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CANCER PATIENTS:
THE REFLEXIVITY OF SOCIAL SUPPORT

by

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ABSTRACT

The interpretation of stressful life events is dependent upon the meaning that individuals construct through interactions with their social support network. Family, friends, neighbours, as well as the medical and helping professions are an integral part of the development of strategies when adjusting to such stress. The past decade has seen a rapid growth in research in the area of social support, emphasizing the importance of social support to the maintenance of health. Recent research has suggested that social support has been found to be critical to individuals coping with major life stressor events.

Studies of social support and illness have focussed their attention on the question of social support as a main effect or buffer against significant life changes. To date, this research has been unable to confirm or disprove either the buffering or main effect of social support. Social support research could benefit by moving away from such an unsolvable question and refocussing efforts on the processes of social support.

In addition, studies of social support have centred their attention on the receipt of support by individuals undergoing stress. The provision of support by individuals

undergoing a health crisis has not been a component of this literature. This view does not take into account the complex nature of social support itself. Social support is an interplay of receipt of support and provision of support by both the social support network and the individual undergoing the stressor event. This thesis examines the bidirectional nature of social support.

Specifically, through 46 interviews with people who have experienced cancer, this thesis focuses on the supportive transactions that occur during this major life stressor event. Interactions between family, friends, and neighbours, as well as participation in social support groups, are explored. It is argued that social support is bidirectional in nature, that is, not only do people receive support during a major life stressor event, but they also provide support to others in their support network.

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CHAPTER ONE

INTRODUCTION

The past decade has seen a rapid growth in research in the area of social support, emphasizing "...the centrality of social relationships and supports to the maintenance of health..." (House et al. 1988:294). This research interest can be traced back as far as Durkheim's (1897 [1951]) study of suicide and the beneficial effects of social integration. Recent research has suggested that social support has been found to be critical to individuals coping with major life stressor events. Alleviation of psychological distress, prevention of illness, and assistance in recovery are all major contributions made by social support networks (Sokolovsky et al. 1978; Kuo and Tsai 1986; Parry 1986).

I. Statement of the Problem

The interpretation of stressful life events (such as cancer) is dependent upon the meaning that individuals construct through interactions with their social support network. Family, friends, as well as the medical and helping professions are an integral part of the development of coping strategies when adjusting to such stress. The reaction of

family and friends to "cancer" can negatively impact the diagnosed individual, particularly when portions of the support network withdraw. Often self-help groups can fill this gap in the social support network, bolstering the individual's self-esteem and support resources by providing information, emotional support and services when needed. However, it has been noted (Plant et al. 1987) that not all patients are willing to attend support groups. At present research has not focussed on this under-utilization of support groups. Why patients do not attend may in part be related to the flexibility of the social support network. As Wellman and Wortley (1990) have pointed out, individuals shop around within their network of family, friends and acquaintances in order to access supportive resources when the need arises.

If a portion of the social support network falls by the wayside, and the individual feels that others can fill the gap, thus ensuring that emotional and instrumental support continues, the threat inherent in the meaning of cancer may be reduced. As a result, the ill person will be partially protected from the impact of cancer through a perceived embeddedness within the support network. It is therefore, important to examine the support transactions that actually occurred during a stressful life event, such as cancer, the interactive nature of those transactions, and the process through which the meaning of cancer is constructed by the person undergoing the stressful event.

Studies of social support and illness (see Croog, Lipson and Levine 1972; Funch and Marshall 1983, 1984; Funch, Marshall and Benhard 1986; Mor 1987; Saunders 1987; Cassileth 1988; Stavraky et al. 1988) have focussed their attention on the receipt of support by individuals undergoing stress. In this body of literature, receipt of support has been conceptualized as the activation of a social support network when an individual undergoes a stressful life event. The interaction between individuals providing and receiving support has not been a component of the social support literature. The prevalent view of social support is simplistic in that it does not take into account the complex nature of social support itself. Social support is an interplay of receipt of support and provision of support by both the social support network and the individual undergoing the stressor event. Therefore, social support must be examined from a perspective that allows the researcher to take into account its interactive nature. In consideration of the complexity of human relationships, this research will focus on the supportive transactions occurring during a major life stressor event.

II. Social Support Literature

In a review of the social support literature, Thoits (1982) addressed the controversy surrounding social support as a main effect or buffer against significant life changes.

Research suggests that social support acts as a buffer only when an individual is undergoing a stressful life event, i.e. cancer. On the other hand, research also suggests that self-esteem and identity develop out of social interaction, which then become important contributors to psychological well-being. Therefore, social support as it "...helps bolster or maintain self-esteem and social identity..." should have a "...direct or main effect upon [the] psychological state" (1982, p. 154). Andrews et al. (1978), and Lin et al. (1979) support the view that social support has a main effect upon psychological well-being. To date, however, this research has been unable to confirm or disprove either the buffering or main effect of social support.

In addition, Thoits points out that there are theoretical, conceptual, and methodological problems in the social support literature. However, this literature at the very least presents social support as an "...important etiological variable in its own right" (1982, p. 155). It is possible that social support not only may act as a buffer against life events, but may also have a role to play as a causal variable. In other words, the level of social support available to an individual may directly effect psychological functioning.

House et al. point out that currently research in the area of social support:

> ...has focussed heavily on two issues: (a) whether the quantity and quality of social relationships are causally related to health; and (b) whether social relationships benefit health principally via buffering (also termed moderating or interactive) effects on the relationships between stress and health or via main (or additive) effects on health. (1988, p. 295)

As a consequence, much of the research into this area has attempted to address "...the issue of buffering versus main effects" (House et al. 1988, p. 295). To date, research examining this issue has "...yielded inconsistent results (Lin et al. 1985, p. 247). That is, although studies consistently find evidence of either a main or buffering effect of social support, a uniform effect of either type of support has not been found (House et al. 1988, p. 295). It is time now to turn from the question of buffering or main effects and to examine the processes of social support. As House et al. state:

> ...it now seems that the more appropriate research question is not whether both effects exist but when, how, and why each occurs. (1988, p. 295)

The processes of social support will, therefore, be the major focus of this research. By examining the interactions between cancer patients and those who provide them with support, such processes can be laid bare.

Role of Kin and Non-Kin

The family, as significant parts of the social support network, can act as an intervening agent between the

individual and the life event or illness (Ensel 1986). However, in times of extreme life stress, such as cancer, a family may undergo a considerable amount of stress in response to a member's diagnosis and be unwilling or unable to provide the social support the individual requires. Research indicates that those experiencing psychological distress invoke distress in those with whom they have contact (Coyne 1976; Strack and Coyne 1983; Coyne et al. 1987) which can lead to a withdrawal or avoidance of contact. Psychological distress can be a reaction to a negative life event (Glick et al. 1974; Wortman and Silver 1987). Consequently as an individual undergoes a negative life event, interactions with other family members may lead to distress within the family itself. In times of extreme stress, when the family cannot respond, non-kin ties can effectively provide the required support (Lin et al. 1979, p. 110). Such ties can provide mediation between stress and illness that would normally be expected of family relationships. To ignore this non-familial portion of an individual's social support network "...may miss as much as half of what is occurring..." (Morgan 1989, p. 106).

Social support does not necessarily come from one universal source. Ideally, the individual has a social network that allows varying responses from a number of different relationships within the network that are tailored to specific stress situations (Morgan 1989). Friendship

relationships, during a stressful life event, can be seen to provide a greater degree of social support than a kinship network (Croog et al. 1972). Such non-kin relationships provide the individual in crisis with the opportunity to create a pattern of flexibility within the support network. This flexibility provides the individual with the ability to draw those who react positively into the social network, while dropping those perceived to react negatively. Those undergoing stress engage in "therapeutic withdrawal" when a portion of the social network itself is perceived to be contributing to the stressful condition (Morgan 1989; Tolsdorf 1989). Thus, social support that is not provided by family can be accessed through a non-kin social network that can be altered, expanded or contracted, according to the needs and perceptions of the individual experiencing a life crisis. In consideration of the importance of support from family and friends, and the possibility that friends can provide what family may be unable to contribute during a time of crisis, support from family and friends has been incorporated into this study. Additionally, the utilization of cancer support groups is also integral to this study.

Effectiveness of Social Support

Utilization of social support cannot occur unless the individual perceives that it is available. Social support, therefore, does not depend exclusively upon the response of

family, neighbours or friends, but, more significantly, upon the perception that the support itself exists.

> ...effects of social support are linked more to *perceptions* of support than to the actual behaviors of others -- i.e., *received* support... Even if the behavior of others suggests the presence of support, if a person does not perceive support to be available, it cannot be used. (Aaronson 1989, p. 4)

Research suggests that perceived support may, therefore, be much more important than received support, since the utilization of support is dependent upon the perception of its existence (Wethington and Kessler 1986; Aaronson 1989). However, for the individual undergoing a negative life event, expectations of social support may not be forthcoming. The suggestion made by some researchers is that individuals undergoing a negative life event may raise the discomfort level of those with whom they interact resulting in avoidance of contact (Silver and Wortman 1980; Dunkel-Schetter and Wortman 1982; Wortman and Lehman 1985).

An individual undergoing a stressful life event does not automatically become the recipient of solicitous actions from family, friends and associates. The level of involvement and concern that exists within a relationship mediates the degree of social support the needy individual receives.

> ...being embedded in a network is only the first step toward having access to support; the final step depends on the *quality* of the relations one is able to find within the network. (Pearlin et al. 1981, p. 340)

Critical variables in a supportive relationship appear to be

intimate communication and a sense of solidarity or trust (Pearlin et al. 1981; Lin et al. 1985). Quality of social support is closely linked with an emotional content (Jacobson 1986). Emotional support is effective in reducing anxiety that arises in the presence of a threatening situation (i.e. cancer) which preciptates a "psychosocial transition" (Jacobson 1986; Pearlin et al. 1985; Thoits 1983). Therefore, the social support system is built around an individual's requirement for security and comfort; however, the network is not called upon to provide such needs until the well-being of an individual is threatened (Jacobson 1986). Cancer is such a threatening situation since those with cancer are faced with an uncertain future or the possibility of a much shortened life-span. This should lead cancer patients to activate their social support network, presenting this study with an opportunity to examine the quality of supportive interactions.

Significance of Crisis

An individual's coping resources are sorely tested according to the severity of a single undesirable life event, or number of events experienced. Thoits suggests that the "...crucial quality of life events is believed to be their undesirability..." (1983, p. 57). The greater the perception of undesirability, the greater the threat to "physical survival" and psychological well-being. This perception of severity of threat:

> ...may be the result of the meanings people attach to, or the cognitive interpretations people make of, events and their aftermaths with respect to the self. (1983, p. 83)

This threat to physical survival and psychological well-being is mediated through an individual's social support network so that the individual regains a sense of self-worth, control, or a combination of each.

Sociological research in the area of social support to date has concentrated on perceptions of support. Surveys have been conducted inquiring into individual expectations of social support should a crisis - financial or otherwise - occur. However, what is perceived to be available if a crisis occurred may, in fact, not be the same as what is received during an actual crisis. Perceptions based upon expectations may be altered by the significance of the crisis, and therefore the perceived availability of social support, as well as the meaning attached to the stressful life event, may alter received support. In consideration of this possibility, the effect of both perceived and received support may be more fruitfully investigated through a particular life event, such as cancer, rather than through generalized surveys (Wethington and Kessler 1986).

IV. Social Support and Theory

An examination of the social support transactions that

occur during cancer can proceed from a number of theoretical perspectives. Functionalism, network analysis, and symbolic interactionism can all be brought to bear in the area. Each perspective, however, has its shortcomings and deserves close scrutiny in order to apply the most appropriate theoretical model.

Functionalism

Talcott Parsons and Rene Fox (1951) conception of the sick role is one perspective that has taken a central position in medical sociology, and has been used more consistently than any other paradigm. Parsons assumed that although the individual does not make deliberate and informed choices to become ill, illness:

> ...must be considered to be an integral part of what may be called the "motivational economy" of the social system...(1951, p. 146)

Illness can be seen, therefore, as a "deviant behavior," drawing the actor to the sick role in order to avoid obligations and responsibilities. It becomes the duty of the medical establishment to provide therapeutic care in an effort to reduce or control such deviant behavior and restore societal equilibrium.

For Parsons and Fox, illness is a social role with criteria guiding both the ill actor and those actors with whom he or she interacts. This interaction is conducted within those social norms that define appropriate behavior for the

actors in the sick role. Parsons and Fox identified four criteria of this role. First,

> ...the exemption of the sick person from performance of certain of his normal social obligations. (1951, p. 150)

This exemption is dependent upon the perceived severity of the illness and legitimation from an authority (the physician). Society is thus protected from the possibility of "malingering...the sick person's claim to exemption must be socially defined and validated" (1951, p. 150).

The second criteria defined by Parsons and Fox is:

> ...the sick person is, in a very specific sense, also exempted from a certain type of responsibility for his own state. (1951, p. 150)

Although the actor may be conceived of as responsible for her/his illness, s/he cannot be expected to will her/himself better. S/he is considered to be in need of outside assistance, and therefore cannot be held responsible for the recovery process, "...except in a peripheral sense" (1951, p. 150).

The third criteria applicable to the sick role is:

> To be sick...is to be in a state which is socially defined as undesirable, to be gotten out of as expeditiously as possible. (1951, p. 150)

It is incumbent upon the actor to recognize that s/he is sick and bring everything to bear in an attempt to return to "normal." Thus, the actor is obliged to get well as quickly as possible.

Finally,

> ...the sick person makes the transition to the additional role of patient...incurs certain obligations, especially that of "co-operating"... (1951, p. 151)

The actor therefore becomes obliged to seek out the services of a physician and co-operate in all efforts to return herself/himself to a state of wellness.

Social roles, attitudes and activities structure the physician-patient interaction within a framework.

> The sick role evokes a set of patterned expectations that define the norms and values appropriate to being sick, both for the individual and for others who interact with the person. (Cockerham 1978, p. 93)

Both the role of the physician and the role of the patient are thus dependent upon the expectations of the other. The patient is motivated toward reestablishing as state of wellness and the physician's role is to "...return the sick person to his normal state of functioning" (Cockerham 1978, p. 93). The social interaction between the patient and physician is, therefore, well-defined and instrumental in structure, resulting in stable and predictable action.

