CANCER AS A CHRONIC ILLNESS:
A STRENGTH-ORIENTED APPROACH TO SOCIAL WORK PRACTICE - RESHAPING AN ECOLOGICAL PERSPECTIVE

by

Kathleen Joan Jenson

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ABSTRACT

In constructing this practicum, the author endeavoured to move away from a disease-model framework for conceptualizing human behaviour. Shaping this process were two observations based on her review of the literature and her practice experience up to that time: 1) the power to effect change was a transactional process between person and environment, and 2) even in the face of loss, living with chronic illness demanded reconstruction and growth. The intent had been to locate an interventive model concerned with the promotion of health and the interplay between person and environment. In choosing Carel B. Germain's construction of the ecological approach which located 'problem' at the interface between person and environment rather than within the person, and which stressed health and potential for growth, the author thought she had found an appropriate model. However, moving the 'problem' to the interface served only to move the 'deficit' in functioning from within the person to the connection between the person and his/her environment. The focus still centred on identifying and correcting problems, limitations or maladaptive transactions instead of locating and promoting the transactional strength of the connections made and the actions put forth. Encountered in the author's work with persons who were experiencing cancer the illness was a forward movement that did not fit the strictures of 'adaptive' or 'maladaptive'. In response to her struggle to develop interventive skills that would address this forward movement, a strength- or competency- oriented model of social work practice evolved. Proposed is a model which combines Germain's construction of the 'person- environment fit' and Anthony N. Maluccio's emphasis on 'competence clarification' into a practice approach that recognizes the forward movement of new learning which occurs through the process of living with chronic debilitating disease.

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To Joan, who heard my struggle, helped give it a voice, and in doing so, gave me room to grow . . .

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INTRODUCTION

The tailoring of psychosocial interventive skills to the needs of those facing chronic debilitating physical illnesses such as cancer is conceptually young. Much of the available literature in this area has concentrated on depicting the human experiencing of long-term physical illness and the process of death and dying. There is little to draw on to direct psychosocial interventions geared towards the daily issues of living with the impact of debilitating illness processes.[1] When reviewing the application of interventive models developed in other areas of practice, none stood out as clearly addressing the needs of those faced with the day-to-day existence of long-term illness. Hence, the reader will <u>not</u> find within this paper the concise, focused development of an interventive approach briefly documented, applied and evaluated in the context of a given setting. This practicum experience began as an exploratory process, simultaneously attempting to put the author in touch with the significance of the situation of illness for the client group involved, help her negotiate with that client group a person-environment fit best suited to cope with that significance, and to improve her interventive skills. Specifically, the author chose to accomplish this by (moving away from traditional therapeutic modalities of intervention which viewed human behaviour out of a disease-model framework, planning instead to develop a more health-oriented focus and approach.) The contents of this practicum report detail the author's rationale for emphasizing a health-oriented approach and her struggle to achieve this in her interventive skill development. The culmination of this struggle is a proposal for the construction of a strength- or competency-oriented model of social work practice for application in the area of chronic debilitating physical illness.

An extension of the work already completed in translating the ecological approach to social work practice into action principles, this model draws heavily on the work of Carel B. Germain[2] and Anthony N. Maluccio.[3] Proposed is a model which she attempts to combine Germain's construction of the 'person-environment fit' and Maluccio's emphasis on 'competence clarification'[4] into a practice approach that recognizes the forward movement of new learning which occurs when an individual or group of individuals confront a chronic debilitating disease.

From the literature and her social work practice experience (extensive background experience with the health care setting), the author She sees saw that chronic illness could represent a number of losses, but that it also demanded reconstruction and growth in order to continue the daily process of living. This process was carried out in ongoing transaction with the environment. Therefore, the any interventive model chosen by the author to direct her practice experience needed to address within its conceptual framework this ongoing person-environment transaction and the demands for reconstruction and growth. Carel B. Germain's application of the ecological perspective to social work practice did both with its emphasis on the interplay between individuals and their environment, and on the adaptive process.[5] Going into this practicum the author did not intend to change or alter Germain's approach, only to test its applicability for social work intervention with those persons experiencing the impact of chronic debilitating disease. However, in the author's struggle to achieve clarity of action in the application of Germain's model, certain conceptual tenets were not congruent with the needs and demands of the practice setting or those of its consumer population. Specifically, the author found Germain's problem-oriented focus to be particularly confining and incongruent with the intended emphasis of Germain's model on 'progressive forces', 'health' and the 'potential for growth'.[6] The author's rationale for abandoning the problem-oriented focus is documented by drawing together support for her position from the literature and from her own struggle to apply Germain's model within The Manitoba Cancer Treatment and Research Foundation.

Initially, the block to the author's use of the problem-oriented focus came from the consistent resistance of consumers to define any part of their struggle to live with the psychosocial impact of cancer as problematic. This resistance persisted even though the author altered her terminology. As the author began to re-examine the focus of her interventive intent, matching what she was hearing and witnessing from the consumer's perspective with what she saw herself being able to offer the consumer, the relevance of a problem-oriented focus for this setting came into question. The consumer was experiencing the forward movement of new learning, but this was neither appreciated nor addressed by a problem-oriented focus. By focusing on the identification of problems, the distress and anxiety inherent in the process of moving forward were seen as problematic and antithetical to the growing process instead of as a necessary part of new learning: for example, that which occurs when a reorientation of perspective or the retracing of one's sense of continuity in response to a loss is required.[7] Whether located within the system or at the interface between the systems concerned, the problem-oriented focus concentrated on identifying and correcting deficits. Forward movement was seen as either blocked or threatened. The need to seek out and identify problems restricted social work's entry into the helping network until a blockage in forward movement had occurred or was threatened. This limited the use of social work's competency to the repair of broken and endangered connections, and restricted its vision of the person-environment fit to determining what was problematic about the nature of the connections made. Normative standards from which deviations could be measured were, therefore, necessitated. In an area where the variety and effectiveness of the ways in which people faced with a chronic illness cope is far from clear, given the context of their life circumstances, the use of normative standards was premature at best.[8]

Moreover Within ~~the context of the model proposed in this paper,~~ interventive efforts are concentrated on assisting the systems concerned (person and environment) to realize their combined potential to enhance one another's existence. This begins by understanding how each one's pursuit of survival and growth is integrated and balanced within the overall network.) Each piece must be understood in the context of its relation to the other components of the systems considered. The forward movement of the systems concerned need not have stopped, slowed or even have been threatened for intervention to occur. The object is to construct the network of connections in such a way as to maximize their potential benefit for the survival and growth of all the parts concerned. (The focus is on enhancing the competencies of the systems involved and the strength of their transactions.)

To survive means ". . . to remain or continue in existence or use . . ."[9] and to grow is ". . . to increase by natural development, as any living organism or part by assimilation of nutrient . . .".[10] Growth in the context of this paper employs the forward movement of new learning and those environmental qualities which nurture this forward direction. It is the author's belief that to determine any living system's adaptive potential, its survival and growth needs must be understood in relation to the survival and growth needs of those living systems with which it connects.

Contained within the first chapter of this practicum report is the author's theoretical rationale for choosing the ecological model of social work practice and her practicum objectives. These are followed in chapter two by a detailed account of Germain and others' construction of the ecological approach, a brief critique regarding its application in the area of chronic illness, and the design of the author's proposed model accompanied by support from the literature for the direction taken. The objective of the third chapter is to familiarize the reader with the nature of cancer the disease and the illness, its chronic features and some of the more defined interventive approaches to its treatment, biologically, psychologically and socially. From this chapter certain themes arise: the unpredictable nature of cancer the disease, the implications of this unpredictability for the human experiencing and treatment of cancer the illness, the prevalence of a problem-solving orientation and the tendency to separate the mind from the body in the construction of interventive approaches utilized in this area. Chapter four introduces the practice setting and begins the process of broadening the reader's focus by mapping the 'structure of the field', its interfaces and communication pathways. This chapter seeks to acquaint the reader with The Manitoba Cancer Treatment and Research Foundation, its origin, subsystems and the systems of which it is a part. To the extent possible, given the author's position in the organization (student) and limited access to informal communication channels, it depicts Oncology Social Work's position in relation to the overall policy and direction of the setting: the amount of influence Oncology Social Work has in determining this direction, its relation to the survival and growth needs of some of the other components that comprise the network, and the implications of all this for social work practice in this setting. The reader, at this point, should have a beginning understanding of how some of the systems connected with the

Cancer Foundation come together, balance and integrate their functions. Because the design of the proposed model grew out of the author's fieldwork experiences, chapter five will depict, through her struggles as a graduate student in the Cancer Foundation, how the systematic connections presented in chapter four influenced the adaptive strivings of the consumer and the author. The conclusion, chapter six, attempts to pull together the major tenets of the practicum report, summarizes how the practicum objectives were met, and puts forth some suggestions for future study.

INTRODUCTION

FOOTNOTES

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Chapter 1

THEORETICAL RATIONALE FOR INTERVENTIVE APPROACH AND PRACTICUM OBJECTIVES

Within the last century, reliance on scientific methods and the evolution of the "germ theory of disease" have helped the medical profession make significant strides in the control of acute, infectious disease.[1] Instrumental in winning public confidence, this success in methodology has encouraged in medicine an emphasis on the biological/physiological processes of the human body and on the elimination of disease entities.[2]

Control of one form of disease, however, only works to uncover the next challenge and new challenges often require a reorientation in perspective. Perspective reorientations force the learner to rework previous frames of reference when they are no longer able to explain what is being encountered.[3] Medical concentration has in recent years shifted from dealing predominantly with acute, infectious disease to chronic disease.[4] Medical confrontation with chronic disease has necessitated a 'perspective reorientation'.

Chronic, by definition, means "lasting a long time or reoccurring".[5] The majority of chronic diseases are not communicable, their onset not as obvious, and their duration longer than that found in acute, infectious disease.[6] Medicine's dependence on an approach that has excluded social and psychological factors in the etiology of disease, and which attempts to isolate a sole biological determinant of the disease process, has not met with the same success in the eradication or control of chronic disease. Chronic disease appears to suggest the influence of several elements, some of which are not biological in origin.[7]

The need to push the boundaries of thought beyond this biological/physiological limitation has also been felt in the treatment realm.[8] Whether people identify themselves as ill, whether they accept treatment goals, and how they respond to treatment efforts all demand consideration of social, environmental and behavioural factors. Efforts to move the treatment of disease beyond its somatic variables, however, have suffered some conceptual difficulties. Previously successful methodologies are not easily revamped or abandoned. Medicine's preoccupation with disease and its physiological determinants has, in George Engel's words (1977), left ". . . no room within its framework for the social, psychological, and behavioral dimensions of illness."[9] The fact that disease and illness conceptually do not have interchangeable identities is not semantically clear from their usage in medical literature.[10] The significance of this for the structure of the therapeutic approach in the treatment of chronic disease is that human behaviour and its appropriateness in the illness realm become tied to the presence or absence of the signs/symptoms of disease. This has resulted in a tendency to confine treatment efforts to the biological eradication or control of disease, without adequate recognition of its social and psychological effects. As well, it has produced a treatment approach to human behaviour that assumes the existence of pre-established norms of behaviour from which deviations can be measured and subsequently adjusted. When behaviour is recognized as influencing the treatment process, the implications of this disease-oriented approach have been to limit the focus of subsequent research and clinical studies to the identification of abnormalities in behavioural responses.[11] Seeking an appreciation of the meaning of the disease for its bearer and those occupying his/her social environment becomes an effort to categorize the response as normal or abnormal, healthy or unhealthy. Jane Rosser (1981) provides us with an example of this in her critique of the literature on the female experience with breast cancer.

> Having established the nature of the problem: an accepted physical treatment may have adverse psychosocial consequences, the literature then adopts a problem-oriented approach. Rather than investigating the meaning of women's experiences, their concern has been to plot the incidence and severity of emotional and physical trauma in women's reactions to loss of a breast, and then to account for the 'abnormal'. The meaning of the 'normal' reaction is taken as unproblematic, the focus of analysis being on deviations from what is perceived as normal.[12]

The danger of such an inductive process is that the helping person assumes an understanding of the appropriate behavioural response and deviations from this theme are no longer seen as legitimate. In Rosser's words, they assume a 'moral value'.

> The woman who reacts 'abnormally' is by definition 'neurotic'. Her reactions stem from 'deeper neurotic conflicts'; they are irrational. They are seen as resulting from her particular defective personality, not as legitimate responses to breast loss.[13]

Treatment efforts become corrective, seeing the cause of the inappropriate response as rooted within the individual. Attention is centred on the individual ignoring external pressures which affect behavioural responses. It disregards the possibility that what is viewed as abnormal may, in reality, be the most appropriate response to a stressful situation for that person.[14] Chronic disease demands a long-term interaction with the health care system. The success of therapeutic interventions to combat the disease process is dependent on the quality of this relationship.

For the purposes of this practicum report, a distinction will be made between illness and disease using Ellen Idler's (1979) definitions.

> Illness, the human experiencing of disease, is an explicitly social phenomenon with both an objective and a subjective quality. A person's experience of ill health includes both behavioral changes and feelings of being sick, each of which are intimately related to the person's social context.
>
> Disease is an abstract, biological-medical conception of pathological abnormalities in peoples' bodies. Diseases are indicated by certain abnormal signs and symptoms which can be observed, measured, recorded, classified and analyzed according to clinical standards of normality.[15]

The subjective element of illness involves the significance of that condition to the individual, while the objective element includes the actual physiological changes and accompanying social alterations the disease process imposes upon the person. Twaddle (1974) indicates that ". . . normative standards against which health and illness are judged vary with medical training, social class, and ethnicity."[16] Therefore, it should be noted that while the abstractions of health and illness may have biological referents, their presence or absence appears to be rooted in psychological and social definition.

> . . . disease can occur in an individual without [her]his ever being aware of feelings of sickness and without those around him[her] knowing him[her] to be other than in a "normal" state . . . .
>
> . . . .
>
> . . . it is also possible that persons may feel sick--even so miserable that they are incapacitated--without any of the organic processes of disease being manifested.[17]

Illness is not always accompanied by disease and vice versa.

Consideration of the psychosocial aspects of chronic disease, more specifically, cancer, has focused on maladjustment and the identification of high-risk groups.[18] While efforts have been made to ascertain the significance of the disease process and its accompanying treatments for the individuals affected, the frameworks used to structure these studies have begun with a problem-oriented focus. Eisenberg (1977) states that "once in place, models act to generate their own verification by excluding phenomena outside the frame of reference the user employs."[19] It is the contention of this report that such beginning points assume a prior knowledge of what is appropriate behaviour, clouding an appreciation of the variance of responses that can occur as a natural product of the illness experience. Because of this focus it becomes important to develop a conceptual framework that does not insist on judging human behaviour as abnormal, unhealthy or maladaptive, but instead, sees all behaviour as an adaptational response to a social situation.

Hinkle (1973) states that survival of the human organism is dependent on the specificity of its response to threats to its internal state.[20] However, the organism's repertoire of adaptational responses directed towards neutralizing or re-routing such threats is limited in its diversity.

> . . . The evolution of adaptive reactions has not proceeded as rapidly as the changes in the situations which evoke these reactions, and there are many vestigial components of these reactions which are not directly useful, and may be damaging.[21]

Considering the many diverse and unfamiliar transactions an individual may encounter with his/her external environment in her/his social and biological life, it is possible that the endurance of his/her adaptive repertoire will be tested frequently throughout this time period. The interaction between the individual and his/her environment is not static and, therefore, is subject to constant change. Hinkle (1973) refers to the internal world of the human organism as being in a constant state of metabolic operation subject to the influence of its external environment in a pursuit to maintain a balance in internal functioning.

> . . . over the lifetime of any one living organism, that organism not only maintains its own organization in the face of many influences that tend to disorganize it, but even increases the degree and complexity of its organization during parts of its life cycle.[22]

Much of the exchange between the human organism and the environment which helps to maintain this balance is informational in nature and mediated via the organism's sensory mechanisms and central nervous system.[23] Hinkle indicates that this exchange is oft times more indirect than direct, stating that a sizable portion of the environment is contained apart from the individual in both immediacy and location, and consists of other persons and social groupings.

The process the individual evolves to maintain a balance in this psychological-physiological network of interchange between the internal state of the organism and the state of its external environment can be viewed as the process of coping. Its success in the maintenance of this balance can be termed adaptation. Using Tom Cox's (1978) definition, stress will be perceived as follows:

> . . . a perceptual phenomenon arising from a comparison between the demand on the person and his[her] ability to cope. An imbalance in this mechanism, when coping is important, gives rise to the experience of stress, and to stress response. The latter attempts at coping with the source of stress. Coping is both psychological (involving cognitive and behavioural strategies) and physiological.[24]

Chronic disease and its accompanying illness experience create a change in a person's life circumstances producing the 'experience of stress', coping response(s) and an attempt by the individual to adapt to this change.

As stated previously, there is a need to appreciate the variance of responses that can occur as a natural product of the illness experience. To develop this 'appreciation', some knowledge must be gained regarding the bio/psycho/social struggle chronic disease presents. Ellen Idler (1979) emphasizes the need to recognize the interplay between the condition of being ill and its significance for each individual. Using Alfred Schutz's view of social reality, Idler sees the bodily operations of the healthy individual as allowing the individual's conscious awareness to concentrate unhindered on the external happenings of daily life. Illness disrupts this process, requiring the individual to be more consciously aware of his/her internal state. In explaining Schutz's thoughts, Idler states that

". . . the natural attitude of everyday life is characterized by a quality of 'taken for grantedness'."[25] This "taken for grantedness" status assumes an important conceptual position when viewing illness behaviour in chronic conditions. Chances are that up until an individual is faced with a chronic condition, his/her experience with illness has been short-term, with finite boundaries of sickness and wellness. In the case of many physical diseases, the term 'chronic' goes beyond meaning a long-term or reoccurring "static" condition; it has become synomymous with progressive deterioration and a state from which total recovery is not a definite option. Chronic illness not only disrupts the individual's life equilibrium--it can demand behavioural changes in both the person and those occupying her/his immediate social environment. Depending on the nature of the disease and its continued effect on bodily functioning, these behavioural changes can be recurrent. When viewed in total, the long-term nature of chronic illness and its lack of finite boundaries between sickness and wellness disrupt one's "taken for grantedness" position in a more immediate and ongoing way than does acute illness.

> . . . the crisis of illness may extend over a relatively long period of time, presenting the patient with a complex set of new issues and circumstances over which [s]he has little control and leaving [her]him in a state of tentative equilibrium which may be shattered at any moment.[26]

Illness brings one's sense of existence to the forefront, emphasizing that it is confined within a beginning and an end.[27] The individual's life-style must now learn to incorporate this new element of chronicity and all that it means in terms of self-concept, changes in roles and functions, and his/her social support network.

Chronic illness can represent a number of losses, but it also demands reconstruction and growth in order to continue the daily process of living. Murray Parkes (1971) uses the term "assumptive world" to describe an individual's perception of his/her environment as it presently exists and as it might exist.[28] Individuals use their concepts of the environment as it might exist to work through a repertoire of possible behaviours to be acted out if this environment becomes a reality. Change which is expected provides the opportunity for preparation, increasing the likelihood of making a smooth transition from one stage to another.[29] Peter Marris (1974) takes the concept of continuity and attempts to distinguish between change as "growth" and change as "loss".[30] Whether change represents another way of meeting the same needs or exposure to previously unexperienced territory, continuity is maintained if the basic assumptions a person holds regarding the 'purposes and expectations' of life remain unchallenged. However, if these 'purposes and expectations' are destroyed or disfigured, the continuity is lost.

> When the loss is irretrievable, there must be a reinterpretation of what we have learned about our purposes and attachments--and the principles which underlie the regularity of experience--radical enough to trace out the thread again.[31]

The change that accompanies the advent of a chronic illness is not usually anticipated and often demands a major reconstruction of the individual's assumptive world. It can challenge the continuity of the meaning of the person's life as (s)he has imagined it up to that point.

Parkes' reconstruction of the 'assumptive world' and Marris' retracing of the 'threads of continuity' are suggestive of an ongoing transaction between the individual and her/his environment carried on throughout the human lifetime. Although both theoretical constructs deal with loss, it is depicted as part of the process of living: an ongoing struggle to adapt to an ever-changing environment. Chronic disease and its treatments do not just effect acute phases of psychological distress, but demand ongoing adaptive reactions. The long-term nature of these adaptational demands is overlooked by much of the research and therapeutic labour concentrated in this area. Mages, et al. (1981) noted that the psychosocial effects of cancer received the most attention, both in the literature and the treatment network, during acute phases of the disease process when the individuals affected were in close proximity to the health care system. This was in spite of their finding that the long-term effects of the illness experience were not fully comprehended until the individuals studied returned to the daily process of living their lives away from this network of services.

> It is when they attempt to resume the interrupted course of their lives that patients come fully to grasp what has happened to them and the pattern of their long term adaptation begins to take shape.[32]

The persistence of this acute care mindset can be more fully recognized in a study by Marcella Davies (1980) which looked at rehabilitative staff in a hospital setting where most of its patient population exhibited one or more chronic illnesses. From her observations she concluded that though the major portion of patient care had restorative aspects that extended beyond the limits of the hospital, these aspects received minimal acknowledgement by the staff.[33] It becomes apparent that chronic illness is dealt with from an acute care framework that concentrates on the 'disease' as an 'entity' rather than the 'person' as 'entity'. The long-term personal struggles to adapt to the residual effects of this illness experience are largely unrecognized. Consequently, it becomes easier to see behaviour which disrupts this focus as problematic and in need of correction, and not as a natural part of negotiating a new balance with a changing environment.

Treatment goals when dealing with acute disease are usually directed towards cure, implying a more short-term association with the health care network. In chronic disease, where cure is less accessible, the treatment goal often becomes control of the disease process, with involvement in the health care system increasing accordingly. There is a greater demand on the individual experiencing the chronic illness to participate in carrying out the treatment regimen, oft times within his/her home setting.[34] Extending the therapeutic program beyond the official hub of medical care (i.e., doctor's office or hospital) involves and affects those occupying this social sphere.

Decisions to make use of medical technology when faced with a chronic disease are difficult. Often the disease-bearer must choose within a limited period of time between a treatment that can create pain and/or physical mutilation or the unrestricted progression of the disease. Introduction to the world of medical technology usually occurs at a pace which runs counter to the human need to gradually assimilate unfamiliar experiences. Being able to organize and understand the course of our lives in order to make the necessary decisions concerning our survival demands that we first make the unknown known. Peter Marris (1974) states that, "We cannot act without some interpretation of what is going on about us, and to interpret it we must first match it with an experience which is familiar."[35] Decisions to participate in treatment efforts require enough skill in communication to gain the information necessary to make this transition and subsequently to negotiate the treatment network. The development of effective interpersonal skills becomes an important adaptive trait.[36]

Confronted with a chronic disease, the person and those (s)he is involved with respond to the meaning of the experience of illness, not just to having that disease. In a disease-focused health care system, the tendency of health care staff is to respond to the disease.

> Cancer represents an extreme example. The dread diagnosis alone elicits anxiety; in addition, patients confront disruption of their life routines, a series of difficult and usually frightening tests and treatments, and the uncertainty of their very survival. While patients focus on these issues, the doctors' attention is riveted on testing or treating that aspect of the cancerous growth relevant to their specialized knowledge, but invisible to the patient.[37]

With the foci of attention on the disease and not the person as a whole, the need to make the therapeutic relationship a mutual involvement becomes less crucial. The norm becomes acceptance of patienthood and compliance with treatment efforts.[38] Implicit in this stance is the assumption that the helping person is in possession of all the necessary knowledge to effect the most desirable course of action. What it does not acknowledge is that the decision to co-operate in therapeutic endeavours is more often than not characterized by a weighing of sacrifice versus gain for the persons involved.[39] While the structure of a disease-focused system may not acknowledge the disease bearer and his/her significant others as a mutual and reciprocal partner, the individuals affected are aware of the totality of their personhood and react accordingly.[40] Hence, the development of effective interpersonal skills aids the individual in drawing attention to his/her personhood, and in an assertive and positive way demands that it be given consideration. In this manner an experience with disruptive potential can be managed more easily, giving the persons involved the breadth to adapt to the changes presented.

Problem-oriented models of psycho-social intervention may elicit a mutuality of involvement in the identification of problems to be worked on and the methods used to effect this action. However, such models still demand that the individual(s) see their concerns as problems which require correction, disclaiming their legitmacy as natural responses to a changing environment. What such approaches fail to recognize in their design is the irretrievability of the loss of health and/or function that chronic disease presents. With acute illness the disruption of the familiar may be traumatic, but it retains the hope of complete restoration; disruption is seen as temporary. In the chronic illness experience, the disruption is ongoing. The familiarity of health itself is lost, and all that it meant for the future course of life as those affected knew it or had planned it. Loss creates a sense of disorientation; it breaks the 'threads of continuity'. Reorientation is a learning process. Taylor (1980) states that movement into the next learning phase does not occur unless the learner is able to confirm with others knowledgeable of the event that the state of disorientation is appropriate to the experience and not a personal failing.[41] If personal affirmation is forthcoming, the learner is able to relax, becoming more open to the exploration without demanding an answer. The need to react, to present ambivalent feelings and to plot out one's own personal experiencing of the change must be acknowledged and allowed to evolve.[42] Such a process of reintegration resists categorization and time limits. When the anxiety which accompanies such disorientation and confusion is viewed as problematic, there is a failure to recognize the forward motion of new learning. To demand a course of action to correct this motion is to impose the constrictions of time and method on a process that resists these confines.

Psyco-social intervention with those experiencing a chronic disease must, therefore, appreciate the following:

1. The totality of the person as a bio/psycho/social being.

2. The significance of the situation of illness for those persons affected.

3. The variance of coping responses that can occur as a natural product of the illness experience.

4. The need to be concerned with reconstruction and growth, seeing the illness experience as a learning process.

5. The need to acknowledge and respect the reciprocal and mutual nature of the relationships established.

6. The need to view human behaviour in its totality: as an ongoing struggle to adapt to an ever-changing environment.

In view of the above, Carel Germain's (1979) ecological perspective of social work practice seemed to appreciate best the interplay between individuals and their environments, seeing it as a natural part of being.

> Emphasis is placed on progressive rather than regressive forces, on health rather than on "sickness", and on the potential for growth.[43]

Within the ecological approach both the "adaptive capacities" of the individual and the "nutritive qualities" of the environment are looked at with the goal of negotiating a more growth-producing intercourse between the two.[44] The focus is not narrowed by concentrating interventive attention solely on the individual. Instead, a structure is provided which can be used to view all the systems affected by the chronic illness experience, including the care-giving network (see eco-map, Germain, 1980). Individual autonomy and competence are respected.

> . . . an ecological perspective views humans as active, goal-seeking, purposive beings who make decisions and choices and take actions guided by the memory of past experiences and anticipation of future possibilities.[45]

Because autonomy and competence are seen as existing in all the human components involved in the helping relationship, the interdependence of the participants becomes more recognizable. All members of the helping relationship bring skills and information, though what is brought may vary in content and development. By seeing the relationship as reciprocal and mutual in gain, it can be conceded that care givers also receive.

> This brings home the common humanity of worker and client and undermines worker-client relationships which are based on an unequal distribution of power.[46]

Interpretation of human behaviour is not confined by the situation in which it occurs but is seen as one part of a lifetime effort to adapt to a continuously changing environment. Behaviour is viewed as the end product of both genetic endowment and environmental conditions, influenced by culture, cognition and the use of free will and choice.[47] The human need to bridge the gap between what has gone before, what is happening in the present and what it will mean for the future[48] is addressed when human action is seen as being influenced by past experience and by assumptions regarding the future.

With these points in mind, the author chose to use Germain's (1979) ecological perspective as an approach to understanding the interventive skills which would be most useful in assisting those experiencing a chronic illness. The primary intent of this practicum was as follows:

1. To increase the author's awareness and understanding of the client's social reality, with social reality being defined as the significance of the situation of illness for the client group involved.

2. To help negotiate a person-environment fit that will best assist clients in coping with that reality.

3. To improve the author's interventive skills.

To make the achievement of this venture more manageable within the time frames proposed, the author chose to explore the human experiencing of one chronic disease group known as cancer. The term "disease group" is used because cancer as a disease has over one hundred different manifestations which are not consistent in their area of occurrence, their speed or form of development, or in the type of treatment used to combat their progression.[49]

Because Germain's ecological approach to social work practice is conceptually young in its development, the finer details of its implementation have not been worked through adequately. As a result, the philosophical aspects of intervention are much better developed than the methods of applying these actions. This poses difficulties in attempting to extract specific interventive skills to be learned as these are not readily identifiable in the literature or in descriptions of practice application. Consequently, the author has attempted to use the philosophical tenets put forward by Germain to guide the development of her own practice style. In doing so she has drawn on the ideas and practice knowledge of other approaches using what can be defined or applied within Germain's ecological framework without changing its philosophical stance.

The goal of the forthcoming chapter is to outline the ecological approach to social work practice in more detail, to assess critically its application within the area of chronic illness, and to describe the author's interventive procedure.

Chapter 1

FOOTNOTES

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Chapter 2

INTERVENTIVE APPROACH

Social work intervention in the medical setting is directly related to the conceptual frameworks out of which the individual social worker and other health care professionals operate. This framework is of vital importance in determining the following:

1. What the client system is (individual, family, group, community, service network).

2. Understanding the behaviour of the client system (illness related, stress reaction, personality, social influences such as ethnic group or religion, reaction to service network).

3. Setting of goals (what is to be worked towards).

4. Methods used to achieve these goals (process of reaching the direction strived for).

Because the dominant normative construct in operation in most medical settings is that of disease, the influences of the mind are viewed as separate entities. What follows from this mind/body dualism is the assumption that psychosocial concerns need only be considered when they present obstacles to the treatment of disease.[1] Mind and body are _not_ recognized as different aspects of the same phenomenon.

The Biomedical Model - Implications for Psychosocial Intervention in Health Care Settings

Because models help people organize and thereby understand their environment, they have an adaptive potential. The 'biomedical model' or 'disease focused' model has received not only wide support within the realms of medicine, it has become the dominant model for understanding disease in North America. Thus, cultural attitudes and belief systems reinforce its existence without questioning its relevance or usefulness in dealing with the phenomenon it faces. Engel describes this unquestioned acceptance as having attained the stature of "dogma". Rather than discard or rebuild the construct when it no longer appropriately explains the factors with which it is confronted, it is retained and the conflicting data are adjusted to accommodate its boundaries or are discounted as unimportant. Though the following quote is written in reference to physicians, it also applies to other health care personnel, be they social workers, nurses, psychologists, etc.

> In our culture the attitudes and belief systems of physicians are molded by this model long before they embark on their professional education, which in turn reinforces it without necessarily clarifying how its use for social adaptation contrasts with its use for scientific research. The biomedical model has thus become a cultural imperative, its limitations easily overlooked.[2]

If psychosocial concerns are seen as secondary to the treatment of disease, services set up to deal with these aspects assume a marginal status in the structure of health care settings. This peripheral existence has strong implications for how those personnel empowered to deal with psychosocial concerns ensure that the system is responsive to these needs.

Psychosocial needs that receive attention only because they divert service energy from the treatment of disease assume a problematic status that requires correction. They become a barrier to the effective accomplishment of the primary purpose of the system. In order to resume the business of treating disease, systematic pressure is placed on changing the individual to effect a better fit with the treatment focus of the system. What is not looked at or questioned is the possibility that the treatment focus may be incongruent with the needs of the individual. Human behaviour is removed from its interactional position and the cause of the disruption is placed within the individual. By accepting a secondary status within the health care network, psychosocial services endorse the central position of disease, thereby relinquishing some of their power to question this position and, subsequently, to change it.

Because it is culturally promoted, the adoption of the disease model focus is so subtle that patterns of behaviour which support this concentration are reinforced even when the health professionals concerned profess to be doing otherwise. Claudia Coulton (1981) used a study by Wooley, Blackwell and Winget (1978) to alert social workers in medical settings to the normative influences of the health care system.[3] Wooley, et al., made the observation that dependent behaviour in patients was unwittingly promoted by health care personnel despite intentions to do the opposite.[4] This observation prompted them to re-examine patient behaviour from an interactional perspective. Where they had previously viewed these behaviours as rooted within the individual independent from the setting in which they occurred, they began to look at the environmental conditions which acted to reinforce the behaviour patterns found. While this article still persisted in viewing the presentation of these behaviour patterns as personal failings of the individuals concerned, it demonstrates that human behaviour does not occur in isolation, but instead is reactive to the environmental conditions the individual confronts.

The subtlety of its indoctrination and the primacy of its position give the disease focus a decisive advantage over psychosocial concerns in the power structure of the health care setting. The reductionism of this biomedical model acts to divert attention from the totality of the person.[5] Scientific method is used to reduce the symptomology into separate diagnostic issues and courses of treatment.

> . . . (in) clinical practice it is typically reflected in the predilection to focus down on one issue at a time and pursue a sequential "ruling out" technique for both diagnosis and treatment.[6]

Psychosocial concerns take their place in this matrix and become separate issues to be dealt with in isolation by separate professionals. Though the approach may be interdisciplinary with each member making a contribution to the process of helping, there is no conceptual incentive to view the effects of their transactions and information exchange on the help offered. Communication becomes limited to that which is necessary for each individual component to complete the task as seen fit.

> . . . the interfaces between the conceptual frameworks of different disciplines are ignored and, as a result, the interfaces between the various arenas of systematic life operation (e.g., biological, psychological, social or individual, family, community) represented by different disciplines are also ignored.[7]

Societal acceptance of this stance leads both the service giver and the service receiver to accept this focus as necessary to the accomplishment of the task at hand and, therefore, they do not question the structure. It becomes enough that psychosocial needs receive attention. The implications of their secondary status and individual acute-care focus for the provision of services are easily overlooked. An article by Rhonda Montgomery (1979) reviewing care policies in long-term care facilities serves to illustrate one form of service outcome indicative of this mindset.

> . . . most policies and regulations have focused on financial administration, medical services, and building codes. Conspicuous by their absence in current regulations and requirements, are provisions which address programs that require personnel to meet the specific social and emotional needs of the people in long term care.[8]

Due to their secondary status, Montgomery states that social service requirements and the execution of these services are substandard. It is her contention that the negative effects of long-term care (i.e., dependency, loss of self-esteem and identity, low staff morale, and high mortality rates) are not an innate element of the institutionalization process; they are the result of an 'individual acute-care model' which gives primacy to the meeting of physical needs. If a conceptual framework views the mind and body as separate processes seeing only the orderly operation of the body as vital to survival, then psychosocial needs not only become secondary in importance, they become expendable.

This procedure of conceptually fragmenting the human organism ignores the complexity of human thought and denies that it is in fact a somatic function in continuous transaction with both internal and external environments. Changes in either of these environments affect and are affected by a person's mental processes. Lazarus (1971) states that it is the individual's interpretation of the meaning of any given stimulus that determines his/her emotional response and, in turn, influences the choice of coping action.[9] He notes two pre-existing conditions which, through their blend, influence the type of emotional reaction produced: "situational" elements, or characteristics of the environmental stimulus, and the "dispositional", or psychological makeup of the person (e.g., personality, values, previously learned behaviour, etc.). Utilizing information from the environment and the person's own internal state, the individual is able to monitor the interchange of reactions between (him)herself and the environment over time, allowing for re-evaluation and changes in the coping response as required. Our capacity for coping is directly related to our ability to 'make sense' of what confronts us.[10] In order to do this we must first determine the meaning of these events for the course of our existence. Peter Marris (1974) states that, ". . . meanings are learned in the context of specific relationships and circumstances, and we may not readily see how to translate them to an apparently different context."[11] The complexity of restructuring our understanding and sense of purpose regarding our interactions with the environment prompts us initially to protect what is familiar, thereby resisting change until the process of reorientation allows us to move forward.

> Resistance to change is, then, as fundamental an aspect of learning as revision, and adaptability comes as much from our ability to protect the assumptions of experience, as on our willingness to reconsider them.[12]

It is human thought that guides the total human organism to seek assistance when its internal operation is disrupted by disease.

Psychosocial processes in interaction with the environment influence the course of this contact. A human system which is blind to the psychosocial needs of its participants is deficient in its understanding of what determines the survival of the human organism.

Viewing human behaviour as problematic when it moves the focus of the system away from disease has important repercussions for what is viewed as adaptive. Because this framework does not draw attention to or question its own role in the transaction, human responses that do not meet its expectations are seen as requiring change.

> Social workers in health care have long focused many of their efforts on attempting to change clients so that the needs of these individuals would be more congruent with what the environment provided.[13]

In order to uphold this conceptual structure, environmental changes must remain as peculiar to the client system in question and as an exception to the prescribed conduct or practice of the system.

> Most social workers are skilled in individual case advocacy, with their own or another agency, securing entitlements for a particular individual, family, or group, or obtaining an exception to a policy or procedure.[14]

Adaptive comes to mean an attitudinal fit which upholds the prevailing technological approach of the treatment modality in use. Change is seen as a cognitive process which begins within the individual and ends with a perceptual alteration of self in transaction with the environment.[15] Because the power for change is believed to reside within the individual, environmental modification is viewed as an individual force made possible when the person is equipped with the required skills. Inability to effect a better fit within the environment becomes a personal failure to master the necessary skills.

> . . . there has been a continuing tendency to see mastery of the environment in terms of intrapsychic mechanisms that allow individuals to control psychologically the environmental stimuli impinging upon them and to maintain a state of personal comfort. . . . some investigators have broadened their scope of study to include such concerns as the learning and use of skills and the direct manipulation of the environment, but this new development has not been very systematically developed. Almost all stress investigators, irrespective of their orientations, neglect consideration of the relationship between social structure and mastery.[16]

While some attention may be given to the societal supports or preparations (i.e., personal history, socio-economic level, etc.) present for the achievement of this person-environment fit, little heed is paid as to how conducive the conceptual structure of the health care setting is to meeting the survival needs of the individual (biologically, psychologically and socially). David Mechanic (1974) states that, "Man's abilities to cope with the environment depend on the efficacy of the solutions that his culture provides, and the skills he develops are dependent on the adequacy of the preparatory institutions to which he has been exposed."[17] A culture that prepares its members to view their psychosocial needs as unimportant when interacting with the health care system does not equip them adequately to cope effectively with the life-changing impact of a chronic disease.

The Ecological Approach - Its Strength

The strength of the ecological approach to social work practice is its 'vantage point'. Its emphasis is not on the identification of pathology or maladaptation, but on developing an appreciation of the variance of adaptive responses possible.[18]

Rather than follow a linear process of reductionism, the area of attention broadens to achieve an understanding of the context in which the event occurs before it narrows to determine the course of action.[19] To negotiate a more growth-producing person-environment fit, it becomes important to understand the nature of the transaction between the person and the environment. It is not necessary to determine the normalcy of the event. Although the data presented may be similar to that observed by other theoretical constructs, what changes is the angle from which it is viewed and, hence, the way it is organized.

> . . . [it] changes the vantage point of the data collector. It focuses precisely on the interfaces and communication processes taking place there. It begins with an analysis of the *structure* of the field, using the common structural and operational properties of systems as criteria for identifying the systems and sub-systems within it. And by tracing the communications within and between systems, it insists that the structure, sources, pathways, repository sites and integrative functions of messages become clear in addition to their content.[20]

Focusing on the interactional process increases the chances that the exchange of information between participants will be an integrative experience as opposed to a fragmenting one. Both client and helper are recognized as learners in a collaborative endeavour where each member of the system provides a resource for the other.

> The relationship itself is viewed as a transactional system in which the worker and client(s) each serves as environment to the other. Each shapes the other. They learn and grow together, and the sense of human relatedness is enhanced in both.[21]

For each participant's investment there is a return and the nature of this return influences the transactional process.

Person-Environment Fit - Reciprocity and Mutuality in the Helping Relationship

By accenting the reciprocal exchange between person and environment, it is no longer possible to view the power for change as resting solely within the individual. The environment is not a passive recipient of the cognitive mastery of the person. It can both discourage or support personal growth, initiative and coping behaviour through the 'climate' it provides.[22]

> . . . the kinds of motivation that people have and the directions in which such motivation will be channeled will depend on the incentive systems in a society--the patterns of behavior and performance that are valued and those that are condemned. Finally, the ability of persons to maintain psychological comfort will depend not only on their intrapsychic resources, but also--and perhaps more importantly--on the social supports available or absent in the environment.[23]

Self-esteem and feelings of personal competence are gained through interactions with fellow human beings and the social systems they occupy. Autonomous behaviour occurs only when the necessary encouragement, time and space are given by the environment, both physically and socially.[24] Personal growth, therefore, is not the specific responsibility of the individual. Growth-producing change is as likely to involve a restructuring of the environment as an alteration in perception of self. Effective social adaptation is decided by the degree to which environmental demands are accompanied by the necessary social supports.[25]

Germain (1981) states that, ". . . work with the environment is usually classified or designated as indirect, in contrast with direct work with clients, conveying an impression to practitioners and students that it is somehow less important."[26] The educational development of most professional helpers has emphasized the need to identify abnormality (problems) in human functioning to discover the cause, and to institute corrective measures.[27] Because the foci of concentration in these frameworks remain on the individual and her(his) intrapsychic functioning, the environment assumes a secondary position. Environmental change becomes localized to that individual and his(her) specific concerns. From this perspective it becomes possible to see alterations in the system's policies and procedures as exceptions made to meet the specific needs of the client(s) and not as questions regarding the adequacy of the system's conceptual framework for meeting human need. The pervasiveness of this focus on individual pathology is evidenced in a study by Anthony Maluccio (1979a) which examined interpersonal helping by comparing the impressions of social workers and their clients.

> Most clients felt that they had received help and gave evidence to support their conviction that they were functioning adequately, that they were strong enough to cope with life challenges, and that they had sufficient resources in themselves and in their environments. Workers, on the other hand, stressed the clients' problems and weaknesses, highlighted their underlying conflicts and raised doubts about their capacity to cope in future life situations. The workers' more pessimistic outlook was evident even in cases in which they acknowledged that there had been positive changes in the clients' functioning.[28]

In identifying aspects of the helping process that were most useful in creating improved functioning, social workers more often noted the worker-client relationship, while clients saw it as only one factor among many in their resource network. Clients more frequently stressed the influence of significant life happenings and informal helping agents (e.g., friends, relatives, etc.). This would appear to suggest that from the viewpoint of the client, the professional helper was one element in a system of resources that clients drew upon to assist them in their interactions with an ever-changing envronment. Maluccio found the workers' preoccupation with the therapeutic importance of the helping relationship led them to overlook the positive influence of events and networks external to this relationship. Workers routinely assigned less importance to the positive and negative influences of the agency's environment, including its policies and procedures, and to the positive aspects of family relationships.

> Clients tended to view positively their relationship with members of the kinship system, whereas social workers tended to define the same relationships as problems and obstacles in the client's functioning.[29]

By concentrating on the worker-client relationship giving the environment only secondary consideration, understanding of how the client and his(her) social/physical environment connect is blocked and, hence, the worker's awareness of (his)her place in this resource network. If the helping professional sees his(her) role as identifying client limitations and weaknesses, giving only passing acknowledgement to client strengths, the task becomes the elimination or control of these elements. The environment is evaluated as supporting/eroding this effort and subject to change depending on the verdict. By focusing on the identification of disease, the strength of the interchange is overlooked. Preoccupation with 'curative powers' diminishes the importance of the growth that has occurred. In addition, it fosters unrealistic expectations of the place and nature of interpersonal helping in the client(s)' sphere of functioning. It distorts the helper's perception of the influence s(he) has on the client(s)' life.

> . . . workers tend to view clients as reactive organisms with underlying weaknesses and limited potentualities, while the latter present themselves as active, autonomous human beings who enhance their competence and functioning through use of personal and environmental resources.[30]

The ecological perspective does not isolate the individual from the environment, but instead sees him(her) as one component in an intricate ecological system.[31] The role of interpersonal helping is to understand the interplay between the many factors that influence the person-environment fit. It is no longer necessary to be obsessed with the need to cure as the object is to promote growth, not diagnose disease.

Understanding the interface between person and environment demands equal recognition of the 'adaptive capacities' of the person and the 'nutritive qualities' of the environment. Neither can assume a secondary status if the helping professional's interest is centred on the interaction between the two. Comprehension of how one component connects with another is not possible if the structure of one or the other remains unknown. By diverting the focus from discovering internal imperfections to understanding what it is like to occupy the individual's life space, energy can be pulled away from defending one's sense of personal competence (both the helping person's and the identified client[s]') and put towards mutual exploration.

Because the professional helper is part of the individual's life space, and vice versa, it is important for the professional to understand the nature of this connection.

> . . . in talking about role induction into counseling or therapy, we should not think simply in terms of induction of the prospective clients, as we usually do. . . . Perhaps more important, we should also think about induction of the worker, who needs to be socialized into the prospective client's norms or ways of thinking, feeling, and perceiving. Socialization, in other words, is a reciprocal undertaking between client and worker rather than the one-way process that is usually portrayed in the literature.[32]

Both must be aware of the influence of their separate statuses in the structure of the helping relationship. The requirements of each position are different and the expectations of each participant vary between members. To provide a productive association, each member must become familiar with how the pressures and demands of each respective role determine the 'climate' of the relationship. In order for reciprocity and mutuality to exist and develop, the professional helper must view her(his) client system as a true partner in the helping process, one which is capable of making a meaningful and equivalent contribution to the course of the association.

If professional helpers see themselves as one resource among many from which clients draw upon for assistance, and not as the primary helping agent, it becomes easier to see clients as competent, autonomous human beings able to initiate and negotiate the type of aid required with the helper. When clients are encouraged to have an active role in determining the nature of a therapeutic association, the knowledge and skills they possess regarding their bio/psycho/socio lives become more assessable. Without client participation the professional helper does not have access to this resource. Failure to gain access and utilize this expertise can profoundly influence the success or failure of the help offered.

> Without direct exposure to the client's environment, the practitioner cannot adequately evaluate its quality or significance in the person's functioning or treatment. Such an evaluation is crucial, since there is considerable evidence of significant interplay and even interdependence between the formal helping system of an agency and relevant social networks and informal influences in the client's life.[33]

Unlike the professional helper, clients have an ongoing involvement in the negotiation of their own person-environment fit. They are in possession of a type and level of knowledge, skill and experience derived from this ongoing transaction--a level of competence that has ensured their survival and growth to that point in time. Mutuality and reciprocity do not imply the development of an egalitarian relationship as the type and level of knowledge, skill and experience offered varies between members within the interpersonal helping system.[34] It does mean, however, the development of a 'climate' that encourages an open exchange of knowledge, skill and action, and an appreciation for the type of competence each participant brings to this association.

The Person

Competence. Anthony Maluccio (1979b) defines competence as ". . . the repertoire of skills, knowledge, and qualities that enable each person to interact effectively with the environment."[35] The level of competence developed and maintained is influenced by an ongoing interaction of internal cognitions of self in relation to the social/physical environment encountered; ". . . competence involves intrinsic as well as extrinsic motivation, social skills as well as personal abilities, and effective performance for self as well as society in one's social roles."[36] Three elements of self-perception in transaction with three complimentary environmental conditions can be seen as significant in molding a sense of personal competence.

> . . . the sense of efficacy or potency in controlling one's destiny; the attitude of hope; and a favorable level of self respect or self-acceptance. Corresponding environmental inputs or components in the social system re: opportunity (e.g., supports or resources), which stimulates and reinforces the sense of hope; respect by others, which provides the social ground for respect of self; and power, which guarantees access to opportunity.[37]

Competence deals with accomplishment, simultaneously drawing attention to both the person and environment, and their transactional strength. When the process of interpersonal helping begins with an attempt to understand the adaptational strength of a behaviour as opposed to its detriments, the professional helper is forced to develop an appreciation for the intricacies of the client system's coping style. The identified client(s) moves from a position of being scrutinized for personal limitations to being seen as a capable human being able to successfully manage the process of living. By focusing on success the need to identify failure diminishes. The object is to understand first what is necessary for survival and, secondly, what maximizes the opportunity for growth-producing interactions. Within the ecological perspective it is recognized that the skills, knowledge and personal attributes necessary for achieving competence are developed through transaction with an environmental climate that provides both the resources to develop these elements and the opportunities to use them. Feelings of competence are not static in their achievement. They must be regained or retested whenever environmental circumstances present new challenges.[38] Each successful transaction promotes a sense of confidence that future transactions will also be successful and, consequently, reinforces feelings of power in determining the course of one's life.

Identity. Identity, or how one sees (him)herself in relation to others, is also ongoing in development and nurtured by the environment. Interpersonal reactions to ethnic origins, sex, socio-economic level, etc., help mold self-perceptions throughout life. Images of self become tied to body presentation, employment, physical and social prowess, etc. Alterations in any of the baselines that an individual uses to define (him)herself in relation to others necessitate a reworking of self in relation to environment. New statuses, such as patienthood or those resulting from physical or social impairment due to the effects of chronic disease, can threaten to change or actually change how the person relates to his(her) social and physical environment. Environments which fail to consider their impact on the individual's sense of worth can act to erode self-esteem placing the person in a devalued position. Because traditionally interpersonal helping has been concerned with identifying pathology and with the need to cure or control, clients have been seen as reactive to helping efforts.[39] When only the expertise of the professional helper is seen as important in the helping process, the client(s) is automatically placed in a devalued role. By failing to acknowledge the client(s)' expertise regarding his(her) own life (past, present and future) it is not seen as relevant to include clients in the process of making decisions and assessments concerning their lives.

> The surgeons and oncologists either lack the time or arrange their schedule in such a way that they cannot provide the time for the kinds of support and information the patients crave. The patients felt their physicians were too impersonal and too authoritarian. They resented not being kept fully informed and being excluded from important decisions regarding their own treatment.[40]

Where interpersonal helping falls short of being a mutual and reciprocal endeavour, there is little incentive to recognize the depreciating effect of this power differential on the client. Ann Hartmann (1978), in an effort to develop a method that would enable social workers in child care agencies to become more in touch with their clientele's life space, developed a technique of mapping* interpersonal relationships using an ecological perspective.[41] She found the following change in worker-client interactions.

> Foster care workers noted that parents who were generally angry and self-protective following placement of their children because of abuse or neglect were almost without exception engaged through the use of the map. Workers were aware of a dramatic decrease in defensiveness. The ecological perspective made it clear to parents that the worker was not searching for their inner defects but rather was interested in finding out what it was like to be in the clients' space, to walk in their shoes.[42]

No helping relationship exists without both investment and gain by all the participants involved. To disregard the importance of any member's contribution is to minimize his/her sense of worth and, hence, the sense of control over her/his life. "To be told the meaning of your life by others, in terms which are not yours, implies that your existence does not matter to them, except as it is reflected in their own."[43]

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*"Eco-map" will be defined and discussed later in this chapter.

Autonomy. The human organism is governed by both an internal organization and an external environment, each of which draws from and gives to the other. By responding to the demands of each, a degree of freedom from both is maintained. Autonomy is determined by the individual's ability to govern this balance of freedom. Bondage to one over the other severely impairs freedom of operation in the neglected sphere.

> . . . if defenses are so strong that one is no longer in touch with inner needs, one is in danger of losing one's autonomy to the environment, passively conforming to environmental demands. If, on the other hand, one fails to maintain one's ties to the environment for any reason, or fails to receive adequate sensory-perceptual stimuli, one is in danger of losing one's autonomy to the inner world, enslaved by biological and autistic preoccupations.[44]

To guard against being overwhelmed by the demands of either domain, the individual must be granted the time and space to assess each situation and to decipher what course of action, if any, is required. White (1976) refers to the need to leave room to 'maneuver' and the time to appraise both the risks and benefits which may emanate from unfamiliar situations.

