THE UNIVERSITY OF MANITOBA

DEVELOPING AN EMOTIONAL SUPPORT SYSTEM FOR THE CANCER PATIENT

BY

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Thank you. Dr. B. Winerman for welcoming this practicum study in the cancer clinic.

To the group members I say: What you have experienced no power on earth can take away from you. All that you have suffered; all this is not lost for you have brought it into being.

Herein lies the recipe for a successful, meaningful and productive practicum year.

1 cup of anticipation anxiety worked through
1 cup of perseverence sprinkled with determination
1 cup of loving husband Yakov's tolerance and support
1 cup of Farber's enthusiasm combined with sound backing
1 cup of Grosser's group work skill mixed with her high expectations of my performance
1 cup of Farber's research skills
1 cup of Grosser's "call me even if its 11pm."
1 cup of McDonald's constant validation and expression of value in the activities I engaged in
1 cup of her bringing out the best in me
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1 cup of Kuyper's excellent direction and guidance
1 HEAPING cup of Kuyper's friendship
1 cup of Winerman's warmth, enthusiasm, open ear and tremendous support
1 cup of St. Boniface Hospital Cancer Clinic nurses' sincere and dedicated interest
1 cup of insight gained from ten genuine individuals who taught me much of what is written on these pages
1 cup of this baby inside of me yet to be born who was patient with me while I pursued a busy pace
BAKE for nine months at 350° and you will thus create an M.S.W.

TABLE OF CONTENTS

DEVELOPING AN EMOTIONAL SUPPORT SYSTEM FOR THE CANCER PATIENT

TABLE OF CONTENTS (cont.)

INTRODUCTION

The practicum described on the following pages was conducted from August 1976 to May 1977. The chosen area of specialization was the exploration and implementation of an emotional support system for the cancer patient. Working in a geriatric hospital setting prior to the practicum provided me with an understanding of the psycho-social element in illness. This experience, coupled with illness in my family led me to explore with more intensity the area of psychological variables in disease. My dear mother, a woman of valor, died October 1975 of cancer following four years of living with this complex disease. As life's events, usually its tragic ones, lead one to meaningful experiences, such was my mother's life and death with cancer; a major force leading me to pursue the development of a group at the outpatient cancer clinic at St. Boniface Hospital. The experiences of a cancer patient's route from diagnosis, through surgeries, treatments, recurrences, and death were familiar to me. My mother's unique way of coping with her disease, and the encouragement and support she offered to many other cancer victims held a lesson for me. I witnessed her involvement in cancer related issues, her new found purpose in life that gave her the strength and will to live through some treacherous periods, and her knowledge as to what could ease the trauma for a person experiencing a life threatening disease. Others may not be as aggressive or outgoing in their reaction to cancer. However, her experience gave me a first-hand insight into the meaning that could be found in suffering, and the personal growth that it held. My concern became one of helping others in her position discover this. The hundreds of telephone calls and letters she received from lonely people who could not share their emotional burdens opened a whole new world to me. These cancer patients were asking to be heard, pleading for an opportunity to open themselves, and share their life events with someone who was able to understand.

My mother divulged the intimacies of her being into a tape recorder night after night. She needed to talk to someone and the tape was this someone. Was she protecting us, her family, from her greatest fears? Subsequent my contacts with cancer patients revealed a similar "protectiveness." Was the protectiveness good, or natural or were these victims of disease reacting to a world which did not know what to ask or what to say, or how to keep contact with a cancered person? The possibility of cancer patients sharing these intimacies with other cancer patients' without an artificial protectiveness, appealed to me. My mother's openess was always cushioned somehow. But need it have been? After her death, I listened to the tapes and learned what was written between the lines, the parts that she could not speak of person to person: "... The days I don't look into the mirror, the days I don't think of future recurrence, I can do everything," "... If I'm not planning for the future I'm not happy," "... I need to be seen as a normal family member, I need to feel useful." I took this package of memories and kept it with me throughout my practicum year. This practicum is dedicated to the memory of my mother, Elvie Blum.

Objectives of the Practicum

The primary objectives of the practicum were to review the literature pertaining to psychological variables and cancer, and develop a role for social work input at an outpatient cancer clinic. Since there had been no major social work input at St. Boniface Hospital Cancer Clinic hitherto, I had to create a role and rational for social work as an integral part of the treatment system. Other objectives included: establishing a credible working relationship with the medical and nursing staff to allow for recognition of the important role of addressing emotional factors in cancer, launching and leading a group for cancer patients, and acquiring advanced skill in the practice of group work. An objective that emerged mid way through the practicum was setting the stage for the possibility and viability of a permanent social work position in the clinic.

The practicum was divided into several time phases. During August and September (1976) the focus was on negotiating a working contract with St. Boniface Hospital Social Work department and Dr. B. Wineiman of the St. Boniface Hospital Cancer Clinic. September through November was spent in observation. Two full days a week were devoted to making contact with patients at the clinic, and working towards the goal of staff system and myself feeling comfortable with each other. At this time a rational and program proposal were developed. Mid November the group was launched and conducted until the end of March. The program was evaluated in April and the worker terminated the practicum with a social action phase. The social action phase which lasted for a month involved the search for funding and support for a permanent social work position in the clinic.

CHAPTER I

PSYCHOLOGICAL VARIABLES IN CANCER : LITERATURE OVERVIEW

More than two thousand years ago, the Greek philosopher Plato advocated a "whole body medicine" approach when he wrote, "The cure of the part should not be attempted without the treatment of the whole, and also no attempt should be made to cure the body without the soul," . . . For this, Plato continued, "is the great error of our day in the treatment of the human body, that physicians separate the soul from the body." Centuries later, Dr. Calèb Parry (1755-1822) wrote, "It is much more important to know what sort of patient has a disease, than what sort of disease he has." (Blythe, 1973)

The "great error" of Plato's day did not rectify itself. The technological revolution transformed the act of medicine into a precise, disciplined science. As man turned a bit of ground glass downward in the tube of a microscope, he was a giant, and he made giant strides toward the identification of physical factors in illness. For the first time the scientist actually saw disease: he saw changes in the diseased cell. The cellular level became the focus of disease because of its very highly dramatic and visual aspects. Then, and now, the thought of emotional factors or psychological variables possessing any causal relationship to illness, or playing an influencing role in development and cause of illness is regarded with skepticism and of little practical significance to the medical world. It is unpalatable to the intellect to accept that any of us can create within themselves a malignant (cancer) disease. It is more comfortable to believe that the human body is invaded by an alien virus which can be studied under the microscope and fought by modern medical technology. So we accept that if this invading host should win the final battle between life and death, this is part of the natural law of survival.

However, one cannot overlook or neglect consideration of the vast amount of literature and research that sheds light on what LeShan calls the overall pattern of the organismic life situation that we call cancer.

> "... The individual does not "get" the malignancy, which starts on the cellular, or immunological or biological or psychological level. The entire organism eventuates towards it, involving all its levels, moves in a direction leading to a total organism-in-an-environment situation which we term neoplastic disease " .... "The different levels at which we work are necessary divisions in terms of our training, our intellectual limitations and our ability to learn. There are no more Renaissance men, unfortunately, and perhaps it is impossible today for there to be any." (Bahanson, 1969)

Dr. L. LeShan, one of the key participants in the Second Conference of Psychophsiological Aspects of Cancer (Bahnson, 1969), asserts that these divisions in our analysis of cancer are myths.

The ability to link what goes on at the psychological level with what goes on at the immunological level, the endocrine or cellular level is where we are still in the dark. Since Galen's time men have been debating whether psychological factors play any role in cancer, or whether cancer can be thought of as a psychosomatically connected disease. The debate continues unabatted.

The writer believes that to divide functioning into the mental and the physical is to make an artificial distinction. We are, in fact, one integrated being functioning as a whole. Every physical state, be it comfort or disease, has emotional components. Similarly, every mental response whether an emotional reaction or an intellectual activity, incorporates a physical process. Dr. David T. Graham of the University of Wisconsin Medical School calls mind versus body terminology "linguistic dualism." (Blythe, 1973) Dr. Franz Alexander, (1941) states the case eloquently:

> "... All our emotions we express through physiological processes: sorrow by weeping; amusement by laughter; and shame by blushing. All emotions are accompanied by physiological changes: fear by palpitation of the heart; anger by increased heart rate, elevation of blood pressure ..."

Many physical sensations are associated with painful emotional states - a "lump in your throat" connotes sadness, "a pain in the neck," connotes frustration and "butterflies in the stomach," connotes fearful anticipations.

While few of us have trouble with the idea that the mind and body are "one" in health, their oneness in illness is difficult to accept. Hutschneckar, (1953) in his book, The Will to Live calls this theoretical inconsistency the "Problem Child of Medicine." Medicine continues to treat the diseased "organ" while the "person" is lost in its midst.

If the word 'disease' is broken down, the sufferer is one who is 'dis-eased' by symptoms. This concept of "dis-ease" entails a myriad of components and motivated the writer to take a closer look at the literature relating to the role of psychological factors in neoplasia. (A mass of new abnormal tissue)

On the premise that emotional factors play a crucial role in all phases of illness and health, a thorough review of the literature relating to psychological factors and cancer was conducted. The goals of this review were, admittedly, guided by the desire to document how emotional factors related to all phases of disease. Furthermore, it was hoped that such a review would demonstrate their equal importance in the treatment of malignancy. The highly sophisticated surgical techniques of cancer management, the complex radiotherapy's (the use of radiant energy in the treatment of symptoms), the multiple chemotherapeutic regimens (medications) and the promising immunotherapeutic (treatment by production of immunity) models all needed to be addressed in the light of the part emotions played in illness, treatment, and cure.

The review of emotionality in cancer focused on many broad questions.

(A) What was the role of psychological variables pertaining to the development of cancer? Was there a correlation between neoplastic disease and certain types of psychological attributes? What if any, was the effect of personality structure on the etiology and development of neoplasms? Were there pre-disposing psychological factors to malignancy? Did these factors predict a potentiality for cancer?

(B) Given a diagnosis of cancer, was there a role that stress, attitudes and emotions played in the course, progression, and outcome of malignancy? Did a "will to live" influence a person's responsiveness to treatment? Did psychological factors contribute to morbidity, relapses, or to sustained remission? Did psycho-social differences account for any variance in cancer survival? Did the body have the power within itself to destroy the cancer?

(C) What were the psychological (defense) mechanisms in patients with cancer? What was the meaning, impact and trauma of a life-threatening disease such as cancer for an individual? What were the effects of this disease on a person's life situation? How did one learn to live and cope with cancer?

(D) If such literature demonstrated and developed its own rationale for psychological interventions, what therapeutic applications of this knowledge existed? Was there any systematic and accepted approach which dealt specifically with the emotional needs of the cancer patient? What types of support systems were available? Were there any treatment modalities based on an assumption of mind-body relationships? What facilitated the patient's desire to return to good health?

Much of the information acquired from the review of the literature can be generalized to other disease states, and the interested reader is advised to draw parallels with disease states such as coronaries, colitis, etc. However, this practicum was strictly cancer-related.

The reader should be aware that all stages of cancer are addressed and that there was difficulty in separating the stages (describes degree of disease progression) of disease in reviewing the literature. Although cancer can be controlled, (no new growth or spread of abnormal cells) some believe cured (disease is eradicated) in some instances, for many patients ultimately it is a terminal illness (describes a state in which death is approaching and treatment is no longer effective) and as such this phrase is used often in this review.

(A) The Role of Psychological Variables in the Development of Cancer

This review will not attempt to give a detailed description of the literature relating to psychological factors in the development of malignant disease, but rather will present a general thematic overview. Most investigations of the relationship between psychological factors and cancer favor one or more of four basic methods: anecdotal analysis interview and case history, sociological and demographic analysis, and psychological testing.

Historical Review

The most comprehensive article available, a historical perspective on works from as early as the 1400's to 1960 in the area of predisposing factors to cancer, was by Dr. L. LeShan. (LeShan, 1959)

For centuries physicians have assigned a role to emotions in the causes of physical illness. LeShan found that cancer was associated with the humoral theory at a very early date. In the second century A.D. Galen believed that melancholic women were more prone to cancer than those of sanguine temperament. In 1402, a physician, Maestro Lorenzo Sassoli wrote to a patient:

> "... let me speak to you regarding the things of which you must most beware. To get angry and shout at times pleases me for this will keep up your natural heat; but what displeases me is your being grieved and taking all matters to heart. For it is this, as the whole of psychic teaches, which destroys our body more than any other cause." (LeShan, 1959)

As early as 1759, Gendron stressed the importance in cancer of, "... Disasters in Life, as occasion much trouble and grief." (Gendron, 1701) Kowal (1955) reviewed the eighteenth and nineteenth century literature on emotions as a cause of cancer. Even at this point physicians were impressed by the frequency by which certain life situations tended to occur prior to the development of a neoplasm. Emotions such as grief, disappointment, despair, and hopelessness were inciting causes of malignant growth. In this country William Parker summed up his fifty-three years of surgical experience with cancer:

> "It is a fact that grief is especially associated with the disease. If cancer patients were as a rule cheerful before the malignant development made its appearance, the physiological theory, no matter how logical must fail; but it is otherwise. The fact substantiates what reason points out." (Parker, 1885)

LeShan cited E. Cutter in this historical perspective who, about the same time as Parker noted that, "Mental depression is too often an element in cancerous cases to be overlooked." (Cutter, 1887) Herbert Snow, working at the London Cancer Hospital, did the first statistical study with the available psychological tools. In his last book, written in 1893, he wrote:

> "... We find that the numbers of instances in which malignant disease of the breast and uterus follows immediately antecedent emotion of a depressing character is too large to be set down to chance, or to that general liability to the buffets of ill fortune which the cancer patients in their passage through life share with most other people not so afflicted."

According to LeShan, the concept that severe emotional trauma contributed radically to the onset and development of cancer was not regarded as radical. The authors and physicians quoted were cancer specialists who wrote, not from a theoretical base, but from years of careful clinical observation. These early writers seemed likely to view the patient as a whole. Yet debate emerged as to the value or utility of advocating emotional factors in the development of cancer. The idea of a psychic factor in the etiology of malignant disease vanished from the literature about 1895.

> "... It was not useful knowledge since there were no tools which could be used to help the patient, advances in surgery and later the promise of radiation seemed to be the answer. These techniques also helped to focus the prevailing medical view on cancer as a "local" phenomenon. The older organismic view was lost and the neoplasm was more and more considered as a problem of a specific body area and not of the body as a whole." (LeShan, 1959)

Notwithstanding this caution, efforts continued to integrate psyche and soma. With the advent of psychoanalysis and especially with advances in the field of psychosomatic medicine, many authors attempted to document life events and personality patterns common to those who developed cancer. The first of these was an intensive study by Elida Evans who reported similarity of psychosocial histories among one hundred cancer patients. Evans reported that:

> "... the typical cancer patient had lost an important emotional relationship prior to the development of the neoplasm and was unable to secure any effective outlet for his psychic energy. Under the stress of intense renunciation, the detached energy had turned inward and, in expressing itself through a primitive erotic outlet had brought the cancer into existence." (Evans, 1926)

Along similar lines LeShan and Worthington (1956) studied the personality and life histories of 250 patients with malignancies, they reported that the cancer patients had four factors which differentiated them from the control group.

1. A lost relationship prior to diagnosis of cancer.
2. An inability to express hostility in their own defense.
3. Feelings of unworthiness and self-dislike.
4. Tension over the relationship of one or both parents.

In addition, a psychodynamic pattern emphasizing a traumatic event in childhood and including the above factors was observed for 62% of the cancer patients and 10% of the controls.

Studies cited thus far (Evans, 1926, LeShan and Worthington, 1956) utilized a research design that contrasted malignancy with non-malignancy groups. They did not differentiate between patients with different types of cancer.

Personality Traits and Psychological Patterns in Different Malignancies

An alternative approach was to contrast patients with specific types of cancer. Studies in this class included those of Tarlaw and Smalleiser, (1951), Bacon, Rennecker, and Cutter, (1952), Greene, (1954), Stephenson and Grace, (1954), LeShan, (1957), and Kissen, (1964).

The work in this latter approach of psychological patterns of different types of malignancies was sketchy at best. While the work was inconclusive, it was most intriguing and served a significant heuristic value. (For a thorough review, see Achterberg, 1976). Several distinguishing factors were reported with the different diseases. In general,

> "... patients with lung cancer have been found to be psychologically more like other lung cancer patients than either healthy controls or other respiratory disease patients. Breast cancer patients are more like other breast cancer patients than other groups and so forth." (Achterberg, 1976)

Dr. D. Kissen, Past Director of the Psychosomatic Research Unit at Southern General Hospital, Glasgow, conducted an indepth study of patients suffering from cancer of the lung. He compared smoking and inhaling habits of lung cancer patients and the general population. It was hypothesized that one basic personality characteristic of the lung cancer patient was a poor outlet for emotional discharge. The results indicate that the mean neuroticism scores on the Maudsley Personality Inventory and the scores on childhood behavior disorders (CBD) were significantly lower for lung cancer patients relative to other groups, both reflecting an inability to accomplish emotional discharge. He concluded that the personality of the patients was more important than the fact that they had been smokers, and it was their personality which prevented them from releasing the tension arising through problems in their personal life. (Kissen, 1964)

Greene studied 100 patients with leukemia and lymphoma over a 15-year period and demonstrated that these cancers developed in an environmental setting in which the patient had dealt with a number of losses or separations which prompted feelings of sadness, anxiety, anger or hopelessness. He hypothesized that the development of the disease was related to the psychological state of the individual represented by despair, hopelessness or discontinuity. (Greene, 1966)

Bacon and Associates obtained psychiatric case histories from forty women with breast cancer and found certain consistent behavioral characteristics. The presence of guilt feelings, delay in treatment, and a masochistic character were all suggestions of what Bacon called an "internalized self-destructive drive." The authors proposed that cancer in some patients may have been utilized as a form of passive suicide. The lack of a control group raised certain objections but the study was suggestive and important. (Bacon, 1952)

In a series of studies, Schmale and Iker (1966, 1971) were able to predict to a significant degree which women hospitalized for cone biopsies would have cervical cancer. A group of healthy women considered to be biologically predisposed to cancer of the cervix based on suspicious Papanicolaou smears were selected. Those having a "helplessness prone personality" were predicted to be eventually diagnosed with malignancy, and those not experiencing this trait would not have the disease present. The investigators designed a means of verifying this sense of helpless frustration via an interview technique. Sixty-eight women have been studied with this method and 50 of 68 have been correctly diagnosed using the psychological information. The authors state that the psychological experience of hopelessness acts as the promotor of cancer. These findings reinforced the idea that loss or conflict which was accompanied by feelings of hopelessness and helplessness predated the development of cancer by a few months. (LeShan and Worthington, 1956)

Studies relating personality traits and psychological patterns of different types of malignancies are recent in the study of cancer and are usually imbedded in the literature of psychosomatic disease. These works validate the premise that people with certain behavioral traits have weaknesses in specific target organs. Research on the psychological factors in heart disease, ulcers, colitis, asthma, etc. are cases in point. In his book The Will to Live, Hutschnecker (1953) cited a chapter titled "We select our illness" in which he says:

> "... the need for a way out, for escape, sacrifice, self-punishment drives us to single out an organ to destroy by illness, ... The decisions about illness, are made in the unconscious court of judgement which sits waking and sleeping within us. They are arrived at by way of involved and turbulent argument without words - the language of emotions. While the choice of illness or health is made emotionally it is carried out through the physical mechanisms of the body."

Dr. G. Groddeck, a German physician proposed in the early 1900's that behind every manifestation of illness there was a reason, and the afflicted organ or limb was specifically selected by a part of the mind which he called 'the It.' If a patient contracted an infection, the question likely to be put to him was Why have you infected yourself? What is it that drove you to cause some of the germs around you and within you to multiply so that you were able to use them to make yourself ill? According to Dr. Groddeck, all illness was a manifestation of the unconscious mind trying to find, by a childlike logic of its own, an answer to the problem currently confronting it.

Stress and the Development of Cancer

Dr. Wilhelm Reich, regarded by many as one of the founders of modern psychosomatic medicine, believed that the body contained a "Life Force" which needed to flow freely inside the body if it was to remain healthy. His ideas were similar to those of Groddecks. Disease crept in when the energy became anchored in any one part of the body. Reich showed how the body mirrored the general tensions and general character of the patient. To become freely functioning, the body defenses, which prevent the free flow of energy, have initially to be broken down. The therapeutic applications of Reich's thoughts have been translated into modern day bio-energetics. (Lowen, 1975) This has relevance in terms of whether a specific constellation of psychological traits can be related to the location of cancer. When a part of the body is submitted to unrelieved stress, or kept in a state of constant tension, preventing the free flow of the life force, this part may collapse and cease to function. (Groddeck, 1967; Blythe, 1973)

Recently, Simonton (1975) has renewed interest in this notion of stress and illness. He develops and describes his own theoretical model in the development of cancer:

> "One very large factor contributing to heart disease is the person's response to stress. Supposing this same thing is true in cancer which seems very strongly to be so, then as surely as the heart patient records the fact that he has this type of personality the cancer patient resisted it even more strongly. The heart disease personality is basically a much more socially acceptable personality than the cancer personality. (Simonton, 1975)

elsewhere, he states,

> "... clinical malignancy occurs then not from a single causal factor, but from the duality of the disease in host resistance and an increase in abnormal cell production. Both of these factors can be traced to the psychologically stressful event. We do not assume that all malignancies follow this course, nor do we assume that the events flow solely in the described direction." (Achterberg, 1976)

Simonton adheres to the surveillance theory of tumor development in which it is believed that the body continuously develops cancer cells that do not go on to develop into clinical malignancy because the body's own defense mechanism destroy the cancer cells prior to tumor development. It follows from this view that psychic factors indirectly offset carcinogenesis via the immune system.