Parsons and Fox can be criticized on four fronts:

1) behavioral variation

2) types of illnesses

3) physician-patient relationship

4) middle class orientation (Cockerham 1978, p. 97)

Contrary to the model, expectations of and behavior toward the sick role has been found to vary between persons and social groups (Gordon 1966; Mechanic 1962; Twaddle 1969;

Zborowski 1952). The model also appears to apply only to acute, temporary, recognizable illnesses that are easily overcome with appropriate medical attention (Birenbaum 1981; Cockerham 1978; Twaddle 1978). The third area of criticism lies in the traditional conception of the physician-patient relationship. The one-to-one interaction between patient and physician conceived by Parsons and Fox is considerably altered in the hospital or family setting. Finally, this is a middle-class model emphasizing individual responsibility, motivation to return to health, and rational problem solving resulting in positive gains. It does not take into account lower economic conditions where denial of the sick role is common and success is an exception to the rule rather than a common occurrence (Cockerham 1978).

There is, however, another criticism of Parsons and Fox's model, that needs to be addressed. The realities of individual actors' lives may not allow them to be exempted from their normal familial duties when they become ill. In their family role, they may see their adoption of the sick role as abandonment of those duties and, therefore, attempt to retain that role in an effort to maintain the "normalcy" of the family atmosphere. This would suggest that Parsons' sick role is an inappropriate model of illness for this particular research.

Network Analysis

Network analysis is extensively used by researchers to examine social support and social networks, and focusses on the central importance of social relationships in the promotion and maintenance of an actor's health. Social support studies assume that individuals with numerous contacts and frequent interactions with others will maintain greater health and longevity due to the quality and structure of the network.

> Networks of small size, strong ties, high density, high homogeneity, and low dispersion appear to be helpful in maintaining social identity and hence health and well-being outcomes when these are promoted by identity maintenance. (House et al. 1988, p. 304)

The focus is on a number of aspects of relationships in which people are embedded.

1) An individual's connectedness to others is fluid, with people simultaneously involved in a number of different networks, serving varying purposes, and structured in alternative ways.

2) For a given individual, the consequences of participation in a variety of different networks is not self-evident.

3) Contrary to more traditional theoretical social-disorganization perspectives, social bonds are not disintegrating but instead new types and styles of social ties are being created continually.

Network analysis presents an evolutionary perspective, in that society is viewed as adapting to change by replacing old bonds with new ones based on shared interests, becoming less territorial and more relational in orientation (Goldenberg

1987, p. 92-98).

Studies utilizing the network analysis approach have become an active area of research over the past several decades. However, this approach, despite its original inductive orientation, relies to a considerable extent on "...mathematical models and statistical methodologies" (Fine and Kleinman, 1983, p. 97). As Goldberg (1985) has suggested, in order to improve research design in the social support area an alternative theoretical perspective needs to be incorporated.

Symbolic Interactionism

Symbolic interactionism provides a major theoretical perspective which allows the researcher to examine how an individual's interactions with the support network helps structure the meaning of cancer and subsequent action in light of that meaning. Fine and Kleinman (1983) suggest that symbolic interactionism can help redefine social support networks as networks continually in a "...state of dynamic tension" (p. 100) with the possibility that:

> ...changes in the meanings of relationships may constrict or expand the range of possible behaviors -- behaviors which can be used in other relationships." (p. 100-101)

Symbolic interactionism rests on three premises:

1) ...human beings act toward things on the basis of the meaning that the things have for them. (Blumer 1969, p. 2)

Everything one takes note of in her/his world, physical, other

persons, categories of people, ideas, institutions, actions of self and others, as well as situations is imbued with meaning. Meaning, however, is not intrinsic to a thing but is instead part of social interaction. Therefore,

> 2) ...the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. (Blumer 1969, p. 2)

Society is made up of the interaction among individuals. Group members actions are created in response or relation to one another, and are taken primarily for granted. This interaction is the "...process that forms human conduct instead of being merely a means or a setting for the expression or release of human conduct" (Blumer 1969, p. 8). Therefore, individuals must take into account the behaviours and anticipated behaviors of others in structuring their own actions. Consequently,

> 3) While the meaning of things is formed in the context of social interaction and is derived by the person from that interaction, it is a mistake to think that the use of meaning by a person is but an application of the meaning so derived. (Blumer 1969, p. 5)

The individual interprets meanings derived from social interaction, and thereby modifies those meanings in order to provide her/himself with a guide for future action.

Funch, et al. (1983) note:

> ...the classification of events as undesirable ...involves the individual's interpretations of events and his reactions to these events, which may be shaped by the individual's social and personal coping resources. (p. 77)

The reaction of an individual's social support network can reinforce previously conceived meanings about cancer, or alter those meanings, as well as alter an individual's response to treatment.

Building upon these three premises of symbolic interactionism, Goffman (1959) suggests that social interaction is viable only when information is available about partner(s) in a joint act. Communication of information occurs through:

> 1) a person's appearance
> 2) a person's experience with other similar individuals
> 3) the social setting
> 4) information communicated by an individual about him/herself through words and actions (Cockerham 1978, p. 48)

The fourth category is the most important, since individuals are able to control information about themselves and can set the "stage" indicating in advance what is expected from others. This is Goffman's "impression management."

Impression management can be seen in the hospital patient who is cheerful and entertaining to visitors. The expectation is that the visitors will reciprocate, relieving a stressful situation and giving the impression that the patient will soon be well.

Symbolic interactionism also emphasizes the role of the self as part of social interaction. The self has two roles to play:

> 1) ...the self as an image of a person formed from the flow of events in an encounter and

2) ...the self as a kind of player in a ritual game who copes judgmentally with a situation. (Cockerham 1978, p. 49)

To individual actors the self is sacred, representing who and what they are. Stress or embarrassment is incurred when the self's integrity becomes subject to question. When individuals display their special self, they place in jeopardy the self they have nourished over a lifetime. If individuals perceive that they are not fulfilling the expectations of a particular role stress is incurred (Goffman 1959). Therefore individual actors may attempt to modify the meaning of cancer patient by creating a self that belies the seriousness of the condition.

Toward a Theoretical Synthesis

Fine and Kleinman (1983) have suggested the use of network analysis might provide symbolic interactionism with a tool to link individual behavior to the macrosocial structure. They contend that despite the tendency of network analysts to consider themselves structuralists, and their reliance on mathematical models and statistical methodologies, network analysis more closely approximates symbolic interactionism. Both approaches emphasize relational aspects in the construction of social order through "...meaningful, self-other interaction" (p. 97).

Symbolic interactionism's reliance on the concept of groups potentially presents two problems:

1) ...the concept tends to imply that group membership is unproblematic and stable.
2) ...conceiving of the group as a behavioral arena precludes consideration of individual's multiple group memberships (Fine and Kleinman 1983, p. 98)

In order to avoid a structuralist approach, group behavior must been seen as "...dynamic, flexible, and open." Concepts developed by network analysis, such as action-sets and quasi-groups, acknowledge that a group cannot exist independent of members participation, and participation is contingent on favourable circumstances. Thus groups can be reconceptualized as "...population systems in which 1) the density of relationships is high and 2) relationships are activated simultaneously (Fine and Kleinman 1983. p. 99). This conception closely approximates Blumer's lines of action:

> The actions of others enter to set what one plans to do...One has to fit one's own line of activity in some manner to the actions of others. (1969, p. 8)

Consistent with the symbolic interactionist perspective of a dynamic social structure, network analysis recognizes that the individual actor has choice in her/his behavior and through those choices, not only produces but has an impact on the social structure. This possibility of change is produced through the continual negotiation of members. The process of assignment and modification of meaning, constant flux becomes an integral part of social relationships. Thus there is a probability that contraction or expansion of the behavioral range across various relationships may alter when meanings

change within other relationships (Fine and Kleinman 1983).

In her/his network ties, the individual actor assigns meaning, interprets and modifies those meanings through positive and negative responses from other members, and uses these modified meanings to further structure her/his action. By referring to anticipated responses from members of the network, the individual actor's perception of her/his specific ties' responses will influence subsequent action.

By synthesizing symbolic interactionism and network analysis the researcher can examine the meaning imputed by actors and how that meaning:

1) reproduces or challenges divisions in the social structure,
2) structures the perceptions of the network as a whole,
3) is brought to each tie - formal or informal and the expectations that arise as a result,
4) is diffused throughout the social network itself.

> By conceiving of the social network as a negotiated, meaningful, cognitive resource for interaction, we can use it to understand how social structure affects behavior and the construction of meaning. (Fine and Kleinman 1983, p. 103)

Fine and Kleinman argue that the focus on action in symbolic interactionism extends to network analysis the ability to focus on relationships, segments of the network, and the network as a whole and the construction of meaning through processes inherent in interaction. These meanings can

then be seen as guidelines in collective action choices and anticipated behavior of others.

Through this approach, interactionist research can be directed in a number of areas:

> 1) ...by examining people's perceptions of their social network, interactionists can study how social structure affects individual behavior: constraints, expectations, and how these beliefs consequently structure individual and collective action.
>
> 2) ...individuals participate in relationships, which provide them with opportunities for expression and action...ground[ing] the network construct in the "real world," where people interpret and act (interact), not only "behave."
>
> 3) ...network orientation allows interactionists to examine the process of diffusion throughout a large social system: i.e. information might be conceived as diffused through closed systems connected by open linkage ties. (Fine and Kleinman 1983, p. 106)

According to Fine and Kleinman, through the incorporation of network analysis as part of the conceptualization of research problems interactionists can expand their research to areas formerly considered inappropriate for study, such as "...widespread communication channels, individual attempts to change the social system, systemic effects on individual behavior" (Fine and Kleinman 1983, p. 106).

Although Fine and Kleinman have presented a strong case for the synthesis of network analysis and symbolic interactionism, their emphasis on the individual actor's influence on the social network is the converse of network analysis' emphasis on the social network's influence on the

individual actor. Consequently, what Fine and Kleinman propose is a repositioning of network analysis to fit into symbolic interactionism's conception of the social structure. For example, rather than looking at social support from a structural point of view, i.e., what support resources are provided by the social network and how does the structure of the network promote or restrain the provision of support, social support should be examined from the individual actor's point of view, i.e., how the actor modifies and restructures the social network. In sum, Fine and Kleinman are suggesting the extension of symbolic interactionism into new areas of research previously considered inappropriate for this perspective.

Summary

In agreement with Fine and Kleinman, it is this researcher's belief that symbolic interactionism may well bring new insight into the social support literature. It is therefore, the purpose of this research to examine social support from a symbolic interactionist perspective, using grounded theory as a vehicle of investigation. Grounded theory (Glaser and Strauss 1967) has been used extensively by symbolic interactionists since it accepts the basic premises of symbolic interactionism (Schwartz and Jacobs 1979). Therefore, it is an appropriate methodological approach for this study, and will be discussed in greater depth in Chapter

Two. Additionally, the implications for research of the synthesis of symbolic interactionism and network analysis will be discussed in Chapter Seven.

In consideration of the focus of past research, this study has concentrated on the supportive transactions between those who are undergoing a life crisis event, cancer, and their family and friends. In addition, their reasons for participation or non-participation in cancer support groups has been examined. Cancer as a life-threatening event sets the context of these supportive transactions, therefore, the examination of the interpretation and reinterpretation of cancer is integral to this research.

This thesis will be developed as follows. Chapter Two will be a discussion of the methodological approach used to study these supportive transactions. Chapter Three will examine how cancer patients modify the meaning of cancer in an effort to gain control over a threat to their ability to control the circumstances of their lives. The supportive transactions that occurred with family members, both nuclear and extended, will be the focus of Chapter Four, while Chapter Five will examine interactions with friends. In Chapter Six the focus will be on participation and non-participation in two cancer support groups. Chapter Seven will provide a conclusion as well as discuss implications for further research in the area of social support.

CHAPTER TWO

RESEARCH DESIGN AND METHODOLOGY

The purpose of this research is to examine the actual support transactions that took place during a negative life event: cancer. The method adopted for this research is exploratory and qualitative. Previous research has overwhelmingly been quantitative in orientation, and consequently cannot examine:

1) the support transactions that occurred
2) the nature of those transactions
3) the process of redefining the meaning of cancer.

In order to examine these processes a qualitative methodology was required. Baltrush (1985), Saunders (1987), and Stavraky (1988) have all noted the need for qualitative analysis in this area of research. Such a methodology provides for richer responses at the respondent level, providing greater detail concerning individual conceptions of social support, as well as the process by which individuals access this support. Symbolic interactionism, the guiding theoretical perspective for this research, is congruent with a qualitative orientation, relying upon the individual's own interpretations and perceptions, providing the opportunity to focus on the actor's perceptions of what actually occurred rather than expectations of support should a crisis occur, the focus of

past research.

I. Conceptualization of Social Support

Before any research could be done in this area, a clear conceptualization of social support had to be provided. Lin et al. (1986) provide a generalized definition of social support as "...forces or factors in the social environment that facilitate the survival of human beings" (p. 17). However, a much more exacting definition is necessary for the purposes of research. By dissecting the concept, it can be noted that the social aspect links the individual to three levels of the social environment: community, social network and intimate relationships. Moreover, support provided by these three sources is composed of both instrumental and expressive actions. Lin et al. suggest that perception must also be incorporated as an integral part of the definition of social support. Therefore social support is defined as "...the perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and confiding partners" (1986, p. 18).

The expressive component of social support, following Thoits (1982), is defined as "...socioemotional aid (e.g., affection, sympathy and understanding, acceptance, and esteem from significant others)..." while the instrumental component of social support is conceptualized as "...advice, information, help with family or work responsibilities,

financial aid" (p. 147).

II. The Semi-Structured Interview

Qualitative researchers have developed a number of strategies in order to reconstruct the experience of research respondents. These strategies include participant observation, analysis of personal accounts, reconstruction of life histories, and open-ended or semi-structured interviews. The most preferred theoretical approach for these methodologies has been symbolic interactionism (Schwartz and Jacobs 1979).

Participant observation of cancer patients undergoing treatment and interacting with their social support network is a very problematic if not impossible task to perform. Since medical records are confidential, and therefore unavailable to this researcher, this was not a possible avenue of investigation. Semi-structured interviews were considered a much more appropriate approach, allowing the interview to begin in a moderately structured manner while still allowing the respondents to provide as much information as they felt willing to disclose. It was felt that through this method of interviewing an additional strategy would be incorporated: personal accounts of their experience would be an integral part of the interview.

