40	38	54	49
Want All Information	93	96	81	79	69	80
Minimal or Good Information	7	4	19	21	31	20
Prefer Minimum Details	40	15	35	40	49	31
Prefer Maximum Details	60	85	65	60	51	59

Table 36

Comparison of Health Locus of Control with Age Groupings

Factor	Percent of Patients in Age Group Selecting Response		
	18-39	40-60	60+
Low Internal	20	44	60
High Internal	80	56	40
Low Chance	33	46	53
High Chance	67	54	47
Low Powerful Others	50	39.5	47
High Powerful Others	50	60.5	53

Table 37

Comparison of Distress Measures by Sex

Symptoms	Percent of Patients Selecting Response	
	Male %	Female %
Low Symptoms	41	44
High Symptoms	59	56
Low Concerns	50	57
High Concerns	50	43
Low TMD	51.5	47
High TMD	48.5	53
Low Vulnerability	56	44
High Vulnerability	44	56

Table 38

Chi Square Contingency Table Comparing Extreme Health Locus of Control Scores with Sex

Sex	Low Internal	High Internal	Total	χ^2	Significance
Female	18	17	35	0.013	NS
Male	16	16	32		
Total	34	33	67		
	Low Chance	High Chance			
Female	21	18	39	0.00	NS
Male	14	12	26		
Total	35	30	55		
	Low Powerful Others	High Powerful Others			
Female	17	20	37	1.31	NS
Male	18	22	30		
Total	35	32	67		

on powerful others while more men fell in the low powerful others group. This trend was not statistically significant.

Distress by Diagnosis

Although findings were not statistically significant, trends were apparent and conform to the hypothesized direction (see Table 39). Patients with lung cancer, lymphomas, leukemia or gastrointestinal cancers tended to fall into the high emotional distress group.

Where the categories of the two studies overlap, the findings of the present study closely parallel the results from Weisman and Worden's study. The pattern of patients in the present study having somewhat higher emotional distress is confirmed again. Differences in results may be a function of the composition of the diagnostic categories. Weisman and Worden's gastrointestinal group consisted of patients with colon cancers only. In the present study patients with cancer of the pancreas, kidney and stomach were included in this group. Also, in the present study patients with skin cancers were included in the group where Weisman and Worden only placed melanoma patients. Finally, Weisman and Worden had only Hodgkins patients in their last group, whereas in the present study patients with other lymphomas and leukemia were included.

Distress by Time Since Diagnosis

Using Chi-square analysis and the composite measure of high emotional distress the categories of time since diagnosis did not

Table 39

Chi Square Contingency Table Comparing Composite High and Lower Emotional Distress Measure across Cancer Diagnosis (N = 106)

	Lung		Breast		Skin Melanoma		Lymphoma Leukemia		G.I.		Gyn.		Others		Totals	Chi	Signifi-
Distress	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	Square	cance
Lower Distress	9	42.9	8	47.	5	62.5	8	40.0	10	43.5	3	100.	6	42.9	49	4.88	NS
High Distress	12	57.1	9	52.9	3	37.5	12	60.0	13	56.5	0	0.0	8	57.1	57		
Totals	21		17		8		20		23		3		14		106		

differ significantly from each other by measure of emotional distress (see Table 40). Trends suggested that patients who were diagnosed less than two weeks were more likely to be high distressed with 65% of patients during this time falling into this category. From two weeks through eleven weeks the trend was for patients to be somewhat less distressed. However, distress appeared to increase for most patients from this point to the end of the first year from diagnosis with 70% of patients falling into the high distress group during this period. After the first year, distress appeared to drop somewhat, level off, and remain consistent with a slight majority of patients falling into the lower distress group.

Comparison of the present findings concerning time since diagnosis with the results from Weisman and Worden's study (see Figure 1) showed that emotional distress in both samples was considerably higher at the time of diagnosis. Patients in the Omega Project were followed longitudinally at five week intervals and showed a steady drop off in emotional distress over time. Their study, however, did not follow patients beyond six months past diagnosis. In the present cross-sectional analysis it appears that patients generally experienced an increase in emotional distress sometime before the end of the first year since diagnosis. Distress levels appear to fall off after this point and remain generally consistent across time.

Examining the separate emotional distress measures shows that patients appeared more likely to fall into the high mood disturbance group and more likely to fall into the low current concerns group at

Table 40

Chi Square Contingency Table Comparing Composite High and Lower Emotional Distress Measure across Time Since Diagnosis (N = 108)

Distress	0-13 Days N	0-13 Days %	2-11 Weeks N	2-11 Weeks %	3-11 Months N	3-11 Months %	1-2 Years N	1-2 Years %	3 Years + N	3 Years + %	Totals N	Chi Square	Significance
Lower Distress	3	37.5	15	55.6	7	30.4	14	51.9	12	52.2	51	4.11	NS
Higher Distress	5	62.5	12	44.4	16	69.6	13	48.1	11	47.8	57		
Totals	8		27		23		27		23		108		