> "... The work on psychological or physical stress indicates that when subjected to prolonged or intense stress there is a decrease in the immune response as well as related changes in hormonal balance. Both the onset and severity of a wide variety of diseases including cancer have been associated statistically with a previous increase in life stresses. However it appears that it is not the stressful situations, per se that are uniformly detrimental to health, but rather the physical response depends upon the resources that an individual has for discharging or dissipating emotional response." (Achterberg, 1976)

Simonton (1976) annotates a collection of readings based on the premise of stress and host resistance in cancer. (Prehn, 1969, Soloman, 1969, Labarba, 1970, Holmes, 1973, and Riley, 1975). Simonton concludes that by the 1960's, "... the evidence was conclusive that prolonged or intense stress predisposed an animal to the development of malignancy and significantly influenced the cause of disease."

In his own experience, LeShan wrote that marked changes in psychological stresses have frequently been associated with sudden changes in the growth rate of tumors (LeShan and Gassman, 1958). To quote LeShan:

> "... If we can determine that certain changes in body chemistry follow certain types of emotional change, and that there is also a correlation with neoplastic development, we may have new ways to attempt therapeutic intervention at different levels of biological function. It is probable that the greatest pragmatic value of research in this field will come from greater understanding of psychophysiological interactions rather than from purely psychological therapies."

Most of the works cited in LeShan's review were retrospective. It was not until Thomas (1974) recently published her longitudinal findings on the identification of personality characteristics in a population prior to any development of disease that LeShan's retrospective studies have received support. Thomas studied the development of five diseases. She found that years prior to the diagnosis of cancer, those individuals perceived less closeness to parents than did any other disease group studied.

In summary, the research and clinical observations of Snow, 1895, Evans, 1926, Kowal, 1955, LeShan and Worthington, 1956, Green, 1966 and Schmale and Iker, 1966, combine to suggest the following:

(1) There seems to be a correlation between neoplastic disease and certain types of psychological situations. This has been widely reported as a result of clinical observations, experimental studies and statistical investigations.

(2) The most consistently reported psychological factor has been the loss of a major emotional relationship prior to the first-noted symptoms of the neoplasm. It seems to be established that this has occurred more often in cancer patients than in various groups who were used to controls.

(3) Many authors highlight the role of a severe emotional trauma accompanied by feelings of sadness and hopelessness preceding the development of a malignancy.

(4) There is recognition by many authors that the hopelessness reaction may play an important facilatory role in the appearance of many forms of cancer.

(5) The recent work on stress and cancer (Simonton, 1976) reinforces previous studies on the role of increased life stresses and the development of disease. This work goes one step further in maintaining that the physical response is dependent upon the resources an individual has for discharging this psychic stress. For the first time, emphasis is placed on the importance of dealing with these emotions.

(6) The works cited presuppose the mind-body phenomenon as a single reality.

(B) The Role of Psychological Variables in the Course and Outcome of Cancer

The idea that the growth rate of cancer may be influenced by psychological phenomena has received some attention and study. (Bacon, 1952, Renneker, 1952, Trunnell, 1952, and West, 1952) A thorough consideration of this was reported by physicians at a symposium on the psychological variables in human cancer (Gengerelli and Kirkner, 1954). West, Cutter, and Ellis, (West, 1954) were impressed with the accuracy of intuitive predictions as to how well a patient would respond to treatment. These predictions were based on psychological and/or emotional aspects of the patient and not on the characteristics of the disease, per se.

A major study reported at the symposium, by Blumberg, West and Ellis (1952), compared "fast" and "slow" growing neoplasms with respect to psychological characteristics as measured by a series of psychological tests. Their psychological research had its origin in daily clinical observation of large numbers of cancer patients.

> "We were impressed by the polite, apologetic, almost painful acquiescence of the patients with rapidly progressing disease, as contrasted with the more expressive and sometimes bizarre personalities of those who responded brilliantly to therapy with long remissions and long survival." (Blumberg et al., 1954)

Results of this study, using the Minnesota Multiphasic Personality Inventory and the Rorschach, indicated that patients with fast growing tumors were more defensive, had a greater motivation to appear good and less disturbed than they really were. They experienced more tension as a result of emotional conflict and an inability to adequately defend themselves against anxiety. They could not successfully reduce their tensions through action. During the second phase of the study these criteria were used to predict tumor growth rates. The prediction proved to be correct in 78% of the 25 subjects evaluated. The slow growing tumor group evidenced a more pronounced ability to reduce excessive emotional stress by motor discharge. In contrast, those with rapid growth were, "... consistently serious, overcooperative, overnice, over anxious, painfully sensitive, passive, apologetic personalities."... (Blumberg et al., 1954)

The authors concluded that psychological factors were operative in relation to the cancer activity of the patients. The data suggested that long-standing and intense emotional stress, and an inability to discharge stress may exert a profoundly stimulating affect on the growth of an established cancer.

> "... If the validity of the findings reported in this paper is supported by the results of our own further work and by independent investigations, one might begin to think of explaining host resistance in the cancer patient in terms of ability to reduce or adapt effectively to stresses induced by environmental and emotional conflicts. Such a concept seeks to explain why for example, of two radiologists who develop the same type of leukemia following similar exposure to X-rays, one lives out his normal live span with little inconvenience and the other dies of leukemia in a matter of months." (Blumberg et al., 1954)

In a Canadian study Stavraky, (1968) compared the survival rates of cancer patients, matching those with the most favourable outcome with stage-matched controls defined as average outcome. The group with the most favourable outcome, differed strikingly from all others. They showed a greater ability to express hostile or angry feelings without loss of emotional control. It was noteworthy that the emerging picture of the patient with a favourable outcome was the antithesis of the 'hopelessness' or giving-up reaction described by Engel (1965) as an antecedent of disease in general and by Schmale (1971) as a predictor of early cervical cancer.

In a recent study, Weisman and Worden (1975) used information from psychological autopsies of cancer deaths, and correlated observed survival (measured in months beyond expected survival) with psychosocial factors.

> "... Patients who lived significantly longer tended to maintain co-operative and mutually responsive relationships especially towards the end of their lives. Patients with death wishes, depression, apathy, and long-standing mutually destructive relationships survived for shorter periods than expectable. Why longetivity occurs in some patients but not in others may be related to different traits which create alienation in personal life and care-taking staff as life draws to a close. More assertive patients ask for and get better attention and services and as a result may live longer."

A more recent study by Achtenberg, Simonton and Simonton, (1976) which used an unusual approach to treatment of cancer (which will be discussed in detail in another chapter) observed twelve cancer patients who lived in excess of two years past incurable diagnosis. They were compared with a control group who died within one year following an incurable diagnosis. The findings echo other studies,

> "... To date we have served trends in several factors under study as well as statistically significant differences in the psychological characteristics of the two groups and have reached the conclusion that there is a relationship between certain psychological factors and the course of disease."

In summary the studies quoted above all suggest that there was a relationship between personality organization and the time from the first-noted symptoms of a neoplasm until the patient died. Certain psychological characteristics, such as acquiescence, passivity, hopelessness, and apathy, kept appearing in the discussion of "premature" cancer deaths. Simonton's (1976) work has attempted to follow up Blumberg's (1954) early thoughts that perhaps host resistance in the cancer patient can be explained by an ability to reduce or adapt effectively to stresses induced by environmental and emotional conflicts.

Some of the studies reported are subject to methodological criticism (Perrin, 1959) in terms of:

(1) The selection of cancer patients (location, extent, or approximate duration of the cancer in patients studied is neglected.

(2) The lack of control groups.

(3) The nature of measuring instruments (either no systematic form of measurement, or interviews conducted without detailed information as to the interview method employed or methods used to classify the results.

(4) Treatment of data (serious lack of stastical tests in many of the studies.

However their combined effect leave little doubt that practitioners dealing with the cancered patient may well find valuable and usable information in the realm of emotional factors. Questions continue to emerge as to the degree of importance of emotional variables and how to incorporate this knowledge in treatment and prevention. One direction, nonetheless, seems clear. Psychotherapeutic support systems for the cancer patient should be designed which attempt the therapeutic explanation of emotional variables, an insight originating over one hundred years ago!

(C) Living With Cancer : The Emotional Impact

The research and literature on the emotional aspects of cancer reinforced the writer's personal experience and echoed statements made by cancer patients themselves. The letters and telephone calls received by my late mother from cancer patients were similar to those described by the author of Make Today Count (Kelly, 1975) - a cancer patient himself.

> "One thing is clear to me from the thousands of letters and telephone calls I have received since Make Today Count was founded. And that is that the emotional problems caused by cancer are as devastating if not more devastating as the physical problems caused by the disease. Very few of those letters and phone calls refer to physical suffering. They deal with mental anguish instead."

The Meaning of Cancer

To many patients cancer means extreme pain, to some disfigurement, and to almost all a serious threat to survival. Changes in body function, possible mutilation, and changes in body image (skin lesions, scars, loss of limbs, paralysis) may represent the violation of one's self-image. Such changes are many times accompanied by a loss of self-esteem and fear of unacceptability. Feeling unacceptable one may also feel isolated and rejected, and if threatened by the inability to fulfill an important role, the person may fear loss of affection. (Sveinson, 1974, Kelly, 1975, Rosenbaum, 1975)

Cancer terrifies people. It is thought of as the prototype of fatal illness conjuring up thoughts of a hopeless, painful and debilitating disease. (Feder, 1966, Shands, 1966, Waxenberg, 1966) Few other illnesses combine the wearing qualities of a long illness with the tearing qualities of an acute one. A person facing a life threatening disease is concerned with disruptions to his patterns of living. This concern can be so intense and distressing that the person, "... faces an obstacle to important life goals that is for a time insurmountable through the utilization of customary methods of problem solving." (Caplan, 1964) The threat of prolonged deprivation, body dysfunction, and mobility restrictions may cause such intense anxiety, that a person may withdraw into a deep depression, too bewildered and frightened to function in any area of his life. (LeShan, 1961) In crisis terminology there is an upset in the state of equilibrium.

A Sense of Helplessness

The diagnosis of cancer spells catastrophic suffering and pain, a destructive force over which the person has no power. Fears of helplessness, dependency, isolation and abandonment are written about extensively in the literature (Feder, 1966, Schmale, 1971, Abrams, 1974, Sveinson, 1974, Kelly, 1975, Rosenbaum, 1975). As Abrams (1974) points out, cancer is one of the few diseases an individual feels he cannot control. Undergoing diagnostic tests and therapeutic procedures can reinforce the feeling that you are no longer in control of what happens to you. The person's feeling that the outcome is uncertain is usually the paramount factor influencing his behavioral response. As Keleman (1974) points out, helplessness is the basic pain of life. Much pain and anxiety derive from that.

> "... Dying is having to face the unknown in a world controlled so thoroughly that unknowns are only fearful experiences. Our society is the on-going result of a history of working hard to control unknowns. In our lifetime there are tremendous studies toward such control."

Many cancer patients have a sense of helplessness that may lead to withdrawal, depression and hopelessness. As Seligman, (1975) who has done much psychological research on helplessness, claims, depression is really the belief in one's own helplessness. His work points to the importance of "control" in one's life, and the lethal consequences of helplessness. In terms of Blumberg's (1954) work on fast and slow growing neoplasm, Stavraky's (1968) work on psychological factors in the outcome of cancer survival, and Schmale's (1971) study on the prediction of early cervical cancer, the emergent picture of the patient with a favourable outcome is one who does not feel hopeless and/or passive regarding his disease. Thus, the emotional response of helplessness would certainly not facilitate reduction in psychic stress; a factor which Simonton (1976) suggested as a key influencing variables in the body's response to disease.

The Crisis Potential of Cancer

The word crisis is derived from the Greek, meaning "turning point". As S. Keleman describes, (1974) discovering our dying is a turning point.

> "... Each turning point is the resolution of loss and an encounter with the unknown. The unknown consists of that which we find unpredictable, and of our feeling helpless in the face of it."

For the newly diagnosed, the "unknown" may be his response to discovery, often creating dramatic changes in his self-view. Discovery is the first crisis for the cancer patient. What crisis could be more devastating than the threat to life? Regardless of the possibility of an optimistic prognosis, death is always a possible outcome and anticipatory grief is present from the time of diagnosis. On hearing he had contacted leukemia, (a malignant disease of the tissues in the bone marrow, spleen, and lymph nodes) an Ontario reporter wrote: "My world seemed to collapse. I felt as if I had just been sentenced to death." (Dempson, 1977) Similarly, an Iowa man cried out:

> "... All of us were silent during the trip home. I was losing my life and my family and I didn't know what to do or say ... Cancer meant death. It meant my death." (Kelly, 1975)

The cancer patient is suddenly and powerfully afflicted by the destruction of a predictable future. The person must contend with the potential of non-existence. The emotional impact has been described as a sudden amputation of the future. Most patients face an extended period of uncertainty with respect to the outcome of their disease.

> "... I know that I'm not a whole human being any longer. From the time my disease was first diagnosed, it was evident that the cancer was pretty widespread....Now I live from day to day on the basis of my various body counts - the counts that indicate how I'm getting along,...the drugs are fighting the cancer, the cancer is fighting to grow again, my body is fighting to regain its natural balances, the chemotherapy drugs are killing the healthy cells as well as the cancerous ones. The battle goes on and every day I wonder just how many more days I can count." (Kelly, 1975)

Golan's (1969) components of an emotional crisis can be applied to the stages a cancer patient passes through. She describes the state of active crisis as: "... The stage of disequilibrium when tension and anxiety have risen to a peak and the individual's built in homeostatic defences no longer operate." Kelly, (1975) in his book, Make Today Count confirms this state.

> "... I needed, and did not really have the will to go on living. I needed to be able to talk honestly and openly to my wife and children. And I could not. I needed to think of myself as a human being. Gravely ill, yes. Under a death sentence. But a human being nevertheless."

Dealing With Cancer : Defense Mechanisms

Many writers have spoken of the changes in attitude involved in facing a life-threatening disease such as cancer. As Shands (1951) writes, for most people it is an impossible integrative effort and they resort to substitutive compensatory mechanisms.

A cancer patient writing to fellow cancer patients remarks:

> "... They will experience the same stages of fear, disbelief, and acceptance that I did. They will be devastated at first, but they will find that as they cope successfully with each stage of fright and denial, they will slowly build the emotional strength that will see them through their ordeal. After a while the feelings of devastation and nakedness will be eased. And they will be grateful as I am, to be alive." (Rosenbaum, 1975)

These compensatory or defense mechanisms vary from person to person. Some experience guilt, some denial, others anger.

> "... Fear and anger are the basic defense reactions in life. Fear is a self-collecting response, anger a self-extending one. Fear and anger - retreat and attack. One uses either of these reactions to try to hold their boundaries together and to prevent change or loss....They are responses necessary to the person's integrity, their wholeness, and to avoid or correct the broken boundary." (Keleman, 1974)

Denial can act as a reprieve from painful consideration of impending death especially where there is no response from treatment. It is regarded by some as an important adaptive mechanism. Denial, like all other mental mechanisms, defends the conscious self and preventing its use may result in vulnerability and more pathological expression. According to S. Freud, every denial is an affirmation, According to other theorists denial is a poor avenue for emotional discharge and often provides none at all. (LeShan and Gassman, 1958) To completely deny a stressful situation probably results in the damming up of a considerable amount of psychological and physiological tension.

The Growth Potential in Crisis

The classical reaction to crisis, as outlined by Lindemann, (1944) as a state of disorganization and tension with disruption to bodily and thought processes, and a decrease in constructive behavior and mounting frustration with feelings of helplessness and defeat, is dependent upon the degree to which one must change (or perceive it as a must) his accustomed ways of relating, how well he feels he will be able to make the adjustment and at the same time be accepted by others. Thus a crisis has within it both danger and opportunity. It can move the individual to regression and disintegration of personality or to resolution, learning, and growth. Rapaport, (1972) maintains that a crisis can be a call to new action, a challenge bringing forth new coping mechanisms which serve to strengthen the individual's adaptive capacity.

> "... Having cancer was the most terrible thing that ever happened to her. It was also the most interesting. In superb understatement she said it was never boring....I used to think that if something ghastly should happen to me I would die. Now I know I can be a survivor. It's good to find out you can get through something tough. I feel better about myself because I know that;....I'm more interested in having fun, I'm also a little less driven about work so I can enjoy other things more than I did before." (Winnipeg Free Press, 1976)

This person discovered a new meaning in life. Her words fulfilled the central theme of existentialism - to live is to suffer and to survive is to find meaning in suffering - a theme having great relevance for many facing a life-threatening disease. A basic tenet of this philosophy is that if there is purpose in life at all, there must be purpose in suffering and dying.

> "... Whenever one is confronted with an unavoidable situation, whenever one has to face a fate which cannot be changed, just then one is given a last chance to actualize the highest value to fulfill the deepest meaning - the meaning of suffering. For what matters above all is the attitude we take toward suffering." (Frankl, 1963)

Frankl's analysis, in his book Man's Search for Meaning, of the experience of prisoners in concentration camps, has significant parallels with the experience of the cancer patient. Both prisoners and cancer victims have the, "... last of human freedoms - the ability to choose one's attitude in a given set of circumstances." (Frankl, 1963)

Kelly, a cancer patient, in his book, Make Today Count, writes,

> "... it is this very awareness of our limited life span that gives us the courage to fight, the strength to carry on, the wisdom to use each day as a gift, and the ability to say "I love you" before it is too late."

Rosenbaum (1975), in his book Living With Cancer quotes from one of his patients,

> "... Disease rearranges your values and you cast off things....There is nothing to be afraid of anymore when you know you are going to die. It is liberating, very liberating. All the lies are dropped and it cleans your life. Then everything becomes more poignant, more vivid, the people you love and the people you do not. Everything is heightened, and the awareness is just incredible." ...

For some people this new state of being, living with cancer, represents a transition in life that brings forth personal growth. Transitions in life may, "... produce a vitality and immediacy in one's life. They are now and real; they release and lead to unplanned learnings and experiences." (Kuypers, 1977)

In summary, research and literature on the emotional aspects of cancer reveal the potential for both crisis and opportunity. Those intimately experiencing the disease disclose the paradoxical meanings in their reactions to cancer. Feelings of fear, isolation, unacceptability, helplessness, and resulting depression are most frequently reported in the literature. Amidst these feelings, lies an unforeseen strength that can be gained from learning to live with cancer. Where and how can that strength be developed?

(D) Psychological Intervention : Application of Theory

Dr. E. Pendergrass, (1959) past president of the American Cancer Society, spoke of the curative power of the mind:

> "... There is solid evidence that the course of disease in general is affected by emotional distress....Thus, we as doctors may begin to emphasize a treatment of the patient as a whole as well as the disease from which the patient is suffering. We may learn how to experience general body systems and through them modify the neoplasm which resides within the body."

His hope was that practitioners would realize that within one's mind is a power capable of exerting forces which can either enhance or inhibit the progress of this disease.

According to Dr. C. Simonton however, there is no systematic or widely accepted approach to deal specifically with the fears and emotional needs of cancer patients (Achterberg, 1976). Simonton cautions, that despite repeated studies correlating cancer growth rates with psychological factors, no apparent change in the emotional care of the cancer patient has transpired. This omission may relate to the drastic alteration of cancer treatment if emotional factors are seriously considered.