> . . . adaptation often calls for delay, strategic retreat, regrouping of forces, abandoning of untenable positions, seeking fresh intelligence, and deploying new weapons. And just as recuperation from serious illness is not the work of a day, . . . so recovery from a personal loss or disaster requires a long period of internal readjustment that may not be well served at the start by forceful action or clarity of perception. Sometimes adaptation to a severely frustrating reality is possible only if full recognition of the bitter truth is for a long time postponed.[45]

Efforts by identified clients to resist professional interpretations of their circumstances or refusals to follow through with treatment plans have been seen by professional helpers as indicative of personal weaknesses within the clients concerned (e.g., unmotivated, defensive, hostile, etc.). Refusals to accept the helping system's stance or goals have rarely been viewed as enactments of autonomous behaviour commanding respect for the client(s)' right to be involved in the planning of actions which affect (his)her existence. White draws attention to a subtle but pervasive supposition in professional dictations that portrays the 'mentally healthy' individual as having strived for and attained a stable level of cognitive mastery over the environment, enabling him(her) to confidently meet life's obstacles with little hesitation.

> . . . in the psychological and psychiatric literature there lies a concealed assumption that dangers must be faced because they are not really there, that any delay, avoidance, retreat, or cognitive distortion of reality is in the end a reprehensible piece of cowardice.[46]

What is ignored is that cognitive mastery is attained within and in response to certain environmental circumstances; it is not static in its acquisition. Neither personal needs nor environmental demands remain constant. Cognitive mastery is an ongoing process in the face of change. Demanding enough freedom from the pressures of an environment (that professional helpers are well acquainted with and indoctrinated into) to assess the merits of compliance and/or learn the mechanics of is not easily understood by the system's members. Seeing themselves as acting from a stance of compassion and humanity, professional helpers often fail to consider the risk of compliance with therapeutic actions, or negate its existence, for the client or client systems with which they deal.

> The patient's attitude to his illness is usually considerably changed during and by the series of physical examinations. These changes, which may profoundly influence the course of a chronic illness, are not taken seriously by the medical profession and, though occasionally mentioned, they have never been subject of a proper scientific investigation. . . . The most that a patient can expect is reassurance--routine, well meant, usually wholesale, and as often as not, ineffective.[47]

Time and space are required to develop an awareness of how personal need interlocks with environmental demand.[48] Information is selectively gathered in response to environmental pressures with the dual purpose of determining patterns of action while concurrently protecting one's sense of self. Self-preservation depends on an ability to predict the course of future events, to test ideas and to influence the terms of negotiation. These movements require appropriate skill development, access to resources (informational, etc.), and an environment which is receptive and supportive to their utilization. When autonomous action is seen as a strength and respected as such, it compels the helping professional to attempt to listen with the goal of understanding the reasoning behind the client's stance. The professional's position is not automatically assumed to be the most appropriate one.

> The tendency to "close down" the reception of new data in a new and threatening situation may look and act like resistance, when it is in fact an adaptive attempt to maintain a sense of self and a sense of control over the environment. . . . Perhaps patients resist therapists because therapists have failed to convince them that the reality they are offering is better than the one the patients already have.[49]

Autonomous action is a product of human relatedness, its expression and form arising from the level of competence and identity formation attained by the individual, family and/or group at any one point in time.

Human relatedness. Human relatedness is the simultaneous development of a sense of difference and a sense of connectedness within both a social and physical environment. It is the coming together of human beings for the purposes of survival and growth, and it is the creation of a sense of place. Above all, it is transactional, happening at the interface where person meets environment.

> Those who are uprooted from their neighborhoods by urban development sometimes respond to the loss with depression. The loss is felt not only with respect to the network of human relationships within the neighborhood, but is also derived from attachment to the layout, design, structure--the ambience--of the neighborhood itself, which has become part of the sense of relatedness and belonging.[50]

Biologically and socially, the bonds human beings form with their physical and social environments are essential to their survival. The psychological and social nurturance that makes movement from birth through adulthood possible is a product of human beings caring for one another. The interactional quality of this interdependence can determine personal survival and the degree and type of growth attainable. Environmental complexity demands group actions to ensure individual survival.[51] As the human organism grows and matures over time, issues of how and when to depend on others or act independently from them must be reworked according to changes in individual needs and in environmental challenges and/or demands. Receiving care and caring for others is a lifelong process with a nature and form that is in constant need of modification to ensure human growth and survival.

> Relatedness is the essence of identity, but it also reflects the kind of autonomy that permits one to be either dependent on others or independent as the situation requires.[52]

Issues of autonomy and interdependence become lost in a health care system that deals only with individuals at an intrapsychic level. To see people as interactive beings means knowing that they are part of a larger system, be that a family, a neighbourhood, a place of employment and/or an ethnic grouping which have interactive significance for them, and which influence and are influenced by the actions and demands of helping professionals and their systems.

Environment

Much has been said within these pages about the "environment" --its demands, the person-environment fit and the importance of its nutritive qualities. Yet, its composition is still to be defined. What is this "environment"? Ecologically, the environment is seen as having two layers: the physical environment and the social environment; and, two textures: time and space.[53] The nature and form these layers and textures take find expression in and are influenced by cultural values, norms, knowledge and beliefs. Each layer can be further stratified into the natural and built worlds of the physical environment, and in the social environment, social networks, organizations and institutions, and the societal level, depending on the stage of social systemization.[54]

Physical environment.

Within the physical environment the natural world consists of animate and inanimate nature. Animate nature contains all living matter, both plant and animal. Inanimate nature contains the mineral, land and water formations, and atmospheric qualities that constitute the earth's planetary makeup, including all planetary and extra-planetary actions governing and changing their relationship to one another (e.g., volcanic action, erosion, changes in the atmospheric layers surrounding the earth, etc.). The built world involves any structure or object created by human initiative, its effects and the effects of any human action on the natural world (e.g., slag dams from mining operations, forest restoration or tree harvesting, designating tracts of land as parkland areas, urban development, therapeutic and iatrogenic medications, food additives, transportation and communication systems).[55] While distinguishing between natural and built worlds assists the conceptual process, this distinction is deceptive.

> Although increasingly alienated from the rest of nature, human beings are inextricably part of the natural world, so their activity is as "natural" as the nest-building of birds. . . . the separation of natural and built is a useful heuristic device for delineating environmental complexities, providing its artificiality is kept in mind.[56]

Noting the illusionary quality of this deception, the contextures of time and space can be seen as weaving the layers of the physical environment together.

Time can be ultradian (less than 24 hours) and circadian (about 24 hours) in its rhythms, such as the daily movement from light to darkness, and it can be seasonal and annual in its cycles governed by the earth's planetary and orbital position in relation to the sun. In the physical realm of the environment, time can also be paced by cyclic motion of human actions.[57] Time is pacing, duration and rhythm.[58] The internal operation of the human body has its own series of biological rhythms. Each system or parts of a system have their own tempo that must mesh with that of other systems or parts of a system. Most of these rhythms and the manner in which they interlock with one another are beyond our conscious awareness, except perhaps when they fail to mesh, such as in the event of damage, disease or stress.

> The discomfort of jet lag is now understood to be due to various systems being out of phase. Body temperature, for example, takes six days to come into phase with the new time schedule, while the heart rhythm takes eight days, and so forth.[59]

These internal rhythms and those of other plants and animals have become entrained through the evolutionary process with the cyclic motions of the physical environment in accord with the earth's planetary movement.[60] Although the rhythmicity of biological rhythms seems to be predetermined by genetic code and is not necessarily extinguished by changes in the environment, these alterations can influence the pace and ability of various internal systems to mesh with one another.

Psychological time appears to be acquired through human beings experiencing their environments.

> Piaget points out that when a baby cries with hunger, [s]he has [her]his first experience with duration, with waiting. When [s]he begins to use a stick to reach a toy, the baby has established a primitive sequence of the succession of events in time.[61]

The organization of 'events in time' (meals, play/work, etc.) to coincide with an individual's biological rhythms can assist future growth and adaptation by aiding the development of an awareness of self in relation to the physical and social spheres of the environment. A disregard for individual physiological pacing may impair functioning in these spheres.

> Certain social cycles of time created by human beings may violate these temporal aspects of our biological nature. Institutions for congregate living, hospitals, schools, social agencies and work sites, for example, have their own temporal structures which may or may not fit humans' biological rhythms.[62]

Being able to recall past happenings and to influence the future through the observation and manipulation of past and present events means human beings can affect and change their environments rather than just being affected by them. Such actions become an integral part of self-identity, giving a sense of connectedness over time.

> The loss of temporal anchors contributes to the pain of those who suffer from disorganized ego states. The loss is experienced as a discontinuity with the past and the lack of a future, in which time itself appears to be empty, even dead. Past, present, and future become hopelessly mixed, so that the sense of identity is fractured as in a dream.[63]

To create a better person-environment fit, all persons attempt to manage time through pacing. Attempts to accommodate new conditions may take the form of delay, moving slowly or overcome with speed, depending on which combination ensures self-protection while meeting the demands of the situation. It may also mean a greater concentration of effort in one area as opposed to another. Attention paid to the temporal balance of events confronting a person and how they fit together may assist individual mastery more than concern with the events themselves.

As with the concept of time, people learn about space through their experience with it over the course of their lives. Where a person is in the life cycle may determine which space is open to exploration and under what circumstances, and which space is off limits (e.g., a cupboard full of cleaning agents is locked to prevent the intrusion of a young child). Through the process of growing older, individuals develop their own sense of what a particular space, its dimensions and organization, mean to them alone and to those around them. This perception becomes part of the formation of their identity, influencing their use of space and its future impact on them. Drawing on the work of Ottelson, Franck, and O'Hanlon (1976)[64], Carol Germain (1981) illustrates this by describing five possible ways of experiencing the physical environment.[65] Individuals may see themselves as being entirely separate from the physical properties of their environment. Their sense of self is distinct and apart in space from the natural and built dimensions of this physical world. In this perception the physical environment may change, but the self remains the same. For others the physical environment forms a part of the self. These persons have a well-defined sense of their human qualities as being distinct from the natural and built worlds of their environment, but see their sense of self firmly rooted in its physical composition. To alter the physical environment, therefore, is perceived as an alteration of the self. There are those for whom the physical environment exists only as a setting in which acts of human connectedness are carried out. The arrangement of objects in space, animate and inanimate, natural and built, are only apparent in the context of shared experiences. Space may be experienced as depleted or hollow, not because of the physical properties it entails, but because of the absence of human involvement.

> . . . the task of mourning is supported by working on the relinquishment of the attachment in the context of shared places, now so stark as one confronts the absence of the loved one.[66]

The environment can also be experienced as an 'emotional territory' where its physical properties stir a sense of emotional connectedness. They may be included in memories, provide links with past, future and familiar events, all drawing forth different emotional dimensions of self, giving the physical layout an emotional quality all its own.

> . . . it ranges from a sense of the sacredness of the homeland to the deep and abiding love for places that were intimately associated with activities of one's childhood, youth, or, perhaps, adulthood. Such a place might be a mountain forest, a street corner, a vista, a neighborhood, or a building. . . . treasured places acquire a curious permanence in the memory, their presence evoked by a fleeting sound or scent.[67]

Last, but not all inclusive, there are those for whom the physical environment is important only as a location for human action. The human experiencing of the environment, as the environment and human action come together in an ongoing reciprocal interactive process, is largely ignored. Action is set apart from the experiencing of it within a designated space.

> Residents and staff alike may take environmental arrangements for granted, and the passive orientation to spatial arrangements may lead to resignation, apathy, and a sense of powerlessness. . . . "rooms are set up initially to be convenient for giving nursing care." . . . Although flexibility in the use of space is admittedly difficult, Brown suggests that because staff become so used to arrangements as they are, they give little or no thought to more therapeutic uses of space that would enhance the patient's individuality, dignity, and autonomy.[68]

Missing from this perception of the physical environment is an understanding of and an appreciation for the ongoing, reciprocal process that determines how the environment will direct human ambition and its execution, while the effects of this human action simultaneously change the scope of future encounters within this environment.

Knowing space and acting upon it through a perception gained by experience with it is only one aspect of this process. There are many forces in the environment, both physical and social, that exist beyond our immediate awareness altering space and/or restricting human use of it. These include phenomena as diverse as the dictates of government, culture and economic status; the effects of and/or responses to disease processes; and, geological or atmospheric alterations such as earthquakes and air pollution. Therefore, the environment is both objective and subjective.

> . . . (1) the objective environment that exists independently of the person's perception of it; and (2) the subjective environment as it is perceived and reported by the person.[69]

Part of each individual's sense of identity, autonomy and social competence is formed and reformed through dynamic and continuous transactions with perceived and actual (objective) environments, be they social or physical.

> As a consequence of social, cultural, and personal factors, people's perceived (subjective) physical environment may differ from the actual (objective) environment, or from the subjective environments of others who share the same physical setting.[70]

Having briefly outlined the layers and textures of the physical environment, it should be remembered that the separations made are artificial and, therefore, deceptive. Although they assist in understanding the complexities of the physical environment, these dimensions--natural and built, time and space--cannot be considered in isolation from one another without distorting understanding. Using the work of Steele (1973) which draws on Maslow's (1954) human need hierarchy, Germain outlines six characteristics of the physical environment that enhance human growth and survival.[71] It is Germain's contention that these characteristics may provide interventive guidelines for increasing the nutritive properties of the physical environment.

The first of these attributes is security and shelter. Physical environments must be structured in such a manner as to provide protection from those environmental elements which could be harmful or whose presence is not desired or requires limitation. This includes protection from the stress these elements can produce, both physiologically and psychologically. Stress occurs when there is an imbalance between environmental demand and the personal skill/capacity needed to meet this demand (see p. 7, chapter 1). An imbalance can result from having to contend with an excess of stimulation, with insufficient stimulation, exposure to injurious environmental toxins, etc. People may, therefore, attempt to structure the settings they occupy to reduce the risk of adverse reactions to toxic, excessive or inadequate environmental elements through the organization of space, development of protective devices, or by limiting the time and level of exposure.

> The functions of shelter are elemental protections--protection for nesting activities; retreat from stimulation, aggression, threat, and social contact; and emotional recuperation. The lack of fit between spatial characteristics and these human needs and interests can retard or prevent the successful resolution of life tasks.[72]

Depending on the struggle, the same physical setting can simultaneously be both a source of distress and protective. Growth means being in a continuous process of change. When faced with the demands of change, however, people may be reluctant to move forward, feeling unsure about their capacity to meet the challenges presented. They may dislike a physical setting because of the lack of stimulation it gives or the restrictions on self-growth it presents, but feel reluctant to leave it because of the protection it offers from those very things.

> . . . the very bland whiteness of the hospital which I railed against and hated so, was also a kind of protection, a welcome insulation within which I could continue to non-feel. . . . Going home to the very people and places I loved most, at the same time as it was welcome and so desirable, also felt intolerable, like there was an unbearable demand about to be made upon me that I would have to meet.[73]

Social contact is the second environmental attribute to be watched for. The ordering of objects in space can have a significant impact on the amount and type of social contact that is initiated and maintained over time. Whether it is the natural world or the built world, the structures of a physical setting can encourage or discourage social contact. Competence involves interactional skills. Certain characteristics of the social environment, and the needs and capacities of the person work in conjunction with the physical environment to sustain and promote the interactional abilities of people. How much social contact is wanted or needed versus how much is actually experienced can mean the difference between being isolated or crowded. The structure of the physical environment can either assist or act as an obstacle to this process.

> A middle-aged woman who suffered paralysis following a stroke had lived in a county nursing home. She was discharged to her mother's home when the county home was closed.

> *At the county home there were places you could go in your wheel chair. There were people to see and to talk to. Now I just sit in one room all day and I seldom see any people at all, especially on weekends.*[74]

Personal space is that region directly encompassing the individual's physical being. Its expanse is determined by such things as culture, sensory acuity, position in the life cycle and psychological disposition. How near or far one stands or sits from another person can give distinct messages about the level of caring, the nature of the relationship (i.e., intimate or otherwise) and personal importance.

> There were women who were like the aide in the hospital who had flirted so nicely with me until she heard my biopsy was positive. Then it was as if I had gone into purdah; she only came near me under the strictest of regulatory distance.
>
> The status of untouchable is a very unreal and lonely one, although it does keep everyone at arm's length, and protects as it insulates.[75]

Miscommunication can occur when the design of a physical space set according to one person's needs for personal space differs from another's needs.

> Because of declining sensory acuity, the aged tend to interact more comfortably at the intimate rather than at the personal zone. Young staff in facilities for the aged react to what they perceive as intrusiveness by holding the aged person at arm's length.[76]

The development of an informal sharing relationship may be hindered by a spatial arrangement which maintains distance between persons and communicates formality. Whether a space is designated as personal or public can influence how much and what type of sharing occurs in it. Violation of the social norms set for a certain space can produce stress for those occupying it. The design of hospital wards, more often than not, excludes space for the discussion of intimate matters relevant to the individual's health care while in hospital, forcing the exchange of this information to take place in close proximity to one or more other patients and/or staff.

> Territorial behavior . . . is considered . . . to be another means of interpersonal boundary regulations. Possession, marking, and defense of spaces and objects create boundaries that limit intimacy. Territorial behaviors include verbal and non-verbal communications, and draw on such environmental devices as doors, locks, fences, hedges, partitions, uniforms and badges for boundary maintenance.[77]

Families use space to help develop the "interpersonal boundaries" necessary for meeting, simultaneously, the needs of its members and the family as a unit, for intimacy and separateness. How space is structured and utilized changes as the family's needs for sharing and apartness change in its movement through the life cycle.

> . . . members must constantly regulate their spatial relations and boundaries to reach a balance between intimacy and separateness appropriate for the life cycle needs of the family members and of the family itself. Moreover, family members have to occupy the same social space, spend time together, and devote energies to the same activities if they are to gain access to love and intimacy, separateness or autonomy, identity, and be able to develop competence.[78]

A physical setting structured to allow room for private moments alone and for times together can promote comfort in moving, both within the family and in the environment outside the family. Physical environments can, by the quality of their structure or the care with which they are maintained, communicate a non-verbal message about the value of that environment and the people or groups of people who use or occupy it. Materials used or not used in its construction, colours, how close or far apart objects are placed within it, restrictions on its use, what is left in its natural state, what is eradicated for the construction of roads and commercial establishments, and whether broken equipment is repaired or garbage removed--all these elements come together in a common voice to portray a single message about its worth and the worth of those persons interacting within it. Germain refers to this as the environment's <u>symbolic identification</u>.

> The building isn't too appealing. . . . It's very plain. . . . Well, you know, they can't do much about that, since the fact of the matter is that most people who go there are poor, elderly, or on welfare. . . . They couldn't afford to pay for anything more elaborate.[79]

> Well, oh. . . . Someone from the suburbs usually wouldn't go there. . . . We couldn't afford anything else at the time. . . . Oh, I felt a little odd whenever we met someone who was obviously poor in the waiting room. . . . My husband felt like me. . . . We didn't really belong there.[80]

The care with which a physical environment is pieced together and/or treated can be a positive and/or negative force in the events that occur within it, including, where applicable, the competency of those staffing and those utilizing its services. Lack of emphasis and, consequently, understanding of the physical setting's effect on interactions between people have resulted in limited action being taken to harness or alter this force in the pursuit of needed transformations in the social environment.

As people move through the life cycle, their physical environment must provide the necessary setting and tools required to perform those tasks appropriate to whatever point they are at in that cycle. This environmental quality is called <u>task instrumentality.</u> Knowing what is provided is not as important as knowing how it is provided and in response to what (needs, demands, etc.). Any life form, including human beings, must have sufficient space available suitable for the accomplishment of all those functions and actions necessary for its survival as a species. In addition to having a suitable setting, the physical form and content of this setting must be developed in such a way as to be supportive to the ways in which that particular group of human beings lives. It must assist those persons occupying it with the transmission and maintenance of their culture (ways of relating to one another, raising young, etc.) from one generation to the next. Drawing on the work of Spivak (1973), Germain speaks of "critical confluence" or, ". . . the coming together of physiological drive or psychosocial need, the objective of that drive or need, the temporal context (life cycle and otherwise), and the specific archetypal place with which the 'whole' behavior is associated."[81] What is important in this concept is its emphasis on the transactional process that occurs at the point where the person meets the environment. If human growth is to occur, the human need, the materials required to satisfy that need, the appropriate level of development, time and the task-related cultural setting all must meet and be accessible.

> . . . cradling and nursing an infant. In order to successfully engage in these movement patterns, and to experience the events fully and to the ultimate satisfaction of the drive, particular temporal and physical criteria must be met.[82]

The absence or obstruction of any of these factors could prevent or severely hinder the accomplishment of the desired task/behaviour limiting the overall growth of the person.

The two final environmental attributes outlined by Germain are pleasure and growth. Pleasure refers to the sense of gratification one receives from being present in a particular physical environment.

The quality of the air, the meeting of colours, the feel of textures, the amount of space available for action, rural or urban--all those elements, built and natural, refresh and captivate those who chance to experience that space. These characteristics, together with the emotional/physical well-being of the person(s) and his/her sense of past, form a singular feeling of enjoyment that can be the experience of one person or shared by many. Pleasurable experiences can act to balance painful ones, relax an individual enough to allow room for personal introspection, reinforce the person's sense of reality, and provide a source of new energy by giving back more than it demands to be experienced. Growth, as an environmental attribute, looks at all those characteristics of the physical environment that promote growth within the individual, family or group concerned. These could involve its variety, challenge, flair for the unexpected, ability to encourage a desired amount of contact among people and/or provide people with information about their interaction with it. For a disabled person a growth-inducing physical environment might be one structured in a manner that enables her/him to manage the daily activities of living independently.

> A man whose legs are paralyzed and depends totally on a wheelchair, is very handicapped if he lives and works in inaccessible buildings and cannot use public transportation. If, however, he moves to a ranch-style house, gets a job in a building which has an elevator and buys a car with hand controls, he is no longer handicapped since his disability no longer affects his ability to function.[83]

Hopefully, by now two things are evident in this quick overview of the dimensions of the physical environment. The first is the emphasis on the interplay among the pieces and the second is the difficulty encountered in highlighting one piece apart from another. For example, even though we have been dealing with the properties of the physical environment, mention of the social environment has been necessary to assist understanding. What desires scrutiny is the way in which the system comes together. This cannot be understood without an awareness of all the parts involved and the dynamics of the process which fits them together allowing them to maintain their union . . . not a passive process, but a mutual and reciprocal one in which each acts upon and changes the other . . . a transactional process.

How one part acts upon and alters another part of a system and to what extent is greatly influenced by the amount of room available for independent action. Autonomous actions do not occur when access to decision-making processes is blocked or when options for alternative actions are not offered or developed. In the North American society access and choice are often governed by social and financial status.

> Poor people without social power, for example, can have little impact on environments created by others, such as housing projects, hospitals, schools, slum housing, work sites, etc.[84]

Persons whose survival, socially or physically, relies on access to certain goods and services will have more to risk in attempting to effect change in these areas than those who can draw on alternative resources to meet their needs. Human beings, through the relationships they build with one another, can increase or decrease one another's access to the decisions made and to the type of options developed.

Social environment. This brings us to the second layer of the environment, the social environment. Germain defines the social environment as a ". . . network of human relations at various levels of organization."[85] These organizational levels are roughly grouped into social networks, organizations and institutions, and the societal level, depending on their stage of social systemization.[86] They are defined as follows:

> A *social network* . . . represents a set of communication paths and relational linkages such that the individual's behavior is influenced by the connections between individuals in the network, including those to whom he or she may not be directly linked. Included in the concept also are systems of mutual aid, self-help groups, and natural helpers [underlining added].[87]
>
> Beyond the social network is the layer of *organizations and institutions* for the provision of services and resources in the private and public arenas, including the social systems of work, education, welfare, housing, and health care. This layer includes especially the practitioner's own agency, which not only shapes one's practice, but is a salient presence in the lives of one's clients. . . . the social environment is layered at the *societal level* by value systems of the culture, by political and economic structures, and by the environment of law, statutes, policy [underlining added].[88]

To stand and move alone through life in a position of strength, a figure of independence, is more fiction than fact. Supportive human networks, informal and formal, are essential ingredients in the formation of human competence, especially in a society where change is ongoing, often uncorrelated, rapid and complex.[89] Human networks are basic tools for survival.

Social workers are often skilled at identifying gaps in the helpee(s)' support systems and equally skilled at the development and/or use of formal human networks to fill in these gaps. What they are often less skilled at is the identification, exploration and mobilization of those support systems that are already in place for that(those) person(s).[90] Being aware of and understanding the nature of these informal networks comes with recognizing the progressive force they exert in the management of daily living and the strength found in sharing coping skills.

> Were it not for the informal services of helping networks, social agencies--whether they recognize it or not--would be swamped. Besides carrying the bulk of the service load in many sectors, . . . helping networks also carry out a widespread preventive program. They offer accessible, individualized services that formal agencies could never match.[91]

Litwak and Szelenyi (1969) illustrated the endurance and the differential use of social networks in response to technological changes that acted to decrease face-to-face contact in one group (i.e., kin) and accelerate membership turnover in another (i.e., neighbours).[92] They looked at three types of supportive human networks--kin, neighbours and friends--collecting data from one city in the United States and two in Hungary. At the time of writing, the major theorists of the day were contending that all primary groups other than the nuclear family would be pressured out of existence by the demands of technological change. However, what Litwak and Szelenyi found was that group structure and function altered according to the needs and availability of the members. Decisions regarding whether to involve neighbours or kin in supportive roles were made according to the urgency of the task, the proximity of kin and the ability to communicate over distance. Friendships tended to serve their greatest value in situations that fluctuated over time and life stage (fashions, discipline of children, interactions with in-laws, etc.).

> . . . friendships deal with the edges of change and fluctuations, because to deal with the changing aspects of our society it is often necessary to find others in almost matching circumstances.[93]

Technology may have altered their traditional structure and function, but these human networks endured.

Because of its acute-care, disease orientation, the design of the present health care system leaves it wanting when confronted with assisting people in their adaptive struggles and the pursuit of well care. Yet, there are sociomedical services required by people in both of these areas. Self-help groups are one form of social network that has developed in response to the need.

> . . . mutual-help organizations are not social clubs. They are groups organized by patients specifically to provide needed and desired sociomedical services that either do not exist or are unavailable to them. . . . especially in the areas of communication and health education.[94]

Gussou and Tracy (1976) make the point that whenever human needs are not addressed by the formal network of institutions and organizations, some form of social network will come together in an attempt to fill in the gap.

> Ostomy clubs, for example, sprang up simultaneously in a number of American cities in the early 1950s within a few years after ileostomy surgery began to be performed regularly. Surgery was now able to correct the medical conditions, but the management of daily problems and rehabilitation was outside the scope of the medical profession.[95]

Individual human survival and growth require the supportive functions of social networks to meet the demands of daily living. In the words of Speck and Attneave (1971), who based their interventive approach on mobilizing the energies of such networks, their goal is ". . . not cure, not treatment, but enabling people to cope and to share their strengths in coping and also in reaping enjoyments and pleasures that restore their potentials and set them up to handle the inevitable next crisis of living."[96]

The elements that link people to one another are diverse, the result of birthright, career choice, politics, leisure-time pursuits, etc. Social networks may be either natural or artificial (constructed) in their form. The term 'natural' refers to those interconnections that have developed between people as part of the process of daily living. These are the connections that exist because people are members of the same family, neighbourhood, friendship group, school or work place. Interconnections between members of artificial or constructed social networks occur because human need, a common purpose or goal have required the strength of shared coping skills and common experience to further the survival and growth of their members. These groups may come to exist with or without professional input.[97] Self-help groups such as Alcoholics Anonymous, CanSurmount, Compassionate Friends, etc., are examples of constructed social networks. Social networks can be viewed from the perspective of one member of the network (focal unit) or looked at in their entirety (whole network) from the position of an outside observer.[98] For example, a neighbourhood may be viewed from the perspective of a particular family with only those linkages that are relevant for that family studied, or the entire neighbourhood with all its interconnections may be looked at. What is exchanged may be diverse and its character as well as the intent of the connection can alter with time and the demands of various life cycle stages.

> An individual may have one network of people who are likely tennis partners, one consisting of people who might contribute to a cause, and another made up of persons whose advice might be sought when buying a house.[99]

Linkages important for the effective functioning of the whole network may not necessarily be seen as significant by the focal unit.[100]

Awareness of all the existing members and their linkages to one another is not necessary to gain entrance into or benefit from a particular social network. Indirect connections provide routes to resources not otherwise obtainable within the confines of the more immediate direct linkages. These indirect routes are called pathways, occurring whenever, ". . . an indirect link between one individual [focal unit] and another through at least one intermediary . . ." exists.[101] J. A. Barnes (1972) speaks of social networks as having two distinctive attributes--multiple interconnections and chain reactions.[102] Changes in one part of the network will effect changes in another. Thus, when determining, for example, the supportive potential of certain network members, it is important that the energizing or draining effects of their other interconnections within the network are understood.

Social networks can be examined using three different dimensions: structural, interactional and functional.

> Structural characteristics refer to links in the overall network. Interactional characteristics refer to the nature of the relationships themselves. Functional characteristics refer to the functions provided by the network.[103]

Structural characteristics include the "range" or number of direct contacts any one unit has, and "density" indicates how many connections exist versus how many could exist. The interactional characteristics are comprised of content, directedness, durability, intensity, frequency, dispersion and homogeneity. Content refers to the significance of the connections for the individuals involved.

> Linkages containing only one content area are termed uniplex, and linkages containing more than one content area are termed multiplex.[104]

Directedness involves the degree to which the connections are mutual and reciprocal in their exchange of services on both the affective and instrumental levels. How sound the linkages remain over time and the degree to which they must alter the nature of their connection to survive determines their durability. Intensity looks at the affectional ties between network members.

> This is sometimes referred to as *strength of ties*, which Granovetter defined as a "combination of the amount of time, the emotional intensity, the intimacy [mutual confiding], and the reciprocal services which characterize the tie."[105]

Frequency refers to the number of interactions occurring among network members, and dispersion is the ease with which these connections are made. Homogeneity is seen as the number of commonalities network members share (e.g., values, norms, education, salary, religion, etc.). Finally, listed within the functional dimension are affective, instrumental and cognitive support, maintenance of social identity and social outreach. The first of these five characteristics, affective support, looks at how and to what degree the intangible emotional commodities of life, such as moral support, caring and love, are furnished. Instrumental support refers to the rendering of concrete forms of assistance either in terms of specific items and/or in services performed (e.g., child care, cash, groceries, etc.). Cognitive support examines the availability of diverse informational resources, new knowledge, sources of feedback and counsel based on another's experience and knowledge, and the ease with which these are accessed. Maintenance of social identity is the manner in which a social network affirms and promotes its member(s)' vision of the world and their place in it. Social outreach is the degree to which the network assists its members in making connections with others and in attaining various social roles.

Using the relevant research of that day to determine relational patterns between the characteristics of social networks as listed above, Craven and Wellman (1973) found support for the following conjectures.

1. Relatively dense networks are generally small, and the linkages among the members quite strong.
2. Loosely knit networks tend to be large, and their members less deeply involved with one another.
3. In general, large, loosely knit networks appear to expedite access to tangible resources, while dense networks with strong ties expedite access to intangible, emotional resources. However, loosely knit networks sometimes supply more intangible resources in an emergency or a crisis situation.[106]

Barbara Israel (1982) examined these and the results of other studies pertaining to social networks with the intent of tracing an association between the supportive functions of social networks and health status. She found the following:

> In particular, the qualitative network characteristics of intensity, reciprocity, and affective support seem to be highly associated with health status. The characteristics of size, density, frequency of interactions, and instrumental support also appear, although less conclusively, to be related to well-being.[107]

These patterns were apparent enough for Israel to highlight certain combinations and propose methods for their incorporation into assessment and program planning schemes in the area of patient counselling and health education. Of particular interest to this practicum were the positive correlations between reciprocity and well-being, suggesting the importance of establishing helping relationships which are mutual and reciprocal in their operation, and a similar correlation between well-being and the intensity of interactions and presence of affective support.

> . . . it would seem beneficial that any type of patient counselling and health education strategies be provided in a manner and atmosphere which is conducive to and encourages the development of interactions that provide feelings of caring, closeness and moral support.[108]

In her discussion of the establishment of reciprocal and mutual helper/helpee relationships, Israel emphasizes the need to assist clients in assuming more responsibility for their health care and for helpers to strive for the development of interdependent associations with their clients.

> Such an approach requires professionals to recognize the existence of lay expertise, which they, too, can learn from and share. This seems especially important when working with hospitalized persons, who may assume, probably based on past experiences, that relationships with health professionals place them in a dependent role.[109]

The variables of size, density, frequency of interactions and instrumental supports which also are associated positively with well-being, although less consistently than the foregoing, suggest that helpers recognize, explore and develop ways of strengthening the helpee's coping skills through the active use of both natural and artificial social networks.

> Programs that encourage participants to join self-help mutual-aid groups or community based service/problem-solving organizations might increase network size, density, frequency of interaction, and the provision of tangible aid. These network characteristics may also be strengthened by strategies that bring together members of an individual's network to address his or her needs.[110]

Mitchell and Trickett (1980) summarized research that looked at the mediating effects of social networks. They found that how a social network develops and is used depends on the available resources and demands of the environment, the personal attributes of the network members (e.g., coping styles, interactional skills, understanding of and approach regarding the network's usefulness, etc.), and the process by which both of these fit together (person-environment fit).[111] Speck and Attneave (1973) found, when using social networks as a mode of intervention, that the network's ability to use its resources and act took form only when members were given enough latitude to do so. Demonstrating a belief in the competence and knowledge of the network through the design of an interventive structure that fosters this process was felt to be a key element in making this happen. These social networks were seen as being capable of designing and implementing workable plans of action tailored to the life-style of those affected.[112]

While Speck and Attneave involve the resources of an entire network, the helping process may be mobilized through the efforts of a key individual, often referred to in the literature as a "natural helper" or a "central figure".[113]

> These are not persons carrying their role because a title or a position gives them their importance. Rather, they have won the confidence of their associates because of their personal characteristics, and they have demonstrated their ability to cope successfully with problems similar to those that their co-workers or neighbors face.[114]

Fulfilling the responsibilities of their job may place them in situations where human need is apparent (i.e., homemaker, caretaker in an apartment complex, etc.), or awareness may be a factor of sharing the same living space (neighbour, colleague, etc.). What these persons demonstrate is a willingness to move beyond the requirements of their association to address the need presented. Their effectiveness in meeting this need is enhanced when the formalized helping system acknowledges and supports them in the use of their own skills and knowledge. Creative actions are born out of efforts to mobilize and free the necessary energy, not by controlling or directing it.

Not all social networks fit together in ways that are nutritive or growth-producing for its members and/or for the network.

> They may undermine self-esteem, withhold resources, demand unreasoned conformity, exploit one member or scapegoat another, exert unrealistic or nonsocial expectations, and interfere with members' growth and development.[115]

Actions that may have ensured survival and/or promoted growth at one stage of the life cycle may no longer serve the same function at another stage. To survive these transitions a network must be able to adapt to the demands of changing needs dealing simultaneously with the losses that inevitably accompany them.[116]

The next level of social systemization, organizations and institutions involves those elements of the social environment that utilize a formalized structure of human relationships to bring together or develop resources and services that address human need. Some of these institutions may be concerned with the provision of food (e.g., a grocery store, a wheat board, etc.), some with tractor parts, and still others with education or health care. Within these formalized structures, goals and functions are defined, boundaries determined, duties and responsibilities allocated, and frameworks for decision-making are set up.

> In order to carry out its function, and to manage external and internal pressures, an organization develops a social structure and various functions. An authority structure, for example, is needed to allocate responsibility and coordinate tasks. Such a chain of command may be overly rigid, rewarding conformity and discouraging innovation. In other instances, authority structures may be too flexible, providing limited accountability and leadership.[117]

The goals, functions and boundaries decided upon have definite implications for both the provider and the user of the service offered. A system may base the design of its service on a philosophy that stigmatizes its consumers requiring them to accept the organization's construction of their needs before they can access its services.

> Clients are sometimes required to fit their problems to the agency's purpose and method rather than agencies being responsive to their needs. At times, the agency's definition of its purpose and services stigmatizes the user of its services by emphasizing pathology and deviance.[118]

An organization's philosophy may be reflected in the attitudes and behaviour of its staff. To utilize its services consumers may have to tolerate a gradual erosion of their sense of self-worth through interactions with personnel who regard them with disdain or who are slow to respond to requests for service.

> . . . refers to respect for patient's life-styles, cultural values, and their social relationships; it confronts directly the dominance of organizational norms in patient care. The patient is expected, for example, to follow medical orders even though [s]he may not understand them, and even if they violate [his]her cultural norms.[119]

Policies and protocols which have been committed to paper over time to ensure unity of action in meeting consumer needs may no longer be relevant in addressing these needs, but may resist change. Policies governing the enactment of the organization's goals and functions may never have been formally documented or may fall short of defining protocols for action leaving this to the discretion of the respective staff person. Insufficient policy direction or procedures which are no longer in touch with consumer needs can lead to erratic distribution of valuable resources and/or practices which value one set of consumers over another.[120] Rigid patterns of relating to consumers and a decreased ability to be responsive to individual need can result as the size of an organization or institution increases and power becomes more centralized at the top.[121]

While the goal of organizations and institutions may be to bring together or develop resources and services to better meet human needs, in doing so they become a system unto themselves which in turn demands that its own needs for survival and growth be met to ensure its operation. This demand may override the organization's primary purpose for existing, causing it to lose touch with consumer need in the administering of its services.

> Some of the passivity inherent in the role of patient is necessary for treatment. Some, however, may derive more from organizational needs and staff convenience, so that patient action and decision-making are discouraged from the onset.[122]

> Questions, personal requests, almost anything that calls for doing things differently may be met with rigid disapproval, and patients who insist upon retaining their sense of personal authority can become quite unpopular. They are confronted with a variety of subtle (and not so subtle) accusations and are made to feel ashamed for not being like "normal" and "satisfied" and "likable" patients.[123]

Routines that exist basically to meet the needs of the organization as opposed to its service component may, in fact, impede the organization's realization of its service commitment. This process may not be overtly apparent to an organization or, if it is, the organization may choose not to recognize it. Organizations and institutions spawn within their formalized frameworks informal groupings of people who in turn evolve their own social system.

> The staff develops its own culture, value, norms, and expectations and its own structure of rewards and sanctions. Thus, the informal system may, for example, impose a professional ideology, or exert pressure toward conformity with bureaucratic norms and practices.[124]

The penalties for deviating from or attempting to function outside this system may be severe enough to threaten the staff person's professional survival. This then has implications for that staff person's ability to demonstrate sensitivity to consumer needs.

The ecological perspective concentrates on the interface between person and environment requiring an awareness and understanding of both these dimensions. Therefore, professional commitment to this approach demands actions that alert the proponent to her/his own organization, its function, policies, formal and informal construction, and philosophical stance with regard to their effect on the organization's ability to meet consumer needs. Acquisition of the knowledge and skills necessary to effect organizational change to achieve a better fit between these two dimensions then follows.

> These include the use of knowledge and skill in locating organizational barriers to service, identifying the forces likely to support or to resist change in policy or procedure, developing bases of support and devising means for neutralizing opposition in both the formal and informal systems. Knowledge and skill are required, also, for analyzing the power and decision-making structures and devising strategies for introducing, implementing, and institutionalizing the proposed change.[125]

Being able to implement organizational change to better address consumer need is made easier when the respective institution views this as an important part of its function and is supportive of staff endeavours to accomplish this end. It may also be a factor of organizational ranking and access to decision-making structures.

Reflected in the actions of the populace and the design of their organizations and institutions, the third layer of the social environment--the societal level--is a complex blend of cultural values, political and economic frameworks, and their documentation in the laws, statutes and policy statements of a given community, country or continent. People are born into and raised within these structures. Hence, their influence on any one individual's perception of life and that person's input into the decision-making processes that determine what needs to meet and how is subtle. Earlier in this chapter (pp. 22-29), the dominance of the 'biomedical' or 'disease focused' model in the design of the North American health care system and its understanding of disease was noted. Professional and layperson alike have been indoctrinated into this approach in most instances since birth.

> . . . in modern Western society biomedicine not only has provided a basis for the scientific study of disease, it has also become our own culturally specific perspective about disease, that is, our folk model. Indeed the biomedical model is now the dominant folk model of disease in the Western world.[126]

Questioning the relevancy of such a model becomes a challenge, not only to the philosophy of the respective institution within which the questioning may take place, but to the basic fabric of that society. Decisions to ban substances shown to have carcinogenic properties are often influenced by economic and political considerations in addition to scientific findings.

> The economic impact of banning a substance or requiring its strict control, the technological feasibility of substituting new processes, the desirability of low-calorie foods in the nation's diet--all these topics are implicit in the saccharin issue.[127]

Culturally-promoted sex role standards are often reflected in therapeutic practices where actions not supportive of the sexual identity deemed appropriate for that person are discouraged. The following is a quote from a woman whose attempt to deal with her mastectomy by not wearing a prothesis became an affront to the helper's concept of appropriate coping.

> And every woman there could have used a reminder that having one breast did not mean her life was over, nor that she was less a woman, nor that she was condemned to the use of a placebo in order to feel good about herself and the way she looked.
>
> Yet a woman who has one breast and refuses to hide that fact behind a pathetic puff of lambswool which has no relationship or likeness to her own breasts, . . . that woman is seen as a threat to the "morale" of a breast surgeon's office![128]

Insistence on the wisdom of a particular therapeutic approach may bear more relation to the processes of socialization than the needs of the consumer or the organization.

Influencing the expression of all three layers of the social environment are the textures of time and space. Evolving constructs of time on which to pace the life patterns of a network of human beings is a basic task of any unfolding civilization. By virtue of their development, these constructs have become rooted in the cultural fabric of the respective society, structuring peoples' ways of relating, their expectations of one another and their doctrines, consciously and unconsciously.

> . . . Spanish-Americans of the southwest tend to emphasize present time--accept each day for what it is, pay little attention to the past, and consider the future to be unpredictable. . . . Middle-class Americans place a high value on change and the expectations of continuing progress, and thus tend to emphasize future time.[129]
>
> Eskimos are not timebound nor are they generally moved to conserve tradition for the affection they bear it. Eskimos are present oriented, with a strong interest in becoming.[130]

Germain refers to this as 'cultural time'. When two people from different cultural backgrounds interact, their understanding and judgement of the interaction is coloured by these constructs. Lack of strong emotional ties to the past and interest in becoming may assist an Eskimo in experimenting with the cultural patterns of another society easing her/his transition into that community. Structuring his/her actions according to a 'present-oriented' time frame may simultaneously bring that same person into conflict with that society if it, in turn, bases its behaviours on a future orientation.

> . . . work is not consciously assigned to provide deliberate training for later-life industriousness. . . .
>
> Eskimo parents instruct their children with a minimum of accompanying explanation; they seldom try to explain why some task should be done or a skill mastered. An explanation, presumably, will be found in the situation by the child itself as [s]he learns

> to understand it through becoming practically, rather than theoretically, involved in it. . . . the school's curriculum forces teachers to ignore this educational technique. . . .[131]

Slow to modify its form in the face of change, cultural time is often outstripped by the demands of social time. Where technological change is rapid and uncorrelated, it is not a matter of repeating former life patterns. More likely, it is a task of developing models of approach that assist people in meeting the demands of ongoing change. Much of what the next generation will encounter will not have been confronted by the former generation and vice versa. Time frames on which personal, family and organizational behaviours were molded may no longer fit the demands of a changed social environment.

Social functioning can be seen as a blend of three different constructions of time--individual, family and organizational--all continuously altered by the forward movement of time. The organization of daily behaviour for the individual is in part the product of internal rhythms which govern bodily functions (e.g., energy levels, sleep cycles, etc.). It is also a response to the 'social rhythms' of the society in which [s]he lives.

> . . . weekly cycles in which Monday, for example, is different from Saturday in terms of weekly activities; monthly cycles in which salaries are paid and rents fall due; annual cycles related to the seasons, and in which vacations and leisure pursuits fall.[132]

Additional adjustment to individual routines may be required by time cycles which do not conform to the more prevalent 'social rhythms', but are instead, peculiar to a particular family or occupation. An individual's daily routine, therefore, is governed by the concurrent operation of a number of distinct time cycles with varying time frames, all of which affect his/her behaviour at any specific instant. Family living demands the meshing of individual temporal cycles to allow time for shared activities and responsibilities. Some schedules may take precedence over others, requiring those remaining schedules to adjust. Adjustment may mean altering their cycle of occurrence in that certain activities take place simultaneously (e.g., work and school schedules), or in the same location (mealtimes, recreation time, etc.).

> Many parents reported family disputes surrounding food and scheduling, two critical aspects of diabetes care and also two areas in which children and other family members have needs.[133]
>
> One father reported to us that when it is urgent that he eat supper on time and his family is slow to come to the table, he screams to get them to hurry, due to the irritability and urgency caused by his low blood sugar level. Another parent usually handled this problem of delayed meals by changing her planned dinner and having a quick snack.[134]

As alluded to in the foregoing quote, co-ordinating the varying time frames of several individuals in a manner that all members' needs are met is not an easily accomplished feat. Once established it is subject to constant reappraisal and change throughout the life cycle to meet the varying demands of each stage of development.

> [The family with young children] is not only characterized by the intense demands of small children, but their extremely rapid development requires an almost constant process of readjustment for their parents. . . . A mother must not only rearrange her daily activities to accommodate her child's growth, she must also gradually move from an almost complete absorption with her newborn infant to allowing her child ever-increasing autonomy as it becomes appropriate.[135]

The developmental needs of one family member may be out of sync with those of another. An aging parent in declining health may demand an increased level of family involvement from a child who is in the process of separating emotionally from her/his family of origin. One family member's needs to develop a separate self collide with another's need for familial closeness.[136] Being out of sync may also mean seeing time from separate perspectives. The need to maintain a sense of tradition, keeping in touch with one's roots for one part of a family may clash with the other part's need to abandon the past and forge forward into the future. Spontaneity of action and continuous change may be the preferred mode of operation, or recurrent predictable patterns may be revered. Living within either framework could be invigorating or incapacitating depending on one's own internal rhythms. Different family members may vary in their desire for time spent together versus time alone. Competing cycles of time may leave them with few opportunities to be together, or they may find their shared time exceeds their need for it. Perceptions regarding the quality of the time spent together may also vary.

> Family members may have differing definitions of good times and bad times, hard times and easy times, wild times and dull times.[137]

Organizations and institutions, as stated earlier, are systems in their own right and as such evolve their own temporal frameworks. These time frames are in turn influenced by the time frames of those professionals, union employees, etc., which people these organizations and institutions. The power to determine these time constructs often lies with organizational bodies that exist independent of the institution affected (professional associations, trade unions, etc.) As a result, the temporal cycle of the institution may not fit the temporal cycles of the people it is set up to serve.

> Social work in many fields of practice continues to be structured on the fifty-minute hour once a week, for example, whether or not it fits need. If it does not fit need, we may think that the client is resistant or unmotivated or else, we question the worker's skill. It may just be, however, that biologically and culturally determined periodicities and cyclical experiences of stress do not always coincide with the temporal linearity of agency appointments as determined by organizational structure.[138]

Organizational pacing may violate the biological rhythms of an individual, thereby reducing the resource base that person has to draw on when adjusting to changed conditions (e.g., hospital routines). It may actively discourage use of its services through lengthy delays in addressing user needs, limiting the duration of contacts, or maintaining strict schedules that do not easily balance with the demands of other time commitments.

> Maybe they should see less people per day. In some meetings I remember that the discussion was hot--you and the counsellor were really going good--and then the darn phone rings and it's time for her next appointment. . . . The next week she would start with where you left off . . . but by then it was hard to remember.[139]
>
> Client: The place is far from my home. . . . It's hard to get there . . . especially with the baby. . . . You know, sometimes I would get going so late that I would have to cancel.[140]

All these elements act as additional stressors taxing the coping energies of those who may require the service offered. Rather than enhancing adaptive efforts, such time constructs could actually hinder them. Germain makes the point that the 'temporal orbits' of consumers targeted to use an organization/institution's services are seldom appreciated in the design or implementation of its programs or in the appraisal of their effectiveness.[141] All human beings, families and groups operate within and must continuously balance many time frames. Understanding and use of the interactive quality of temporal structuring can actively strengthen motivation and coping efforts within and between people.

Space is more than the physical dimensions of a setting. In the social environment it is the regulation of self-other relations through behaviour and the blending of personal perceptions of and needs for space with those of others who help to make up a person's social being. A physical environment which offers little nutritive value in its structure can offer a rich social network that gives its inhabitants the strength to grow beyond the physical limitations of the setting.

> Social networks, in the view of investigators, provide important means of coping with the oppression of poverty, and make the difference in residents finding their neighborhoods satisfactory. Slum dwellers may be dissatisfied with their specific dwellings, and yet be satisfied with their neighborhood because of the social supports it provides.[142]

When attempting to illustrate human spatial behavior, Germain draws heavily from the work of Irving Altman (1975), and David Kantor and William Lehr (1975).[143] At the heart of Altman's social-psychological perspective is the concept of privacy where human beings are in a continuous process of defining and redefining their interactions with others in relation to their needs for 'personal distance' and 'territoriality'. Whether the perspective is that of a person or a group of people, the goal is to maintain a preferred level of social interaction. The form this perspective takes is subject to the effects of life stage, sex, culture, health status, the circumstances of the involvement, its participants and past exposure to similar situations. These elements blend together throughout life producing a psychological judgement regarding what constitutes an appropriate level of human interaction.

> Crowding results when a person's demand for space exceeds the available supply or when the amount of social interaction is greater than desired. Isolation occurs when space is in excess so that one is more distant from others than one wishes to be: the amount of social interaction is less than is desired.[144]

How many people actually occupy a given space or the numerical quantification of their interactions (density) is not important. What is important is what is 'perceived' to be too little or too much social contact. Personal distance or how much/how little space to maintain between self and others to ensure comfort in relating is one way of measuring social contact. Composed of that space directly encompassing a person's physical being, the dimensions of this zone vary according to the nature of the association, life cycle stage, health status, culture, etc. How much personal space is required is often determined by the functional quality of the interaction.[145] Differing degrees of distance between persons is maintained depending on whether the contact is with a lover, a family member, friend, employer or stranger. When intent is not clear, encroachment on another's sense of personal space can be perceived as an unwarranted invasion.

> There was a guy there that I didn't know, but some of the other kids did. He seemed interested in me. He came over to me and stood really close, as if he knew me well, and leaned so close that I felt pretty uncomfortable. I moved away from him and stayed close to my girlfriend that night, because I wasn't sure what he was trying to do.[146]

Individual needs for intimacy and separateness can be communicated by varying the dimensions of the zone. Certain social groupings may display spatial behaviours that distinguish their particular group as belonging more to one set of individuals than to another. These territorial behaviours help group members develop stable connections for purposes of reciprocal support and protection. Unfamiliar faces can be readily identified with decisions made regarding the nature of their encroachment and the most appropriate response. Territorial relations have the potential to decrease discord and increase the congruency in messages sent and received by clarifying expectations regarding interpersonal or intergroup connections. By providing individual and/or group definition, they aid in the development of a sense of identity.

> The school years are characterized by territorial relations with in-groups and out-groups of peers, and by increasing distance between the child and [her]his family as [s]he reaches farther and farther out into the space occupied by school, recreational organizations, neighborhood, and so on.[147]

> . . . family members have to occupy the same social space, spend time together, and devote energies to the same activities if they are to gain access to love and intimacy, separateness or autonomy, identity, and be able to develop competence.[148]

Individuals, families and groups use their perceptions of personal space and their territorial behaviours to monitor the nature of their interactions with other human beings. The sharing of space is more than a reactive process. Human beings are capable of orchestrating environmental change through competent action in an attempt to achieve a better person-environment fit. How supportive the environment is of such efforts may govern whether the action is growth-producing or limiting in its expression.

Culture

All that is social about the environment occurs in a physical setting. Social and physical, time and space--all are intricately interwoven. Culture fashions human interactions, subtly structuring our perceptions of time and space, and our understanding and style of relating to our physical world.

> Cultural values and social forces influence the construction, location, and design of public mental hospitals, housing projects, and welfare offices, which have an impact on the self-image and sense of identity of those dependent upon the services, shaping the nature of their social interaction.[149]

The physical and social layers of the environment and their textures of time and space cannot be fully understood without acknowledging their cultural context. Diversity in human need, ability and ambition within a culture or combination of cultures is rarely appreciated. In an attempt to give order to and ensure action in an often confusing world, it is the similarity of expression that is more frequently addressed. Therefore, knowledge regarding what nutritive elements need to be present within an environment to respond to this variety is piecemeal at best.