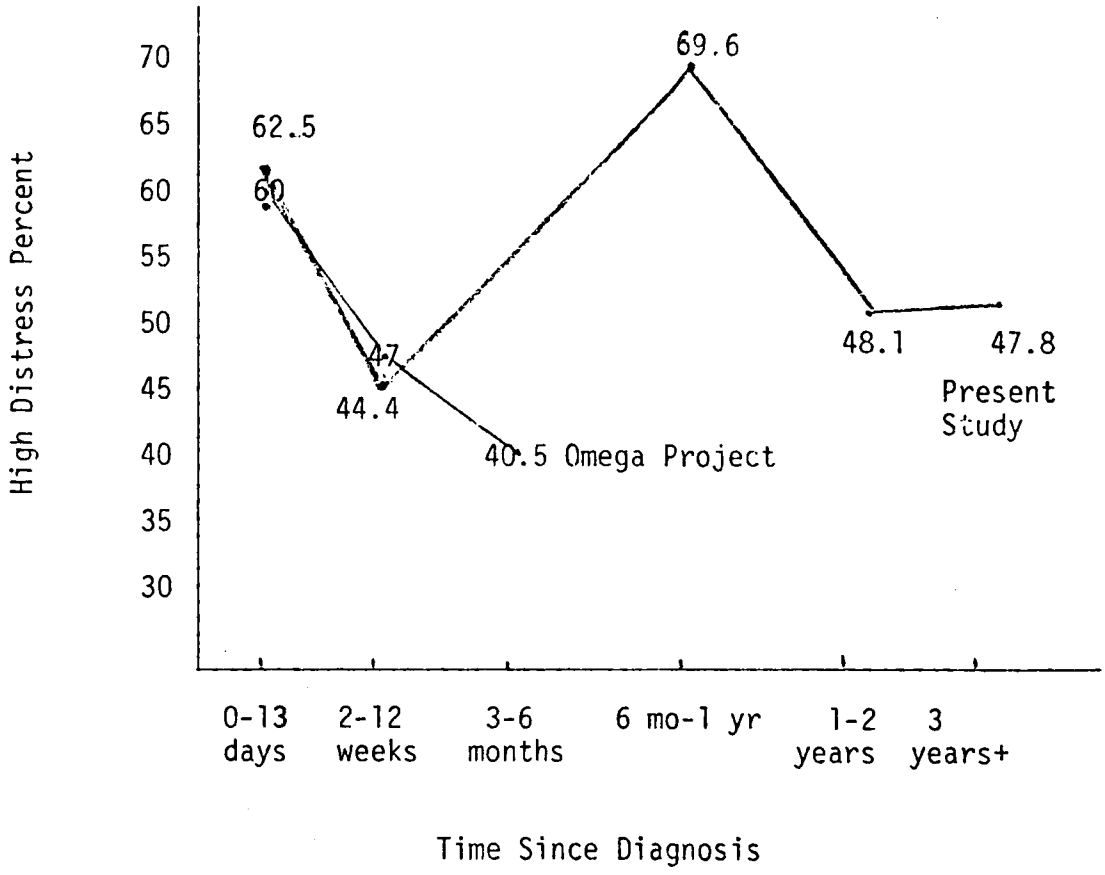


Figure 1

Comparison of Findings from Omega Project and Present Study on Percent of Patients Experiencing High Distress by Time Since Diagnosis

the time of initial diagnosis. During the next three months, however, mood disturbance appeared to drop off, with 72% of patients falling into the low mood disturbance group (see Table 41). During the same period and through the first year from diagnosis current concerns appeared to consistently increase. These frequencies conform to the hypothesized direction, but the number of subjects in each category is small, statistical significance was not achieved and inferences about the meaningfulness of these findings are not warranted. Another interesting, but not surprising, trend was for 75% of newly diagnosed patients to be rated with high vulnerability, while only 40% of patients diagnosed longer than one year fell into this category.

Table 41

Chi Square Contingency Table Comparing Lower and Upper Third Frequencies of Distress Measures across Time Since Diagnosis

	0-13 Days	2-11 Weeks	3-11 Months	1-3 Years	3 Years	Chi Sq.	Signifi-cance
Low ICC	60%	47%	39%	64%	42%	2.65	NS
High ICC	40%	53%	61%	36%	58%		
Low TMD	43%	72%	47%	47%	27%	6.09	NS
High TMD	57%	28%	53%	53%	73%		
Low VUL	25%	56%	33%	59%	61%	4.28	NS
High VUL	75%	44%	67%	41%	39%		

CHAPTER IV

DISCUSSION

In the present research, 109 patients with cancer were given a comprehensive psychosocial evaluation. An effort was made to assess the kind and amount of emotional distress they were experiencing and to assess their desires for information about their illness as well as their expectancies and beliefs about who was responsible for their health. On the basis of previous literature it was hypothesized that, in general, cancer patients with internal health locus of control orientations would experience less emotional distress and would have greater preferences for information about their illness. The results from the empirical testing of these main hypotheses will be reviewed and discussed in this chapter along with related hypotheses and relevant issues.

The sampling of patients in this study appears to have been demographically well balanced. Subjects were evenly distributed across age, sex, education, variety of cancer diagnoses, time since diagnosis, extent of illness and performance status. The modal patient in the study was female, 57 years old, college educated, inpatient with a diagnosis of a form of gastrointestinal cancer. She had been diagnosed for approximately three months, had a tumor which was localized and was receiving chemotherapy. She was able to work and needed no special care, although she complained of some pain, fatigue, loss of weight and difficulty in sleeping.

Data from the Inventory of Current concerns suggests that cancer patients are most worried about existential issues, such as whether there is an afterlife or wishing one could forget past mistakes. Concerns about work and finance were also relatively very high. Working steady and up to par and having the money for medical expenses were primary issues in the present sample as well as in the Omega Project sample (Weisman and Worden, 1976). Concerns about health and being able to maintain independence in activities were also significant concerns. In both samples, concerns about family and friends were lowest. The largest difference between the samples was on religious concerns. Prayer, faith and getting to church were clearly more important to the patients in the current sample, although not in the Omega sample. Such differences can perhaps be attributed to the predominantly southern, rural, fundamentalist Christian orientation of many patients in our sample.

The Profile of Mood States subscale scores were generally even and low relative to a psychiatric population. Only fatigue was relatively high which is understandable given the illness of the patients evaluated. Subscale scores on Tension, Anger, Depression, Fatigue and Confusion were higher than the sample from the Omega Project, while vigor scores were lower. Total Mood Disturbance was also higher for our sample. These results were consistent with the ICC where the present sample experienced consistently higher concerns on each subscale. This pattern was corroborated by clinical ratings from the Index of Vulnerability, which rated patients in the present sample to have overall greater vulnerability.

To some extent the greater emotional distress in the current sample can be understood by medical factors. The present sample complained of more physical symptoms and had significantly more patients with advanced stage cancers. Also, our patients were somewhat older. Significantly, the present sample included many patients who were diagnosed longer than six months, while the Omega Project only screened patients diagnosed less than six months. Although the Omega Project screening was completed with five longitudinal follow-up assessments and the present sampling was cross-sectional, the current sample would seem to offer a broader range of patients across time since diagnosis.

Data from the Multidimensional Health Locus of Control Inventory in the present study confirmed previous findings that patients with chronic illness have higher scores on chance and powerful others, compared to healthy adults, while internal health scores remain high. Cancer patients were higher on the external health locus of control dimensions than patients with other chronic illnesses, while internal beliefs were somewhat lower. These findings are understandable, given the physically debilitating nature of cancer, which often drastically increases one's dependence on others, the aggressiveness of the treatments which limits the activity and personal control of the patient, and the socially conditioned association of cancer with death. With cancer the patient typically has felt the need and pressure to place his trust in the physician specialist and hope for the best outcome. Such conditions make it difficult to maintain expectations

and beliefs in one's personal control and responsibility for their own health. Belief in the role of fate, luck and the importance of physicians in their getting well is understandably higher.

Examining the results from the Information Styles Questionnaire shows that, in general, patients want to have as much information as possible about their illness even if it is bad news, they want to participate in decisions about their medical treatment, and they have told most of their friends and neighbors of their diagnoses. This is a consistent finding across both the present sample and the Cassileth (1980) sample at the University of Pennsylvania Cancer Center. When the open-ended question, "Is there any other information you feel you need?" was asked, three-quarters of both samples said no, suggesting perhaps that, even though their perceived needs for information were high, they were generally satisfied with the amount of information already received. An alternative explanation is that cancer patients may be indicating a presumed preference for detailed information both good and bad in principle, but when given an opportunity to pursue getting this information they tend to back off, thus suggesting a form of denial, or information avoidance, or at least a passive orientation to receiving information about their illness. This questionnaire was unable adequately to distinguish between patients' expressed wishes about information and participation preferences and what these patients would actually do in various situations to seek out and actively receive information or participate in medical decisions. This is an important point which applies to

other findings in this study and will be considered at some length later in this discussion.