> "... In reviewing the articles that cite the psychological factors that predispose the development of cancer, we see that these are common psychological characteristics that are dealt with normally in a psychotherapeutic practice. Problems of intense situational depression, anxiety, inability to express emotion, sexual maladjustment - all these are readily addressable through existing psychotherapeutic approaches." (Achterberg, 1976)

Simonton's Approach

Dr. Simonton, an American radiologist discouraged with the negative attitude many cancer patients had, suspected that patients who felt their

Figure 1

Psychophysiological Model of Cancer Growth

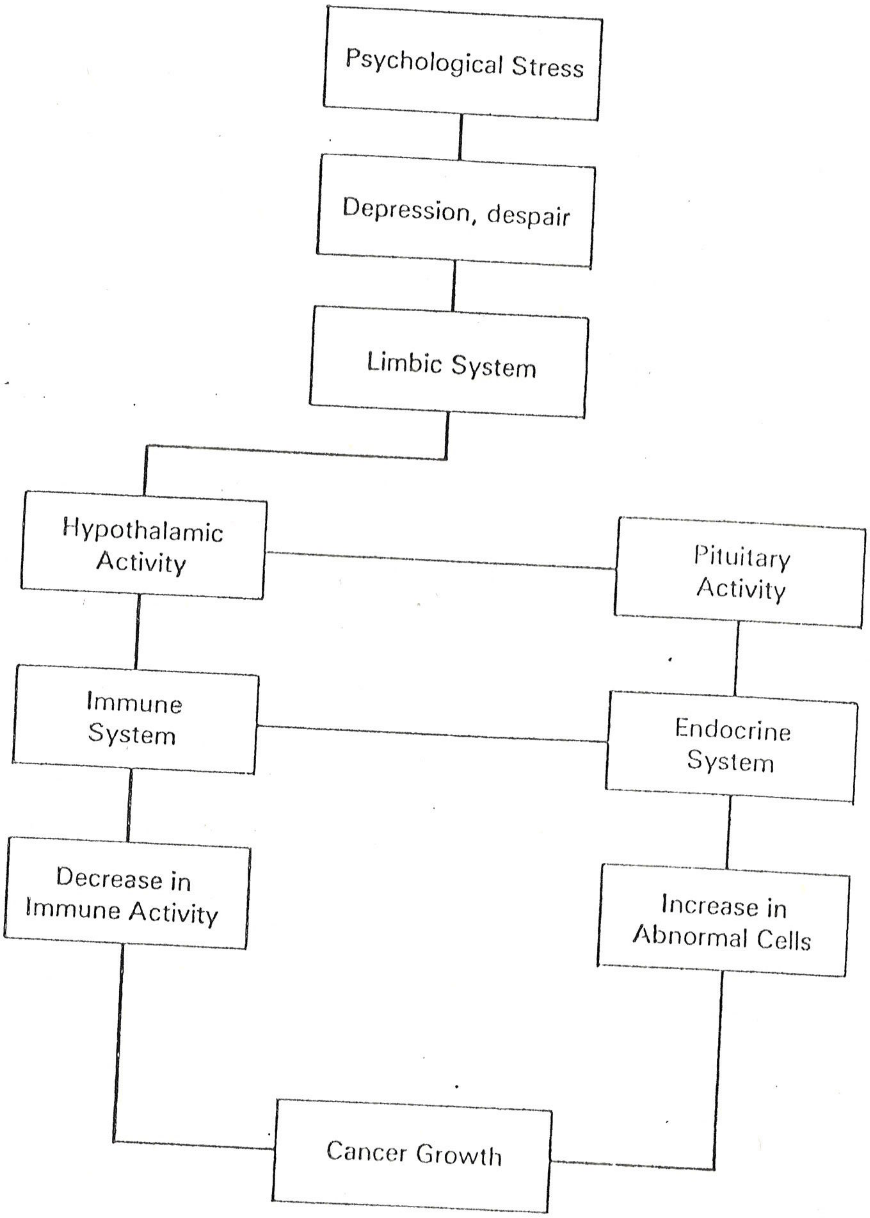
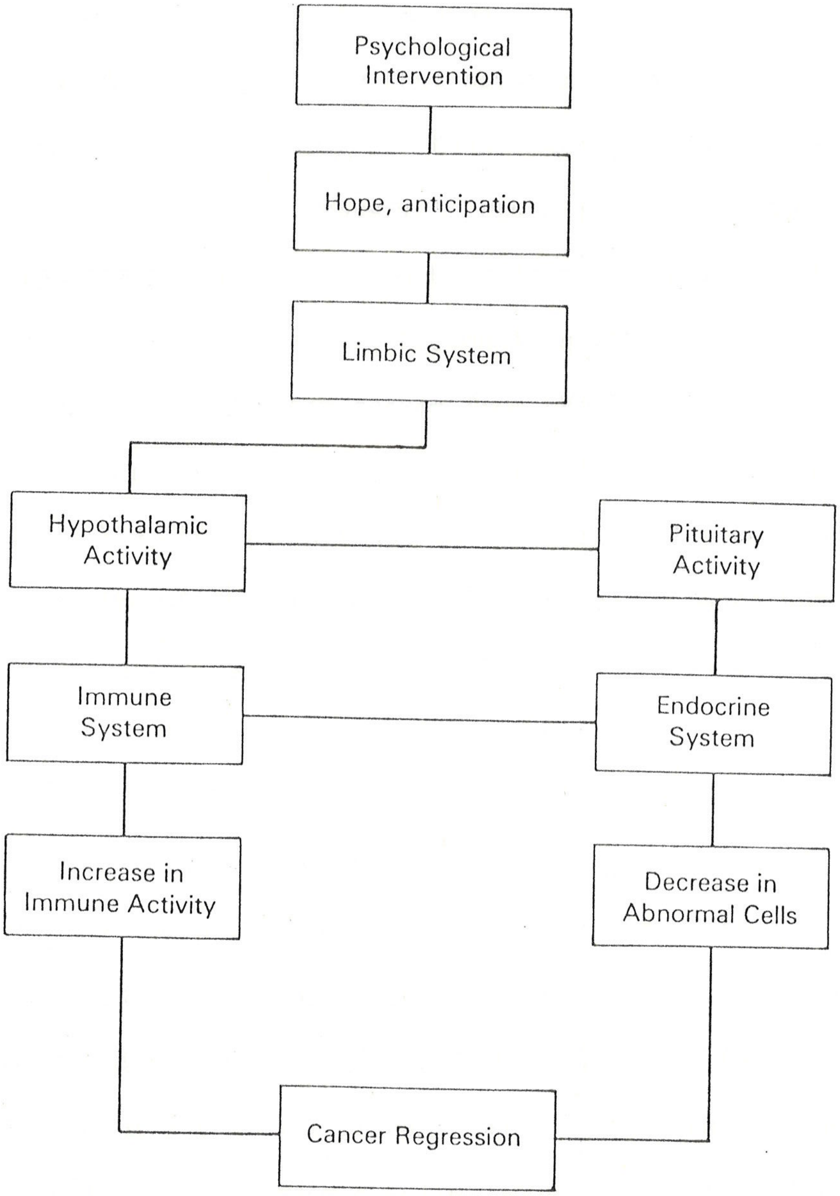


Figure 2

Psychophysiological Model of Cancer Regression



disease, was beyond control simply gave up and succumbed to their disease unnecessarily, a self-fulfilling prophecy related to hopelessness.

> "We try to convey the idea to the patient that it's just as if you were to deny your body food for too long; we know that you would eventually die. The same is true emotionally. We have emotional needs that are very real and very concrete and if these are denied life loses its meaning. We will begin to seek the end of our life." (Simonton, 1975)

Simonton's Theory and Treatment

Simonton (Achterberg, Simonton & Simonton, 1976) considers psychological intervention as "... any activity that elicits a positive emotional response on a systematic basis including attitude change, a pleasant physical event, regular relaxation and visual imagery." His theory holds that positive emotional responses are accompanied by a decrease in depression, fear and anxiety and a re-establishment of hormonal equilibrium. His theory is based on the premise that malignancy occurs from the duality of the decrease in host resistence (the immune system is inefficiently recognizing and destroying cancer cells) and an increase in abnormal cell production. A positive attitude, or the will to live, he maintains can enhance the effectiveness of traditional treatment in a quite un-mysterious fashion, by releasing inhibition of the immune system. This idea is illustrated in chart form in Fig. 1 and 2 (Achterberg, 1976).

Underlying the specific psychological treatment proposed by Simonton is the idea that in order for a patient to believe in their ability to extend and improve life in the face of cancer, two factors are important: 1) full recognition of the extent of malignancy and 2) the belief that the body has a built-in mechanism to fight disease and to return to a homeostatic condition of health. The person's belief about cancer and illness in general are crucial. Does he feel that the illness is being forced upon him by an uncontrollable external world? Does he feel personally responsible for his illness? If you believe you are a victim of the disease, Simonton maintains that the patient cannot actively participate in the emotional aspects of treatment. The feeling of helplessness, (observed by Seligman (1975) in his extensive psychological research) makes people more susceptible to pathogens in their environment. Simonton's treatment moves the person out of the role of victim into the role of participant, who accepts responsibility in influencing his own future. The person, not the disease, is in charge.

Much of Simonton's thought is based upon past studies ignored by most present day clinicians. These studies quoted in earlier sections all attempt to research the psycho-social component in cancer development, course, and outcome. Simonton's work demonstrates a resurgence of interest in a total organism-in-an-environment situation which we term neoplastic disease, rather than a focus strictly on a cellular level.

Cancer patients who work with the Simonton's (Dr. and Mrs. Simonton) are screened on the basis of their stated willingness to accept an active role in their medical treatment and in assuming responsibility for their own return to health. Simonton's emphasis on personal responsibility is central to his approach.

> "... In order to really grasp the concept that they can mentally influence their body's immune mechanisms, they must eventually realize that their mood and emotions and body act as a unit and can't be separated." (Simonton, 1975)

The treatment combines standard medical procedures (patient must continue chemotherapy, radiation etc.) with psychotherapy and a relaxation visual imagery technique designed to counteract the stress response.

Relaxation and visual imagery provides a self-help tool to deal with anxieties and fears. Psychotherapy provides insight into behavior patterns and attitudes that are maladaptive in responding to cancer.

The person practices the relaxation visual imagery six weeks prior to coming to Simonton's clinic. The visualization and relaxation are task oriented activities to help reduce depression, and allow the person to begin to participate in his disease.

Specific instructions have the person meditate three times a day during this six week period. The person visualizes the cancer as it appears to him, then pictures his treatment and its effect on shrinking the tumor, and finally visualizes his own white blood cells fighting the disease. Finally, the person pictures himself getting up and carrying on his day's activities, as he projects himself into the future thinking about what he wants to do years from now. This future anticipation activity is derived from the theory on expectancy.

The expectation of improvement noted in crisis intervention, the therapists expressed expectation that the present crisis can be resolved and that the patient will feel better, is a powerful force for producing exactly such change. The expectation "... elevates the self-esteem of the individual and employs the positive transference to create an optimism that in turn influences mood, allays anxiety, and thereby improves cognition." (Small, 1971) The utilization of imagery helps the person to create a future for himself, by imagining what it would be like to feel healthy. Although the person is still aware of his disease, he shifts the focus away from it.

Following the six week period, the patient participates in one week of intensive group sessions where they are further exposed to Simonton's concept of how the mind interacts with the body and how attitude plays a major role. In the group sessions, patients begin to look at their life situation when cancer developed. They are encouraged to ask how they allowed their body defense mechanisms to break down and influence the course of the disease. This bears striking similarity to Groddeck's work and later Reichian thought. Both maintained that a reason existed behind every manifestation of illness, and that the afflicted organ was specifically selected by the patient as an answer to a problem currently confronting it. The patient is helped to find a meaning for his disease. The person is directed to look at his life today to determine whether the disease holds a creative message that will hold a positive potential for him/her in the future. Here, a parallel can be drawn with existential thought referred to earlier in this paper. Simonton demonstrates recognition in the value of providing the patient with a sense of meaning and purpose in his suffering.

Throughout this process, the group serves many functions: 1) heightening awareness, 2) acting as a community of support during the resolution of crisis, and 3) working in a conscious way to modify people's visual image of their disease to the point where it will be more meaningful in his body's ability to fight it. Members meet other patients who have succeeded in coping with their cancer to help heighten the feeling that they too can cope. Group goals aim to strengthen the feeling that there is a future to live for and that mental activity, imagery involvement, and sharing, can effect treatment

ii) Individual and Group Interventions

Others besides Simonton have developed a philosophy and orientation towards facilitating adjustment to cancer.

LeShan (1961, 1969) adopts a more traditional psychotherapeutic approach in his work, and proposes that psychological interventions be directed toward greater self-understanding and inner growth. The goal is to realize the new meaning and validity life can have when living with cancer. This bears striking similarity both to the attitudes of cancer patients quoted earlier on, and existential thought. A further goal in therapy is increasing the degree of independence and inner strength in the patient. Gains in self-understanding, self-respect and personal enrichment that come from self-exploration are important and worthwhile whatever life expectancy may be.

> "... In this process it has often proved useful to help the patient emotionally accept the concept that the universe offers no one any guarantees and that no human being has assurances about the future. If we waste today worrying about tomorrow we have lost both. We can only attempt to live fully in the present while attempting to arrange things so that the future will offer the same or more opportunities, but no one has a guarantee that he will have a future. This is the human condition."
> (LeShan and Gassman, 1958)

Self-Help Groups

LeShan's philosophy is strikingly similar to that behind Make Today Count, a self-help organization launched by O. Kelly in 1974, that has since spread throughout the United States. Kelly's first group of eighteen cancer patients and members of their families developed what today has become a series of on-going, self-support groups, loosely linked together as an organization. The basic thrust of Make Today Count is implied in its title, living each day fully, so that the quality of life is improved for people to whom terminal illness is a real and personal matter.

> "... If Make Today Count is to accomplish its purpose - to become a gateway back into the mainstream of life for those whose lives have been shattered by illness - its members must be willing to be open in discussing their problems and their experiences."

Similar groups are conducted at the Michael Reese Hospital in Chicago. The groups run there are conducted by social workers, whereas many in the communities throughout the United States are strictly self-help.

> "... I had a lung removed because of cancer five years ago and was told I had a year to live. Physically I had great care but emotionally I had nothing. I didn't have anyone to talk to about my fear. Then I met other cancer patients. We shared common ground. Getting together with other cancer patients in Make Today Count Group has been my therapy." (Chicago Sun - Times, October, 1976)

Others in such groups comment "... It is reassuring to know others have the same fears you have." The probability of recurrence is the most common fear according to one of the social workers leading the sessions. To try to overcome that fear patients are advised to live for the present and not to dwell on what the future might bring - thus "making today count."

Sveinson, (1974) a cancer patient, supports Kelly's claim for self-help groups.

> "... Through my contacts with other cancer patients I have seen a need for patients new and old, to gain from their similar experiences through sharing them. Most if not all these experiences will be in non-medical areas."

With regards to groups Sveinson writes, "... your fellow patients will give you moral support merely by being there as living testimonies of courage."

Sveinson describes his low periods in which he would try and talk himself out of his depression:

> "... but sometimes my logical thinking would go out of the window and that was when I would look for a punching bag. I needed a verbal release rather than a physical one. I needed someone to sit and listen while I punched them around with my tale of woe."

Staff-Patient Groups

Rosenbaum, (1975) a cancer specialist, describes a staff-patient discussion group started in 1972 being conducted at the Claire Zeller Bach Saroni Tumor Institute, at the Mount Zion Hospital, in San Francisco. The group is composed of 50% patients in remission (abatement of disease symptoms) and 50% with progressive disease. The group includes patients with different diagnosis, ages, stages of disease and family situations, usually eight to fourteen patients plus two or three staff members per session, meeting once a week for two hours. The focus is helping patients to develop a way of life rather than an approach to death. Dr. Rosenbaum questions the social workers conducting these sessions as to how the group is successful in helping patients to think through their problems. He asks what steps are involved in accomplishing this.

> "... They began, as I said by telling their medical stories and talking about their unhappy feelings. Then they began to talk about their personal problems. They got a lot of support from the other members of the group and they soon began to take more responsibility for directing their lives in areas over which they had some control....I've discovered that people who are willing to talk and use talk as a way of relating to others and solving problems, get the most out of this kind of therapy."

The attitude of the group members is "First you mourn and grieve your condition and then you figure out what you can do to improve your life."

(Rosenbaum, 1975) Evaluating the program, the social worker comments,

> "... I learned from the questionnaires that patients slept better, were less depressed, and were able to talk about their illness with greater comfort as a result of being in the group for several months. The group is therefore one of several possible means by which patients can become more comfortable with what is essentially a stress situation."
> (Rosenbaum, 1975)

Up to this point, most support systems which have been discussed were limited to those in the United States. Here in Canada, (Toronto) Mary Vachon, has been conducting groups, and has been engaged in evaluation research to test the hypothesis that participating in such groups will improve the patients adaptation to cancer. (Vachon, 1976) Weekly group meetings are run at Princess Margaret Hospital Lodge, a unit for outpatients from outside Toronto who are receiving radiotherapy treatments at the hospital. Groups are co-led by the head nurse of the lodge along with Vachon (R.N,M.A.) The groups are attended by newly diagnosed patients and those receiving active treatment for recurrence. Family members are encouraged to attend. As an outgrowth of the Lodge groups, a similar program was initiated on two in-patient units, as well as for parents of children with cancer. A few group members have gone on to develop similar programs in their home communities upon discharge from hospital.

The extent of the group meetings at the lodge is to provide additional emotional support for patients undergoing radiotherapy. (Vachon and Lyall, 1976) The focus is on living with the disease and effectively coping with some of the problems it entails. The purpose of the group is fourfold (Vachon et al, 1976)

(1) To give an opportunity to meet with other cancer patients to give and receive mutual support.

(2) To clarify misconceptions about cancer and its treatment.
(3) To meet more "experienced" patients who have lived with the disease for an extended period of time and who, therefore serve as role models.
(4) To improve communication with family, friends, physicians and hospital staff.

The establishment of such groups grew out of an observation by Vachon (1976) that frequently, by the time a patient is diagnosed as terminal, his relationships with family, friends, and physicians have deteriorated considerably. The patient maybe stripped of his sense of control over his destiny and may respond with tremendous depression, fear and anger. (Vachon, Lyall, and Pollack, 1974) Here again, there is an underlying premise that this sense of loss of control or helplessness is detrimental. The question became of one the possibility of effectively intervening sooner with patients and families in the early stages of their illness to alleviate some of the later problems. The group meetings are not conceived of as "therapy" but rather as discussion and support sessions where patients and families can talk openly about some of the crucial and transitional periods in living with cancer. According to the authors, the patients' realization that there are potential solutions to some of their problems decreases their sense of helplessness and passivity.

> "... Through the groups patients are encouraged to express their feelings of fear, isolation, depression and anger. They gain understanding, acceptance and support of these feelings from other group members. In addition, the more experienced cancer patients are able to offer suggestions for living with the stigma of cancer, overcoming the fears of family and friends, and coping with the panic so frequently associated with a diagnosis of cancer." (Vachon et al, 1976)

The research involves a study of women with breast cancer, a group living in the lodge, participating in the group sessions matched with a group of outpatients on stage of disease, surgical procedure, and radiotherapy treatment, (Vachon et al, 1976) Preliminary results demonstrate the Lodge patients were under more stress at the beginning of treatment than outpatients. By the end of treatment however, Lodge patients were seen to be experiencing significantly less stress. Lodge patients were significantly more apt to talk frankly about their illness and received significantly more help from other patients. In addition, Lodge patients consistently reported higher satisfaction with treatment, medical personnel and other hospital staff.

In summary the groups discussed in this paper vary considerably as to leadership, membership, physical setting, and central thrust, but they all share the common ground of

(1) recognition of the need for verbal release.
(2) recognition of the value of discussion and sharing of common experiences.
(3) focus on living in the present and developing a suitable way of life rather than an approach to death.
(4) reassurance gained from knowing others have similar fears and concerns.
(5) recognition and provision of emtional support.

The Will to Live : Thematic Underpinning of Group Intervention

LeShan, (1969) Sveinson, (1974) Rosenbaum, (1975) Vachon, (1976) and Simonton, (1976) all emphasize the importance of the patients' "Will to Live." As he lived with his own cancer, Kelly (1975) wrote:

> "... Although there is certainly no way of verifying scientifically what I am about to say, I believe that a good part of the reason I've lived as long as I have since my cancer was diagnosed is that I've wanted to live."

Hutschnecker, (1953) in his book The Will to Live describes this phenomenon:

> "... Deep within every human being there exists the will to live, that inborn dynamic principle whose purpose is to preserve the individual as well as the race. This biological will to live seems not enough to support us through the complexities of life in a civilized world. We need a moral and emotional force to make the struggle endurable. As long as we have something to live for the will to live carries us through the moments of crisis which are inevitable in every life."

Sveinson, (1974) concurs with this thought. His message to fellow cancer patients is:

> "If you have a goal that is important to you, one that excites you and keeps you enthusiastic, you have more to live for. No matter whether the goal is big or little, it is something to shoot for."

Frankl, (1963) writes that those who survived Nazi concentration camps of World War II were those who were interested in survival, those who had goals in the outside world,

> "... Those who know how close the connection between the state of mind of man - his courage and hope or lack of them, and the state of

> immunity of his body will understand that the sudden loss of hope and courage can have a deadly effect."

Hutschnecker, (1953) claims that if we truly have something to live for - this no matter how sick we may be, if we have not exhausted the last of our physical resources, we do not die. But the incentive has to be one in which we inwardly, utterly believe.

Rosenbaum, (1975) in discussion with one of his patients, whose approach to his disease was one of personal responsibility for both its development and its eradication writes,

> Dr. R.: "You and I have been talking about the desire to live that is in all of us. Our philosophies about how to accomplish a cure are different, but we both know the will to live makes a difference and that patients who have the desire to survive fight harder and do better medically than those who lack the drive. It is an intangible, unmeasurable force that makes a difference. I believe it makes all the difference."
>
> Anthony replied: "If you have the faith that you are going to make it, if you have the will to win, you'll make it. And if you introduce any doubts, you've had it."
>
> Dr. R.: "But we know of no specific effect on cancer cells that is caused by a positive state of mind."
>
> Anthony: ... "You convince yourself. You know you have something and you say, Well, I'm going to have something else instead, something that's healthy. What would it be like to feel healthy right now even though I'm sick. In that way you begin to create a future for yourself. You shift your focus, your concentration away from the disease, even though you still are aware of it."

In summary, the experiences of these cancer patients and specialists suggest much in the way of psychological intervention. The thread that ties together the interventions and philosophies the writer has highlighted in cancer counselling, is the emphasis on life and importance of living in the present. All confirm the benefit in eliciting a positive emotional response. The writing's combine to suggest that to prolong life one ought to regard the whole person, his interest in living, and his adjustment to psychic stresses imposed by his disease. Attending exclusively to the physical body is not enough! An attempt should be made to stimulate the difficult to conceptualize "will to live." This approach implies a philosophy of health and disease that attitude can and does affect the outcome of illness. It implies also that a passive helpless attitude may interfere with treatment and reduce the potential period of life.