Environmental Modification

People are complex and in continuous change, and so are the environments of which they are a part. Interdependence of person and environment produces an ever-evolving blend of external reality in continuous transaction with internal cognition (objective and subjective reality). While there has long been an awareness of the reciprocal influence of person on environment (environment on person), approaches to this connection have centred on either the person <u>or</u> the environment, rarely, if ever, on the interface between the two. In the development of conceptual models and action principles for change, people have fared better than environments.

> Ways to influence the thoughts, feelings and behaviors of the client have been carefully, and at times exquisitely, formulated. However, ways to influence the thoughts, feelings, and behaviors of people who constitute the social environment of the client--and whose actions and attitudes affect the outcome of his problem-solving efforts--have received little or no attention. . . .[150]

It could be contended that within the health care system more models are available to alter human behaviour to be more responsive to the system than there are to change the system to be more responsive to human need. When all efforts are concentrated in conceptually understanding and developing action principles in one area, the tendency is to assume and/or deal with the adjacent area as a constant, not acknowledging that it, too, is in continuous motion, altered by this interaction and other forces less readily apparent. To consider both person and environment, however, can seem overpowering in its magnitude.

The absence of conceptual frameworks or action principles that draw the two together with any precision of approach would seem to support the contention that many theorists have chosen to handle this dilemma by not handling it. Consequently, environmental modification (action principles directed towards changing the environment) has come to be seen as being both distinct from and subordinate to therapy (action principles directed towards changing the person).

> Paralleling the subordination of the environment to the person, social workers have always reserved a place for environmental modification in their treatment armamentarium but, at the same time, have relegated it to a second-class citizenship.[151]

Grinnell, Kyte and Bostwick (1981) have listed three possible reasons for this inferior status, the first being the resistance by seemingly inflexible environments to labourious attempts to effect change.

> Social workers tended to retreat to a focus on the person, where they felt greater competence and perceived more opportunities for bringing about change.[152]

The second reason is the common assumption that environmental modification is basically a process of making connections with the appropriate support services and providing practical assistance. Routine at its best, it requires little training or skilled creativity to accomplish. What is not recognized is that orchestrating change in the environmental context is both complex and requires a highly developed set of action principles.

> . . . environmental modification is not just a matter of routine collateral contact, of providing concrete services, of fixing or arranging things. It almost always involves influencing the feelings, attitudes, and behavior of people. Not only is the client involved, but also those others who are to be the instruments or personalizations of the change. . . .[153]

Because of a greater concentration on the development of person-oriented approaches, conceptual constructions and action principles concerning the environment have been slow to materialize. It is this lack of meaningful models to help guide environmental interventions that Grinnell and his associates see as the third and most critical reason. While advocating a dedication of effort similar to that given to the person to correct this imbalance, they contend that this should be accomplished in conjunction with the advances in knowledge and skills regarding the person. Germain's ecological model is seen as offering a theoretical context where person and environment are united through a focus on their transactions.

> . . . the practitioner's primary focus is not on the client or [her]his environment but on the multiple interactions and exchanges occurring between them. The individual and his[her] environment are viewed as constituting a transactional system in which each influences and is in turn influenced by the other.[154]

Action principles are developed through understanding the nature of the connection and its influence on the survival and growth of the participants involved. To accomplish this the needs and potentials of each must be explored. Each is involved in a process of adapting to the needs and demands of the other.

Germain defines <u>environmental competence</u> as follows:

> . . . a combination of awareness of the environment, and its influence on efforts to reach goals and meet needs, and the ability to decide what environmental changes are necessary and to act effectively on such decisions.[155]

Awareness is not an instantaneous occurrence, but comes from increasing familiarity with what is being faced with all its subtle paradoxes. It means understanding the impact of the environment in combination with self. The ability to identify and determine environmental change requires access to appropriate sources of information, the power to influence decision-making processes, and the possibility of choice--in short, the opportunity for informed autonomous behaviour. Autonomous action, however, involves risk-taking and with risk-taking comes increased vulnerability. Therefore, if autonomous action is to occur, the environment must encourage its expression, support efforts to develop alternative coping skills and provide a social and emotional climate capable of empathetic understanding and backing.[156] Environmental competence is not an innate characteristic within the person but an outcome of ongoing transactions between person and environment as each changes and is changed over time. Environmental modification, then, moves to introduce or reconstruct opportunities and resources that further the adaptive potential of the fit between person and environment. It ". . . strives to help the client to successfully negotiate his environment and the environment to respond positively to the needs of the client."[157]

Transactional Thought

The key to the ecological approach is transactional thought and assessment or, in other words, understanding and working with the interface between person and environment. Transactional concepts are rooted in systems theory[158] and, like the systems of which they are a part, they are in a constant state of "becoming" rather than "being".[159] Comparing 'linear time' with 'transactional time' illustrates this transformation of thought.[160] Within the structure of the disease model, cause is followed by effect in a singular direction through time. Present events are the outcome of past events and will determine that which is still to come. To think transactionally about time, however, means concentrating on the configurations and the series of actions by which events come together, the cycles and the helical effects as they amass over time.

> It focuses on the manifest and latent functions of what is going on, rather than on the division into effects neatly preceded by causes. . . . In transactional time, change is directed less toward the historical roots of motivation and more toward present transactions that continue the past in current relations with all elements of the complex environment.[161]

Mapping out the sequence of events is no longer relevant. What is important is the circular nature and reciprocal effect of the interconnections and exchanges. Be it individual, family or group, they are viewed in the context of their particular life space at that point in time. Murray Parks (1971) defines 'life space' as follows:

> . . . Those parts of the environment with which the self interacts and in relation to which behavior is organized; other persons, material possessions, the familiar world of home and place of work, and the individual's body and mind in so far as he can view these as separate from his self.[162]

Five concepts found within systems theory are particularly useful in fostering transactional thinking. Because of their concern with connections, these concepts act as theoretical tools for examining the processes by which these connections are maintained. The first of these looks at the extent to which a system is open or closed to reciprocal transactions with its environment. This is influenced by the degree to which any system is dependent upon other systems for its continued survival and growth. By engaging in synergistic transactions, resources within an open system can be replenished as they are used, thereby creating a potential for increasing one another's effectiveness because of their co-operative efforts. A closed system does not seek or maintain connections with its environment, nor require these connections for its present survival. Generally, such systems are seen as having finite quantities of utilizable resources and energy, leading the system to become more disorganized in its functioning as these stores are gradually exhausted. No system can be totally open or closed, as in the first instance it would be indiscernible from its surroundings, and in the second its process of existence would eventually lead to nonexistence.[163] It is this element of degree that is useful in understanding the nature of the connection between person and environment. Survival is possible within a more closed system, but growth may be suppressed or restricted. Although an interchange exists, neither system has connected with the other in a manner that accesses their combined potential for enhancing each other's capacity for existence. Hence, the more open a system is to a mutual and reciprocal exchange of resources and energy with its environment, the greater their combined potential for mutual survival <u>and</u> growth (remembering that each constitutes the other's environment). However, the openness stops short of each losing its identity to the other.

The second concept concerns the exchange of energy.

> Anderson and Carter (1974) define energy broadly to include both actual and potential resources and information that provide the system with capacity for action, action, and power to effect change.[164]

Energy may be drawn from environmental sources, as well as from the system's own infrastructure (subsystems). This energy is then remodeled into a form that tries to fulfill the action needs of the system in relation to its environment. The resulting actions (output) elicit a response from both the system itself and the environment acted upon (feedback), which then is used to judge the form of future actions, thus completing a circular pathway. Transactional assessment of energy exchanges begins by developing an awareness of the present and potential energy sources which exist for both the person and the environment, their selection processes and their missed options. It means determining how each processes what it receives and what the end effect is for each one's survival and growth with respect to itself and adjoining systems. The system may not be cognizant of all the available sources of energy or, because of its processing procedures, it may be unable to make adequate use of feedback. Again, it is the "exchange" of energy that is important. How much energy is expended by each to maintain the connection, how much is received in return, and from where, to replenish that which is being expended? The need to continue the connection may lessen if more energy is spent in the process than is regained. The energy exchanged may be sufficient for survival but inadequate for the occurrence of growth.

Continuing with the premise that continuity in survival and growth stems from the active interdependency of various systems, the 'ripple effect principle' follows. It suggests that alterations in one segment of a system will lead to alterations in all other sections of that system. Simultaneously, changes in this system will then give rise to changes in all bordering systems. Change can either increase the effective functioning of the system and its respective parts or it can be degenerative in its influence. According to René Dubos (1980), to gain the 'success of life' for either an individual organism or an entire population, two primary dictates must be honoured:[165] firstly, in the face of change, effective performance is maintained only to the degree that the alterations made still respect the boundaries of the system's internal organization, outside of which its existence is threatened; secondly, the actions taken to meet the demands of change should assist the system in dealing with the altered circumstances.

Respecting the boundaries of the system's internal organization does not necessarily mean returning it to its former state. The demands of change may be such that this is neither possible and/or desirable. Because of the forward movement of events in time, the time available for response may be limited. Decisions to act, then, are often made with regard to what is familiar and tested, rather than what is the most effective response given the circumstances.

> . . . [it] is not so much the maintenance of an absolute constancy of the internal environment as the selection for each particular case of one kind of response out of several alternative possibilities available to the organism. Not only does the response often fail to return the internal environment to its original state; in many cases the response is not even appropriate for the welfare of the organism.[166]

Actions taken may allow the system to survive at this point in time, but this survival may be threatened at a future date when, for example, its energy reserves are drained or its needs for continued growth are blocked.

Following from the 'ripple effect' are the principles of maximum reverberation and equifinality. The point of maximum reverberation is that place in any system where intervention will have the most far-reaching effect in favourably altering all that system's respective segments. Equifinality means, simply, that the same end can be achieved from a multiplicity of routes. These two concepts encourage transactional thought, not by focusing on the sequence of effects as in linear thinking, but instead, they concentrate on the manner in which the parts come together to reach the final outcome. Since the same end can be reached through a variety of combinations, it is a matter of putting into action the one with the greatest potential for benefitting all the parts concerned.

> . . . the central theme should be the potential for continued growth and change, both in the present and in the future. The system, therefore, must be regarded as not only "being" but also continually in the process of "becoming" . . .[167]

How a system's actions contribute to its survival must be understood in the context of its needs for continued growth. It is a matter of mobilizing the system's adaptive capacity to move towards growth, thereby building on its competence.

The Eco-map

Systems, by their nature, generate numerous and complex transactions. Understanding how these transactions contribute to their survival and growth seems anything but manageable.

> Social workers, in attempting to understand their traditional unit of attention--the person in [her]his total life space over time--are faced with an overwhelming amount of data. These data must be ordered, selected, and arranged to reduce confusion and overload.[168]

To assist in this organizational process, helping professionals have, by virtue of their training and life experiences, developed a series of 'cognitive charts'. Whether a product of their training, life experiences or both, these charts strongly shape their perception of reality. Continuous use of these charts to deal with the flow of reality can move awareness of their existence to an unconscious level, blinding the professional to their mediating influence. Traditionally, these maps have been linear and reductive in their operation, making it difficult to visualize and work with the multiplicity of transactions that characterize reality. Hartman (1978) offers a diagrammatic assessment tool that helps give direction to efforts to picture and understand systematic connections and the effects of change on these connections. Known as an ecological map or 'eco-map', it attempts to visualize an individual, family or group within the context of their life space.

> . . . its primary value is in its visual impact and its ability to organize and present concurrently not only a great deal of factual information but also the relationships between variables in a situation.[169]

Ecology is a science of understanding balance and the mutuality of exchanges between living organisms and their environments, as well as the impact of change on these relationships. Similarly, an eco-map is concerned with how the interfaces between the systems are depicted; how open or closed each system is to the other's influence; what their sources of nurturance, stimulation and support are; and, how resources flow within or between the systems involved. Are there breaks or fluctuations in this flow? How much energy is expended by each to maintain the connections? How much energy is regained as a result of the connection? Does this exchange come easily or is it fraught with conflict? Because each constitutes the other's environment, each must have the necessary skills to access the other's present and potential resources, and to manage the demands made by each upon the other. Are the social, relationship and instrumental skills present to make this happen? All of these movements are made in an attempt to ensure the survival and growth within and between each of the systems involved. Hence, each exchange must be weighed with regard to its contribution to this process. What is their combined potential for enhancing each other's existence? How can this be accessed and will the changes demanded by this association respect each system's internal organization, giving them the tools required to manage the altered circumstances?

Eco-maps, therefore, provide a medium where the totality of the interactions and the connections can be viewed. It portrays each piece's sense of integration and balance with another's, while simultaneously making contrasts apparent.

> This mapping procedure highlights the nature of the interfaces and points to conflicts to be mediated, bridges to be built, and resources to be sought and mobilized.[170]

It characterizes a living whole, rather than a sequence of parts. The direct involvement of the person, family or group whose life space it is, is required to gather sufficient information to trace out the connections and assess their meaning. Without this joint participation, the helper cannot truly understand the nature of the fit. A reciprocal and mutual relationship between helper and helpee is encouraged in the mapping, assessing, and also in the decision-making regarding change. Through the process of gaining an understanding of the nature of the connections, it encourages an exploration of self.

> . . . an almost empty eco-map helps the client objectify and share loneliness and isolation. An eco-map full of stressful relationships showing all of the arrows pointing away from the family may lead a father to say, "No wonder I feel drained, everything is going out and nothing is coming in!"[171]

It can be employed to compare past with present and/or future, mapping out the effects of change. Used over time change can be measured. Its influence on the system's ability to retain its own sense of personal integration, while maintaining a sense of integration and balance with the many systems that constitute its life space can be traced.

To experience a chronic illness that demands long-term interaction with a highly complex health care system automatically enlarges the number of significant systems included within that person, family or group's life space. Because the 'living parts' that make up these systems are numerous, it is difficult to see the events and actions of the whole. Each component has its own sense of integration and balance to maintain and, therefore, its own investment in any changes to be made or attempted. An eco-map which recognizes the combined influences of both the helper and helpee's life space is one means of visualizing the effects of the whole.

Germain's Construction of the Ecological Approach - A Critique

Because it encourages transactional thought and analysis within its theoretical structure, the ecological approach supports efforts to visualize and understand the totality of a given situation, its sense of balance and integration. In doing so, a framework emerges where the variance of adaptive responses can be seen and their contribution to the survival and growth of the network, as a whole and as individual pieces, can be grasped without first being judged. To this extent, it obtains some freedom from cultural bias.

> Many studies of the impact of social work look at client behavior according to some normative criteria that may not have relevance to the primary environment of the person. This fit concept allows persons to be judged according to the norms,

> expectations, and demands of their own environment. It also avoids assuming that all people are the same in terms of their needs and expectations.[172]

Germain's development of the ecological approach for social work practice, however, does not break as completely from the disease model of structuring helping efforts as her de-emphasis of identifying pathology and emphasis on growth and development would lead the reader to believe. Implied in her concentration on 'problem definition'[173] is a focus on 'lack' of fit or on the identification of weaknesses, limitations and shortcomings existent in the transactions between person and environment. Though attentions are now centred at the interface, actions still must be categorized as adaptive or maladaptive.

> If people's needs and problems are located in the interface *between person and environment*, and defined as maladaptive transactions within the life space, then the professional intervention is likely to be formulated in terms of reciprocal adaptive processes, on a life model. Goals will refer to a strengthened adaptive capacity and increased environmental responsiveness.[174]

There is no room for the recognition that a behaviour may be adaptive in that it aids the survival and growth of the systems concerned, but is not the most growth-enhancing choice considering the alternatives available to the overall network. The object, in this instance, would not be to identify a 'problem', but to move towards maximizing the combined potential of the fit. Nor does this beginning point acknowledge that the same behaviour may in fact be a strength in helping the person survive by meeting the demands of the situation, but limiting in terms of that person's continued growth. The same behaviour may be growth-enhancing or limiting depending on the situation in which it is employed or the point in time. Thus, what is an effective coping action in one sector of a person, family or group's life space may be limiting in another sector.

> Those who express their emotions may draw attention to themselves and their symptoms, resulting in more diagnostic tests, greater frequency of hospitalization, and more intensive drug regimens, all of which could improve their chances of surviving a disease like cancer. However, in other illnesses, such as obstructive pulmonary syndrome, emotional expression can directly exacerbate symptoms and hasten the disease process.[175]

> . . . those involved in efforts to change Type A behavior because it predisposes to greater risk of cardiovascular disease than for persons who are less pressured, aggressive, and achievement-oriented, often forget that for the Type A person the alternative may be to give up a social value to which he or she has made a lifelong commitment in favor of another which, for that person, is anathema. Is lowered risk of disease more important than personal satisfaction? . . . Fulfilling deeply entrenched social and personal values as a Type A may increase both morale and risk of illness.[176]

It is not simply a matter of recognizing an incongruence in fit, identifying and categorizing adaptive and maladaptive actions, then instituting measures to mobilize adaptive actions to either change what is maladaptive or overcome its influence. It is understanding the meaning of the fit for the survival and growth of the whole and all its respective parts. The focus is on understanding how actions <u>contribute</u> to survival and growth within the context of the situation and for the parts involved. At present there is insufficient knowledge available regarding the variance of coping responses and their process of operation to accurately determine what constitutes effective and ineffective coping in a given situation.

> There is no longer any doubt that values are inextricably tied to the evaluation of coping effectiveness. We have to ask, "Coping effectiveness for what?" "And at what cost?" The stakes include somatic health or illness, psychological morale, and social functioning.

> The great dilemma is that, just as we know little about the patterns of coping most people use, we also are not clear about which patterns of coping work for certain types of persons, how they work, and the specific sets of circumstances under which they are effective.[177]

Germain (1984) uses the level of stress present to determine coping effectiveness and ineffectiveness. "Effective coping reduces or eliminates the stress. Ineffective coping results in unrelieved or even intensified stress."[178] However, the level of stress present may be the result of an ever-changing set of demands, rather than the effectiveness of the coping responses offered. For example, a particular disease process may be characterized by a rapid or fluctuating rate of physical deterioration, keeping the stress level elevated by continuously changing the nature of the demands made on the persons concerned and the types of resources required to meet these demands. Coping responses in this instance may be highly effective but unable to reduce stress levels. Germain's need to establish such evaluative categories is confining. She moves away from the disease model by locating the problem at the interface as opposed to within the person or the environment and by emphasizing its interactional origin.[179] In addition, she reconstructs it as 'needs and problems in living', implying a commonality of human experience with struggles over the life cycle. However, even when accompanied by a well-articulated push to work with the potential for growth and development, the initial focus is still on identifying problems. It is the contention of this paper that in working with the transactions between person and environment, the beginning point is identifying and understanding their <u>contributions</u> to the survival and growth of the systems involved given the totality of the situation. In doing so, the competency of the systems within the context they find themselves becomes the focal point. To begin by identifying 'problems' is to automatically divert the focus from the competencies existent in the situation to a quest for weaknesses or limitations.

> . . . [social workers] are taught to engage in a process of assessment of the clients' functioning that is essentially a search for problems, weaknesses, and limitations in the clients. Although there is also appreciation of the clients' strengths and resources, the latter are not emphasized. . . .
>
> . . . .
>
> . . . there is a need to shift the focus in social work education from pathology to human strengths, resources and potentualities. . . . Workers would then be better able to place emphasis "not on exploring pathology, but on finding, enhancing, and rewarding competence."[180]

It is difficult to maintain a growth-oriented direction if the starting point is centred on what is lacking or problematic.

This is especially critical in the area of chronic illness where, depending on the long-term effects of the disease, a process of new learning is demanded. To decide how to respond in a manner that promotes the survival and growth of those involved means identifying and understanding what the effects of chronicity are on the nature of the connections made, how they come together and for what purpose. What is the impact of the environment in combination with self? Sobel and Worden (1982) state that ". . . most cancer patients do not regard themselves as 'emotionally distressed' or in need of psychological assistance . . . ,"[181] and therefore, more readily involved themselves in helping relationships if an educational model were used. Could this be because new learning is, in fact, occurring and previous frames of reference are being reworked as they are no longer able to explain what is being encountered? Distress, ambivalence and confusion are a part of this adaptational process and neither cancer patients nor the general public view this as out of place. To be viewed as emotionally distressed, however, is to be seen as not coping or as having a problem. Problem, though more acceptable if located at the interface, implies a situation in need of correction. The persons affected by cancer may in fact be struggling and feel emotionally vulnerable, but they may view this and their efforts to tackle a difficult situation as appropriate given the circumstances of their life space. In educational settings persons undergoing a new learning process are not expected to tag their behaviour responses to this process as problematic. They may struggle with the incorporation of new knowledge, skills, etc., and may feel vulnerable as a result, but this is seen as indicative of their openness to risk new learning. If the word "problem" enters this domain in reference to the process of learning, it is generally regarded as a failing or deficit. Struggling with new learning is not seen as such.

This may appear as an effort in semantics, but these conceptual subtleties have important implications for when and how help is offered and accepted. The following is a quote from a tape titled "Understanding the Cancer Patient", produced by Worden and Sobel (1982).

> The reason we use concern rather than the word problem is that in our early work with cancer patients many patients often did not respond to the notion of a problem. If you asked, for example, "What problems are you facing?", the patient would say, "Oh, I'm not having any problems, Doctor." Then ten minutes later, they'd be telling you about their problems. We found that many patients found it easier to talk about concerns rather than about problems.[182]

The process of engaging these people in a helping relationship clearly demanded a word change, but it was seen by the helpers as a reluctance to acknowledge as such the 'problems' they were, in fact, experiencing. It is the belief of this paper that the reluctance is on the part of Worden and Sobel to let go of an orientation that does not fit with what is being encountered. While Worden and Sobel anticipate that new learning will take place as a result of their interventive approach, its need arises because the individuals involved are seen as not demonstrating the required level of competency in their coping skills. This is evidenced by the persons' expression of a high level of distress.

> We felt that it was essential to design an intervention which not only would attempt to correct the problem-solving deficits of high-distressed patients but also would be syntonic with their own expectations as medical patients. The average medical patient certainly does not often expect to receive "psychotherapy" following a cancer diagnosis.[183]

The expression of 'some' distress is appropriate to the situation, but a 'high' level of expression is evidence of a deficit in coping skills. Hence, a normative standard is evolving in an area where the variance of coping responses has yet to be explored, let alone the efficacy.[184] It is no longer a matter of reaching a certain point and moving on from there; behaviour is perceived as falling short of the mark and in need of assistance to be brought up to the appropriate level. It is an approach that assumes prior knowledge of that level. To partake of this helping process, then, individuals must view themselves as being incomplete or defective and in need of correction. The visibility of their distress with having encountered cancer and its effects on their lives becomes the measure of their skill in coping. If they resist this definition of their competency, a word is changed, but the mindset of the helper remains the same. The possibility that the learning to be done is a forward movement with no deficit involved is not considered.

Worden and Sobel are cognizant of the cancer patient's social being, but choose to focus on individual coping skills.

> Although this program has emphasized individual care and cognition, we want to conclude by reminding the counselor that cancer has an important social context. Most patients are attempting to cope among others, within a number of systems, including a family.[185]

Germain's approach places its emphasis on the interface between person and environment. However, this does not remove the deficit nature of problem-centred definition. Although Germain acknowledges that stress is a component of challenge, for use in the health care field she differentiates it from challenge by suggesting that 'distressing' features are at odds with the more stimulating dimensions of the concept of challenge.

> The distinction between stress and challenge lies in the stress-related negative feelings such as anxiety, depression, guilt, despair, lower self-esteem, and the sense of being in jeopardy as against the positive feelings of rest and anticipated mastery and growth associated with challenge, even though challenges are stressful. It is true that some persons do experience illness as a challenge, but it is not deliberately sought (except, perhaps, among a relatively few patients whose motivations might then be considered problematic).[186]

Thus, it is intimated that an event can be challenging only if it engenders positive feelings and that negative feelings such as those listed above stand apart from those involved in mastery and growth. Within this structure the problem becomes the stress arising from these negative emotions.

> In health care practice the adaptational paradigm focuses the process of *problem definition* on the emotional and social consequences of the illness or disability for the patient and/or family members. Thus needs and problems are defined as problems in living. The problems are viewed as arising from the stress (harms, losses, threats) posed by discrepancy between the demands and the capabilities for dealing with them.[187]

The implication is that these negative emotions, if left unattended, have the potential to block growth. Stress arising from their presence, therefore, becomes the deficit. Hence, a primary distinguishing feature of effective coping is stress elimination or reduction to provide room for growth and mastery to occur. While the normative standards are more subtle, there is a need to separate one set of emotions from another, linking one to growth and mastery, and slating the other for possible eradication. Is such a separation appropriate? Is it not possible that these negative emotions are a by-product of the struggle to continue to survive and grow? New learning demands risk-taking--a willingness to be open to unfamiliar ideas and experiences. There is a vulnerability of self in chancing to hear, see and experience that which is unfamiliar. Is not the most basic challenge for any living organism the challenge to its survival and growth? If so, is the process of moving forward--growth--always pleasant? This is an important issue for those experiencing a chronic illness, as the challenge is first how to survive and then how to continue to grow when confronted by a part of life not necessarily asked for or welcomed. Here the struggle is not how to eliminate feelings of anxiety, depression, guilt, etc., but to understand their connection with what is being encountered and in doing so, devise ways to manage them when they do occur. They have a place in this struggle to survive and grow.

Because the variety of ways in which people cope is not yet understood, especially in the area of chronic illness, how people fit with their environments and how chronic illness effects this fit needs to be explored . . . not with the intention of identifying problems, but with the goal of understanding how the transactions further survival and growth of those involved, including the helpers and their life space.

> An ecological perspective is concerned with the transactions between people and environments that, on the one hand, promote or inhibit growth, development, and the release of human potential and, on the other hand, promote or inhibit the capacity of environments to support the diversity of human potential.[188]

Again, the intent is to attend to the impact of the environment in combination with self and make visible the subtle paradoxes existent within the connections.[189] Commonalities of experience regarding what might be encountered and the ways others have managed these are gathered, organized and shared, not with the intent of establishing normative standards, but in order to learn from the experiences of others and to determine how these fit with the person, family or group's own life context. Having problems identified by others or identifying them oneself is not necessary to gain access to this information. It is shared because of the frequency with which it is encountered at any given point or because it seems to match that which is being experienced at that moment. The intent is to smooth the intensity of the struggle, not necessarily to prevent it. Always the object is to determine its applicability to survival and growth within the dimensions of the person's own life space.

Strength-oriented Social Work Practice - An Interventive Model

The Beginning. Given the above, what is the beginning point for entry into the helping relationship and what type of interventive approach unfolds? This is of particular concern in the area of chronic diseases such as cancer where psychosocial intervention is seldom expected, let alone sought.[190] Thus, for the person and her/his significant others who have become aware of the existence of chronic disease, the offer of social work services is most often worker-initiated. In view of the emphasis on uncovering deficits in functioning that a major portion of the helping modalities embody, offers of help bring the potential of stigma.

> There is a stigma about not being able to make it on your own. The implication is that if you have the right to live your own life as you see fit, you also have the responsibility to know how to do it successfully.[191]

Because of these implications, offers of help frequently are met with guarded resistance. It has been indicated already that models of helping which employ an educational emphasis are better received. Therefore, if the contention of this paper is accurate--that this occurs because what is being experienced is the forward movement of new learning--it is important that the offer of service reflect an understanding of this. Part of the process of meeting the challenge of change is to comprehend enough about what is being encountered and its effects on the person(s)' life up to that point, to be able to know what needs to be let go of and what needs to develop in order to continue to move forward.[192] Tracing out realistic expectations and goals for self and others is a key struggle in dealing with the effects of a chronic debilitating disease. When every corner of life has been altered by the advent of disease, it is difficult to know if growth is still possible or if survival is all that can be hoped for.[193] Thus, a logical entry point, and the essence of the approach to follow, is to recognize that change has occurred and to offer people assistance in determining its effects and meeting its demands.

This is a collaborative effort. Each has knowledge, skill and access to different resources and opportunities, all of which become available for use if their combined potential is promoted. Hence, part of the process of engagement involves determining what the potential benefit of the association could be. This is not a search for defective functioning in one party's transactions requiring the skills of the other to correct, but one to which each comes with his/her own area of competency which in combination could enhance the existence of all concerned. Each has 'adaptive capacities' and 'nutritive qualities', and each brings a level of competency relevant to the association. The person(s) affected by the chronic illness bring the competency that has allowed them to survive and grow up to this point in time. The worker brings the knowledge and skills that develop out of her(his) profession (interpersonal skills, theoretical approach, etc.), position in the setting (access to decision-making, informal associations, etc.), contacts with others facing a similar illness experience, and life's experience. Each position comes with its own pressures and demands which together determine the climate of the relationship and the expectations each will have of the other. Because each participant does not invest in the association without the expectation of gain, the nature of the intended gain influences the transactional process.

Germain (1984) highlights the need for preparation prior to the initial contact with the client system in order to achieve a greater level of receptiveness to the apparent and less apparent dimensions of what might be experienced.

> Such preparation helps assure openness to both the manifest and the latent content of the communications in the session. The worker is then in a firmer position to offer a service that will fit the needs being experienced by the patient, family, or group. And, finally, these preliminary steps can aid in self-awareness. They are helpful to the student and new practitioner in preparing for their own likely responses to what may be new experiences with intense pain, unpleasant sights and smells, and the anguish of lost function or of bereavement. The weaving together of affective and cognitive processes needed for empathic caring is of critical importance throughout the entire helping process.[194]

While this paper does not completely endorse Germain's development of this idea, it agrees with the basic premise stated above. Position in the setting and exposure to a number of persons managing the effects of long-term illness over time gives social workers access to two very important systems that are not necessarily available to those person(s) coming to terms with the effects of chronic illness on their lives. Given this, their level of competence is enhanced and, subsequently, what they have to offer the client system if they develop their knowledge and skills in two primary directions. The first is to become attuned to the <u>variety</u> of adaptive responses used and their <u>contribution</u> to the survival and growth of the persons concerned. Hopefully, this will engender an appreciation for both the 'adaptive capacities' and 'nutritive qualities', and its own expectations of gain in relation to where it invests energy. How all these systems come together, balance and integrate their functions has an impact on the adaptive strivings of the person(s) experiencing the chronic illness. For example, Martin Nacman (1985) noted that structurally organizations such as hospitals often operate in fragmented parts with little or no continuity between them.[195] Thus, attempts to resolve conflicts often occur at the patient level, when they could be more effectively addressed at another point in the structure. At its most basic level, social work in health care settings cannot function in isolation of the competencies of others who comprise the health care system.

> . . . for effective intervention with clinical social work clients, who are also medical patients, or potential patients, and their significant others, . . . deficits in biomedical knowledge . . . impede the clinician's ability to understand what clients are experiencing physically, emotionally, and socially, and how they are experiencing it. To have such understanding, the clinical social worker must turn to knowledge outside of social work's own domain, that is, to medicine and other biomedical sciences.[196]

Knowledge of the connections and their contribution to the balance and integration of the overall network can assist social work in uncovering incongruencies and paradoxical messages/actions that exist at the level of the individual, family or group directly struggling with the effects of the chronic disease.

> In spite of the pervasiveness of their effect, paradoxes and binds produced by contradictory messages are difficult to pinpoint by the person exposed to them, partly because of the subtlety of some of the paradoxes and partly because the messages are posed at different communicational channels and different logical levels

> (such as a *democratic statement* within an *autocratic structure* or in an *autocratic organization*). The effect of the paradoxes is therefore felt even without the paradox itself being explicitly detected.[197]

An ability to influence the nature and form of these connections can afford social work the power to directly address and change these incongruencies and paradoxes at the appropriate level. Because of the individual, family or group's position in the system's structure and their dependence on the system for essential services, their ability to be knowledgeable of and access these channels is severely reduced. Hence, worker competency and, therefore, benefit to the person(s) facing the chronic illness, are increased through knowledge of the transactional process of the system(s) and an ability to impact the decision-making bodies that determine its direction and balance. A beginning step in obtaining this influence is to move collaborative relationships with other helpers in the system beyond the consultation level.

> *Consulting*, more formal and more structured, involves less reciprocal exchange than conferring. In this process the consultee usually seeks out the consultant as someone believed to have the knowledge and skill to provide needed advice or guidance in a matter related to health, illness, or disability. Whereas in conferring the participants put their heads together and compare notes and exchange views, in consulting one participant is the seeker of information or advice and the other is the provider.[198]

It is the 'reciprocal exchange' of ideas, knowledge and ability that is sought: the production of a climate without threat and with enough freedom of movement to foster the expression of needs and views even though they may conflict.

> It requires reciprocal respect and trust so that observations are exchanged, views are freely expressed and compared, each is free to agree or disagree. Ideally, greater clarity about a need or problem is achieved, and feasible solutions are developed, to be carried out mutually or singly as appropriate.[199]

A collaborative connection that heeds its own sense of integration works to enhance each helper's existence by seeking out and promoting their combined potential. Preparedness, then, is more than merely visualizing what might be occurring in a particular situation concerning certain person(s) directly affected by the chronic disease. Its dimensions are more global than theory or hypothesis about what might be happening in that situation. Preparedness is, in essence, an attempt to see and comprehend the totality of a situation to the degree that this can be realized, to secure a position of influence within the system where the impact of that system on the needs of those directly confronting the disease process can be addressed, and changes to secure a more growth-enhancing fit can be advanced. Thus, it is an ongoing process that does not stop the moment contact is made with the person(s) experiencing the chronic illness.

The next step in unfolding this interventive approach can be identified as 'competence clarification'.

> . . . the process of identifying and understanding the person's or persons' competence in dealing with the environment at a particular point in time. Clarification encompasses, to the extent that this is possible, the totality of a person and environment. The overall aim is to understand the complexity of the person-environment transaction, since this interface is *the* unit of attention and intervention.[200]

Within the ecological model the overall objective is to promote growth. In the area of chronic illness, identifying and understanding the change that has occurred and its effects on the survival and growth of those affected is one way of doing this. A second way is for the worker to use her(his) knowledge, position and skills, in combination with those affected, to assist in the process of meeting the accompanying demands of change. Given this, the beginning point in competence clarification is to identify and understand the nature of the fit between the person(s) concerned and their respective environments, and how chronic illness affects this fit. The goal at this stage is to understand how the various transactions further the survival and growth of those involved, including the helpers and their life space. Access to the nature and form of these connections is not possible without the collaborative efforts of those involved. Remember that each part of the network constitutes the other's environment.

To develop a unified awareness of the totality of a situation, its sense of balance and integration is difficult to accomplish without some form of visual aid. The construction of an eco-map, therefore, would seem a logical action. This process is begun by identifying the major systems that make up that individual, family or group's life space. To the degree that it can be seen as separate from self, an individual's body could be included. Additional systems are added as their significance becomes apparent. In mapping out the connections, consider the following:

1. How open or closed is each system to the other's influence?

2. What are their sources of nurturance, stimulation and support?

3. How do resources flow within or between the systems involved? Are there breaks or fluctuations in this flow?

4. How much energy is expended by each to maintain the connections? How much energy is regained? Does this exchange come easily or is it fraught with conflict?

5. What are the skills--social, relationship and instrumental--present for each to access the other's resources--present and potential--and to manage the demands made by each upon the other?

6. What is the contribution of each exchange with regard to survival and growth within and between each of the systems involved? Note the incongruencies and paradoxical messages/actions existent within and between the connections and their effect on the balance and integration of the overall network and its respective parts.

7. What is their combined potential for enhancing each other's existence?

Action responses/behaviours are examined with respect to their <u>contribution</u> to the survival and growth of the individual, family or group involved. Once their <u>strength</u> has been determined, then their limiting effects for survival and growth can be looked at. Understanding the <u>competency</u> of the individuals, families or groups concerned is the focal point. If it is not apparent already, determine how the layers--social and physical--and textures--time and space--are played out within and between the systems. What is the combined effect?

When examining the effects of chronic illness on the foregoing, consider how the disease is manifesting itself and the demands and challenges peculiar to this process. Look at the individual, family or group's perceptions of the disease--its nature, etiology and beliefs regarding appropriate treatment. Do these differ from the perceptions of others within the situation? Of particular importance is the life stage at which the presence of disease becomes apparent. This involves individual and familial life stages for both the person(s) experiencing the disease <u>and</u> the helpers.

> . . . families often do not proceed through adaptive stages as a unit. The disability of a young adult will affect a spouse, a parent or a sibling very differently. The meaning of the disability for each and, thus, the ability to adapt and the rate at which adaptation occurs, are related to the individual's own developmental stage as well as to his or her role in the young adult's family.[201]

For a family with young children involved in the push towards continued growth and development, and one parent facing possible death from cancer, the emotional and cognitive struggles of simultaneously working through two seemingly contradictory processes can be overwhelming. Chronic illness may also push the developmental needs of one family member into conflict with those of another by increasing, for instance, the sense of urgency to work these through within a certain time frame (as in the following example of a sixty-nine-year-old woman with cardiovascular disease).

> The mother's developmental needs to come to terms with her life and her impending death occurred "off-time" from the perspective of her daughter's developmental readiness. The aging mother was needing to draw her family close at the end of her life, to reaffirm her life values, and to feel she had successfully fulfilled her role as a mother. The young adult daughter

> was threatened by the surge of longings for closeness and dependency at a time of impending loss when she was not yet secure in her own individuation.[202]

Helpers struggle with their own survival and growth issues within the context of their own life spaces. When these become interfaced with similar life processes in the lives of those persons directly confronting the disease, it becomes more difficult to accurately perceive and respond to what is happening for those persons as separate from what is happening for self.[203] Carter and McGoldrick (1980) view life-cycle issues from a three-generational perspective in which families and their members are seen as responding to the joint influences of past and present relationships.[204] There are those ". . . patterns of relating and functioning that are transmitted down the generations . . . ,"[205] and those which occur as the result of advancing through the life cycle. In the latter, stress may be predictable, such as that engendered in moving from one stage to the next, or it may occur as a product of unpredictable events such as chronic illness. Where past and present intersect, stress from one area can act to intensify stress being experienced in the other. A family dealing with the unpredictable course of a chronic disease may find a small amount of transgenerational stress highly disruptive to their struggles to continue to survive and grow with the presence of a chronic illness. It can be seen from the following quote that a family, at any given moment, must contend with the operation of a multiplicity of systematic pressures.

> In addition to stress "inherited" from generations, and that experienced while moving through the family life cycle, there is, of course, the stress of living in *this* place at *this* time.[206]

Life cycle stage can also influence the ability and skill an individual may have available to invest in establishing effective interpersonal processes with the health care system.

> One of the skills that families must develop . . . is learning how to interact with physicians and other health personnel in order to gain the information they need and to combat their feelings of powerlessness. . . . Young adults' inexperience with the health care system and with an advocate role exaggerates this problem.[207]

The maintenance of interpersonal processes in the face of the changes spawned by the chronic illness experience can be a challenge in their own right. Family members may reduce their connectedness, feeling the stress of the illness experience itself on any given member is enough to confront, let alone sharing these individual reactions with one another. They may be immobilized by the intensity of their emotive reactions, seeing them as inappropriate to the situation and/or to how they envision themselves. Former patterns of interpersonal communication may be altered or completely changed by the disease process.

> The disabled individual has a whole set of experiences--hospitalization, struggling with adaptive equipment, facing strangers' curiosity--which the able-bodied spouse does not have. Furthermore, the disabled individual may not be able to return caring in tangible ways: "I could not hold my husband and meet his need" is an example of this imbalance in sharing.[208]

The survival and growth needs of one person may seem and may in fact be incompatible with the circumstances of the situation as it stands at that point in time. Helpers deal directly or indirectly with all these happenings within themselves and interpersonally, despite their point of entry into the helper role, whether or not they choose to acknowledge them. Accompanying a particular chronic disease, the rapidity of physiological change and its effects, can be highly taxing given the time and effort it takes to mobilize systems change or to create new resources or opportunities. Life cycle and transgenerational issues, environmental pressures, and interpersonal processes all influence and are influenced by the chronic illness experience.

Having clarified the strength of the connections for the survival and growth of those involved, and how the nature of the illness affects this fit, the combined potential of the connections for enhancing the existence of each of the systems concerned should begin to become apparent. Given the effects of the chronic illness within the context of the total situation, how can this potential be accessed? Will the changes required by this association respect each system's internal organization? Will it provide them with the tools required to manage the altered circumstances? Finally, what is the point of maximum reverberation or, in other words, that place in the total network where intervention has the greatest potential for benefitting all the parts concerned?

> Always consider the multiple possibilities for intervention; avoid clinical myopia and preconceived notions about which type of cases or clients is best suited to which type of intervention.[209]

It should be remembered that this process of clarification is ongoing. All significant transactions may not be visible initially or their nature and form fully understood. Person(s) in key positions for gaining access to this information may be unwilling to involve themselves in the collaborative exploration necessary to reveal this information. The helper may lack membership in the appropriate decision-making groups, thereby preventing access to relevant resources, opportunities and vehicles of influence. Also, the systems that comprise the network are not static in their operation, but are in continuous motion and, therefore, change. This, coupled with the day-to-day manifestations of a chronic disease that may be essentially unpredictable, means that clarification is a continuous action in the face of change.

Contracting, like the process of 'competence clarification', is a repeated motion in the unfolding of the overall intervention.[210] In moving forward with the outline for competence clarification, agreement of the parties concerned to participate was assumed. However, preceding this step, and at its culmination, a contracting process is required. Initially, it is an act of determining whether the combined interactive potential of the worker and client system will further one another's survival and growth, given the circumstances at the time of the offer. Germain lists the following as one of the skills of engagement:

> . . . [the c]onnecting [of] the offer of service to the particular illness and individualized situation, presenting clearly the social work function and role, and the worker's relationship to the physician, nurses and other staff.[211]

Essentially, the questions for the client system are: what does this social worker have to give to this situation that, in conjunction with the client system's own level of competence, will contribute to the client system's survival and growth, and how does this fit into what has been offered previously? Drawing on knowledge gained from the experiences of others facing similar illness processes, relevant literature and professional exposure, the social worker must then connect this with the illness experience of that particular person or persons. Awareness that chronic illness introduces people to an array of unfamiliar people, technology and procedures that change or threaten to change the course of life as it has been known up to that point may lead the worker to indicate that confrontation with such change often results in a need to verbalize as a means of comprehending its impact the conflicting and confusing thoughts/feelings that arise. Knowledge about what some of these changes entail--the demands and the losses they incur--and that these are often unexpected and unprepared for can assist the worker in personalizing the service offered by naming explicitly for the client system that which was formerly felt implicitly.

> Health professionals can be of great assistance to family members by helping them identify their loss and by providing them the opportunity to speak of their own grief.[212]

Initially, the central purpose of a contract may be identifying only the change that has occurred and understanding its impact on continued survival and growth. Beyond connecting the help offered to individual experience, the worker must be able to identify for the client system and other helpers how her(his) proposal of service fits in with that extended by other helpers. What is the nature and form of the worker's connection with these helpers and how do the various services put forward compliment one another? By providing this information, the worker is indicating the benefit of his(her) position in the setting for the client system.

Seabury (1976) states that in social work a contract is primarily ". . . an agreement between client and worker that sets forth the purpose of their interaction and the processes through which that purpose is to be achieved."[213] It spells out the reason for the interaction, targets the survival and growth issues to be promoted, identifies the means by which this will be accomplished, a time frame for measuring progress, and the parameters which must be respected in effecting any change. Because the contract is in a continuous state of development as the intervention evolves, clarity of purpose is not necessarily achieved in the beginning stages. Seabury speaks of a trial effort:

> Here there is an ambivalent, tentative agreement to try out the process despite the many uncertainties and reservations that remain before a firm commitment is made. The client and the worker will not, as yet, have agreed on goals and procedures, but there is a commitment to continue the process in hope that mutual goals and procedures will emerge.[214]

In view of its exploratory function, competence clarification may, in fact, be the essence of this trial effort. Thus, the 'preliminary phase' of the contracting process would involve a collaborative endeavour to clarify the nature of the connections within and between the systems that comprise the overall network--capacities, demands, energy flow, incongruencies, paradoxes, etc. After detailing what this means for the short-term and long-term survival and growth of the systems involved, what needs to be let go of, what needs to develop, and where these need to happen to ensure forward movement can now be determined.

> By this time, the worker and the client will have reached a mutual and explicit understanding of the goals and procedures of the process. Terms are clear and accepted. . . .[215]

A time frame for measuring progress can now be drawn up. The contracting process is not limited to those directly faced with the chronic illness, but could include any or all of the systems that comprise the total network. Contracting is ". . . the central, organizing strategy for the social work process."[216]

Previously, it was stated that tracing out realistic expectations and goals in the presence of a chronic debilitating disease is a key struggle for those immediately experiencing the chronic illness. All interventions, whether primarily biological, psychological or social in their direction, influence and are influenced by the totality of the situation. Therefore, all intervention with the illness process, regardless of its point of entry, is intimately involved in the same process of delineating realistic expectations and goals with which to guide future actions given the context of the situation.

> It is important to recognize that the presence of a chronic illness inevitably poses extraordinary constraints because staff and family are locked into a treatment course in which neither can exit but where neither is completely comfortable. . . . Family and staff must participate in encounters in which neither has complete control of the situation but where each needs the others.[217]

Realization of the connectedness of all the systems involved is not necessarily readily recognized by all those who comprise these systems. In hierarchical structures the connections tend to run upward towards the top with only conciliatory attention paid to the horizontal associations. Conflict is muffled rather than drawn out and explored.

> Communications between staff members are therefore to a large extent formal and written and need not involve a full understanding by each worker of the nature of the others' tasks. As long as the hierarchical division of labor is recognized and orders clearly given, little further interchange between staff members is thought to be necessary.[218]

The difficulty with the above orientation is that the interconnections exist and continue to have reciprocal effects on one another whether or not they are recognized. Hierarchical structuring is not just a characteristic of a particular organization's model of functioning, it is the dominant model for measuring competency in the Western world.[219]

> A man who has the resources to control the environment to get what he wants may perceive himself or be perceived by others as very competent, in control of his life choices, self-confident and so forth even though it might require other's . . . subordination and limited development. Being effective while maintaining close and respectful connections with other people constitutes a redefinition of competence . . .[220]

Attempts to think and act from a transactional perspective may not be incongruent only with the organizational thinking of the setting, it may be accorded a secondary status as a competent method of functioning. The idea that a higher level of competency in service given can be obtained by identifying, understanding and enhancing these interconnections may appear absurd if the systems concerned feel they can accomplish their respective tasks without such considerations. Witness the following statement made by a surgeon regarding social work demands in a study by Susan Watt (1977) of social work's role in an Ontario hospital.

> I don't know why they can't do what I ask. All I get is questions and more questions. All I want is to go ahead with my job. I wish they'd just do theirs. I know how to tell someone he is dying and I'll do it when I know the time is right. All I want is the patient out of the hospital. Families don't want to do anything so the social worker should instead of asking me all those questions. I'll manage the patient. She just has to get the bed. Can you imagine, one of them had the nerve to refuse to see a patient unless I answered her questions.[221]

In a predominantly acute-care, disease-oriented health care system, which is structured and has socialized its members to respect a hierarchical form of operation in and out of hospital settings, a transactional approach necessitates a perspective reorientation. Thus, attempts to operate from such a framework will not automatically elicit the collaborative efforts required to fully realize the potential of the connections. The need to work towards establishing these connections still remains, but time and space must be provided for others to make sense of this framework's demands for the purposes of their own existence.

Confronting changing demands is not solely the domain or responsibility of the person(s) experiencing the disease. What become changing demands for these person(s) become changing demands for those attempting to help. Interventive strategies must be reworked to accommodate these and any other changes.

> . . . attention to family members' concerns lessens the sense of helplessness that is ordinarily part and parcel of coping with a chronic illness. As families experience their feelings as being heard and their wishes as being respected, they may be more likely to integrate arduous treatment regimens into family life, which become truly "theirs" rather than the alien orders of a fearsome authority. The experience of sharing decision making and responsibility for regimens also allows for more honest transaction between staff and family. Professional caregivers do not have to pretend that they know all the answers. Family members can admit more of their anxieties and misgivings.[222]

In this context helpers struggle with what they can realistically expect of themselves in relation to others given the parameters of the situation and what type of goals they should strive for in the service they offer. If co-ordination of effort is sought, it is not always clear what form this should take or what it entails. The mechanics of sharing information, decision-making and responsibility are not always understood or developed adequately. However, because each needs the other's competence to deal with what is happening, each must decide what they need to put towards the connection to access these resources.

Much of what transpires for the specific instance will be drawn from and built on what is gleaned from the process of competence clarification (i.e., what needs to be let go of, what needs to be developed, where this needs to happen, etc.). However, there are some guiding principles for interventive action which, while in need of modification according to the parameters of the situation, can give direction in a sparsely charted region. Building on this practicum's basic premise that new learning is taking place and that the struggle is to continue to survive and grow within this context, what are the initial adaptational issues that must be worked through for all concerned? Depending on the nature of the disease and its meaning for those directly affected, the initial reaction is generally to resist the validity of what has happened. The continuity of life as it has been known is broken, or at the very least, threatened. A loss has occurred simply in the act of knowing.

> As families move through this stage, they must begin to cope with their grief and begin to mobilize their strengths toward adaptation.[223]

At a time when anxiety and confusion about what has just transpired is high, action is demanded. New information must be incorporated and skills learned. Survival becomes the basic concern. First, there is the technology of medicine, then the personnel for whom this is a familiar setting, and finally, the demands for action before a sense of what has happened can be gained. New knowledge, therefore, must be processed carefully but rapidly in order to aid decision-making regarding action. Clarity and swiftness of action are difficult to access when feelings of anxiety and confusion are high. Thus, the rate at which adaptation proceeds depends in part on the ability of the helpers to realize what is being asked and to structure their behaviour accordingly. To enhance the competency of the connections made, the process of creating them and understanding what each system needs from the other to advance its operation requires attention.

> In order to begin to cope with the medical setting as well as with the diagnosis and its implications, the family must have access to information--information that health care providers must give repeatedly and in a language that parents, spouse, and patient understand. Often either the information or the appropriate timing are lacking, impeding the family's progress toward adaptation.[224]

Attempting to gain sufficient information in a form and at a rate which appreciates the process of comprehension and assimilation is the first step in securing survival. The next is to ensure room for autonomous action in influencing the course of what is to occur, by obtaining access to decision-making processes. When dealing with a system which does not appreciate the reciprocal influence of its connections or their combined potential, this is not an easy maneuver.

> Complex decisions about medical management and rehabilitation are often made by health personnel without giving the patient or the family enough information or a real opportunity to participate in the decision. Family members feel powerless. For example, a young spouse may find her developing role as confidant and helpmate to the patient seriously undermined. Parents, in an effort to maintain their own sense of autonomy, may be tempted to

> take over decision-making for the young adult, and professionals may inadvertently encourage this by relating to the parents rather than the patient.[225]

Without a sense of the global implications of their actions, helpers can stress or limit the connectedness of the systems with which they interact, thereby not accessing the full potential of these systems as a resource in realizing common goals. Such actions may also threaten the boundaries of the system's internal operation engendering that system's resistance in an effort to ensure that its internal integrity is respected. The ability to maintain a certain level of autonomy in relation to one's environment is a necessary adaptive component for survival and when respected enhances the forward movement of new learning. Inclusion in relevant decision-making processes helps to familiarize those affected with the complexity of the issues to be decided and in doing so, guides their understanding of what needs to be confronted. With this understanding they can better determine, in conjunction with their own expertise regarding the functioning of their lives, what needs to be let go of, what needs to develop and where. For this combined effort to occur, the intent to work at joint participation must be genuine. The survival and growth potential of the connections must be appreciated. A third step in ensuring survival in the face of change is to preserve enough of an 'internal balance' so that data can be received and incorporated, and action taken. Frequently, accompanying the initial anxiety and confusion is an array of other emotions such as blame, guilt, shame, depression, all of which must be recognized and worked with whether the internal struggle occurs on an individual, family or group level. The presence, variety and/or intensity of these emotions may be entirely unexpected and/or seem incongruent with how the individual, family or group sees themselves or the situation. Familiar patterns of communication may alter as the person(s) concerned attempt to make sense of what is happening before chancing to share it with others. Connections may become fragmented or broken in such instances, particularly if the person(s) concerned view their reactions as inappropriate or disruptive to the forward movement of the situation. Reluctance or inability to clearly communicate what is occurring make it difficult to work jointly towards fitting actions to the needs and demands of the change encountered and those affected by it. Helping persons can facilitate the strength of the connections by creating a climate where the expression of these emotions is encouraged and legitimized. This includes the expression of the helpers' emotions, which for reasons similar to those felt by the people directly experiencing the illness, might also limit the helper from realizing her/his true potential in the connections made. The arena of expression may differ, but the purpose is similar.