In her paper, Cassileth (1980) writes that

> a potential source of bias in this research arises from the fact that patients studied were under treatment in a major urban medical center. The setting itself may have encouraged preferences for information, and patients who seek treatment in large medical centers may differ from those who go elsewhere for cancer treatment. Therefore, the extent to which data can be generalized to patients in nonacademic or community hospitals is unknown.

The present research essentially replicates Cassileth's findings with data from a relatively small community hospital which draws its patients largely from rural areas. That is, cancer patients in both samples say they wanted detailed information and prefer to participate in decision making with their doctors. The differences between the samples are rather small, but are consistent. Some 8% fewer patients in the present study want as many details as possible about their illness; 4% fewer patients want information that is both good and bad, while 4% more patients want information only if it is good news; and 5% fewer patients in the present sample want to participate in decisions regarding their medical treatment. It is unclear to what extent these differences are a function of the cultural and socioeconomic background of the patients in the present sample, which seems to be a reasonable speculation, or a function of differences between the two samples on variables such as age, extent of illness, performance status, or time since diagnosis. The distribution of patients within each of these variables appears quite similar in both samples.

The measures of emotional distress chosen for the present study, and the summary indices chosen to represent them, appeared to adequately tap into the patients' predominant concerns and feelings. The clinical rating measure of distress, vulnerability ratings, despite adequate reliability, seemed generally less sensitive than the self-report measures in that their relationship to other measures of distress, locus of control and information preferences were typically weaker than the self-report measures of distress. Nonetheless, high scores on any one measure of distress were likely to result in high scores on other measures. Scatter plots in a post hoc analysis showed the three measures to share roughly one-third common variance. Thus, the measures appear to share a common construct of emotional distress, as well as different properties.

It was hypothesized that the Inventory of Current Concerns was more a measure of cognitive distress and as such would probably be highest sometime after the initial period of impact of the diagnosis, when the patient begins having to function and cope with the problems of living which their illness presents. On the other hand, the Profile of Mood States was thought to be more a measure of affective distress and thus was hypothesized to be more evident during crisis periods such as the time immediately following the initial diagnosis. This type of distress was also thought to be relatively less apparent during times of remission and adjustment. These hypotheses conform to the previous findings of Gorden et al. (1980). Results from the present research support the direction of these hypotheses, but failed to reach statistical significance. It seems that the areas in which cognitive

and affective distress overlap and are different from one another are not sufficiently clear across these measures, and better operational definitions need to be created before further assessment of this hypothesis can be worthwhile.

The designation of a composite higher emotional distress group offered a stronger and more comprehensive measure of high distress than any of the single measures of distress by themselves. The composite measure was defined more broadly in the present study than the high distress measure used in the Omega Project (Sobel and Worden, 1979) which included high scores on TMD and VUL, but not the ICC. The measure used in the present study was similar to the measure used in the Omega Project in designating low distress patients as any patient who was not high distressed. This was because both studies were primarily concerned with the nature of high emotional distress. Results from the present research, however, suggest that cancer patients with the lowest emotional distress may also be a distinctive and important group with common coping styles, locus of control orientations and information preferences. Future research should look at this group of patients directly, rather than incidently, with tighter operational definitions for what constitutes the best coping among cancer patients.

Medical factors, such as extent of disease, Karnovsky performance status, and physical symptoms were understandably shown to be related to one another. They were also shown to be significantly related to the amount of emotional distress a patient experienced. A number of separate statistical analyses demonstrated that physical symptoms had the strongest relationship to emotional distress among the various

measures of medical status. The present research supports the previous findings of Weisman and Worden (1977) and Gorden et al. (1980) in showing that physical symptoms have an important impact on the amount of emotional distress experienced by the cancer patient. Weisman and Worden, who used examiner ratings, concluded that between 40% and 60% of emotional distress could be accounted for by medical data. The present research, which used self report data, questions these judgments. The present findings are much closer to those of Gorden et al. who also used self report data and found 12% of the variance in distress to be accounted for by medical data.

The present study essentially replicates Weisman and Worden's (1980) pattern of findings concerning the relationship of emotional distress to cancer diagnosis. Usually aggressive cancers such as leukemia and lung cancer were associated with high emotional distress and patients with the relatively less serious melanomas and skin cancers were more frequently found in the low distress group. These findings are understandable given that patients with the more deadly cancers are usually sicker and also typically receive more extensive and aggressive treatments which are both physically and emotionally demanding and which are nonetheless likely to result in a high mortality rate. These patients had more extensive health concerns which could be expected, whereas skin and melanoma patients had more existential worries, work and financial concerns.

Weisman and Worden (1980) found that emotional distress was typically highest at the time of diagnosis and then rapidly decreased

during the following five months, presumably as patients adjusted to their illness. The present study replicates these findings. However, the present study assessed patients who were diagnosed longer than three to six months and found a significant rise in distress in the period between six months and one year before dropping and leveling off. Weisman and Worden (1976) term the period of the first 100 days post-diagnosis as the period of highest vulnerability and "existential crisis." The present results suggest that maximum vulnerability may occur for an individual patient at almost any time postdiagnosis depending on the course of their disease, the status of their treatments, their physical ability to manage the tasks of daily living, and a host of other factors. The rise in emotional distress for the current sample during the second half of their first year with cancer may be a function of the deterioration of many of the sicker patients who were approaching the terminal phase of their illness after a brief period of treatment postdiagnosis. Patients who had survived longer than one year since diagnosis appeared to have made a steady and stable adjustment to their illness. Many of these patients were in remission and had finished their course of treatment. For many of these patients disease recurrence had become the most troubling worry. The present study lends support to carrying a longitudinal study on emotional distress in cancer patients beyond six months postdiagnosis. In addition, future research should systematically explore the differences in distress over time for specific cancer types and cancer treatments. For example, one could expect surgery patients to experience peak distress earlier in diagnosis than chemotherapy or radiation patients, and lung cancer patients, for

example, would likely show a steady rise in distress over time compared to patients with less aggressive cancers.

The focal hypothesis of the present research was that cancer patients with an internal health locus of control should have less emotional distress than health externals. Examining the results from the testing of this hypothesis has shown that no significant relationship could be found between emotional distress and health locus of control in cancer patients. Pearson product-moment correlations comparing these measures were consistently low. Multiple regression analysis revealed that less than .13 to .24 of the variance of the measures of emotional distress was a function of locus of control. The findings of chi-square analyses and multiple *t*-tests which compared high and low extreme emotional distress scores across locus of control also rarely found results that could be considered significantly different from chance variation alone.

However, where significance was achieved throughout the various analyses the findings were almost without exception in the hypothesized direction. To summarize, health internals generally had lower mood disturbance and lower composite distress, whereas low internals had significantly higher mood disturbance. These findings conform to the judgments of raters in Weisman and Worden's research (1980) that cancer patients with internal beliefs and expectations experience less emotional distress. These findings also conform to the theory of health locus of control as formulated by Wallston and Wallston (1981).