CHAPTER II

OBSERVATION AND EXPLORATION IN THE CANCER OUTPATIENT CLINIC

A) How a Program is Established : Entering and Attaining System Support and Acceptance

The process of "entrance" as a stage in program development is rarely discussed in social work literature, nor does the literature speak of the unique aspect of entry into an established medical system. The system addressed in this paper is the cancer chemotherapy outpatient clinic at St. Boniface Hospital.

As a system, the clinic may be described as a set of interrelated elements with a capacity for certain kinds of performance. Its most significant component, the oncologist (tumor specialist) was viewed as the ultimate expert in defining illness. His most significant task was the delineation of pathology and the treatment of malignancy. Value was placed both by himself and others, on his ability and knowledge regarding the chemotherapeutic treatment of cancer. The nursing staff functioned interdependently with the oncologist, prepared the patient for examination, and followed examination with the necessary treatment. They perceived themselves in a secondary role to the physician, in many cases simply following his orders. Several nurses saw themselves as providing emotional support for patients by offering comfort and reassurance to those in distress.

The clinic, the large system, contained sub-systems of staff and patients, both surrounded by an even larger and more complex hospital system, which in turn, was surrounded by the suprasystem, consisting of the system in its environment. All parts of this clinic worked together with a sufficient degree of harmony to maintain the system in a steady state.

A system in such a steady state according to Chin (1969) reacts to outside impingements by resisting the influence of the disturbance, refusing to achnowledge its existence, or by building a protective wall against the intrusion. A contract between the oncologist and myself permitting me to observe the clinic for two months created such an outside "impingement." The system's boundaries, the region separating it from other systems were such, that the clinic's treatment regime historically paid little formal attention to the emotional factors in illness. The great error of Plato's day that of separating the soul from the body in treatment had not rectified itself. The worker was faced with the task of permeating that boundary, of helping new information filter through thus creating a change in the outputs from the system. Could the worker influence established values and attitudes, intervene with the system's functions, so that tasks might change? Would the system recognize in time that it was important to know what sort of a patient had a disease as well as knowing what sort of disease he had.

Permission to observe, gave the worker a starting point. However, was this sufficient in attaining program implementation? While initially encouraged, I was aware that "working with the system" contained many dangers, which advised one to move slowly and cautiously. The worker had the dual task of selling both herself and later the program. The interventive steps in this process are worth noting.

Each component in the system had a particular function and a fixed familiar role. One of the first major tasks facing the worker was establishing such a role and function for herself. One of the potential dangers of entering a medically dominated system was the tendency to see and use non-medical people as "allied" to the doctor or nurse. As an outsider, I had no central quarters or space. Further, as part of my efforts to know and be known by all elements of the system, a great deal of time was spent with the physician, following his white coat around in and out of examination rooms. The worker was beginning to lose her perspective as a social worker. The staff was familiar with the social work assistant role of assisting people with cheques, applications, referrals and the like. Could I establish a credible social work role for myself that moved beyond that? Would I succeed in presenting myself as a vital component of this clinic with a clearly differentiated task? Intervention and the resulting system's reaction to change would no doubt lead to varying degrees of stresses and strains on the clinic and its significant components. The issue of territoriality concerned the writer. Would I be viewed as an intruder, invading and encroaching on well-established territory. Since several nurses perceived themselves as providing emotional support, perhaps my presence would be rejected because of a collision of tasks. The system operated hitherto strictly with medical and nursing staff. Would a social worker be viewed as interfering or sabotaging existing staff-patient relationships? Thus, concerns of inter-professional rivalry emerged in my mind. All of these issues meant establishing trust with the staff, trust in me, trust in my ways of thinking, and in my capacity to do professional work.

The worker's introduction to the clinic and its staff was through a memo written by the oncologist. A first mistake in interventive strategy! Without the ability to dialogue personally, untold questions went unanswered, feeding the natural skepticism and resistance of the system. The first mistake required correction in the form of time spent with nursing staff explaining the many aspects of my role in the clinic. The process of developing trust was slow, complex, yet essential and I learned that building trust takes time. The initial steps of system entry should guarantee time to become known, to dialogue informally without the expectation of committment and to establish a level of personal confidence and trust.

Two months of the practicum time were directed toward "entering." One basic learning derived from this stage related to the issue of timing; when one should introduce a new idea and how to create optimal conditions for this introduction so that it becomes accepted. "Working with the system" meant keeping staff informed at all times, clarifying the observer role, soliciting suggestions, and observations of my interaction with patients, involving staff in thinking through the value of an emotional support system, envisioning with them what that might look like, and sharing perceptions of "the way it was for patients" as it was conveyed to me. Thus the clinic system was gaining information from the worker about how it was functioning, and feeding that back into the system to affect succeeding outputs or future operations. This process of feedback was occurring as well for the worker.

These activities required both formal and informal meetings with the staff prior to the launching of the group. The worker's introduction of the group idea was presented to staff one month following her first visit. This time element made it easier for the system to incorporate such a change. The formal meetings were a first in the clinic's history of staff meeting together, in relation to a specific topic. Thus my bringing them together constituted a change in their patterned way of interacting. These contacts were invaluable in terms of attaining solid backing from staff at a later date. Staff approval, especially that of the physician, in turn influenced patients willingness to participate in a new venture.

These activities also showed the layering of systems and their subparts. An intervention on the worker's part in one sub-system held implications for another sub-system. For example, patient's attraction or repulsion towards the worker created an immediate curiosity in the clinic. This input in one sub-system generated response and required that worker energy be directed in the other.

Since the patient system was so intimately linked with the clinic system, the worker had a dual focus directed at the interface of these two systems. The transaction or exchange between the cancer patient and his situation (organism) and the cancer clinic in the hospital (environment) called forth a matching effort focusing on the coping behavior of the organism and the qualities of the impingeing environment. The worker's hope was that an encounter between the organism and the environment would leave both changed.

> "This point is of special importance because it raises the crucial question of how we judge the outcome of an exchange? Gordon's answer is that the best transactions are those which promote the growth and development of the organism while at the same time are ameliorative to the environment, that is making it a better place for all systems depending upon that environment for their sustenances."
> (Hearn, 1974)

During this observation and exploratory phase the worker's goal was to understand the patients' coping behavior, and as well to become familiar with the qualities of the impingeing clinic environment. Only then could the worker attempt to structure a more meaningful exchange between the two. Staff accepted this raison d'etre and allowed the worker a supportive role through which the realization of these goals was possible.

Worker's Uncertainties

Introducing a new program into an established setting posed many questions for the worker. I and/or the programs engaged in would consequently be seen as a demonstration project and perhaps set precedence for future social work activity. Thus, any ambivalence in the system's components towards the worker's proposal was initially threatening.

The effort to establish a defined task for myself was slowed down during the process of observation. The doctors' room's were medical and his language was medical. Due to sheer physical proximity and amount of time spent with the physician, he treated me like a medical student. I felt the doctor was converting me. Was I also trying to convert him? Apparently so, since an attempt was made to convince him of the link between psychological factors and cancer. His expressed skepticism of many of the literature articles was distressing. Was the skepticism related to me and my role in the clinic? Was the research literature used to establish my personal credibility? I was cautious and critical of his "medical model," just as he was cautious of my "social work" model. Yet, I began to see clearly that while I represented a model of analysis and intervention, we shared the common ground of valuing, the quality of life without strict adherence to a "model" of influence. When this common ground was mutually respected, issues of trust and credibility began to resolve themselves. Shared values and attitudes towards patients once expressed allowed considerable leeway in independent decision making and activity. With system support and acceptance, the worker could proceed more confidently in contacting patients.

In summary, the key concern at this point was gaining acquaintance with the system's significant components, learning what their tasks were comprised of, how they perceived these tasks, and understanding the nature of their value orientation. Only then, could the worker gain entrance into the system and attempt to promote a change in the operation.

B) Understanding the World of the Cancer Patient : A Phenomenological Approach

The worker's intervention was based on a phenomenological approach, a practice guided by a desire to understand the subjective experience of clinic participation. People's perceptions of their situation were the guiding social facts.

> "... an understanding developing between the two persons and the perceptive 'insight' of the worker into the behavior of the client, is perhaps useful only when it is grasped by the client as an expression of his being 'understood' in the same way he understands himself." (Leighton, 1973)

The phenomenological approach concerns itself with the meaning people give to the world they live in, and to their self within that world.

What Type of Social Work Activity?

Worker activity was based on an interactionist perspective. Leighton (1973) defines this as:

> "... all activities of intervening in the pattern of interactions between individuals and the world in which they live which are carried out in such a way as to consider and attempt to reduce, the destructive elements of the intervention."

Leighton argues that insofar as social work is concerned with change of situations and change of response to situations, then it is necessarily concerned with changes in perceptions of situations. The literature reviewed earlier in relation to coping with cancer (Sveinson, 1974, Kelly, 1975, and Rosenbaum, 1975), suggest much of what Leighton (1973) delineates as common presumptions of social work practice. Included in Leighton's list are:

(1) Perceptions of situations can be changed by the exercise of a choice of the person's relationship to that situation.

(2) A person's relationship to the situation depends upon what they

believe possible for them in that situation.

(3) The basis of change lies in the positive use of new experiences and the constructive responses to those experiences. These responses may modify the image of what is possible for the self.

Thus, the worker's first task was becoming aware of the patients' perception of their situation, and the intervention whatever form it took would be directed towards facilitating new responses to that situation. The theory on helplessness, the literature relating to the 'will to live', and the literature and studies devoted to the influence of psycho-social variables on the course of disease shared this phenomenological underpinning of changed perceptions. The last of human freedoms - the ability to choose one's attitude in any given set of circumstances that Frankl (1963) wrote about meant there were alternatives to a passive helpless acceptance of cancer as a killer disease. The positive use of new experiences and the constructive responses to those experiences meant adopting a positive attitude towards the disease. Thus, adjustment to cancer in the writer's terms meant recognition on the part of the patient of the full extent of his malignancy, along with the realization that choices existed in dealing with the disease.

The cancer chemotherapy outpatient clinic operated in a strict medical sense; patients come to the laboratory for blood tests, were examined by the oncologist, and then proceeded to the treatment room to be injected with a powerful chemotherapeutic agent. The patient was then on his/her own until the following visit when this procedure was repeated. The worker became concerned with, 1) the experience and meaning of having to attend a cancer clinic with such regularity and to such length, (see *) 2) what transpired

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* Treatment schedules varied according to type and stage of disease. A common treatment procedure involved five days on treatment (attending daily for an I.V.) and five weeks off. Many patients were scheduled for a two year period of treatment.

while an individual spent two to four hours at the clinic usually waiting to see the doctor, and usually in a waiting room sourrounded by "strangers" with similar distress, 3) what emotional strain the individual experienced as a function of his/her clinic contact, and 4) what events transpired at home in-between treatments. What effect did these circumstances have on a person's attitude toward his disease? Were these circumstances amenable to change?

During the observation period the worker developed a role which included being present while patients were examined, watching their treatment procedure, sitting in the waiting room, and making as much contact with patients as possible. This period of telescopic viewing provided the worker with a glimpse of the cancer patient's world at the clinic, what was talked about and what was not talked about, whether patients interacted, on what level and under what circumstance, whether patients shared emotional concerns with staff, and what types of behaviors they displayed.

As observational information was gained, the worker began to question the patients informally: 1) were their needs presently fulfilled, 2) what (if anything) was missing in their treatment, 3) were there situations in which they had difficulty with, and 4) were there concerns they were unable to share with medical and nursing staff. These questions served as openers, and offered an opportunity for ventilation around a whole range of issues. The intent was to determine whether the patients, if given the opportunity, would share their experiences and seek additional ways to gain emotional support.

Contacting Patients

While the worker's role as an observer created new strains on the established doctor-patient and nurse-patient routines, subsequent attempts to talk with patients presented a series of unforeseen problems as well.

However, in order to facilitate innovation and change in the system, the possibility of increasing tensions existed. The following issues were encountered while the worker attempt to establish a relationship with the patients.

A) Issue of Trust. Patients had never seen the worker before. She had no office or space of her own. What did she do? Mystery and mystique surrounded her presence. Patients might well have asked: Why should I disclose personal matters to a stranger? Did she care? Would she return? Why was she approaching me? Did I have a special problem with my disease?

B) Awkwardness of My Being Present in the Examination Room. Patients histories were reviewed openly as the worker sat in the examing room. Was I further invading their already invaded privacy? Their physical privacy was also trespassed with my presence.

C) Constraints of Engaging Patients in Meaningful Discussions. Patients rarely initiated conversation with the worker. A balance had to be struck between probing too deeply thus preventing further meaningful discussion, yet eliciting enough information to help the worker assess the need for an emotional support group. Furthermore, patients often waited one to three hours for the doctor. I felt awkward detaining them further for discussion. Patients often felt ill and anxious at the clinic. Certainly, the setting and circumstances of their visits were not conducive to open discussions. In many cases they had been given enough information to cope with, without the worker introducing more. To make matters worse, rarely was there an empty room for discussion. Interviews, therefore, were conducted in close proximity with other staff or patients.

D) Unrealistic Expectations of Disclosure. It took many contacts for patients to share their feelings. I learned that there were degrees of display; that the private matters were very private. Should the worker have been protecting each stage of disclosure?

The question for the worker was, under what conditions does the information carried on the feedback loop promote change and under what conditions does it inhibit change? Would the worker's contact with patients and staff create new conditions for both? Notwithstanding the difficulties mentioned, patients did talk openly, speaking of their urgent need to talk with someone who was concerned with the non-medical aspects of their experience. The worker proceeded to understand the world of these patients from their eyes, and to walk in their shoes for a short distance.

<u>What did I Observe?</u>

> "It ... is my belief that any group of persons, prisoners, primitives, pilots, or patients - develop a life of their own - that becomes meaningful, reasonable, and normal once you get close to it, and that a good way to learn about anyone of these worlds is to submit oneself in the company of the members to the daily round of petty contingencies to which they are subject." (Goffman, 1961)

Many hours spent observing both patient and physician revealed that the majority of patients confined their questions and comments to medical matters. There was much discussion around reactions to treatments, new symptoms detected, discomforts, uncertainties, and comments by the physician as to patients' overall progress. Many patients sought clarification in relation to symptoms they had discovered or side-effects of the treatment. There was fear expressed and reassurance sought as to the significance of new symptoms. People seemed to be asking, whether this was a routine side effect or whether it was the disease creeping up again? Very few displayed any emotion. Rarely did the worker observe patients discussing their feelings, fears, doubts, apprehensions, consequent life disruptions, or difficulties at home. Neither the physician nor the patient perceived the doctor's task as a counsellor.

If the patient did discuss his fears, the physician responded in an effort to allay anxieties. However, in the treatment room there was a greater tendency to display emotion. Here people were observed crying and openly expressing fear. Usually, conversations were restricted to topics unrelated to the emotional impact of disease. In time, the worker learned that patients felt the doctor did not have time to, "hear those kinds of things," since his "time was so precious." A tremendous amount of trust was invested in the doctor and a comment frequently heard was, "he is taking care of me." Very few patients credited themselves for their part in this disease process, or considered that they were playing an active role. Their task was to act as a recipient in this process. This attitude was specifically what Simonton's (1976) treatment approach attempts to eliminate. If the patient feels the illness is being forced upon him by an uncontrollable external agent, there is little personally that he can do to change those circumstances. This feeling of helplessness places the disease, not the person in charge

The cancer clinic was overcrowded and patients were rushed in and out of examination rooms. Many waited long hours to complete the time consuming routine of blood taking, examination and treatment. The one chemotherapy nurse ran three I.V.'s (administration of fluids through a vein) at one time in order to accommodate everyone. Following treatment patients had to leave the clinic to allow space for others. There was little time for discussions. At any given time there were a group of people sitting in the waiting room, waiting for blood results. This was anxiety producing in itself, not only due to the wait but due to the fact that the blood count result may have been such that patients would not be able to have an injection, thus setting treatment back further. The worker observed, generally, excellent rapport, open communication, empathy and insight into the impact of cancer on people's lives on the part of medical and nursing staff. Staff related on a personal level with many of the patients. However, this did not erase the market-place like atmosphere nor the tendency for patients to keep their intimate concerns to themselves.

Hopefulness was a theme which characterized one mood in the clinic. In most cases, patients were encouraged to believe that chemotherapy would hold the disease in check. Sometimes remission was highly probable. Was this the incentive for tolerating the horrendous side effects of these treatments? The worker heard many patients express the desire to live at all costs. The worker recognized the importance of conveying hope as demonstrated by many of the research studies. (Engel, 1965, Stavraky, 1968, Schmale, 1971)

The worker became acquainted with a diverse group of patients. Ages ranged from early twenties to late seventies, single and married, employed and unemployed, urban and rural. Some came with family, others came alone. Some were on their first course of chemotherapy, others were back due to recurrence, and still others were given only palliative (relieving symptoms without curing the disease) treatment. Many had experienced cancer in their families, cared for and lost a spouse or parent from cancer. The display of emotion varied from total stoicism, to composure, to one particular patient who vomited every time he approached the treatment room. Although not always verbally expressed, much tenseness, visible distress, despair and an inability to use the word "cancer" was observed. These reactions to clinic participation bore striking similarity to those reported by Sveinson, (1974), Kelly (1975), and Rosenbaum, (1975) in literature on the emotional impact of cancer. The worker felt uneasy observing patients at their first appointment. Many of them were told then, that the next two years of their lives were charted out for treatments. A de facto plan for them was presented. Within a brief moment the course of their lives was drastically changed. Usually there were few questions asked.

Occasionally a person spoke about dying, recent deterioration, and the feeling that their situation would not improve. A few more discussed problems they were experiencing in communicating with family. Often patients reported that family members did not want to talk about the cancer.

A commaraderie amongst patients was observed especially in the treatment room where several were undergoing treatment at one time. This reinforced what Sveinson (1975) wrote about cancer patients needing to share experiences in non-medical areas. Others sat quietly by themselves. After the worker introduced one man to another and witnessed their immediate "contact" and sharing of experiences, the conviction was that this informal unstructured commaraderie was worth developing.

After several contacts with the same individual were made, they began to express what really troubled them. Patients spoke about the disruptions in their lives caused by cancer, at home, at work, and in social spheres. Expressions of isolation and fear were released. Bitterness and anger were expressed over past relationships with medical staff; that important matters were not explained leaving them confused and bewildered. Several people reported suffering intense depression, and many expressed a desire to find meaning in life, hoping to make up for lost opportunities. These revelations further emphasized Kelly's (1975) statement "... that the emotional problems caused by cancer are as devastating as the physical problems caused by the disease." A few people identified their need for some type of emotional support. Many expressed a need to protect their families. These people, consequently, kept much of their distress to themselves. There were a few, however, who sought more compassion and understanding from family, and wanted to share the truths of their feelings with them. These people were in the minority.

The discontent patients expressed with the manner in which they dealt with their disease was potentially creating a disturbance both for the patient and clinic systems. The worker did not wish to minimize these reports, as she understood that a system can establish another steady state if and when the disturbing external condition is prolonged. The process of self-regulation would balance any initial disturbance caused by the worker's intervention.

Time spent observing and communicating with patients confirmed much of what the literature suggested. The worker's most important observations were:

(1) Although hopeful, many patients assumed a passive role in the disease process.

(2) Many patients were experiencing difficulty dealing with the disruptions in their lives caused by cancer.

Given these two conditions, the possibilities for establishing some type of support system was the next logical step in this process.

C) Introduction of a New Program : Prepatory Work in Pre-Launching of Group

1) Rationale. The observation period built the rationale for the activity the worker engaged in during the following four months. Patients at the clinic defined the real problems in cancer as emotional or mental, and remarked that the emotional cancer can be more crippling than the original cancer. The worker ventured with greater clarity and committment into disseminating the idea of starting up a group, in an attempt to combat much of this emotional suffering. If, as the literature suggested physical response may be dependent upon the resources an individual had for discharging or reducing psychic stress imposed by emotional conflicts, could the group facilitate this process? Could the group elicit a "positive emotional respnse," Simonton (1976) viewed as necessary in enhancing the effectiveness of traditional treatment.

Psychotherapy is typically defined as forms of treatment in which "... certain types of therapy rely primarily on the healer's ability to mobilize healing forces in the sufferer by psychological means." (Frank, 1973) My attempt differed slightly. The group and its members would become the healers. This system would create not one, but many helping relationships. According to a noted author, the helping relationship as we know it, is one in which the client possesses the only real and lasting means to his own ends. (Schwartz, 1961) The worker is but one resource in a life situation which encompasses many significant relationships. People with similar concerns help each other in ways that are significantly different from the ways in which a worker can help them in a one-to-one relationship. Concerns related to the stigma of cancer, difficulties experienced at work and at home are held in common. This sharing noted in the discussion themes (explored in Chapter 3) has a different texture than the sharing between worker and client.

Members have the feeling that they are understood in the same way they understand themselves fulfilling one of the basic tenets of the phenomenological approach. (Tropp, 1969) Members in a group take help from one another. This is what makes the group experience both meaningful and useful. For these reasons the group was chosen as the preferred method of intervention.

11) Humanistic View of Social Group Work. The worker's model for intervening on a group level held tenets of the humanistic view of social group work. (Tropp, 1969) Such a philisophical base found commonalities with the self-help cancer groups that were familiar through reading and contacts. For the worker, the humanistic thesis in group work meant that she shared the common human condition, the potential for misfortune, crisis, and mortality, with members of the group. Thus, the worker had a natural ability to feel and be with a part of the member's experience as it connected with her own humanity. For the group, it meant that people would gather around a common life situation, bringing them together. This commonality would serve as the prime move for whatever gains might be forthcoming for its members.