> . . . regular consultation to or support for the "health care family" can often be of enormous benefit in helping the providers to communicate with and support the patient's actual family.[226]

The Middle. Following the impact of knowing a chronic disease is present is a maturing awareness of its meaning for present and future life. When the by-products of disease persist over time and disease-related treatment regimens become a fact of life, the element of chronicity becomes real. Frequently accompanying this budding awareness is a growing sense of injustice, anger at the perceived and actual dimensions of what is unfolding. The losses are real and mounting. Again, this is tempered by the nature of the disease and its expression. Personal ability to influence or direct the course of life seems to be eroded, firstly, by a disease process whose full expression is yet unknown and, secondly, by a dependence on the unfamiliar technology and social milieu of a health care system. Decisions that have repercussions for the person(s)' entire being are predominantly made by people with limited knowledge of the implications of these decisions. Yet, their competency and technology are vital for that person or family's existence. Skill in reminding these helpers of the individual or family's competence and need to be included in the decision-making process must, therefore, be developed without alienating them. All this is to be mastered while internally struggling with the emotional turmoil of grieving losses already incurred and coming to terms with whether they in fact had to or have to be incurred. Open expression of ambivalent and often intense feelings can speed their resolution, but to be open and honest about emotional reactions is difficult when they are intense and generally perceived negatively when expressed.

> Expressing dissatisfaction and anger to those who control the care of one's loved one is difficult to do. Health personnel need to understand the reasons for the family's anger and respond appropriately by changing their own behavior when necessary and by trying to facilitate openness and trust in communication with the family.[227]

Being self-aware and the ability to recognize the need for and encourage 'openness and trust in communication' are traits that are not necessarily nurtured among helpers in the health care system, particularly if the emotions requiring expression are negatively viewed. When struggling with one's own survival and growth within a system, it is difficult to be cognizant of and responsive to others when that threatens to increase this struggle. The formality and authoritarian behaviour fostered by hierarchical structures nurtures power of position rather than the strength of connections.

> Doctors say some extraordinary things to their patients and no doubt other, less studied members of the health profession would also qualify for such comment. . . . For example: "*Don't argue with me, I'm the doctor and you are the patient. You will do as I say or go.*"
>
> The intensity of the doctor's feelings suggests a serious threat to his self-esteem and authority. The patient is left with Hobson's choice: to submit or fight back, but it is unlikely that either course would help much. The relationship is clear "the doctor has absolute authority or else . . .".[228]

It suggests roles that must be complied with, despite a conflictual fit, and that understanding the emotional underpinnings is not necessary to the accomplishment of the tasks at hand.

> Many patients want to understand and negotiate their diagnoses, treatments, prognoses and paths to health. Too few doctors and nurses are prepared to let them negotiate.[229]

Then there is the pressure of pace . . . more than superficial communication requires a different organization of time.

> One of the interesting features about very busy working conditions is that many doctors and nurses become proud of their pace of work, as if the hallmark of . . . success is speed.[230]

When speed itself becomes the measure of achievement, slowing down long enough to determine 'at what cost' becomes the antithesis of progress. Being able to hear and understand what is occurring at the interface demands a different tempo and orientation. Medicine, the dominant professional power in the health care system, has only recently incorporated formal training in interviewing skills into its educational program.[231] Thus, while helpers may use their time to facilitate the required communication, they may not have the necessary skills to make it happen.

> Unfortunately, the clinician who is blind to or unprepared for the more delicate aspects of communication is unlikely to perceive his weaknesses and can continue for years to ride rough-shod over the very issues the patients are most concerned about, particularly when problems are multiple or couched in indirect language or cultural diversity.[232]

The need to facilitate communication between the various helpers is real, but perhaps receives less attention than helper/helpee connections because of the vertical emphasis in the system. Horizontal communication is not seen to be as crucial to task accomplishment. While the survival and growth of the systems concerned can be enhanced by opening up the lines of communication and encouraging ongoing attention to the connections made, moves to do so may be interpreted as a threat to the structure of the system and the integrity of its operation. Thus, there are many incongruencies and paradoxical associations within and between the systems that comprise the total situation, but which must be contended with at any given moment. Any interventive action must respect the context in which survival and growth issues are worked out for both the helper and helpee, and the capacities of each for response.

In addition to establishing effective lines of communication with the health care system and a means of articulating conflicting and ambivalent emotions to maintain an adequate internal balance, there is the task of integrating the chronic illness into the dimensions of the person(s)' lifestyle. Part of this process is determining what losses must be incurred in order to move forward and what can be saved through reorganization or access to additional resources and opportunities. This is not an easy task nor one that can be accomplished without input from the health care system, its technologies and the competencies of its people. Inability to predict the implications of the future course of the disease, in combination with self and a lack of familiarity with others' experiences in facing a similar illness process make it hard to decide what supports to secure or reinforce, how to organize them, and then how to use them. Helpers can encourage or discourage a balanced use of the resources available by how they incorporate them into the interventive approach. Witness the following example where the chronically-ill family member is the child:

> . . . if only the mother is involved in contacts with professionals, then the family may receive the message that it is important for her (rather than anyone else) to be involved in subsequent contacts with staff. The disadvantages of a mother-centered approach to comprehensive care is that it places an unreasonable responsibility on an already highly stressed caregiver, may disrupt the parents' capacity to support one another, and may isolate the father from the child's care.[233]

Because the person(s) directly affected are frequently unfamiliar with what to expect or how to link effectively with the health care system, they look to the system for guidance or cues. Hence, from the beginning stages, interventions need to respect the survival and growth potential of the systems with which they are attempting to link. Building on the above example, the following illustrates the act of considering what is known about supportive connections within a family context from experience and relevant research, and using this to access the potential of the connections in such a way that all benefit by the association.

> Siblings often have a great many worries about what is happening to their chronically ill brother or sister. Moreover, they feel "left out" and deprived of parental attention. Our experience indicates that siblings also can be significant sources of support for the chronically ill child over the entire course of the illness, but *only* if they are informed and involved. Informing siblings about the illness makes their experience more understandable and less frightening and can facilitate their development.[234]

Those persons most immediately affected by the illness experience on a daily basis may attempt to continue to live their lives by the same role and task definitions by which they had defined themselves prior to the onset of the disease without regard for the long-term effects on their survival and growth. One parent may continue to assume primary care responsibilities for all the children even though the medical care demands for the chronically ill child severely tax this parent's energy reserves. Helping action in this instance may be to assist the family in looking at and reorienting their connections by reallocating tasks and/or drawing in uninvolved members.

> Health professionals can facilitate shifting roles by encouraging open discussion of task division. . . . reassessment of roles may be more difficult if "traditional" sex-role divisions previously determined task assignment. Helping the couple to view the whole range of tasks as valuable to the family can be an important step in the adaptive process.[235]

For the person with the loss of function due to the disease process, this may mean identifying those activities that need attention and which are within that person's physical capacity to accomplish. In task reallocation and in the surrendering of roles and responsibilities, especially those which previously gave personal definition, emphasis should be on maintaining personal autonomy and an interdependency with others. Seeing self as capable of independent action and able to give something of value to others as well as receive is an important component of human relatedness and of adapting to a chronic illness. Again, the focus should be structured towards the person(s)' competencies rather than limitations. Emphasis on the latter tends to channel thinking into what cannot be accomplished, not towards what can be done. All of the above necessitates an awareness of what might be encountered and, to the degree it can be determined, how the disease is expressing itself physically and its meaning for continued function. For example, in the latter instance it is important to know what can be demanded of the physical aspect of self biologically/psychologically/socially without overstressing its internal connections, thereby arresting forward movement. To determine the thrust of future action, it is important also to understand to the extent possible what effects can be attributed to the disease process, to drugs and/or to the balance of one's internal emotional state. In facilitating the former, a combination of formal helpers (doctors, nurses, social workers, etc.) and those encountering a similar illness experience (informal helpers) might share their knowledge about that with which they or others have struggled and the various coping strategies used.

Learning to integrate a chronic illness into the parameters of one's life space means also that those parameters are somewhat changed by the presence of the illness. As a result, there are losses for all those affected that must be mourned and adjusted to. Yet, the number and dimensions of the losses incurred can be minimized by providing both a climate for the articulation of the anxiety, anger and confusion experienced, and genuine access to information, decision-making and responsibility through collaborative transactions that respect and focus on the competencies gained as a result of the connections. This is more than a simple act of consultation between parties, each with their own tasks to complete, but whose efforts at times require some joint participation. Resource management is a very serious undertaking in the wake of changes brought about by the expression of a chronic disease. The energy available from the person(s) directly affected, the health care system personnel, and other formal and informal resources is limited. To use it wisely, ensuring its availability when most needed over the course of an unpredictable illness, means that all who participate--helper to helper, helper to helpee--must be aware of what exists and involved jointly in its planned use. Helpers must look at their own resource potential in a given situation, how it can be accessed best to give maximum benefit to all concerned, and be able to communicate this to others. They must foster this in, and be open to, hearing it from the others involved in order to monitor the nature of their own actions.

Time is a significant element in the maintenance of connections. Balancing and pacing the exchange of energy according to needs and capacities are made easier when the span of time and events filling it has a somewhat predictable course and finite boundaries. The greater the number of unknowns embodied within a situation, the greater the difficulty in balancing and pacing resource use. Pattison (1977) describes four pathways of expression for chronic incurable diseases: 'certain death at a known time'; 'certain death at an unknown time'; 'uncertain death, but a known time when the question will be resolved'; and, 'uncertain death and an unknown time when the question will be resolved.'[236] The first of these would give the greatest scope for effective planning and the last situation the least scope. Due to their varying degrees of predictability, each demands a different approach in the development of coping responses and, hence, the management of valuable resources. Within each one living/dying issues vary in their balance, intensity and immediacy over time.

> For a chronic illness, such as cancer or arthritis, the family must deal with remission and the uncertainty of that state. The family must regulate its hopefulness and "balance its image of the patient as presently well, but eventually ill again."[237]

Capacity and need fluctuate, and the number of resources available may decline with the person(s)' ability to function independently of others.

> . . . chronically ill homebound clients, . . . [can] be extremely demanding at times. Contacts in the outside world often drift away, and those contacts that remain assume greater importance. At times it is difficult for the people involved to be needed that much.[238]

Coping with unknowns, then, means a constant readjustment of response according to the demands of the moment. It also means that the resource base must have the time and space available for regeneration, either by replenishing what is already present or widening its base by creating links to additional resources and opportunities. The greater the number of unknowns, the more important it is to share the knowns. Each person in the network can, therefore, plan with the other's actions, needs and capacities in mind.

Issues of daily living can be further complicated by the demands of chronic illness. The intra- and inter-personal requirements for change can be immense. Measures of own and other(s)' self-worth frequently must be reworked entirely. Unfamiliar and often complex medical regimens must be dealt with. In the aftermath of all this, it is easy to overlook the other aspects of life which require room and attention to grow.

> The family must find a way of balancing the demands made upon them for rearranging their lives, so as to be able to provide special care to the patient . . . and to advocate for the other needs of family members for continued growth and differentiation.[239]

The impact of chronic illness can be so far reaching in its effects and its pressures so immediate that the person(s) affected may feel it is inappropriate to direct energies elsewhere. This approach can be unwittingly reinforced by helpers who restrict their vision and emphasis only to the immediacies of managing the disease. The rigors of following certain treatment regimens can ". . . seem to swallow up all time. There is neither time nor energy remaining for activities of family life, work life, and community life."[240] To give issues of balance, pacing and the meeting of needs other than those associated with the disease process room for expression, both helper and helpee must move their attention and combined efforts beyond survival to the promotion of growth.

Clearly, no matter what the competency level of the social worker or those person(s) directly experiencing the chronic illness, neither can facilitate the coping action needed by themselves with only occasional consultation with others to exchange or gain the required information or a minor alteration of approach. Every person involved has control of one piece of the total picture and it is the combined potential of all these parts that must be accessed. Each is a resource for the other and none can truly realize the potential of its input without the participation of the other. The key is not just to confer or consult, but to integrate efforts and actions . . . and this demands that connections be made with a regard for their effect on the total picture to the extent that this is possible. Given that this form of approach runs counter to the organization and value base of the present health care system, its cultural context and, hence, what it sees as necessary for its survival and growth, how can social work intervene to promote a more effective person-environment fit?

If the contentions cited within this practicum are correct, then it would follow that new learning regarding the potential for interventive effectiveness needs to occur. The struggle, therefore, is to re-work the survival and growth needs of the systems involved within this context. This means identifying and understanding the context in which survival and growth issues have been defined up to this point in time, and its influence on the system(s)' capacity for alternative response. Clarifying the nature of these connections will help provide cues for where and how new information, ideas, etc., can be introduced with maximum potential for benefitting all the systems concerned. For any perspective reorientation to occur, those affected must have sufficient time and space to make sense of its demands for their own existence. Again, the emphasis is working with the competencies of the systems concerned. Thus, initially, the goals are to establish collaborative connections between social work and other helpers within the health care system that move beyond formal associations, and to gain access to decision-making bodies where program philosophy and service expectations are determined. The object is to create connections where sufficient respect and trust exist to engender an openness to new ideas and alternative action responses. All this must be accompanied by an awareness of where social work fits into the overall structure and its survival and growth needs as a result of this position. Goals and expectations for services offered on a situation-to-situation basis are constructed with regard for their capacity to increase the overall responsiveness of the system. For instance, to ensure clarity of communication between helper and helpee, a similar congruency in transactions needs to occur from helper to helper in spite of pulls to keep the lines of exchange running vertically. Ambivalent and conflicting feelings need permission to surface between helpers, rather than finding indirect expression in the helper-helpee relationship. Constructing a climate between helpers where the expression of emotions is encouraged and legitimized not only aids them in maintaining enough of an internal balance to free energy for issues of forward movement, it helps them extend this opportunity to the helpee.

Developing an awareness of how the overall picture comes together helps to uncover incongruencies and paradoxical messages/actions and makes conscious their effects. It helps draw attention to the complexity of the issues to be faced and decided upon. In doing so, it puts the worker in a position that Germain (1984) refers to as the 'enabler role'.[241] The reciprocal influence of the connections can be clarified, actions interpreted and confronted, fears expressed, grief and mourning legitimized and informal support systems identified. If worked out with those directly affected by the chronic illness, these person(s) and the social worker can move from an informed position of better understanding about what it is they are confronting and attempting to work with. The worker can draw on her/his own knowledge of the system's participants and work collaboratively with those person(s) experiencing the illness to develop the necessary linkages with other helpers. For example, this may involve coaching them on how to approach the various persons who people the system in order to effectively connect with them. The worker may push to make the system more responsive by encouraging the helpers concerned to share informaton, decision-making and responsibility in order to help the person(s) experiencing the illness balance any decision made in the context of their own life space. With these actions the worker enters the role of 'broker' or acting at the interface between client and resources.[243] This role assumes that each of the respective systems sees the other as a potential resource and, therefore, sees a purpose in enacting a connection. Once connections are made, upkeep is required. If one or both of the systems involved does not view this as important or sees the investment of energy as the other's responsibility, the connection may become severed or blurred, preventing the exchange of information and/or barring access to that system's decision-making powers. Maintaining a sensitivity to how the connections are balanced, the pace of their transactions, alterations in their energy exchange and the structural space available for maintenance functions can alert the worker to occasions where mediating skills are required to sustain the survival and growth potential of the connection.

> . . . mediation presumes a common bond, or complementarity of interest, between the client and the resource system. In brokerage, this common bond is functional. In mediation, however, it has broken down or grown obscure. What results is conflict, a sign that one or both parties have lost sight of their need for one another. . . . [the] primary function is to help them rediscover their mutual need, thereby freeing each to contribute again to the other's welfare.[243]

Mediation is a process of tracing out each one's need to access the other's competencies, identifying their combined potential and using these as a means to re-establish or clarify the connection.

> In addition, the mediator helps the involved parties identify the boundaries beyond which their agreement produces consequences for other systems in their respective social networks. That is, [s]he helps the parties become cognizant of the ramifications that their relationship and decisions may have on other systems to which they are related or of which they are a part.[244]

Resistance to the connection is drawn out, confronted and worked through jointly, with the mediator assuming a position of neutrality. However, there are occasions when sides must be taken requiring the use of an advocacy role.

> The advocate role refers to the defending, promoting, or pleading of a cause, to action taken in [sic] behalf of an aggrieved individual or group of individuals. The advocate's primary function is to remove obstacles or barriers that prevent people from exercising their rights or receiving the benefits and using the resources they need. . . .[245]

This may mean supporting efforts to gain information, access to decision-making and shared responsibility necessary to one system's survival and growth when it is denied by another system. Because advocacy is for one stance, it is automatically against another. It holds the potential of threatening the internal organization of the system whose stance it is against, engendering that system's resistance. Hence, it is important to understand the context in which the system defines its survival and growth needs and to proceed accordingly. If power of position is promoted, as within hierarchical structures, it is wise to heed its chain of command by entering at the appropriate level and proceeding upward until the required linkages are made. Because advocacy deals with opposing forces where access to certain resources and/or opportunities has been denied by one, it is asking that force to rethink its position, thereby challenging its sense of competency in a given circumstance. It is a role that risks the possibility of alienating that force by virtue of the advocate role's refusal to accept that force's position.

> . . . the client of the social advocate is generally relatively powerless--[her]his resources (e.g., money, political influence) are not equal to those of the withholding party. In addition, [s]he is frequently dependent upon the resources dispensed by that party. Thus, the outcome of opposing that party may be even harder to live with than not receiving the withheld benefit.[246]

Due to the potential risks involved, this is a role that is used only after the other roles cited have not produced the desired results, and then only with the informed consent of all those who will bear the consequences of a negative outcome. The efficacy with which these roles proceed will depend on the worker's ability to cultivate open and trusting connections and social work's ability to be perceived as a valuable resource within the overall system.

The Ending. The ending phase is the structural occasion in the intervention where collaborative efforts are drawn to a close and progress towards common goals and objectives is measured against the expectations of those involved and the demands of the situation. Because effectively meeting survival and growth needs is a transactional process, especially in the context of change brought about by the onset of a chronic illness, the power to shape coping responses is not the sole possession of the person(s) directly experiencing the chronic illness. Nor can its potential be released simply through the process of working collaboratively with a competent social worker. It requires the integrated efforts of all those who control a piece of the overall network. The survival and growth issues to be promoted initially may be targeted through the collaborative efforts of the social worker and those person(s) directly experiencing the chronic illness, but the process of promotion may involve engaging and mobilizing the transactional energies of the other components that comprise the overall network. Because the focus of other helpers within the health care system is on the consumer of services--intra- as opposed to interpersonal--asking them to focus valuable energy on the connection is asking them to relate in a manner not formerly envisioned as part of their role. Consequently, progress towards common goals and objectives cannot be measured solely by the action responses of those directly facing the chronic illness. It must incorporate the responses of the other systems involved as well. Since the focus is on the interface, it is the progress at the point of connection that is relevant. What is their combined potential for enhancing each other's capacity for existence and what progress has been made towards accessing this potential? Thus, while the person(s) experiencing the chronic illness and those systems occupying their life space may leave the network, ending this set of collaborative relationships, the worker may continue to work on enhancing the potential of his/her connections with other components of the network. Although goals and objectives will be individualized according to the parameters of the situation, the overall objective is to promote growth. The route to accomplishing this is to clarify the competencies of the systems involved and strengthen their potential for enhancing one another's continued survival and growth in the face of change by focusing on their transactions. This may mean assisting one or more systems with the process of letting go and the expression of grief and mourning which accompanies that. It may mean identifying what needs to develop and working towards making that happen. It may also mean learning how to balance the issues of living with those of dying on a day-to-day basis. It does mean promoting transactional thinking, having each system view the other as a resource, structuring connections with a regard for their effect on the total picture, integrating efforts and actions, and in the end creating a more effective person-environment fit. In moving towards this, time and space must be supplied for each system to make sense of the demands made for its own existence.

In addition to the helping model used and the nature of the transactions made, ending a set of collaborative endeavours with a particular system(s) will be influenced by the demography of the population served, the structure and function of the organizational setting, and death of the participants.[247] For those where the expression of the chronic illness has made them highly dependent upon their environments for survival and growth, the ending of a service commitment becomes another loss to be grieved. The impact of such an ending is heightened by the rate at which loss has had to be endured up to this point.

> The sick elderly and very young, and the disabled of all ages, are particularly dependent upon their environments. . . . Hence the loss of a relationship to a caring and helpful social worker may be painful to the client, evoking grief and its components of anger, self-hate, and sadness. And the social worker may feel guilt at "abandoning" such a client.[248]

Boundaries of policies and programs may impose endings where needs have changed and the resources and opportunities to meet that need are not present within that organizational setting. A transfer to another health care setting may involve a total reconstruction of relationships with new people in a new setting with little, if any, attention paid to continuity between programs. A means of smoothing the point of transition would then need to be structured into the ending phase. Death, its point in the life cycle and its place in the evolution of the helping relationship affects endings. Death may come sooner than expected or the person may live beyond the expected survival time.

> Families in which a member has a long illness, such as cancer, suffer from the stresses of permanent uncertainty. They are never sure of the course of the illness. Every remission brings the hope of life; every exacerbation, the fear of death. This constant uncertainty wears the family out emotionally.[249]

Although the angle of approach may be different, helpers are not immune to this emotional wearing and must also balance the issues of living with the issues of dying in determining their interventive direction. The life cycle stage at which death occurs has a special impact for all concerned, helper and helpee alike.

> In human experience there is a correct time to die and a wrong time to die. Because death is a psychosocial event, whether its time is right or wrong will depend, in part, on the individual's age and roles, the self concept and the conception of death, the nature of the illness, the cultural context (particularly ethnicity and religion), and the presence or absence of supportive human relationships.[250]

For all involved, there is a process of letting go.

Keeping the implications of the foregoing in mind, how then does the process of termination unfold? Lawrence Shulman (1979) lists six termination skills:

> . . . (1) pointing out endings, (2) responding directly to indirect cues, (3) acknowledging the client's ending feelings, (4) sharing the worker's ending feelings, (5) crediting the client, and (6) inviting the client's positive and negative evaluations of the shared work.[251]

In closing off any collaborative effort where there has been an investment of self, there must be structural time and space for response--for emotions to surface, be expressed and worked through. There is an ambivalency to the process of letting go: a knowledge that it must happen, but a hesitation to follow through. The intensity of this hesitation is increased if the ending comes prior to the natural culmination of the efforts invested. A sense of what all this has meant and will mean must be gained; the strengthening and limiting aspects of the connection shared. How the goals and objectives reached for have contributed towards each member's continued survival and growth are looked at in relation to their expectations and the demands of the situation. Individual and collective successes are acknowledged and owned. This is equally important for all members involved in ending the connection as all must be able to crystallize the learning gained as a result of the connection in order to use it for forward movement.

> This lays the base for ongoing tasks for the client after termination or transfer, and it also supports the professional development of the worker. The client is helped to generalize the experience to other future demands and opportunities, while the worker is helped by the process to generalize to future helping situations what has been learned from this one.[252]

Because there is vulnerability in sharing, the possibility of rejection or ridicule, the worker may need to take responsibility for initiating the process. By demonstrating a willingness to trust others with an exposure of self and by facilitating the open expression of indirect communications, even if the content or tone is difficult to hear, these others may be more willing to reciprocate. A climate can then be created that legitimizes the expression of both positively and negatively viewed emotions. Again, it should be remembered that this process of ending occurs between helpers as well as helper to helpee. Also, there may be endings with one segment of the overall network but a continuity of involvement with other parts.

Chapter 2

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Chapter 3

CANCER AS A CHRONIC ILLNESS

Understanding the illness, the human experiencing of cancer, requires some understanding of the nature of the disease. What is the disease cancer and how does it express itself? Once its presence is verified, what can be expected in terms of treatment? The purpose of this chapter, then, is to define the nature of the disease, identify its chronic features, note the human experiencing of cancer, and discuss some of the more defined approaches to its treatment, biologically and psycho-socially.

Evolved from a normal cell, cancer is a mutant cell, or cells, that has somehow altered its basic characteristics, either naturally or induced by external forces, so that it no longer functions as it was intended to within the body.[1] Unlike its predecessor, this mutant cell or cells has a longer life span, can continue the process of cell division indefinitely and can encroach upon neighbouring tissue. As well, one or more of these cells can leave the original location and journey to distant body tissue, forming secondary growths called metastases. When viewed via microscopic magnification, cancer cells frequently have a disordered look. However, because these cells maintain some of the same structure and secretions as their predecessor, their origin can be traced, thereby indicating whether their present location is their original site or a metastasis.

> . . . If, for example, the offspring of a cancerous skin cell (melanoma) has spread to the lungs, the doctor can tell from the presence of skin pigment in the lungs, and from the structure of the cell, that the cancer in the lung is a secondary growth and that the primary growth is a melanoma.[2]

Because cancer is an uncontrolled cell growth with no function and an indefinite life span, it continues to divide, taking over the space available for functional cells.

> The cancerous cells, because they live much longer than normal cells and divide recklessly, keep on multiplying and spreading without end, crowding normal cells, until the organs of the body are choked to death.[3]

In its beginning phase, there is some indication that the body's immune system is able to eliminate these mutant cells. However, it is believed that cancer cells may secrete a cell product that immobilizes these eradication efforts. This is often referred to as the 'blocking factor'. Exactly what the blocking factor is and its process of operation are still unknown. Altering the genetic makeup of a functional cell in such a way that a mutant cell evolves and reproduces itself is a process occurring over a period of time rather than instantaneously. Cancer resulting from exposure to cancer-causing substances in the present will not be identifiable until several years later.

> The radiation a person is exposed to now, for example, may cause cancer in ten to fifty years; or the job a person has at age eighteen may be the cause of a cancer he develops at age sixty-five.[4]

Although the existence of cancer may take a number of years to appear, once it has surfaced, its growth rate and the progress of any metastases vary according to the type of cancer. In a previous chapter the term 'disease group' was used in reference to cancer.

Though the foregoing paragraph has outlined some of the similarities, cancer has in fact over one hundred different manifestations.

> . . . some originate in the muscle and bone (sarcomas), some in the skin or in the linings of organs (carcinomas), some in the blood (leukemias), some in the lymphatic system (lymphomas); some develop slowly, some quickly; some grow like a balloon, some spread like a lava flow; some respond to treatment, some do not; some are mushy, some fibrous; some are common in the young, some in the old; some appear more often in one country or occupation, some in another.[5]

Depending on the type of cancer and its form of expression, cancer can disseminate throughout the body by the following means, with the latter three giving rise to metastatic growths.

> . . . (i) invading neighboring tissue with amoeba-like movements; (ii) traveling through the lymphatic vessels to the lymph nodes; . . . (iii) traveling through the veins to other parts of the body, particularly to the lungs, the bones, and the liver; (iv) invading a body cavity, particularly the abdominal cavity or the chest cavity.[6]

The lymphatic system and blood vessels network throughout the body providing transportation routes for cancer cells which have become dislodged from a primary growth. These cells tend to locate themselves in the body tissues through which these systems pass. Leukemias are marked by a proliferation of immature white blood cells in the blood itself which do not possess the disease-fighting capacity of normal white blood cells. Because these cells replace normal white blood cells, they weaken the body's resistance to infectious disease. They overrun the blood with their numbers, taking over space available for platelets and red blood cells necessary in the control of bleeding and in transporting oxygen supplies to the body.[7] Thus, a person may die from an infection (s)he is unable to defend against or from the effects of internal bleeding, rather than the cancer itself. The most frequent ways cancer results in death are as follows:

> . . . (i) by causing a general weakening of the body (cachexia) until the body fails; or (ii) by crippling particular organs--for example, the kidneys--so that they cannot function; or (iii) by exerting pressure on the skull and brain; or (iv) by obstructing an air passage or a major blood vessel; or (v) by destroying the blood coagulants so that any cut or injury is subject to hemorrhage; or (vi) by blocking the immune system so that the body cannot fight disease--for example, pneumonia.[8]

Though a number of advances have been made in the early identification and treatment of cancer, thereby resulting in cures for some cancers and in significantly lengthening the survival time for others, two-thirds of those who develop a form of cancer will die from it.[9] The efficacy of the treatment at the point of discovery depends more on how large the cancer is, its point of development, its position in the body and the speed with which it spreads than its type. The possibility for cure diminishes with increases in the degree of spread. Widespread cancer is cancer that has metastasized.

> If a tumor is discovered early enough--that is, before the cancerous cells take root somewhere else--the tumor can be destroyed and the cancer completely eradicated. But once the cancerous cells have metastasized--to the liver or lung or bone, for example--treatment can seldom produce a cure.[10]

In a large number of instances, by the time it becomes detectable, the cancer has already metastasized. Because of the number of cells that usually dislodge from the primary site and the extensiveness of the lymphatic system and blood vessels within the body, the likelihood of several secondary growths occurring is high.

Even though a complete cure may not be obtainable in a number of cancers, significant strides have been made in increasing survival time. Cancer cures are usually calculated in terms of the number of years an individual is able to maintain a symptom-free existence.

> A cancer is considered "cured" if after treatment the patient remains free from symptoms for five years. But just as an infection may appear to be cured only to recur, so too may a cancer appear to be cured only to recur. And just as one infection may be cured only to be followed by a different, unrelated infection, so too may one cancer be cured only to be followed by a different, unrelated cancer.[11]

Thus, the cure could be complete or for an indeterminate span of years. From the physiological dimension, treatment can be categorized roughly as curative or symptomatic. Curative treatments are used when there exists some hope of obtaining a remission in the disease process. Symptomatic treatment, often referred to as terminal treatment, occurs when the disease has progressed to a point where it is no longer responsive to curative efforts.

> The difficulty is that no clear line divides improvement from decline. For the doctor to be certain that the patient is no longer curable, [s]he may have to subject the patient to considerable pain and expense. The doctor's dilemma may be stated in this way: [s]he must, by means of imperfect tests, determine when the patient has crossed the line from curable to incurable. . . . the doctor must often rely on inconclusive data, the judgement of other doctors, and [her]his own experience.[12]

Symptomatic treatment concentrates on relieving discomfort produced by the disease (pain, nausea, vomiting, constipation, shortness of breath, loss of appetite, etc.). In doing so, the comfort level of the person experiencing the disease is increased to the extent possible until death occurs. Curative efforts, however, can often be a source of such discomforts. The following is an account of some of the possible side effects of chemotherapy:

> Nausea, loss of appetite, hair loss and diarrhea are among the most troublesome side effects to patients. But more serious is the tendency of many drugs to destroy white blood cells, reducing

> the body's resistance to infection, as well as platelets--blood components needed to prevent bleeding. The antibiotic Adriamycin can damage the heart muscle and Vincristine can harm nerve tissue. Finally, chemotherapy itself can cause cancer: about 5 percent of patients treated for Hodgkin's disease can develop leukemia about ten years later.[13]

Although the implications of the treatment efforts employed are far reaching in their impact on those experiencing the disease, demarcating which direction to move in is not easily defined. A reflection of the limits of present-day knowledge and technique, there is much about cancer that is still unknown and, therefore, unpredictable. The scope of its expression relies on many factors, most of which are beyond the reach of present-day observation.

Greatly simplified for the purposes of this paper, the foregoing only begins to detail the complexity and uncertainty of dealing with cancer when the primary focus includes just the eradication and/or control of the disease itself. What happens when this focus is broadened to include the human experiencing of cancer? Because the linkages between what come together to produce cancer and what does produce cancer have yet to be defined, the selection process of who will develop a particular cancer under what conditions seems to the outside observer, and perhaps those with a more inside view, at best a matter of chance.[14] Although heart disease still heads the list above cancer as a leading cause of death in North America, cancer is still the more feared.

> Heart disease and stroke account for nearly 50 percent of all deaths in the United States. Cancer accounts for less than 17 percent. Certainly we are concerned about heart disease and stroke, worried about these diseases of the circulatory system

> that are so pervasive and so debilitating, that kill nearly one of every two of us. But we are terrified of cancer, not heart disease.[15]

A Canadian study (Vachon, et al., 1977) surveying the reactions of two groups of widows to their husbands' deaths, one group where the death resulted from cancer, the other from cardiovascular disease, found the following:

> Factors of social desirability coloured the experiences of patient and spouse. Cancer is still associated with evil, dirt, pain and death, whereas cardiovascular disease is seen as being more "manly" and the aftermath of working too hard. These unspoken social attitudes contributed to making the final illness and the bereavement period more difficult for the widow.[16]

The dimensions this fear can assume is witnessed in a quote from Robert Cantor's book, <u>And a Time to Live</u> (1978):

> Before the age of enlightenment, most people believed in the Devil. He was the embodiment of evil. He was the source of all immoral tendencies, bad thoughts and dark deeds. What man wanted to disavow in himself was attributed to the Devil. . . . For many of us today, cancer has come to be experienced with precisely the same terror the Devil inspired in our great grandparents.[17]

Thus, for many the diagnosis of cancer brings forth images of pain, death and a sense of having been catapulted unwillingly into an unknown future that suddenly seems to have been significantly shortened by the knowledge of having developed a life-threatening disease. The person(s) concerned are confronted with an awareness of their own mortality and with it the mortality of all the human connections of which they are a part. Continuity is threatened, giving the bonds that link one person with another a finite quality.[18]

> . . . a person is not only reacting to the actual medical facts, but to all the frightening emotional, and social associations bound up with the diagnosis of cancer.[19]

Part of this terror stems from cancer's unpredictability. The disease may be present without the knowledge of its host, making detection difficult; its spread may be rapid or slow; it may go into an unexplainable spontaneous remission; even its cure is defined in years of symptom-free existence rather than in absolute terms.

> . . . the unpredictability of cancer--the constant potential for renewed crisis, for recurrence and spread of disease; the other physical setbacks or the breakdowns in the patient's support system. In fact, patients repeat again and again that it is the uncertainty that is most difficult to bear; that if they know what to expect, they can cope, but the not knowing is difficult.[20]

McIntosh (1974), in his review of the literature regarding cancer and communication in hospital settings, identifies uncertainty over the nature and outcome of the disease as a "central theme" in the ongoing care of persons with cancer and, therefore, an important factor in shaping communications in this area. [21] Unpredictability threatens control. Control is difficult in the face of unexpected change. While active measures such as the monitoring of activity levels, medication and diet give a sense of being able to influence directly the course of diseases such as diabetes or heart disease, cancer offers to date no such 'felt' sense of control.[22]

> As they watched their husband being ravaged by the disease, they felt they could do little more than provide him with emotional support as he coped with pain, deterioration and the threat of impending death. Furthermore, they often had to stand by helplessly as their husband expressed a longing for death as a release from suffering. . . .
>
> The role of the widows whose husbands had died from cardiovascular disease was much more active. These women could be helpful to their husband and possibly gain control over his disease by careful attention to his diet and activity.[23]

Personal sense of control is further assaulted when this is coupled with the indignities of treatment. Because the health care system constructs its primary focus in biological terms, recognition of the individual's personhood in such settings becomes a bonus rather than an expectation. Understanding the ways of the system or knowing that certain invasions of personal privacy must be endured for treatment to occur does not necessarily ease the indignity of the position.

> Hospitalization is a "single-minded realm" that leaves "nothing for the special grace of being." Identity and uniqueness are reduced to biological anomalies, and the dramatic loss of one's identity can be extremely painful to experience.[24]

Because the course of the disease is unpredictable and two-thirds of the time fatal with any chance of visible control appearing to arise from its biomedical treatment, such treatment can assume a guardian-like status despite its accompanying discomforts. Kardinal and Cupper (1977), in a study of fifty patients with advanced cancer, found that while anger was readily expressed regarding the actions of former health care personnel involved in their treatment, no such anger was directed at those presently involved. Instead, the efforts of these persons received nothing but acclaim.[25] Mitchell and Glicksman (1977) interviewed fifty patients undergoing radiotherapy for treatment of malignant tumors. When asked whether they would like their physician to be more attentive to the emotional impact of the disease and its treatment, some persons gave the following response:

> . . . nearly 20% of the sample, said they would not tell their doctors about emotional problems! The reason: treatment for the cancer would suffer if time were spent by the treating physician on other problems in living.[26]

While Kardinal and Cupper felt patients were willing to endure nearly any discomfort in treatment if progress of the disease could be arrested, they saw patients as gradually losing control of their futures in the process of the interaction and becoming increasingly bound to the treatment facility.[27]

Loss of control can be felt in other ways. The effects of treatments which have not been explained adequately or have not been processed fully because of a stressed internal balance can have a frightening impact on a person's sense of mastery. To be confronted with the unexpected, even when it is unavoidable, robs people of choice, effectively excluding them from active decision-making regarding their lives. Often, in an attempt to navigate the initial shock of the disease and the treatment network to which it introduces the person(s), the dimensions of what has occurred are not fully acknowledged until the person(s) concerned are in a safe environment where their pace can be relaxed.

> It is then that the fears and fantasies and dreaded consequences are permitted to come pouring into awareness. Even the physical realities are first acknowledged at home.[28]

It is here that conflicting emotions are experienced and their intensity realized. All the unknowns regarding the disease itself, and now the magnitude of emotions whose presence may seem alien to self, can defy the patterned existence of life as it has been understood up to that point.

> To be "possessed" by such feelings is temporarily to surrender conscious control for the purpose of serving a greater emotional need.[29]

Cantor makes the observation that this is a particularly perplexing need in a culture which emphasizes the "rational" plotting of experience.

> Cancer can and usually does evoke the irrational. It is frightening to feel out of control, but denial of one's experience or blind adherence to some ideal of rationality can intensify fearful fantasies and result in a yet more incapacitating sense of being out of control. There is no "normal" way to react to the cancer experience.[30]

It is Cantor's contention that internal order is regained and competency enhanced not by harnessing such needs within a normative structure, but by understanding their adaptive strength for those involved.

Reaching for that internal sense of control of life and future is difficult enough when one's destiny suddenly has become fused to a treatment facility. Yet, even when freedom from cancer is pronounced, there are no means of guaranteeing the accuracy of this pronouncement.

> I am often afraid to this day, but even more so angry at having to be afraid, of having to spend so much of my energies, interrupting my work, simply upon fear and worry. Does my incomplete gall bladder series mean I have cancer of the gall bladder? Is my complexion growing yellow again like it did last year, a sure sign, I believe, of the malignant process that had begun within my system?[31]

Pattison (1978) speaks of the 'living-dying interval' or that span of time interposed ". . . between the *crisis of knowledge of death and the point of death* . . .".[32] He separates this interval into the acute crisis, the chronic living-dying phase, and the terminal phase. The acute crisis phase is entered at that point when the person(s) concerned become aware that the boundaries of their life may be prematurely shortened.

> All of us project ahead a *trajectory* of our life; that is, we anticipate a certain life span within which we arrange our activities and plan our lives. And then abruptly we may be confronted with a crisis--*the crisis of knowledge of death.* Whether by illness or accident our potential trajectory is suddenly changed.[33]

There is no longer the same sense of quantity of time. The impact of this awareness must be acknowledged and worked through in its own right. Whether a matter of weeks, months or several years, the chronic living/dying phase embodies the adaptive integration of issues of dying with those of living so that life may continue with a respect for its quality and the pushes and pulls of each of its stages. The terminal phase sees a change in the nature of hope.

> At the outset of the living-dying interval, the dying patient has an *expectational hope*; that is, a set of expectations that have some possibility for fulfillment. They may be remissions, arrests, sometimes possible cures. They may be weeks, months, years of some rewarding life yet to be fulfilled.[34]
>
> . . . [in the terminal phase] expectational hope now changes to *desirable hope*, that is, the patient may still hope that [s]he might not die and this is a desirable thought, but it is no longer expectable as a hope.[35]

Interspersed with recurring stress, the living-dying interval places demands on psychic energies that are at risk of being significantly depleted by the physiological expression of the disease.

With each recurrence of the disease or each decline in ability to function, individual images of personal worth are re-evaluated. Fears of being abandoned or forced into isolation begin to well, either because the manifestation of the disease or the treatment has altered body form, mobility or energy levels. In danger of being lost may be the attributes from which self value is drawn and connections to others are assumed to be, or actually are, built. "Pain, anxiety, and fear stimulate the need to be cared for and cared about on both emotional and physical grounds."[36] Although fears of abandonment and isolation are present in the wake of other chronic illnesses, cancer's association with evil, dirt and pain acts to magnify these fears.

> I remember attending a small party one evening while on a pass from the hospital. Everything seemed to be going all right until I noticed that I was being served my drinks in a paper cup, while everyone else had glasses! The hostess obviously believed cancer might be contagious.[37]

Faced with a lot of unknowns and a disease whose course and treatment can erode function, the need to draw on and be dependent on other(s)' competencies is very real. Yet, the desire to preserve one's independence is equally strong.

> The cancer experience can intensify both the need for dependence and the need for independence. Great confusion results when these conflicting needs are experienced and expressed. One moment a patient might be outraged at not having been consulted and the next moment quite easily say: "You take care of things." The conflict is an unavoidable part of the cancer experience.[38]

Human survival demands that everyone be both dependent and independent throughout his/her lifetime. Thus, the essence of survival is to achieve a balance between the two within the context of his/her existence. More than dependence or independence, there must be interdependence. To receive, there must be a sense of giving and in giving, a sense of gain. The quality of human connectedness depends on this energy exchange. Fears of abandonment and isolation are heightened when the individual(s) concerned feel they can no longer offer anything of value to balance what is received.

The lack of definitive physiological guidelines marking when the move from curative to symptomatic treatment of the cancer should take place is reflected in the human experiencing of the disease. As the dimensions of illness reach beyond the biological expression of the disease, so also do the indications that signal when this move should come. However, given the limitations of human understanding, their presentation is no less vague and, therefore, equally as difficult to decifer.

> Some of the most poignant and stressful conflicts related to cancer treatment issue from the struggle between those valiantly holding on and those trying to let go. Each person perceives the circumstances differently, sometimes even self-righteously, and acts according to his[her] perceptions.[39]

Reading the signs is complicated further by fatigue. Pursuit of the elusive cure is an exhausting process for both those directly experiencing the disease and for health care personnel. Long-term illnesses have a draining effect on emotional and physical energies. There may come a point when merely the act of knowing is too taxing, and there seems to be nothing left to give.

> At what point can one say that the physical pain from disease and treatment, as well as the isolation and loss of control, exceed a threshold of tolerance? And does such a threshold exist?[40]

Thus, the persons involved can be faced simultaneously with a desire to undergo whatever it takes to effect a cure and a wish for an end. For those directly experiencing the illness, Murray Parkes (1975) describes acceptance of the need to move from a curative to a symptomatic approach in treatment as a process of realization.

> . . . there is a greater and greater tendency, as the disease progresses, for the patient to give up, a few at a time, many of the assumptions about [her]himself which have been invalidated by the illness. [S]He may, for instance, decide that [s]he is not going to walk again. But [s]he does not necessarily mean that [s]he expects to die. . . . Realization, therefore, tends to occur in fits and starts which often correspond to a fresh incident in the course of the illness . . .[41]

Decisions to change the direction of physiological treatment from curative to symptomatic involve more than just reading the biological signs. To effectively change direction, readings from all three dimensions--biological, psychological and social--must be attended to and integrated. Meeting the challenge of cancer biologically, psychologically and socially involves many dilemmas and contradictions, both internally and externally. Cancer the disease and cancer the illness have many dimensions, none of which is clear cut in its presentation. Perhaps the following quote is the most complete way to sum up the human experiencing of cancer.

> Adjusting to cancer is long-term, ongoing, and periodic. The problem is acutely, chronically there, so long as the cancer is, and periodically for years thereafter.[42]

Given this, what is comprehensive care when the presence of cancer is confirmed? Ultimately, it should be an approach in which, from the moment of contact with the health care system, bio/psycho/social dimensions are appreciated and addressed as a total unit. However, because the health care system has primarily drawn its approach from a biomedical basis, its major concentration is on the biological expression of cancer with psychosocial concerns occupying a secondary status. Mind and body are essentially separated in thought and action.

> Comprehensive cancer care . . . rarely assesses a patient's psychosocial needs and liabilities. As a rule, care is construed as surgery, radiation, chemotherapy, and, more recently, immunotherapy. Physiotherapy, physical rehabilitation, social service, and extended nursing are wholly ancillary, if that.[43]

Weisman and Worden (1977) contend that the incorporation of psychosocial elements is merely a matter of widening the boundaries of an already well-known construct within the field, that of the association between tumor and host.

> We believe that the term, Host, refers to much more than the physical body, but to the patient as a person. For the cancer patient, the psychosocial predicament may intersect physical diagnosis and treatment, requiring special investigation and systematic appraisal.[44]

The separation of the psychosocial from the biological approach has had a number of repercussions for those who have developed a type of cancer, some of which the following two quotes represent:

> In our present zeal to improve the care of the terminally ill, we are often working against insurmountable odds because we are intervening too late. Frequently, by the time a patient is diagnosed as being terminal [her]his relationships with family, friends and physician have deterioriated considerably, [s]he is stripped of [her]his sense of control over [her]his own destiny and [s]he responds with tremendous depression, fear and anger.[45]
>
> Despite the millions of dollars spent each year on biomedical research, the health care industry in this country is just beginning to sensitize itself to the need for developing effective psychosocial support systems for patients and families facing life-threatening illness.[46]

Attention to the psychosocial concerns is given only after deterioration in this area has already occurred, and monies directed towards the development of program dimensions to address psychosocial issues come as an afterthought. Yet, evidence that the human organism responds as a total bio/psycho/social unit throughout the diagnosis and treatment of cancer has been documented repeatedly. Vachon, et al.'s (1977) study of widows whose husbands died of cancer found that at the end of a two-year period following bereavement, a number of these women saw living with the illness far more stressful than the process of mourning their husbands' death.[47] They saw themselves as having had a greater need for supportive psychosocial services during the struggle of living with the illness, more so than in the period of bereavement. Kardinal and Cupper (1977) concluded that clear and honest lines of communication between family members, the person bearing the cancer, and the physician may be the most critical obstacles a cancer patient confronts during treatment, and a major factor in the person's ability to come to terms with her/his illness.[48] Mitchell and Glicksman's (1977) sample of fifty radiotherapy patients gave the following responses:

> When asked about their emotional reactions to therapy and to their underlying disease, 14 patients denied having any personal problems (although by the end of the interview one-half of these had referred to problems they were experiencing). An additional 26 patients discussed openly the fact that they were having serious problems in living concerning internal thoughts and/or interpersonal relations. Of these, 82% mentioned depressed mood, 46% had family difficulties, 85% wished to "discuss their situation more fully", and 8% spontaneously said that they had been suicidal during their illness.[49]

Cohen and Wellisch (1978) noted in their work with families in which a member had developed cancer that knowledge of the presence of a life-threatening disease resulted in short- and long-term disruption in family and individual functioning.[50] As can be seen, psychosocial dimensions do exist even when they do not receive equal thought and attention in the overall care of the illness and disease.

With this appreciation in mind, the rest of this chapter will examine some of the more defined approaches to the care of those person(s) who most directly experience this group of diseases called cancer. Beginning with the biological dimension, the established treatment approaches to date are surgery, radiotherapy and chemotherapy. Though still largely in the experimental stage, immunotherapy has given a favourable indication that it, too, may eventually join the ranks of credible treatment approaches. Surgery is the oldest form of 'proven' cancer treatment, with a major portion of present-day surgical procedures dating back in use between five to twenty-five years. Improvements in cancer surgery take the form of perfection of technique, and new developments in anaesthetics, blood banking and antibiotics.[51] The objective is to excise surgically the complete cancerous mass with the least amount of alteration to the individual's quality of life. To what degree this goal can be accomplished cannot be accurately assessed until the operation occurs and the nature and form of the spread can be seen.

> Lava tumors are difficult to remove because they fragment and invade neighboring tissue early in the disease. Balloon tumors, on the other hand, can be removed completely, because they enlarge in encapsulated form and do not invade neighboring tissue until late in the disease.[52]

Removal of some healthy tissue may necessarily occur in the process of ensuring complete excision of the cancerous mass. The balance strived for is to keep this to a minimum without compromising a cure level. Cure is achieved with the complete removal of the cancer. Pursuit of a surgical route depends upon how and the extent to which the cancer has spread; whether the parts concerned are vital to continued existence; the physical and emotional capacity of the person to endure the proposed procedure; the ability to leave intact the basic human shape; and, the degree to which the cancer and encompassing tissue altered by it can be excised.

> When cancer of the lung occurs close to the heart, for example, surgery may be impossible: if any portion of the heart is removed, the patient may die. Surgery may also be impossible when cancer attacks the major bones in the pelvic area; if the lower half of the body is cut off, the patient will suffer horrible mutilation.[53]

Though a fast-spreading cancer is not a likely candidate for surgical treatment, partial removal is sometimes sought. In such instances, the surgeon must be alert to keeping the tumor intact, as cutting through it may release cancerous cells into the body. The scope of the surgery to be performed for any cancer is usually determined by where the cancer is situated and its dimensions. Surgery can alter function and, therefore, life's quality.

> If parts of the mouth or the throat are removed, for example, the surgery must affect swallowing and speaking. If the bladder or the rectum is removed, a new opening for urine (a utostomy) or for feces (colostomy) must be constructed in the abdominal wall.[54]

Surgery can also result in significant physical disfigurement, while ensuring continued existence. Thus, it is essential that the person(s) concerned comprehend to what extent the proposed procedures will alter life as they have come to know it.

Radiotherapy seeks to eliminate cancer cells by exposing them to X-rays or gamma rays.

> X-rays are produced by machines--for example, linear accelerators and betatrons. Gamma rays, which are a type of X-ray are given off by radioactive substances like cobalt and cesium, iridium and radium.[55]

There are three ways in which radioactive substances are packaged and administered to people for treatment purposes--enclosed in a machine designed to direct the rays, packaged in tiny receptacles for placement in body cavities, or inserted immediately into the tumor as in, for instance, needle implants.[56] First discovered in 1895, by the turn of the century, X-rays were found to be effective in the treatment of facial cancers, their use subsequently expanding to the treatment of other forms of cancer. However, this expansion involved numerous years of experimentation before dosage levels could be regulated and outcome predicted with any degree of precision. To this day, the means by which X-rays change cells is still unknown.

> . . . they know that cells die, probably because X-rays have damaged their genes. Some irradiated cells die instantly; but most die only when they attempt to divide.[57]

Cure via radiotherapy can happen by either killing the cells making up the tumor or by cutting off the tumor's blood supply by severely injuring the blood vessels carrying it. Some forms of cancer are appreciably more susceptible than non-cancerous tissue to the damaging influences of X-rays (lymphatic cancers, some testicle cancers, and a major number of childhood cancers) and are, therefore, the ones most amenable to cure with the least amount of injury to normal cells when treated with radiotherapy.

> The majority of cancers are only slightly more sensitive than normal tissue. Radiotherapy, then, is generally used only when the area to be treated is small, so that the body can tolerate the destruction of the irradiated tissue.[58]

Though radiotherapy cannot effect a cure in widespread cancer, it can provide symptomatic relief increasing comfort and ability to function. Radiotherapy is usually the treatment of choice when surgical excision is either not possible or, for reasons of function, not advisable. Often it accompanies surgical approaches to treatment administered following surgery when there is concern that some cancerous cells have escaped the surgeon's scalpel, or both prior to and following surgery as a safeguard to surgical effectiveness in cancers of the uterus, bladder or colon.[59] On occasion radiotherapy will be employed prior to chemotherapy to increase a tumor's receptiveness to the drugs used. How much radiotherapy given and over what area of the body is determined by the intent of treatment (curative requires more radiation than symptomatic); whether it accompanies another method of treatment (if so, requires less radiation); tumor size (the bigger the tumor, the more radiation used); and, how susceptible the cancer is to destruction via radiation. Radiotherapy will induce feelings of tiredness and other side-effects depending on which section of the human form is being treated.