Interviews were conducted over a period of eight months; from January to August, 1990. Each interview ranged from one

to four hours in length, with the respondent setting the pace and tone of the interview. The time and location of the interview was at the respondent's discretion. With a few exceptions, interviews were conducted in the resondent's home. Of the 46 interviews, three took place in the respondent's business office, three were conducted in the researcher's home, and one over the telephone. Since the location of the interview was selected by the respondent, it was felt that an atmosphere of comfort and control was provided for the participant.

Each interview was recorded with the permission of the interviewee. Since the researcher also has a knowledge of shorthand, this method of recording was used on the three occasions when the recorder failed. As recommended by Schwartz and Jacobs (1979), recording interviews allows the researcher "...to concentrate on the interview without distracting the respondent (or himself) by taking notes and still retain all that the respondent related" (p. 43). A cautionary note they express is the possibility that this procedure might intimidate some respondents, as well as the interviewer. In order to minimize this possibility, a small recorder was used and an emphasis was placed on the complete voluntariness of its use. In addition to the inconspicuousness of the small recorder, eye contact was maintained with the interviewee throughout the interview, further minimizing the presence of the recorder. Eye contact

not only demonstrates the interest the interview holds for the interviewer, but also by ignoring the recorder, except to check the tape occasionally, it suggests to the interviewee that he or she can also disregard its presence.

A drawback mentioned by Schwartz and Jacobs (1979) is the possibility that the interviewer may become somewhat inattentive since she will have a complete spoken record of all that transpired. An understanding that this can be problematic helped to maintain a high level of attentiveness during each interview.

Interview questions were structured in such a manner as to be very general so that respondents had as much freedom as possible to include what they felt was a significant part of their experience. Information that is unsolicited, provided voluntarily by an interviewee, has greater validity than information that is structured by a response to a specific question (Becker 1957). In this manner, it was expected that the responses of the participants would have greater validity than responses that might be provided by narrowly defined questions. By allowing the interviewee to provide what he or she felt was significant, new information could be collected that would not be available otherwise. Rosenblum (1987) refers to this as "fresh talk." If the social science interview can be conceived as a continuum with a "professional" demeanor at one end of the continuum and a "personal" demeanor at the other end, as the interviewer moves

toward a more personal mode of interviewing "fresh talk" will occur within the context of the interview. Rosenblum states at a minimum,

> ...when an interviewer produces brief exclamations, asides, or encouraging subvocalizations, s/he moves the interaction somewhat away from a purely professional model, while still encouraging the respondent's production of utterances. (1987, p. 390)

In order to encourage fresh talk, the interviewer moved away from the purely professional social science interview while still attempting to maintain enough distance from a personal model of interviewing to maintain the integrity of the interview. In a discussion of techniques for interviewing women, Oakley (1981) encourages scholars to adopt a much more interactive style of interviewing, incorporating the willingness to respond to inquiries directed toward the interviewer by the interviewee. For example, interviewees periodically would inquire into the researcher's experiences during an interview:

> Did this happen to you?
>
> Do you know what I mean?

Although this may appear to inject bias into the interview, we must always be aware that the interview itself is an interaction that does not stand outside the respondent's experience but becomes an integral part of that experience and therefore can itself bring meaning to not only the research but the respondent's "world."

In his discussion of interviewing style, Dijkstra (1987) concludes that "...the style of interviewing (personal versus formal) affects the motivational level of the respondent rather than the tendency to ingratiate oneself with the interviewer" (p. 330). Therefore, interviewers who demonstrate their interest, empathy, and willingness to engage in an interactive situation initiated by the respondent may increase the motivation level with little or no resulting tendency toward ingratiation. This provided the researcher with the opportunity to respond to interviewees' questions, thus motivating them to share their experiences. The level of rapport between interviewer and interviewee was deepened through this technique. In addition, fresh talk became a common experience during interviews.

III. Data Analysis

Each interview was transcribed verbatim for data analysis. In order to analyse systematically qualitative data, Glaser and Strauss (1967), Glaser (1978), and Strauss and Corbin (1990) have developed the constant comparative method. Altheide summarizes this method of data analysis as:

> ...[a] reflexive movement between concept development, sampling, data collection, data coding, data analysis, and interpretation. The aim is to be systematic and analytic, but not rigid. (1987, p. 68)

Sampling and interviewing are conducted until the data collection no longer makes a contribution to and understanding

of social support. At this point, it was felt that the categories developed during the process of interviewing were sufficiently saturated and subsequent interviews were not contributing to an extended understanding of these categories. That is themes that had developed in earlier interviews were being repeated and confirmed by succeeding interviews. For example, in early interviews it was noted that social support was a two-way process. As interviewing progressed, this theme was continually noted and developed until no new information about this two-way process was gathered.

Data analysis through the constant comparative method (Glaser and Strauss, 1967, pp. 101-115) allowed for the identification of additional important areas of concern. Through this method the researcher was provided with the flexibility to incorporate new respondents in the sample. As interviewing progressed it became apparent that the experience of male cancer patients would be an important point of comparison in the development of themes of provision and receipt of support. Since this concern occurred early in the process of data collection, it was possible to obtain and interview male respondents.

Open coding, axial coding, and selective coding are all important processes in the constant comparative method. Open coding is "[t]he process of breaking down, examining, comparing, and categorizing data" (Strauss and Corbin, 1990, p. 61). Axial coding is "[a] set of procedures whereby data

are put back together in new ways after open coding, by making connections between categories" (Strauss and Corbin, 1990, p. 96). Selective coding is "[t]he process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (Strauss and Corbin, 1990, p. 116). This method strengthens qualitative research as a scientific endeavour by establishing a systematic approach to a difficult method of data collection and analysis. The objective of such research is the discovery of new theoretical concepts and propositions. Here these are woven into a grounded theory of perception of social support among adult cancer patients that remains true to the data.

IV. Grounded Theory and Fresh Talk

Since the objective of grounded theory is the discovery of new theoretical concepts and propositions, the incorporation of a style of interviewing that allows for fresh talk facilitates this process. The conversational mode of this style of interviewing allows interviewees to provide unexpected information, for example:

> Researcher: Is there anyone in your family you talk to in addition to your husband?
>
> Interviewee: My mum and dad. Their reaction was shock. My father was really mad, he wouldn't talk about it...
>
> Researcher: Your dad's having a little bit of difficulty?

> Interviewee: Yes, he's better now, he's talking on the phone now...I was just so frustrated and it was just this big black fog that nobody would help me out of, and so he's coming around...
>
> Researcher: So I gather it helps a lot to talk to your family?
>
> Interviewee: Oh yah. I want to do as much to reassure them as much as I can.

As a result of this and similar exchanges, the bidirectional nature of social support became explicit. In subsequent interviews, the researcher was able to listen for similar statements, and incorporate questions relating to the provision of support by the cancer patient. Interviewees were encouraged to provide in depth information about their participation in the provision of support to others. This fostering of fresh talk became an integral part of the development of social support as bidirectional.

V. The Sample

Respondents for this research were obtained through multiple sampling procedures. A purposive sample was obtained from two cancer support groups, Cancermount and Reach to Recovery (both affiliated with the Canadian Cancer Society). In addition, participants were gained through snowball sampling (participants referred to the researcher through mutual friends), as well as newspaper advertisements (exclusively male participants were obtained in this manner).

An alternative method of sampling was considered before beginning the interviews. At first it was felt that a simple

random sample could be obtained from the Tom Baker Cancer Centre's list of currently active patients. However, in discussion with a member of Psychosocial Services, it was determined that the research orientation of the Tom Baker Cancer Centre is predominantly quantitative. Therefore, this research would have had to be redesigned to accommodate that orientation, compromising the original intent of the project. In addition, it became apparent that the Ethics Committee at the Tom Baker Cancer Centre would not welcome research that the gave the appearance of a psychological orientation, defined as delving into a respondent's feelings about their social support system, particularly when the researcher was a sociologist rather than a member of the medical profession.

Another consideration connected with using a list of patients supplied by the Cancer Centre was the possibility that the patient list would not be complete since those patients who were felt to be a possible psychological risk, that would be exacerbated by participation in this study, would not be included. This could become very problematic if the definition of psychological risk was applied to a large number of patients. As a consequence, without access to all the patients so that each and every one has a fair and equal chance of selection, the integrity of the sample is compromised. In consideration of the research orientation of the Tom Baker Cancer Centre, and the possibility that, had the proposal passed the Ethics Committe, control of who was or was

not included on the patient list would be out of the hands of the researcher, it was decided that this was not an acceptable method of sampling, and a purposive sample would more readily facilitate the research.

To obtain participants from Cancermount and Reach to Recovery, letters were prepared explaining the purpose of the research project and soliciting participation from the membership. These letters were distributed at two meetings of each of the groups. In January 1990, each support group received 40 copies of the solicitation letter which requested that if individuals wished to participate they contact the Researcher. No one volunteered to participate. It was then decided that a better approach would be to attend the group meetings in order to present the research and solicit participation. At a second meeting of Cancermount, in February 1990, the researcher attended and presented her objectives and solicited the participation of the membership. This resulted in 15 individuals volunteering to participate in the study. It was concluded that the members themselves felt more comfortable volunteering to participate in a study when the researcher was known to them, disclosed the purpose of the research, and indicated that she was a former cancer patient as well. This established a situation of trust, and began the process of developing rapport with potential interviewees.

Although the presence of the researcher could be seen as a pressure to participate, the presentation of the research

project was made in a very low key manner. The voluntary nature of the research was stressed. The decision to participate was then left with the membership without further comment. It can, therefore, be stated with confidence that the pressure to participate was at a low level. The presentation lasted only 10 minutes and the membership immediately adjourned for coffee, creating an atmosphere in which they could approach the researcher to participate or go about other business. This was the same approach that was used at the June 1990 training session of Reach to Recovery. No one from Reach to Recovery volunteered to participate in the study until the researcher gave the same presentation to a training session of new members. At this meeting 14 individuals volunteered to participate, of which four later withdrew for various reasons, predominantly time related.

Ten participants were obtained through a snowball sample. These were individuals who were contacted by friends of the researcher, informed of the research and asked if they were interested in participating. Only one individual who had agreed to participate later withdrew. She indicated she regretted her decision to participate and, in order to remove any pressure to participate, the decision was accepted and she was assured that this was not a problem.

This approach to snowball sampling allows respondents to make their decision with little or no pressure from the researcher. A negative decision can be made without the

knowledge of the researcher, minimizing any feelings of obligation since there is no contact until after the decision to participate has been made.

All but five male respondents were obtained through newspaper advertisements[1] in the *Calgary Herald*, the *Mirror*, *Neighbours*, the *Calgary Sun*, and the *Bargain Finder Press*. Fourteen male participants responded to the advertisements. The remaining five male participants were obtained through Cancermount (four) and the snowball method mentioned above (one). The advantage to the respondent of participating through advertisements lies in the complete voluntariness of participation. There is no pressure whatsoever from the researcher to participate, since the researcher is present only symbolically in the advertisement. The respondent must contact the researcher and therefore his or her anonymity is assured until he or she voluntarily discloses it. One interview was conducted over the telephone because the participant felt obliged to maintain his anonymity.

This method of sampling presents the opportunity to interview respondents who would not otherwise participate. For example, one male respondent was interested in participating in the research because he had no relationship with the researcher. Since he would only be in contact with the researcher during the duration of the interview, he felt

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[1]UofC researcher would like to interview cancer patients either in treatment or remission. Please call 239-1491.

he did not have to bear the consequences of possible comments that might hurt or offend a spouse, relative, or friend with whom he would have to maintain a continuing relationship. Another male respondent felt he was more willing to participate because he had made the decision entirely without prior contact with the researcher. He felt this allowed him more control over the situation. If other males who answered the advertisement also did so because they had no prior contact with the researcher, there is a possibility that experiences of those who would not normally participate in this research may have been captured.

A comment on the lack of response to newspaper advertisements by female respondents is warranted. Since women may be more circumspect in their behaviors due to the emphasis in the media regarding violent crime, they perhaps are much more suspicious of an advertisement for participation in research. In other words, they may suspect the motives of the researcher. This may in part be an explanation for the reluctance of women to respond to the advertisements.

Interviews were arranged as individuals who fulfilled the requirements contacted the researcher and agreed to participate in the study. Originally 30 interviews were targeted. However, the lack of male participation lead the researcher to increase the number of interviews to a final number of 46 in order to incorporate more males into the sample. The sample consisted of 19 women who had experienced

breast cancer, eight women and 19 men who had experienced other forms of cancer. The sample was collected from Calgary, Fort McMurray, Medicine Hat, Rocky Mountain House, Millet and Canmore. The structure of the sample makes it possible to compare the responses of women and men.

In order to reduce the problems of selective recall, it was desirable to interview respondents as soon after the onset of this stressful life event as reasonably possible (Neuling and Winefield, 1988). However, due to the limitations of sampling, an inability to conduct qualitative research in the medical setting, the researcher found herself faced with the possibility of interviewing individuals who had been separated from their treatment for an extended period of time. However, this was seen as an opportunity to evaluate critically Neuling and Winefield's hypothesis.

Seven women and five men were interviewed within three months of the beginning of their cancer treatments. While interviewing these respondents, it became apparent that they found the questions about social support required more reflection than those who had been separated from treatment for a longer period of time. So, for some respondents the closer the negative life crisis the more difficult it was for an individual to assess their social support. For example, one individual, who had just completed chemotherapy treatments two weeks prior to the interview, was unsure whether she had any social support whatsoever, although there were constant

phone calls during the interview from friends asking after her health and inquiring if they could do things for her. It would appear that an individual needs time to reflect upon the type of social support they required and utilized as well as who was effective in providing that support.

In addition, initially the intent was to control for treatment by limiting the sample to those individuals undergoing chemotherapy in order to prevent any confounding of the data that might occur as a result of differing treatments, such as radiation versus chemotherapy. However, this aspect of the research was also impossible to control since there was no access to patients at the Tom Baker Cancer Centre. As the interviews progressed it became clear that a generalized meaning of cancer was more important in social interaction than a specific type of cancer or treatment. The generalized meaning of cancer is more important in the context of social support.

VI. Demographics of the Sample

The following tables present the demographic distribution of the sample according to age, education, employment, income and marital status.

Table 1 Age by Gender

Age	Female	Male
18-30 years	-	4
31-40 years	3	2
41-50 years	10	1
51-60 years	7	5
61-70 years	6	5
71+ years	1	2
Total # Respondents	27	19

The youngest respondent was 24 years, the oldest was 76. There was a relatively equal distribution over the age range for men. Women have a concentration in the 41-50 age category; this may be a result of such a high representation of women who have had breast cancer. This category falls into the age range where breast cancer is most prevalent and would therefore result in an overrepresentation in this age group.