Illich (1976) in Limits to Medicine comments;

> "... society that can reduce professional intervention to the minimum will provide the best conditions for health. The greater the potential for autonomous adaptation to self, to others, and to the environment, the less management of adaptation will be needed or tolerated."

The purpose of the group was to tap this natural healing resource.

The worker foresaw the group as an enterprise in mutual aid; the thread that could potentially tie people together to work on certain common problems. This basic element was common to all the groups referred to earlier in the literature review. This need for each other would be embodied in certain common tasks for the group to pursue. The worker envisioned a group where spontaneity could occur, where people would have the opportunity to be authentically themselves. There would be little room for the medical or analytical models based on study, diagnosis and treatment. Rather, the worker's vital role was clearly that of helping the group use its natural qualities of mutual aid to help its members. Many forms of primitive healing required that the patient do something for others. Frank, (1973) maintains that "... Altruism combats morbid self-centeredness, enhances the individual's feelings of kinship with others, and strengthens his personal worth and power." The group was envisioned as a place where people might gain the incentive and opportunity to help one another. Perhaps, the meaning in the suffering could be discovered in the sense of helping each other. Both Frankl's (1963) focus on existential thought and Leighton's (1973) theory on the basis of change, address the positive use and constructive response to new experiences, cancer or otherwise.

The emphsis on mutual aid, sponteneity, and authenticity was the writer's translation of the humanistic framework. The writer was hopeful that members could laugh, that the group would be a place where members could enjoy themselves amidst the seriousness - where members could be genuinely "human."

It was the worker's hope that the group would provide a vehicle in which members could find the courage and support to express feelings and thoughts otherwise suppressed in usual social situations. Benefit and value was seen in providing the cancer patient with an opportunity to ventilate his/her anxieties and not left alone to speculate on the emotional and biological causes and effects of cancer in dreadful solitude. This condition might lead to the "painful acquiescence" noted by Blumberg (1954) in those patients with rapidly progressing disease. Rather than allowing fears and frustrations to fester until they became too frightening to mention, or forcing the person into irretrievable isolation, the group would be the place where such matters could be aired, and where support could be offered to people during what Parks (1971) termed the difficult "psychosocial transition of adjusting to a life-threatening illness."

111) <u>Identifying Purposes and Goals of the Group : Worker, Staff, and Patients.</u>

The purposes of the group as the social worker identified prior to its launching were:

A) The group could provide satisfaction of the most fundamental of human needs - <u>belonging</u>.

B) The group could provide the feeling that one is not alone. Members might learn that others in the group have similar feelings, thus potentially helping them overcome a sense of alienation from others.

C) The group could provide the readiness for members to take help from one another rather than from the worker. Members can learn from observing how others handle difficulties. Information from others in the group can aid in self-understanding and provide a powerful incentive for change. Seeing other group members improve physically and emotionally may inspire emulation and raise hope.

D) Opportunities for self-expression and release of pent-up feelings may-be provided under circumstances in which others can appreciate it. Keleman (1974) writes that, "Mourning is the freedom to express feelings that weren't or couldn't be expressed under normal life circumstances. It is also a ritual for the expression of some of the deepest and most intimate feelings of our existence." Members' acceptance of each other's trials and tribulations will assist in th much needed feeling that one is understood, a strong antidote to feelings of alienation.

E) The group could provide opportunities to <u>give</u> as well as <u>receive</u> help.

Members can help each other by comparing experiences or giving useful insights or advice. This capacity to give may be a great aid to regaining or supporting one's sense of self-worth.

F) The group could provide a place for "healing"; a place where we might all benefit thus arousing the members expectation of help.

> "... The very fact of the group's existence and task at hand creates expectations for coping. This expectation of coping is a built-in dynamic that calls forth the strengths in the members. In this medium, ... the member becomes truly the source of his own growth and takes his life in his own hands gaining strength from others who also share a portion for his life challenge." (Tropp, 1969)

G) The group could provide and maintain a temporary refuge from the demands and distractions of daily life.

H) The group could assist members to identify a "meaning" in suffering by exploring the creative, growth producing messages that could be derived from the experience of cancer.

The medical and nursing staff identified purposes of the group as "emotional support," "an advantage to those who have no one to relate to or are alone," as a medium in which, "open discussion with others" would be possible, and a medium in which, "understanding, compassion and encouragement would be available to those patients who were not in a position to receive it from close friends or family." Several of the nurses, placed themselves in the patient's role in determining for themselves whether they would participate in such a group. They concluded it was an individual experience, some would reach out for this, others felt it would intensify their depression.

During the interview period, thirteen patients identified different purposes for their participation in the group. The most frequent response was, "I feel I can help others in need." Some of the other responses were: "I need a night out on my own;" "a place where I can share things that I would rather not discuss with my family;" "I think it will be of comfort to hear that others have similar problems;" "the group can act in making changes for the new patient in the clinic;" "perhaps the group can offer me courage and support;" "an opportunity to unload;" "to share information about treatment reactions and hear other peoples' stories;" "desire to feel needed." Thus patients identified several purposes depending on how they perceived their needs. Several of these matched closely with those identified by the worker.

Several specific goals followed from the general purposes identified. Many of these goals sound grandiose, however it was the hope of all involved that we might approach the fulfillment of some of them. Several of these goals were measurable to different degrees and will be discussed in the section on evaluation.

A) To decrease the stress response, (See *) associated with experiencing a life threatening disease with the goal of helping patients become more comfortable with a stressful experience, and maintaining equilibrium in the presence of emotional and physical disruption.

B) To de-mystify the experience of living with cancer by assisting members to make sense out of inchoate feelings, thereby heightening their sense of mastery and control over them.

To de-sensitize the trauma associated with cancer by naming and confronting frightening issues, thereby making sense out of them and keeping them in check.

C) To overcome the demoralizing sense of alienation, isolation and aloneness.

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* The stress response is defined here as the concommitant human reactions to living with cancer - feelings of fear, anger, anxiety and depression.

D) To arouse hope and bolster morale in relation to members ability to adjust to the disease and live as normal a life as possible with cancer. To gain hope from meeting other cancer patients who are coping well with the disease.

E) To nurture and support this "will to live" expressed by members by developing a sense that their attitude can effect the outcome of their illness at least to some degree so that they do not assume a passive helpless attitude toward their disease.

F) To improve coping mechanisms through an exchange of practical suggestions and insights.

G) To bolster self-esteem, self-worth, and feelings of purposefulness through discovery of the ability to help each other and those outside the group.

H) To improve patients communication with family, and friends, so that all are able to share intimate feelings.

I) To improve communication with the cancer clinic staff, and facilitate a more open interaction with the oncologist.

J) To stir and arouse members emotionally, a prerequisite for any attitudinal or behavioral change aimed for in the group.

K) To modify the clinic environment so that it can support the group members in their effort toward growth and change. To create a nurturing atmosphere in the clinic in support of members' goals in the group.

The above goals were developed out of a framework of mutual assessment of many of the cancer patients' current life situation, and the obstacles it presented.

Very few of the group members were specific as to their goals prior to coming to the group meetings; this evolved during the course of the group. However, some of the stated goals prior to its launching were:

> "Resolving to give what I could and accept from the group their views of our situation with cancer."
>
> "I felt some benefit might be gained through the meetings by all members including myself.
>
> "To be able to help others and others to help me cope with cancer."
>
> "I knew I could get some help if needed."
>
> "To help someone over a difficult time maybe by some experiences I'd had. To talk to someone in the same position as myself."
>
> "Comfort to know I wasn't alone. To find some friends with the same ailment to whom I could talk."
>
> "To meet fellow patients and to learn about our disease especially as it affects different people."

In instances where several group members were ambivalent and apprehensive about the process and outcome of this new experience, their goals were stated in negative terms, and a hope expressed that the group would not create this.

> "Was a little apprehensive that I would subsequently feel like someone handicapped, apart from the rest of the world, who is going to try to learn to live as a handicapped person in the world where I might feel part alien."

The clinic staff did not identify goals for the group prior to its launching. Being an experimental venture they had nothing to compare it to. Rather, they observed and noted patients' reactions carefully throughout the course of the sessions, and consequently aligned themselves with the goals the worker had identified prior to group formation.

Many of the purposes and goals the worker identified were developed from conclusions reached in the literature and research on psychological variables in cancer. As an example, decreasing the stress response viewed as crucial in influencing the course and outcome of illness was a recurrent theme in the studies reviewed. (Simonton, 1976) Although my data was limited in supporting this premise, decreasing stress in an effort to facilitate a comfortable level of living with cancer, justified addressing this factor seriously in the group. Several of the purposes and goals were similar to those identified by other groups reported in the literature review. (Kelly, 1975, Rosenbaum, 1975, Vachon, 1976)

1V Selection and Interviewing of Group Members

In retrospect the worker learned that careful selection of group members was paramount to a well functioning group. She was faced with the task of selecting ten to fifteen people out of a potential pool of over one hundred. Many questions arose: Who would most benefit? Who should be mixed with whom in a group? Which stage of disease should be focused on? Should there be concentration on one particular form of cancer? The literature provided few answers to these questions. Intuition coupled with several guiding principles facilitated the selection process. Although staff made suggestions as to who they felt would be interested in the group and the worker consulted with them throughout this process, the ultimate decision in selection was hers. The worker pursued the group idea with those who expressed a willingness to discuss this type of service even if their refusal to participate was anticipated. Those from rural areas and those who refused immediately were eliminated. Some expressed negativism, fear, and apprehension related to the idea of group involvement.

> "It would further depress me to talk about cancer, and I want to avoid the subject and avoid mixing with sick people."
>
> "I want to live as normal a life as possible."
>
> "I do not want to share a personal experience with strangers. I do not want to hear other peoples' problems."
>
> "I couldn't cope with a death in the group or someone becoming very ill."

Some of these people refused to participate and thus were ruled out in selection.

After meeting many patients two frequent patterns were observed. 1) Initially, some people saw their role in the group strictly as givers, helpers, or "minitherapists" to others. 2) A few people saw themselves in a receiver tole, expressing a need to learn and take courage from others. Thus in the selection process the worker was looking for a balance of:

A) Givers and Receivers, from the patients' perspective.

B) Patients Who Used "Talk" as a Method of Problem Solving. There were of course degrees of this "talk" but the worker drifted towards those who demonstrated a willingness to open themselves and share their concerns.

C) Voluntary Participation, especially where the motivation was strong on their part. While no one was refused entrance, since not all patients had equal access, once fourteen people for the group were selected the worker left the clinic and terminated this period of interviewing.

D) Balance of New Patients (First Course of Chemotherapy) and Cancer. "Veterans." Since the stages of disease and types of cancer were so varied, it was decided to include representation of each, rather than concentrating on any one particular group. The recently diagnosed group were included because at this stage the worker felt that the crisis was most acute. Following surgery or mere identification of the disease, the program of chemotherapy reinforced and intensified the reality of the diagnosis. At this stage when the patient was most uncertain and unfamiliar with his/her future, when he faced major obstacles to important life goals, depression and feelings of isolation were likely to set in. Those new patients who identified their state of confusion and disruption, and were reaching out, would likely be open to directions and support from others in the group. The approach to them was that the group could offer the opportunity to talk to people who had years of experience with cancer and who could understand what they were going through. Caution was exercised in approaching the new patients so as not to further bewilder or frighten them with more information overload. The "cancer veterans" (those who had lived with cancer from one to ten years) were selected for their potential to act as role models for the recently diagnosed group members. These veterans, by their very existence could act as a source of courage for the new patient. Veterans in remission, as well as those in a state of decline, were included. The deterioration represented the iminence of death, a reality factor to be reconciled in the adjustment to cancer, and an issue expected to emerge in the group. Some of those in decline saw the group as a place where they could receive moral support and courage. The worker anticipated that these cancer veterans would be able to offer suggestions for living with the stigma of cancer, overcoming fears, and coping with the panic frequently associated with the diagnosis of cancer, (they expressed this during the initial interviewing). In sum, they had much to offer from the experiences in living with cancer. Vachon's (1976) groups included cancer veterans and her work confirmed the value of their participation.

New members were not selected once the group sessions began. It was felt that if the group experienced constant changes in membership it would perpetually be in the formative phase. The development of a climate of trust would be slowed and other issues of intimacy, power, and authority in the group would take more time to resolve.

Once the selection process was completed, an intensive interview was conducted with each person, either at the hospital or in their home. The most productive interviews were conducted in their own milieu away from the clinic where the worker had a glimpse of "the person" not "the patient." This was the most valuable stage in the planning for the group. Many purposes were served:

A) The patient and worker became more comfortable and trusting of each other prior to the group meeting.

B) The interview allowed for some unloading and ventilation regarding apprehensions related to the group.

C) The interview identified individual purposes, expectations and goals for joining the group. The interview allowed the worker to point out the common ground between group members in an effort to bring them together "spiritually" before the first meeting. An attempt was made to relate general purpose of the group to their individual goals.

D) The interview lent material for future content in group meetings.

E) The interview involved patients in planning for the group.

F) The interview provided an opportunity for setting a "contract" between clinic, worker and members as to the task in the group. This served to clarify what we would be "working on" in the group. The purpose of the group was stated with sufficient breadth to allow members to formulate their own purposes.

G) The interview assisted in gaining committment from the members as to their participation in the group. Here, space was allowed for reservations to be expressed; so that members' degree of involvement was not beyond their readiness.

> "... In a social work group the struggle with accepting the stated purpose is tied in with the decision about future close associations with the people." (Frey and Meyer, 1973)

During the interview phase, hints were casually dropped from two or three people as to the possibility of dropping out of the group. Responses such as, "During the winter I might not come to every meeting," "I'm now involved with the senior citizen centre and the group might conflict," "My

Family are worried that this might depress me," were prepared exits some patients were creating for themselves. Rather than pursuing these statements, the worker allowed these ambivalences to be aired. The importance of these clues was not minimized, yet a worker should be aware that clues from many people might create a large number of future drop-outs. Thus there may be reason to discourage many of these people from joining the group.

The worker realized that the person in the group is not the same person pre-group. Only one interview was held so that there was no "figuring out" or "planning for" an individual member before his entrance into the group.

> "The fact of knowing so much about the individual, rather than being helpful will very likely interfere with the relationship by creating a constant strain on the possibilities for a real and spontaneous relationship. When the worker brings with him considerable data, this tends to add up to an awareness of problem or inadequacy. Instead of structuring for strength, for capacity, for expectation, the stage is set for weakness." (Tropp, 1969)

Initial Skepticism. The worker experienced some frustration and ambivalence during this stage of selection and interviewing. There was constant questioning on her part as to whether a real need was identified. I experienced discomfort with the fact that the group idea, although it created much enthusiasm, did not come from the patients. If the idea had originated with me, did that make it any less worthy? Even before selection was completed the worker had an obsession with beginning the group as soon as possible. Difficulty was experienced observing, floating around, without giving service, as the latter was more in line with what we social workers are "supposed" to do. There were several factors related to this urgency.

1) Would group idea lose its energy?

2) Would patients feel abandoned or let down, sensing that the group would not materialize.

3) The time element was crucial especially in cases where patients were deteriorating.

Thus the worker tried to maintain regular contact with group members until the first group meeting.

Throughout the interview phase the worker struggled with several doubts. Would the group increase tension, anxiety and intensify depression as a result of,

A) concentration on cancer related issues - perhaps people need a release from this?

B) discussion of sad fearful experiences.

C) possibility of rapid deterioration or death during course of group.

D) potential problem area of patients comparing their symptoms and course of illness too closely.

As deep as my conviction was of the need for such an emotional support system, the worker still had apprehension and doubts related to treading on such intimate grounds. How could we make this a growth producing experience?

I realized how flexible the worker would have to be to cope with the rapid and sporadic changes experienced by these people, the unpredictability of their disease and treatment effects. Reviewing their medical charts I was shocked at the intensity of horrendous experiences these people had undergone; several surgeries, several courses of radiotherapy and chemotherapy, and the tremendous changes in their disease pattern. Their susceptibility to viruses, colds, flu, and complications due to lowered resistance was enough in itself. The worker quickly realized just how intense their experiences were.

The worker had developed a rational for the group based on literature reviewed and contacts made with patients at the clinic. Purposes and goals were identified, members selected and interviewed, and doubts openly shared with the medical and nursing staff. In summary the scene was now set for the

CHAPTER III

THE GROUP

Introduction

The writer wishes to capture the meaning of the group experience for both worker and members in the following chapter. The content of discussion, the intensity with which certain subjects were addressed and others neglected, the roles members subscribed to, the leaders interventions, and the movement of the group through several stages of development, is portrayed both by the worker's impressions and the members reporting of their experience.

actual group happening despite ambivalence expressed by everyone involved. Only time would tell if meaning lied in this new venture.

The literature and studies on the psychological component in cancer clearly indicated the need for the development of support systems to fulfill needs neglected by standard medical treatment. Patients at the clinic reinforced and confirmed this as they spoke openly with the writer, and related their need to talk with someone who was concerned with the non-medical aspects of their experiences. Clinic staff recognized the vacuum that existed in this area and supported both worker and members in this new venture. The writer was aware that if the emotional component in illness was seriously addressed, treatment would be drastically altered. Perhaps the group was a start in this direction.

A) Content Highlights

i) Discussion Themes

What does a group of this nature focus on for four months? Important and recurrent topics of conversation throughout the group's life history, (See *) will be highlighted in this section.

1. Members Exchanged Cancer Histories. Most group members desired to know what the others had experienced in terms of surgeries and treatments. This sharing began with an identification of each other's particular cancer, and progressed to indepth discussions of the types of treatments, their side effects, and an exchange of practical hints as to how to manage these effects. The realization that potential solutions existed to some of the management problems was noted by Vachon (1976) as decreasing the members sense of helplessness and passivity. Perhaps comparing their cancers afforded several members relief with the fact that others were more seriously ill.

These discussions led the group into the more difficult areas. The issues of "uncertainty" in cancer, and fear of recurrence, were frequently discussed especially when members faced these issues directly. The probability of recurrence was the most frequent fear noted by the social worker conducting groups at the Michael Reese Hospital in Chicago. (Chicago Sun-Times, October, (1976)

> "... The curiosity will more often than not tie you in knots. The unknown - you're always apprehensive about it. We never know if its going to strike again ..."

Ambivalence and fear felt toward the treatments due to the limitations it imposed was openly expressed. Any resentments felt around having to be "chemotherapized" were given free expression. The issue of exercising personal

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* Most of the quotes in this chapter unless otherwise specified are taken from group members.

choice in one's treatment was discussed.

2. Member's Relationship with the Medical and Nursing Staff, specifically the oncologist, was addressed. These discussions covered the range of experiences members had had, both past and present, with their doctors; and how they would have preferred these relationships to have been.

i) Members discussed what kinds of questions to ask the doctor and how to ask them. They explored the kinds of responses they wanted to hear, and the manner in which these responses were communicated to them. (both medical information and questions pertaining to emotional difficulties)

> "I undress, he pokes there, you don't know if you're dying. He says okay everything is fine. Am I supposed to ask him anything? You have so many questions but the moment you see him you freeze."

ii) Members discussed the manner in which a doctor conveyed a diagnosis. Bitterness was expressed over insensitivity demonstrated to several of the members, yet a recognition of the difficulties inherent in conveying a diagnosis of cancer was also evident.

> "I was told by a surgeon and never saw him again. I had no one to turn to."
>
> "... Put yourself in their position. How do they come to a decision. Well yours is terminal. Perhaps he feels I wouldn't be strong enough to accept it. In many instances we've heard where they avoid. I wonder if this is the reason why."

This piece of discussion was similar to that reported by Vachon (1976) in her groups. Learning how to "negotiate" the medical system was one of the purposes of the groups developed at the Princess Margaret Lodge in Toronto. The goal was to improve patients' communication with hospital staff so that greater satisfaction with treatment and medical personnel would be achieved. As noted earlier, Weisman and Worden (1975) discovered in their studies that cancer patients who lived significantly longer tended to maintain co-operative and mutually responsive relationships especially towards the end of their lives. They concluded that more assertive patients asked for and received better attention and services and as a result may have lived longer.

3. The Cancer Clinic, and its routines were discussed. Members constantly remarked about how busy the clinic was, how long the wait was, and how staff attitude could and did at times change these inconveniences for the better. Anger in relation to the constant waiting was openly aired.

4. Difficulties Experienced in the Family, as a result of living with cancer were discussed. Members spoke about family members "protecting" each other, and their hiding the progression of the disease from their family, which also caused strain on them.

> "I wonder how many of us really sit down with our families and discuss it or do we keep them in the dark."
> "... I do completely because my wife scares so easy. I try to hide it. I don't know if its the right thing."
>
> "We've been very close (sister). This (my cancer) hurts her very much so I have to be up. (See *) She can hardly phone me or come over. I don't think I've heard her mention the word cancer yet. She can't see how I go to these groups."

5. Members Discussed the Changes in their Social Life. (i) The tendency to use cancer as a prop, or as an excuse for removing oneself from certain obligations was spoken about.

11) Discussion around the stigma of cancer underlined on how people felt and were made to feel isolated from society.

111) Members discussed how now was so different than before. The reluctance

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* "up" meaning cheerful.

to participate in customary social activities because of embarrassment due to loss of hair was discussed. Members spoke about their friends withdrawing and social circle shrinking.