> When the throat is irradiated, for example, the patient may experience a sore throat and difficulty in swallowing. When the bladder or the rectum is irradiated, [s]he may experience frequent urination, diarrhea, or cramps. When the stomach is irradiated, [s]he may experience nausea.[60]

While the above lists some of the immediate side-effects of radiotherapy, among the delayed effects may be the occurrence of new cancerous growths. Although the gains can be extensive, they are not without risks.

Chemotherapy, the most recent of the three established methods of treatment, came into being following the Second World War and now employs approximately fifty drugs in various combinations to eliminate cancer cells.[61] This elimination process occurs when the drug(s) concerned disrupt the cell's ability to complete actions which ensure its continued existence.

> One type of drug prevents cells from forming the proteins and enzymes that keep them alive. Another type kills by disrupting a step in the process of cell division. A third type, by upsetting the balance of hormones in a patient's body, creates conditions unsuitable for the survival of some cancers.[62]

Drugs are selected and combined according to the stage in the cancer cell's life cycle where they are the most lethal. Thus, a number of drugs working together to destroy the cancer cells at various points in their development can be more efficacious than one drug working alone.[63] However, while these drugs tend to destroy cancer cells predominantly, they also destroy normal cells. Because the drugs disrupt life-sustaining processes such as cell division, the cells most susceptible to their effects are those which develop and divide quickly.[64] Normal tissues which are composed of rapidly dividing cells incur the highest degree of injury (stomach, intestines, mucous membranes, hair follicles and bone marrow). At the same time, rapidly-growing cancers like acute leukemia, cancers of the placenta, ovary and testicles can often be cured with chemotherapy. Slow-growing, larger tumors largely go unaffected.

> The solid tumors . . . have low growth rates. The larger a tumor gets, the slower its cells divide, . . . And many cells seem never to divide at all. Like an army that has outdistanced its lines of supply, the cells have trouble getting nutrients from the blood and become dormant. . . .
>
> In the early stages, however, even solid tumors grow rapidly and make DNA.[65]

Given the above, it was realized that chemotherapy begun in the early period of tumor growth had an opportunity to destroy even these forms of cancerous growth effectively. Thus, when either surgery or radiotherapy has eliminated the primary growth, chemotherapy may then be introduced to eradicate any remaining cancerous cells that would once again be in a period of rapid cell division.

> Now many patients who undergo surgery for cancer of the bowel, bladder, breast and other solid tumors routinely get "adjuvant" chemotherapy--the immediate administration of drugs to hit the small, fast-growing colonies of cells that have spread from the original tumor.[66]

Adjuvant chemotherapy is employed most frequently in instances where cancer cells have been found in the lymph nodes. Unlike surgery or radiotherapy which are confined to a particuar site, drugs can network throughout the body encountering and eliminating cancer cells undetected by other methods. Even though the major portion of cancers cannot be cured by chemotherapy, skillful administration of the various drugs at the appropriate time can significantly lengthen survival time. The type of chemotherapy and how it is given are judged by the purpose of the treatment, the drugs used, responsiveness of the cancer to the drugs, the degree of cancerous growth, and the health of the major life-sustaining organs. Most chemotherapy treatment is done on an outpatient basis. However, a person may be hospitalized if rigid sequencing of drugs is required, if the method of getting the drugs into the body's system necessitates a special procedure (e.g., slow drip into veins), or if bodily function is threatened by the expression of the disease or the side-effects of the treatment. (Specific side-effects of chemotherapy have been outlined earlier in this chapter.) Biologically speaking, whether surgery, radiotherapy or chemotherapy, the 'art' of administering treatment for cancer is to achieve the greatest benefit with the least amount of injury to human functioning . . . hardly a clear-cut procedure--especially when the peculiarities of each person's reaction and the particular expression of his/her cancer are considered.

Efforts to control cancer are proceeding primarily in five relatively distinct directions: attempts to identify and block the cancer-causing processes of various agents; to increase human resistance to cancer; to identify cancer in its beginning stages, thereby increasing the chances of cure; to alter cancerous cells so that they are no longer cancerous; and, to create new, more effective methods of treatment.[67] Research into the efficacy of immunotherapy is an example of exploration directed towards developing new treatment methods. Over the years several observations have been made, the first being that a significant number of persons with cancer have deficient immune systems. "Cancer patients, for example, accept transplanted grafts of skin much more easily than healthy people."[68] Secondly, those whose immune systems are functioning at a very low level are not as responsive to chemotherapy and radiotherapy as those persons with stronger immune systems. In addition, persons whose immune systems are deficient for other reasons develop cancer at ten times their demographically defined rate. Hence, a relationship is evident, but the precise nature of the linkage has yet to be traced.

Essentially, immunotherapy involves stimulating the immune system to eradicate cancer cells.[69] Vander, Sherman and Luciano (1975) define immunity as ". . . all the physiological mechanisms which allow the body to recognize materials which are foreign to itself and to neutralize or eliminate them."[70] These physiological mechanisms can be divided into specific and nonspecific immune reactions. Nonspecific immunity comes into action when the host is first exposed to an alien organism. Specific immunity, however, relies on previous experience with that same organism. From this contact an immune response is tailored that recognizes and reacts solely with the organism that initiated the original immune reaction (or one closely resembling it). Subsequent encounters with the same substance will therefore evoke a stronger and more immediate immune response. The body is able to recognize intruders because the surfaces of the invading cells are studded with substances called antigens. Hence, the theorem develops:

> If cancerous cells, like foreign intruders, bear fingerprints (antigens), the immune system may, like a good detective, be able to track them down or perhaps even destroy them. [71]

Thus, it may be possible to develop a vaccine that would eliminate cancer cells as they occur (immunoprophylaxis) or to identify certain cancer-specific antigens resulting in early detection, or increase the capacity of the body's immune system to eliminate cancer cells (immunotherapy).[72] Several of those involved in the treatment of cancer believe that cures are achieved through the combined efforts of the person's immune system and radiotherapy, chemotherapy and/or surgery.

> It is likely, for example, that surgery and radiotherapy usually fail to destroy some cancerous cells that have traveled far from the site of the primary tumor. Even drugs, which circulate throughout the body, can easily miss cancerous cells hidden in the brain or in other drug-resistant tissue. Thus, patients who have been cured of their cancers are probably those who were able to help cure themselves.[73]

Immunotherapy is seen more as an adjunct to present-day treatment approaches rather than a method used on the basis of its own curative powers. Immunotherapy can be either passive or active. Passive immunotherapy involves injecting the cancerous cells of one person into another. These cells are recognized as alien by that person's immune system which, subsequently, reacts to eliminate them. A specific immunity is developed and these substances (blood serum or white blood cells) are then injected into the original donor in the hope that they will destroy that person's cancer. While some success has been achieved in animal experiments, in human beings these substances are most often seen as foreign by that person's immune system and rejected. Active immunotherapy involves the injection of foreign substances into a person's body in order to stimulate that person's immune system to eliminate both the invader and the person's cancer. However, to date, most of the substances that are capable of activating such a response are toxic to the human system.[74]

Before leaving this reference to the immune system, some mention should be made of the physiological parallels drawn between the immune system, stress and cancer. Based on the assumption that the immune system recognizes cancerous cells as foreign to the human body and that primary protection from abnormal cell growth is immunological,[75] it theorizes that an efficiently operating immune system would automatically destroy any abnormal cells growths. In hypothesizing the relationship of stress to cancer onset and development, Bernard Fox (1978) has speculated that in the duration of a lifetime, an individual with a genetically determined set of susceptibilities receives varied exposure to an assortment of carcinogens.[76] Depending on the strength and consistency of the individual's immunological defenses and the strength of the exposure, the individual may or may not manifest tissue changes that will lead to cancer. It is proposed that prolonged or repeated stress could create sufficient fluctuation or depression in the immune response to allow neoplastic cells to escape immunological controls.

> The nature of cancer induction, I believe, requires long-continued exposure to a carcinogen if it has low or moderate mutagenic capability. If such exposure is accompanied by a fluctuating level of protection, and that level involves more occasions of immunosuppression, then the odds are that the person will more often meet an occasion when the immune system can't handle the cancer cell than will a person who does not have repeated or continuous stress and who therefore does not suffer so many occasions of immunosuppression.[77]

Just how the psychic response produced by a stress-inducing stimulus might translate into a neoplastic state via its influence on the immune system involves a complex set of physiological links. Though animal research in this area is much more revealing in its examination of the possible physiological mediating mechanisms than is work with human subjects, it is far from able to trace out the connections adequately. At best a relationship is indicated, but the essence of the bond remains unknown.

In order to consolidate data in cancer research, allowing for national and international comparisons in findings, and collaboration in research design and execution, a system of cancer staging has been developed. Essentially, it is a means of plotting the life course of a particular cancer, its size, whether spreading to nearby lymph nodes has occurred, or if a metastasis (distant spread) is involved.

> As a primary tumor increases in size throughout its time span, at some point (probably early) local invasion occurs, followed by spread to the regional lymph nodes draining the area of the tumor. . . . It is usually later, and often in the middle or older period of life span of the cancer, that distant spread or metastasis (M) becomes evident from clinical examination. Thus metastasis (M) is the third and usually latest time marker.[78]

Its stage of evolution is recorded at the time of initial diagnosis and at certain junctures in the course of any physiological therapeutic intervention thereafter.

> Stage classification is thus a method of designating the state of a cancer at various points in time and is related to the natural course of this particular type of cancer. It is intended to provide a way by which this information can be readily communicated to others, to assist in decisions regarding treatment, and to be a factor in judgement as to prognosis. Ultimately, it provides a mechanism for comparing like or unlike groups of cases, particularly in regard to the results of different therapeutic procedures.[79]

In addition to physiologically mapping the cancer, the ability of the person so affected to carry out the daily routines of her/his life on an ongoing basis is noted in accordance with the development of the cancer. By following persons from the point of diagnosis and at designated intervals throughout their lives, recurrent or new cancers can be detected early in their development and appropriate treatment and rehabilitative efforts instituted as needed to achieve the highest quality in living possible, given the circumstances of the disease.[80] Emphasis for enhancing quality of life is primarily focused on the manipulation of various physiological elements to achieve a greater capacity for bodily function and, thereby, an increased capacity for participation in the daily activities of living.

Moving into the psychosocial dimensions of intervention, one is confronted with a literature full of bits and pieces of isolated, largely anecdotal attempts using a variety of techniques and theoretical approaches.

> Despite diligent efforts within the past decade or two to study psychosocial oncology systematically, much of what we know and do is largely anecdontal, impressionistic, and regrettably, dogmatic. Informal interventions may be helpful, but we have no way of knowing. Nevertheless, clinicians as well as patients reach out for instruction about interventions that simply are not there to be learned.[81]

A great percentage of what has been written with respect to psychosocial intervention with those experiencing cancer has concentrated on death and dying.[82]

> Obviously, many cancer patients do in fact enter a terminal phase, but it is becoming more common for this phase to be significantly delayed as the disease is managed through surgery, chemotherapy, immunotherapy, and radiation.
>
> For many cancer patients and their families, the responsibilities and tasks of living with cancer pose even greater stresses than dying from the disease.[83]

In view of this, only those approaches which have been more precisely defined and laid out for specific application in dealing with the psychosocial dimensions of 'living' with cancer will be reviewed. People respond to cancer as a total unit--biologically, psychologically and socially--and must sustain threats to their being by a disease which impacts on all three of these dimensions of living. For all those involved, including health care personnel, there are elements of crisis, a need to evolve developmentally, and an immediate call for adaptive energies to be rallied and put into action in a form best able to meet the demands being made.[84] While the major portion of the literature pertaining to psychosocial intervention in dealing with cancer attempts to alleviate the distressful elements of its impact, they work at accomplishing this from essentially two different beginning points. One group of approaches is based on the supposition of psychological involvement in the etiology of cancer, while concern in the second group is centred more on preventing the emotional deterioration often witnessed in those having to live with cancer.

Proponents of the first group contend that certain psychological and social-psychological factors predispose people to the onset of cancer by exerting an influence on the physiological operation of their bodies, creating a biological climate conducive to the occurrence and multiplication of cancerous cells. Efforts to validate psychological causation in research using human subjects have tended to draw from one of two lines of thought.

> . . . (1) the "personality" hypothesis, which specifies that there are particular personality characteristics found more frequently in the cancer patients than in normal controls, and (2) the "loss-depression" hypothesis, which suggests that an emotional trauma of separation or loss precedes the development of cancer, with ensuing feelings of helplessness and hopelessness.[85]

Research based on the personality hypothesis claims to have uncovered three prominent personality traits of those persons most likely to develop cancer. These persons suppress the expression of emotions in general; particularly, they constrain the expression of anger/ aggression, and are frequently described as exceedingly 'nice' people.[86] It is the suppression of emotion, especially intense emotion, that is linked with cancer causation. The essence of these findings in the "loss-depression" research is that the person concerned has lost, either through death or separation, a significant relationship which previous to that point defined his/her existence. With the loss of this relationship comes a loss of self and an inability to come to terms with the emotional magnitude of the void created. This culminates in the person feeling helpless and hopeless regarding her/his ability to control the direction of her/his life.[87]

> One of the fundamental characteristics of these patients was the despair was "bottled up". These individuals were unable to let other people know they felt hurt, angry, hostile.[88]

The repression of emotion, coupled with a sense of being victimized by life and being powerless to control it, is believed to disturb the physiological balance of the body sufficiently to lead to cancer.[89] This sequence of events, however, is escapable if the person employs coping strategies that encourage the grieving process, allowing the loss to be mourned. The physiological component believed capable of transforming psychological pain/conflict into the biological linkages that lead to cancer is the neuro-hormonal system.

> . . . the grand master of the whole neuro-hormonal system is now thought to be the hypothalamus, through which neural impulses pass, are decoded, and finally sent on through either the nervous system or the endocrine glandular system. Psychological distress (stress), then, is translated directly into physiology.
>
> Adrenal-cortical hormones are known to interfere with the immune system's ability to make antibodies.[90]

Antibodies are substances produced by the immune system in response to the presence of antigens (carried on the surfaces of invading cells). Specific antibodies are manufactured to react with specific antigens. Uniting with these antigens chemically, antibodies label trespassing cells as alien, distinguishing them from the body's own cells and thereby marking them for destruction. Any series of physiological reactions which inhibit the production of antibodies are seen as increasing the chances that abnormal cell growth will go unchecked by the immune system. Repression of emotions is seen as a form of chronic stress.

Based on the supposition that both psychological and physiological factors play a significant role in cancer causation, Carl Simonton and Stephanie Matthews-Simonton (1978) developed an approach they referred to as the "whole-person model of cancer recovery" to be used in conjunction with biological interventions for cancer. They see the person's cognitive, affective and physiological operations all functioning as a total unit, with the dynamics governing one part's operation having implications for the ongoing actions of the other pieces. As a result, they view the person's cognitive and emotional disposition as having a strong influence on physiological proneness to the occurrence of and recovery from disease. Unless all three of these components are working together in the same direction, the influence of biological interventions will be reduced or thwarted. The process by which the person confronts the changes embodied in living is seen as the key to whether or not physiological conditions will be ripe for the development of cancer.

> We believe that cancer is often an indication of problems elsewhere in an individual's life, problems aggravated or compounded by a series of stresses six to eighteen months prior to the onset of cancer. The cancer patient has typically responded to these problems with a deep sense of hopelessness, or giving up. This emotional response, we believe, in turn triggers a set of physiological responses that suppress the body's natural defenses and make it susceptible to producing abnormal cells.[91]

The psychological sequencing of this predisposition begins in childhood where certain of life's events create a personal resolve to behave towards life in a particular manner. In the course of living, the person undergoes a series of stressful circumstances which leave him/her in what (s)he sees as a 'no win' situation given his/her beliefs about life and his/her own behaviour. Because (s)he feels powerless to change the situation (s)he begins to back away from it, clinging more strongly to his/her belief system and ways of reacting to life. At this point a major illness or death is seen as an answer to the situation by providing an out or by delaying the need to deal with it. The person may or may not be aware that (s)he is responding this way.

> It is this giving up on life that plays a role in interfering with the immune system and may, through changes in hormonal balance, lead to an increase in the production of abnormal cells. Physically, it creates a climate that is right for the development of cancer.[92]

Basic to this approach is the belief that all people shape their psychological outlook towards living and are, therefore, capable of reshaping negative orientations, where they see themselves as victimized by external forces they are powerless to change, into positive orientations where they become self-responsible persons with a capacity for change.

> Each of us *chooses*--although not always at a conscious level--how we are going to react. The intensity of the stress is determined by the meaning we assign to it and the rules we have established for how we will cope with stress.[93]

Recovery begins with the diagnosis of serious illness where the magnitude of what is confronting them provides the impetus to change their cognitive and emotional manner of tackling life. Individuals review the content of their lives just prior to the onset of cancer, tagging those psychological processes which could create a need for the illness.[94] Once these have been identified, they move towards addressing these needs head on, removing the need for ill health. Former ways of moving through life are revamped, rules governing behaviour are either altered or abandoned, and the individuals concerned learn to trust that they can grow in new directions without a loss of self. Because a new sense of optimism about living is generated in this process, hope is restored and these people once again feel in control of their lives. The will to continue living is re-ignited which reinforces physiological functioning. This process has people rethink their ideas about the potency of the cancer cell in the face of treatment approaches and the power of their own bodies. The cancer cell is reconceptualized as weak and confused rather than all powerful. In the act of confronting previously avoided conflicts/problems, confidence may falter, possibly resulting in short-term physiological setbacks. However, by the end of the recovery process, individuals present as "weller than well".

> . . . meaning that the state of emotional health to which they have been restored is in fact superior to what they had considered "well" before their illness. . . . They have a psychological strength, a positive self-concept, a sense of control over their lives that clearly represent an improved level of psychological development. . . . they are victims no longer.[95]

Thus, in conjunction with input from biological interventions, the energies of the whole person are activated in the direction of health.

The Simontons note that the North American culture is structured to emphasize productivity and labour, and to downplay emotional expression, especially negatively-valued emotions such as sadness, anger and grief. Achievements are secured without regard for their effect on the person's internal climatic conditions where emotional growth and nurturing occur.[96] Hence, for the Simontons, the idea that individuals participate in the onset of cancer by not respecting their needs for emotional expression is positively reinforced by society.

> After a patient has been diagnosed with a severe illness, emotion is expected and accepted. A patient, perhaps for the first time in [her]his life, may give [her]himself permission to do many things that [s]he would not do if [s]he were healthy, such as asking for help or for love and expressing unhappiness.[97]

Illness provides a socially-condoned context for nurturing the emotional dimension of self. When the major portion of this process occurs subtly and is beyond conscious awareness, asking people to assume responsibility for illness onset is not asking them to blame themselves. The following quote lists some of the means by which the Simontons feel people influence their physiological operation through the psychological stance.

> Some individuals may have participated by creating or allowing undue stresses in their lives or by refusing to recognize that they have emotional limits. Others may have subordinated their own needs to everybody else's until they had no strength left to devote to themselves. Still others participated by reacting to stresses with feelings of helplessness or hopelessness.[98]

Hence, the primary focus of this approach is to remove psychological blocks which inhibit total person movement towards health. This is accomplished through self-examination, life-style changes (diet, exercise, attitudes), visual imagery, relaxation techniques, goal-setting and mobilizing family supports. A subsequent publication by Stephanie Matthews Simonton (1984) outlines more precisely the family's role in moving the person with cancer towards recovery.[99] While the needs of family members are looked at, this is done primarily with the intent of mobilizing and maintaining their energy reserves as a source of support for the person directly experiencing the cancer.

Advocates of the second group of approaches support the notion that the cognitive, emotional and physiological dimensions of the person represent a unitary system; however, they stop short of implying that psychological influences are involved in cancer causation or that at this point in time they can be harnessed to prevent or reduce abnormal cell growth.

> . . . clinical applications to actual cancer patients are premature and potentially counter-therapeutic. No solid longitudinal empirical evidence presently exists that can justify helping a cancer patient to influence tumor remission through psychological means. We are unable to find adequate data that uses [sic] controlled clinical trials and large numbers of patients--which shows a direct cause-effect relationship between cognitive interventions and the alteration of tumor growth.[100]

This group recognizes that having a diagnosis of cancer means more than just the unchecked growth of abnormal cells, and that comprehensive care involves more than biological intervention directed towards a cancerous growth. However, opinions vary about what psychosocial intervention should involve and when it should come into play. Basically, there are three positions concerning whom should be offered psychosocial services: 1) all those diagnosed as having cancer, 2) only those who exhibit signs of psychosocial deterioration, or 3) those matching criteria which place them at higher risk for developing psychosocial complications later on.[101] Proponents of the first approach contend that the adaptational demands of the disease and its biological treatment are such that all persons so affected can benefit from psychosocial intervention. The opposition feels this is not cost-effective as a number of people can adjust their lives to meet the disruptive influences of these demands independently of these external supports.[102] While the second approach addresses human need, it does so after deterioration has been demonstrated. There are those who believe that if intervention had occurred earlier, this deterioration could have been prevented. The third approach necessitates that normative measures be established regarding those personal characteristics most likely to signal future difficulties in managing the demands made by the disease and its biological treatment.

Usually the crux of this approach is the identification of major stressors, those persons who are most susceptible to their influence, and why. Interventions are then constructed to correct the identified deficits in coping.

One such intervention is the problem-solving model developed by Sobel and Worden (1982) specifically for use with cancer patients.[103] Within the context of an eight-year longitudinal study, they started by surveying newly-diagnosed cancer patients--the level of concerns, its variance over time and the means used to resolve the concerns. They then developed a screening instrument and two interventions from the findings which they subsequently tested on a population of 358 newly-diagnosed patients. In constructing the screening instrument, they were looking for traits or processes that would act as reliable predictors of the type of distress which necessitates psychological intervention. What they found was that high emotional distress most often correlated with inadequate problem resolution. High-distress persons tended to present as more pessimistic regarding the future, with a higher number of marital difficulties, were generally from the lower socio-economic range, often came from multi-problem families, had a background of psychiatric intervention and/or suicidal ideation, and basically had more difficulties of all forms.[104] In addition, these persons saw their doctors as less supportive than low-distress persons.

> . . . the high-distressed patient was an individual who: (1) used fewer coping strategies; (2) employed less effective strategies; (3) had significantly more problems or concerns; and (4) achieved poor resolutions when attempting to solve critical illness-related concerns.[105]

Sobel and Worden also found that within a six-month time span following diagnosis, 40-60% of the distress shown by all study participants was generated by biomedical concerns, and 40-60% by personal disposition and non-medical dilemmas.[106] Hence, while people differed in their ability to work through their concerns independently of psychosocial intervention, the psychosocial dimensions of their lives were definitely affected by the cancer experience. Given this, Sobel and Worden established that the coping strategies most likely to bring about problem resolution and a decrease in emotional distress were confrontation, redefinition (capacity to identify positive elements in a negative situation), and compliance with authority, particularly where medical concerns were at issue. An intermediate standing was assigned to seeking information (relies on person's skill in obtaining it), sharing concerns (effective if person could discriminate when, how and with whom to do so), and distraction (has value as a "time-out" mechanism). Based on these findings, they then determined that the effective coper was a person who could confront ". . . a problem 'hopefully' and then imagine a range of conditions, consequences, and circumstances that might come about by using different strategies."[107] Because the high-distress individuals tended to exhibit deficits in coping, an interventive approach was designed to correct this. The end result was actually two interventions both constructed to aid problem-solving efforts and remove self-generated barriers to action responses by focusing on the person's cognitions. Viable solutions become possible depending on how the person appraises the dilemma being faced.

> . . . tries to help cancer patients develop an awareness of the interpersonal context of many vexing problems, and to see how they can contribute to generating intermediate steps toward an adequate resolution.[108]

Individuals are instilled with the idea that they have the personal power to effect change, and are given a means of regaining control of their lives and restoring internal balance (both of which are threatened by the cancer experience). The first interventive approach is tailored to the needs of the particular person involved and looks at how the cancer is impacting on her/his life and those with whom (s)he shares it. Much more attention is afforded to understanding the emotive dimensions in the process of clarifying problems and behaviours.

> Essentially, this first intervention focuses on a patient's problems, looking at what they are doing and trying to help them explore alternative strategies for problem-solving. It is a problem-solving approach, like the cognitive program, but is patient centered and is not highly structured.[109]

The second interventive approach is designed to teach the 'process' of problem-solving, using relaxation training and a series of picture cards which sensitize the person with cancer to possible problematic or stressful situations (s)he may encounter following the initial diagnosis. Emphasis is placed on learning the technique and how to apply it, rather than concentrating on concerns specific to the individual involved. Persons are led through a process which trains them to identify and examine what it is they are confronting, reconceptualizing it if necessary to make resolution attainable. A range of alternatives and their consequences are examined and choices made regarding possible solutions. This process is brought to a close by asking the person to think about the original problem and consider its positive elements.

> The objective is to strengthen internal controls, and to reinforce flexibility about coping strategies, choice in goals, and personal resourcefulness.[110]

It is hoped that the person will then be able to apply this technique to achieve resolution of future problematic situations. Both interventions are designed to be brief (four to six sessions) and to be used in conjunction with the screening instrument which acts to locate high distress persons--those most likely to benefit from psychosocial intervention. It is seen as a means of practising preventive mental health because it increases the person's range of coping skills and intervenes before difficulties arise. However, it is not meant to be used in isolation of other techniques or without an understanding of the influences of other significant systems of which the person is a part (family, health care system, etc.).

> If we are to be successful at immunizing patients against debilitating emotions and thoughts, then we must integrate the reality of social systems and contexts. A humanistic health care program cannot be exclusively patient-centered and also expect to be effective.[111]

Amid the wide range of other psychosocial interventions contained within this second cluster of approaches is the use of groups. These vary in purpose, size and style, but generally are set up with the intent of sharing information, providing support, creating connections between persons experiencing cancer and/or increasing communication between and amongst members of the health care system and those utilizing its services. The groups can be open either to a continuous flow of new members, or closed, only periodically opening to change their membership.[112] They may be run by a combination of professionals and/or lay people or be the sole responsibility of one faction (nursing, social work, etc.). Vachon, et al. (1976, 1977), and Johnson and Stark (1980) are two examples of groups organized specifically for those experiencing cancer. For Vachon, et al., the idea of using groups to address psychosocial needs came as a response to the frustrations of intervening with people who were entering the terminal phase of the illness angry and with deteriorated interpersonal relationships.[113] Much of this deterioration and anger was felt to be a direct result of not attending to the psychosocial dimensions of the cancer experience and, therefore, was seen as avoidable if psychosocial supports could be built in at an earlier point. The end result was group meetings held at weekly intervals for persons recently diagnosed as having cancer, and those further on in the treatment of the disease. Meetings were open-ended and invited the participation of both the person with cancer and family members.

> Here they were encouraged to express their feelings of fear, isolation, depression and anger which they were experiencing. They gained understanding, acceptance and support for these feelings from other group members. In addition, the "more experienced" cancer patients were able to offer suggestions for living with the stigma of cancer, overcoming the fear of family and friends and coping with the panic so often associated with their new diagnosis.[114]

Needs to reclaim control of one's life were addressed by encouraging individuals to assume an active stance towards their care and treatment, beginning by clearly communicating to their physicians how much information was desired regarding their disease. Because the group provided a safe environment in which to work through anger, its intensity could be reduced to a level where effective communication with the necessary persons could occur. Johnson and Stark (1980) felt a group approach could meet the emotional needs of those experiencing cancer more effectively than individual intervention.

> . . . we found that feelings of fear, anxiety, and loneliness were shared more easily with others who were also experiencing those same feelings, and that being able to share them was helpful in reducing their impact.
>
> . . . not available in the one-to-one approach were that being in a group allowed an individual to gain insight and a feeling of support without overtly participating, and also allowed group members the therapeutically valuable experience of helping one another.[115]

In the process of using the group format, they became aware of the need for access to information about the disease and ways of dealing with its effects. Thus, the final outcome was a 'multidisciplinary information-support program' available to the person with cancer and his/her significant others.

> The group program consists of three one-hour afternoon sessions a week: Tuesday groups deal with basic information about cancer, Wednesday groups provide opportunity for discussion, and Thursday groups focus on information concerning psychosocial issues (personal and family adjustment, faith, activity and relaxation, and nutrition). . . . There is a brief presentation in the information group sessions followed by time for questions, discussion and mutual problem solving.[116]

Seeing a need for the involvement of one person experienced in group work but wanting to integrate the competencies of other staff professionals (especially in view of the program's content), they set up a co-leadership design drawing on both types of input. In addition, the other staff professionals were introduced to concepts of group work, co-leadership dynamics and the emotional force of participating in these groups via a one-session seminar including the use of role-playing. Staff meetings were held once a month to offer mutual support and to maintain each staff member's individual interest and investment in its successful operation. Johnson and Stark saw the groups aiding family cohesion by providing a setting for them to share ideas, thoughts and feelings with one another. As well, they saw them giving health care staff the opportunity to witness other dimensions of those they saw individually by observing them in both a family and group context. Vachon, et al., and Johnson and Stark both offer groups designed to encourage the expression of emotions and aid individual efforts to cope with the cancer experience; however, Johnson and Stark pay particular attention to nurturing the reciprocal exchange between the groups and the health care staff.

As previously mentioned, there are numerous approaches to psychosocial intervention for those with cancer scattered in many different directions throughout the professional literature. The foregoing has been an attempt to sift out and represent those which are the most definitely presented and which address issues of living with cancer rather than dying from it. Interventions which utilize structured family therapy[117] and crisis theory[118] are other examples of attempts to address the psychosocial dimensions of cancer care. What all these approaches have in common, despite their beginning point, is a problem-solving orientation towards coping and a psychological and social-psychological change format. In other words, the psychosocial stresses of the cancer experience are implied to be more a matter of change that needs to occur within the person and his/her orientation towards life and the health care system, rather than a change in the way the system approaches psychosocial needs. In

In both Simonton, et al. (1978), and Sobel and Worden's (1982) approaches, it is the person's coping skills which are deficit and must be corrected. For example, in Sobel and Worden's profile of the high distress person, the reader is given the impression that perhaps the reason these persons have more stresses to contend with in their lives (i.e., marital problems, less money, etc.) is because they have inadequate problem-solving skills. In fact, when discussing the high distress person's doctor-patient relationship, they state:

> . . . our research clearly showed that these patients saw their physician or physicians as less helpful. Now again, this probably ties in with their more pessimistic style. In other words, they come with pessimistic attitudes such as, "It's all over. Nobody's going to help me, so I have to help myself."[119]

Nowhere is it suggested that this might be an accurate assessment of a health care system whose primary focus is the biological dimension and is, therefore, less adept at dealing with people who have much more to balance in their lives in the face of cancer, often with fewer resources on which to draw. Is it because they are less skillful in coping or that in light of what they are up against it is more imperative that the system be sensitive to their need to balance the psychosocial dimensions of their existence with the physiological? Even when the system is implicated in the need to change, the bulk of responsibility for making this happen is left with the person utilizing the service--all this at a time when coping energies are drained by what is being confronted physiologically. Examine the following statement by Simonton, et al. (1978):

> We believe it interferes with therapy if patients feel they are being treated impersonally. Under such conditions, we encourage patients to alter their existing relationship and, if that does not work, to find a new physician or health team. It

> is important that patients see their treatment as an ally, a friend, and that they be aware of the effort and skill that have gone into developing the medical therapies that are currently available.[120]

Beyond acknowledging that psychosocial concerns occupy a secondary status in the health care system, none of the approaches offers the 'helper' any well-defined guidelines for working with the health care system's inattentiveness to the importance of the psychosocial dimensions for people's existence.

A great deal of time and space in the literature has been afforded to verifying that persons respond to the experience of having cancer as a total bio/psycho/social unit (much of which has been quoted from within the confines of this paper). Yet, the primacy of biological intervention has generally gone unquestioned. Witness a quote from the report of the findings from the descriptive study used by Sobel and Worden (1982) to construct their screening instrument and interventive approaches:

> Psychosocial programs must and should always be adjuncts of physical care. But there are situations in which adequate, even imperative psychosocial care transcends in time and effort that expended on medical treatments. One can adopt an intervention approach for all cancer patients, regardless of need, or use a more selective method to find patients who are at highest risk of distress and expend effort with them. However, these choices are not incompatible. Good nutrition is always desirable; but diabetics, for example, need special dietary attention.[121]

What this seems to be saying is that psychosocial care is most advisable only in those instances where it cannot be avoided. Given Sobel and Worden's emphasis on compliance with authority in their interventive design, one wonders if this actually means where it will inevitably interfere with compliance with biological treatment. Even apart from this a contradiction appears: on one hand, cancer has been promoted in the literature as a disease which impacts on the total self--biologically, psychologically and socially--and is responded to as such. Yet, comprehensive cancer care is believed to emanate from a system which attempts to limit its transactions to the biological self. Such an approach overlooks the part the system plays in creating psychosocial stress by ignoring its impact on these dimensions of the person, except when psychosocial concerns threaten to disrupt biological care.

By ignoring the health care system's influence on the psychosocial dimension of experiencing cancer and by concentrating on changing the person, two assumptions subsequently become interwoven into the fabric of the resulting interventions: the first is that the only limitations to problem resolution lie within the person, his/her methods of resolving it and/or attitude towards it; and secondly, that the person has the power to effect the necessary change. Yet, inadequate organizational mechanisms for dealing with conflict may force an interprofessional dispute to be fought on the patient level. Without access to the internal dynamics of the organization, clarification of what is being confronted may not be possible on the level of the individual, even though the effects are real and ongoing for that person. Despite efforts to request clearly information, health care personnel may be unwilling to share certain details, or lack the communication skills or time to do so in an easily comprehendable manner. Inattentiveness to how the health care system connects with a family may unduly stress one of its members. In sum, there are many subtle, paradoxical messages and demands that are made on those most directly experiencing the disease by the health care system that are not readily discernible to persons with little knowledge of the internal operation of that system. Distress stemming from such sources rarely fits neatly into reductive, linear problem-solving designs.

The fact that certain coping skills can be seen as deficient and in need of correction automatically implies a normative stance in an area where what constitutes appropriate coping is anything but clear.[122] Viewing the ability to cope as an innate process that exists independently of the environment which demands its use is to assume that both the person and environment are static variables and that action and reaction occur without any basic alteration in the components involved.[123]

> . . . in examining the individual in an environmental context, one must introduce considerations of the ecological impact of coping efforts--that is, their effect on the individual's larger social or environmental network and the ramifications for subsequent coping efforts. This of necessity vastly increases the potential for incongruence among competing considerations.[124]

Not only can person and environment not be separated from the reciprocal flow of the transaction, neither can be seen apart from their larger context in order to understand the nature of the transaction.

In meeting the learning needs of the person(s) faced with cancer, perhaps Johnson and Stark (1980) come closest. Though still viewing the identification of problems as an essential part of their process, their groups are designed to familiarize both those utilizing the services and those providing them with each other, their competencies and ways of relating. Basic information about commonly found concerns is provided allowing each person to incorporate it into her/his lifestyle and ways of relating as (s)he sees fit. A forum for emotional expression is provided and the fact that the disease impacts on more than just the person with it (i.e., family) is built into the design of the groups. Issues of daily living are looked at from alterations in relationships to faith, nutrition and relaxation.[125] It is concerned with survival and continued growth. Both Sobel and Worden (1982), and Simonton, et al. (1978), are more concerned with the correction of deficits.

Cancer the disease, as this chapter depicts, is unpredictable. This uncertainty has implications for the human experiencing and treatment of cancer the illness. In responding to cancer the disease, as well as cancer the illness, interventive practice has been to separate the mind from the body and to shape the approach from a problem-oriented focus. Moving into the next two chapters, the reader will see how these themes translate into the design of a specific health care setting as the writer experienced them in that system.

Chapter 3

FOOTNOTES

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Chapter 4

THE MANITOBA CANCER TREATMENT AND RESEARCH FOUNDATION

Cancer the disease and cancer the illness have been introduced, interventive approaches reviewed and critiqued. What is to follow now is an introduction to the practice setting. The Manitoba Cancer Treatment and Research Foundation was and is the Province of Manitoba's centre for the research and treatment of cancer the disease. Yet, this is more than a description of a 'practice setting'; it is part of the ecological approach developed and outlined in chapter two. It is one of the areas where the development of social work skill and knowledge acts to broaden the worker's focus of the 'structure of the field', its interfaces and communication channels. What is the Manitoba Cancer Treatment and Research Foundation (also referred to as the Cancer Foundation), its subsystems and the systems of which it is a part? How does the Cancer Foundation's overall structure, programs, policies, philosophy, physical layout, etc., influence the nature of the help offered? Where does social work fit into this and what form of access does it have to significant decision-making bodies? Where does social work stand in relation to the overall policy and direction of the practice setting? How do all these systems come together, balance and integrate their survival and growth needs? What is the impact of all this on the adaptive strivings of the person(s) directly experiencing the chronic illness?

The subtleties that help build connections within and between systems are not always open to direct observation, nor can they usually be found committed to paper in policy manuals. Dalton (1973) states that the 'behaviour' of an organization is composed of people and the nature of the connections they build among themselves.[1] Thus, once the formal construction of an organization is built, the persons it chooses to people its operations create an informal structure all their own which influences and is influenced by the formal structure. Value judgements and personal visions regarding how organizational and self direction blend are held in varying forms and degrees by these persons throughout the organization's framework. If the visions of the organizational elite are to become a reality, the energy and support of staff must be gained. Both consumer needs and staff needs must be incorporated into the framework and continuously balanced to ensure organizational survival.[2] Adjusting the fit between the formal and informal structure, therefore, is an ongoing demand in the organization's life.

Brager and Holloway (1978) use the term 'human service organization' to refer to all those organizations set up to address the biological, social, emotional and/or cognitive needs of the community in which they exist.

> The broad goal of human service organizations is the alteration of some aspect of the individuals served. Such alterations, be they in behavior, perspective, social status, or in the individual's share of life-sustaining resources, are defined by the organization to serve the interest of both the client and the larger society.[3]

Their intent is to strengthen human functioning and existence. Socially sanctioned to provide this service, they reflect the value and belief base of the society in which they operate. Set up to serve the needs of both the consumer of the service and the society of which they are a part, they are often faced simultaneously with divergent and contradictory demands. What is in the best interests of society does not necessarily meet the needs of the consumer and vice versa. A society may place a high value on being able to achieve success through individual effort, yet simultaneously believe that human beings should be responsive to one another's needs. In such a society, organized efforts to help address these needs may be publicly sanctioned, but a message is communicated that those requiring the services are either personally deficit in their ability to master environmental forces or are abusing the system by refusing to apply their abilities.[4] Either way, it is a matter of personal failing, existing apart from the structure of the system. In a health care setting, this may be expressed by a belief that psychosocial dimensions of care require organized attention only in those instances where the person is unable to comply with the demands of the system, either because of inadequate coping skills, resources or a lack of desire to do so. The inadequacy is on the part of the person to comply rather than on the system to address human need. The assumption made is that for the majority of persons utilizing the health care system, an organized effort to address the psychosocial dimensions is not required.

The emergence of divergent and contradictory forces is inherent in the building of organizations. Different levels of responsibility and power require and give access to varying types of information, thus generating different, possibly contradictory, orientations towards organizational operations. Job specialization gives exposure to different segments of the whole picture producing different understandings of what is being confronted and different investments in the outcome of the whole.[5] Add to this policies/rules which have evolved over time in response to the thrust of different organizational visions to draw together and guide divergent forces. As the vision changes, some lose their relevancy and/or conflict with more recently designed policies. Thus, while the goal may be to strengthen human functioning and existence, organizational needs to respond to these divergent and contradictory forces may lead to programs structured more with the intent of social control than the advance of human welfare.

With this in mind, what is the Manitoba Cancer Treatment and Research Foundation? First of all, it is a human service organization with its roots in the end of the Nineteenth Century and the beginning of the Twentieth. During this span of time, special centres for the treatment of cancer had begun to appear throughout the United States and Europe, spurred on by the effective use of X-rays and radioactivity in the treatment of malignant disease. This was an era when cancer education was unheard of and persons with cancer were avoided by a significant number of physicians. Written in reference to Manitoba following the end of World War I in 1918, the quotes listed below give an indication of what was being confronted.

> . . . --malignant disease was common, especially cancer of the stomach in men and cancer of the breast and cervix in women--and always presenting in the late stages. Cancer of the lip was seen frequently in pipe smokers. Cancer of the colon and rectum

> were common. There were many lymphomas, occasional bone sarcomas, and many metastatic bone tumors. Skin cancer was common on the face and dorsum of the hand. Kidney and bladder tumors were less common and primary lung cancer almost unknown.
>
> . . . .
>
> The medical profession appeared to accept cancer as a horrible reality and many physicians were happy to avoid cancer patients. Even the surgeons who were the only source of help, such as it was, were seldom enthusiastic.[6]

The use of surgery for the treatment of cancer occurred primarily for the relief of physical discomfort rather than as an attempt to arrest the progress of the disease. Surgical training was in the process of moving from the apprenticeship method to the scientific method, anaesthesiology was just beginning to develop, and specialized training for the surgical treatment of cancer in centres noted for cancer treatment was yet to come.

> Curative surgery was inhibited to a considerable degree by the risk of prolonged anaesthesia. After two hours one realized time was getting short and the limit was less than 4 hours. Many of the problems of transfusion were yet to be solved.[7]

Given all these factors, it became apparent to both the medical establishment in Manitoba and the general public that a concerted effort was needed to combat cancer the disease. Subsequently, on April 14, 1930, The Cancer Relief Act was approved by the Lieutenant-Governor following its passage by the Legislative Assembly of Manitoba. The intent of the Act was to assemble a board of knowledgeable persons--representatives from the government, the Manitoba Medical Association, the Winnipeg Medical Society, rural Manitoba, the major city hospitals, the Manitoba Hospital Association and the University of Manitoba--to consider the 'cancer problem' rather than to develop a specialized treatment centre. Hence came the birth of the Cancer Relief and Research Institute.

> The Board defined its function "to deal with malignant diseases, their diagnosis, prevention, treatment and investigation in their broadest aspects."[9]

Given the recent advances in the use of radioactive substances in the treatment of cancer, the Board saw the introduction of radiotherapy to the province as its initial task.

> Professor Allen (Physics, University of Manitoba) outlined his concept of the ideal organization from the point of view of a physicist. His general plan was that there "should be a full time Professor, expert in theory and practice of radiation in all its phases, and a full time technical assistant, and that the Institute should not only prepare radium in its various forms for clinical uses, but should instruct medical students and students of physics and medical practitioners."[10]

The plan was for the Institute to take the lead in those phases of development which required a co-ordinated acquisition and pooling of expertise and funds, while encouraging the incorporation of other phases of cancer control into the daily operations of generalized medicine and hospital care. Because of the high cost of radium, its need for specialized care and handling, and the need for expertise in the application of radiotherapy, the Institute assumed responsibility for the implementation of this phase. However, it also placed an emphasis on using these skilled services to train others, on educating the public to recognize early signs of malignant disease and seek prompt medical attention, and encouraging hospitals to upgrade their efforts to identify the presence of cancer. A postal biopsy service was established in 1937 to give rural physicians access to specialized resources for cancer detection.[11]

> The Institute hired one full-time staff member--Dr. P. A. MacDonald as Physicist and granted Professor Allen an honorarium as consultant. The budget for the first year of operation was $9500.00. This included a university student hired at $40.00 per month to assist in the laboratory. Dr. MacDonald was sent to New York to gain experience with the radium emanation plant--his expenses "not to exceed $100 per month".[12]

Funding arrangements were dubious, relying on donations from service clubs such as the Rotary and Kiwanis Clubs, fund-raising events, private donations, and fees for radium treatments judged according to the amounts of radium used. Often, however, persons requiring treatment did not have the money necessary to meet the costs, leaving the Institute in a deficit position. Attempts to persuade the General Hospital to cover these fees were to no avail as they also lacked the required funds. Reprieves from the costs of winter heating were then sought from the Medical College which housed the radium supplies.[13]

Continuing with their intent to provide the people of Manitoba with radiotherapy for the treatment of cancer and to generate more physician interest in learning the skills of its use, a radiotherapy division was established in the Winnipeg General Hospital in 1938 and the St. Boniface Hospital in 1955. To further advance cancer diagnosis and treatment, the Institute, in conjunction with the Manitoba Medical Association, combined resources to establish diagnostic services specifically tailored to cancer identification at the Winnipeg and St. Boniface General Hospitals, both major teaching centres. Physician time was donated, while other program expenditures were covered by the Cancer Relief and Research Institute. Five years later in 1955, a Clinical Research Group came into being through the efforts and guidance of the Research Committee of the Institute.

Following, in 1957, the Canadian Cancer Society was asked to establish in Manitoba to take over fund-raising responsibilities, public education and support services for cancer patients.

> The Canadian Cancer Society who had agreed to remain inactive in Manitoba as long as the Institute felt it could carry on alone was invited to establish a Manitoba Division of the Canadian Cancer Society to assume the responsibilities involving the collection of funds by public appeal for the support of research, for lay education, and for welfare services to cancer patients. With the establishment of the Manitoba Division it was obvious that the main direction of the Institute's work would change requiring a modification of the statute.[14]

Thus, the Cancer Relief and Research Institute died, giving birth to a new Act and the Manitoba Cancer Treatment and Research Foundation. Improved facilities needed for the Winnipeg General Hospital's radiotherapy program spurred the Cancer Foundation's new board, within one year of its existence, into lobbying the Manitoba Provincial Government for a new physical structure that could bring the Foundation's Department of Physics, administration, statistics and tumor service together under one roof. Construction was approved by the Province in 1959 with the new building opening in 1963. By this point, the Foundation had assumed province-wide responsibility for examining and recalibrating 'all radiation-emitting equipment' (Radiation Protection Service - Medical Physics) and for diagnostic services to aid in cervical cancer identification (Cytology Service). In 1964 the Manitoba Hospital Services Commission (now known as the Manitoba Health Services Commission) became a major source of funding for expenditures relating to treatment, diagnostic and other associated services. Funding of the Radiation Protection Service was covered through another Provincial Government department.

Two other dates bear historical significance in the Cancer Foundation's campaign to combat cancer the disease. The first date, 1967, marked the emergence of a scheme to establish an interdisciplinary research institute responsible for research and training in how the disease mechanisms of cancer and other diseases are expressed at the cellular level.

> A committee comprised of representatives from the Foundation and the University of Manitoba proposed the formation of the Manitoba Institute of Cell Biology, comprising divisions of Biophysics, Molecular Biology and Clinical Science involving a total of approximately 25 senior research workers. On August 21st, 1969, the two sponsoring bodies, the University of Manitoba and the Manitoba Cancer Treatment and Research Foundation approved the formation of the Manitoba Institute of Cell Biology and appointed a Board comprised of three representatives from the Foundation, three from the University of Manitoba and up to five appointed jointly by the Foundation and the University.[15]

To accommodate the Institute's need for specialized research facilities, the Foundation's physical structure was expanded. Construction was completed in 1980.

> The entire second floor of the new addition to the Manitoba Cancer Treatment and Research Foundation has been allocated to the Manitoba Institute of Cell Biology. This has provided an additional 10,500 square feet of laboratory space.[16]

The second significant date was the 1973 amalgamation of the Winnipeg General, Children's and Rehabilitation Hospitals into the Health Sciences Centre. A formal accordance was struck between the Health Sciences Centre and the Foundation in 1974 whereby the Foundation would retain its separate identity, but work jointly with the Health Sciences Centre to develop ". . . a comprehensive program, with the highest possible standards for cancer diagnosis, treatment, education and research . . ." within the Health Sciences Centre structure that would be effectively integrated with the provincial program.[17]

> The Centre and the Foundation jointly select and appoint a director of both the Provincial Program and the Joint Program. The Director is in charge of and responsible for the direction of the clinical, teaching and research activities of the professional staff and the administration of the Cancer Centre. The Director is also responsible to the Foundation for the maintenance, co-ordination and supervision of the Provincial Program.[18]

Maintaining current statistical documentation of cancer in Manitoba (reportable under The Manitoba Public Health Act), centralized medical records, linkages with local, national and international bodies involved in cancer research and patient care, and administering and co-ordinating the care of person(s) being treated for cancer outside the Health Sciences Centre are just some of the responsibilities entailed in the position.

Historical documentation is suggestive of the psychosocial costs of cancer the disease and of the sense of powerlessness that the Province's health care system felt in responding to this need. However, while the psychosocial costs may have provided an impetus for action, the approach which evolved was decisively biological in its focus. The need for psychosocial supports receives mention when the human need for the service is present, but the ability to pay for it is not. Though Oncology Social Work came into being as a department within the Foundation in 1974, its absence from three historical accounts of the Cancer Foundation's progress compiled after that date (1975, 1977, 1980) would seem to indicate that attending to the psychosocial dimensions of cancer's impact is not part of the Foundation's overall vision of comprehensive cancer care.[19] Educational and training thrusts for cancer treatment and research have been concentrated primarily in the medical and physiological sciences.

Attention given to the psychosocial dimensions of health care prior to the establishment of an Oncology Social Work Department consisted basically of practical services such as transportation, meals, lodging and linkages with appropriate community resources for financial assistance and other social support services. Facilitation of these services was necessary if those persons directly experiencing the cancer and their families were to honour treatment commitments and to attend outpatient clinics. Nursing assumed responsibility for co-ordinating these support services. Emotional and cognitive needs which exceeded these resources were either addressed by referral to community agencies or, more often, by drawing on the social work resources of the Health Sciences Centre. Feeling a strain on its resources, the Health Sciences Centre Social Work Department initiated a survey to determine the need for a full-time oncology social worker.[20] On the basis of this report and interest expressed by various factions of the Cancer Foundation, the Health Sciences Centre agreed to fund one full-time social work position to be based in the Cancer Foundation and to deal strictly with the psychosocial needs of persons dealing with cancer the illness. This meant that the social services co-ordinated and staffed by nursing would now be the responsibility of social work. The withdrawal of nursing from this sector of responsibility occurred gradually over the next four years. In 1976 the Social Work Department was seen as being composed of both nursing and social work, with nursing moving to a liaison position in

1977/78, and a total withdrawal in 1979.[21] There is some indication that this relinquishment of involvement occurred with some discomfort to the participants.

> Like any new program, it has had its share of difficulties during the process of program implementation. New programs involve change and changes invariably create anxiety for those involved. . . . In spite of these difficulties, it's reassuring to know that many patients, families and many colleagues in the community do appreciate the availability of a more comprehensive social work program at the Foundation.[22]

Offering a more comprehensive social work resource meant moving the present services beyond discharge planning and the practical services previously noted to addressing the impact of cancer the disease on the psychosocial dimensions of the persons using the Cancer Foundation's services. The mechanisms of making this happen, however, involved shifting the emphasis of the department away from the provision of practical services towards a more overall concern for the human experiencing of cancer. For those persons peopling the organizational structure of the Cancer Foundation, this necessitated a change in how they had come to understand the need to attend to the psychosocial dimensions of health care. While it was understood that these other dimensions existed, the need to include them in assessing and planning biological treatments was seen as appropriate only in those instances where progress in the biological realm would be hindered if they were not addressed. Even then it was assumed that the majority of these persons could manage the psychosocial impact of the disease and its treatments given a few practical supports. Hence, the push to address more adequately the psychosocial dimensions of cancer care began through efforts to increase the Foundation's awareness of the existence of the cognitive and emotional needs of its clientele.