There were also few significant findings regarding the relationship of chance and powerful others to emotional distress, although consistent

trends suggested that patients with high chance scores had more concerns, vulnerability and higher composite emotional distress. Patients with high powerful other scores tended to have a greater number of concerns. Although this finding was not significant it conforms to the direction hypothesized by the traditional understanding of powerful others as a measure of external locus of control. However, more recent thinking, as of now unpublished (Wallston, K., personal communication), postulates that health locus of control may be a construct that is more situation specific, as opposed to a predisposing personality trait, than was previously theorized. This is thought to be more likely to be true in situations where persons are faced with chronic and devastating illness. Given this reorientation in theory, Wallston suggests that, in a population of cancer patients, having a powerful others orientation may be more, rather than less, adaptive. Wallston goes further in suggesting that the very best copers with cancer may be those who combine both a high internal with a high powerful others orientation. These are patients who theoretically take responsibility for their health to the extent that it is in their control, but are flexible enough to turn control over to powerful others, such as doctors, when it is appropriate to do so.

The present findings do not contradict this line of reasoning, but show that the combined high powerful others and internal locus of control group is no more likely to experience low distress than the high internal group alone. Perhaps, powerful others is a locus of control construct that becomes contaminated in a serious illness

situation. For some patients this orientation may signal a giving up or resignation that the cancer experience is beyond their ability to cope with and thus they sign away their responsibility to doctors as their only hope for survival. Another group of patients with a powerful others orientation may see physicians as collaborators in restoring their health, professional consultants upon whose expertise they rely. While the first group could be expected to be more distressed than the second group, it is clear that these are hypotheses which cannot be tested with the current Multidimensional Health Locus of Control Inventory. What is needed is a cancer patient locus of control questionnaire which could help to differentiate the wider variety of attitudes and expectations these patients are likely to have. At some point this test may need to be made more specific still, into a breast cancer postmastectomy locus of control inventory, for example. In short, combining the dimensions of powerful others and internal locus of control appears to create too broad a theoretical category and is not likely to produce clear or consistent empirical findings.

In the current research the only apparent trend for the combined internal-powerful others group was for patients who scored low on both of these dimensions to have higher total mood disturbance. One could speculate that this group of patients seemed to have more distress because they could turn neither to themselves, nor to powerful others for the expectation of control and responsibility for returning themselves to health.

Returning to the powerful others locus of control dimension, patients who scored high with these expectations tended to report few physical symptoms (regression analysis). One could infer that this group of patients had faith that doctors were able to control their symptoms. In addition, the most disabled patients tended to have higher chance scores suggesting perhaps that this group of patients may have lost faith in the doctor's ability to manage their illness.

It is important to note that all of the trends of the major hypotheses in the present research conform to the expected direction except one. That is, to the extent physical symptoms are a measure of emotional distress, and since distress should be associated with externality, symptoms ought to be positively correlated with chance and powerful others locus of control. The present findings show the trend to be exactly the opposite. Symptoms were reported lower in patients with chance and powerful others expectations. While these findings may be a function of chance variation alone, Nehemkis et al. (1982) had very similar findings. They hypothesized, based on locus of control theory, that internally oriented cancer patients would be more likely to reattribute cancer pain to a source that was benign, other than the cancer, and therefore would rate the pain as less severe. Since pain was hypothesized to be less severe when perceived to be under one's control, internals were predicted to have less pain. Unexpectedly, they found that patients with external locus of control rated their pain as significantly less severe than internals. Patients with a greater tendency to ascribe their life situation to fate rated

their pain as the least severe. The more impoverished the patient's feelings of self-direction and control, the less severe did they perceive any discomfort. Contrary to their hypotheses, externals were more likely to reattribute pain to a benign source and rate it as less severe. They concluded that denial may have been operating as a moderator variable, but that to the extent it actually served to reduce the severity of pain, it had positive adaptional value.

Goldstein (1976) specifically linked an external locus of control orientation with denial. Compared with control subjects, chronic hemodialysis patients were found to have higher scores on both externality and denial. Denial was measured by repression scale scores from the MMPI. The relationship between denial and externality was highly significant for the group of patients with chronic, life threatening, illness, whereas no relationship was found between externality and denial in patients who were recovering from minor medical problems. Goldstein concluded that the relationship between these variables is only evident during times of extreme stress when patients experience a higher degree of powerlessness. Thus, among patients who do not have an internal locus of control orientation, denial appears to be used in an attempt to manage highly stressful situations. Harrow and Ferrante (1969) suggest that externality may be used in an attempt to lessen anxiety which would result from the recognition that one is no longer effective in dealing with the environment.

In the present research there is also reason to suspect that denial might be operating as a moderator variable. Its effect would

be to lower the reported emotional distress of patients who are high externals and/or low internals. Thus, the presence of denial would contaminate the results expected from the relationship between emotional distress and locus of control and may be a significant factor in explaining the lack of a more clear and significant relationship between these variables.

In addition to essentially corroborating the findings of Nehemkis et al. that physical symptoms are reported to be less, rather than more, distressing in patients with an external locus of control, the present research also focuses on the kind of patient population which Goldstein found most susceptible to using denial among its externally oriented patients. These factors suggest that denial could be operating to some extent among externally oriented patients in the current study. However, without further evidence in the current findings this remains a speculation with little support.

Closer examination of the data in the current research suggests that there is a pattern of avoidance and/or denial operating among a specific segment of the patients in the sample. In short, as the age of patients in the study increased, their level of reported emotional distress decreased, their level of internal locus of control decreased and their information and participation preferences also consistently decreased. Even though the group of patients older than 60 years were much more likely to be physically and functionally disabled by their disease, and that typically the patients unable to care for themselves had high chance health locus of control scores,

the elderly patients consistently and significantly reported less distress. The oldest group of patients had fewer total current concerns; on the POMS they had less anger, tension, depression and confusion as well as significantly lower total mood disturbance; they were rated with lower vulnerability; and they were significantly more likely to fall into the composite low emotional distress and the composite low depression groups.

In agreement with traditional locus of control theory, Weisman and Worden (1980) argue that patients who actively seek out information about their illness and prefer to be actively involved with their physicians in making decisions regarding the course of their treatment ought to be the best copers and thereby experience the least emotional disturbance. The present findings clearly contradict this postulate. The subgroup of patients in the current study who can be defined as reporting the least emotional distress were the elderly patients who also had the least need for information about their illness, who preferred to leave decisions about their medical treatment up to their doctors, and among all patients, were comparatively the group most content with minimal details or information that supplied only good news about their illness.