6. Difficulties Experienced at Work were Discussed: i) Members frequently mentioned hiding the fact of cancer to avoid being discriminated against. "I never told anyone at work. I wanted to be treated as an equal, I lied for seven years."

ii) Discussions revolved around the inconveniences of chemotherapy forcing some absenteeism and consequent reactions by fellow workers.

iii) Members related how companies refused to hire cancer patients. "I've got to stay with my present company until I retire or can't work. Even though I have the training, know how, and experience, I.B.M. wouldn't look at me because I'm a cancer patient. I'm nailed."

7. Members Discussed how their Attitude to Life had Changed since the diagnosis of cancer, as a result of a growing appreciation of things unnoticed in the past. "You understand what's important and what isn't." "Life is dearer because there is a price tag on it." These discussions were similar to remarks made by cancer patients in the literature, that everything became more poignant and vivid. The discussions reinforced the idea of meaning in suffering and gave members a sense of the validity life can have when living with cancer. The realization of this new meaning was stated by LeShan (1969) as a goal in psychological intervention.

8. Members Discussed Death.

i) They spoke about the clergy's assumption of their "being ready for the box," (grave) and how they were confronted with this in the hospital.

ii) Discussions began with members relating stories of how "others" they knew had died of cancer in the past. Towards the last few meetings, members shared deaths recently experienced with friends and family.

iii) Ambivalence related to conflicting feelings of fighting for life and wanting death, was expressed.

> "If I get to the point where life wasn't worth living I hope I go fast.
>
> "When its time for your treatment wouldn't you reach out?"
>
> "... I ask myself lots of times, if I had only two months to live would I really want to know. Some days I can't come up with an answer."

iv) Members discussed how the end should be, some strongly expressed their desire to die when their time was up and not to be hooked up to life-prolonging machinery.

9. <u>"Terminal" Illness was Discussed</u>. Members had to grapple with one persons rapid physical decline and approaching death in the group.

> S. "... Right now I'd like to ask the doctor how much time I have, but I can't get it out of my mouth ..."
>
> M. "I don't think he could tell you."
>
> L. "Do your fear its that close?"
>
> S. "Yes. I've already gone past my time according to the first doctor."

Since most of the members did not consider themselves terminal, this issue may not have been raised if it were not for this one person in the group. The discussions about death were more intense following this person's disclosure of her terminal condition. Prior to that, it was a topic addressed only in passing.

Members introduced their own discussion material. Both the content and intensity of discussion changed as the group became more cohesive. The group, with time, explored these issues in depth until a comfortable level was discovered. One is struck with the wide range of issues discussed and with the fact that they each, in their own way, relate to the real practical and emotional consequences of living with cancer. Indeed, it is important to remember that very few, if any, of the group members felt that the world of friends, work, and family, encouraged open discussion of these "life with cancer" realities. The group helped take the difficulties far beyon the level of inner, private monologue. On this basis alone, the group served a useful function.

ii) Recurrent Messages

There were several underlying messages throughout the discussions, strongly felt and strongly expressed. These messages gave one an indication of how the members utilized the group experience.

The most pervasive and intense theme was that of "optimism." The leader viewed this not as a denial of cancer but rather as a need to futurize.

> "... The projection of ourselves into the future extends our existence and guarantees the continuity of our on goingness. Generally whatever inhibits our thrust to the future causes fear. We cannot imagine a space in which there is no longer a personal identity. We fear not existing whether we know it or not. We simply have no form of reference to it." (Keleman, 1974)

Optimism. In the beginning stages of the group, members offered each other reasons for optimism such as, "... I have a friend who had a breast removed twenty-two years ago and has been fine." Stories such as this were repeatedly told. Members were constantly reassuring each other of their improvement and expectation to beat the disease. "If I lick this thing and I have every reason to think I will..." "I'm positive I'm going to be alright." Early on in the life of the group the norm of optimism was set clearly. One member remarked, in response to a discussion about a slide presentation on death, "... I don't think the purpose of our group is to depress anyone. We are all looking for something positive." This was confirmed at the end of the group in the members evaluation.

> "... I don't think we've simply unloaded ourselves and released all the tensions. We have developed an attitude of not just handling cancer but an attitude toward life from here on ..."

There was a clear demonstration of the need to be hopeful and offer hope to one another. This positive attitude was noted by Simonton (1976) as important in enhancing the effectiveness of traditional treatment. The expectation to "beat the disease" was one of the goals of his treatment procedure - the person's belief in his/her ability to extend and improve life in the face of cancer.

At times, optimism coincided with a realistic improvement in one's condition but often it was there regardless of one's physical status. Sometimes this optimism bordered on denial, but perhaps this too was a struggle to stay alive and reflected a feeling that one's state of mind would assist in this process.

> "... It doesn't bother me to say I'm terminal (she pounded her chest three times and said I'm terminal, terminal, terminal). I'm going tomorrow to buy spring clothes. I'm not going to die before I wear them out. I'm not going to give up. I keep cheating. I say G-d don't take me now ..."

As three members in the group went off treatment and were in a state of remission, the state of optimism in the group grew. There was a feeling expressed that perhaps this could happen to all of them. There was also a clear minimization of each one's condition in relation to his/her fellow group member. Was this a way of comforting oneself? Members comforted themselves and felt optimistic with the thought that advances in cancer treatment provided them with more hope than ten years ago. Many of them had observed family members dying of cancer many years ago when there was no chemotherapy. One member in the group recognized and really believed the potential optimism held for prolonging one's life. He remarked:

> "I believe that we can kill our cancer ourselves without any chemotherapy just by looking in the right direction and saying I got you licked fellow. To a great extent we can help ourselves this way and the group is an ideal tool for the job."

Other group members recognized the important part that <u>attitude</u> played in the course of illness. In one discussion with the chemotherapy nurse the members told her that, "... attitude can have a lot to do although it can't be proven.

If you can somehow find strength to change your attitude and say - I'm going to beat it, its got to help." This attitude, the antithesis of a helpless giving-up reaction noted in the literature reviewed, as having lethal consequences, was the natural outcome of discussions the group engaged in prior to the nurse's visit. Here again, the future anticipation activity, part of Simonton's treatment, was recognized as important by the members of the group.

There was a forced optimism in the group when this norm began dictating people's responses to one another. When the death of one member was staring the group in the face there was refusal to accept this "giving up." Several members did not want to hear her or blocked out much of what she was saying. Did this positive, optimistic attitude interfere with the members preparation for this event?

Courage. Paralleling the optimism adopted by the group, was the message of courage members gave each other. The leader perceived an inherent paradox in this message, since in one breath people gave each other permission to share their "down times," yet expected each other to behave courageously. This norm demonstrated itself in the expectation to come to meetings even if members weren't feeling well. Constant reference was made to this attendance issue. Absence from meetings triggered a fear reaction that perhaps members were deteriorating.

Members gave each other positive reinforcement for any effort shown towards "feeling well." Comments such as, "I'm glad to see you up and around," were frequent. A dialogue between two members illustrated this.

> S. "When you first came you were scared and nervous
> I was shocked when I saw you a few times after.
> You're not like that now."
>
> F. "I'm better in this group than I am in any other
> group."

One session the leader brought a few books written by cancer patients.

This triggered an expression of sadness in some, while the others felt these books were uplifting. One member remarked that the book, Make Today Count, "gives you a lift because he is so courageous about it." Was this an expectation she had of herself and others? Another member repeatedly mentioned that because "... we have cancer we become stronger than other people, and can cope with so much more because what is there to lose." Statements such as, "you never know you might be around in another three years," placed heavy demands on her. When she was finally admitted to hospital the group was forced to face the reality. Her hospitalization provided the group with the opportunity to confront their own fears. "... We should all face this reality. We are all at various stages of cancer. At some time in the future someone in the group will not progress but will regress." Thus, although an optimistic courageous attitude fulfilled a useful function in the group and was nurtured and encouraged by the leader, it also held an inherent danger - that of not always permitting weakness or fearful thoughts to emerge.

Honesty. Honesty and openess, an objective expressed by the members in the first meeting, soon became a norm that members were expected to respect. "If we can't be honest here than what is the value of coming."

The message in the group quickly became, this is a place where we can feel free to disclose our most fearful feelings. Members expressed annoyance with having to wear a facade in usual social situations and a desire to "drop that face" in the group. Each member's disclosure gave the other permission to do so. For several members this new found liberty of sharing was rewarding. This sharing of common ground and the reassurance of knowing others had similar fears was noted by members of similar groups reviewed in the literature (Sveinson, 1974, Chicago Sun Times, 1976). The humanistic framework was clearly given additional meaning by the sharing of a common life situation, that brought the members together and served as a prime force in the gains members, made in the group. C. Rodgers (1970) wrote that the risk of being one's inner self is one of the steps toward relieving the loneliness that exists in each one of us and putting us in genuine touch with other human beings. One member in response to another's tale of pain said, "... I feel a great deal of pain is accentuated by loneliness. When you feel there is no one to share your pain it makes it that much worse. This may be what is needed here." For those who weren't as open or ready to listen or be heard, this honesty held a crisis potential. Several minor confrontations revolved around this issue beginning with the first meeting. S. to G. "You can't tell me you don't have inner fears. You're just kidding yourself." The more "open" members pressured the quieter members at times into disclosing personal matters without respecting their need for privacy. The major crisis in the group which resulted in one member terminating prematurely, may have been due in part (will be discussed in other sections) to the threatening nature of this openess and honesty in the group. There was a struggle between respecting this norm of honesty and spontaneity, and showing consideration for others feelings and degrees of acceptance of their disease. One of the comments that triggered the conflict in the group between two women held a threatening potential for the woman who wasn't as open and defenseless as the other.

> S. "... I had a girl friend and it finally went to her head. Once it gets to your brain it doesn't last long."
>
> C. "I don't like to hear you say what you just did, once it hits the brain that's it, because it hit my brain two years ago."

While one woman accepted her own terminality, the other was just coming to terms with such a likelihood for herself and this comment heightened what she may have tried to avoid.

> "... They zeroed in on just what's frightening me. I have been wanting to ask the doctor about my prognosis but am too afraid of what he'll say. I want to ask him if he doesn't know, or just doesn't want to tell me."

Resolving this "crisis" allowed the group to explore this concept of honesty further until a comfortable level was reached for the remainder of the sessions.

Healing. Many authors have written about the power to heal (like the power to create illness) residing in the patient. (Rodgers, 1970; Weil, 1972; Frank, 1974) According to Weil, (1972) an outside healer, may it be the physician or a group leader (if healing be her goal) can, do no more than two things: he can remove any obstacles to healing that are present, and he can motivate the patient to get well. The message in the group was that these two conditions were possible accomplishments between members.

(2nd meeting) G. to W. "I jump to the conclusion that you're sharing with us brought your spirits up."

W. "Yes it did very much. I felt so much better. There are people who care."

This message of healing began within the group and carried over in-between sessions, in extra group developments. After a month of being together members drove each other home, and telephoned each other regularly in-between sessions, especially when someone was ill, troubled, or had good news to share. When a member was hospitalized the group saw its purpose as giving her support. There were again elements of a forced optimism in the following comment.

> "... Now is the time we show the strength in the group. Lets not leave it at this. Lets all of us get up there and give her the gears, get her thinking that she can't give up."

This is exactly what happened. Until this woman died the group visited and offered her comfort until no longer possible. Throughout the sessions members identified the purpose of the group as a place where support, encouragement, and courage, could be gleaned. One member stated this succintly: "... We've each given each other strength perhaps not knowing it." The purpose of the group prior to its formation was identified as a "mutual aid system." The leader conveyed the belief that an incredible gift of healing was possessed by many persons, if they felt free to give it. This translated itself in several forms. Several members felt that by helping others they were helping themselves.

> "... I think this is another plus of the group. Instead of thinking of oneself so much, we're playing down our own role by thinking of others and trying to help them."

This feeling of self-worth created a positive emotional response, noted by Simonton as crucial in decreasing depression, fear, and anxiety.

Friendship. Another recurrent message in the group was that a certain type of friendship evolved, one that was difficult to find anywhere else. This related to the feeling that only in the group could certain topics be explored, or that they were shared here with greater ease. One member interpreted the meaning of the group in just this sense.

> "... I think this group is more of having a friendship group and sense of commaraderie rather than discussing cancer. Some are able to feel uninhibited and relaxed where they can't elsewhere. Its worth its weight in gold if that alone is accomplished."

Evaluating the group, one member gave "... a testimonial to the gift we have all given each other, the gift of love, showing that we can all feel for each other and give of ourselves." Several social events that the group enjoyed together clarified for everyone just how strong the bonds were, and that members enjoyed each other's company in varied situations.

After a few group sessions, members remarked how different the contact at the clinic was with other group members. They marvelled at the closeness and friendship people showed each other outside the group, during treatments.

Humor. The first meeting the leader voiced hope in the possibility of the group being a place where we could have fun amidst the seriousness. From then on there was an injection of humor, sometimes balancing the seriousness gracefully, other times distracting us from our central purpose. There was a clear demonstration of the need to laugh and joke even when things weren't so funny.

In summary, there were commonly accepted expectations of how the members should behave and react. Each message held within it a paradoxical message; or was it just the polarity existing in most human emotions? Optimism allowed members to be hopeful and lent comfort in distressing situations. It also set up an avoidance pattern in the face of reality. Courage and strength were gained from the meetings, but weakness was acceptable only to a limited degree. Honesty permitted a sharing of pent-up feelings, but in its extreme form proved threatening to some. Humor kept the group from falling on its face with despair, yet at times prevented us from deeper exploration of frightening issues.

B) Roles

i) The Role of the Family

Were families shut off from member's innermost feelings? Was the burden lightened for families? Did communication with families improve as the group progressed? Did families feel a sense of rejection or isolation? What role did the group play in response to these and many more questions? Since there was no quantitative measurement of how this group experience affected families, these impressions are derived from what families told the leader, and what members spoke of at the meetings.

Several families involved themselves by encouraging their loved one to attend meetings, thus maximizing the experience for them. One daughter planned a surprise birthday party for her mother at the meeting. One husband (meeting at member's home) remarked that he could never understand why his wife had joined such a group until he observed the group himself, listened from his bedroom to the "energy" and "exuberance," and then joined us towards the end during a celebration we were having. Several families remarked to me on the phone that this was the only socializing this person engaged in and thanked me for providing such an opportunity. Others expressed their initial skepticism about the group and then realized how helpful the meetings were, especially in making it easier for the patients to come to the cancer clinic.

Several members experienced initial problems with their families when they decided to join the group. Since the leader made no contact with families prior to group formation, the patients were responsible for explaining the purpose of the group to them. This comment was typical of most in the group.

> B - Group "I'm sure from everyone in here there is one of your families that must have told you - if its going to get you down don't go. My husband told me that in the beginning."

Support from families in this new venture was important for most in the group.

Some members expressed an inability to share personal matters with the family and could not see this changing. This choice was respected. When the leader asked the group if they wished to invite family to a meeting the response was surprisingly negative.

> "... We (group) have a certain feeling towards cancer. This is all new to family. If we start talking about terminal illness, they'll all be in shock."
>
> "... Maybe we're just being chicken and taking the cowards way out. Its a little safer not having them around."
>
> "... I'm afraid my wife would get depressed listening to you ladies, my cancer came as a terrible shock to her."

Upon termination members recognized that their families needed help in coping with cancer and even saw the potential for family groups. They felt, however, that these two groups should mix only when they each felt ready to really hear each other.

Questions remain as to how to best integrate families into the experience, so that both group member and family benefit during this time. Both Kelly (1975) and Simonton (1976) encourage family members to join the group, however their writings do not elaborate on the specifics of family membership. The writer's key concern is whether this group created additional strains on the family, or whether in fact families found it easier to deal with cancer in their midst as a result of this group. Future studies might explore this area so that families are incorporated in the treatment intervention.

11) Role Behavior in the Group

A frequent theme in the literature on groups focuses on the concept of roles. Roles are defined as functions members take on in a group because of the capabilities they bring, which interact with the pre-group capabilities of other members and the task inputs accepted by the system. (Berrien, 1968) Some roles were ascribed by others, some roles were self-chosen, and other roles became entrenched, as members grew to expect certain patterns of behavior from certain people.

As identified earlier in this paper, prior to group formation, people saw themselves as helpers, others as receivers. These two roles unfolded in the group, with some members subscribing or being ascribed one particular role, and other members blending the two. The "helper" role carried elements of a "consoler", "reassurer", "comforter", a kind of "mini-therapist."

Several people acted as advisers in the group offering advice and suggestions when difficulties arose. Those that saw themselves in a helping role, felt that they had adjusted well to their disease and could offer from the strength of their experience. One man became the "sensitivity" expert due to his attendance at different workshops and the group looked to him in time of conflict. His contribution laid in his ability to sensitize the group to peoples' emotions. "... If someone in the group feels bad, we accept that rather than try to change that because thats their feeling."
One woman played the "hero role", and focused a lot of attention on herself from a position of strength. She repeated time and time again, "I've had cancer for ten years", and then made it known how well she carried on in spite of being told she was terminal. This commanded much attention. This same woman, took on another woman "under her wing", always speaking on her behalf and behaving in a maternalistic manner towards her. This was easily accomplished as the second woman identified herself as being in a receiver role.

> "... I think its a little too early for her to go up and see somebody who is very ill, because its very hard for her."

Since the group was identified by worker and members as a mutual aid system, roles that may have been assumed by the leader in other groups, were assumed by the members. Rather than identifying the leader as "the helper", the members found these qualities in each other.

The receivers, identified themselves as such. "I'm asking for help to cope with the uncertainty of the unknown." One person who came was a "helper", and was very vocal, offering suggestions to the others, became more passive towards the end and commented that she felt she could receive more from the group than give. Most of the members eventually saw themselves in both roles.

> "... I approached this group with the idea that I didn't need anybody and no one can help me but if I can help I'll feel good about it. I feel much humbler now because I've received and given help. I've changed just by virtue of being here. I am a convert. I was on both ends."

Several people adopted the role of humorist and were relied on to lighten matters with jokes and stories.

One man in the group played the role of "issue-focuser." As we drifted from our purpose, he tried to bring the group back. He was concerned that the group maximize the experience of each meeting and that no time be wasted in side conversations. This member played task roles of initiating activity, seeking and giving information and opinions, and elaborating and summarizing for the group. He also served the function, along with several others, of group building and maintenance by expressing group feelings and making constant references to the value, purpose, and benefit of the group.

> "... I had a call from a lady on the next street who lost her son from cancer. She wanted to know if

> she could join the group. I never knew her. She talked to me for two hours. My goodness how far we've reached.

M – F "... You can honestly say that talking as much as you do in the group here doesn't depress you. It is helping you. That is the way I felt all along."

M – Dr. "... You can see how we gain from our discussions here."

Several men in the group shared in the leadership. This became more pronounced around the time of the confrontation in the group between two women. The three men acted as "stabilizers", "balancers", assisting the leader in conveying to the group the natural element in this confrontation.

> "... It was a healthy thing (confrontation). It indicates we are close. There couldn't be ill feelings unless there was an atmosphere of intimacy."

Two people in the group acted as "gate-keepers" trying to elicit a response from the quieter members, and assisted me in drawing them out. Several members acted as rule-setters or standard-setters in the group. This role revolved around three or four people, each taking their turn.

One woman (who eventually dropped out in February after ten of the seventeen sessions) became the scapegoat for the group. This most likely occurred when the group felt threatened and vulnerable in the face of her demonstration of what they perceived as weakness. Three major incidents surrounded this final scapegoating. In reaction to several books the leader brought to a meeting, she cried, ran out of the room, and then refused to discuss her feelings with the group. The second incident was already mentioned – her reaction to a comment made about cancer "going to the head." In the third instance, she ran out of the room in a fit of rage when another member expressed impatience with her repetition of the same story and said, "... we've heard that story before and we'll hear it again." These three incidents were blown out of proportion both in and out of meetings by both this person and several other group members until a crisis erupted and she dropped out.

Two women in the group commanded the most attention, however one did it from a position of strength the other from a position of weakness. Was it easier for the group to respond to strength? In effect this was the norm in the group. Interestingly enough both women were ten year cancer veterans and had experienced equally trying circumstances. Was it a case of others wanting to break down, elicit sympathy and command attention and did they therefore resent her performance? Was it that this weakness aroused a basic fear and anxiety in the others projected onto her as their defense mechanism. Her behavior may have activated similar feelings in several group members which they probably preferred to suppress, but felt easier to project it onto one person. Or was it a case that as long as she was the weak one, they could be strong? The women accused her of child-like immature behavior. Her running out of the room in a fit of rage triggered resentment and she was accused of avoiding issues, including not being able to accept the reality of her condition. The group unknowingly possessed its own rites, and strictly subjected its members to them. Each member was expected to acknowledge the full extent of their disease.

One meeting, a few weeks following her running out, several members had final comments to make, (she was not present) clearly demonstrating the scapegoating.

> "... There is nothing you can do for her. She doesn't want to be helped. She doesn't want to hear anything that will upset her. We're here to open ourselves up. She doesn't want to face it. She upset the whole group.

Many of the roles that evolved related to norms established in the group. The "receivers" were responding to the expectation members had that they could disclose their most fearful feelings in an honest manner, and receive support during this process. The "helpers" were responding to the norm of optimism, reassuring those in distress, that their situation would improve. The humorists were responding to the leader's signal that yes people could have fun in the group.

It is not the purpose of this review to do an indepth analysis of role behavior, rather to highlight what the writer found interesting and significant. For the most part, the roles members took on were acceptable to others and allowed the group to move relatively smoothly in its development. The basic learning for the leader derived from observing role behavior, was the groups' need to scapegoat and outcast one of its members, perhaps to alleviate some of its own anxieties. The worker questions whether this phenomenon could have been avoided had the leader been able to forecast its route.