> . . . evidence has been accumulated and has suggested the need for an increasingly comprehensive network of psychological services that previously have not been acknowledged. Cancer is still a very frightening disease. Fear, misunderstanding and social stigma often present a great deal of stress to the patient as well as [her]his family. It would be ideal and therapeutic if each and every new patient and/or [her]his family could be seen by a social work staff at the point of entry to the Foundation.[23]

In addition to those received from the Foundation and the Health Sciences Centre, requests for counselling to address the impact of the disease on people's lives came from the St. Boniface Hospital Oncology Unit, community agencies both in and outside of Winnipeg, and those persons bearing the disease and/or their families. Occurring simultaneously was a move to reduce the percentage of social work time devoted to discharge planning and the co-ordination of practical services, thereby freeing more time for counselling.

> The traditional and the easily identified services such as discharge planning, transportation, lodging and other forms of practical assistance continue to account for a greater percentage of our staff time. . . .
>
> . . . .
>
> . . . As far as the more complex psycho-social problems encountered by cancer patients and their families are concerned, the oncology social worker, who has administrative as well as program development responsibilities has only part of her time to devote to counselling.[24]

With the development of new biologically-focused treatments, the number of persons being seen at the Cancer Foundation was increasing and along with it demands for social work services. Given the scope of what was being encountered, the oncology social worker began to advocate for additional professional social work staff (1977). Gaining access to people before significant psychosocial deterioration had occurred was a struggle. By 1979 the majority of planning for transfers between health care facilities was managed by the discharge officer of the Health Sciences Centre, Social Work Department. Responsibility for co-ordinating practical services (transportation, meals, lodging) had been assumed by the Oncology Social Work Department's secretary using volunteers recruited by the Canadian Cancer Society. Counselling services directed towards the psychological impact of cancer the disease were moving into the forefront in the department's service emphasis.

> Social work intervention at an early stage can alleviate or might even prevent emotional breakdown. High-risk groups of patients, such as the elderly living alone, single parents, divorced and separated individuals and patients with problems relating to alcohol, etc., should routinely be referred for an initial social assessment.
>
> . . . Unfortunately, due to the lack of professional staff and the present referral system, many of the referrals come almost at the time of crisis.[25]

Tagged as high risk were those persons who, because of the specialized nature of their social situation, were more likely to require a health care approach that demonstrated a sensitivity to their psychosocial needs either because of a reduced resource base on which to draw, specialized needs peculiar to their circumstances, and/or a heavier load of emotional and cognitive issues with which to contend. Although the need to include psychosocial dimensions in the health care approach was more apparent in these situations, it still left this attention in the realm of the exception to be mobilized only in special circumstances rather than a basic need of all those confronting cancer the disease. Obtaining office space appropriate for counselling one or more persons was still an obstacle.

As cited earlier, 1980 marked the expansion of the Cancer Foundation's building. With this expansion came three new developments for Oncology Social Work: new centrally located offices with enough space for two social workers and a secretary, funding from the Cancer Foundation for another social work position, and the provision of field placements for two social work students from the University of Manitoba (undergraduate and graduate). Already in its second year of operation was a community home visiting program for third-year-degree nursing students from the University of Manitoba. The central positioning of social work in the physical layout of the Cancer Foundation's structure acted to increase visibility and access to social work services for staff, thereby facilitating communication.[26] Receiving financial backing from the Canadian Cancer Society, a series of educational and support groups for persons with cancer were completed, with a decision to move to a one-to-one support program (CanSurmount) co-ordinated on a voluntary basis by a cancer survivor assisted by an advisory committee, including the Director of Oncology Social Work. Other developments for Oncology Social Work in 1980 included the establishment of a free-flowing communication channel (facilitated by an on-site visit) with the social work department of the Fred Hutchinson Cancer Research Center in Seattle, which was providing bone marrow transplants for a number of the Foundation's leukemic patients. Oncology Social Work now listed its goals as the ". . . extension of counselling services, screening all high risk groups of new patients and closer liaison with community agencies and follow up services."[27]

Thus, it was in 1981 that Oncology Social Work filled its new social work position and the field work for this practicum was begun and completed. The Department's sense of its services at that time was as follows:

> Present arrangements for Social Work coverage for oncology in-patients at the General Hospital and the Women's Hospital are far from ideal. Social Work services to all adult cancer patients should be coordinated through the Department of Oncology Social Work at the Cancer Foundation. This means that services required by cancer patients should be program-oriented instead of hospital-oriented.[28]

In July, 1981, assessment of people's needs for accommodation and transportation was taken over by a Canadian Cancer Society staff person located in the Cancer Foundation. Plans were in the making for the establishment of a ten-week program for the physical and emotional recovery of post-mastectomy women to be located at the Young Women's Christian Association in Winnipeg. Its realization involved the combined energies of Oncology Social Work, the Mastectomy Visitation Coordinator, the Cancer Society, and Y.W.C.A. Developmental Services Coordinator. Extension of counselling services was still a priority with an indication that this should encompass group as well as individual approaches. Early identification of those persons most in need of psychosocial supports continued to be the focus of this push. Stronger interconnections with community-based resources were being urged and social work was participating in the exchange of ideas regarding the feasibility of the Foundation establishing its own palliative care unit. Oncology Social Work's overall emphasis was on the need for a multidisciplinary team approach to the rehabilitative efforts of cancer care.

The purpose of this historical account has been to begin to build a sense of what the Manitoba Cancer Treatment and Research Foundation is and the evolution of social work within it, up to and including the time span when field work for this practicum was completed. Sequentially placed, this account does not give a sense of the living whole, its interconnections and communication pathways, nor how social work sees itself in this overall network. Consequently, the remainder of this chapter will be used to construct, with the aid of an eco-map, a picture of this whole, its interconnections and communication pathways, and social work's place in it--to the extent that this is possible given the writer's position in the organization (student), limited access to informal communication channels, and the original intent of this practicum.

From this historical account two themes become evident: one is a commitment to teaching; and, the second is a commitment to research. The present-day organization embodies both of these features. All medical and science departments within the Cancer Foundation are involved in teaching and research with the University of Manitoba, with one or more members of each department holding faculty appointments.[29] A third historically rooted thrust is the provision of a centrally located pool of expertise and data collection directed towards the eradication and/or control of cancer the disease. Maintained within the Foundation is an extensive and detailed record of cancer incidence and mortality in Manitoba (Oncology Records and Registry).

> The Central Cancer Registry, in continuous operation since its inception in 1937, became population-based in 1951. It now has assembled data on approximately 130,000 cancer patients. This is of demographic significance because of the comparatively stable nature of the population.[30]

Thus, a significant base of statistical data for research endeavours is in place. Coupled with the physical and organizational incorporation of the talents of the Manitoba Institute of Cell Biology and joint pursuit of treatment and research projects with national (e.g., Breast Screening Program) and international bodies, expertise is both encouraged and attracted.

> The Department of Medical Oncology also participates in clinical trials sponsored by several national and international clinical trial co-operative groups. These include the Children's Cancer Study Group . . ., the National Cancer Institute of Canada . . ., and the National Surgical Adjuvant Programme for Breast and Bowel Cancers. As well, formal liaisons for participation in co-operative protocols with the Baltimore Cancer Research Centre have been established for a number of disease sites.[31]

Some of these national and international connections are represented on Eco-map One, which looks at the Cancer Foundation as a whole. While this emphasis on teaching, research, and acquiring and nurturing national and international linkages for the purpose of preserving a forward momentum towards cancer control and/or cure permeates the operations of the Foundation, it is, with few exceptions, a biological movement concerned with cancer the disease rather than cancer the illness. Though Oncology Social Work is linked to the University of Manitoba through its provision of field work sites for undergraduate nursing and social work students and graduate social work students, in 1981 it held no faculty appointments for either teaching or research purposes and did not hold major responsibility for designing the clinical expression of social work skills acquired in its setting.

Its one international linkage with the Fred Hutchinson Cancer Research Center's Department of Social Work was and is primarily a service-oriented connection engendered to ensure that adequate psychosocial supports are provided for persons with leukemia and their families while undergoing bone marrow transplants. When examining the connection between Administration and Oncology Social Work on Eco-map Two, there would appear to be no organizational push to perform otherwise. The connection is a strong one indicating an administrative satisfaction with the quality of service given, but for purposes of Oncology Social Work's professional growth and possible influence in furthering a more comprehensive approach to the psychosocial dimensions of cancer care, the connection is social work initiated.

As evidenced in its historical evolution and in its present-day administrative organization, those persons awarded the major responsibility for plotting the organizational mission of the Foundation have come from professions which, until very recently, gave little attention to the psychosocial dimensions of their work or training.[32] They have been professions whose focal point has been understanding the biological expression of disease and in doing so, designing treatment approaches to combat the disease. Psychosocial concerns have entered this focus only when they have threatened to impede progress in this sphere or as beneficiaries of biological advance. The administrative head of the Foundation has a medical and science background tailored to the care of cancer the disease. As is shown on Eco-map One, he is strongly connected to the Advisory Medical

Board which embodies representatives from Radiation Oncology, the Oncology Unit at St. Boniface Hospital, and Medical Oncology, plus one representative from the Cancer Foundation's Board of Directors. Both Administration and the Advisory Medical Board are connected in varying degrees to the Foundation's Board of Directors. Linked to Administration and the Board of Directors is the Finance Committee. Noted earlier in this chapter was the Manitoba Institute of Cell Biology management board's composition: representatives from the Cancer Foundation and University of Manitoba, as well as five additional members appointed jointly by the Foundation and the University. It would seem most likely that visions regarding the organization's mission would be formulated in different proportions within these organizational clusters, all of which are made up of professional groupings which are decisively biologically oriented in their emphasis. There would appear to be very little present to promote a forceful psychosocial influence. If exposure is consistently gained to only one segment of the overall picture, cancer the disease, it would follow that organizational vision would automatically afford a major portion of its attention to the biological dimension of cancer's impact, seeing the psychological and social dimensions as adjuncts to the organization's primary function.

Again, looking at Eco-map One, both chemotherapy and radiotherapy nurses are strongly linked to their respective departments. If this is an accurate representation of the connection, it would indicate that each sees a large percentage of her/his survival and growth being strongly tied to the design of these departments. Generally, nursing is well represented in the Foundation's research ventures, often occupying positions of responsibility for its implementation. However, it would seem that much, if not all, of this effort is carried out under the auspices of medicine, rather than as an independent nursing venture. Organizationally, this may mean that nursing is viewed as a support service to those professions responsible for realizing the organization's overall mission rather than as a profession in its own right with the capacity for formulating a piece of that vision. If this is so, it is significant since nursing as a profession devotes a sizeable portion of its training and practice to addressing the psychosocial dimensions in conjunction with the biological.

The form these linkages between nursing and their respective departments take also has implications for their connection with social work. Eco-map Two indicates that chemotherapy nurses have a higher level of participation in program decision-making than do radiotherapy nurses where the physicians are more reluctant to share this process. Oncology Social Work's connection with the medical component of radiotherapy in 1981 was there, but it was tenuous. Although the linkage to radiotherapy nursing is much stronger, it does not compare to the connection between social work and chemotherapy nursing. Because radiotherapy nursing in 1981 had less independence from the medical component in radiotherapy, the capacity to freely share information with social work was restricted. How and who they referred for social work assistance and how much information was given regarding the referrals made was influenced by the attitudes of the medical personnel involved. Chemotherapy nurses, however, in conjunction with a higher level of participation in program decision-making, had more room to act autonomously from the medical personnel in matters of judgement, particularly in patient care concerns. Decisions regarding who was referred to social work, when, and how much information was shared could be determined by the chemotherapy nurse relying on his/her own judgement apart from the physician. Therefore, how the survival and growth of nursing are linked to the behaviour and attitudes of the medical component influences nursing's ability to work on strengthening its connection to social work. If nursing's survival and growth are highly dependent on their linkage to medicine, they will act on strengthening that connection to social work only to the point that this effort does not endanger the link to the medical element (note arrows depicting flow of energy and resources on Eco-map Two).

Oncology Social Work's connection to Medical Oncology (see Eco-map Two) is strong, but slightly less so than its connection to chemotherapy nursing. The flow of energy and resources used to maintain the connection between social work and chemotherapy nursing suggests two groups of professionals with a strong informal connection, both of whom value the connection and are able to put their full effort towards making it happen. Because the energy exchange is equal, neither one is drained by the connection. This last statement is also true for the connection between Medical Oncology and social work. However, the percentage of effort extended towards maintaining the connection is less signifying in this instance the full potential of the connection is not being utilized. When comparing this connection to social work's linkage with Radiation Oncology, two pieces of information are useful for understanding what factors might account for the difference. Medical Oncology tends to be staffed by a younger group of physicians whose educational exposure has accorded a greater emphasis to the development of a psychosocial awareness. Radiation Oncology was represented in 1981 by an older physician population whose medical training gave little, if any, attention to the psychosocial elements of personhood and medical care. Essentially, this means that Medical Oncology is better equipped to connect with social work because of an increased understanding of the psychosocial emphasis with which social work deals. They are also able to be more attentive to nursing's efforts to draw attention to, and address these dimensions in conjunction with the biological concerns presented. Attending to these dimensions is within the program's mission. Radiation Oncology, having had exposure to and being used to working only with the biological dimension, may understand that the psychosocial dimensions exist, but not how they influence what (s)he does. Thus, these physicians will have more difficulty understanding what it is that nursing and social work are asking them to address. They will be more likely to see these dimensions as lying outside the program's mission and as a drain on limited time and energy resources. The end result is that they will be less inclined to expend the energy required to maintain connections solely for the purpose of addressing psychosocial issues. If social work sees a need for these dimensions to be attended to in this department, it will have to expect to put forth more energy and resources to create a connection and keep it in place than it receives in return. Consequently, for social work this connection will be draining, both in time and energy, with little incentive from Radiation Oncology to sustain the bond. Returning to social work's linkage with Medical Oncology, it was stated that the full potential of this connection was not being realized. While Medical Oncology is aware of and addresses the psychosocial dimensions, its connection with social work is still largely on a referral basis. Psychosocial concerns are attended to as they arise, but they still occupy a secondary status to the biological treatment of cancer. Plans for medical intervention may consider psychosocial impact, but the focal point is cancer the disease, not cancer the illness.

Given that the foregoing represents how it is, what does all this mean for social work in relation to the overall policy and direction of the setting? First of all, it would appear that social work and nursing are seen by the Cancer Foundation as support services, essential in helping the organization realize its mission, but not as participants in formulating the vision of that mission. While nursing is involved in research, it is so as part of medicine. Social work has made a significant contribution in providing psychosocial services to the consumer segment of the Foundation, but it is not encouraged by Administration or elsewhere to develop its program beyond the direct service sector (i.e., research regarding approaches to the psychosocial impact of cancer). Medical Oncology is aware of and addresses the psychosocial dimensions fostering a strong connection with social work, but the biological dimension is still primary. Seeking out and nurturing national/international linkages for purposes of engendering joint participation in research and access to advanced treatment approaches towards cancer control and/or eradication is a consistent theme within the Foundation, but only in regard to cancer the disease. Teaching others and sharing knowledge regarding current approaches to cancer also is an important program thrust, but again, only within the biological realm. Nursing and social work are the two professions within the Cancer Foundation whose training and practice place an emphasis on attending to the psycho-social dimensions in conjunction with the biological dimension as opposed to being its an adjunct. If these professions are valued solely for their support service function, what chance does the Cancer Foundation have of constructing a vision of comprehensive cancer care that includes all three dimensions--biological, psychological and social?

From the historical account, it is known that the Foundation's original concept of social work input did not extend much beyond discharge planning and co-ordinating practical services. Gaining sufficient room to address cancer's cognitive and emotional impact required concentrated long-term effort on the part of the oncology social worker. It is also known that the original push and funding needed to incorporate social work as part of the Cancer Foundation's service package came from the Health Sciences Centre's Department of Social Work. Both in 1981 and presently, funding for the Director's position in Oncology Social Work has come from the Health Sciences Centre. Thus, administratively, the Director of Oncology Social Work is responsible to both the Cancer Foundation and the Health Sciences Centre's Department of Social Work. Eco-map Two shows Oncology Social Work strongly connected to the Cancer Foundation Administration, but with only a medium connection to the Health Sciences Centre's Department of Social Work. To maintain the medium connection, Oncology Social Work sees itself as extending 130% in energy and resources and gaining nothing in return, while it is able to keep a strong connection with the Foundation's Administration with only a 60% expenditure in energy and resources. This would seem to indicate that while both connections give back the same amount in upkeep towards the linkages, Oncology Social Work feels a greater sense of solidarity with one connection over the other. Further exploration regarding the nature of these linkages leaves the impression that Oncology Social Work is to a large extent administratively overlooked by the Health Sciences Centre's Department of Social Work. (Concerns regarding program development for the provision of more comprehensive psychosocial care for person(s) experiencing cancer appear to be left largely unaddressed by this Department.) Within the Cancer Foundation there is a sense of being listened to by Administration when Social Work invests the energy to present its concerns, however, the scope of what is put forth is not always comprehended. Thus, it would seem that Oncology Social Work is caught between two administrative bodies--one with the commonality in education and practice background to appreciate the psychosocial dimensions of health care but seemingly inattentive to Oncology Social Work's program concerns, and another willing to listen to these concerns but with a conceptual view of social work as a support service in the realization of a biological mission.

Keeping the foregoing in mind, consider that both oncology social workers have direct service commitments. This means that the Director of Oncology Social Work must balance her energy resources between meeting client needs, administrative needs and program development. In attempting to meet the clinical needs of the position, there is a perceived need for a different form of service approach in order to more adequately address the psychosocial impact of cancer. Yet, the energy, time and space required to formulate and sell new program directions to the Cancer Foundation's Administration is taken up in meeting clinical and administrative demands. To secure more energy, time and space for program development, Oncology Social Work may choose to withdraw from some of its direct service commitments. However, the feasibility of such a move must be weighed in conjunction with its impact on social work's other connections and the combined influence of all these on its survival and growth as a viable entity within the organization. This is particularly important considering the value of Oncology Social Work as a direct service component of the Foundation.

When one examines some of Oncology Social Work's other connections, it can be seen that minimal linkages exist between social work and Pediatric Oncology, and between social work and Oncology, St. Boniface Hospital. Although both of these are sections of the Cancer Foundation's overall program, they have their own social workers and independent connections with other programs. The

St. Boniface Hospital, operating as a separate teaching hospital, has its own social work department, and while the Children's Centre is part of the Health Sciences Centre complex, it has an intricately connected team approach focused on children and based within the Children's Centre that reaches out to include Pediatric Oncology. More interprogram transactions occur between the worker connected with Oncology, St. Boniface Hospital, and social work than with Pediatric Oncology, but for both the energy exchange is balanced and the transactions largely related to direct service issues. The energy exchanges for Epidemiology and Biostatistics and the Breast Screening Program are also balanced and direct-service related. Other linkages related to direct service include Oncology Social Work's connections to the Princess Elizabeth Hospital and the Canadian Cancer Society's Services to Patients Committee. Because the Health Sciences Centre was and is set up as an acute-care treatment facility, in 1981 those persons in the terminal phase of their illness and requiring hospital-based symptomatic care (e.g., adjustment of pain medication) were referred to the Princess Elizabeth Hospital's Palliative Care Unit. Housing its own program-based social work supports, social work coverage was assumed by these workers during the person's stay, but with the necessary communication links with Oncology Social Work where continuity of care was required. As noted in the historical account, the Canadian Cancer Society was gradually assuming more responsibility for the co-ordination of the practical services such as transportation and lodging. In 1981 Oncology Social Work was still involved in this process. At that point, Oncology Social Work still felt that too much of its time was allotted to the provision of these services, leaving insufficient time, space and energy for meeting the cognitive and emotional needs of those confronting the impact of cancer the illness. Given social work's vision of comprehensive cancer, their involvement in the provision of these services was felt to require a significant energy investment but one that would do little to further social work's growth in the direction in which it saw itself needing to move.

Social work's connection with Oncology Records and Registry was and is administratively profitable. Having developed a strong, easily-formed connection with a minimum of energy required to maintain it, both departments readily support one another in the administrative management of their respective areas. Clerical staff move easily between the two departments, providing an additional person to assist during peak periods in workload for Oncology Records and Registry, and holiday coverage for Social Work's secretary. Because of the ease with which this occurs, time is saved by both departments that can then be put towards other pursuits. Oncology Social Work's Director participates, in conjunction with other social work management within the Health Sciences Centre, in the Manitoba Association of Social Work Administrators in Health Care Facilities. This provides a structural context for discussing social work administration in health care settings with other social workers in administrative positions generating a sharing of ideas, experiences and resources. Within the Foundation social work takes part with the Director of Nursing and other department heads in regularly-held meetings for the discussion of the Foundation's programs, research grants, etc. Psychosocial issues which arise in the context of these meetings are frequently directed towards social work for comment. The impact this input has towards furthering social work's vision of psychosocial care within the Foundation depends on the type of issues to which it has access, its ability to frame its vision of psychosocial needs in terms that catch the interest of others, and the receptiveness of others to this input.

Returning to social work's connection to the University of Manitoba, it can be seen from Eco-map Two that Oncology Social Work invests a large amount of energy (80%) into a medium connection with a low rate of return (20%). Oncology Social Work is responsible for co-ordinating the students' on-site experience--serving as an immediate resource for practice information, finding client situations appropriate for student involvement, preparing the Foundation for the student's presence, ensuring [s]he has access to the Foundation's resources, etc. In return social work students provide a source of experienced professional help already familiar with the Foundation and its programs when holiday coverage is required. While the students provide a temporary source of person power to help address client needs, the source is temporary and primarily structured for the purpose of providing a rich practice exposure for the students rather than contributing towards the Cancer Foundation's awareness of and ability to address the psychosocial dimensions of cancer care. In this respect it does not immediately advance Oncology Social Work's efforts to alter the Foundation's concept of addressing the psychosocial impact of cancer. Given this, the type of practice issues students confront in the setting help nurture a beginning awareness of the bio/psycho/social dimensions of chronic illness and the profession's ability to adequately address these. In doing so, it heightens the profession's awareness of the unmet psychosocial needs existent in this area and, hopefully, engenders the urge to develop new ways of meeting this need.

The final connection to be examined on Eco-map Two is social work's connection to the Foundation's library. From the following quote, the library saw itself in 1981 as a vital part of the Foundation's resource base.

> It is an indispensable resource not only for scientific research but also for clinical patient care, and for the Foundation's professional education and outreach programs. All these areas require quick and easy access to the most recent literature.[33]

Yet, for Oncology Social Work, the connection is minimal, citing only the occasional request for or circulation of journals or articles. Part of the reason for this limited connection is that journals, books and articles tailored for the needs of social workers have been brought together and stored in the Health Sciences Centre's library. Another significant factor is that the major portion of the literature addressing the psychosocial needs of persons confronting long-term illnesses such as cancer are scattered in bits and pieces, and in numerous directions throughout the professional literature, making it difficult to keep abreast of current psychosocial research and/or clinical efforts in this area. It was not until 1984 that an Oncology Social Work journal began publication in the United States and became available to the Health Sciences Centre's library. Thus, the Cancer Foundation may have contained a small specialized library with current and readily accessible information regarding cancer, but its emphasis in 1981 was biological rather than psychosocial. The energy required by Oncology Social Work to draw together and keep abreast of the recent literature in 1981 was not often available, particularly in view of its direct service commitments.

Cancer in the early part of the Twentieth Century was a disparaging disease for Manitobans, the general public and medical profession alike. One of Manitoba's strengths as a province was its ability to mobilize a provincial commitment to confront the impact of this disease. Its beginning point--the assembling of a broad but knowledgeable group of persons to identify the scope of what was being confronted and to then propose a plan of action--spawned an approach that established an advanced pool of expertise and technology capable of expanding and renewing itself. The need for early diagnosis, better methods of treatment and research into cancer's nature and possible control and/or eradication were all identified objectives. Manitoba's skill and technological capacity for the early diagnosis and treatment of cancer the disease has made impressive progress since the inception of The Cancer Relief Act in 1930. Evident throughout the program structure of the Foundation is its commitment to the acquisition and dissemination of knowledge through ongoing research and the teaching of others. In its pursuit of these thrusts, the Foundation has endeavoured to secure and maintain national and international linkages; it co-ordinates specialized oncology programs in

Winnipeg's two teaching hospitals, and participates in Formal Tumor Rounds (Radiation Oncology) in several other community hospitals. As well, it has established a Cancer Outreach Programme for rural Manitobans.

> The purpose was to test the feasibility of utilizing designated general practitioners, living in communities across the province, to administer ongoing chemotherapy and maintain longterm follow-up of patients initially seen at the Manitoba Cancer Treatment and Research Foundation. . . . The hypothesis of the experiment was that these supervised general practitioners could administer chemotherapy safely and effectively at a distance from the tertiary treatment centre and hence facilitate the delivery of cancer care throughout the province without compromising care quality.[34]

Yet, despite these impressive strides to address human need, the Foundation has defined its mission to deal with cancer solely in biological terms seeing advances in this realm as naturally righting cancer's impact in the psychosocial realms. Essentially, the Foundation is structured to see only one dimension of the person--the biological. Recent trends towards acknowledging the influence of psychosocial issues in cancer care still award these issues a secondary status, failing to comprehend the unity of human response and of cancer's impact (both in the manifestation of the disease and its treatment). The Foundation's vision of comprehensive cancer care does not include the psychosocial dimensions. It does not push for the acquisition and dissemination of knowledge through ongoing research and teaching in this area. Attention given to the psychosocial dimensions is seen primarily as a support service function necessary for the realization of the Foundation's biological objectives.

The narrowness of this focus is due partly to the specialized focus of those professions which originally generated the formation of the Cancer Relief and Research Institute and their successors whose education and practice automatically gave primacy to the biological dimension. Another factor in the formation of this approach is the tendency of the biomedical model to relate to mind and body as separate entities, and to reduce the elements with which they are faced into separate diagnostic issues and courses of treatment. Under the influence of such a framework, it is difficult to see the bio/psycho/social unity of human response with all its inter-connections. Finally, the biomedical model is the dominant model of disease in Western society.[35] Consequently, while consumers may encounter the impact of cancer from all three dimensions, they may be reluctant to demand a more comprehensive approach, accepting the primacy of the biological dimension and seeing cancer's psychosocial impact as separate from the Foundation's basic function. Attention to the psychosocial dimensions now becomes the exception necessary in those instances where it is unavoidable if biological treatment goals are to be realized. Social work's function, while still motivated for the purpose of meeting human need, becomes one of working for the system rather than for the welfare of the person.

When the psychosocial dimensions are seen as separate from and secondary to the biological dimension, it follows that they are seen as static variables that can be understood independently from their connection to the biological dimension and, therefore, addressed as such. The idea that all three dimensions cannot be adequately understood or addressed outside of their relationship to one another is a foreign concept. Consequently, attempts by social work to address the manner in which the systems come together--that which occurs at the interface--will most likely be met by confusion and be seen as acting out of context to their organizational role. The systematic pressure of the dominant conceptual framework (one to which social work is not immune) forces social work into a position of trying to address transactional events as static conditions essentially independent of the context in which they occur. For example, the difficulties encountered become a result of the expression of the disease, the personal disposition of the persons concerned or the peculiarities of their situation, as opposed to the manner in which the overall system addresses the psychosocial dimensions of cancer care.

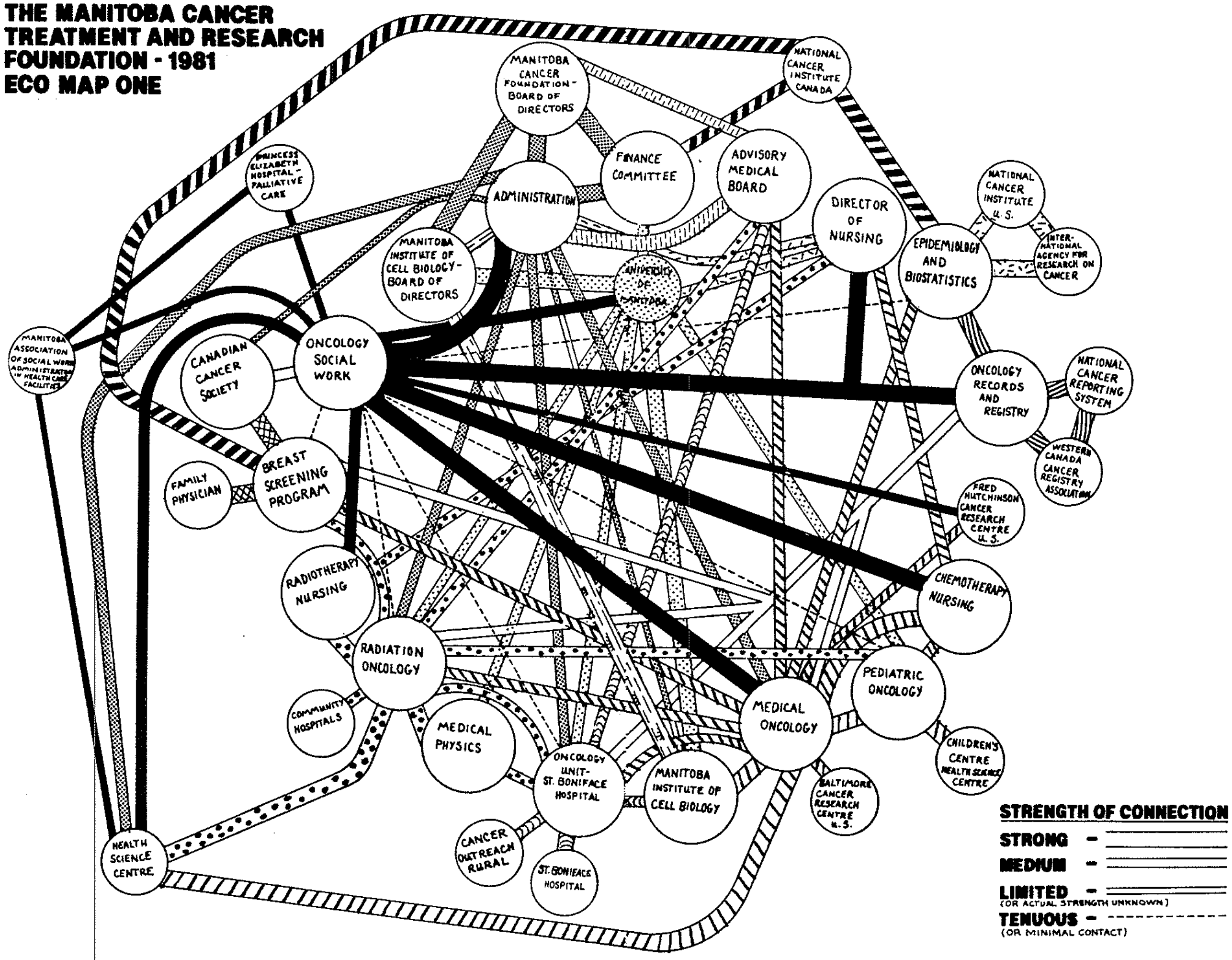
Oncology Social Work, in its attempt to confront the impact of cancer the illness, has emphasized the emotional and cognitive effects of living with cancer. In its descriptions of the need to address these effects, the focus is overwhelmingly on the consumer of the service and his/her reaction to the disease.

> Psychological reaction to cancer varies from patient to patient and from family to family. A great deal depends on the individual's support system, psychological makeup, age, occupation and general health. Most patients, however, do react to a diagnosis of cancer with shock which leads to anger that eventually turns into depression. These patients will benefit most if referred early for counselling. Social work intervention at an early stage can alleviate and prevent emotional breakdown.[36]

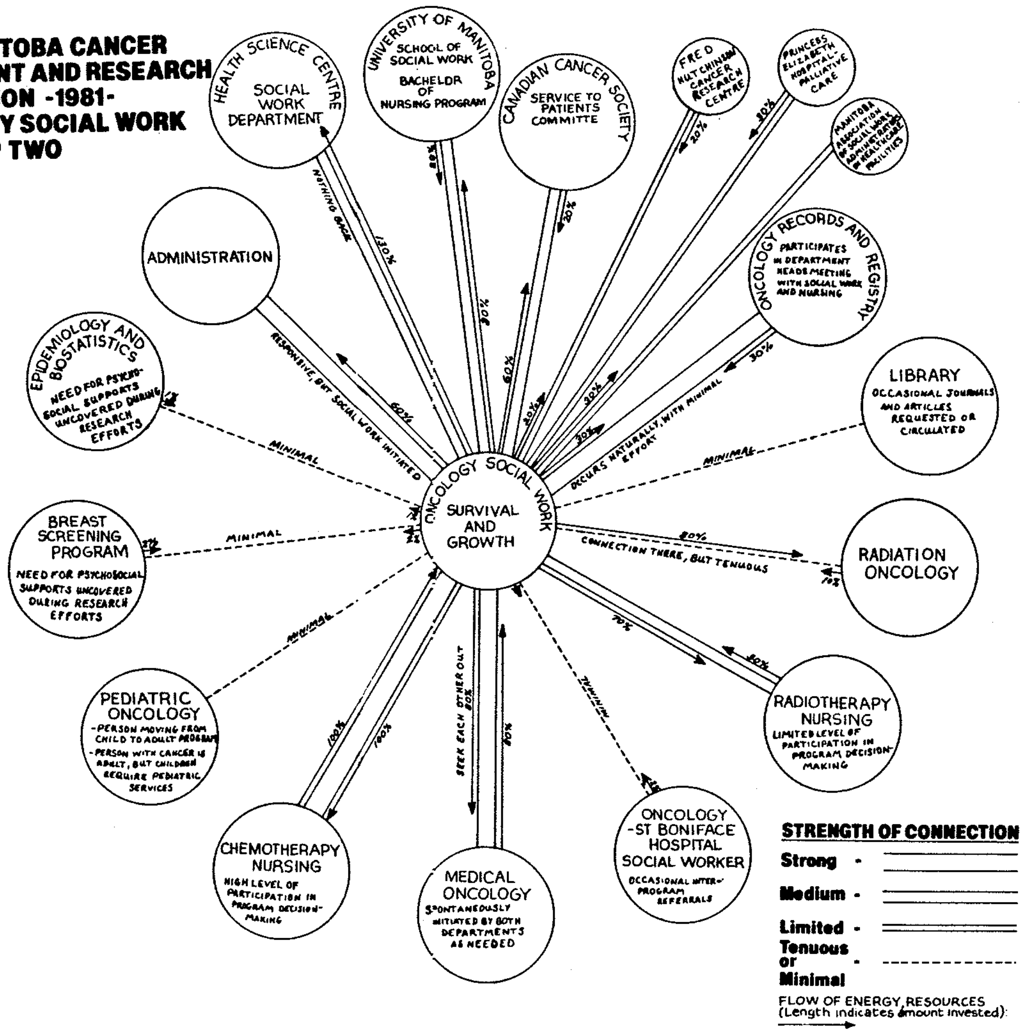
While other sections of the above account refer to 'collaboration and consultation' with doctors and other persons peopling the system,[37] they leave the impression that the changes to be made occur primarily within the person(s) experiencing the effects of the illness and in the context of the counselling relationship. The picture is of a separate set of processes that take place and can be dealt with apart from the process of dealing with the biological dimension.

The impact of all this on the adaptive strivings of those person(s) directly experiencing the chronicity of cancer will be the subject of the next chapter.

THE MANITOBA CANCER TREATMENT AND RESEARCH FOUNDATION - 1981 ECO MAP ONE



THE MANITOBA CANCER TREATMENT AND RESEARCH FOUNDATION -1981- ONCOLOGY SOCIAL WORK ECO-MAP TWO



Chapter 4

FOOTNOTES

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9. Israels, "1930-1980: from the minutes of the early years," p. 7.

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16. The Manitoba Cancer Treatment and Research Foundation, 1981 Annual Report (Winnipeg, Manitoba: University of Manitoba, Printing Services, 1981), p. 57.

17. Publow, "Manitoba Cancer Treatment and Research Foundation," p. 3.

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24. The Manitoba Cancer Treatment and Research Foundation, 1977 Annual Report (Winnipeg, Manitoba: University of Manitoba, Printing Services, 1977), p. 36.

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26. The Manitoba Cancer Treatment and Research Foundation, 1980 Annual Report (Winnipeg, Manitoba: University of Manitoba, Printing Services, 1980), p. 48.

27. Ibid., p. 49.

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37. Ibid., p. 48.

NOTE: The construction of Eco-maps One and Two was developed from the author's personal observations, staff contacts, and the connections noted in The Manitoba Cancer Treatment and Research Foundation's Annual Report, 1976-1981.

Chapter 5

WORKING WITH THE CONSUMER

From the preceding chapter a picture of where social work fits into the organizational structure of the Manitoba Cancer Treatment and Research Foundation has been constructed. An overview of its survival and growth needs has been presented in connection with the competing survival and growth needs of some of the other systems that make up this organizational structure. Because what has been depicted thus far is from the vantage point of the author and her position within the organization's network, it should be remembered that access to different communication pathways could result in a restructuring of the picture. Eco-maps are a way of taking what is known and what is observed about a series of relationships, placing it together in a picture, and thereby gaining a sense of the whole. They are meant to pose questions and generate ideas about the circular nature and reciprocal effects of the connections made and how they come together to determine the survival and growth of the overall system. Perceptions thus formed require verification from those who form the connections to ensure their authenticity. Hence, what is gained at this stage is a sense of direction about what seems to be, what requires further exploration, and some ideas regarding where to start. With this understanding the content of this chapter will depict how the systematic connections so far presented join with the adaptive strivings of the consumer* (see p. 333) and the student position of the author.

Three observations were made in the chapter four regarding the Cancer Foundation, the psychosocial dimensions and social work. First, the Foundation has defined its mission in biological terms; second, attending to the psychosocial dimensions is seen as secondary to the overall function of the organization; and third, Oncology Social Work, in addressing the impact of cancer the illness, has centred its focus on the psychological dimension. Building on this last observation, the power to enact the changes to be made and the changes themselves appeared to be located within the person(s) concerned and in the context of their relationship with social work. From this perspective it seemed as if change was essentially a cognitive process beginning within the individual and ending with a perceptual alteration of self in relation to the environment. The perceptual alterations were depicted as occurring both within the person(s) with cancer and the family or significant others with whom they shared their life. Absent was any indication by Oncology Social Work or other Foundation staff that understanding the person(s)' social context (e.g., family, finances, community) was important beyond its relevance for understanding the individual's psychological response. No attention seems to be given to developing an awareness of, or consideration for how, linkages are formed with the social dimension when planning action directed towards occurrences in the biological dimension. If this is in fact the way it is, social work and those professions concerned with the biological dimension will view themselves as capable of accomplishing their respective tasks predominantly independent of one another.

In 1981 Oncology Social Work accepted the author as its first graduate social work student. Because Oncology Social Work had responsibility for co-ordinating the field placement but not for guiding the development of clinical skills within the student, the student was connected to the University of Manitoba's School of Social Work via an advisor. This advisor was charged with the responsibility of shaping the development of the student's clinical skills. Thus, to meet her educational goals, the student was simultaneously responsible for identifying and adapting to the needs and demands of the practice setting, the educational goals of her respective social work program and that segment of the consumer population with which she connected. As noted in the beginning of this practicum report, the author's educational goals were to increase her awareness and understanding of the client's social reality, to help negotiate a person-environment fit that would best assist clients in coping with that reality, and to improve her clinical skills. Because of the conceptual youth of Germain's ecological approach at the time of its application in this practicum, the author was confronted with the task of translating conceptual frameworks into action principles appropriate to the practice setting and the consumer's needs. As a result, what evolved was an attempt to decipher the relevancy of the approach as a model for clinical practice in the Cancer Foundation with its consumer group, while simultaneously building an in-depth understanding of the conceptual tenets of the ecological approach and skill in this model's application. One of the first steps in meeting the author's first two educational goals and determining the ecological model's relevancy was to connect with the practice setting and its consumer population in a way that facilitated exposure to the challenges faced by people confronted with the diagnosis and treatment of cancer as a chronic illness, and the demands on social work as a profession to assist them in responding to these challenges. It is within the context of this adaptive struggle that the author will attempt to depict the adaptive strivings of consumers with whom she connected. From this base some observations will be drawn regarding the implications of the systematic connections presented in this and the preceding chapter for social work practice and those persons facing cancer.

Born into a culture, receiving her undergraduate education and practicing social work in a system which all view assessment primarily as the identification of weaknesses, limitations and problems within the identified client system, and which separate the mind from the body in their actions, the author automatically began the construction of her field work experience with a conceptually narrow focus. Although the psychosocial experience of cancer was seen as inseparable from the biological experience, it was the author's belief that the changes to be addressed in the psychosocial realms and the power to enact change could be identified, understood and brought about within the context of the client-worker relationship. In this instance, the client system was seen as those persons with cancer and their significant others. It was recognized that the service network could in fact be the client system; however, in building the connection, it was felt that sufficient momentum for change could be obtained through task-oriented, consultation-based exchanges (i.e., information shared in a formal, structured manner with a low level of reciprocal exchange). Given the three-month time span during which the bulk of the field work was to occur, the author saw little room for securing more developed connections. Hence, the focus for change and social work intervention was essentially psychological, even though it was seen to transpire within a social context. The capacity to assist people in their psychosocial adjustment to cancer and its treatments was seen as best achieved in an atmosphere of mutual and reciprocal collaboration with those medical personnel specifically concerned with the biological dimension. However, it was still considered a possibility that the psychosocial dimensions could be addressed independently of those actions directed towards the biological dimension.

Therefore, the author began her field work experience envisioning her primary target as the persons with cancer and their significant others, the changes to be mastered as psychological or social-psychological lodged within the members of this group, and the context for enacting change as the relationships formed between the worker and these persons. Other actors in the health care system--physicians, nurses, etc.--were seen as resources to be drawn upon to clarify certain points of intersection between the psychosocial dimensions and the biological dimension. Literature relevant to psychosocial intervention reviewed by the author up to that point, and the outward appearance of Oncology Social Work's function within the Cancer Foundation presented little to refute this orientation. Since the author wanted to increase her understanding of the human experiencing of chronic debilitating illness, she drew her target group from that segment of the Cancer Foundation's consumer population which met the following criteria:

> The presentation of the disease should involve a gradual decline in health interspersed with stable periods, and try the coping resources of the individual and family in planning for an unknown future. Included in the client population will be the person with cancer and those immediate family members whose daily life-styles are affected by the diagnosis and subsequent treatment of the disease (e.g., spouse, children, etc.).[1]

A total of fifteen contacts were intitiated--two male and thirteen female, from which seven women emerged to form the primary group. Of this group of seven, four involved consistent contact throughout the three-month duration of the field placement, two consistent but short-term contact (less than one month), and one intermittent contact over the three months. Two of the seven were newly diagnosed (contact made within one month of initial diagnosis), both with metastatic cancers; one had delayed seeking treatment for six months following the identification of a breast lump (contact made four months following mastectomy); two were being treated for recurrent cancers, seven months and two years, respectively, following surgical removal of the initial cancer; another had been undergoing active treatment intermittently for one year and three months; and, the last member of the seven had just entered a period of rapid physical decline three and one-half years after her initial diagnosis. All of the seven were females, four were currently married and residing with their spouse, two were divorced, one widowed, and all had adult children. Of the adult children, only one resided with the parent. Age, marital status, number of children, and cancer site for each participant are listed in the following table. To ensure the privacy of the participants, letters are substituted for names.

The Consumer Populations

	Age	Marital Status	Adult Children	Cancer Site
Mrs. Z.	52	M	1	Cancer of the ovary.
Mrs. E.	76	W	3	Cancer of the bladder.
Mrs. B.	66	M	1	Cancer of the right breast (mastectomy, June, 1981).
Mrs. W.	75	D	1	Cancer of the lung (lobectomy, 1979). Cancer of the inner nasal alae with possible metastases to bone (skull, right thigh bone).
Mrs. L.	63	M	3	Cancer of the breast with bone metastases (shoulder, spine, hip).
Mrs. G.	64	M	2	First primary - cancer of the lung. Secondary primary - cancer of the right breast with bony metastases to left eye, spine, liver, bone, skull.
Mrs. S.	47	D	2	Cancer of the larynx (laryngectomy, March, 1981). Cancer of the left breast (left radical mastectomy, October, 1981).

Theoretically, the author saw a need to move away from traditional therapeutic modalities of intervention which viewed human behaviour from a disease-model framework towards a health- or growth-oriented model of approach.

> It is my belief that such models create barriers to understanding the individual's social reality; in that, it centers attention onto the individual ignoring external pressures which affect behavioral responses. As well, it ignores the possibility that what may be viewed as abnormal, is in reality a healthy response to a stressful situation for that individual. . . . Because of this focus it becomes important to develop a conceptual

> framework which is health oriented as opposed to disease oriented.[2]

Acquiring knowledge of and skill in interventive actions that represented such a move was part of the intent of this field work. Germain's emphasis on 'problems in living' arising out of a lack of fit between person and environment seemed an appropriate beginning point, given that the 'problem' was located at the interface between the person and environment, thereby demanding an awareness of both to define. The idea that both the 'adaptive' strengths of the person and the 'nutritive' qualities of the environment would be identified and mobilized to effect change also appealed to the worker's need to move away from the disease-model orientation. Thus, the foundation was laid for the author's first conceptual struggle.

Because the tendency to separate mind from body is a cultural phenomenon shared with the consumer, consumers with physiologically-defined diseases such as cancer rarely see the need to initiate contact with professions believed to be associated solely with the psychosocial dimensions of personhood. Consequently, a sizeable portion of Oncology Social Work's consumer contacts are social work initiated. Unbeknownst to the consumer, (s)he may present characteristics which match a previously determined set of high-risk criteria (age, absence of human resources, specialized needs, etc.) resulting in an automatic referral to Oncology Social Work. In those instances where social work help is offered to rather than requested by the consumer, the onus is on the worker to explain to the consumer the wisdom of forming such a liaison. To secure a focus in these initial worker-client transactions, the author began by trying to centre on cancer's disruptive impact for the person-environment fit. Her concern was with how the person(s) so affected were managing the difficulties/distress resulting from any identified lack of fit. The 'problems in living' were the difficulties/distress encountered; the interventive goal to identify and mobilize the 'adaptive' strengths of the person(s) and the 'nutritive' qualities of the environment to reduce the lack of person-environment fit. With this understanding in mind, the author immediately met with repeated resistance to her efforts to engage prospective clients. Efforts to identify 'problems in living' were met with statements of denial from these people regarding the existence of any problems. Yes, having cancer was both distressing and difficult, but apart from eradicating the disease these consumers saw little that could change these circumstances. Clearly, in their minds there was no need for psychosocial intervention. Sensing the need for a change of terms, the word 'concerns' was substituted for the word 'problems'. This gave the author access to a wealth of information regarding the often dramatic changes in life-style these persons faced following the identification of cancer, however, it brought the consumer no closer to seeing the author as a significant resource. Most consumers already felt strong and open connections with nursing and medical staff, and most saw themselves and their significant others as managing well given the circumstances. Surely, there must be others more in need of social work's services! Confronted with such overwhelming and consistent presentations of 'we are coping', the author was unsure of how to proceed. Perhaps medical and nursing staff were already adequately addressing the psychosocial needs of those consumers making social work intervention unnecessary. It could be that these consumers had enough personal resources at this time from which to draw to meet the challenges they were confronting. Possibly the skills social work offered were best utilized in the exceptional circumstances or at the point the individuals concerned became stalled in their movement to trace out a new direction for their lives. The author was not sure how and to what extent their psychosocial concerns were being attended to in the context of their connections with the health care system or within their own personal resource network. However, due to the intimate nature of these connections, achieving greater clarity was hindered by the absence of a mutually established contract with the consumer which would allow the author to explore these connections further.

In her attempt to uncover 'problems in living', the author became confused about what conditions could be defined as problematic. The distress and lack of person-environment fit resulting from the illness experience was evident, yet the individuals encountering this upheaval were denying that any 'problems' existed. Because of her professional training, skill development and practical experience in dealing with the psychosocial dimensions, the author was conscious that she possessed a level of competency which could ease, speed up or maximize the effectiveness of the consumers' quest to trace out a new life balance. Yet, the consumers saw those competencies directed towards their biological dimension as more relevant sources of help. Perplexed, the author then wondered at what point the upheaval created by the impact of cancer would demand a more psychosocially-oriented approach. At what level would the distress and disruption become problematic enough to justify her intervention? How would prevention and the maintenance of psychosocial health fit into a model which begins by attempting to identify problems?

What the author did not understand was that these consumers saw the process they were encountering, including the distress emanating from it, as demands for adaptation: a forward movement. Although the author had substituted the word 'concern' for 'problem', her approach was still problem-focused, intent on focusing on the disruptive effects of the illness and moving to alleviate or ease the resultant distress. For the consumer the distress and disruptive effects of the illness experience were unavoidable realities with which to be dealt, subject to neither elimination nor control, except through the eradication or management of the disease itself. Certainly, their sense of life's direction had become disfigured, but forward movement had not been arrested. They were now actively engaged in the process of tracing out a new pathway more in harmony with their altered circumstances. What could social work offer that would assist them in this process?

Having no mutually agreed upon 'problem' to act as a starting point and insufficient information regarding how the psychosocial concerns were being attended to within the context of the consumer's other connections, the author was not sure if the services she could provide were distinct from those already being received. Certainly, she had a solid knowledge and skill base in interpersonal skills and in negotiating health care systems, but she could not gain access to the consumer population to prove their worth without first establishing the existence of a 'problem' that could provide sufficient reason to develop a contract for service. An extensive review of the literature detailing the dilemmas of living with cancer, and some previous experience in working with persons with chronic illnesses, had left the author struggling with a diverse store of information that required sorting to determine what matched the realities of the population with which she was trying to connect and the context in which this match occurred. Due to her status and recent arrival in the Cancer Foundation's system, she was not yet familiar with how the various helping disciplines connected and the nature of their informal communication pathways. Thus, she could not project with confidence those situations faced by consumers that would best benefit from the type of social work skills she could provide. It was from this position of uncertainty that the author secured her first worker-consumer commitment to contract for social work services.

Mrs. W., a seventy-five-year-old woman, six years divorced from her husband of thirty-eight years, had arrived in Winnipeg, Manitoba, from a distant province in April, 1981. The move had been arranged by her only child, a son, who resided in Winnipeg with his wife and four children (two children in high school, one in the work force but living at home, and the fourth working away from home). During the two years following her divorce from her husband, Mrs. W. had lived independently in her own home, owning and driving a car. An active member of a New Horizons Club for seniors, she had often frequented their weekly social gatherings. Poor health necessitated the surrender of her driver's licence, the selling of her home and car, and a move into a 900-bed senior-citizen lodge where she had been required to share a room with another elderly woman. Mrs. W. had found the physical layout of the lodge appealing, but the age and health of its residents was a difficult situation to which to adjust. She described most of them as being in their upper eighties and in poor health. There appeared to be an absence of people with 'a bit of spirit, a sense of fun and mischief, but not silly', as well as insufficient staff in her judgement to create a caring atmosphere. Admittance to a psychiatric care facility for depression had afforded her an opportunity to leave what had become in her mind an intolerable living arrangement. It was then that her son arranged for her move to Winnipeg. The author's involvement was initiated at the request of Mrs. W.'s son who had become concerned about his mother's recent decline in spirit and her increasing social isolation.

Two closely-spaced home visits by the author revealed that Mrs. W. was the second-youngest of ten children, six of whom had cancer. Of these six, she was the oldest one of two still living. She had undergone a lobectomy in 1979 for cancer of the lung and was now being treated for a recurrence of cancer of the inner nasal with possible metastases to the bone. Her divorce from her husband was described as being related to his excessive use of alcohol. Since that time she had maintained no contact with him. In her youth she had trained as a psychiatric nurse in the United States, working in a private hospital which served the community's affluent at a time when it was as not fashionable for women to aspire to careers (1929-1937). She left nursing to marry and raise her child, returning to do 'book work' in an industrial setting when her son was eleven years old. In the context of these visits she shared with the author keepsakes from her days as a nurse and her driver's licence. As well, she showed the author a small, painful circular area at the back of her head behind her right ear that had expanded to approximately four inches in diameter over the last two weeks. It was clear that she thought this was cancer and that it was spreading. She had wanted to 'go fast', but was 'going slow' instead.