These findings are clearly documented in the present results and represent a point for point replication of Cassileth's (1980) significant findings regarding the relationship between age and information and participation preferences among cancer patients. In fact, by comparing the frequency of patients in each category of age, the sample of elderly

patients in the current study can be considered greater information avoiders, and even less willing to participate in treatment decisions, than the sample of patients from the University of Pennsylvania Cancer Center. Moreover, while nearly 70% of patients less than 60 years of age fell into the high internal locus of control group, 60% of patients over 60 indicate that they do not consider themselves significantly responsible for their own health. Although the elderly patients do not give themselves relatively higher rankings on chance or powerful others locus of control compared to younger patients, it appears to be a consistent finding that the patients over 60 years of age did not give themselves high rankings on any measure throughout the psychological screening.

To summarize, the relevant literature suggests that health locus of control is a concept which can be used to identify a predisposition that people have for attributing responsibility for maintaining their health. People with an internal orientation have been hypothesized to behave more responsibly in maintaining their health and to cope more effectively in recovering from illness than externals. The present research has identified consistent trends for internals to have fewer concerns, less mood disturbance and less overall vulnerability than externals. However, results were not statistically significant and the hypothesized patterns did not emerge as expected.

To account for this it is reasoned that premorbid patterns of health locus of control may become altered in situations of serious and life threatening chronic illness such as cancer. While externals

in a variety of less devastating circumstances may admit to coping less effectively and experiencing more distress, the emotional intensity of facing one's death appears to lead many of these typically more vulnerable patients to the use of denial, suppression and avoidance in an attempt to cope with the intensity of their present reality. Thus, as a group, these patients end up reporting less distress than they otherwise might have, therefore making it more difficult to differentiate them from internally oriented patients on measures of emotional distress. This line of thinking is supported in the present research by the finding that the oldest group of patients, despite not having an internal locus of control orientation, consistently reported less emotional distress, and at the same time reported a greater tendency to avoid information about their illness.

While it may be that these findings contradict locus of control theroy, it is understandable why elderly cancer patients tend to use denial, suppression and avoidance. This group of patients lived through the many years cancer was uniformly recognized as a death sentence. These patients are less likely to be hopeful about receiving successful treatment than younger patients who are living at a time when steady progress is being made against the disease. While older patients may be more resigned to the spread of their cancer, they are perhaps also more aware that by virtue of their years they are closer to a natural time for death. Death is more expected and older patients more likely are prepared for it than younger patients. Therefore, they have less press to fight for information that may aid them in their intent to survive and recover.

Moreover, times have clearly changed with regard to informed consent. Twenty-five years ago patients were rarely told they had cancer at the time of diagnosis (Novack et al., 1979). Patients were protected from bad news and were generally not encouraged to ask questions or to participate in decisions about their medical care and treatment. The paternalistic model of medical care has only recently been supplanted by a more collaborative and contractual model (Graber, 1979; Ryan, 1979). Elderly patients may have been conditioned to be information avoiders and to have a less active internal locus of control.

In contrast to elderly patients, the present research shows younger patients to be relatively more emotionally distressed, to have a much stronger internal locus of control, and clearly to be information seekers. These patients want to be actively involved in the process of their treatment and recovery. The finding that such internally oriented patients should be relatively more emotionally distressed also contradicts locus of control theory, but again is understandable, given the nature of their situation. These are patients approaching, or living in, the prime years of their lives. Their aim and expectation is to be productive in their work and generative in raising their children. Because cancer and the threat of death are less expected compared to when one is older, the shock can be emotionally devastating. In addition, younger patients are likely to have more responsibilities and a greater likelihood for others to be dependent on them compared to senior citizens. Thus, they are likely to have comparatively more

difficulty in functioning and managing the impact that cancer has on their lives.

It is important to note that even though locus of control among cancer victims may not be a significant factor in determining the reported experience of emotional distress, this does not necessarily imply that locus of control is not an important factor in determining whether one effectively copes with their distress. The younger, internally oriented patients may be reporting an experience of more emotional distress, but may be coping more effectively with the impact of their illness, whereas the oldest patients, who report less distress, may actually be less able to manage the demands of living with cancer. This possible difference between "actual coping" and "experienced distress" may explain why Weisman and Worden (1980), who used examiner ratings of locus of control, judged internals to be more effective in coping with cancer than externals. Goldstein (1976) also looked at the relationship of externality to coping and found that "a person pays a heavy toll in adjustment as he becomes increasingly external" (page 17). Externally oriented patients on dialysis were less able to cope with the demands of a restricted diet, self-administered medication and making accurate reports of their condition. Goldstein concluded that denial and external locus of control were counterproductive in keeping these patients alive.

Similar to the pattern of findings concerning locus of control and emotional distress, the hypothesis concerning the relationship of information preferences to emotional distress was supported by weak but generally consistent findings. Patients with low current concerns

tended to want more details about their illness, preferred to participate in medical decisions and were more likely to tell friends of their diagnoses than patients with a high number of concerns. Patients rated with low vulnerability were significantly more likely to want maximum details about their illness, to want to participate in treatment decisions with their doctors and to have told most of their friends of their diagnoses, compared to patients rated with high vulnerability. Patients with low vulnerability were also significantly more likely to prefer all information, even if it was bad news, about their illness. In addition, patients who complained of many physical symptoms were significantly less likely to want details about their illness and preferred to only have minimal information that they needed to care for themselves.

These findings support the inference that emotional distress and information preferences are inversely related. Apparently, patients who are already distressed and vulnerable view additional information or expectations to participate in treatment decisions, as further unwanted stress with which they would have to contend. Additional information was generally not viewed by highly distressed patients as a means of reducing their stress.

The validity of these inferences are challenged by the finding that patients who had high scores on total mood disturbance were significantly more likely to want maximum details about their illness, even if it was bad news, compared to patients who scored lowest on TMD. These results, which are in the opposite direction of the findings concerning

the relationship between information preferences and the other distress measures, are difficult to interpret, but again may be a function of the impact of the subgroup of older patients who were both information avoiders and were significantly more likely to fall into the low TMD group. The POMS specifically tests how much affect patients admit to and among all the measures of distress is therefore most likely to be influenced by patients who are invested in limiting the amount of affect they report. Since a significant number of patients in the present study who were information avoiders were also affect avoiders, it is understandable why patients who admitted to experiencing high mood disturbance were found to be relatively greater information seekers. This form of denial, most evident on the POMS, may also explain why no significant relationship was found between the composite depression measure and chance locus of control scores as was specifically hypothesized.

The pattern of results for both locus of control and information preferences suggests that each is generally related to emotional distress in the ways that were hypothesized, but that both are significantly mediated by the effect of avoidance, denial and suppression from the subgroup of older patients. It is difficult to determine to what extent denial may have influenced the specific relationship between locus of control and information preferences. The hypothesized relationship was supported in that high internal locus of control patients were significantly likely to want maximum details about their illness. They also wanted all types of information, both good and bad,

and they were significantly likely to prefer participating with their physicians in treatment decisions. Chance locus of control patients showed a tendency to avoid maximum details or to want to participate in treatment decisions in weak negative correlations. Powerful others patients did not appear to have distinct information preferences. It seems reasonable to infer that externally oriented patients were not found to be information avoiders because the strongest group of information avoiders, the elderly, would not admit to being highly external. Instead, they preferred to report being low internals which had the effect of helping to define more explicitly the difference between high and low internals on information preferences.