C) Leader Looks at Leader

Although the leader's and members' roles and functions differed, we were both subject to the same strengths and weaknesses, pains and joys, both searching for meaning in life. Thus we both shared this common human condition. Through the entire process of the practicum I realized that I could only find a better way to help others, if I allowed the group to teach me their needs and aspirations. I saw myself as a single element in the totality of the member's experience, one, among many in the group, all involved in a common undertaking.

Initially I struggled to find a comfortable role for myself. How directive should I be? I was searching for a balance between structure and spontaneity. As I became more comfortable and allowed the unpredictable to unfold, I realized herein lay the real meaning of group process. My planned agendas remained in my pocket (most of the time) as members introduced enough material to deal with. My occasional mechanical techniques met with resistance and thwarted any productive work. My attempts at imposing structure in the beginning probably for my own security were resisted. Spontaneity was the spice of group life. It took time for both leader and member to accept this format. Some structuring might be helpful to a leader but not at the expense of spontaneity.

I struggled with the process of divorcing myself from the "success or failure" of the group. As I had so much investment in this "demonstration" project, I was blind to the reality that I could not assume total responsibility for the workings of the group. The first month the attendance issue plagued me. If only five out of ten people showed, I convinced myself the group was doomed to failure. Members missed meetings due to the unpredictable nature of their disease yet, I had a hard time accepting and adjusting to this reality. Members expressed both annoyance and concern with those absent. This may in part have been due to the leaders anxieties spilling over into the group. We resolved this in time, when both leader and members felt the group venture had taken flight. When initial ambivalence towards the value of the group was strongly expressed by one of the members during the second meeting, I felt threatened. Rather than allowing the sores to be opened and using this as an opportunity for the other group members to explore their ambivalences, the discussion became a dialogue between leader and one member. This also derived from my equation of group survival and leader.

Throughout the sessions the leader had difficulty coming to terms with how she felt the group <u>should</u> be progressing, versus what faced her in practice. Specifically with regard to "termination" difficulty was experienced with the group's resistance to this and their focus on continuation. After all, was not the leader supposed to help them work through and accept the groups' termination as stated in the contract? The group quickly tuned into this artificiality. I discovered that as soon as the worker decided the way it ought to be, she was through, because the members did not always respond to the leader's aspirations in this particular group. This most likely related to the manner in which the leader presented herself from the start, as non-directive and spontaneous.

The more I befriended these people and experienced their pain with them, the more difficult it was for me <u>not</u> to intellectualize. I expressed the hope that members would not hide under the veil of intellectualizing, but I too, at times, succumbed to this defence.

The literature on groups specific to cancer patients did not address itself to the role of the leader. Thus, there were few guidelines as to how I might function in such a situation. The literature (Kelly, 1975, Simonton, 1976, Vachon, 1976) focused on the group, not its leader.

In retrospect the role of the leader in the group was:

A) The leader identified and reinforced the common ground of experiences, facilitated the emergence of affect between members, helped the group place its concerns on the agenda, reviewed the purpose of the group, and began the working relationship of the group with a clear "contract" and common understanding of the issue.

B) The leader reinforced the group as the medium and focal point of interaction between worker and members. Selective handling of individual members was limited, and any and all conflicts were brought to the group for their resolution. This avoided any accusations by members that the worker was showing favouritism or aligning herself with sub-groupings (this function developed only after the leader learned from her mistake of allowing conflicts to be resolved outside the group, by meeting with one member in between sessions, much to the dismay of the group members.

C) The leader reinforced the mutual aid capacity of the members by limiting her role in the group meetings and encouraging members to seek help from each other in between sessions. The leader followed-up in between sessions if special need dictated, however this was done with caution. A few outside sessions with one member created accusations by members of my showing favouritism.

D) The leader assisted the group in staying with and exploring emotionally charged issues, helped members to sink deeper into fearful feelings when the tendency existed to avoid expression of those feelings. The worker's role was to call attention to the existing obstacles and impediments in the group such as recognition of the possibility of deterioration and death and provided members the opportunity to confront that fear.

E) The leader facilitated a mutual understanding between the patient and staff systems. As suggested by Schwartz (1961) she "mediated the individual - social transaction." Staff were present in several sessions, and listened selection of tapes, so that both systems gained a more complete understanding of each other's situation, and were brought "closer" together, in an effort to make improvements where possible.

(Patient) "It is something for them to see us sitting in a chair without a sleeve rolled up. They recognize us as people outside that clinic."

(Staff Nurse) "Maybe we're doing enough socializing new patients, introducing them to other people who have been on treatment for a while."

F) The leader maintained the focus on the purpose and task functions of the group lest it be lost in the preoccupation of confrontations and interpersonal conflicts. Any group development crisis was normalized as being a natural group process and its message was utilized to help the group move on.

G) The leader reinforced her belief and conviction in the group's purpose and accomplishments, the productive capacities of its members, its self-help and mutual aid value.

H) The leader functioned in a variety of roles depending upon the need: as clarifier, as interpreter, recognized the feeling beneath the words, lent a vision in terms of "speaking about the unspeakable," helped members make connections, and talk to each other, identified blocks, opened up this "internal dialogue", lent structure, assisted the group in review and evaluation of its experience, and withdrew this role of conductor near termination.

The leader also had work to do in the group and shared in the expectations she had of others of disclosure and openness. This involved feedback to the group as to how she saw them operating, how she observed herself, her discomforts as a leader, and an invitation for feedback from the group on "how they saw her." The demand the leader placed on herself to share a part of herself with the group, was far more challenging than acting on professional skill alone from a removed one-up position. Most of the leader's functions described were not specific to this particular group, but common to most social work groups indentified in the social work literature. (Schwarts, 1961, Tropp, 1969)

In summary, I would like to be remembered by the group in two ways: 1) as a friend who assisted them in facing and living more comfortably with many of the inherent miseries of cancer 2) as someone who was able to help them derive meaning in this suffering and utilize their condition in a positive growth producing manner.

A piece of sound advice to any and all health professionals working with cancer patients. It may be your living but its their life!

D) Process of Group Development

Birth The group was born out of a joining of ten strangers. Each came into the group focusing on himself; his/her problems were the most serious. This phenomenon of "ego-centrism" demonstrated itself in the difficulty people had listening to each other, the restlessness displayed in the group and the inability to give each other time to explore fully their individual feelings. The finiteness of life was heightened, and the selfish drive to focus on "only me" was its natural derivative. Thus, the first major process to work through was recognition that one's time had to be shared with others. This period carried with it the experience of anxiety about becoming involved in the group. Members approached involvement because of the potential gratifications it promised avoided it due to the potential frustrations and pains.

Just who were these people? Members spent a great deal of time identifying their commonalities. They needed the common base of cancer to start, but then moved on to identification of their common humanity.

Mutual Aid From a state of "aloneness" members gradually moved towards each other and were ready to engage in this mutual aid process. Members became interested in each others accomplishments and adjustments. They followed each other's developments closely both in and out of the group. Concern was expressed when members were absent. The morale and cohesion in the group intensified and members viewed themselves as a system and took pride in their accomplishments. "... It shows you what can happen in a group of this kind. The whole room was with her." They now had an investment in the group's continuation. With growing trust several members were able to ventilate bitterness and anger toward the clinic and receive relief from the release of these feelings. They reached the stage as well of being able to share their feelings openly about the clinic directly with the staff.

Patient - Dr. (in meeting) "Do you realize how important the emotional side is - that a patient needs a friend, someone to talk to about problems with family, at work, sex problems. This is just as important as treatment. I think it is the Dr.'s obligation to help the patient with that side of it."

Interpersonal Conflicts. The closeness and intimacy which developed in the group was not without its problems. As members became increasingly open with each other, the possibility for interpersonal conflicts, power and control issues, clique formation and finally the unveiling of scapegoatism existed. This period cast a doubt on the group's survival, as two members threatened to leave. This stage was frequently noted in the literature on groups. (Bernstein, 1973) Here again, the need for several members to command group attention for themselves, some more successfully than others, was evident. The resolution of one of the major interpersonal conflicts in the group portrayed inner struggles that other individuals not directly involved were experiencing. Thus, it was worth exploring. However, several members made it clear to the leader that there were more important things to talk about, and that the group was not a forum for arguments. The resolution of this crisis was an uncomfortable area. The members weren't energized to work on cleaning up process difficulties.

Interpersonal Involvement. Following this episode, after one woman left the group, the members fortified their walls once again and there was an intensification of personal involvement. During this period the group supported one member during a very difficult process of rapid physical decline. Her disclosure to them of her "terminal" diagnosis led the group into exploring this most difficult area. When she was hospitalized the members grappled with the reality of her death.

Termination. Termination became a giant issue for both leader and member. The doctor was concerned from the start that the group end when the worker leaves in April. This frequent expression was related to his uneasiness with the group meeting on its own without professional leadership. What if a problem arose? How would he know? Who would the members turn to? These fears exerted some pressure on the leader, since she herself was not certain as to the best outcome of this program. On the one hand, continuation would be a testimonial to the value and need for such a group, and to the members ability to function without a leader. The client reaching a state of autonomy was a practice value recognized by the leader. On the other hand, the group may not function well on its own and its very existence may create new additional problems for its members. This debate continued between the leader and clinic staff throughout the entire program.

The symbolism of the word, "terminal" associating the life of the group with their own lives made it difficult for members to accept the "death" of the group. The group had to "live" on, even in a modified form. While the leader was urging the acceptance of termination, the members were urging for the group's continuation.

> "... People avoid endings. The feelings are too permanent. We resist leave-taking because it seems so much like being abandoned. Parting, ending seems like a loss of orientation, or of control. Ending reinforces the image that life is a finite linear connection, and that to break the connection is to lose the life." (Keleman, 1974)

Their greatest concern was with breaking the bonds and losing contact with people. This most likely related to their fears of sudden discovery of each other's decline. Maintaining close contact in meetings had a way of easing this shock. As one member said, "we're interested more in one another's progress and continued progress week to week.

> "... our group could keep on in a way. We could all boost each other's morale as we go down. Maybe we could branch out and help others."

Thus termination was an important issue and should be addressed in the early stages of the group. Initially the group felt comfortable about meeting occasionally following my leave. During the last group meeting, they were far more fervent about setting of a schedule for future meetings, and calendar dates were selected for the next few meetings.

My concerns related to helping the members make the transition from the group to outside situations, assisting them with the movement back into their own life spaces since one time or other this ending would arise. I identified the resistance to ending, and the group responded to me with some annoyance. "... We feel we have a common ground. Do you (leader) see that as a sign of weakness?"

The leader and members finally met on the common ground of accepting that one phase of the group had terminated - my contract with them. With that recognition we utilized the termination process to review and evaluate the experience, discussed to what extent we had accomplished our objectives, and whether the learning could be transferred and become a frame of reference for approaching new social, group, and familial situations. There was recognition that the need for frequent meetings (once a week) was now not as pressing; a recognition that following four months of group sessions they felt more "calm" and needed less to unload. The group utilized the last few meetings to discuss the manner of continuation. Following my leave, the group continued to meet twice a month in each other's homes (except one member who stopped attending).

Social Action. The members of this group travelled through several passages. They started alone in their battle with cancer, moved on to sharing and caring for others within the confines of the group, and finally moved out of the group into a phase of social action reaching out to other cancer patients and helping we "professionals," become aware of what its all about. Quite a trip!

This latter process is what the worker had hoped to accomplish, (although the social action phase was not planned) that these people would have the opportunity to achieve something through their suffering. My question prior to group formation was - Could they make a victory out of their experiences, turning life into an inner triumph and challenge? The answer was yes. Many of the members found opportunity and meaning in their suffering.

This process began with members accompanying the leader to conferences on cancer. During the group sessions we were approached to do nursing inservice workshops. These patients suddenly found themselves in a teaching role and loved it. As one member so aptly said, "just shows you 'patients' is a virtue," and proceeded to ask if there were more inservices coming up. They were valued as the source of learning for health professionals. Towards the end of the group, members participated in a letter writing campaign to hospital and agency administrators in an effort to pressure for the creation of a social work position in the cancer clinic so that more groups could be established. Members realized the power and impact that lay within their hands, "Now we're becoming a voice" and many decided to become as involved as possible in staff education at the hospital, in lobbying for the establishment of more groups, and in reaching out to new patients distress. The leader as well participated in this phase of social action soliciting support for future groups in the clinic. Commenting on their letters, several members said:

> "... Why should we just settle for healing (treatments) We're entitled to a full life. Just because we have cancer doesn't mean nothing."
>
> "... I think we're getting the point across. We need help."

Were these people really saying, I may have a disease but I'm not a disease? Towards the end of the group, members were redefining and reconstituting group purpose according to their new capabilities and opportunities. They felt they had accomplished their purpose of overcoming their own fears and adjusting to the disease, and were ready to accept a more advanced notion as their purpose. They had become authorities on "Living with Cancer."

> "... I started off sick and now I'm pretty well back on my feet. I figure it could help others besides us here. I'd like to see that what we have gleaned from this group be passed on to someone else."

Following my leave, members have been actively involved in education sessions both in hospitals and University. They have made new contacts with patients at St. Boniface Hospital and Misericordia Hospital, and have made themselves readily available to interested parties.

> F. "... I hope we have received enough, to help someone else. It isn't just the group now. We have reached out to others."
>
> B. "... This group inspired this kind of thing. I don't want ever not to be a part of some program that is going to be of help to cancer patients whether its this group or not."

The question remains as to when and how the group will disband. Will members differentiate self from group to the extent of no longer needing this community of support? Had the worker urged more discussion on termination, rather than continuation, perhaps the group would have ended with the worker's leave.

E) Cautions - Traps

The following are cautions and potential traps worth noting in a group of this nature.

As experienced in this group members may overidentify with each others symptoms, thus increasing their sense of fear. People in a group must be aware of and be reminded that each individual cancer is different, and that disease patterns and responses to treatment are quite unique. Group members want to share their disease histories, yet these comparisons can serve a destructive function.

For this reason the writer now questions the advantages of placing people in different stages of cancer together in one group. Including patients in physical decline with recently diagnosed patients increases the probability that members will be observing and participating in each other's dying and deaths. With the potential of several people in the group dying (either during the life of the group or shortly following the termination) the question is raised as to whether this is subjecting people to additional burdens. Since the leader terminated with the group two women have died. Both were admitted to the same terminal care unit prior to their death. The group was involved with both right up until the deaths. Members visited the two women contacted each other in between visits to check on latest developments, and attended their funerals (two group members did not attend either funeral and were subject to some criticism by the others). The group kept the worker well informed even though she was no longer leading meetings. Here again subtle pressure was exerted to keep their leader involved. Following these events the group began focusing far more on death than they did in the sessions with the leader. (They reported this to the leader) One member commented to the leader, "Well I wonder whose next? Looks like we're all going to that unit." This causes me to question the value of selecting members for the group who are close to death. But who ever knows who is close? This is a key issue that should be examined more closely in setting up future groups.

Members express different degrees of acceptance of their disease. Caution should be exercised so that members do not pressure or threaten each other into "the acceptance of cancer," or into using the "right words" such as "terminal." Each member has certain needs, and deals with these in his own special way. Respecting these differences is crucial to the smooth functioning of the group.

The leader should be careful not to become trapped by avoidance patterns used by members as a problem-solving mechanism. If an important issue is relevant to the groups survival, it must be handled within the group whether members give or withhold permission to do so. Interpersonal conflicts must be solved by those concerned within the group, rather than the leader attempting to solve them in-between sessions.

The writer questions how termination should be dealt with in such a group. Does the leader have some responsibility to provide the group or any of its members with a person or place to turn to following termination? Should a group such as this be created if there is no follow-up provided? Perhaps a phase should be added to the group process to explore with members the process of functioning without a leader, when it becomes clear that the group chooses not to terminate? These concerns require further thinking for the establishment of future groups.

Finally, the leader should consider that the group can not be expected to deal with difficulties that go beyond the illness. There is only so much a group can deal with or tolerate. In this case, one member behaved in such a way that increased the likelihood of others rejecting her and resulted in this very rejection. The group should not be held responsible, in total, for her dropping out, as in many ways she was the contributing factor.

F) Goals and Purposes Revisited

Prior to the group's launching the writer identified several purposes and goals derived from contact with patients at the clinic. Were these objectives accomplished? Did the goals and purposes identified during the sessions differ from those originally stated? The evaluation as to the degree of goal accomplishment is directly related to how members perceived the group's purpose, and how they identified the accomplishment of goals. Here the writer is citing both personal goal accomplishments and group goal accomplishments as constructed in the minds of group members prior to termination. The following were the goals and purposes more frequently referred to in the group.

Purposes

A) Confirmation by members that their emotional needs called for attention, was frequently mentioned thus lending rationale to the purpose of the group.

> "... Basically it is an emotional illness we're fighting. It upset me more to lose my hair than it did to know I had cancer. To lose it terrified me. I had never worn a wig before in my life."

The experience of the group restated the plea made in the literature - that the emotional component in disease must be addressed as seriously as the physical treatment.

B) Confirmation of the common experience of cancer that members shared and the value of the liason potential was noted as a basic rationale for establishing such a group.

> "... We feel we have a common ground. Here we can discuss our problems and understand one another. I think this is where the need arises."

This reinforced the humanistic framework envisioned by the worker in the group's original inception.

C) Confirmation of the value in self-expression and release of pent-up feelings under circumstances in which others appreciated it, was noted several times.

> "We can talk easier amongst ourselves in the group than among friends.
>
> "Thats the purpose of our meeting, where there has been a regression we can talk about it frankly. This is the whole strength of our deal."

This gave further meaning to what Kelly (1975) wrote about not being able to talk honestly and openly with his wife and children at the point of crisis in his life. The writer is now curious as to whether fearful feelings once explored in the group, may facilitate this same process later in the family.

D) Confirmation of the readiness of people to take help from one another was noted.

> "... We discuss how we feel towards our sickness We're here to try and help each other as best as we can. Whenever there is a problem we hope we can find a way to make it lighter."

This highlighted what the writer meant by her earlier statement that people with similar concerns can help each other in ways that are significantly different from the ways in which a worker can help them in a one-to-one relationship.

<u>Goals</u>

A) Members recognized their ability to give each other hope and bolster morale.

> "... We've given each other hope and a different approach. We're looking forward."
>
> "... Just talking amongst ourselves has given me a great lift."

B) Members realized that the trauma associated with cancer, was de-sensitized and they gained a sense of control over their fears and doubts by confronting them.

> M - B. "You probably gave vent to your anger and that helped you. Thats really what this group is all about. Once we talk about our problems it is not as great."

> "... It has also been proven that because of our group and talking as frankly as we have my attitude has changed from first off. I was scared to death when I found out I had cancer and now my attitude has changed for the better."

C) Members recognized that a positive attitude or "will to live" can effect the outcome of disease at least to some extent so that they did not assume a passive helpless attitude.

> "... I read a book about a man with leukemia. He had so much to do that this actually prolonged his life. When all these things were done he died."

D) The discovery of members' ability to help each other, as well as those outside the group bolstered their self-esteem and feelings of purposefulness. They discovered a sense of meaning or new found purpose derived from the group experience.

> "... May be those that have been quiet have done a lot of talking outside the group. I have with a friend who had the same operation as me one month ago. Through her I've had other contacts."

E) Patients' communication with the cancer clinic and nursing staff was improved and a greater understanding of the holistic approach to treatment was facilitated.

> "... The staff sympathize with us and we're more than guinea pigs to them. Although chemotherapy is still developing we are not to being used as guinea pigs. They think of us as people and they talk to us as friends."

Cancer for these people was so unpredictable, unfinished, that one could never reach a sense of completion or wholeness until one died. A general hypothesis related to purpose worth exploring in future work, is whether the sense of being able to complete smaller and more manageable situations gave these people a feeling of wholeness. In the group this opportunity was presented with the realization that there were potential solutions to practical problems.

One of the group's major accomplishments lay in fulfilling what Spinoza proclaimed in his Ethics: "Emotion which is suffering ceases to be suffering as soon as we form a clear and precise picture of it."

The purposes and goals of the group identified by members' remarks were similar to those proposed by the worker prior to group development. Their comments regarding attitude, hopefulness, sense of control and meaning in their lives, were one and the same as those noted in the literature reviewed.

In summary, it was the writer's intent to portray the significance of the group by identifying common themes the group explored. Certainly these themes covered a wide range and were followed in varying degrees of depth. In many ways, however, the important element was not what was talked about, but the simple fact that these people were talking at all, and the quality of personal sharing and bonding which developed. Through the course of the group evaluation, a new "family" of experience was born wherein individual members moved far beyond viewing the group as a time-limited treatment program. They became friends and confidants, supports and allies. The group had a personal vividness and vitality based on the personal committment of each member. To a degree, the group displayed a striking similarity to the literature on the emotional growth potential in living with cancer. It seemed, at times, that these people had studied the literature and knew that unforeseen strength could be a consequence of cancer, or that a life-threatening disease could lead to transformation of meaning wherein "Life to Live" took on a special urgency.

CHAPTER 1V

EVALUATION

A) Introduction

The writer was interested in the group's effect on its members in terms of the stated goals, as well as its effect on the cancer clinic system. The medical staff was concerned that an objective evaluation of program effectiveness be conducted. Data documenting the value of this intervention would be vital if this program were ever to become established. The writer's evaluative efforts were process-oriented and designed primarily as monitoring devices to contribute information to the group members, to medical and nursing staff, and later on to key administrators.