Three problem areas were readily identifiable and could be agreed upon mutually between the author and Mrs. W. as beginning points for effecting a better person-environment fit. The recurrence of cancer in the inner nasal region, a non-functioning kidney and follow-up care for some corrective measures taken to improve her eyesight had necessitated the involvement of six different physicians affiliated with two different hospitals (Health Sciences Centre and Grace General Hospital), and three different clinic operations (Cancer Foundation, Abbott Clinic and the family physician's practice). Connections are represented on Eco-map Three. Mrs. W. lived approximately four blocks from the Cancer Foundation and Health Sciences Centre, but was geographically distant from the other health care settings (transit linkages required one or more transfers between buses). The number of follow-up procedures, investigative measures, treatments, and medical and nursing personnel with whom she had to relate had become overwhelming, leaving Mrs. W. confused regarding what was being done to her body--where, when, how and by whom. Thus, the first interventive goal was to alleviate/reduce this confusion. The second area of concern for Mrs. W. was an absence of social contacts. Residing in a guest home, she had her own room, spacious enough to allow her to include pieces of her own furniture in its decor, her own telephone, and bathroom facilities (shared with two other women) in close proximity to her room. Meals were provided in a communal dining room in a separate part of the building and residents were responsible for the light housekeeping of their rooms (dusting, straightening bedcovers, etc.). There was a lounge area for residents to meet in and some organized activities to facilitate this. Mrs. W. was overjoyed with the privacy her room afforded her, its brightness and newness, and the opportunity to display and touch her own belongings. However, she found herself at odds with the nationality and religion of the home's proprietors. She disliked the cultural differences represented in the food and found most of the staff to be impersonal (the more personable staff were the least skilled). Again, she found the home's other residents to be in poorer health than she and lacking in spirit. Still physicially able to handle the four blocks to the Cancer Foundation and the Health Sciences Centre at the time of the author's initial contact, she was unsure of her ability to negotiate a bus ride to a local seniors' centre in an unfamiliar city. Weekends were spent at her son's home; he picked her up each Saturday before supper, returning her to the guest home on Sunday evening. The second goal, therefore, was to increase Mrs. W.'s range of social contacts while respecting the limiting influences of her physical state. From these first contacts it was evident that Mrs. W. placed a high value on her personal capacity for independent action and on having a physical space that could be claimed as her own--defined by her own belongings and used as a means of regulating human involvements. Equally apparent was the reality that her capacity for independent action and, hence, her ability to determine the boundaries of her own private living space were being eroded by the progression of the disease. Declining physical function had and was forcing her to give up more and more of those objects that defined her independence and ensured her freedom to move in and out of human associations (her car, home, etc.). Although Mrs. W. appeared to have a strong solid connection with her son, it was one fraught with conflict. The absence of other close personal relationships in Mrs. W.'s life led the author to suggest the third interventive goal: the provision of an environment where Mrs. W. could express and work with the emotive impact of the erosion of her independence and of living with the discomfort of the disease and its treatments.

Having identified and mutually agreed upon the major areas for change and the interventive goals with Mrs. W., the author proceeded to plot a series of action responses, moving towards the achievement of these goals on a series of scales (Goal Attainment Scaling).

> . . . These five descriptions range from the "most favourable outcome thought likely" to "more than expected level of outcome" to "expected level of outcome" to "most favorable outcome thought likely".
>
> . . . .
>
> . . . The expected level presents the best and most realistic prediction possible of the outcome which will have been reached by the client by the date of the follow-up interview. The expectations ought to be pragmatic so that the expected level of

> each scale reflects what outcome actually "could" be attained by the follow-up date, not necessarily what "should" be attained.[3]

By establishing and using these scales in collaboration with Mrs. W., the author planned to determine if change had taken place and, if so, was it at the 'expected' level?. Not anticipated was the cancer's rate of spread. The scales were invalid before they could be completed given the changes resulting from the spread of the disease. Within the three months Mrs. W. went from being able to walk the four blocks to the Cancer Foundation to being assisted in and out of bed and requiring the use of a wheel chair; she underwent radiotherapy, two hospital admissions (Grace General Hospital) and a transfer to a third hospital (Princess Elizabeth Hospital). While some medical and nursing personnel remained the same, several new people were introduced, including two additional social workers (one each from Grace General Hospital and the Princess Elizabeth Hospital). Between the two hospital admissions Mrs. W. returned to the guest home for one week. As quickly as the author could become cognizant of the members of each new system and some of their interconnections, the dominant system with which to be dealt would change. Originally, the author had planned to approach the first goal by clarifying the transactional nature of the connections involved, part of which would be determining Mrs. W.'s input to the system and its influence on all the systematic connections. Given the number of medical personnel and health care centres committed to her biological care, the author needed to know if anyone had assumed responsibility for co-ordinating the medical investigations and treatments. Were they aware of each other's existence and direction? Was any one person responsible for ensuring that Mrs. W. understood everyone's involvement, proposed care plans and how they fit together?

Athough the family physician had initiated her contact with both the Cancer Foundation and Abbott Clinic, Mrs. W.'s progress through the system did not appear to be a defined part of the care plan. Contact with her son revealed that he had less understanding of his mother's medical follow-up than she did, that he wished to know more but was hesitant to inquire further without Mrs. W. first requesting this, especially in view of her strong desire to manage her own affairs and the conflictual nature of their connection to one another. Further inquiry determined that each system of health care personnel was planning its respective investigations and treatment approaches independently of one another and, in one instance, unbeknownst of the other's presence. With the exception of Mrs. W., no one person was responsible for co-ordinating the overall health care plan or for ensuring her comprehension of it. One of Mrs. W.'s fears was being slated for admission to two separate hospitals for two separate treatment procedures, both on the same day. The following is an excerpt from the author's notes describing Mrs. W.'s attempt to ensure that this did not occur.

> While at the Health Sciences Centre, Mrs. W. saw Dr. A. in the hallway. She attempted to talk with him regarding sore spot on her head. However, he was in a hurry and did not stop. Mrs. W. spoke with Dr. A.'s nurse regarding Mrs. W.'s bone scan appointment (where to go, etc.). At that time Mrs. W. started to ask for an appointment with Dr. A. to have him explain treatments for her cancer of the nose, to ensure he knew about the sore spot on her head (its rate of growth and increasing level of tenderness), and to make sure he was aware of Dr. B.'s plans to admit Mrs. W. to Grace General Hospital for her non-functioning kidney. Mrs. W. became confused when explaining her request for the appointment to

> the nurse. Mrs. W. then indicated it did not matter and left. Afterwards she became angry with herself for not following through. She did not want to make a nuisance of herself, but felt she had a right to know what was happening to her body.[4]

For Mrs. W. the health care system's non-verbal message, intentional or not, was that requesting valuable time for such clarification was unnecessary. By reaffirming the legitimacy of her request, helping her to clarify her concerns, commit them to paper, and then having her call Dr. A.'s nurse, the appointment was set. However, from this and subsequent encounters, the author began to wonder about the type of connections medical personnel formed between themselves, their decision-making power over Mrs. W.'s biological being and their responsibility to keep one another informed of their investigations and treatment directions. If the physicians were concerned solely about their respective areas and none saw it as her/his responsibility to maintain a global picture of Mrs. W. as an entire person, biologically, psychologically and socially, how then did co-ordination of their different inputs happen?

Despite efforts to secure a more cohesive understanding of Mrs. W.'s blend of biological care and inform those responsible for this care of her concerns, the author was no more confident than Mrs. W. that each segment would plan with consideration of the others involved or ensure that Mrs. W. understood what would take place. The author was becoming increasingly aware that neither she nor Mrs. W. had the power to alleviate or reduce the confusion surrounding the care directed towards Mrs. W.'s biological dimension, as neither she nor Mrs. W. had sufficient access to and understanding of the necessary information, or the power to enact a process to enable this to happen without the participation of the medical personnel involved. Attempts to share the author's knowledge of the psychosocial impact of Mrs. W.'s cancer and its treatments were acknowledged but not encouraged, nor was the author's knowledge used in the construction of biologically-oriented treatment approaches. Inquiries about the nature of inter-physician communications were met with puzzlement regarding the need for such knowledge. Because of the author's student status within the system, lack of established interprofessional linkages and inexperience with the execution of her chosen interventive model, she was not as assertive in securing this information as she might have been given more time to build an understanding of and confidence in her approach.

Midway through the author's three-month field work exposure, two incongruencies became apparent. First, for those individuals faced with the impact of cancer, the task-oriented, biological/ physiological focus of the system towards the management of disease appeared to undermine their struggle to maintain some element of control over ministrations directed towards their bodies, even if that meant only being aware of the tests/treatments, their purpose and the results, or the reasons, where possible, for discomfort or pain. The second incongruency concerned the health care system's pace. Time was a premium item. Pervading all aspects of the system worked in was the unspoken message that the number and urgency of the tasks to be accomplished demanded that only minimal time be allotted to issues not directly relevant to the tasks at hand. Comprehension by those health care personnel concerned of the effects of the person(s)' emotional and cognitive digestion of either the influence of the disease process or of the treatments enacted (including their side effects) on the overall treatment plan was seen as unnecessary unless it somehow disrupted or threatened to disrupt therapeutic movement in the biological realm. Hence, the person's struggle to adapt to the demands of these changes appeared to occur predominantly outside the conscious awareness of the system. A certain level of ventilation of feelings was encouraged and compassion demonstrated (particularly within the Cancer Foundation). However, attention afforded to psychosocial concerns seemed to be viewed as necessary for the individuals directly facing the cancer, but not for the construction of the biological treatment plan. Consequently, in the rush to accomplish the tasks of the day (particularly within the Health Sciences Centre), people rarely took time to listen effectively to each other or plan together. The complexities of the information exchanged needed to be condensed into a form that could be shared briefly and concisely during short intervals of time between tasks. Often the exchanges were isolated unidirectional efforts, except during moments of crisis where the exchange became the task to be accomplished and the sharing of information occurred on a more reciprocal and mutual basis.

Especially frustrating to the author was having access to a wealth of information regarding the coping efforts of those persons confronting the cancer on a personal level and their struggle to deal with the intricacies of the health care system that could directly enhance the nature of their connections with certain health care personnel, but being unable to use this awareness in the construction of biological treatment pursuits because it was viewed as unnecessary to the ongoing life of the connection. In the major portion of these instances, the connection would endure without this information, but the quality and effectiveness of the connection would not realize its potential. The subtleties of the communication process such as the skills involved in facilitating the expression of a concern, linking its significance to the person involved or to the context of the situation were frequently overlooked in the structure of these connections in favour of the factual verbal content of the messages sent. Yet the action responses by both parties were often based on the unspoken messages received. The primacy of the biological intervention to the system and the secondary status of the psychosocial dimensions and, hence, interventions attending to these dimensions led the author to make the following notation.

> Social work's role appears to be marginal at best to the operation of the treatment system. Most of its work is done from a marginal position, rather than as part of the overall treatment plan. Attending to psychosocial concerns seems to be acknowledged as necessary to the individual, but not the treatment plan and therefore, an act to be accomplished within the structure of the worker-client relationship apart from those persons concerned with the treatment of the biological dimension. Barriers to effective communication between the various disciplines seem almost insurmountable at times.[5]

While the author saw the structure of the health care system worked in and the orientation of those peopling it as part of the client system to be worked with in conjunction with the consumers (at the interface where person and environment meet), it was evident that the health care system did not see itself as part of the client system, especially when a specific problem had not been identified. The system's disease focus and tendency to separate the biological dimension from the psychosocial dimensions made behaviour to the contrary appear out of context, outside the boundaries of social work's function within this network. Conceptually, the disease focus tends to locate the 'problem' within the individual and decipher interpersonal relationships in linear 'cause and effect' terms. By identifying the cause, corrective actions can then be instituted. To concentrate on determining the circular nature and reciprocal effects of the connections moving away from the sequential mapping of 'cause and effect' relations was confusing at best and more often just not understood by those who plotted their action responses from the biomedical- or disease-focused model. Attempts to draw these persons into the client system, particularly in the absence of an identified problem, was equivalent to assigning causative motives to their actions. When nothing was seen as deviating from the norm or problematic, given the peculiarities in a certain situation, such behaviour on the part of the social worker was perceived as disruptive to the efficient flow of the service network. Hence, what was part of the natural progression of one conceptual framework was to deviate from the flow of the other. The author was now beginning to understand that the identification of 'problems', whether located within the individual or at the interface where person and environment meet, was unnecessary and actually prevented the psychosocial dimensions from being attended to until the forward movement of those involved, helper and/or helpee, became blocked. What seemed more relevant was to gain an understanding of the challenges to be faced by all those involved--consumer and health care personnel alike, the purpose and strengths of the connections made, and their contribution to the survival and growth of each participant given the context of their respective life space. Once this was understood, then the limiting effects of the connections for the survival and growth of the participants could be looked at and their combined potential for enhancing each other's existence determined. The author was in the process of realizing that it was the combined effect of the competencies of the individuals, families and health care personnel that needed to be focused on and enhanced. The object was to determine the blend of action that would best achieve each one's respective survival and growth needs. None of this could be realized outside the context of one's association with the other. By centering on competency, variety of response could be explored and appreciated and a more preventive stance taken by building on the system's strengths before blockages developed. The task now was how to put this conceptual awareness into practice in a health care system where consumer and health care personnel alike structured their actions according to a biomedical framework.

When calculating the time and energy expended to work with segments of the health care system which did not acknowledge their inclusion in social work's client network and who were often at a loss to understand the need to alter their actions, the author became consciously aware of the consequences for the consumer. First came the realization of the power of the health care system to resist change in view of its size and complexity, and to demand change from the consumer whose biological survival was reliant on the competencies of this same system. Cognizant of social work's own marginal position within the health care system and the secondary status of the psychosocial dimensions in relation to the biological dimension, from the author's perspective social work's ability to resist operating from a disease-focused model was significantly reduced. Assessing how much energy social work had as a department and/or as an individual social worker and how much energy was required to change an identified segment of the health care system's operation, compromises seemed inevitable. Note the following excerpt from the author's personal notes:

> Person-environment fit is difficult to negotiate under the present system. When faced with the power of the health care system to resist change, it becomes easier to work towards changing the individual to fit with the system even though, in a number of instances, it is the health care environment that needs to be more responsive to human need.[6]

The narrowness of the author's conceptual focus was now becoming apparent. Attempts to negotiate a more effective person-environment fit for that segment of the Cancer Foundation's consumer population connected with revealed that the author's focal point had been the consumer and those connections emanating from that person(s) to the social and physical environments comprising his/her life space and the segment of the health care system concerned with her/his care. Effecting a better person-environment fit meant effecting a better person-environment fit between the consumer and his/her respective life space and/or health care contacts. Missing from this construction was the author and social work's fit with the health care environment. To engender the power to effect a better consumer-health care environment fit, both social work and the psychosocial dimensions had to move out of their marginal/secondary status and the mind and body unified rather than separated in the structure of the health care system. Somehow the bio/psycho/social dimensions of the person needed to be unified in the design of the service approach of the system.

By failing to incorporate the psychosocial dimensions into the design of the biological treatment approach, those helpers concerned with that dimension based their action responses primarily on the biological expression of the disease. Alterations in their approach, such as including the person(s) experiencing the cancer as valued participants in the decision-making processes regarding treatment, automatically received secondary consideration in view of the structure of the health care approach. Social work may have been responsive to the need of individuals to maintain a certain level of control over ministrations to their bodies over the course of their health care, but only those health care personnel concerned with those procedures and decisions had the power to structure their approach to afford the consumer that control. In the absence of design and thought given to the mechanics of instituting an approach that respected all three human dimensions, the pace and task orientation of the system mitigated against taking sufficient time to rethink the mode of operation. The unspoken message was that the organization of the health care system could not be challenged or questioned, only adjusted to. Social work must then work from the position of helping people adjust to this control rather than helping them gain control, i.e., seeking short-term alterations in approach peculiar to the circumstances at hand. Created was an illusion that these situations represented the exception in human need, not what is basic in human need. In this sense the biological expression of the cancer took control of the individual's life path and all those people associated with it, rather than the control being located with the wholeness of the persons living it.

Given the above, targeting specific behaviours to be worked on between the author and the consumer using a previously-agreed-upon interventive mode was insufficient and in a number of instances inappropriate. Before any specific behaviour could be understood, its place in the survival and growth needs/demands of the overall network required clarification. This meant transcending the boundaries of a specific social work-consumer relationship, gaining an understanding of the survival and growth needs of all the system participants (including the connections between the helpers), and how they fit together in order to meet these needs, each one in turn placing demands on the other. Goal-attainment scaling, as it was detailed in the literature in 1981, did not meet the evaluative demands of such an approach given goal-attainment scaling's problem orientation, linear construction and placement of the clinician and her/his network connections outside the scaling process.[7] Needed was an evaluative model that could simultaneously depict the nature and form of the connections present and measure the survival and growth potential of the fit for the participants involved. The use of eco-maps as an evaluative tool began to emerge as a possibility. However, at this point, halfway through the author's time allotment for her field work, fine-tuning an evaluative design which utilized the eco-maps during the application of the author's interventive framework was no longer an option. In fact, the author was still in the initial stages of piecing together an understanding of the ecological approach that could meet the demands of practical application in the context of the Cancer Foundation and yield a unified forward-moving direction that respected the wholeness of the person. Evolving for the author was a new grasp of the meaning of broadening one's focus to identify the 'structure of the field'.

For Mrs. W., effecting a better person-environment fit involved more than raising physician awareness regarding the impact of their multiple connections and lack of connections on her capacity to understand and negotiate her health care needs. The author required an understanding of how the various components of the system connected and their survival and growth needs to be able to determine what could be asked of each component given the boundaries of its internal organization and the demands of this and other connections. For example, none of the physicians involved could be expected to co-ordinate Mrs. W.'s health care in a manner that enhanced her ability to comprehend the fit and negotiate the demands of this network if their education and practice exposure placed this task outside the function of their role and/or did not prepare them with the skills necessary to enact such a response. In the first instance, they would not comprehend the need for their involvement, while in the second, they may be cognizant of the need but lack the skill to act. The author's application of the definition of social reality was changing. Originally, when she had conceptualized social reality as the 'significance of the situation of illness for the client group involved', she had thought of client group as those persons with cancer and their significant others. She had not visualized the helpers in the service network as part of this group. Yet their comprehension of the significance of the situation of illness for themselves and others from their position in the system influenced the system's structure and, hence, its responsiveness to the significance of the situation of illness for the consumer.

The foregoing evolved in the process of connecting with and defining the nature of the connections made with the consumer. Consequently, how the author initiated and developed these connections was still largely rooted in her original understanding of social reality and within the bounds of a problem-oriented focus. Although the author was now questioning the relevancy of a problem-oriented focus for this practice setting, she was unsure of the mechanics of developing an alternative model. The forthcoming consumer situations, in conjunction with what has been detailed previously, are presented with the intent of helping the reader follow the evolution of the author's proposed model as outlined in chapter two. Each situation will be presented separately up to the point of the initial contract for social work service to provide a context for the development of each one's struggle. New author-consumer linkages will be set in italic type (e.g., *Mrs. E.*) the first time each appears to signal movement from one consumer's situation to another's. The writer then will draw on each situation as needed to illustrate key points of discovery regarding the significance of the illness experience (social reality) for these people and the author as it evolved in the context of the worker-consumer relationship.

Close to the time that contact was initiated with Mrs. W., *Mrs. E.* was referred for Oncology Social Work follow-up. A seventy-six-year-old widow, Mrs. E. had been admitted to a medical ward in the Health Sciences Centre (Winnipeg General Hospital) on the request of a community-based nurse who, in the context of a home visit, had found Mrs. E. to be dizzy and unable to care for herself. Mrs. E. had been diagnosed with cancer of the bladder in June, 1980, following a three-year history of urinary tract infections, and had survived a heart attack in 1974. She lived alone in a basement apartment, accessible by a series of ten steps, and was the mother of three adult children (two males and one female, all married and living in Winnipeg). Her husband had died of leukemia approximately nineteen years earlier and her fifty-two-year-old daughter was in the midst of a four-year struggle with cancer of the ovary. The author followed Mrs. E. throughout her seven-week stay in hospital and for five weeks following her discharge home. Through the author's involvement with Mrs. E., the author became connected to Mrs. E.'s daughter, *Mrs. Z.* Both Mrs. E. and Mrs. Z.'s connections are represented on Eco-map Four.

Mrs. E.'s referral to Oncology Social Work came about as the result of her age and visible distress over her own hospitalization and the health of her daughter, both factors placing her within the high-risk criteria targeting the need for social work involvement.

Mrs. Z., however, was more stoic in her presentation of self to the health care system, had a well-developed support network of family (daughter, son-in-law and husband), close personal friends and neighbours, and strong solid connections with her physician and nursing personnel (see connections leading from Mrs. Z. to the Cancer Foundation and Women's Centre). She was, in the eyes of the health care system, coping. Mrs. E.'s coping capacity was in question.

Contact with Mrs. Z. was initiated by the author in response to her description of her struggle to cope with her own rapidly deteriorating physical state, while still attempting to be supportive to her mother. Seven home visits, paced at one-week intervals were contracted for with Mrs. Z. Five of the seven sessions took place. Essentially, Mrs. Z. wanted to expand her support network to include one individual with whom she could share the most painful areas of her illness experience without needing to protect that person from the impact of the pain. She saw in herself a need to explore, with someone's help, areas of her living and dying. The author agreed to use her inter-personal skills to facilitate Mrs. Z.'s expression of these painful areas, assisting Mrs. Z. in clarifying and connecting the thoughts, and in tracing out the patterns in her reactions.

Contracting with Mrs. E. took place in two phases--the first phase centering on her stay in hospital, the second on her return home. For each phase, the focus of the service contracted for was different. Much of the distress experienced by Mrs. E. during her hospital stay concerned her adjustment to the pace of the medical ward she was on, her physical discomfort and her connections with the health care personnel peopling that ward. Similar to Mrs. W.'s concerns, Mrs. E. found the number of people moving in and out of her room, asking her questions, examining her, etc., over the course of any given day confusing and often overwhelming. Being a teaching hospital affiliated with the University of Manitoba, the Health Sciences Centre and, consequently, the medical ward that Mrs. E. was on, experienced a continuous turnover of medical students, rotating interns and residents, nursing students and social work students (to name a few). Coupled with those persons employed by the hospital to staff that ward, a large number of heavy-care patients and the fast pace required to accomplish the day's tasks, it was difficult to decipher whom to ask for assistance or with whom it was necessary to share life's personal details in order to obtain the required health care. Because a large portion of these people carried out their functions independently of others operating within the same ward environment, communication tended to move vertically from the patient up the authority lines of designated positions rather than horizontally or between positions. Structurally, the opportunities for miscommunication were numerous. Admitted to hospital with vague symptoms not rooted in a specific cause, Mrs. E. had undergone numerous tests to clarify the reason for her symptom presentation. She experienced ongoing discomfort when she urinated and had shared this information with nursing and medical staff, but was unsure of how or if they had responded through the medications she was receiving, by doing additional tests or by waiting to observe what developed. At one point she became distressed thinking she had shared this information with the wrong people (those unable to take action). Hence, the essence of the initial contract with Mrs. E. centred on clarifying the nature and form of her multiple connections with health care staff (i.e., who was involved and for what purpose), determining if the information shared had been received by those with the power to respond, and what form of action had been taken to date (medication, tests, their purpose, etc.). How Mrs. E. was sending her messages to the health care personnel concerned with her care, how they were being received, and vice versa, needed to be determined.

Following Mrs. E.'s discharge home, the focus of her concerns changed from her physical functioning and care to facing her fears about her daughter's death. The unarrested decline in her health since April, 1981 had increased the possibility of death as an outcome of Mrs. Z.'s struggle with cancer. Specifically, Mrs. E. feared that her daughter would predecease her. "________ doesn't need me in the same way as I need her. . . . I was always the strong one, you know. But she has more strength than I have."[8] Mrs. E. struggled to balance her concerns regarding her own health and functioning with those regarding her daughter's well-being, simultaneously needing her daughter's strength and support, yet wanting to be strong and supportive for her. The aim of the second contract for social work assistance was to help Mrs. E. work out this balance.

Initial contact was made with *Mrs. L.* and her husband via a home visit approximately one week after the author had connected with Mrs. E. The intent of making this connection was to offer Mrs. L. and her husband support in coping with the knowledge that Mrs. L. had cancer and the impact that this would have on their lives. Mrs. L. was a sixty-three-year-old, active and youthful woman whose husband's retirement had just commenced at the time of her initial diagnosis of metastatic cancer. At the point of the home visit, Mrs. L. had been home from hospital for only a matter of days. The diagnosis of cancer of the breast with bone metastases to the shoulder, spine and hip was the culmination of eleven months of knowing something more than her arthritis was physiologically amiss. Discomfort that was first experienced after a fall in October, 1980 had continued to recur as a vague shooting pain in her back which appeared to change locations and occasionally was accompanied by numbness in her right leg. Originally, it was thought to be symptomatic of either a cracked pelvis (resulting from the 1980 fall) or her arthritis. However, feelings of unwellness persisted and the pain continued to occur, leading Mrs. L. to suspect something more was involved. While her physicians kept emphasizing her healthy presentation, she found herself withdrawing from more and more activities, unable to cope with their demands. Fears arose that something mentally was askew when she found herself unable to cope with driving the car, even though she had been driving since age sixteen. Two to three weeks prior to her admission to hospital, the pain worsened and she became unable to get out of bed. Up to this point she felt her doctors viewed her as a "neurotic housewife" who was "imagining the pain". A forceful presentation at the Health Sciences Centre Emergency Department resulted in her admission when the diagnosis of cancer was made. An unusual presentation of the breast cancer had made its detection difficult. Hospital personnel were frank and open with Mrs. L. regarding the seriousness of her cancer, but held out hope. Appreciative of their honesty and the compassion of the presentation, Mrs. L. now knew what she was confronting. And knowing was particularly significant for Mrs. L.: her mother had died from cancer of the breast, but was never told that she in fact had cancer. The cancer had metastasized from the breast to the lung, even though her mother had undergone a radical mastectomy. Factual information regarding the mother's condition had been shared freely between friends, family and medical personnel, but not with Mrs. L.'s mother. Mrs. L., having cared for her mother until the mother's death, saw this conspiracy of silence as unnecessarily straining family connections and abilities to be mutually supportive to one another. "She may not have known she had cancer, but she knew she had more than pleurisy [diagnosis given to mother]."[9]

Now at home, Mrs. L. had recovered from the initial shock of hearing her diagnosis and was experiencing a sense of relief at knowing the reasons for her feelings of unwellness and pain. Concerns regarding the cancer's impact on her relationship with her husband were now taking form. Would he be able to remain actively involved in his many pursuits (curling, golf, board activities, etc.), or would her care needs or concern for her welfare impede his ability to continue these activities? Mr. L. had developed difficulties with his vision (double vision), necessitating a series of tests involving the brain during Mrs. L.'s hospitalization. Fearing this might be stress-related given the combined effects of his recent retirement and the impact of her illness, her concerns were magnified. Mrs. L. saw a need to work through these changes and their effect on her and her husband's lives within the context of their relationship without outside intervention. From her first day home, she and Mr. L. had been able to share their reactions to Mrs. L.'s health status with one another. As well, they had received supports from friends and neighbours: meals, visiting, books relevant to the struggles at hand, etc. Time and personal space were needed to adjust to the situation. Negotiating more than a superficial relationship with social work at this stage was seen as an additional stressor. It was agreed that the author would maintain periodic follow-up via the telephone or through hospital contacts (if further hospitalization occurred) unless Mrs. L. indicated a need for increased social work involvement. The intent was to establish enough of a linkage to engender trust, provide room for the open expression of ambivalent/confusing emotions and to trace out the subtleties of what was being faced as required or requested. Eco-map Six details Mrs. L.'s connections. Note that Mrs. L.'s primary physician is an oncologist based in the Winnipeg Clinic, but who utilizes the Cancer Foundation as part of her resource base.

During the second month of the author's three-month practicum experience, she met *Mrs. B.* (see Eco-map Five). Mrs. B. previously had been referred to and seen by Oncology Social Work for assistance in adjusting to the loss of her breast through a mastectomy and in managing a high level of anxiety each time she returned to the Foundation for continued treatment (i.e., chemotherapy and radiotherapy). Because Mrs. B. had delayed seeking medical treatment for six months following the discovery of a lump in her breast, she struggled daily with strong feelings of guilt. She saw her need for continued treatment as a direct result of her inability to face the diagnosis of cancer earlier.

> It was so tiny at the time it would have been nothing. I imagine I would have had the breast off, but it wouldn't have resulted in treatments.
>
> I was so positive it was that and I was afraid of finding it . . . afraid of going in . . . afraid of finding it.[10]

In 1960 Mrs. B. had sought medical attention for what turned out to be a benign lump in her breast. That same year she lost two close friends whom she had known since childhood through death from cancer.

> . . . she passed away in 1960. She had both breasts off. I've forgotten what she had, it's so long ago . . . . cobalt? In 1960 she was only 46. Terribly young! . . . She had the first breast off, then two years later had the second one off and died almost right away.
>
> Her sister died of cancer. They both died the same year. I knew ________ was unwell, but I had no idea she was that sick.[11]

When Mrs. B.'s family physician discovered the most recent lump, Mrs. B. stated she had a "nervous breakdown".

> I lost my taste and lost my smell and went right down to 120 pounds. My nerves were so bad . . . that was about four or five months of that. . . . it took me a long time to get my strength back and my nerves back.[12]

A sensation that the cancer was growing finally gave Mrs. B. the push she needed to phone the Foundation. "I thought if I could talk to someone, some lady who had been through it and [she could] give me some encouragement."[13] Her call was intercepted by a nurse who, with the aid of Mrs. B.'s husband got Mrs. B. in to see the surgeon that day. Surgery was scheduled and in June, 1981, Mrs. B. underwent a right-breast mastectomy. In September, 1981 she began chemotherapy.

With six treatments completed, a lump was found near the incision scar in the breast area.

> . . . it was a lump they missed when doing the operation. Easy to miss. Thank God, it wasn't a new one! If it had been a new one, that would have been terribly hard to take.[14]

Removal of this lump occurred quickly and simply.

The appearance of the mastectomy site "shocked" her. Although she was able to show it to her husband and daughter, she was unable to examine the site of the operation herself or talk about the experience of losing her breast for approximately three and one-half months following the surgery. Supportive contact from a Mastectomy Visitation Program volunteer was refused. The inability to examine the site of the operation or verbalize its impact continued until the weeks just prior to the writer's first home contact.

> One thing, dear, I've come a long way. I wouldn't let anyone come around for the longest time. [The oncology social worker] can tell you that! Now I can look at this and discuss it. Oh, I thought I was never going to feel this way.
>
> I can at least talk about it. Before I would just break down.[15]

Part of the process of putting the impact of cancer and its treatments into words was begun in the initial contacts with Oncology Social Work and continued by a student nurse (Third Year Degree Program) in a series of four home visits. Both encounters proved to be positive experiences fostering within Mrs. B. a willingness to move further in her struggle to regain a sense of meaning in living.

> You lose interest, that's the part. You see I'm always . . ., where I make a mistake, I look into the future too far. Like what's going to happen three years from now. I'm not even thinking I'm going to live two years, a year.[16]
>
> You worry about not being a part of that future, therefore, what's the point of continuing on to cope with today.[17]

Cancer's impact on her personhood--the surgery, the treatments, etc.--had threatened Mrs. B.'s survival and the continuity of her connections with others, consumed a large portion of her physical and emotional energy in adapting to its demands and sharpened her sense of personal vulnerability. Sharing the personal depth of her struggle with others who did not care to grasp its significance for her and the continuity of her life would act to increase her vulnerability at a time when she lacked the energy for self- protection. Hence, trust in any transaction was built slowly and cautiously, heedful of any abuse of the confidences shared.

> The average person--that's you--know or don't know. I don't kind of trust them. You feel you may talk about it and when they leave they may discuss it, not in the way you want them to discuss it.[18]

Mrs. B.'s trust had been honoured in her contacts with the oncology social worker and the student nurse, increasing her receptiveness to the writer's offer of social work assistance. However, the limited number of contacts and the opportunity to withdraw from the connection at any time were also factors in her decision to risk involvement. The contract, then, was to continue the process of being able to verbalize the experience of having cancer without "breaking down" emotionally, looking at the nature of the struggle--its form and direction, and its meaning for continued life. In doing so, the author planned to trace out Mrs. B.'s coping style.

Mrs. G.'s home was located in a distant rural community and *Mrs. S.* was in the final stages of moving to another province when her need for surgical intervention became apparent. Hence, the connections established with Mrs. G. and Mrs. S. were hospital-based and short-term.

Sixty-four years old, married with two adult children, Mrs. G. had never been ill except for the occasional bout of minor illness (cold, flu, etc.) or hospitalized for reasons other than the births of her two children. In July, 1981 she experienced a "flu-like" illness and the acute onset of "blurry vision" and pain in her left eye. After being examined by several ophthalmologists, retinal detachment and an invasive tumor behind the left eyeball were found. In the span of three months, Mrs. G. had moved from seeing herself as an exceedingly healthy woman to an awareness of the existence of multiple cancer tumors behind her left eye and on her left lung, and of cancer of the right breast with metastases to the left eye, spine, liver, bone and skull. Compounding the impact of this diagnosis was the knowledge that Mrs. G.'s daughter, who resided out of the province, was already struggling with cancer of the breast. Social work involvment with Mrs. G. had been requested by the nursing staff because of their concern regarding her depressed state and refusal to eat.

> Very depressed, wants to die. Wants to be in [name of home town] with her family.
>
> Can't discharge home with present temperature, etc., depression makes physical condition worse.[19]

Mrs. G., however, did not share the nurses' concern as she felt her emotional state was congruent with the magnitude of what she was confronting. "I just don't feel that well, I'm not . . . I don't feel like eating."[20] Her health had been lost, her future significantly shortened, and she was in pain. From Mrs. G.'s perspective, she had a right both to experience and express her grief. Masking her grief required energy and her energy was limited at present. She saw no need for social work involvement, but agreed to allow the author to check with her periodically during her hospital stay (three weeks) regarding the process of her adjustment to this sudden change in her health status.

Mrs. S. was attempting to recover from a laryngectomy (complete removal of the larynx) performed in March, 1981, following the discovery of cancer of the larynx. Because the vocal cords are located in the larynx, its removal necessitated learning how to speak with the aid of an artificial larynx (an electromechanical device which simulates laryngeal activity for purposes of speech). While allowing her to converse with others, she found its mechanical "robot-like" sound distressing. Clarifying her sex during phone conversations and enduring the immediate visibility she gained whenever conversation was attempted had an eroding effect on her sense of personhood. Now less than seven months later (October, 1981), a diagnosis of cancer of the breast had been made and a radical mastectomy involving her left breast performed.

> . . . Crying most of the evening. Saying if she has cancer of breast that the cancer will probably come back in a different place.[20]

> . . . 2nd operation quite a shock--hasn't had time to get over 1st operation. Just feels where is it going to strike next. . . .[21]

Divorced and the mother of two adult children in their early twenties (both self-supporting in independent living situations), Mrs. S. recently had left her job and was in the process of moving to another province to be geographically closer to her daughters. She had planned on beginning a job search once she was relocated, but now was faced with delaying these plans to allow sufficient time for recovery from the physical and emotional toll of surgery. Forty-seven years old and not a part of any intimate male/female relationship, Mrs. S. had feared the laryngectomy and use of the artificial larynx would act as a block to future intimate involvements. Enduring further physical disfigurement from a mastectomy seemed too much to bear. How would anyone find her personally or sexually attractive in the face of such disfigurement? She had left her former work setting because of its suspected contribution to her laryngeal cancer, thus was receiving Workers' Compensation until work place involvement could be confirmed or refuted. Extended medical coverage would finance the cost of her medications and up to seventy dollars for a prothesis (cost: approximately $80.00-100.00). Hence, enough financial security was present to allow room for a brief recovery period once she was relocated. Since the author's contact was initiated at the point of transition in Mrs. S.'s geographic relocation to another province, the contract for social work assistance provided by the writer was short-term, consisting of five hospital-based sessions and two telephone contacts over a three-week period. The essence of the contract was: to begin discussing the shock of the second operation in such close proximity to the first, the disfigurement and her threatened future; to investigate the range of support services for persons with cancer available in the area to which she was moving; and, to secure a contact person in that area who would be capable of linking Mrs. S. with the system in a way that ensured her psychosocial needs would be addressed in conjunction with her biological needs.

The span of time during which the connections between the author, Mrs. G. and Mrs. S. were initiated and terminated was the point where the writer was just becoming aware of the narrowness of her conceptual field. Hence, the process used by the author to establish these connections and the terms of the contracts made did not yield enough data to construct eco-maps capable of reliably representing the number or types of systems involved, their connections or the nature of their transactions. Consequently, eco-maps for Mrs. G. and Mrs. S. have not been included in this report.

All seven consumer contacts now have been introduced, a brief overview given of each one's situation and of the contract around which the writer-consumer connection developed. Documented in the context of the author's struggle with the application of the ecological approach to social work practice, the remainder of this chapter highlights those points where the writer experienced a lack of fit with Germain's construction of the model and the consumer(s)' experience of the illness.

The author was in the initial stages of questioning the relevancy of the problem-oriented focus in this setting when she responded to the nurses' request for social work involvement with Mrs. G. In meeting with Mrs. G. it was clear that, although Mrs. G. did not welcome her emotional state, she was comfortable with its expression and saw it as appropriate to the circumstances of her illness situation. Discussions with the nursing staff made it equally apparent that Mrs. G.'s refusal to eat was hindering her body's physical capacity to contend with the disease process and an accompanying infection. For nursing, the construction of the situation was straight-forward. Mrs. G. needed to eat to help her body ward off infection and battle the cancer, but was refusing to eat and presenting with a depressed mood. If her spirits could be raised, she might regain her appetite, enabling her body to reinstate a certain measure of its physiological strength. From the nurses' perspective, social work's role was to explore with Mrs. G. the reasons for her depressed state and, in the process, alleviate her distress. Mrs. G. was quite willing to share with the author the essence of her struggle to confront her illness situation, but saw the expression of her distress as part of the process of coming to terms with the discomfort and seriousness of the disease. She was, in fact, mourning the loss of her health. The author felt caught between two different constructions of the same situation, both equally valid, but appearing to demand opposing action responses from her. Could the mourning process or the distress resulting from it legitimately be labelled as problematic? Certainly, from the perspective of the nurses and their role in the system, Mrs. G.'s actions were problematic. If their role was to monitor and help promote Mrs. G.'s biological ability to contend with her disease, tests and treatments, Mrs. G.'s refusal to eat was an obstacle to the accomplishment of that process. Also, Mrs. G.'s refusal to eat did not help her biological dimension realize its potential to ward off infection and battle the cancer. Yet, Mrs. G.'s state of wellness had in fact been lost, her self-concept altered, and her future shortened by the advent of the cancer. All these events involved a loss and demanded a reaction. To deny this process would only delay its occurrence; to mask it would require the use of valuable energy already in limited supply. The same behaviour simultaneously was a strength and had limiting features. For the writer, Mrs. G.'s comfort with the natural unfolding and expression of her emotional response to her illness situation was a strength to be promoted. However, the writer also felt a need to address the nurses' dilemma. It was then that author became aware that her focus had been on Mrs. G. as the primary client, when in fact the initial contract for social work services was with the nurses. Mrs. G.'s behaviour was not problematic; it just did not fit with the purpose and goals of the system of which she was presently a part: the hospital ward. She was not giving primacy to her biological dimension in a system structured specifically for that purpose. As it stood, the nurses saw Mrs. G.'s depressed state as problematic for both them and herself, but Mrs. G. was refusing to accept that definition of her behaviour and, therefore, was not working to change her response. Moving the interventive focus away from Mrs. G. to the interface between the nurses and Mrs. G. necessitated understanding each part's survival and growth needs given the demands of their respective positions in the hospital system and how they were attempting to fit together to meet the needs and demands of these positions. The interventive goal was how to structure the connection in such a way that the nurses could accomplish their purpose while supporting Mrs. G.'s ability to confront and mourn her losses.

Conceptually, the author had moved only as far as locating the struggle at the interface between Mrs. G. and the nurses, and identifying the contract for social work involvement as existing between the nurses and the writer. Therefore, in her attempt to move the focus away from Mrs. G., she moved it to the interface between herself and the nurses, seeking to redefine what she saw as the original terms of their contract (i.e., to reduce Mrs. G.'s level of distress). In the writer's construction of the situation, she indicated an inability and/or unwillingness to work at lessening Mrs. G.'s depressed state. This acted to return the responsibility for resolving the 'problem' to the nurses, who still saw the solution as improving Mrs. G.'s mood. Thus, Mrs. G. was moved from a single-occupancy room to a shared room in the hope that the company of another patient would take her mind off the gravity of her own situation, thereby raising her spirits. Mrs. G.'s emotional presentation in fact did improve and she began to eat again. However, in the context of a subsequent visit by the writer, she revealed that the depression remained but was masked by a more optimistic outward appearance and that she was eating to meet the needs of the nurses. In this way the nurses were content with her efforts to help her body confront the disease and her physical strength would improve enough to allow her to return to her home community. The nurses were able to accomplish their tasks in caring for Mrs. G., and Mrs. G.'s improved condition resulted in her discharge home. In the eyes of the system, the problem was Mrs. G.'s distressed behaviour; for Mrs. G., the problem was the system's inability to accept her need to grieve. It was becoming clearer to the author that the 'connection' required restructuring in a way that realized and dealt with the needs and demands of both parties (i.e., Mrs. G. and the nurses). This also meant recognizing the construction of social work's role within this transaction. As well, the author was not comfortable with the system's more subtle message regarding the appropriateness of Mrs. G.'s behaviour. Mrs. G.'s expression of her depressed emotional state was negatively valued and assigned a problem-oriented construct, thereby equating the expression of negatively valued emotions with inappropriate coping behaviour and the repression of these feelings with forward movement. It was the writer's opinion that the strength of Mrs. G.'s 'actions' in helping her meet the challenges of her illness situation, by giving her the emotional room to grieve her losses, had gone unnoticed by the system due to the problematic status of these actions in the achievement of the system's goals.

The author now was beginning to see other subtle ways in which the hospital system (and health care system) was conveying a message equating the open expression of negatively valued emotions with inappropriate coping behaviour. Depending on the level of distress shown, its open expression could result in a request for social work involvement. Because of social work's problem-oriented construction of its helping actions, the message given was that the individual concerned was experiencing 'problems' in adjusting to the impact of the illness experience. Whether seen as the result of inadequate skill development, a lack of resources or environmental pressures, 'problem' became equivalent to a deficit in the person's ability to cope with the situation. The expression of a low level of distress therefore equated effective coping with no need for social work intervention. Missing from this construction was the message that contending with negatively valued emotions such as anger and depression was a natural part of adjusting to a chronic debilitating illness and, therefore, their acknowledgement and expression an effective means of meeting the demands of the illness situation.[22] Comprehending the strength of this response was not part of the construction of the helping system's approach. Room for emotional expression was not built into the structure of the system. Physically, this was represented by a lack of private space on the wards where the intimate details of the psychosocial dimensions of the persons concerned could be discussed out of the hearing of other patients. Securing such space usually meant moving the person off the ward, often to a distant location in the building several floors away. Given the physical state of these individuals and the mechanics of moving them, this was rarely feasible. The pace at which tasks were accomplished, the number of persons needed to accomplish them and the primacy of addressing the needs of the biological dimension gave the message that psychosocial concerns had no place in the organization of the system. Space often appeared to be seen by hospital personnel as important only as a location for meeting the needs and demands of the person's biological dimension. The intrapsychic and interpersonal changes that the situation of illness demanded were somehow expected to occur separately from those happening in the biological realm and outside the health care setting.

Each ward had its own tempo which seemed to affect the willingness of hospital personnel, particularly the nurses, to consciously address those psychosocial struggles which arose for persons occupying their respective units. For example, the pace on Mrs. G.'s ward, although busy, was slower, less pressured and more informal than the rate of movement on Mrs. E.'s ward. There appeared to be more time for information sharing and working collaboratively across professions on Mrs. G.'s ward. Mrs. E.'s ward was fast-moving and formal with seemingly little time for information exchange. The writer had a strong sense that on Mrs. E.'s ward accomplishing the number of tasks directed towards the biological realm within the time frame allotted left little, if any, time to consider the other dimensions of personhood. Hence, the author saw a greater potential to work collaboratively with health care personnel on Mrs. G.'s ward than on Mrs. E.'s. On Mrs. E.'s ward, the nonverbal message for the writer was to explore and address the person's psychosocial concerns to the extent possible separately from the involvement of other health care personnel. It is interesting to note that much of the author's work with Mrs. E. while she was in hospital centred on effecting clearer and more open lines of communication between health care personnel and Mrs. E. Efforts to accomplish this clarity in communication were better received, and therefore instituted in the contained-ward environment, than in Mrs. W.'s situation where the health care personnel were scattered throughout several separate and distinct health care settings. Providing a physical location for the convergence of action, the ward environment encouraged ease and frequency of contact between helpers, thereby enabling the author to establish trust in her actions and gain admittance to some of the more informal communication pathways. Access to some of the subtleties of the ward's operation and power structure assisted the writer in deciding how and where to intervene to secure the desired person-environment fit.

Because the author was still viewing the persons directly facing the cancer as her primary clients and was focusing on locating and correcting problematic fits between these clients and their environments, she was not broadening out to view the structure of the field. For example, the writer at no time consciously explored how nursing was connected to other health care personnel or how nurses saw their needs and demands for survival and growth being met within the hospital network. By failing to make herself aware of the needs and demands of other systematic connections, the author reduced her ability to understand their actions and to intervene in the network at the point where the greatest potential existed for creating a better person-environment fit. Consequently, the writer's change efforts became centred on, and peculiar to, the specific person encountering the lack of fit. The need for change took its place in the realm of the exception rather than as a dimension of personhood the structure of the system needed to address. It became the person's failure to cope, rather than the sytem's inability to meet human need. Social work, with its problem-oriented focus, was reinforcing this construction. In the search for problems the survival and growth value of the system's connections, given the context of their existence, assumed a secondary status, and the strength of each component's actions was overlooked in the concentration on their limitations.

As the author struggled to establish an interventive focus in her consumer connections, a moment of conceptual clarity appeared. The distress evidenced by the consumers was emanating from the process of reconstruction and growth . . . not as a blockage to its progress, but as a natural part of its forward movement. New learning was occurring for these people as they struggled to manage a previously uncharted territory in their life experience. Moving forward involved risk, vulnerability and the act of letting go and reshaping some of what had come before. The problem-oriented focus had allowed the writer to recognize the distress, but it did not push her to see the growth. Hence, her response had been directed towards alleviating the distress rather than towards enhancing the growth. Yet, to enhance the growth, the author needed to understand what the survival and growth issues were for each consumer, given the context of the consumer's life space and cancer's impact on it. For example, Mrs. S.'s single status meant that her personal care depended on her ability to function independently of others. Actions which threatened this capacity for independent function became threats to her survival as she saw it and were strongly resisted. Hence, a nurse's attempt to help clean her throat hole, although well intentioned, engendered an intense defensive reaction from Mrs. S. "I'm very independent. It scares me when someone tries to do this for me."[23] Actions directed towards enhancing Mrs. S.'s survival and growth in the face of her experience with cancer, whether biologically, psychologically or socially directed needed to respect Mrs. S.'s sense of her own survival.

This conceptual clarity prompted another observation. The contracts the author was establishing with her consumer population (in fact, what consumers had been attempting to explain to her all along about their struggles) had more to do with enhancing each one's ability to maintain her forward movement than with identifying and correcting 'problems' of fit. The focus was still at the interface between person and environment, but its concern was with identifying the <u>transactional strength</u> of the connection for the survival and growth of those involved and their combined potential for enhancing each member's continued existence. Moving now to understand the transactional strength of each consumer's actions in the context of their survival and growth needs, the writer gained a different appreciation of the coping capacities of those consumers with whom she had connected.

Listening with a different purpose, the author heard what her former conceptual framework had blocked. By emphasizing the limiting features of certain behaviours and linkages, their strength was overlooked. Mrs. W.'s 'caustic' presentation of self and her refusal to negotiate relationship difficulties made the resolution of interpersonal conflicts cumbersome. However, in those situations where Mrs. W. saw her vulnerability of self as high, this behaviour quickly secured a safe degree of emotional distance and gave her a felt sense of control; that is, it was self-protective. By devaluing or invalidating the significance of the other person and his/her actions, she was able to allow herself to deny any responsibility for the outcome and thereby justified her refusal to work jointly with this person to resolve the conflict. Particularly threatening was the vulnerability of self and loss of control felt within the intimacies of close personal relationships. Hence, Mrs. W. tended to gravitate towards professional associations where her needs for interpersonal involvement and caring could be met with less self-exposure. Being able to use and maintain her own physical space was another means of regulating emotional involvement. Cancer increased Mrs. W.'s vulnerability by impairing her ability to function independently of others, to maintain a separate physical space and to keep her emotions contained. Consequently, the need to negotiate interpersonal relationships increased, as did the need to face in herself those thoughts, emotions and actions for which she previously had blamed others. This demand for reconstruction and growth was occurring at a time when her physical energy was declining rapidly. Cancer was stripping Mrs. W. of more than her biological survival; it was eroding her means of negotiating interpersonal relationships. The cancer experience was demanding that Mrs. W. let go of a method of self-protection that she had no desire to change at a time when clarity of thought and internal control were required to comprehend the extent of what was occurring.

> "I'm full of it! I can't tell my son! I wanted to die fast, I'm not going to." Tears. "I'm glad [the doctor] confirmed my diagnosis. I'm glad you were there with me. If I were by myself, my head would have been so tense, I wouldn't have been able to concentrate on what he said. All my life I've been independent, I've taken care of others. Now. . . ."[24]

In seeing the transactional strength of Mrs. W.'s actions, the writer also could see the limitations for Mrs. W.'s survival and growth. More importantly, however, she could appreciate the magnitude of Mrs. W.'s struggle. She was simultaneously confronting issues of living and dying . . . continuing to grow while letting go.

Biological treatment occurs in a social context and has bio/psycho/social impact. It was inevitable that Mrs. W.'s method of relationship negotiation would impact on relationships formed in this context (with nurses, physicians, etc.). If the nature of this impact could be anticipated and its self-protective value appreciated, the construction of biologically oriented services could be directed in a way which respected her sense of survival rather than further eroding it.

Self-protection and control were important elements of the illness experience for all of the consumers connected with. Decisions to connect with the author were based strongly on the consumer's ability to exercise some control in establishing the direction of the contact and her sense of personal safety within the connection. Could she trust the author to understand her struggle and help her piece it together without judging her effort or actions? Would the author be sensitive to her need to make sense of what was happening to her in her own terms and for her own existence? The following is an excerpt from the termination session with Mrs. Z.

> At least I know the purpose--that there are people available without them totally taking over your life. . . . You need someone who is kind of removed from the anguish of losing their hair.[25]

Cancer the disease gave them no felt sense of control, leaving them in a tentative state of vulnerability with no map to plot out the future. Open expression of the confused and ambivalent feelings this generated was required to help maintain a clarity of thought and action. However, this meant relaxing self-protective actions enough to let the process flow, thereby increasing vulnerability. To share this process with another person entailed trusting that person not to take advantage of that vulnerability.

For Mrs. B., who attempted to structure life in terms of absolutes, living with the unpredictability of cancer was almost unbearable.