As expected, the present research did not find a significant relationship between sex and emotional distress among cancer patients, nor were there sex differences of significance on the locus of control variables. The findings of Leigh et al. (1980) that significantly more males had an internal locus of control was not replicated. Their results also showed a confusing pattern of denial among patients. Male patients in their study were found to be more ignorant of the seriousness of their illness, were more unaware of the number of radiation treatments they had remaining, and were more unaware of their diagnoses compared to female patients. The male patients claimed to be coping better, experiencing less distress and generally feeling more in control. While the present research does not corroborate sex differences on locus of control, the present research, along with the few published papers which have examined the relationship of locus of

control and emotional distress in cancer patients, found denial and avoidance to have an important impact on the relationship between these variables.

The present research has attempted to document the relationship of emotional distress to locus of control and information preferences among cancer patients. Future research will need to explore the relationship of real-life coping and functioning with locus of control and emotional distress in a cancer population. Particular attention will need to be paid to the role of denial, suppression and avoidance as it relates to coping among these patients. A closer look should also be given to the subgroup of elderly patients to determine if they are actually as low distressed as they report themselves to be, or if there is a form of quiet suffering among these patients which was not detected in the current study.

In conclusion, it is clear that the psychosocial aspects of coping with the impact of cancer are multifaceted. Coping with cancer means facing an ongoing series of problems and challenges over time. A patient may cope very well with one set of problems and very poorly with another. How one copes in a particular situation depends upon one's diagnosis, the extent of disease and physical debilitation, the number and intensity of physical symptoms, age, support systems among family, friends and work, coexisting stresses, preexisting coping patterns, and undoubtedly a long list of important factors.

Given how varied and complex the factors are which contribute to the cancer victim's ultimate success or failure in managing the changing stresses which their illness presents, it is clear that psychosocial

intervention and management for these patients should be flexible. To date, the large majority of intervention programs for cancer patients seem to offer a standard course of objectives. Typically, these objectives include a focus on encouraging patients to become more active in participating in the course of their treatment and in seeking information which will aid them in these efforts. It is true that modern patients are better informed, less submissive, and more demanding than were their passive predecessors. They ask questions and expect informed, intelligible answers. Blanket reassurances, such as "Leave everything to me; don't worry" may incite, rather than settle, the doubts of a patient with an internal locus of control. However, this approach has not been shown to be best for helping all patients, regardless of their difficulties or their locus of control orientation, to feel better. Indeed, some externally oriented patients who are relying on avoidance to lessen their distress, may become considerably more distressed if confronted with the general expectation that it is important to take personal responsibility and rely more upon themselves for control in their time of crisis. Contrary to the contemporary convictions of many, not all patients want, need, or will cope better with a maximum amount of information and control. The key for health professionals is to know who needs information and control, and in what areas, and to what extent. Psychosocial intervention needs to offer different kinds of support, to different kinds of patients at different times during their illness. The success of these interventions ultimately relies upon the cancer counselor's fund of knowledge about the

psychosocial aspects of this disease and his or her ability to use this expertise in making a careful psychosocial assessment of the individual patient.

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APPENDIX

ITEMS IN APPENDIX

Informed Consent Form

Psychosocial Screening Interview

Medical Data Checklist

Inventory of Current Concerns

Profile of Mood States

Index of Vulnerability Rating Scales

Multidimensional Health Locus of Control Inventory

Informational Styles Questionnaire

INFORMED CONSENT

Representatives of the Psychosocial Clinic of the Hematology/ Oncology Consultation Service will be administering a series of questionnaires and asking a variety of questions which we hope will enable us to offer more personal services to those of you needing and desiring them. This information, supplied by you, is an invaluable assistance to us in our search for further ways to help you in your treatment of this disease. You have the right to refuse to take these screening tests, or to withdraw from this procedure, without jeopardizing the medical treatment you will receive.

The results of this information and our conclusions will be available to you normally within two weeks.

The results of this survey will be available and possibly published in the future. All information and individuals furnishing it will be presented in such a way that no individual can be identified directly or indirectly.

"I understand that in the event of injury resulting from the research procedure, financial compensation is not available and medical treatment is not provided free of charge."

_____ _____

Signature of Patient Date

_____ _____

Signature of Witness Date

PSYCHOSOCIAL SCREENING INTERVIEW

Patient's Name: _____ Age: _____ Birthdate: _____

Education: _____ Occupation: _____

Spouse or Other: _____ Age: _____ Race: _____

Education: _____ Occupation: _____

Address: _____ Marital Status: _____

Telephone: _____ Children and Ages: _____

Name of Insurance (Medicare or Medicaid): _____

Date of Interview: _____ Diagnosis: _____

How long have you known of your present diagnosis? _____

1. How did you first discover that you had cancer?

2. How did you react to the news? How did your family react?

3. Do you talk about your cancer (ask questions, read about, actively seek information)?

4. Is there any family history of cancer?

5. Have you had major medical problems in the past?

6. When you think about your total situation, what causes you the greatest amount of worry?

7. What are your typical moods (nerves) like now? How has this affected your family? How has your mood (nerves) changed since your diagnosis?

8. How is your appetite since your diagnosis? How have you been sleeping?

9. Who can you discuss your illness with best among family and friends? Who do you have difficulty discussing your illness with?

10. Since you found out that you have cancer, how has your life with your family or friends changed?

11. Does your family ask for your help as much as usual? Are others doing the chores you normally do?

12. What do you imagine happening in the future (i.e., changes in yourself, your relationships, cancer)?

13. What kind of financial or work-related concerns do you have?

14. What kinds of emotionally difficult times have you had in your life (i.e., with others, work, home, loss or change)?

15. Have you ever had counseling or psychotherapy? When? For what reason?

16. What sources of strength have you had in your life? Which ones remain and will continue (i.e., others, religion, social activities, work)?

17. What do you do to relax?

18. Any other pertinent information.

Patient's Name _____

Inpatient _____

Outpatient _____

Extent of Disease:

Localized tomors _____

Regionally invasive tumors _____

Distantly disseminated tumors _____

Type of Treatment

Chemotherapy _____

Radiation _____

Surgery _____

Combination (specify):

_____

No treatment at present _____

When treatment expected _____

During the past month, how much have you been bothered by each of the following:

	Not at all	Some	A great deal
Pain	1	2	3
Tiredness and loss of energy	1	2	3
Loss of weight	1	2	3
Trouble sleeping	1	2	3
Swelling, irritation, lumps, or poor healing	1	2	3
Trouble with vision or hearing	1	2	3
Difficulty walking or keeping balance	1	2	3
Nausea, vomiting, or trouble eating	1	2	3
Diarrhea, constipation, or cramps	1	2	3
Difficulty urinating	1	2	3
Cough or shortness of breath	1	2	3
Heart problems	1	2	3
Feeling depressed, worried, or tearful	1	2	3
Subtotal	___	___	___
Speech difficulty	1	2	3
Hair loss	1	2	3
Bleeding	1	2	3
Total	___	___	___

Karnovsky Index:

Duration of symptoms:

INVENTORY OF CURRENT CONCERNS
(ICC)

Project Omega
Massachusetts General Hospital
Harvard Medical School
Boston, Massachusetts

© Avery D. Weisman, M.D. and J. William Worden, Ph.D., 1977

Many of the statements listed below are true to some extent for everyone.