Much of this evaluation examined subjective components of patient and staff impressions of the group. Group members were engaged in reporting their moods, feelings and attitudes throughout the four months. The group was an experimental project, viewed by patients and staff as a demonstration project. As such, evaluation of the program offered information designed to guide future changes and to elicit a clearer definition of the character of this program, its purposes, and goals.

B) Evaluation Design

Three evaluation tools utilized were field-based techniques; a psychodiagnostic measure was also used, the Goldberg General Health Questionnaire (Goldberg, 1972). The following techniques will be discussed:

(1) Tape Recordings Each meeting was recorded from beginning to end for the purpose of monitoring group development.

(11) Autobiographies During the interview, group members were asked to write or tape a short history of their lives including material on their present physical and emotional condition. The autobiography was requested for the first or second group meeting. This assignment was open ended giving them opportunity to discuss whatever they felt important to relate to the worker, so that she might understand their life experience.

(111) Evaluation Forms Forms designed by the writer were distributed to both group members and clinic staff one week prior to the group's termination in order to obtain information about their impressions of this experience.

(1V) The Goldberg General Health Questionnaire The G.H.Q. was designed by Goldberg (1972) to provide normative data about the symptoms and signs that defined non-psychotic illness in an English population. The test items were designed to stress the here and now situation. The emphasis was on how the individual's present state differed from his usual state.

Test-retest reliability and split-half reliability studies were conducted. (Goldberg (1972), for results see P. 71) Content and concurrent validity were demonstrated. (Goldberg (1972), for results see P. 72)

The original long form questionnaire of one hundred and forty items was shortened to thirty, twenty, and twelve items respectively. All these selections were 'balanced' for overall agreement set. The reliability and validity co-efficients show gradual fall with progressively shorter versions, but do not greatly alter the accuracy of results.

The version that correlates most highly with the one hundred and twenty item scale was the sixty item questionnaire. The thirty item scale was selected for this study, as this version is now widely used in Ontario, in researching the effects of psychological intervention with cancer patients (Vachon, 1976). The writer thus had some means of comparison with the study conducted there.

The G.H.Q. was administered five times (four during the course of the group, one following its termination) in accordance with the time-series design discussed by Campbell and Stanley (1963). This was used as the sole quantitative measurement of emotional distress. The worker's primary purpose in selecting this measurement was due to its wide use in Ontario.

C) Discussion and Results

(1) Tape Recordings All meetings were recorded in an attempt to lend insight into just how change was actually produced (or not) over time. The worker was interested in monitoring changes in group development and interaction, changes in the nature and intensity of discussion themes, changes in members' attitude toward their disease, as well as monitoring changes in the leader's intervention. When exerpts from meetings were played for the clinic staff, they were able to hear directly from patients, rather than from myself just how these sessions were helpful to members. Thus, this technique fulfilled the purpose of sharing with staff the content, purpose, benefits, and limitations of the group. As a learning device for the worker, the tape recordings were useful in supervision and ongoing evaluation of myself and the group by my committee of advisers. This tool proved helpful then in learning, evaluation, and communication with the clinic staff, patients, and committee of advisers.

(11) Autobiographies The purpose of this tool, prior to the initiation of the group was to encourage members to speak for themselves about their lives and present attitudes toward their situation. Most group members, however, felt uneasy about this task and saw it as a chore. The idea was eventually discarded by the fourth meeting. The writer had hoped, that along with this autobiography members would keep personal logs, so that these would have a basis for comparison of their self-perceptions. Perhaps there could have been another approach to explaining this technique to the group. Had the group been interpreted more as a research project perhaps the response would have been different. Their resistance to this activity may have reflected a fear of revealing self to others, or looking at oneself closely. Especially in the early life of the group, members were not motivated to become involved in this technique.

(111) Evaluation Forms (see Appendix B and C). Two different questionnaires were distributed, one to clinic staff, and one to group members. Each questionnaire contained nine open-ended questions, including a section in which they could respond with general comments.

Patient Evaluation Eight out of ten group members (one member died, one member dropped out and did not want to fill out the form) returned their evaluation forms. The following comments are highlights from several of the questions asked. Many of these responses can be related to the statement of worker's goals prior to group formation.

(1) Was the group helpful to you in any way through working through any difficulties you may have had?

Four out of eight members responded similarly: that the sense of alienation or aloneness was overcome.

> "Just knowing others were going through the same crisis and, made me realize that I was not alone and that I was a real person."
>
> "The group's main lesson for me was that someone cares."
>
> "More than anything I became less introspective, came to realize that there are many other people with troubles and that I care about people."

The other four, placed the value on honesty and openness in sharing, as helping them. This related back to the originally stated purpose of creating an opportunity for self-expression and release of pent-up feelings through the group process.

> "The honesty with which most of the group presented their case about cancer and their concern about mine."
>
> "Opening myself to others, not afraid to talk about my condition as well as family problems."
>
> "To view cancer realistically and still find happiness."

> "Any difficulties I have had have been worked out as a result of talking to one another."

(2) Has the group been responsible for any changes in your attitude or belief about your disease?

Three people responded similarly, supporting the original goal that the group would assist people in improving coping mechanisms so that members' were better able to master life experiences related to cancer.

> "If it does come back I can cope with it."

> "It has helped me in a way that I would be able to accept better if I should have to get any other operation in the future."

> "I am more able to cope now with minor problems as well as home problems."

One person's response related to the goal of confronting fears in the group as a means of keeping them in check.

> "Very definitely so. I no longer have the fear first experienced. To see the courage displayed by the other members has been a real revelation and inspiration to me."

(3) At this very moment, what do you think about your situation? Is it different than before?

Six respondents commented on a positive change. These responses correlated with the writer's overall goal of helping people become more comfortable with a stressful experience.

> "I feel I am able to cope much better than six months ago."
> "I am more involved now in hours of happiness whereas before this group I foresaw only days of depression."

> "I think I am very fortunate to have been enlightened.
> I am not worried about the future and I hope I am going to make the present worthwhile. This is somehat different than before."

> "I feel very well and things look very much brighter than before. I was not alone!"

(4) General Comments The responses under "general comments" tended to support the idea of the usefulness of a mutual aid group for cancer patients.

> "This sort of group is important for all people but certainly someone who is faced with a life-threatening disease is in urgent need of adjustment and reconciliation with the situation."

> "I would like to see many more groups of this nature started, where cancer patients get the opportunity to talk honestly about their feelings with others whose circumstances are similar."

Staff Evaluation

Nine forms were distributed, four were completed. (1 Doctor, 3 nurses) Four out of the five incompleted were those distributed to ward clerks whose involvement in this venture was limited to informal observing of my interaction with patients during the first two months in the clinic. They were not present during meetings nor were they consulted as were other clinic staff. However, the writer was curious as to whether they wished to note their own observations or wished to provide information that they may have received from group members. When approached, they told me they did not know enough about the group to fill out the evaluation form. Some staff members in addition to filling out the evaluation form provided informal evaluative information about the group program throughout its life. On-going formal evaluative sessions took place within seven staff meetings. Staff reported changes in patient behavior, patients' comments on the group experience, as well as their own reaction to this venture.

(1) What implications did the group have with your relationship with the patients? All answered similarly to the following response.

> "The patients belonging to the group seemed to feel free to ask more questions."

one added "I became quite involved with the patients because of the group."

This related directly to the worker's goals of improving patient communication with staff, and facilitating a more open interaction between patients and staff so that patients could receive whatever information about their disease and treatment that they wanted.

(2) Did you observe any changes in group members' attitudes, moods or approach to their disease during the time of the group? Would you feel comfortable attributing this to the group process?

All responses related to a sense of acceptance and openness about cancer that patients displayed, and all attributed this to the group.

> "Patients in the group were more positive and open in discussing their disease."
>
> "Group as a whole all seemed to come to 'terms' with their disease."

This related to the goal of bolstering morale in relation to patients' ability to adjust to cancer as live as normal a life as possible.

(3) Are groups of this nature an advantage to the clinic?

> "Yes, the patients involved were not as frightened. From their experiences they are able to help other non-group members."
> "Patients become more at ease with treatments."
> "Patients appeared more relaxed during their visits."

This related to the goal of de-sensitizing the trauma and decreasing the sense of fear felt by many cancer patients.

(4) To what extent did you feel involved in the events of the group and to what extent would you have liked to be involved?

All of the staff saw themselves "peripherally" involved and preferred to remain as such. They all felt too much involvement by staff would have been "detrimental." Other comments were:

> "Frequent references to the group were made by patients during treatment."

(5) Do you feel there were any negative effects of the group?

> "There might be with an unpicked group."

> "There can be. It can be destructive to some patients - especially if the group is not supervised."

> "Yes, threatening feeling and personality clashes."

General Comments

> "I was really pleased to be asked to the meetings. It seems I understood the patients so much better."

> "I think it was a positive experience for the clinic and generally for the patients.

Summary

On the whole, both patient and staff evaluation of the group corresponded with the writer's initial statement of goals and purposes. This lends some validity to the effectiveness and benefits derived by participation in this experience.

Letters

The desire by group members to write letters to key administrators (to convince them of the need for such groups) acted as a testimonial in itself as to how members valued this experience. This activity was not part of the planned evaluation design. There was recognition that such groups should be led by professionals, and thus an appeal made to allocate funds towards such an important endeavour. The letters were responsible for a lot of future "talk" held by administrators on this subject, and aroused curiosity on the part of those addressed as to the unquestionable need these people were presenting.

> "... The traumatic ramifications that accompany the shock of discovering that one is a Cancer Victim are many, and so are there are many needs to be attended to aside from medical treatment."

> "I feel this group has helped me to appreciate living, if not entirely a full life, at least a worthwhile life."

> "The result has been that many of us have gained strength from the sessions, and have changed our outlook towards cancer in general, now discuss it quite openly and have erased much of the fear associated with the disease in its many forms."

These letters fulfilled the purpose of the autobiography in the way of demonstrating to the worker that patients self-perceptions had indeed changed.

(1V) The Goldberg General Health Questionnaire - 30 item U.S. Scale.

The G.H.Q. (see Appendix A) was administered five times over a period of five months, according to the following schedule.

Time 1 - Pre-Test	G.H.Q. mailed two weeks prior to first group session but after selection for the group.
Time 2	G.H.Q. distributed 1st meeting.
Time 3	G.H.Q. distributed 8th meeting.
Time 4	G.H.Q. distributed 16th meeting (total of 17 meetings).
Time 5	G.H.Q. mailed one month following group termination.

TABLE 1

Goldberg General Health Questionnaire Scores Gathered from Eight Group Members

Time 1				Subjects			G.H.Q. Scores
$\bar{X}$ = 3.75 1 2	2 12 *	3 0	4 8	5 Absent	6 1	7 0	8 7
Time 2 $\bar{X}$ = 3.25 1	8	0	6	8	0	0	3
Time 3 $\bar{X}$ = 2.50 11 *	0	0	2	5	1	0	1
Time 4 $\bar{X}$ = 2.50 1	16 *	1	0	1	1	0	0
Time 5 1.25 2	1	6	0	0	1	0	0
$\bar{X}$ = Mean							

N = 8 number that remained in the group

0 = least distress

30 = most distress

Observations - Speculations (see Table 1)

Subject 1 - Time 3 - Score "11"

This person reported to the writer as she handed back the G.H.Q. that she was in a "terrible mood" at the time she filled out the form due to family problems unrelated to her cancer, and wanted me to know that her response would be very different than on previous occasions.

Subject 2 - Time 1 - Score "12"
Subject 2 - Time 4 - Score "16" - so deviant from remainder of scores at Time 4.

Both scores can be linked to this person's perception of her disease state as she related to the writer. The first score of "12" coincided with the possibility of disease recurrence and general distress in reaction to that. The second score of "16" also coincided with a change in treatments causing this person much discomfort. She, as well, named her distress as being partly attributable to recent family problems with a separated daughter moving back home causing some disruption.

Subject 3 - Time 5 - Score "6"

Note a change from little or no distress to a score of "6". This clearly coincided with a rapid physical deterioration, hospitalization and death two weeks following completion of the G.H.Q.

A question raised by several of the individual extreme scores is whether the group's effectiveness is limited when it comes to family problems, since scores in a few cases were high in relation to this. Although members reported family difficulties, the questionnaire is not designed with items to measure one's relation with one's spouse, parents, or children, even though they may all be sensitive indicators of emotional distress. (Goldberg, 1972)

Conclusions

The mean score results show a tendency toward a downward trend

($\bar{X}$ = 3.75, 3.25, 2.50, 2.50, 1.25). However the means are of limited value as a measure of central tendency due to the small population size n = 8, and the high variability of scores.

In this analysis, it is probably more meaningful to note individual patterns of the eight remaining group members: (see Table 1) Two subjects (#6 and 7) showed a stable pattern of low distress. One subject (#1) showed a stable low pattern with one dramatic increase. Three subjects (#4,5,8) showed a pattern of initial moderate distress to low distress. One subject (#3) showed initial low distress with an increase after the group's termination. One subject (#2) showed a highly variable pattern.

With such a small sample group, I question the value of the Goldberg General Health Questionnaire as a measure which indeed allows a quantitative index of group.

Measures would be best used to demonstrate periodic distress member changes levels of individual members. With a much larger sample size and control group design, this evaluative tool probably would be more effective (as demonstrated by Vachon's research in Ontario).

Summary

It is my hope that this study will provide a basis upon which more in-depth evaluative research will be performed. My aim in this study was to provide the vividness of "what it was like" with an appropriate degree of clarity. Questions currently being posed by those looking to fund future endeavours of this nature have not been completely addressed by this study, at least not in quantitative terms. The evaluative component is vital with respect to the recognition and acceptance of the emotional components in illness as legitimate and necessary targets for treatment, and hence the need to establish permanent programs which will address the issue.

D) Termination Revisited

Although the worker's contract terminated in April, much has developed since then as a result of the year's work. The chief oncologist at the cancer clinic has been pressing various departments for funding of a social work position to continue this type of work on a more established basis. Thus, the writer has been involved in several meetings with key administrators, presenting program descriptions, and speaking to funding bodies (Manitoba Cancer Society, Manitoba Cancer Research Foundation) to solicit support for psychological services for the cancer patient. The current direction involves the preparation of a research proposal for a grant large enough to develop several groups, and to include a built-in evaluative component. Local interest has been aroused in the value of emotional support systems for cancer patients.

The Toronto Conference, Symposium on Coping with Cancer, (April 1977) sponsered by the Canadian Cancer Society highlighted the "lacks" in cancer treatment. A strong representation from patients in the symposium presentations caused a shift from the traditional emphasis on medical care, to"holistic care." A plea was made to allocate a few thousand out of the millions devoted to cancer research (all biology research) on helping those "who do not know how to cope."

Thus for me and the members, this group was only a beginning. Both worker and members have been involved in health professional inservice programs.*

The usefulness of this study has been demonstrated by the expressed desire of the part of the oncologist at the cancer clinic to hire a social worker to implement support services of a similar nature. It is my hope that the establishment of such a position will become a reality. The oncologist's strong interest in itself fulfilled one of my key objectives of addressing the medical technology of cancer in light of the role that emotions play.

* To date (August 1977) the group has been invited to six gatherings of health professionals [nurses, social workers, and students]. Three to five of the surviving eight group members have attended these sessions. As well several members have made many visits to other cancer patients upon request by hospital nursing and social work staff.

NAME

DATE

APPENDIX A

Goldberg General Health Questionnaire
30 item U.S. Scale

IN THE PAST MONTH:

1) - been able to concentrate on whatever you're doing?

better than usual	same as usual	less than usual	much less than usual

2) - lost much sleep over worry?

not at all	no more than usual	rather more than usual	much more than usual

3) - been feeling mentally alert and wide awake?

better than usual	same as usual	less alert than usual	much less alert

4) - been feeling full of energy?

better than usual	same as usual	less energy than usual	much less energetic

5) - been having restless, disturbed nights?

not at all	no more than usual	rather more than usual	much more than usual

6) - been managing to keep yourself busy and occupied?

more so than usual	same as usual	rather less than usual	much less than usual

7) - been getting out of the house as much as usual?

more than usual	same as usual	less than usual	much less than usual

8) - been managing as well as most people would in your place?

better than most	about the same	rather less well	much less well

9) - felt on the whole you were doing things well?

better than usual	about the same	less well than usual	much less well

10) - been able to feel warmth and affection for those near to you?

better than usual	about same as usual	less well than usual	much less well

IN THE PAST MONTH:

11) - been finding it easy to get on with other people?

better than usual	about same as usual	less well than usual	much less well

12) - felt that you are playing a useful part in things?

more so than usual	same as usual	less useful than usual	much less useful

13) - felt capable of making decisions about things?

more so than usual	same as usual	less so than usual	much less capable

14) - felt constantly under strain?

not at all	no more than usual	rather more than usual	much more than usual

15) - felt you couldn't overcome your difficulties?

not at all	no more than usual	rather more than usual	much more than usual

16) - been finding life a struggle all the time?

not at all	no more than usual	rather more than usual	much more than usual

17) - been able to enjoy your normal day-to-day activities?

more so than usual	same as usual	less so than usual	much less than usual

18) - been taking things hard?

not at all	no more than usual	rather more than usual	much more than usual

19) - been getting scared or panicky for no good reason?

not at all	no more than usual	rather more than usual	much more than usual

20) - been able to face up to your problems?

more so than usual	same as usual	less able than usual	much less able

IN THE PAST MONTH:

21) - found everything too much for you?

not at all	no more than usual	rather more than usual	much more than usual

22) - been feeling unhappy and depressed?

not at all	no more than usual	rather more than usual	much more than usual

23) - been losing confidence in yourself?

not at all	no more than usual	rather more than usual	much more than usual

24) - been thinking of yourself as a worthless person?

not at all	no more than usual	rather more than usual	much more than usual

25) - felt that life is entirely hopeless?

not at all	no more than usual	rather more than usual	much more than usual

26) - been feeling hopeful about your own future?

more so than usual	about same as usual	less so than usual	much less hopeful

27) - been feeling reasonably happy, all things considered?

more so than usual	about same as usual	less so than usual	much less than usual

28) - been feeling nervous and strung-up?

not at all	no more than usual	rather more than usual	much more than usual

29) - felt that life isn't worth living?

not at all	no more than usual	rather more than usual	much more than usual

30) - found that you couldn't do anything because your nerves were too bad?

not at all	no more than usual	rather more than usual	much more than usual

APPENDIX B

Hôpital Général - St. Boniface - General Hospital
409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6
(204) 233-8563

PLEASE CHECK: **EVALUATION OF CANCER GROUP** DATE: ____________

Nurse ________
Nursing Assistant ______
Physician ________

Please give each question some thought and try to elaborate. Please return to Karen Behar or John Farber in the Social Work Department by April 8, 1977.

1) What implications did the group have with your relationship with the patients? eg. demands placed on you, group members seeking more and/or different kinds of information regarding their disease and treatment, questions regarding procedures, etc.

2) Did you observe any changes in group members' attitudes, moods, or approach to their disease during the time of the group?

If so, what?

Would you feel comfortable attributing this change to the group process?

3a) Have you had any positive feedback from group members regarding the group?

If so, what?

3b) Have you had any negative feedback from group members regarding the group?

If so, what?

3c) Which was dominant (positive or negative feedback)?

....2

4) To what extent did you feel involved in the events of the group?

To what extent would you have liked to have been involved? Please explain.

5a) Are groups of this nature an advantage to the patients? Please elaborate.

5b) Are groups of this nature an advantage to the clinic? Please elaborat

5c) If groups are an advantage, which types of patients should be selected for this?

5d) Who should be responsible for leading such a group.

6) Do you feel there are any negative effects of the group? Please elaborate.

7) Would you like to see a social worker employed in the Cancer Clinic? If so, why?

If not, why?

8) In addition to my running the group, what activities would you have lik me to engage in at the clinic? Please elaborate.

9) General Comments:

APPENDIX C

Hôpital Général - St. Boniface - General Hospital
409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6
(204) 233-8563

NAME: ____________________ EVALUATION DATE: ____________________

Please give each question some thought and try to elaborate. Please return this to me next week.

1a) Prior to attending the group, what were your expectations regarding what might happen at the meetings?

Were these expectations fulfilled? __________ If so, in what way?

If not, in what way?

1b) Prior to attending the group, what were your expectations regarding the outcome of these meetings?

Were these expectations fulfilled? __________ If so, in what way?

If not, in what way?

2a) Was the group helpful to you in any way with working through any difficulties you may have had? Please rate how helpful, by circling a number on the following line. (0 = least helpful; 10 = most helpful)

0 1 2 3 4 5 6 7 8 9 10

Explain what was helpful to you.

2b) Was the group harmful to you any way working through any difficulties. Please rate how harmful by circling a number on the following line. (0 = not harmful; 10 = most harmful)

0 1 2 3 4 5 6 7 8 9 10

Explain what was harmful to you.

3) What did you think of the leader?

....2

What were the leader's three strongest points?
1.

2.

3.

What were the leader's three weakest points?
1.

2.

3.

4) If such a group were to run again, what changes would you have made. Please explain.

1. Number of meetings
2. (Time) length of meetings
3. Choice of group members
4. Leader
5. Location (home or hospital)
6. Any other changes

5) Would you have preferred the group to continue indefinitely or for a different length of time? Please explain.

6) Was there anything you would have liked to discuss that was not covered in the group meetings? Please explain.

7) Has the group been responsible for any changes in your attitude or belie about your disease? If so, what changes?

....3

8) At this very moment, what do you think about your situation?

Is it different than before?

9) General Comments:

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