> Mrs. B.: . . . when you have a cold you get over it, when you have the flu you get over it, but you never, never get over this. If anything, it gets worse. That is the dreadful part. That's the terrible part to live with.
>
> Author: You like dealing with absolutes.
>
> Mrs. B.: Yes! The same with my reading material. It's one or the other, nothing in between. The same with my friends. I like or dislike. There's nothing in between.[26]
>
> Years ago when my daughter would be sick as a child, I would experience the same feelings of panic. However, I would console myself that this time next week she would be better. With cancer this time next week you are not better. The cancer is still there.[27]

Cancer challenged Mrs. B.'s approach to life. Because it offered few absolutes, the cancer demanded by its presence that Mrs. B. evolve a means of living with uncertainty. In her original construction of the illness situation, cancer equaled death; it had robbed her of longevity. Hence, it followed that if she could not be a part of the future, there was no point in struggling with today. If complete freedom from cancer was unobtainable and nothing she could do in the present would afford her this absolute, death from cancer would be the outcome of any of her efforts. Yet, if she wanted to continue to participate in life connected to those persons most important to her (and she did), this construction needed to change. "You have to go to bed, you have to get up, you have to eventually live with it. There's no doubt about it."[28] Learning to manage the anxiety that living with uncertainty produced was one aspect of this reorientation, and regaining her belief that her present-day actions could still influence her continued existence was another. From a problem-oriented perspective, Mrs. B.'s anxiety was a deficit, an inability to manage the changes accompanying the advent of a life-threatening chronic illness. Structured as a flaw in her ability to cope, the forward movement of her struggle is missed, the strength in her approach overlooked. By concentrating on the transactional strength of her actions, their value for her survival up to this point in time could be appreciated and the progressive force in her struggle understood. Reconstruction and growth were occurring, not a breakdown in her ability to cope that needed to be righted. Before Mrs. B. could let go of her preferred style of approaching life, she had to experience its lack of fit with the demands of the situation being faced, and have the energy, space, time and security to risk the ambiguity of evolving a new method of approach. Such a process develops its own tempo, defying imposed constrictions of time and method.

Aware that she could not eliminate the uncertainty, Mrs. B. faced it by attempting to achieve clarity where it was possible, by checking out her fears and doubts with appropriate health care personnel and by maintaining internal control.

> One thing with this, I don't want my nerves to get any worse, 'cause I know I've been through that and I don't want to have to face that as well as this. There's no way you can fight both.[29]

She utilized the relationship with the writer to achieve a sharper understanding of her internal struggle and its forward movement. As well, Mrs. B. built a network of connections with other persons who had cancer. These associations were used to glean information about the expression of each one's disease, his/her treatments, the side-effects, and how each one managed the challenges of having cancer. From her own reactions and those of others to the disease process, she could see the commonalities and the differences. This gave her the information she needed to form questions that could be asked of health care personnel which were appropriate to increasing her understanding of cancer's course and its possible impact on her life.

> I was just taking half of what I heard. Because I was thinking no matter what happens I still have to go through my treatment and it will affect me differently.[30]
>
> But you read and you hear. You see I've lost so many. They've been told the same story that they've caught everything and they've died within 2-3 years.[31]

Given her obvious struggle with feelings of anxiety, others tended to discourage Mrs. B. from exposing herself to divergent opinions and experiences with cancer. Although Mrs. B. did monitor her exposure according to her emotional sensitivity and energy for dealing with it, she saw this as a useful method of reducing ambiguity in a highly ambiguous area.

> . . . [a television program] which I mentioned to Dr. ________. He wasn't too pleased with me. He said I shouldn't be listening to things like that. [Dr. ________ said,] "You know we wouldn't be doing this if we thought it would turn to leukemia." I said I know, dear, but as you read all about this and see it on T.V., you wonder if this is the best thing for you. I do know that chemotherapy isn't the best thing for some of the organs. It's like everything else you have to take a chance if it's going to help you.[32]

Mrs. B.'s high level of anxiety had been assigned a problematic status by some in the health care system and its reduction was seen as necessary to help her deal with the biological treatment of her disease process. At times the writer felt that so much attention was focused on reducing the 'level' of distress expressed that the process Mrs. B. was evolving to manage the anxiety was bypassed, lost in the pace of the health care system. It appeared that the system actually was reinforcing the suppression of negatively valued emotions rather than supporting the person in developing a means of managing them.

Regaining her belief in her personal ability to actively influence her continued existence was a fragile process for Mrs. B. Rebuilding her sense of hope was a part of this. "What will tell the tale is if I have any other symptoms. . . . If I have any other symptoms, I know that will put me back."[33] Each day that life went on without a recurrence of the cancer--and her continued ability to withstand the treatments and their side-effects--all helped to provide tangible reasons for believing again.

Mrs. B.: Now you see with these [radiotherapy] treatments I never thought I'd make ten. 'Cause you see this lady, she couldn't even have two 'cause she was so sick. [Mine was a] large area, [I was] able to make the twenty treatments!

With the treatments and with the pills . . . you stand a better chance and that gives you hope, too.

Author: With the success in the treatments cancer moves from not equaling 'a long life' to maybe it can equal a 'longer' life than what you imagined.

Mrs. B.: Oh, yes, right away! Yes. Because you see, with me, without hope you just feel as if there is nothing to live for. . . .[34]

The willingness of health care personnel dealing with the biological realm (particularly physicians and nurses) to openly address Mrs. B.'s fears and doubts assumed a major role in rebuilding her hope.

> [Dr. ________ told me,] be free to ask me any time. Don't sit on it and worry about it. I felt better that way.
>
> The nurses, they're the ones who told me more about it than average.
>
> Trust is the most important thing. That's what I like about Dr. ________. She's very, uhm, if you ask her anything, you know she's going to answer you the best she knows how and honestly. I believed her when she told me I wouldn't be sick!
>
> Dr. ________ is very good. He's busy, but . . . he said, "I'm very pleased with the way it looks." He turned to [my husband] and said, "She's done very well." Unless [the cancer] touches you, you just don't realize [what that means].[35]

Even though some of the physicians chose to deal with Mrs. B.'s anxious presentation of self with the message, 'trust me, I know what is best for you', Mrs. B. persisted in her efforts to check out her concerns. The author admired her perseverance in defining her own needs and having them addressed.

Mrs. Z.'s construction of hope was different from Mrs. B.'s. She wanted more than openness and honesty in her transactions with nurses and doctors. Mrs. Z. needed to feel a mutuality of purpose and action. "We can work together to do this, with an emphasis on the 'we' and 'together'."[36] She needed to know that the fight for her life was a mutual action. This was particularly important because, now in the fourth year since her initial diagnosis, the nature of the fight had changed.

> Mrs. Z.: I felt so well up until last April. I'll bet you'd never even have known there was anything wrong with me. I think that is why it was so easy for us to fight this because we thought we were winning all the time. We were positive we had licked this. I think that's why it was so hard when we found that it came back. And then to see myself going down! That was almost harder than hearing it the first time. It upset me more because when you first hear the word you don't believe it, but then after you've been through it you know what it's like and how horrible it can be. And then to think you've gotta fight harder and with what?!
>
> Author: With less.
>
> Mrs. Z.: With less.[37]

The fight had changed, and with it the demands of the illness experience. Issues of dying and death were pushing to be heard. Existing simultaneously was the need to believe, "we are going to lick this thing," and a need to consider, "maybe we won't". Did considering the possibility of death mean that the cancer had won? The dramatic changes in her appearance, physical energy, ability to control the pain, and to function independently of others were forcing Mrs. Z. to consider the possibility that she was dying. Acknowledging these thoughts and what they meant for her continued existence was frightening. Not sure of her readiness to face them, she found they refused to be ignored. Considering the panic these thoughts evoked within her, she knew that confronting them needed to be a shared experience. Yet, to have the strength and courage to consider death and dying, Mrs. Z. needed those closest to her to continue to believe that she would once again achieve wellness. This group included her husband, the nurses, the physician, all those who were caring for her biological dimension; she needed them to maintain hope for her recovery. Hope softened the fear of thinking about dying. Because others believed in her continued existence, she could find the strength to go on, even if she did look at the possibility of death.

Who, then, could she draw upon to help her face these frightening thoughts? Required was a person with the time to sit and to listen, and who was open to hearing these thoughts. "You need someone who is sort of removed from the anguish of losing [their] hair and [their] skin and everything else."[38] It was essential that they appreciate the impact of the disease for Mrs. Z., be able to help her order what was occurring giving it a perspective, and respect the pace at which she needed to move.

> . . . I can't be pushed into what's too far out. What we talk about is really what's happening today. I hope what happens next month is going to be good, but I don't dwell on it.[39]

The future could not be relied on, but the present was here now and needed to be lived. Mrs. Z., like Mrs. B., was securing a resource base tailored to her particular survival and growth needs given the demands of the illness experience. This was a forward movement in meeting the adaptive demands of the illness and the author was to be part of this. Bringing a competency in facilitating the expression of inner thoughts and a knowledge of communication, the author had both time and a willingness to hear.

The writer now understood that resource management was a necessary part of survival and growth in the presence of a long-term illness. An adequate resource base was diverse, but specific to the needs and demands of the present situation. Consequently, its use and membership could change over time depending on the expression of the illness and its impact on the persons involved. Flexibility was required to maintain forward momentum. There was pain in sharing the emotional and physical aspects of the struggle to face living and dying simultaneously, and this pain needed to be balanced. How much could be shared, when and with whom without overburdening the support network?

> . . . I would feel badly if his whole life . . . if he felt like . . . he was suffocating under all this pressure. I don't like to put any unnecessary pressure on him. That's why I'll cover my feelings sometimes. He knows enough what is happening.[40]

Each family member's emotional readiness to confront painful issues does not necessarily occur at the same time. The struggle is peculiar to their place in the life cycle, their relationship to the person with the illness, and the illness' impact on their own survival and growth needs.

> I'll say something: maybe I won't be around, or something like that. And I can see that's very upsetting. It's hurting to him. It hurts him. You can see the hurt. It will come. It will have to sometime. . . . There will be a time for that.[41]

Remaining as independent as her physical state of being would allow her was a means of conserving her support network's finite energy supplies for the stage in her illness when Mrs. Z. would need their strength most. "I can still take care of myself. Nothing is that bad."[42] She monitored her pain medication, cooked those parts of meals of which she was still physically capable, prepared for the birth of her first grandchild, shopped for maternity clothes with her daughter, and maintained her physical appearance through clothes, makeup, wigs, etc. This occurred even though Mrs. Z. was in constant pain and frequently nauseated to the point of vomiting. Sessions with the author were often preceded by episodes of vomiting and participated in by maintaining a rocking motion to contain the pain. Participation in life meant maintaining the ability to give as well as receive.

Management of internal energy had a transactional reality for Mrs. Z. Shielding others from the magnitude of her internal suffering depleted limited energy reserves. There came a time when this type of energy expenditure was no longer possible.

> I haven't got the strength to put on a better front than I'm putting on now. If it hurts, it hurts. I just made up my mind that I couldn't cover up all the time.
>
> I'm tired of covering. I really feel I'm getting more and more tired of covering as the days and the weeks go on.[43]

Mrs. Z. now had to learn how to ask others to trust her to manage the pain. She was coping and this was how she coped. If they could understand and trust her abilities to manage, she could surrender the cover more easily. There would no longer be the need to protect others from the upset of seeing her pain. Mrs. Z.'s openness was especially stressful for Mrs. E., who had watched her husband die of cancer, was witnessing her only daughter move closer to death because of it, and was confronting cancer's presence in herself. There was a need to reach out and comfort her daughter, the anguish of seeing a loved one in pain, and a fear that this could be her at a future date. Older now, she no longer had the same strength to meet these challenges. There were moments where Mrs. E. was too afraid to see what Mrs. Z. could not continue to hide. The emotional pain had a circular motion. "We hurt because we see each other hurt."[44]

The progression of the disease seemed to reduce Mrs. Z.'s level of energy on those occasions when more, not less, energy was required. She struggled daily with defining her physical limitations and determining the tempo of her movements.

> Mrs. Z.: Today I've got that terrible feeling. That scared feeling. God, am I going to get sick for Christmas?! Is this leg going to get worse? It's that worrying. Am I going to spoil it for someone? Am I going to make it for dinner? All these terrible things. . . .
>
> Author: It's just before Christmas. A lot has to be done. And this is a 'bad' month. You don't have the energy.
>
> Mrs. Z.: And I'm mad at myself because I didn't do in November what I should have done when I had that good month. And I know better and I'm mad. I'm really just mad at myself.
>
> You can't let one day go by. You can't put it off another day. If you feel so lousy today, tomorrow you could feel worse.[45]

Life had been reduced to a daily event in her capacity to predict the form of her participation in it.

> I'd love to say, yes, we're going to Hawaii for the month of February . . . but knowing full well I can't do that. Or saying, I'll fly to Montreal for the weekend or . . . let's go for the smorgasbord on Friday. Now, I can't.[46]

Part of this struggle was differentiating respect for her physical limitations from giving in to the disease by her actions. Adjusting her pain medication schedule expressed one form of this struggle.

> Mrs. Z.: You see, I can adjust it. I could have had it at that time. But by adjusting it, I feel as though I'm giving in to it a little too soon. Fifteen to twenty minutes--I don't mind adjusting it that amount. But to adjust it an hour means that I'm not getting enough for it to carry me the four hours and that's probably bothering me.
>
> Author: Sounds like the pain breaking through has scared you.
>
> Mrs. Z.: Yes, it has. . . . I'm going back to . . . I find myself getting up in the middle of the night and going back to this rocking. That's kind of a security thing. . . .
>
> Author: Controlling the pain means a lot [to you] in terms of controlling the illness. When that looks like it might not be quite on, there's a panic reaction.
>
> Mrs. Z.: Yes! Yes! I think that's exactly what's started to happen. Because . . . well, the week I spent at my mom's . . . a couple of nights were really bad nights. And I woke up one night just screaming in pain. But I think there were many things that brought that on, partly that I was tense. But that's when it really started to break through.[47]

Entangled in this struggle was the fear of what her body might be telling her. Was this her body's way of saying she was dying, that the battle already had been lost? How was she supposed to read the signs? What did she 'need' the signs to say? Pacing herself, honouring her physical limitations, confronting what she needed to confront a piece at a time, and controlling the panic . . . they were all a form of resource management.

Entering the system from a different vantage point than that of the consumer or biologically-oriented health care staff, with a defined interest and responsibility for addressing the psychosocial dimensions, the writer struggled with her own sensitivity to the issues at hand. Did she recognize the seriousness or the magnitude of the struggles shared or did she take them too lightly? Questions posed regarding interpersonal transactions were complex. The 'rules' for human transactions were changed by the expression of a disease which affected each family member's capacity for response. Tracing out this capacity entailed a combining of knowledge from biological as well as psychosocial realms. Yet, collaborative efforts to integrate different knowledge bases for combined use were mitigated against by the pace of the system and its hierarchical emphasis. Hence, there were times when the writer felt herself facing uncharted territory with no model that matched enough of what was being encountered to help plot a forward direction. The author scrambled to readjust her interventive response to the rapidity of Mrs. W.'s physical decline, and the emotional and social impact of this on Mrs. W.'s life. Mrs. W.'s personal space shrank, her dependence on others increased, her spirits declined and the number of participants involved in her care increased. If the system had been difficult to negotiate before, it was overwhelming now. Even as it happened, the speed of Mrs. W.'s decline had not been predicted. It was difficult to plan ahead when her physiological state changed before each week ended. The author wondered about Mrs. W.'s will to live and the possible eroding effects of the health care system on her spirit. Did the health care system have any responsibility to address this in its quest to realize its biological care goals? Finally, where in the system were the needs of family members explored and addressed?

Care goals within the health care system were constructed and carried out from an individual focus, with family members appearing to occupy the periphery. The supportive function of the family was acknowledged verbally by the system and family distress, when expressed, was responded to. However, there seemed to be no 'conscious' effort made by the system to 'anticipate and plan' for the influence of the cancer's diagnosis and treatment on family structure or individual family members. Connections between significant others and the Cancer Foundation are represented by the eco-maps contained within this chapter, however, information shared with the author during her consumer contacts indicated that the strength of the connections made depended on the initiative taken by family members to introduce and structure them.

The Cancer Foundation, in its initial contacts with consumers, began by centering on the biological struggle of the person with cancer. Consumers, accepting the primacy of the biological dimension in this setting, did not tend to question this beginning point. As indicated at the start of this chapter, social work services were offered more frequently to, rather than requested by, consumers. Hence, the system's focus, consumer acceptance of this focus, social work's point of entry, and the writer's lack of experience with broadening the consumer network within the context of a suggested rather than requested service, all influenced the author's decision to gain access to the family context by first centering on the individual struggle. The plan was to emphasize the transactional nature of the issues being faced, thereby drawing in other family members. As with the author's beginning attempts to establish contracts with consumers, her initiatives to expand the network to include other family members were resisted by consumers. Part of this refusal stemmed from the individual focus of the contracts formed, however, another factor was the use of the problem-oriented construction to frame consumer concerns. Family members were seen by the consumers as requiring psychosocial assistance only when forward momentum was threatened or became blocked, or if their support was required to help the person with cancer work through a concern. Again, the message was, yes, it is emotionally distressing, but 'we're coping'.

> He's going through every pain. He watches your face and you know, [he] sees every pain. But I don't know if that is something he would want to discuss. I don't know that he would. I really don't know. But I know that this affects him a great deal and he's coping with this as best he can.[48]

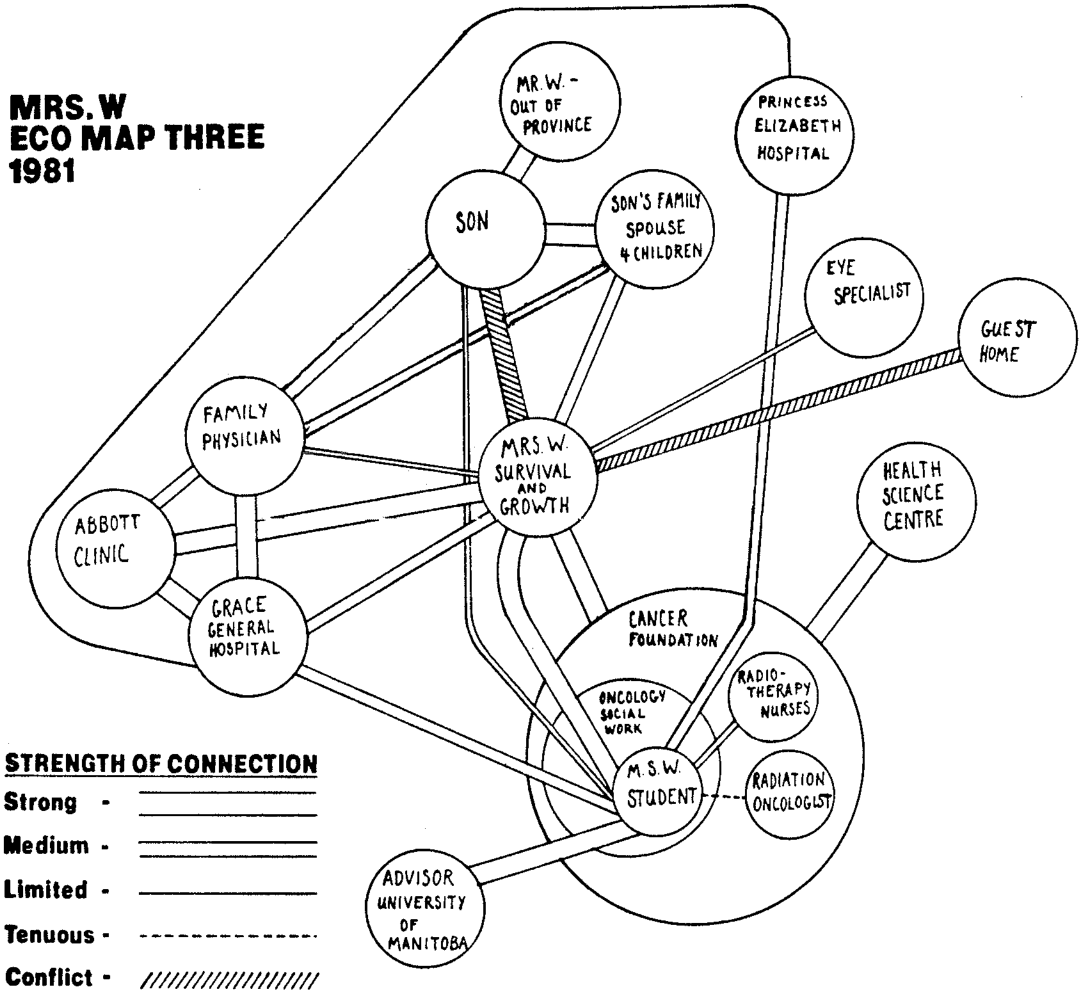
The message for the author was that for family members to feel they could draw on the system's psychosocial supports, they had to define themselves as not coping or in a deficit position that needed correcting. At this stage the author no longer believed there was such a thing as not coping and she was beginning to see that definitions of what constituted ineffective coping depended on whose survival and growth needs were being considered at the point of question. Several incongruencies had surfaced for the writer. In the lives of the consumers with whom she had connected, cancer the illness had demanded a major reorientation of their psychological and social selves. Throughout the sessions there were constant direct and indirect references to the occurrence of a similar process for their significant others. Given that addressing psychosocial concerns was viewed as secondary to the Foundation's prime function, the absence of any conscious effort by the system to anticipate and plan for its impact on family, and the author's awareness of how connections between the Foundation and family members within her range of consumer contacts had come into being, she questioned the availability of personnel in this system for assisting family members in their quest to make sense of the cancer experience for their own existence. Perhaps, then, these family members had other network resources to assist them in the evolution of their coping actions. Restrictions of time, both in the span of time available and the amount of time used by the writer to reach a level of clarity in her focus, prevented a more thorough exploration of this resource area. However, the author did pursue this concern somewhat with Mrs. Z., whose husband was involved in caring for both his wife and her mother (Mrs. E.) in addition to maintaining a highly responsible work position outside the home.

> I've seen him break down. And I don't know who he would choose to talk to. I don't think he'd choose a friend or anything. It would have to be a professional person. He's so aware of what is going on and always has been. It would have to be someone who really knew what they were talking about or my husband would see right through it.[49]

A knowledge of cancer the disease and the human experiencing of it appeared to be required, as well as skill in helping the person pull it all together in the context of her/his own existence. From Mrs. Z.'s description of her husband's support network, it was not clear whether he drew solace from any other sources outside of his private relationship with God. Perhaps this was enough. Yet, knowing the pain that Mrs. Z. and her husband shared, the 'isolating' effects for Mrs. Z of her unshared pain, and Mrs. Z.'s need for her husband to be strong for her, the author wondered from where Mr. Z. drew his strength, with whom he shared his pain, or if, indeed, he shared it at all. Given the strength demanded to face the struggle of living with cancer, the author questioned the usefulness of a helping model which framed the need for psychosocial support in deficit terms.

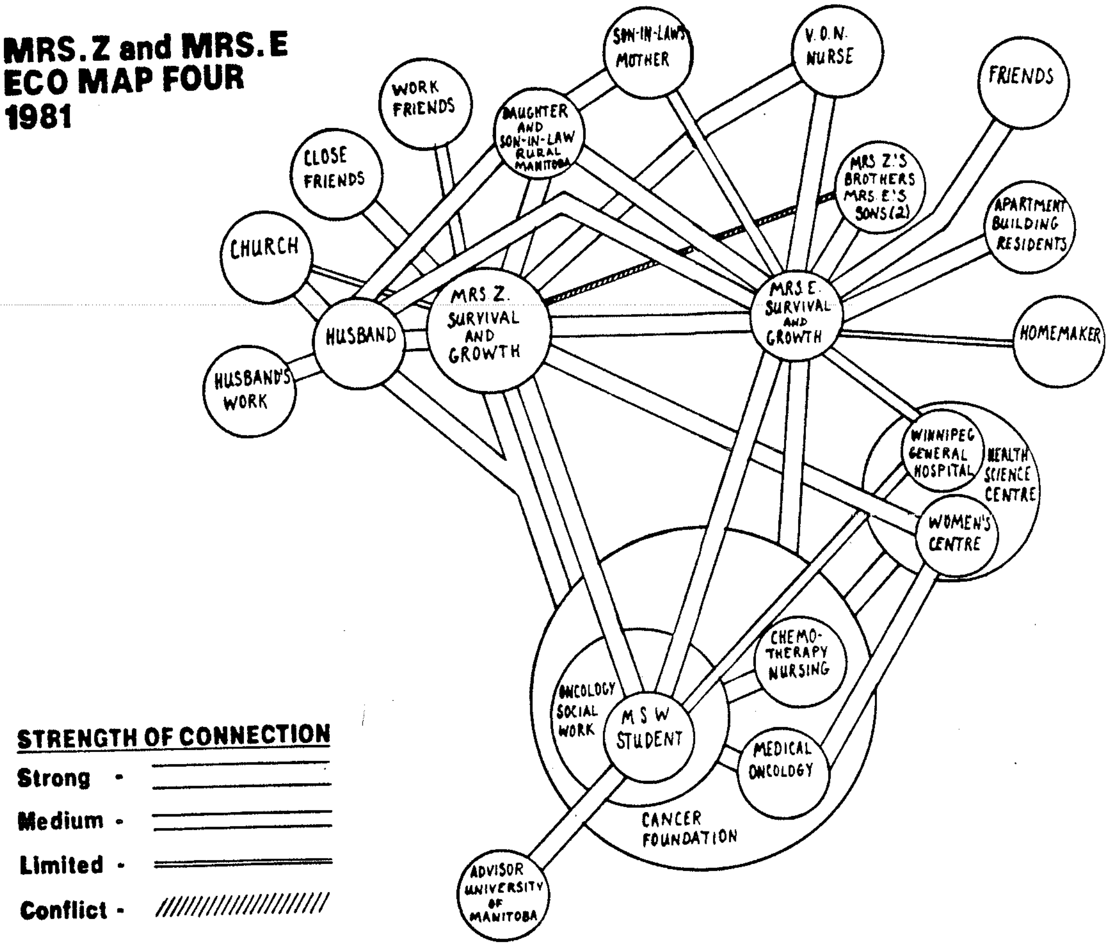
While there were many other moments of revelation in the writer's transactions with these seven consumers, the context of this paper and its space restrict their inclusion. Mrs. L. shared with the author the beginning points of what Mrs. Z. was already into, but with a different perspective. For Mrs. L. there was a knowing that she was dying, coupled with a hope that she would not. Both she and Mrs. Z. brought the experience of having lived with a person who had a long-term illness: Mrs. L., as a young married woman with small children nursing her sick mother; and, Mrs. Z., as an adolescent had a father who was coping with tuberculosis (he died from leukemia when she was thirty years old). Each drew from these experiences to pattern her own coping and to monitor the nature of her demands on those around her. Previous exposure had yielded guidelines for directing the process of living with the impact of her own illness situation. These coping responses, and those which are contained in the preceding pages, are acts of forward movement--of learning to live with uncertainty . . . of learning how, when and of what to let go--while continuing to survive and grow.

Theoretical models which focus on emotional distress or on what is lacking in the person-environment fit miss the transactional strength of the connections made, and with it, the competency of the coping actions put forth. They tend to cast behaviour and the linkages formed as either strengths or limitations, ignoring that the same behaviour or connection can be both simultaneously, and must be weighed in the context of its survival and growth potential for all those involved. In choosing to begin by centering on the identification of the 'problem', the broader structure of the field is overlooked. This places the focal point on the consumer and those connections emanating from that person to the surrounding social and physical environment. Absent from such a design is the context in which helping actions occur and the influence of the systematic connections that comprise this context on the assistance offered. Meeting the challenge of cancer the disease and the illness demands an awareness and blending of the competencies of all the players involved. There is no single defined set of coping actions that exists apart from the realities of the context in which coping happens. Whether primarily biologically, psychologically or socially motivated, all helping actions address and influence the totality of the person. Actions directed towards one dimension cannot be realized in isolation from actions directed towards other dimensions. Each participant in the system brings his/her own set of competencies and each controls one piece of the total picture. It is the combined potential of all these parts that must be accessed. Each component in the system is a resource for the other and none can truly realize the 'potential' of its input without the participation of the other.

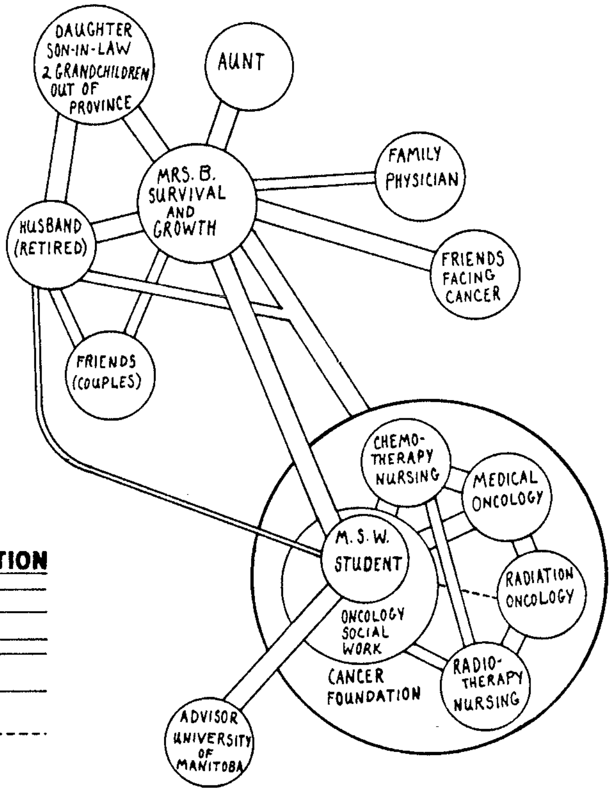


MRS. W
ECO MAP THREE
1981

MRS. Z and MRS. E
ECO MAP FOUR
1981



MRS. B
ECO MAP FIVE
1981



STRENGTH OF CONNECTION

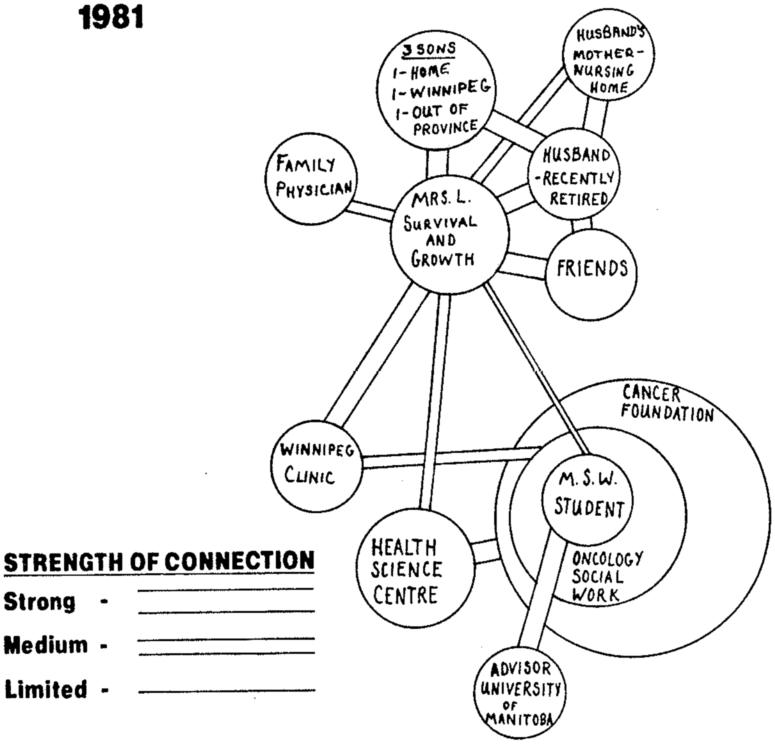
Strong - ≡

Medium - ═

Limited - —

Tenuous - ---------------

MRS. L.
ECO MAP SIX
1981



Chapter 5

FOOTNOTES

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7. Kiresuk and Garwick, "Goal attainment scaling," pp. 412-421.

8. Mrs. E., Personal Communication, November 13, 1981.

9. Mrs. L., Personal Communication, October 8, 1981.

10. Mrs. B., Personal Communication, November 20, 1981.

11. Ibid.

12. Ibid.

13. Ibid.

14. Ibid.

15. Ibid.

16. Ibid.

17. Mrs. B., Personal Communication, November 26, 1981.

18. Mrs. B., Personal Communication, December 10, 1981.

19. Mrs. G., Nurses' Chart Notes, October 6, 1981.

20. Mrs. S., Nurses' Chart Notes, October 14, 1981.

21. Mrs. S., Nurses' Chart Notes, October 21, 1981.

22. Ireys, Henry T., and Burr, Carolynn Keith, "Apart and a part: family issues for young adults with chronic illness and disability," chapter 9, *Chronic Illness and Disability through the Life Span: Effects of Self and Family*, edited by M. G. Eisenberg, L. C. Sutkin, and M. A. Jansen (New York: Springer Publishing Company, 1984), p. 201.

23. Mrs. S., Personal Communication, October 21, 1981.

24. Mrs. W., Personal Communication, October 22, 1981.

25. Mrs. Z., Personal Communication, December 21, 1981.

26. Mrs. B., Personal Communication, December 17, 1981.

27. Mrs. B., Personal Communication, December 10, 1981.

28. Mrs. B., Personal Communication, December 17. 1981.

29. *Ibid*.

30. *Ibid*.

31. Mrs. B., Personal Communication, December 10, 1981.

32. Mrs. B., Personal Communication, November 20, 1981.

33. Mrs. B., Personal Communication, December 17, 1981.

34. *Ibid*.

35. *Ibid*.

36. Mrs. Z., Personal Communication, December 7, 1981.

37. Mrs. Z., Personal Communication, December 21, 1981.

38. *Ibid*.

39. *Ibid*.

40. *Ibid*.

41. *Ibid*.

42. *Ibid*.

43. Mrs. Z., Personal Communication, December 7, 1981.

44. _Ibid_.

45. Mrs. Z., Personal Communication, December 21, 1981.

46. _Ibid_.

47. _Ibid_.

48. _Ibid_.

49. _Ibid_.

*NOTE: Part of the struggle in writing this document was securing a language which portrayed the experience. The word 'consumer' represents one compromise.

Chapter 6

CONCLUSION

Moving into this practicum experience, the author had endeavoured to increase her awareness and understanding of the significance of the situation of illness for the client group involved (i.e., social reality), help negotiate a person-environment fit that could best assist clients in coping with that reality, and improve her interventive skills. Carol B. Germain's (1979) ecological construction of social work practice, its conceptual and interventive tenets, were used to shape the writer's practice approach. Seeing a need to break away from theoretical models of intervention which conceptualized human behaviour from a disease model framework, the author chose Germain's approach because of its stated emphasis on 'progressive forces', 'health' and the 'potential for growth'.[2] Early in the process of applying this interventive mode, however, it became apparent that certain aspects of its theoretical construction were not congruent with the needs and demands of the practice setting or those of the population it served.

Specifically, Germain's problem-oriented focus masked, in deficit terms, the 'progressive force' of the connections formed and the coping actions demonstrated. Within Germain's construction of the ecological approach, distress evidenced 'ineffective coping', while 'effective coping' was represented by a reduction in, or elimination of, stress.[3] Distress, as witnessed by the author in those persons with whom she connected, emanated from the process of reconstruction and growth, not as a blockage to its progress but as a natural part of its forward movement. Its reduction or elimination was neither possible nor, in a number of instances, desirable. Moving forward involved risk, vulnerability and the act of letting go or reshaping some of what had come before--all stress-inducing actions. New learning was occurring. Previous frames of reference were being reworked as they were no longer able to explain or give direction to what was being encountered. While the problem-oriented focus drew attention to the distress which resulted from enacting this process, it did not push the author to see the growth.

Because distress under Germain's model was seen as problematic and antithetical to the growing process, helping actions were directed towards identifying and correcting those behaviours and person-environment fits which generated these negatively valued emotions. Coping actions and the linkages engendered were cast as either adaptive or maladaptive,[4] evoking the need for normative measures in an area where what constitutes effective/ineffective coping has yet to be determined.[5] What was not readily apparent within Germain's construction was that the same action or connection concurrently could be both a strength and a limitation. By centering on the limitations of a given linkage or behaviour, the transactional strength of the connection was overlooked, and with it, the competency of the coping actions. Interventive vision narrowed to locate maladaptive connections and behaviours; rather than broaden to comprehend the structure of the field. The problem-oriented focus, through its concentration on identifying and correcting deficits, restricted social work's entry into the helping network until a blockage in forward movement had occurred or was threatened. Social work competency was therefore limited to the repair of broken and endangered connections, and its vision of the person-environment fit confined to uncovering problematic features of the connections made. The pervasiveness of this focus in Germain's approach is portrayed in a book co-authored with Alex Gitterman, where an entire chapter devoted to influencing the service network is centred on identifying and correcting problematic fits.[6] Passed over in this construction was an examination of the context in which the helping actions occurred with the intent of understanding the transactional strength of the linkages that comprised this context, and their 'combined potential' for 'enhancing' the survival and growth of all the network's participants, including the consumer.

For the author, Germain's focus and entry point were confining and did not address the forward momentum of new learning encountered in the author's linkages with those most directly experiencing the impact of cancer in their lives. In fact, interventive actions structured according to this focus were resisted strongly by consumers who refused to define any part of their struggle to live with the psychosocial impact of cancer as problematic. Delaying social work's entry into the helping network until problems in the psychosocial realms occurred or were threatened, in the author's opinion, short-circuited the use of social work's skill and knowledge for increasing the 'potential' of the system to realize its goals, whether they were directed towards the biological or psychosocial dimensions of personhood. Choosing to begin by concentrating on problems or maladaptations cast prevention as an act of screening for problematic connections or identifying high-risk groups (those most likely to develop psychosocial problems). Opportunities for comprehending and building on the competencies demonstrated were, therefore, missed.

Within the design of the health care system (and the Cancer Foundation), psychosocial dimensions are seen as separate from, and secondary to, the biological dimension. They are viewed as static variables that can be understood independently from their connection to the biological dimension and, subsequently, addressed as such. The idea that all three dimensions must be understood in the context of their relationship to one another was a foreign concept. Hence, attempts by social work to address the manner in which the system comes together to attend to these three dimensions is, at best, perplexing when compared to how the system sees itself accomplishing its function. In the evolution of this paper, an attempt has been made to depict the bio/psycho/social unity of human response to the impact of cancer, the disease/illness and its treatments. In addition, this document has sought to expose as an illusion the belief that the biological dimension can be separated or dealt with in isolation from the the psychosocial dimensions and vice versa. There is a need to unify the mind and body within the organization of the health care system, making it structurally possible to recognize and respond to the bio/psycho/social reality of the situation of illness. This bio/psycho/social reality exists for helper and helpee alike and must be understood in relation to each one's survival and growth needs, and place in the system.

It is this last point that represents the transformation of the writer's original understanding of the client group's social reality. Entering her practicum experience, the author had viewed those persons with cancer and their significant others as comprising this client group. She had seen the development of an awareness and understanding of the significance of the situation of illness for this client group as a necessary step in learning how to negotiate a person-environment fit that could best assist clients in dealing with that reality. Helping persons such as other health care personnel, etc., were viewed as environmental resources to be drawn on when need indicated. Existent in this perspective was an acceptance of the health care system's separation of the mind from the body. At that point the writer saw it as desirable for those primarily responsible for care directed towards the psychosocial dimensions to work collaboratively with those caring for the biological dimension, but felt it was structurally possible to attend to the care needs of the psychosocial dimensions independently of those actions directed towards the care of the biological dimension. This perspective acted to centre the author's attention on the consumer and those linkages emanating from that person to the surrounding social and physical environment. Effecting a better person-environment fit meant effecting a better person-environment fit between the consumer and her/his respective life space and/or health care contacts. The author's and social work's fit with the health care environment was not afforded as much attention.

Working at the interface between person and environment brought the author face to face with the nature of her own and social work's connections with other health care system participants, as well as with the secondary status afforded the psychosocial dimensions. Cancer demanded that those persons with cancer and their significant others expand their social network to include those segments of the health care environment related to the treatment of cancer the disease. New linkages demanded the development of ways of relating to frequently unfamiliar treatment procedures and a hospital environment with its own social organization. All this was happening at a time when the person's survival was threatened by a disease process whose treatment was reliant on the maintenance of these connections. Although the health care system was structured to attend primarily to cancer's impact on the biological dimension of the person, the psychological and social dimensions were automatically influenced and required to participate in the person's response. The total person was affected and the total person responded. And so it was true for the helpers who responded on the basis of their bio/psycho/social reality. Their energy levels, the significance of the situation of illness for them and the form of their linkages with other health care system members all determined the nature of their response to each of the system's participants, helper and helpee alike. Separation of the biological from the psychosocial was not possible; each dimension was affected and affected the other. Yet, in the structure of the system, the psychosocial dimensions essentially were separated and reduced in status from the biological dimension, with the expectation that actions directed towards each aspect could be carried out in isolation from one another. Helping actions were expected to move vertically down the lines of each respective helping discipline towards the person with cancer with minimal horizontal exchange.[7] In fact, all helping actions within the health care structure in which the author participated took place in a social context with both vertical and horizontal exchanges, and every transaction involved the totality of each person to maintain the linkage. Knowledge of the psychosocial dimensions, as well as the biological dimension, were needed and often used by helping persons to direct where and how they connected with each other and particular persons/families in constructing their approach, whether it was biologically or psychosocially motivated. However, because this was not consciously acknowledged by the system or by a large portion of its participants, the combined influence of the bio/psycho/social dimensions was not comprehended, explored or consciously incorporated into the design of what constituted comprehensive cancer care.

The author became acutely aware that no one helping discipline had all the knowledge and skill it needed to realize the potential of its input. Each one needed to draw on and work collaboratively with the competencies of others. The power to shape coping responses was not the sole possession of the person(s) directly experiencing the cancer. Nor could its potential be released simply through the process of engaging in a collaborative relationship with a competent social worker. It required the integrated efforts of all those who controlled a piece of the overall network. The survival and growth issues to be promoted may have been targeted initially through the collaborative efforts of the social worker and those people directly experiencing the cancer, but the process of promotion often necessitated the mobilization of the transactional energies of other network members. Understanding the significance of the situation of illness from the perspective of each member of the overall network was required in order to comprehend the relationship of the transactions to each component's survival and growth needs. Each component's vision of its function and its fit with other network members influenced the performance of the whole and, hence, was reflected in the services offered. Visions of what constituted comprehensive cancer care were not generated solely from the needs and demands of those persons with cancer, but also represented how the larger system understood the significance of the situation of illness and the resources required to meet that significance. This understanding was shaped by the emphasis of each network member's educational and practice background, and position in the network. Hence, in the evolution of this practicum experience, the writer achieved a broader awareness and understanding of the significance of the situation of illness for all those involved, acquiring a beginning awareness of how it all fit together to form the whole of the service design. In doing so, her views regarding social work's helping potential and professional responsibility changed.

It was this larger social reality that social work needed to comprehend and work with. Concentrating on effecting social-psychological changes within and between persons directly facing the cancer experience did not address the potential of the system to assist these people in meeting the challenges of living with a long-term illness. Left at this level, environmental change efforts became localized to specific individuals and the peculiarities of their concerns. The system's approach to cancer care remained unaltered. Coping with cancer entailed far more than receiving biological care. Its psychological and social impact could not be avoided by those persons facing the cancer experience on an intimate level, nor was it successfully eluded by the health care system. The bio/psycho/social reality of human response existed for both helper and helpee. Separating the biological from the psychosocial dimensions and awarding the latter a secondary status in the design of the service approach belied the impact of having cancer and reduced the health care system's helping potential. Attempting to operate hierarchically rather than consciously attending to the horizontal design of the connections made also drained helping potential by de-emphasizing the need for collaborative exchange of the competencies present within the helping system.

Social work's competency and responsibility extend beyond ensuring the provision of practical supports (lodging, money, transportation, etc.) or social-psychological counselling centred on those persons directly experiencing the illness. It has a responsibility to gain, to the extent possible, a global picture of the structure of the system and how the transactions within and between the components that comprise that system, including the consumer of the service, further each one's survival and growth. Negotiating a better person-environment fit necessitates this broadening in perspective. Change that occurs at the interface affects all those who make up the targeted transaction and must be balanced with the needs and demands of their other linkages within the system. Each member of the system forms a piece of the other member(s)' environment and each has its own needs and demands for survival and growth within that system. Before social work can determine the change that needs to occur, and how or where it needs to take place, the profession must comprehend the transactional strength of the actions put forth and their 'combined potential' for enhancing each participant's survival and growth. Confronting cancer is a forward movement that involves new learning. There are challenges to be faced by all those involved--helper and helpee alike. It is the combined effect of the competencies of the players in meeting these challenges that needs to be focused on and enhanced. The goal is to determine the blend of action that can best achieve each one's respective survival and growth needs given the context of their association with one another. This cannot be achieved without a broader understanding of the 'structure of the field'.

The foregoing highlights briefly the process of discovery encountered by the author and the conclusions she drew from her practicum experience. It also proposes a shift in the interventive focus from a problem-oriented construction to a strength- or competency-oriented approach. As stated at the start of this chapter, in constructing her practicum experience, the author had endeavoured to move away from a disease model framework for conceptualizing human behaviour. She had begun this process with two observations based on her review of the literature (see chapter one) and her practice experience up to that time. The first observation was that the power to effect change was a transactional process between person and environment; the second was that even in the face of loss, living with a chronic illness demanded reconstruction and growth. Her intent had been to locate an interventive model that was concerned with the promotion of health and addressed the interplay between person and environment. In choosing Germain's approach which located the 'problem' at the interface between person and environment rather than within the person, and which stressed health and the potential for growth, the author thought she had found an appropriate model. However, moving the 'problem' to the interface only served to move the 'deficit' in functioning from within the person to the connection between the person and his/her environment. The focus still centred on identifying and correcting problems, limitations or maladaptive transactions instead of locating and promoting the transactional strength of the connections made and the actions put forth. What the author encountered in working with persons who were experiencing cancer the illness was a forward movement that did not fit the strictures of 'adaptive' or 'maladaptive'. In response to her struggle to develop interventive skills relevant for social practice in the area of chronic debilitating physical illness, the writer proposed in detail (see chapter two) a strength- or competence-oriented interventive model as an extension of the work already completed in translating the ecological approach to social work practice into action principles. In the formulation of this design, the author has clarified her focus and point of entry into the helping network, and in doing so, has given clarity to her interventive approach in this area. This accomplishes the practicum objective of improving interventive skills.

When eco-maps three to six in chapter five are examined, it becomes evident there was resource potential that was bypassed in the process of the struggle due to the pressures from (and the author's acceptance of) a system which separates the biological from the psychosocial in its design. Clearly depicted in the maps is a shortage of connections between the author and biologically motivated helpers. This represents a separation of those actions directed towards the biological dimension from those aimed at the psychosocial realms. It also indicates that a large measure of the author's helping efforts were restricted to social-psychological counselling which was centred on those persons directly experiencing the cancer. Part of this restriction in focus was due to the narrowness of the author's beginning vision of social work's point of entry into the helping network; however, it was also the product of a system which saw attention afforded to psychosocial concerns as necessary for the individuals directly facing the cancer but not for the construction of the biological treatment plan. Due to the narrowness of the author's beginning focus, she missed opportunities to connect with other health care professionals (i.e., the community health nurse [V.O.N.] involved with Mrs. E. and Mrs. Z.). Yet, in other instances, her interest in working with the broader network was met with confusion; conceptually, this action did not fit with the system's vision of social work's function (for example, Mrs. W. and co-ordinating the communication linkages between health care personnel).

If the bio/psycho/social reality of living and working with cancer is ever to be recognized and its unity addressed from the vantage point of both helper and helpee, social work and the psychosocial dimensions have to move out of their marginal/secondary status and unify the mind and body within the design of the system's service approach. For the Manitoba Cancer Treatment and Research Foundation, comprehensive cancer care has to evolve to mean more than innovative biological care. The psychosocial dimensions need to be attended to in conjunction with the biological dimension . . . not with the intent of identifying problems or those people most likely to experience psychosocial breakdowns, but with the recognition that new learning is occurring. A means of facilitating the forward movement of this process needs to be incorporated into the design of the system. The challenge of living with cancer on a day-to-day basis shapes continued survival and growth in the face of uncertainty, loss and change. This has a bio/psycho/social reality. To meet cancer's challenge, then, the Cancer Foundation must find a way of combining the competencies of each piece of its network to address the whole of the persons concerned. At present the Foundation has pursued this only in regard to the biological dimension. Involved in this proposed shift is a reconceptualization of social work and nursing's functions within the Foundation. They would no longer be viewed only as support staff necessary for the realization of the Foundation's biological goals but would be seen as professionals whose responsibility for and proficiency in addressing the psychosocial dimensions would be combined with the biological competencies of the network to formulate a more unified image of comprehensive cancer care. Such a move would give Oncology Social Work the latitude to broaden its own definition of its place in the helping network beyond social-psychological counselling with those people intimately faced with cancer towards enhancing the potential of the 'system' to assist these people in meeting the challenges of living with a long-term illness. This would mean identifying and promoting the transactional strength of the connections and the coping actions. It would also entail gaining an understanding of the significance of the 'situation of illness' for the survival and growth of <u>all</u> those involved and working to access their combined potential to enhance one another's existence. With other network members, Oncology Social Work would address the manner in which the overall network came together to meet the needs of its service population.

The Cancer Foundation constantly must be aware of how its vision of the significance of situation of illness fits with the needs and demands of those it was created to serve. Any organization set up to meet the needs of a segment of humanity takes on a life of its own in the process. In realizing its own survival and growth, it must respect in others those same needs. It should continue to survive and grow, but not at the expense of any other; it has to move forward in harmony with that other.

As a profession, social work is unique in its commitment to work with the needs and demands of both person and environment in its helping actions. However, in an attempt to create a better fit between itself and its environment, social work too often has surrendered the power inherent in this perspective. It has given up a holistic mode of thought to effect a better blend with the prevailing conceptual orientation of the helping network. North American society is structured to emphasize productivity and labour, and to downplay emotional expression, especially negatively valued emotions.[8] Achievements are measured in terms of their outcomes rather than the process of their realization. Social work practice has tended to concentrate more on 'process' and 'interaction' rather than 'outcome'.[9] It has been, and continues to be, attentive to the connections, an action incongruent with the larger cultural scheme. Susan Watt (1977), in her study of social work's role in the acute-care hospital, portrays social work's struggle to manage this lack of harmony.[10] Social work's 'ideal of care' seems to be constructed differently from that of the larger helping network. Carol Gilligan (1982) contrasts the images of heirarchy and web in tracing out the male and female experience of life. She contends that females see the 'ideal of care' as an act of human relatedness--of perceiving and attending to need, caring through the sustenance of connection (web).[11] Hierarchies structure relationships according to the power of position. In one of these constructions the act of caring evolves from the process of the connection, while in the other it is a function of the position. Thus, an incongruency occurs regarding the channeling of the energies invested in order to realize the act of caring. Social work is a predominantly female-populated profession. Could it be that social work brings a different voice to the health care system, asking it to rethink its perspective of helping?

The ecological approach provides a conceptual framework that allows social work to re-assert its commitment to the totality of the person and express this within the design of its helping actions. By attending to the 'structure of the field', the broader social reality of a situation is perceived, revealing the context of its existence.

Chapter 6

FOOTNOTES

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4. Germain and Gitterman, *The Life Model of Social Work Practice*, p. 12.

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SPECIAL SOURCE MATERIALS

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Oncology Social Work Department. Client Files: "Mrs. L.," September 24, 1981.

NOTE: For reasons of confidentiality, the following source materials will be destroyed subsequent to the acceptance of this document for purposes of graduation from the University of Manitoba's Master of Social Work Program.

Jenson, Kathy, Personal Notes: "Mrs. L.," October 8, 1981, November 17, 1981, December 8, 1981; "Mrs. W.," October 1, 6, 16 and 22, 1981, November 3, 10 and 12, 1981, December 3, 14 and 22, 1981; "Mrs. S.," October 21, 1981.

________, Personal Notes: "Movement through field placement," September 23 and 30, 1981, October 7, 14 and 28, 1981, November 3, 4, 10, 18 and 25, 1981, December 2, 9, 14 and 21, 1981.

Audio Cassettes: Mrs. B., taped sessions, November 20 and 26, 1981, December 10 and 17, 1981; Mrs. E., taped sessions, December 1, 11 and 23, 1981; Mrs. W., taped sessions, November 17 and 20, 1981; Mrs. Z., taped sessions, November 6, 13 and 24, 1981, December 7 and 21, 1981.