Please check the degree to which these statements have been *true for you* within the past month including today.

I am concerned about:		True	Somewhat True	Not True
1. Feeling tired most of the time	1.			
2. Having lengthy treatments	2.			
3. Being more religious	3.			
4. Needing financial assistance	4.			
5. Having too many decisions made for me	5.			
6. How long I might live	6.			
7. Having to move away from my neighborhood	7.			
8. Being very lonely	8.			
9. Losing interest in things	9.			
10. My poor appetite	10.			
11. My persistent cough	11.			
12. Whether there is an afterlife	12.			
13. Future unemployment	13.			
14. Feeling rejected by my family	14.			
15. The future	15.			
16. Asking friends for help and assistance	16.			
17. Feeling anxious and restless	17.			
18. Being too careful to do the right thing	18.			
I wish that:				
19. I wasn't losing weight	19.			
20. I wasn't bothered by headaches	20.			
21. I didn't doubt the value of prayer	21.			
22. I could work regularly	22.			
23. My family understood me	23.			
24. There were fewer quarrels at home	24.			
25. Friends were more dependable	25.			
26. I had more sexual satisfaction	26.			
27. I was not so honest and outspoken	27.			
28. I could get around better	28.			
29. I could get better treatment	29.			
30. I could get satisfactory help from religion	30.			
31. I could have a steady income	31.			
32. I could fulfill my spouse's expectations	32.			
33. I weren't so dependent on my family	33.			
34. I could see more of my friends	34.			
35. I weren't so discouraged	35.			
36. I didn't take things so seriously	36.			

I am afraid that:		True	Somewhat True	Not True
37. My stomach and bowels bother me	37.			
38. I occasionally feel faint	38.			
39. I don't get to church often enough	39.			
40. I will have to spend all of my savings	40.			
41. My marriage is breaking apart	41.			
42. I face an uncertain future	42.			
43. I am being a burden on my friends	43.			
44. I am too moody	44.			
45. I will be thought a bad person	45.			
46. My treatments are not satisfactory	46.			
47. I want more from my doctors	47.			
48. I'm losing my earlier religious faith	48.			
49. I'm not doing my job well	49.			
50. I'm not getting along with a member of my family	50.			
51. I am losing hope in the future	51.			
52. My friends treat me differently because of illness	52.			
53. I might hurt myself	53.			
54. I am getting too old	54.			
I would feel better if:				
55. I didn't face an operation	55.			
56. I wasn't bothered by shortness of breath	56.			
57. I could feel closer to God	57.			
58. I could keep up with my work and chores	58.			
59. I could be closer with my family	59.			
60. I didn't have to live with relatives	60.			
61. I had a good friend to confide in	61.			
62. I could forget past mistakes	62.			
63. I was able to do more things for myself	63.			
64. I could sleep better	64.			
65. I had less pain	65.			
66. I weren't so indifferent to religion	66.			
67. I had enough money for medical expenses	67.			
68. My children were settled in life	68.			
69. My family could be counted on	69.			
70. I weren't alone so much	70.			
71. I weren't so irritable	71.			
72. I could think more clearly	72.			

Name_____ Date_____

Age_____ Sex_____ Primary_____ Months_____

	T × 2	+	ST × 1	=	Total	÷	= % of category
HE						32	
RE						16	
WF						16	
FA						24	
EX						8	
FR						16	
SA						32	
Total:					$\sum$ = _____	144	

NAME _____ DATE _____

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in ONE space in the column to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

The numbers refer to these phrases.
0 = Not at all
1 = A little
2 = Moderately
3 = Quite a bit
4 = Extremely

		0 NOT AT ALL	1 A LITTLE	2 MODERATELY	3 QUITE A BIT	4 EXTREMELY
T	1. Friendly	0	1	2	3	4
	2. Tense	0	1	2	3	4
D	3. Angry	0	1	2	3	4
	4. Worn out	0	1	2	3	4
	5. Unhappy	0	1	2	3	4
A	6. Clear-headed	0	1	2	3	4
	7. Lively	0	1	2	3	4
	8. Confused	0	1	2	3	4
V	9. Sorry for things done	0	1	2	3	4
	10. Shaky	0	1	2	3	4
	11. Listless	0	1	2	3	4
F	12. Peeved	0	1	2	3	4
	13. Considerate	0	1	2	3	4
	14. Sad	0	1	2	3	4
C	15. Active	0	1	2	3	4
	16. On edge	0	1	2	3	4
	17. Grouchy	0	1	2	3	4
	18. Blue	0	1	2	3	4
	19. Energetic	0	1	2	3	4
	20. Panicky	0	1	2	3	4
	21. Hopeless	0	1	2	3	4
	22. Relaxed	0	1	2	3	4
	23. Unworthy	0	1	2	3	4
	24. Spiteful	0	1	2	3	4
	25. Sympathetic	0	1	2	3	4
	26. Uneasy	0	1	2	3	4
	27. Restless	0	1	2	3	4
	28. Unable to concentrate	0	1	2	3	4
	29. Fatigued	0	1	2	3	4
	30. Helpful	0	1	2	3	4
	31. Annoyed	0	1	2	3	4
	32. Discouraged	0	1	2	3	4
	33. Resentful	0	1	2	3	4
	34. Nervous	0	1	2	3	4
	35. Lonely	0	1	2	3	4
	36. Miserable	0	1	2	3	4
	37. Muddled	0	1	2	3	4
	38. Cheerful	0	1	2	3	4
	39. Bitter	0	1	2	3	4
	40. Exhausted	0	1	2	3	4
	41. Anxious	0	1	2	3	4
	42. Ready to fight	0	1	2	3	4
	43. Good natured	0	1	2	3	4
	44. Gloomy	0	1	2	3	4
	45. Desperate	0	1	2	3	4
	46. Sluggish	0	1	2	3	4
	47. Rebellious	0	1	2	3	4
	48. Helpless	0	1	2	3	4
	49. Weary	0	1	2	3	4
	50. Bewildered	0	1	2	3	4
	51. Alert	0	1	2	3	4
	52. Deceived	0	1	2	3	4
	53. Furious	0	1	2	3	4
	54. Efficient	0	1	2	3	4
	55. Trusting	0	1	2	3	4
	56. Full of pep	0	1	2	3	4
	57. Bad-tempered	0	1	2	3	4
	58. Worthless	0	1	2	3	4
	59. Forgetful	0	1	2	3	4
	60. Carefree	0	1	2	3	4
	61. Terrified	0	1	2	3	4
	62. Guilty	0	1	2	3	4
	63. Vigorous	0	1	2	3	4
	64. Uncertain about things	0	1	2	3	4
	65. Bushed	0	1	2	3	4

* MAKE SURE YOU HAVE ANSWERED EVERY ITEM.