The sample is fairly well distributed over all but the lowest education categories. Of the sample, women have a higher representation in the post secondary category than the men (females 80%, males 47%). This could reflect the small

sample size of 46 respondents and as the sample size increases the education distribution would be considerably altered.

Table 2 Education by Gender

Education	Female	Male
Grade 1-6	-	-
Grade 7-9	-	2
Grade 10-12	5	8
Some College	6	1
College Diploma	4	1
Some University	4	1
B.A., B.Sc.	5	3
Graduate Degree	2	1
Professional Degree (i.e. C.A., M.D., LLB)	-	2
Missing	1	-
Total # Respondents	26	19

The work distribution for men is predominantly full-time

employment or retired (only three identified themselves in other categories). Women are much more equally distributed over all work categories with the exception of unemployed, which could be a result of seeing oneself as keeping house rather than unemployed.

Table 3 Work by Gender

Work	Female	Male
Labour Force Full-Time	7	10
Labour Force Part-Time	6	1
Unemployed	-	1
Full-Time Housework	5	1
Student	1	-
Retired	7	6
Missing	1	-
Total # Respondents	26	19

Both men and women are represented in all categories of income, with the highest representation in each case in the middle income category ($30,000 to $44,999).

Table 4 Income by Gender

Income	Female	Male
$ 0 - 14,999	2	1
15,000 - 29,999	1	2
30,000 - 44,999	10	8
45,000 - 59,999	6	2
60,000 - 74,999	1	3
75,000+	3	2
Missing	4	1
Total # Respondents	23	18

For the most part, the sample consisted of married people, with very few single, separated, divorced or widowed individuals participating. As of the 1986 Census 60.4% of all adults in Canada were married (Devereaux, 1990). Seventy-four percent of the research sample were married at the time of the interviews. This overrepresentation of married individuals could be a reflection of the average age of the respondents, which was 51.8 years, and as sample size increased the proportion of married persons would be brought more into line

with the general population.

Table 5 Marital Status by Gender

Marital Status	Female	Male
Single (never married)	2	1
Married/living with partner	20	14
Separated	-	1
Divorced	3	3
Widowed	2	-
Total # Respondents	27	19

Summary

This chapter has outlined the methodology employed in this thesis. A working definition of social support was developed as the perception or actual receipt of instrumental and/or expressive aid provided by members of the community, social networks and significant others. Incorporated into this definition were the concepts of instrumental and expressive support. Instrumental support was defined as advice, information, financial assistance, and assistance with family or work responsibilities. While expressive support was defined as aid provided by significant others in the form of

expressions of sympathy, understanding affection, acceptance and esteem.

Semi-structured interviews were conducted using a personal mode of interviewing in order to encourage "fresh talk" that might provide greater insight into the interactions between interviewees and those who provided them with social support. A multiple sampling procedure was used in order to obtain participants, incorporating a purposive sample from Cancermount and Reach to Recovery, a snowball sample, and newspaper advertisements. This resulted in interviews with 27 women and 19 men.

A grounded theory approach to data analysis was discussed as compatible with symbolic interactionism. This method allows the researcher flexibility in developing categories and themes grounded in the data, while maintaining a systematic approach to social scientific research. The following chapters will discuss the results of these interviews.

CHAPTER THREE

THE MEANING OF CANCER

The primary concern of this thesis is the utilization of social support by individuals undergoing a significant life crisis: cancer. As discussed in Chapter One, the theoretical perspective is symbolic interactionism. In order to understand how an individual utilizes his or her social support we must first understand what meaning cancer holds for this same individual.

To recapitulate, the important premises of symbolic interactionism that guide this research, all things have symbolic meaning, and these meanings are "...formed in the context of social interaction and [are] derived by the person from that interaction... (Blumer 1969, p. 5). However, this involves an interpretive process whereby the actor communicates with her/himself about the thing and as a result modifies meanings in order to guide future action. The interpretive process structures the meaning of cancer for individuals who have been diagnosed as cancer patients. The meaning of cancer for these persons is formulated through their past experience with others who may have had cancer, as well as general societal attitudes toward the disease itself. This past history provides people with a context of meaning

within which they interpret their own diagnosis. However, interpretation is a continuous process. Therefore, their personal experience with cancer allows them to add information to the meaning they have constructed out of their own past history and modify or reinterpret what meaning cancer now holds in light of the interaction between themselves and cancer, and their social support system and cancer.

In order to determine the meaning of cancer, participants were asked a number of questions which would provide some insight into the process of reinterpretation. For example, "Before you knew you had cancer, what did you think cancer was like?" and "Since you have had cancer, how do you feel about it now?" These questions, along with several others regarding changes in lifestyle and relationships, were designed to tap into the process of reinterpretation. They answer how a personal experience with cancer alters the meaning of cancer for the individual. Changes in action can then be linked to that newly recreated meaning. These answers are retrospective accounts, and might be limited by the passage of time, as well as a tendency to revise past personal history.

This process of interpretation will be discussed further in this chapter, but first a discussion of the societal beliefs and discourse surrounding cancer is necessary in order to understand the social context of the person with cancer.

I. Social Context of Cancer

An integral part of the construction of the meaning of cancer is societal attitudes and their impression upon the individual newly diagnosed as a cancer patient. These attitudes help the individual define cancer and subsequently guide the individual's reaction when s/he is informed of the cancer diagnosis. In addition, this meaning provides a guide to the possible expected response of family, friends, and neighbours when they also become cognizant of the diagnosis. However, this is not to say that the meaning of cancer stands alone as a guide to expectations. In addition the individual carries with her/him expectations of the role of family, friends and neighbours in times of crisis.

Susan Sontag (1978), in her book *Illness as Metaphor*, discusses the public discourse that surrounds cancer. This discourse provides the individual with a reference to establish the meaning of cancer. Cancer is seen as "...an evil, invincible predator, not just a disease..." (p. 7) and is "...identified with death itself" (p. 18). Militaristic terms are applied to cancer through phrases such as the "war against cancer," "losing the battle with cancer," "an invasion of the body." Treatment is also couched in military metaphors: tumors are "bombarded" in radiotherapy, chemotherapy "kills" cancer cells (1978, pp. 64-65), and those who are pronounced in remission view themselves as "survivors" having "defeated" cancer. Moreover, our metaphorical response

to political corruption is that it is a "cancer in the body politic," suggesting cancer is a corrupting force within the human body as well. This discourse emphasizes the need for a "military expert," the medical profession, and assists in the construction of meaning and cancer patients' actions toward the self or others when cancer becomes a part of the consciousness and perception of physical being.

Cancer patients often find themselves in a situation whereby they feel themselves to be responsible for their condition. A depressive personality, or a tendency to withhold feelings such as anger, fear, despair, worry, is often seen as causally related to cancer.

> ...today many people believe that cancer is a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous, incapable of expressing anger. (p. 21).

This belief continues to be supported by research in the medical community. For example, Boyd (1984), in a study of the psychological correlates of breast cancer, hypothesized that psychological factors in a woman's life may express themselves in breast cancer. The conclusion was the attitudes that a woman holds toward her body, her mother and other women, sexual experiences, as well as "...her ability to come to terms with the way becoming a woman has influenced her life..." may influence the development of breast cancer more than "...genetic history or social and economic circumstances" (1984, p. 11).

Adding to the discourse surrounding the "just world" phenomenon, Sontag (1978) argues there is a perception in society that we live in a just world and disease can be viewed as retribution for immoral behaviour. Society tends to judge people as responsible for their disease; their inappropriate or immoral past behavior has brought them to this impasse. Good outcomes are expected to happen to good people, while so-called bad people are expected to experience bad outcomes (Lerner 1980). An illness viewed as fatal, and this is certainly the case with cancer, becomes a test of an individual's "...moral character" (Sontag 1978, p. 41). This perspective, combined with the fear associated with cancer, makes the victim responsible for her/his own physical condition. To accept cancer as a result of the "fickle finger of fate," would mean that everyone is vulnerable (Lerner 1980).

The meaning of cancer is not solely constructed within the context of cancer discourse. Cancer also falls within the context of life crisis and familial ideology plays an important part in such crises. When individuals are diagnosed as cancer patients, a crisis situation, the family is viewed as a "haven in a heartless world" (Lasch 1977) and therefore as the appropriate place to receive comfort and help in such times. Individuals undergoing treatment for cancer will expect to receive comfort and caring, and may even expect to become dependent upon others within the family context.

"Basic to the ideology of familialism are...ideals of how men, women, and children should behave" (Luxton 1988, p. 238). Assumptions about the roles others play in an individual's life are permeated by the ideology of familialism. These assumptions are made not only by members of a particular family, but also by those external to the family, such as medical professionals. For example,

> Someone in hospital for a major illness is permitted to have "immediate family" visit, while friends are excluded, even though these friends may in fact provide the only real love and caring in the patient's life and the "proper" family may be estranged and uncaring. (Luxton 1988, p. 239)

The response of family members of cancer and the cancer patient contributes significantly to the meaning constructed out of the interaction surrounding the exchanging of information about the illness, and the search for comfort and caring. As Luxton argues,

> Because family relations are supposed to provide love and intimacy, and because it is so difficult to get these elsewhere, family relations give us strength and undermine us simultaneously. (1988, p. 254)

The difficulty for the family and the cancer patient is the construction of a shared meaning. The interaction of family members with the cancer patient and their response to cancer will modify the meaning of cancer, and that subsequent meaning will guide the actions of the cancer patient when utilizing the available social support.

The construction of the meaning of cancer is a complex

process. It does not exist as a simple result of public discourse, but also must be considered within the context of familial ideology, and the interaction within the family as a result of the sudden encroachment of cancer.

Two important questions for social support in the context of cancer are: What meaning is attached to cancer by cancer patients and what is the process of reinterpretation of cancer in light of personal experience? Through an analysis of the data the meaning of cancer pre-diagnosis, can be compared to the meaning of cancer post-diagnosis, within the context of public discourse and personal knowledge and experience. Again, it should be kept in mind that these are retrospective accounts.

II. Cancer as a Negative Experience

The meaning of cancer, for interviewees, varies with their degree of familiarity (see Table 6). For some, a possible diagnosis was a terrifying prospect, while for others, it was not a consideration in their lives. Familiarity is defined here as first-hand experience with cancer whether it be a family member, close friend or a professional experience, as in the case of a nurse working with cancer patients. A fear of cancer is bounded by an understanding of others' experiences, personal lifestyle, and an ability to deal with a crisis such as cancer.

Table 6 Fear of Cancer

Meaning	Familiar	Unfamiliar
Something to be Feared	22	-
No Fear	13	8
Missing	3	
Total # Respondents	35	8

For 22 interviewees, their familiarity with cancer resulted in a fear of cancer. This fear is not necessarily connected with the death from cancer of a family member, friend or patient. Those interviewees who were most fearful of cancer, before their own experience, concentrated on the negative aspects, emphasizing death, even when they knew people who had recovered many years before.

> Cancer, cancer was death...My father-in-law had had cancer, but he didn't die, he got cancer when he was about 65, he died when he was about 84.

> A friend of mine got cancer two years before I did [still living], I thought the world should stop, I thought dust shouldn't settle, I felt a whole community should just go on hold because this must be like an enormous worm just eating one's inside. I thought it was the most tragic thing that could happen.

Even though cancer treatments are increasing the possibility of survival, these people held onto the belief that cancer was equated with death. The negative perception of cancer remained even when there was daily experience with cancer

patients:

> Well I guess I imagined it was death, an automatic death sentence...I'm a nurse, so all I see basically is the dying people, right...

This nurse held onto her belief that cancer was terminal, even though she most likely had contact with cancer patients who did not die.

For 13 interviewees, familiarity did not result in a fear of cancer and possible death as a consequence. Their main concern was connected with an ability to deal with cancer and its subsequent treatment:

> I thought it was an awful disease, but I also knew it was very curable because my mother's side of the family is loaded with it, and my father...I kept hoping it would make me braver...

> I was familiar with it because my mother had a mastectomy and she handled that so well that when I had one in 1973 I expected it as a matter of course...my biggest fear was that I wouldn't be able to handle the side effects.

For those who were unfamiliar or had little experience with cancer, eight interviewees, there was a belief that cancer was not an important consideration in their lives. It was not a part of their self-concept. Predominantly they had an abiding belief that their healthy lifestyle should protect them from the vagaries of disease:

> I never really thought much about cancer, I really didn't. I didn't really have a lot of incidence of cancer in my family. I just sort of ignored it...I was so shocked because it was of a female nature and I had taken care of my female health.

> I hadn't really thought of it before...I just didn't think it would happen to me because I was so healthy.
>
> I worked for over thirty years in construction and only missed a few days of work...you're never sick, you are never aware...I have a tendency to ignore sickness.

One interviewee, a dentist, was quite familiar with the diagnostic process through his practice. However, any patient that had a suspected cancer was referred elsewhere and he was not part of the treatment process. This most likely allowed him to distance himself from any further familiarity with cancer. He also emphasized his own health:

> I never gave it much thought, so to speak, whether I'd ever get it myself, because I was in perfect health and I felt great.

III. Reinterpretation of Cancer

After a personal experience with cancer, interviewees established three differing modes of reinterpretation. All three involve the conceptualization of cancer as a problem of control:

1) cancer as a loss of control,
2) establishment of control by taking personal responsibility for cancer and recovery, and
3) establishment of control by reinterpreting cancer as less threatening.

Loss of Control

A number of researchers (see Kelley 1971; Lerner 1980; Wortman and Lehman 1985) have argued people attempt to retain

the belief that they control their environment. A stressful life event, such as cancer, can wear away a person's belief they can control the circumstances of their life (Caplan 1981; Pearlin, Menaghan, Lieberman, and Mullan 1981). If the cancer patients sees their condition as inexplicable, and not causally related to their own behavior they are faced with the possibility that this is a random event. The randomness of some events in life is brought to the fore for 12 interviewees. Cancer gives them a sense of loss of control over their bodies and a feeling the "fickle finger of fate" is pointing their way. For example, one woman felt she had no control over what would happen next. If she had no control over whether or not she developed cancer, then perhaps she had no control over other aspects of her life:

> I'm waiting for the other shoe to drop. Like I just feel so good inside I'm just waiting for something's going to hit. This is too easy.

As part of this belief in cancer as a random event in people's lives, cancer was invested with mystical properties. Luck was a large component of whether or not you developed cancer, as well as whether or not you survived the illness.

> Cancer was a mystery as some died but others survived. The mystery remains as how did I produce cancer cells?

> I guess, I guess you think you're lucky... you hear of a lot of people who do die of it, and it might be the same as you, and you think "Now why did it spread through them so quickly and not through me so quickly?"

For these people, cancer has emphasized their inability

to control the circumstances of their lives. It is a random occurrence that can happen to anyone. Treatment is also seen as random in its effectiveness. Some people die of cancer and others do not. Treatment does not provide cancer patients or their physicians with control over the disease. Instead cancer has its own course, and follows through, without human intervention.

Regaining Control

Although cancer remained a random event with luck playing a large part in the type of cancer you develop, one man felt the mystical properties of cancer could be dissipated through acceptance of personal responsiblity:

> ...a lot depends on what kind you get and whether you're smart enough to go to the doctor when you first find a symptom.

By accepting personal responsiblity for cancer, 24 interviewees managed to regain control of what appeared to them at first to be a loss of control over their lives. As one man expressed his philosophy surrounding cancer:

> I just basically take it as it comes, because you learn to handle it I guess, live with it. Far as I'm concerned just keep a positive attitude about it. It's just a part of life. There's not much you can do about it once you get it. You can only get rid of it.

One theme that did arise during these interviews was the development of a positive attitude as a way of taking control of cancer. Positive attitudes were manifested in talk about taking control:

> I made myself think positive, and if I hadn't I wouldn't be here.
>
> So I think what I feel now is if someone has got to have cancer, someone I care about has to have it, I would prefer it to be me, because when it's me I feel I can do something.

This positive attitude can then be directed at this life threatening experience. Cancer becomes a challenge to be overcome:

> ...hey, they're not going to get me after all. I'm going to get better...
>
> It was an experience. It was a challenge. It definitely was life-threatening.

In keeping with the rhetoric that surrounds cancer, it was seen by some as a battle to be won with the reward of a second chance at life.

> I feel that my disease was a victory, emotionally and physically for me, and I believe it has given me another chance.
>
> ...it really isn't such a doom and gloom type of thing...it's a far different attitude than I had, and I know that it can be beaten...coping is not good enough, that isn't in my language. I conquer, I don't see coping at all...I'm getting on with my life.

The suddenness of the disease, and the opportunity to have a second chance at life, lead these interviewees to restructure their lifestyle. Interviewees assessed their past behaviours. By pinpointing possible causes of cancer, the randomness of the disease can be eliminated.

> Your outlook changes a little. You slow down because the world moves pretty fast. You take more time. You look at things a whole lot different. You appreciate the things that you have and you don't worry about the things that you don't have. Probably you live day to day...You accept the things that are now, and you don't worry about what's happening tomorrow. And you forget about the things that happened before.
>
> It's almost immediate, you know, where you stop and take a look at yourself after. I don't mean the second you know, or even before you go through the treatments. It doesn't take that long when the priorities start to change. You start to look at yourself, you know, the supermom. The person who could do everything, and the person who asked for nothing...and I was one of them, a super achiever. My whole life, push, push, push, and I don't even know if it was ambition. It was just push, push, push to the limits, you know. Push beyond what's healthy or what's good for you.

One man persisted in the belief that cancer was not a part of his conscious thought. This would suggest that for some people cancer was not a threat, nor did it present the possibility of loss of control over one's life. However, at the same time he repeatedly indicated that he had changed his lifestyle:

> Well, of course, I'm into nutrition...

and,

> Now I'm starting to take care of myself through nutrition.

So, although his perception is that cancer is not a part of his conscious thought, he has attempted to regain control through accepting personal responsibility for his future good health.

By taking responsibility for both past and present

behaviours, interviewees were able to take control of their life circumstances. Through acceptance of responsibility for their health, cancer was no longer a random event. It could now be controlled. Through a number of strategies directed at establishing control, interviewees altered the meaning of cancer and gained power over what they saw as an enemy. These strategies included the development of a positive attitude, allowing them to accept cancer as a challenge, with a reward to be won: a second chance at life. This second chance allowed them to restructure their lifestyle in order to eliminate or modify behaviours that in the past might have lead to cancer. In an effort to continue the belief that humans control their own environment, they accepted responsibility for cancer and consequently could now see themselves as controlling the disease rather than it controlling them.

Reduction of Threat

Personally experiencing cancer for nine interviewees allowed them to view it as less threatening and within their sphere of control:

> I don't find it near as scary, which surprised me. I, before I always had this thing of cancer being this great huge black cloud, and if it descended on me there was no way of getting out of it. I feel it was a setback in my life that I can conquer.

Through their experience with cancer, interviewees redefined cancer as a treatable disease, and consequently it became less

threatening:

> The thing that I'm so thankful about is that it's so treatable.

Incorporated into this idea of cancer as a treatable disease, and therefore less threatening, is the belief that even if a recurrence was a possibility, it was no longer life threatening.

> ...even if it does come back it's treatable... it need not be a terrible thing, and also the concept that cancer is always fatal or if it is not that's an exception, that concept has certainly changed.

> It's always in the back of your mind...but I don't think of it was an automatic death sentence any more. Even if it is ten years down the road, it's not diagnosed today and dead tomorrow sort of thing.

For these interviewees, cancer becomes another of life's problems that can be handled. No longer does it mean a death sentence. Interviewees could look forward to a future and make plans.

> It's not as terrifying...you can cope with it. I feel more confident in the future.

Summary

When constructing the meaning of cancer, interviewees draw their interpretations from the society around them. Society defines cancer as a fatal disease, and those afflicted rarely survive. Additionally, society often identifies people as responsible for their own condition. Within this context, the majority of interviewees who were familiar with

cancer feared cancer as a death sentence. However, a significant number (13) of those interviewees familiar with cancer did not see it as a death sentence, but instead concentrated on their ability to deal with the treatments. Those interviewees who were unfamiliar with cancer believed that their healthy lifestyle would protect them from negative health events.

The experience each of these interviewees had led them to reinterpret cancer as a problem of control. For those who saw it as a loss of control, cancer was a random event that could strike anyone at any time. Cancer treatments were not seen as the way to gain control over cancer, since treatments also were viewed as random in effectiveness.

The majority of interviewees attempted to regain control of their lives by taking personal responsibility for their cancer. This control took two forms: 1) the development of a positive attitude and 2) the restructuring of their lifestyle. By taking control of their lives, these interviewees also took control of cancer.

The last group of interviewees came to view cancer as a health problem that could be overcome. Successful recovery was assured by proper medical treatment. For these interviewees cancer had become another treatable disease, and consequently they were able to reduce the threat the word cancer may have had for them.

Within this context of the meaning of cancer, and the

attempts by interviewees to regain control over their lives, the following chapters will examine supportive transactions from family and friends, and participation in cancer support groups.

CHAPTER FOUR

SOCIAL SUPPORT AND THE FAMILY

A large portion of this research was an examination of social support from family members, both the nuclear family and the extended family. During the interviews, it became apparent that support transactions within the family were a two-way process. Instead of the cancer patient acting as a receiver of social support transactions, it was evident that interviewees, both male and female, also provided support to family members. Although approaches differed between male and female interviewees, in effect they were not passive actors in the process.

In North America love has been identified in feminine terms, that is love is demonstrated through expressive interactions.

> ...aspects of love that women prefer and in which women tend to be more skilled than men. (Cancian 1986, p. 692).

Cancian suggests that what is needed is an understanding that men express love through instrumental actions, by doing things for those they love. The suggestion is made that male expressions of love need to be incorporated into an androgynous perspective. This can also be seen in supportive interactions within the family, both nuclear and extended.

Women focus on the expressive component of supportive transactions and men focus on the instrumental aspects of support (Wellman and Wortley 1990; Krause and Keith 1989). Although men and women approach the provision of social support through different channels, in effect they are attempting to provide the same thing. In this chapter we will see how men and women differ both in their approach to the receipt and provision of supportive interactions.

The discussion will focus on the bidirectional nature of social support within the family context. The provision of support by family members is constrained by expectations of each member's role within the family as well as differing perceptions of a family member's ability to provide support. Support provided to family members by the cancer patient is constrained by expections they place upon themselves as well as their role within the family.

I. Nuclear Family

Provision of Support to Cancer Patients

Fourteen male interviewees were married or living with a partner at the time of the interviews. It would appear that all fourteen interviewees expected their female partners to continue in, or take on, the role of family caregiver. The maintenance of a normal family atmosphere appears to be important to these men. This is demonstrated not only by the role in which they cast their partners, but also the

insistence that their children act in as normal a manner as possible. The nature of support from children will be discussed in a later section. Partners were expected to and, in the case of 12 men, did provide both instrumental and expressive support despite the difficulty of the situation. For example, the following comments were commonly made by those men who indicated their partners or wives were supportive:

> I know she was really worried about it, but she did not show it either, like she carried on.
>
> Well she carried on and she visited me in the hospital and did what she could to help me.
>
> [She provided] everything I could have wished for and more. In fact too much.

As part of the provision of social support, there is a recognition that a partner also needs social support. The receipt of social support by a spouse or partner can be an indirect source of support for men. That is to say, if a partner receives some other form of social support, such as baby sitting services from a friend or neighbour, while the male cancer patient is undergoing treatment for cancer, the wife/partner is then more capable of providing him with the amount and type of social support that he needs at that time. When discussing this aspect of social support, one man indicated:

> She had tremendous support from the family, and doctor and friends. Towards me she seemed perfect. She managed to hide her anxieties from me.

This nurturant role that men expect from their partners

is an unspoken one. Expectations are not communicated between partners, but societal norms that establish family roles are expected to be fulfilled. A common sentiment was that wives automatically understood what was required:

> She knows just how to handle me. I suppose in most good marriages there has to be a sense of what your partner is going through, and I think this whole thing has just sort of brought that to a maximum.

Of these 14 interviewees, two men felt that their wife or partner was not able to provide them with support. Both men expected their partner to step into the nurturant role, even though that expectation was not expressed by them to their partner. As a result, they were both very disappointed when they discovered that both women were unable to respond appropriately. As one man expressed his disappointment with his wife's inability to respond to his unspoken need for comfort:

> I didn't tell her what was going on. I didn't complain because I was at the hospital getting the last word on the cancer...and so she wasn't told, but she had a knowledge of what was pending though. And I had hoped that she would reach out to me physically, not words, but for once put her arms around me. "I can't do anything for you but I'm here," but actually she turned her back on me.

This is not to say that men do not understand that there are limitations to what a spouse or partner can provide. In other words, social support is a finite, albeit renewable, resource and the finiteness of this resource is recognized by these men.

> I think part of it was that she couldn't do anything. It was just one of those things that she had to sit tight and see what was going to happen. And that's basically all a person on the outside can do.
>
> Family members want to help...and they can't do anything about it, you know, because there's nothing they can do. They can try but what can they do?

Female partners are expected to continue in their role as family caregiver, maintaining as normal a family atmosphere as is possible given the circumstances and the changed lifestyle (i.e., treatment schedules, family anxiety levels). There is a recognition that in order for a partner to provide support she must also be the recipient of support. Other family members or friends may be able to assist a male patient's spouse deal with the changed circumstances of their lives. As a result, she may then be able to assist her husband in maintaining what appears to be the most important ingredient, as close an approximation of a normal family atmosphere as can be maintained.

Of the 22 female interviewees that were married or living with a partner, 19 viewed their partner as very supportive. This perception held even if the relationship was in trouble before the diagnosis of cancer. One woman, who indicated that her marriage was in difficulty before her diagnosis of cancer, felt her husband was very supportive:

> Oh, super-supportive. Nothing in the past mattered. There was nothing in the world that couldn't be worked out.

This did not, however, alter the fact that the relationships

were deteriorating, and the support lasted for a limited amount of time and subsequently relationships were broken off or divorce ensued. The family crisis of cancer only delayed the inevitable or precipitated the final severing of the relationship. For example, one woman's partner left her shortly after she was informed by her physician that she was cancer free.

> He was very supportive at the time. I believe it had a large part in the breaking off. Before diagnosis [breast cancer] everything was going well.

For the most part, these women placed an emphasis on expressive support from their partners.

> He was a terrific support. I don't think I would have made it without him. He was there. [He provided] emotional support and I can't really say what emotional support. It was there, I knew it was there.

The importance of a positive source of expressive social support from their partners was emphasized, enabling them to maintain a positive attitude themselves. The following comments were typical of female interviewees:

> He's your eternal optimist, so he's just wonderful. Anything he could do, or talk, or hug, or hold, or, you know. If I had a rough day then he left work and he was home.

> He would be so positive all the time, and "Oh you are just going to be fine you know, and this is going to work and all that." He was trying his darndest to be so supportive and everything, and for that I was extremely thankful.

Female interviewees felt their male partners were very supportive. This attitude held throughout behaviors that

would otherwise be considered unsupportive. For example, one woman indicated that her husband increased his drinking during her cancer treatments:

> He got into the martinis when I was initially ill and that used to disturb me and my young son, when he'd ricochet around the kitchen and pots and pans would be flying and it would be because he was high as a kite, still thinking that he had to step in for me.

However, she continued to view him as very supportive:

> He was very supportive and certainly during the time [of her cancer treatments]. He certainly would talk to me about it if I wanted to talk about it.

Another woman maintained that her husband was very supportive, even when he asked that she no longer discuss her cancer or her concerns with him, but instead find a friend that would be much more willing to listen.

> One day he said to me, about three months later, he said "I can't have you talking about death so much." Like I was working out the whole death thing. He said "I can't handle it." And I didn't take that as a sign that he couldn't support me. That was the honesty in our relationship. And he says "You have these friends out there. I know you can talk to them about death..."

Women appear to require from their male companions expressive support. Some men offered instrumental as well as expressive support, but still the women emphasized the need for expressive support from their partners.

> He was with me every time I had a treatment. He stayed. I had to go the day before each time for a checkup, before I could have a treatment and he came with me for that... He did everything.

Even when discussing instrumental support provided by a

partner, women emphasized the expressive component of that support. For example,

> I felt strengthened by his reaction...His concern for what the doctors were doing helped me relax. He handled the details and brought me things from home...He provides the 'push' to have things checked by the doctor. He knows when to keep the children busy so I can have some time to myself.