EDITS
TEST

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Date _____ Rater _____

OMEGA VULNERABILITY RATING SCALES

S 1 2 3 4 A B C

	4	3	2	1
HOPELESSNESS	No hope for recovery	Doubtful regarding recovery	Cautious	Confident regarding recovery
TURMOIL	Highly agitated	Very restless	Fidgety	Calm and composed
FRUSTRATION	Very frustrated; angry over plight	Moderate frustration and anger	Irritable; Mild frustration	Feels problems are being adequately handled
DEPRESSION	Very depressed and dejected	Sad; moderately depressed	Mild depression	Not at all depressed
POWERLESSNESS	Feels overpowered; unable to initiate effective action	Not sure if help can help	Needy but able to ask for help	Resourceful and self-sufficient
ANXIETY	Panicky; feels overwhelmed	Frightened, with specific fears	Uneasy; qualms	Feels safe and in little danger
EXHAUSTION	Exhausted; too tired to care	Fatigued and somewhat apathetic	Tired but still cares; seems engaged	Zestful and engaged

	4	3	2	1
WORTHLESSNESS	Worthless; not okay and never will be; undeserving	I'm not okay; feels flawed & inadequate	I'm okay but I goof up, make mistakes	I'm okay; strong self regard
ABANDONMENT	Feels abandoned and rejected	Lonely and isolated	Feels somewhat neglected	Feels cared for and well looked after
DENIAL	Avoids speaking word "cancer" or its equivalent	Admits diagnosis and illness, but denies implications	Uncertain or uses euphemism	Correct perception of illness and related problems
TRUCULENCE	Feels victimized, bitter, mistreated by caregivers	Has doubts and serious questions regarding care and treatment	Believes that only adequate care is being given	Feels that very good care is received. Very plus attitude to caregivers
REPUDIATION OF SKO	Rejects or antagonizes sources of support	Mild rejection of others; somewhat sullen	Accepts help grudgingly	Gladly accepts sources of help and support
TIME PERSPECTIVE	Closed; no tomorrow	Only a day at a time	Cautious about future; wait and see	Unlimited; foresees future as if no illness

Score _____

MHLC

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2. No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3. Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4. Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5. Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
6. I am in control of my health.	1	2	3	4	5	6
7. My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
8.	When I get sick I am to blame.	1	2	3	4	5	6
9.	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10.	Health professionals control my health.	1	2	3	4	5	6
11.	My good health is largely a matter of good fortune.	1	2	3	4	5	6
12.	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13.	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14.	When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15.	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16.	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
17.	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18.	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Scoring Instructions HLC

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

Internal Items:	1,	6,	8,	12,	13,	17
Chance Items:	2,	4,	9,	11,	15,	16
Powerful Others Items:	3,	5,	7,	10,	14,	18

PATIENT INFORMATION QUESTIONNAIRE

1. After they have all the information they need about their illness and treatment, some patients prefer not to get any more details, and others prefer to get additional information. Please circle the statement that best describes your preference.

1	2	3	4	5
No more details than needed	A few more details	Some more details	Many more details	As many more details as possible

2. Which statement best describes your point of view? (Circle one)

   A. I prefer to leave decisions about my medical care and treatment up to my doctor.

   B. I prefer to participate in decisions about my medical care and treatment.

3. Is there any other information which you feel you need? No _____

   Yes (Please explain) _____

4. Do your friends know what your exact diagnosis is? (Please circle one)

   A. No

   B. Yes, but only my most intimate friends

   C. Yes, most of my friends and neighbors

   Comments _____

   _____

5. Which statement best reflects your attitude toward information about your illness? (Please circle one letter)

   A. I want only the information needed to care for myself properly.

   B. I want additional information only if it is good news.

   C. I want as much information as possible, good and bad.

   Please explain your choice: _____

   _____

   _____

THANK YOU VERY MUCH FOR YOUR HELP!

6. Below is a list of different kinds of information about illness and treatment. For each item on the list, please indicate whether you absolutely need this information; whether you would like to have this information; or whether you do not want this information

	I absolutely need this information	I would like to have this information	I do not want this information
A. Whether or not it is cancer			
B. What the specific medical name of the illness is			
C. Whether all parts of the body are involved			
D. What the day-to-day (or week-to-week) progress is			
E. What the likelihood of cure is			
D. Whether it is inherited or contagious			
G. What the treatment will accomplish			
H. What all the possible side effects are			
I. How effective the treatment has been for other patients			
J. Exactly what the treatment will do inside my body			
K. Examples of cases where the treatment has been effective			
L. Examples of cases where the treatment has not been effective			
M. Other _____ _____ _____			

VITA

Richard James Fitzpatrick was born in Amityville, New York, in September 1953. He lived there through his late teens and attended St. Anthony's High School in Smithtown. In 1975, Mr. Fitzpatrick was awarded the Bachelor of Arts degree summa cum laude from St. John Fisher College in Rochester, New York. He chose to major in psychology following his return from Europe where he had studied history for one year.

Mr. Fitzpatrick spent the next two years completing his course work for the Master's degree and Certificate of Advanced Study in school psychology at the State University of New York in Oswego. In the summer of 1977, he began a doctoral level internship in clinical psychology in the Child and Adolescent Psychiatric Service of Mount Sinai Hospital in Hartford, Connecticut.

After completing his internship, Mr. Fitzpatrick moved to Knoxville, Tennessee, with his fiancé, Amy Esdale, M.D., where he began study toward the Doctor of Philosophy degree with a major in psychology at The University of Tennessee, Knoxville. He was married in 1979 and two years later he and his wife returned to the northeast where he completed a Clinical Psychology Internship at Boston's Beth Israel Hospital and the Harvard Medical School in June 1982. While completing his dissertation requirements Mr. Fitzpatrick worked as a clinical fellow and staff practice psychologist at the Beth Israel Hospital.

Mr. Fitzpatrick's research and professional interests include psychodynamic psychotherapy, issues of mind-body integration, general hospital consultation-liaison psychology and hypnosis. He is among the faculty for the 1983 workshops of the Society of Clinical and Experimental Hypnosis.

Mr. Fitzpatrick has been appointed as an Instructor of Psychology in the Department of Psychiatry at the Beth Israel Hospital and the Harvard Medical School and will be working as a staff psychologist in the Clinical Psychology Internship training program beginning in August 1983. He has also been awarded a half-time postdoctoral fellowship in psychotherapy at the Harvard Community Health Plan, beginning July 1983.