In their intimate relationships with partners, the women in this study required expressive support. This type of support can help maintain the nuclear family as an intimate private world, reinforcing the notion of a "safe haven in a heartless world" (Lasch 1977). As primarily responsible for relationships and their success within the nuclear family, the expressive support received from their partners would indicate that the relationship is on firm ground.

Although instrumental support may be forthcoming from a male partner, these women viewed such support in expressive terms. This may be the result of women's familial role as caregiver. As we shall see in later discussions, women turn to other women, children, sisters, mothers, and friends for additional expressive support as well as instrumental support.

Children were an important component of support for 38 men and women interviewees. Children demonstrated social support both instrumentally and expressively. They collected information, went with their parent during treatments, and provided emotional support.

> S____ read everything she could on cancer. She went to the library, she asked questions, she phoned the doctor. She would call the nurse. She wanted facts and she went after them, and she got them. C____ had taken over the house...She'd taken over mum's job... M____ made it lighter for everyone.

This support ranges from the very young (two and four years of age) to adult children. For example, one woman talked about the support she received from her 11 year old son:

> We don't talk about it, but he's supportive in every way. When I'm not happy or when I'm sad or when I'm sick he always says "Are you all right mummy?" He's a very caring person.

For another woman, it was sufficient that her two children (two and four years of age) were able to come and see her during her hospital stay. This visit, albeit brief, was interpreted as the little bit of social support her small children could provide. Just seeing them could possibly assist in her recovery.

Children are viewed as supportive even if all they can do is accompany a parent.

> I think my girls have been great. They came with me for treatment, like you come to chemo-therapy because you get a free bottle of pop...

For those who viewed their children as supportive, the emphasis was placed upon the children showing concern for the parent. Support could be demonstrated in any form:

> They did things, coming to see me, talking. You know just little things that they did... Screen my phone calls...and if anybody came to the door he'd say "She's having a nap now, you can see her later..."

> My oldest daughter is, she's a very comforting support person. She came right away from Vancouver as soon as she found out...all three of the children were with me at the hospital when I had the biopsy done...all three of them went with me to our family doctor afterward...
>
> They were very worried. They ask how I am... They are interested, and they ask how I am and they visit.

Children who are adults are not expected to interrupt their own lives. Parents do not place heavy expectations for support on their adult children. Whatever support they do provide is viewed as very positive. As a result, parents are not disappointed by their children's reactions and subsequent actions:

> They felt bad, but they all have their own lives.
>
> We didn't tell him until afterward because he was right in the middle of his training and he was kind of annoyed that we hadn't told him that it was going to happen and only found out about it afterwards ...he's very good about keeping in touch and you know that if you needed him he'd be there, but he's got, you know, he's got his own life and he's a busy person, so...
>
> They had to concentrate on a variety of things, like school, work, homework and that...
>
> Well they were very supportive of me. We talked and wrote to them and they said they were sorry.

For both men and women interviewees the emphasis was placed upon children demonstrating a concern for their parent. However, this concern could be demonstrated through either instrumental or expressive support, and the support itself did not have to be forthcoming. Children were expected to maintain their own lives as adults, and small children, of

course, could merely add their presence and that would be construed as support. If a child expressed concern and interest in their parent's situation that would be viewed as sufficient support.

Although the expectation was that children should get on with their lives, those children who did not express concern or interest in their parent's situation were a disappointment to the affected parent. Three interviewees indicated they had a negative experience with their children (one woman and two men). The woman rationalized her children's response as their inability to cope:

> I don't know because they'd, they really didn't talk about it...maybe kids try to avoid it, I don't know.

Through this process of rationalization this woman maintained her role as family caregiver. This is a role that is adopted by many of the women interviewees, and will be discussed in the next section of this chapter.

Both men were disappointed in their children's reactions:

> I don't mean to be critical but the buzzards are circling. What am I going to be left in your will? Is my sister going to get more than I am? Is my brother going to get more than I am?

> Neither one of them have said "If you need to talk, come talk to me." My daughter and my son also view me as the source of money. If I died they might just inherit my money. I really wonder about how they see you, you know, when the chips are down.

Both men see themselves in the traditional breadwinner role within their family (Parsons 1955). However, when they are

treated as just that by their children they experience disappointment. The father's role of breadwinner may be preventing these children from providing social support to their father. In the past they related to him as family financial support, suddenly he is cast in a role they are not used to and cannot respond to, a parent in crisis. The traditional expressive role of women within the family allows this one women to rationalize her children's lack of support. The traditional instrumental role of these two men, on the other hand, not only prevents their children from providing support but does not provide them with a way to rationalize that lack of support.

Provision of Support by Cancer Patients

Of the 27 women who participated in the study, 21 continued their role of caregiver to their family, the nurturant wife and mother. These women typically tried to protect their families from what they perceived to be a difficult situation and strived to create the same normal atmosphere they felt was there before the disease struck. As one woman stated:

> I suppose that I'm fairly independent...I like to handle things as much as I can myself, so I don't lean on him [her husband].

While suggesting that her husband was very supportive, she also indicated that she met most of her own instrumental and expressive needs herself.

As part of the nurturant role, women take responsibility for their spouse or partner's adjustment to cancer. For example,

> I have to calm him down, you know: You're going overboard, you're getting carried away ...Maybe he doesn't understand it as well as he might. Maybe I should talk more to him.

and,

> I went home, I wanted to get home and in my little shell and think this out and I was kind of shaky and concerned and besides that I wanted to wait in case my husband was phoning me, so I could tell him and share it and have him come, and you know, share my strength.

Often the emphasis was on remaining strong and reassuring family members, particularly the children:

> ...I could do this, I was real tough and I had to stay tough, had to be strong, had to do this, had to be a mother to my kids...I didn't want to put too much of a burden on the kids.

This strength was exhibited in a number of ways:

> Children always take on, whether they realize it or not, they do take on your feelings. I really had to get my mind around each moment and accept it and deal with it in a positive way because it affected them.

> ...but you have to cope when you have children, and I have seven. The kids came first.

In an effort to create a normal family atmosphere, women are even willing to change their lifestyle. For one woman this meant giving up her teaching career so she could be a "better" mother to her elementary school-aged children:

> ...it's been great to be able to be a real at home mother...being up with the kids in the morning and making what they want...and being home and talking, you know telling you about the day.

Embedded in this desire to become a traditional mother is the belief that cancer is equated with death and, therefore, she may have only a short time to demonstrate her "motherliness" to her children.

For these women, familial ideology stands somewhat in opposition to the expected role of women when social support becomes an issue. Role expectations within the nuclear family assign expressive functions to the wife and instrumental functions to the husband (Parsons 1955). Traditionally these roles define financial, decision making and disciplinary responsibilities as primarily male and child care, housekeeping, and nurturance (i.e., marital stability, care of the sick, emotional support in times of crisis) as primarily female roles (Mackie 1983). Even without illness, women can find it stressful to be primarily responsible for the expressive needs of their family. However, when a woman undergoes a significant life crisis, such as cancer, she can find herself in the confusing position of primary nurturer in need of nurturance.

Sixteen male informants concentrated on the receipt of social support. Any efforts that were made to alleviate stress that may be occurring within the family were activated when such stress was pointed out to them by a third party.

> I spent most of my time convincing her I didn't have it. I thought they'd made a mistake somewhere along the line, twice.

In his attempts to convince his wife that he did not have cancer, this man was attempting to reduce her fears. It seems likely that through this approach he could increase his own receipt of support. If he could convince his wife that everything was fine, life would continue its normal flow. This was a theme that recurred again and again with male informants. There was a belief that if life continued in a "normal" manner, everything was well. Incorporated in this was a desire to view the nuclear family as able to cope well with the situation. For one man it was important that his wife was able to keep her fears from him:

> She managed to hide her anxieties from me.

There was a lack of recognition that there might be family stress. In fact, the men did not seem to recognize the effect that their own cancer might be having on their family. For example,

> ...they didn't seem concerned, you know. They didn't say anything.
>
> They seemed all to carry on in the old way.

If they had some idea that members of the family were undergoing stress related to the cancer, the emphasis was still placed on maintaining a normal family atmosphere.

> Like I say, they all, they talked to each other, and they all didn't show much. I know it was bothering them but they didn't. Nothing changed much in our home life.

If the emotional turmoil being experienced by family members was drawn to the attention of the male interviewee, then there was an acknowledgement that he needed to provide some form of social support. However, this need for support had to be pointed out to the interviewee before it was recognized. After being informed that his elementary school-aged child was having trouble with school, one male interviewee was then able to take steps to provide support to his child:

> I didn't realize they were picking it up that way...so right away I went over and talked to her [teacher]...and then I spoke, I talked to him [son] and he seemed to be okay after that. We haven't talked about it a whole lot since then.

Another male interviewee was told by one of his sons that he was having trouble with university courses. At that point he attempted to provide support to this particular son:

> ...as a matter of fact he had problems in school because of that...I tried to reassure him that the doctors were doing everything they could and subsequently, of course, the pressure was relieved, mentally and physically, and so everything's fine right now.

To summarize, it would appear the need for social support by members of the nuclear family had to be brought to the attention of these male interviewees before it was recognized. At that point these men would provide support to the family member in need. It is possible the needs of other family members may go unrecognized in the male patient's effort to maintain as normal a family atmosphere as possible. This

maintenance of a normal atmosphere is a form of social support to the cancer patient himself. However, when the normalcy of the family milieu is unavoidably broken, then male interviewees would take action to provide social support to other members of the nuclear family.

II. Extended Family

Provision of Support to Cancer Patients

Of the 46 interviewees, nine men and 22 women had at least one living parent. For these male and female interviewees, parents were an important source of both expressive and instrumental support. However, both men and women focussed primarily on their mothers as their main source of parental support. Mothers are viewed as very strong and capable of absorbing the shock of an adult child with cancer. When mothers lived nearby or were able to make the journey to be close to their child during treatment their role as the family caregiver was re-established.

> Mom was very supportive. She came to care for our children while I had surgery and healed. She provided care, drove me to appointments, called after check-ups and provided a strong Christian faith.
>
> She worried about me, of course. She was very concerned. How are you feeling and are you alright. If there'd been any financial things, I'm sure she'd have helped too...
>
> She did come out in May and she stayed for a couple of months. Just looking after me...She was everything, help and emotional and everything.

> Just being there, making sure that I was okay and she had everything arranged so that when I got home she would be comfortable knowing that she had a whole army of her friends and a lot of my relatives that so if I just didn't feel I had enough strength to take a shower that someone would come over and be in the house.

Although both mothers and fathers may be a source of social support, the focus remains on the mother as the primary caregiver. Thus, when an adult child undergoes a life event crisis, the traditional caregiver role is re-established by both the mother and the adult child.

> Mother is very, very strong. They were with me right through the hospital stay, and then an appointment had been arranged with the neurosurgeon and they had to fly to New Brunswick. So she was in New Brunswick when she phoned that night just to find out how things had gone.

When parents were unable to make the journey to be with the cancer patient, the focus was on expressive support and the difficulty that would be encountered if the parent was present.

> ...my parents weren't here. They were gone. They were always phoning and asking how I felt...

> Mum said she should have been here, but I think it would have been probably harder to have her here.

Sometimes the difficulty was expressed in terms of the parent's health:

> Well I didn't see her that much, because she was out at the farm northeast of Cochrane and her arthritic problem bothered her.

Both male and female interviewees focussed on their mothers as the primary agent of parental social support, both

instrumental and expressive. As a consequence, the traditional role of caregiver is re-established by the mother and the adult child. However, the extent of the caregiver role is contrained by the availability of the parent. Social support is restricted primarily to the expressive mode when a parent must remain at a geographical distance.

Eleven male and 21 female interviewees had at least one living sibling. Of these interviewees, none expected to receive as much support from their siblings as they would expect to receive from a spouse or parent. They indicated that the type of support they received from siblings was expressive support, although some instrumental support was forthcoming when it was required.

> One of my other brothers is so supportive. He came right away and he's here right now...The two sisters that I'm really close to are terribly supportive. They phoned all the time and wanted to know as much as I knew.
>
> Very concerned, really supportive. I've only got one sister living here, two sisters overseas, one in England and one in Israel and they both came during the summer to visit...My sister lives here around the corner. She would have my lunch ready while [my wife] was teaching.

For one man, a leukemia patient, instrumental support from a sibling became an issue of survival. However, this instrumental support also contained an element of expressive support.

> ...they said "You're going to need a bone marrow." And they were right there. I didn't have to ask.

Since the bone marrow was offered without a request on the

part of the interviewee, the brother and sister had demonstrated how much concern they had for their brother.

The demonstration of expressive support at times was used as an indicator for the possibility of additional forms of support.

> Very, very supportive...We're not into hugs and kisses like you see on TV...but they were all phoning all the time, they were all writing. They were all concerned. Really good, really, really good. You could count on them, which was really nice.

Interviewees, both male and female, recognized that the social support coming from siblings was flexible, that is, they recognized that if one sibling could not cope with the crisis another could be used as a source of support. For example,

> I dreaded phoning my middle sister, and God I don't know how many times she phoned back, but she was so upset...She doesn't want to talk about it. She doesn't want to see the incision. She just doesn't want to talk about it. She doesn't want to think about it...My youngest sister...she can just handle things...she provided my husband with support...

For one woman, social support meant utilizing different members of her family for differing purposes according to her needs.

> ...like I wouldn't take Mum into confidence with some things I take [brother], or my sister. Like I might tell her something that I couldn't tell Mum. Like she wouldn't understand. She's in a different generation, you know.

> ...like I wouldn't take Mum into confidence with some things I take [brother], or my sister. Like I might tell her something that I couldn't tell Mum. Like she wouldn't understand. She's in a different generation, you know.

As part of the extended family, sisters-in-law often became an important source of social support, both instrumental and expressive. For each of the three women who indicated that their sisters-in-law were supportive, there was also an indication that their brother was not. The sister-in-law can be seen as a proxy for the brother-sister relationship and the lack of support forthcoming from the more expected source. One woman when speaking of her relationship with her brothers indicated:

> They could have been [more supportive]. They phoned quite a bit...[Brother] came for a visit and my sister-in-law came and she really did a heck of a lot when she was here. She got the cook, and she got in touch with homecare and got [a homecare worker]...

For this woman instrumental support was more important since her treatments prevented her from doing many of the chores she would normally have been able to accomplish. In addition, she had an extremely elderly mother (94) living with her, and perhaps this type of support would also provide an expressive component by alleviating worries about her mother's care.

Sisters-in-law appear to form a bond that fosters social support that may enhance or fill in for support that is not forthcoming from other family members. For example, one woman indicated her sister-in-law performed duties that she expected of her brother:

> Last year...she visited once a day. She checked my mail, water[ed] my plants and made sure he [cat] had some food, and played with him. She did a great deal for me.

When sisters-in-law share the common experience of cancer the social support can be immediate. This can help alleviate the disappointment that may result when other family members may not be as supportive as might have been expected. One woman talked about how her sister-in-law was the first to respond to her needs:

> ...my little sister-in-law, who was also a cancer patient, she was the first one here when I came out of the hospital...She left her six children and came and stayed with me.

For both male and female interviewees, siblings can be a welcome source of social support. However, there is an understanding that not all siblings can be expected to provide support, perhaps due to an inability to deal with the crisis. As Wellman and Wortley (1990) indicate, interviewees, as a consequence, "shopped" among their siblings for those who can best answer their particular needs. Part of this utilization of alternative family members as sources of support incorporates sisters-in-law as substitutes for brothers who do not respond. In addition, a family member who shares the experience of cancer can produce a response that may reduce the disappointment that other family members may create through their own lack of response.

Provision of Support by Cancer Patients

While seeking social support from the extended family,

that is parents and siblings, an ambivalent relationship was created for 23 women interviewees. As with the nuclear family, the need to protect and nurture family members reaches into the extended family.

There was a sense of responsibility for aging and elderly parents and a concern about the effect learning that their daughter has cancer would have on parents:

> I was more worried about her [mother] because she was, you know, she was pretty elderly, in her seventies, and I thought "Oh she's going to have a fit over this" because my dad was dead and I was the only one here.
>
> It was very difficult for my mother because... she is a very fragile person, emotionally anyway, and I was doing the protecting...I have to more or less hold her hand...

The caregiving role also extended to siblings, in an effort to reassure them:

> I want to do as much to reassure them as I can.
>
> I felt everyone was walking around on eggshells and I felt really bad, you know...I had to eliminate the discomfort level for them.

These women took on the responsibility of caring for their elderly parents. As a parent ages, the parent-daughter relationship undergoes a reversal of roles, and the daughter, in effect, becomes the nurturing parent. As a consequence, when the need for expressive support becomes important, the parenting role that has been adopted by a daughter can interfere with the receipt of such support. The daughter continues to protect her parents from the cruelties and

stresses of life by attempting to soften the effect the new may have, thus short circuiting any attempts at support that may be forthcoming from her parents.

However, familial ideology comes into play when the extended family rejects the member with cancer. For three women seeking to be 'enfolded in the loving arms of her family' rejection was bewildering and painful.

> ...I've also learned that in anything that's really big I can't count on them whatsoever and that was hard to accept...I don't understand people, I just don't understand.

The expection was of unconditional acceptance and forthcoming nurturance:

> It's not fair if they're going to do this, it's me and they should be able to accept that and they just weren't the way I thought they would be...I sort of expected them...you know, they'll treat me nice and that sort of thing.

Consequently, these women felt abandoned and confused and betrayed by what they perceived to be the role of the family: nurturance and comfort in their time of need. For one woman the perception was that the family was already treating her as if she had died and is attempting to enter the grieving phase that her presence denied:

> I felt sometimes as though they already considered me dead, and so they wouldn't have to have any emotions if it happened.

Here we can see the ambivalent nature inherent in the familial relationship. The role of the individual is to protect the family from too great an exposure to the realities of her own feelings and fears about cancer. The interviewee

the women suggest that family interaction should proceed as usual. Her family reacts by facilitating business as usual. But her needs aren't being met - because they aren't being perceived - because she perceives she isn't allowed to change roles and act out her illness. On the other hand, despite their lack of information about her need for support, the family is expected to respond, providing her with the desired affection, acceptance, sympathy, understanding and self-esteem she believes they are obliged to provide. Similar to women with breast cancer, the desire is for intimate family contact.

> ...closeness to other family members appears to be a good thing that women with breast cancer cannot get too much of. (Friedman 1988, p. 38)

Yet when the opportunity for closeness arises the tendency is to keep the family at a distance for fear it will cause them too much distress.

Similar to the women who adopted a caregiver role with respect to their extended family, three male interviewees also attempted to soften the effect cancer would have on parents and siblings. Two of these interviewees did not tell their parents that they had cancer. This was viewed as a supportive act since the parents then would not have to "worry" about their child.

> I've always taken care of them. They did not know that I had the problem. No I did not tell them. When I was in the hospital my wife told them that I was away on a convention, and I was actually in the hospital. They did not know that...I did not want to worry them.

Another stated,

> I don't even know if I told them. You see they were in Scotland, so I didn't see any point in letting people worry because they were so far away.

The siblings of one interviewee were told about his cancer by a third party, his mother. It was treated as simply provision of information, and his mother was left to deal with the feelings of those informed.

> Once I told Mother, then she talked to them. They talked to me afterwards. They never really went into anything.

This same interviewee, when faced with the possibility that members of his family were undergoing stress related to his cancer, attempted to provide them with social support. However, the support was offered in such a manner that it would increase their ability to provide him with appropriate support:

> I had to reassure them that I was okay. Like, at first it was "D__ are you going to be okay" from everybody in my family, but then I reversed it and it was me going "Look I'm okay, like you gotta let me do this. You gotta know I can do this. I'm alive, hey..." I reversed it, and I was helping them to learn about me.

It would appear the concerns of family members provided this man with the opportunity to increase his own level of social support (the need to maintain a normal lifestyle) by teaching them about his needs. Therefore, he couched his provision of social support in terms that increased his own receipt of support. This focus allowed him to modify that

support to suit his own requirements.

All three men provided support to family members by refraining from advising parents and siblings about their diagnosis of cancer. Although differing in approach from the women in this study, they were providing support by reducing stress and not giving family members cause to worry about themselves. Since men use wives, partners, or female friends as their main source of social support (Wellman and Wortley, 1990) they may not feel that they need the additional support that would be expected from other family members. Two men depended on their wives as their main source of support, and one depended on a female friend as his main source of support. Traditionally women are the caregivers within both the nuclear and extended families. Consequently these men may have felt that they had sufficient support through those females with whom they felt most comfortable.

Research into gender differences in seeking support indicates that men are much more reluctant to seek social support from significant others in times of crisis (Kessler, McLeod, and Wethington 1985; DeFares, Brandes, Nass, and van der Ploeg 1985). Therefore, it seems that these men most likely withheld information from family members not only because they interpreted it as a supportive action, but also because they did not wish to place themselves in the uncomfortable position of appearing to ask for support. Wilson (1987), referring to the work of Foucault, suggests

"...silence on a subject is a way of maintaining the power relations that are embodied in it" (p. 147). By remaining silent on the issue of their disease these men are exercising control over cancer, and denying it the power to demonstrate their lack of control over the circumstances of their lives.

III. Social Support Within the Family Context

For these women, the caregiver role was not put on hold while they went through the cancer experience. They sought social support from their family members, both nuclear and extended. However, they also provided support to those same family members. Although they did focus on their own health and well-being, it was often framed by the caregiver role. They were sensitive to the feelings and concerns of other family members and had a desire to maintain or create a family atmosphere that would prove to be supportive for them. Thus, they externally focussed on social support, concentrating on the needs of other family members in order to maximize the receipt of social support by their family.

The men involved in this study, on the other hand, focussed their attention on their own recoveries. This is not to say that they did not provide support to other family members when they became cognizant of the need for such support. However, support was more directed toward their own recovery. As has been mentioned previously, gender roles within the home assign expressive roles to women and

instrumental roles for men. In order to maintain or regain this role within the family, a male cancer patient would need to re-establish a normal family atmosphere as quickly as possible. Consequently, these men would have to focus on their own need for support in order to restore normal family functioning.

Summary

The theme that arises out of this portion of the data analysis is social support as a reflexive relationship. Not only do people seek support, but they also provide support to those family members around them that they perceive to be in need of support. This suggests that social support within the family context is a complex relationship. The provision of support by individuals undergoing a life stressor event to members of their own support network has not been a component of the social support literature. As this research demonstrates, social support within the family is an interplay of receipt of support and provision of support by both family members and the individual undergoing the stressful life event.

Additionally, in their efforts to provide support to members of their family, the issue of personal control is also a component of the provision and receipt of supportive interactions. This two-way interaction of provision and receipt of support allows both the men and women interviewees

to maintain control over the crisis situation. As stated in Chapter Three, cancer can make people feel a loss of control over the circumstances of their lives. For women maintaining a traditional role within the family can re-establish their control of the situation. For the men the lack of personal disclosure about cancer and, for one man, helping others provide adequate support may also provide them with the same mastery of the situation. Through their different approaches, these men and women were able to gain control, and as a consequence, perhaps reduce the threat cancer may pose.

CHAPTER FIVE

FRIENDS, NEIGHBORS AND SOCIAL SUPPORT

Chapter Four concentrated on the social support provided by family, both nuclear and extended. It was demonstrated that social support is modified by perceptions of family roles as well as gender roles, and the reported unwillingness of individuals to withdraw from those roles during times of crisis. Relationships within the nuclear and extended family are such that an individual requires a support network that does not contain the deep emotional bonding of family relationships nor the volatile emotional context. Friends and neighbours can provide this support network in times of crisis.

Due to their proximity, neighbours are a potentially rich source of social support. Although friends are often neighbours, neighbours are not necessarily friends. Neighbours are often strangers or dislike each other (Wellman and Wortley 1990), and the neighbour relationship is not by choice so much as by happenstance. This does not negate the fact that in a crisis situation neighbours can occassionally provide much needed social support.

Friends, on the other hand, choose each other and these choices are made consciously. Friendships incorporate shared

beliefs and values. In comparison to family relationships, the nature of friendship, its flexibility, lower expectations, and clearer boundaries (Rubin 1985), allows the cancer patient to be less protective and much more forthcoming about feelings and fears. This disclosure "...can be cathartic...[it] can serve a 'therapeutic' function for the self by sharing or diffusing the burden of such information" (Schneider and Conrad 1984:239). It lessens the gap between those who have cancer and those who do not. However, this is not an automatic process. Indeed it is not as simple as a cancer patient needing a friend to lean on, then simply picking one and proceeding to expose the depth and intensity of their emotions. The perception must be there that a friend is willing to listen and provide the required support.

There are gender differences in friendships. Men and women do not approach friendship in the same manner. Mackie (1983) indicates women maintain much more intimate and confidence-sharing friendships, while men tend to be less willing to share personal information. The expressive nature of women's friendships mean women are more likely not only to reveal more of their own thoughts and feelings, but also are more likely to be privy to the thoughts and feelings of others. On the other hand, men stress the instrumental component of friendship focussing on mutually shared activities. Mackie suggests that in their stereotypical approach to friendship, women encourage intimacy while men

discourage shared intimacy.

Stein (1986) notes that men find the development of friendships much more difficult than do women, partially because of their reluctance to demonstrate feelings of affection and tenderness toward other men. Stebbins (1988) suggests this is a consequence of the male need to establish and maintain control within close relationships. The affective dimension of male companionship is replaced substantially by wives (Farrell 1986). As a consequence male friendship does not have the same degree of intimacy that women appear to maintain in their friendship interactions. This may, in part, explain why men depend upon their wives, partners, or female friends much more for expressive support (Stebbins 1988) in times of crisis since male friendships would be much less effective if the groundwork has not been laid beforehand.

The focus of this chapter will be upon the social support received from friends and neighbours. The analysis will separate social support received from friends and neighbours as well as the differences between men and women interviewees' experiences. Again, the bidirectional nature of support is seen through the expectations placed on friends and neighbours, and the expectations interviewees place on their own role within these relationships.

I. Friends and Neighbours

The women interviewees in this study received support, expressive and instrumental, from both neighbours and friends. Nine received some form of support from both friends and neighbours, 13 received support from friends only, two did not receive support from either friends or neighbours, and one woman received support only from neighbours. For the most part, friends were the major source of both instrumental and expressive support from non-family (See Table 7.)

For the men interviewees in this study, family was the most frequently utilized source of social support. Friends and neighbours were a source of social support for three, 12 received support from friends only, and three did not receive support from either friends or neighbours. Similar to the women interviewees, friends were the major source of both instrumental and expressive support from non-kin (See Table 7.)

Table 7 Receipt of Social Support From Friends and Neighbours

Source of Support	Women	Men
Friends	13	12
Neighbours	1	-
Friends and Neighbours	9	3
None Received	2	3
Missing	2	1
Total # Respondents	25	18

Women, Friends and Neighbours

Although neighbours were not as prevalent a source of social support, they did provide important services at crucial times. Due to their proximity, neighbours can provide help on short notice that others may be at too great a distance or unable to perform. For example, one woman indicated a neighbour visited during a critical time:

> She sent a little note over cause she didn't want to interrupt what was going on, saying "My mother-in-law will look after my little boy tomorrow morning." They were going to book me into the hospital at 1:00 o'clock so all she knew is that I was going to be here by myself.

Neighbours can also provide services on short notice:

> They would phone and see if there was anything I needed, or bring lunch over, or dinner, that sort of thing, when I wasn't feeling like doing too much.
>
> They have helped with baby sitting and sent food. They all wanted to help.

Neighbours most often provided a combination of instrumental and expressive aid. However, three women only received emotional aid in the form of phone calls to inquire about health or neighbourly conversations, such as swapping stories or simply passing the time of day in general conversation.

> I have good neighbours, just sort of saying "Hi!" and "How goes it?" and that sort of thing. Nothing gushy, gushy.

The maintenance of the normal flow of neighbourliness was important to these women. When neighbours made an unusual or unexpected effort, it came as a surprise:

> She and her daughter came up to visit me in the hospital. And her daughter, you know, brought me a gift and everything, a little basket, a little bag of all sorts of goodies. That she should care enough, you know, to come up to see me, that was just terrific, but I saw how much they cared. Why I just never realized that they cared for me that much.

Of the 27 women interviewees, 25 discussed support from neighbours and friends. Of these 25 women, 15 either had very little or no supportive contacts with their neighbours. In comparison, only three women had little or no supportive contacts from friends. The reasons given for lack of contact was simply not knowing the neighbours, or maintaining an impersonal relationship. Although neighbours have potential as a rich source of social support, particularly providing what one woman referred to as "immediate needs," they are an underutilized source in times of personal health crisis.

Friends were a major source of social support outside the family, providing a large portion of both expressive and instrumental support. Before a friend is accessed for social support, trust must be demonstrated by the friend's willingness to listen to a cancer patient's concerns. For example, one woman indicated:

> I have to keep in mind that I can discuss cancer until hell wouldn't have it with people who have had cancer, but that I have to remind myself that not everybody has cancer and that there is another world out there. And people ask me how I am and I say "I'm well," and if they ask me anything more I will expand on it.

Friends must present themselves as:

> ...a properly receptive audience: that is listeners who are supportive, encouraging, empathetic, and nonjudgmental. (Schneider and Conrad 1984, p. 239)

As one woman indicated, when asked if she ever discussed cancer with friends:

> Yes, I have done. I mean they've asked me.

Thus, friends have to demonstrate a willingness to talk about cancer and through this interaction the perception that this is a source of social support is created. It was at this point that women were then willing to disclose to their women friends their feelings about cancer and need for supportive interactions. For one woman, friends were only able to offer this demonstration of support through conditions beyond her control:

> I did tell one friend, and the only reason I told her I was going into the hospital was because I knew I was going to be on her floor, she's a nurse...because I really preferred not to tell anybody till I knew the outcome myself.

Since there is a reluctance to involve friends, and instead look for social support primarily among family members, interviewees again expressed surprise (as they did with neighbours) at the response of friends to their needs:

> I've been surprised by the depth of support.

> They were wonderful...I found it quite overwhelming in a way, which is nice, but it was quite a surprise.

Not all friends were supportive when they discovered the interviewee had cancer. Chesler and Barbarin (1984),

investigating supportive interactions between parents of children with cancer and their friends, argue that friends:

> ...are shocked and depressed by information about the illness. They also hesitate to bring up painful topics to parents and do not want to add to parents' distress...parents and their long-term friends do 'feel for one another,' and their mutual concerns about each other's emotional status create reciprocal difficulties in the helping process. (p. 130)

When the illness strikes even closer, a friend rather than their child, the effect of the diagnosis may be even greater, emotionally disabling friends from providing support. Friends may not know how to respond to another's situation, particularly in the case of cancer. As Goffman (1963) argues, people close to those with a stigmatizing condition are often uncertain about how interactions should progress. It may become easier to withhold support in an uncertain situation, than to provide what may be viewed as clumsy or inappropriate support. However, Chesler and Babarin (1984) also argue that friends are not unaware of "...the risks or vulnerabilities involved" (p. 130) in the provision and receipt of social support.

When friends were unable or unwilling to provide social support, unlike the pain and bewilderment that would accompany the same situation with family members, interviewees made excuses for the lack of commitment.

> She's started up her own consulting business. She just doesn't have time.

Friends are often excused for being unable to respond at all.

> ...because they weren't familiar with it, they didn't have any knowledge of it. I wouldn't know what to say to a lot of people beforehand either...
>
> Some people would just not say anything, you know and I'm sure I can understand that, they don't know what to say so they don't say anything.

There is a much more forgiving element in friendship relations than familial relationships. The clearer boundaries that are established through interactions with friends, make much more explicit expectations and understandings of the quality of the relationship. So in the search for social support:

> Friends choose to do what kin are obliged to do. With friends, we must earn the rights and privileges that with family usually come just for being part of the collectivity. (Rubin 1985, p. 22)

This allows people to access social support from those friends they perceive as supportive, while permitting other friends to withdraw, either temporarily or permanently with greater understanding than that afforded family members. Cancer has a greater effect on people, because it is equated with death, while other medical conditions, such as a heart attack, may be much more easily accepted. Those friends who withdraw may be forgiven for their inability to deal with cancer. As one woman stated:

> Your friends and some family are not very supportive because they have a hard time dealing with the disease themselves.

Men, Friends and Neighbours

Most of the male interviewees did not have a great deal of contact with their neighbours, and therefore they either didn't tell their neighbours about their cancer or there was little or no response from neighbours when they were told. Emphasis was placed on impersonal relationships with neighbours:

> We're not that close with them.

As one man summed it up:

> We don't speak to the neighbours. You can't escape your neighbours.

For the three men who indicated that neighbours did provide some form of social support, two received a form of expressive support, hospital and home visits. The remaining man received both instrumental and expressive support from his neighbours:

> When my wife was away, he came down and saw me. I told him what was going on. He's a good neighbour. His wife today was really very straight with me. Actually, I'm pleased. She said she sort of understood and hoped I recovered well from the surgery and sort of assured me that they'd be around the house.

Similar to women interviewees, men indicated they either did not know their neighbours or maintained an impersonal relationship. They were, however, more willing to indicate that they distanced themselves from their neighbours, wishing to maintain their privacy. Gilligan's (1982) concept of connectedness can shed light on the difference between men and women. Women feel a responsibility for maintaining social

relationships. As a consequence, they may wish to maintain connections between themselves and their neighbours. Even though they admit that they, in fact, have little or no contact with neighbours, women may still be unwilling to close the door on the possibility of future increased contact with these same people. Women are frequently at home more often than men, and therefore have greater opportunity for increased contact with neighbours. Men, on the other hand, having less opportunity to develop neighbourhood contacts, may be much more willing to close the door not feeling responsible for maintaining such relationships.

Friends provided both expressive and instrumental support to 12 male interviewees. Expressive support was in the form of hospital and home visits, and phone calls, and was limited to expressions of sympathy and indications of caring:

> What few people there were, they were very supportive and I've had people that worried about me, you know. You don't want to have people worrying about you, but it's nice.

As Stein (1986) and Stebbins (1988) indicate, these men are reluctant to share their inner feelings and fears with their male friends. As one man said about himself:

> I never spoke to anyone about [personal feelings]. I know it helped me to hold back a lot. I didn't want people to think I had the attitude "why me, poor me." I would try to present myself as if I could handle it myself.

Two men spoke of sharing their feelings and fears but indicated the individuals they talked to were women friends:

> ...she was the only one I ever talked to and that was fine. She was just really, really easy to talk to.

In the case of one interviewee, when a male friend exposed his emotions and concern about the interviewee's illness, it resulted in confusion on the part of the recipient of such concern.

> He said "You've always been there for me and I just want you to know that I'm here, that I care, and I want to thank you." It's about the craziest thing. I didn't know how to react.

For these men, friends can provide some expressive support, as long as the support was limited to expressions of sympathy and concern. These interviewees were reluctant to share their own feelings about cancer with their male friends. As previously stated, this reluctance could be an indication of their dependence upon women for expressive support within an intimate context. To expose their own feelings about cancer may jeopardize their carefully constructed control over the disease itself.

Five, out of a total of 18 interviewees, received instrumental support from their friends. For these men, and in keeping with men's emphasis on instrumental support, this was an indication of the depth of a friend's commitment to their friendship.

> You really found out who your friends are.

Instrumental support was offered in a number of ways:

> I do a lot for my mother-in-law and so they said "We'll look in on your mother-in-law." They volunteered to pick up the slack. People don't have to say much, just say "I'll do it."

An individual who was formerly a business acquaintance was redefined by one interviewee as a friend because of the instrumental support he provided. This employer was defined as a friend when he indicated he would look after this man's family:

> I want you to just worry about getting better. I will take care of [wife and child].

This same employer arranged for taxis to pick up and deliver the man to and from work, since, due to the nature of his cancer, he was no longer permitted to drive.

For one man, a female friend contributed instrumental support in the form of providing information for his wife:

> ...we had one friend, she had no fear at all about being up front and point blank. Whatever she was curious about or wants to know she asks...the discussions we had probably did more for my wife. She would ask me questions my wife wouldn't ask.

He interpreted the friend's inquiry not as expressive support for himself, but instead as instrumental support for his wife. By providing information in this indirect manner, she was helping his wife better understand cancer.

For these men, expressive support was an important component of friendship relationships. Similar to the women in this sample, male interviewees were reluctant to tell friends about their cancer. However, they did differ from

women when friends indicated their concern. While women indicated that they were free to share their feelings with friends when interest was shown, men continued to withhold their feelings about their illness with male friends. Instrumental support seemed to be a much more comfortable form of social support. In this manner, the discussion of emotional concerns could be avoided. This de-emphasis on the sharing of emotions with other male friends can be a result of life-long socialization (Kessler, McLeod, and Wethington 1985; DeFares, Brandes, Nass, and van der Ploeg 1985), or help maintain the feeling of control that men strive to develop within close relationships (Stebbins 1988). Alternatively, as stated in Chapter Four, Cancian (1986) suggests that instrumental action is the male expression of caring. Researchers must be willing to equate this with women's emphasis on expressive interactions, since in the end for men it may have the same effect.

Although male interviewees did not appear to expect support from friends, when friends withdrew support it was a disappointment. Only one male interviewee indicated that he had experienced the withdrawal of friends. He expected his friends to continue the level of support they had provided when he was going through cancer treatments. However, friends drifted away and he lost contact with them. He stated his disappointment rather bitterly:

> It's funny, when you get sick everybody wants to help. As soon as you're better you never hear from them again. You know like, they do it so they can turn around and say "Hey I helped him out." If they're interested they would still have been around. They were putting on a show for maybe their friends.

In contrast to women, this man was not as amenable to forgiving friends for their unwillingness to continue supportive interactions.

Summary

For both men and women cancer patients, neighbours are a potential source of social support and indeed they are able to provide immediate help when it is needed. However, there is a low level of contact between the interviewees and their neighbours. As stated before, some friends were neighbours but the majority of interviewees maintained an impersonal relationship with their neighbours. The physical setting can explain this lack of contact with neighbours. However, all interviews were conducted in an urban setting, so neighbours were close at hand rather than at a distance as they would be in a rural setting. In addition, only two men and four women lived in either an apartment or a condominium. Two of these women indicated they were recipients of support from their neighbours. Since interviewees, for the most part, did not maintain close contact with their neighbours, the norms of relating to one another would be more formal than those guiding interactions with family and friends. Consequently,

this would explain the underutilization of neighbours as a source of social support.

Outside the family context, friends were a major source of both instrumental and expressive support. Both men and women depended on friends for expressive support. Women felt free to express their feelings to friends once friends had indicated a concern and willingness to listen. Men on the other hand accepted expressions of concern from male friends, but remained unwilling to expose their own feelings, except in the case of cross-sex friendships. If a friend was unable to demonstrate concern, women were very forgiving, making excuses when support was not forthcoming. On the other hand, when friends were unable to demonstrate concern, the one man involved was not as forgiving.

As discussed in Chapter Four, when interviewees felt that appropriate support was not provided by family members, a great deal of disappointment was felt by the cancer patient. As Rubin indicates,

> Because our kin relations rest on the bonds forged in our earliest childhood years, they have an elemental quality that touches the deepest layers of our inner life and stirs our most primitive emotional responses. (1985, p. 20)

Female interviewees were less forgiving of the negative responses they experienced with family members. However, they were much more forgiving of negative reactions from friends. Friends are chosen by individuals and, in turn, choose those same individuals. People can change their friends when they

do not meet expectations with less pain than when they feel rejected by family members. Women are, therefore, much more tolerant of negative responses from friends.

Similar to women interviewees, men interviewees were also unforgiving of negative responses they experienced with family members. However, in contrast to women, the one man who had also experienced the withdrawal of friends remained unforgiving.

Men withheld their feelings from male friends. This may be a consequence of their gender socialization and a possible attempt to maintain control of the relationship during the cancer experience. Expressive support for men was provided by their wives and partners. In the absence of a wife or partner, a female friend was the source of expressive support.

The depth of friendship for men was indicated by a friend's willingness to provide instrumental support. Women accepted both instrumental and expressive support as indications of friendship. However, women do tend to couch instrumental support in expressive terms, thus maintaining the relational nature of social support.

CHAPTER SIX

PARTICIPATION IN SOCIAL SUPPORT GROUPS

As noted in Chapter Two, a significant number of the interviewees were members of two cancer support groups, Cancermount and Reach to Recovery. Ten women and six men were members of Cancermount, 10 women were members of Reach to Recovery, one woman was a member of both Cancermount and Reach to Recovery, and one woman was a member of a hospital support group. Five women and 13 men did not belong to any cancer support group.

One of the original intentions of this research was to investigate why cancer patients did or did not join support groups. As previously mentioned in Chapter One, their level of participation may be a result of the response of their social support network. Taylor et al. suggest cancer patients may seek support groups when support "...fails to materialize or may miscarry when stressful events, such as a cancer diagnosis, occur" (1988, p. 188). Summarizing the literature in this area, they suggest that family and friends can "victimize" cancer patients through two reactions: 1) fear and aversion toward the disease, and 2) maintaining a cheerful and optimistic approach in the mistaken belief that this is the best way to behave when in the company of a cancer

patient. The conflicting emotions resulting from these reactions may lead to an avoidance of the patient, or an inability to communicate openly. The conclusion was that this undermining of social support that accompanies cancer may lead the cancer patient to turn to outside sources for the support they feel is necessary.

When asked why they did or did not join a support group, subjects reported reasons set forth in Table 8:

Table 8 Participation in Social Support Groups by Gender

Reason	Women	Men
To Help Others	14	6
Support for Self	8	-
Don't Need Them	2	7
Not Ready	2	1
No Knowledge	-	1
Other	1	4
Total	27	19

For the most part, those men and women who joined a support group, joined because they believed they could help other cancer patients. Only women indicated that they joined in order to receive support themselves. Five women and 13 men did not join a support group. The most common reason for not joining was given by nine interviewees, who felt they had no need of additional support. A total of nine interviewees stated various reasons for non-participation. Table 8 is explained at greater length

below.

I. Participation

Cancermount and Reach to Recovery are two support groups sponsored by the Canadian Cancer Society. Reach to Recovery provides support for women who have or have had breast cancer. Consurmount provides support for men and women who have or have had various types of cancer. Both groups provide support to two groups of cancer patients: 1) members of the group, and 2) recent cancer patients who are not members. In addition, Cancermount provides support to family members of cancer patients.

Although not all members do so, some members of Cancermount and Reach to Recovery also act as volunteers in the provision of support to non-members. So, in addition to receiving support, at monthly meetings, they provide support to new cancer patients on a one-to-one basis, either over the telephone or through hospital visits.

Again, the theme of social support as a bidirectional process occurs. Not only do interviewees join cancer support groups in order to receive support, but they also join to provide support because they perceive other cancer patients as being in need of support from someone who has shared the experience.

Generally, the women interviewed participated in the social support groups for one of two reasons. Most joined

because they believed they could help other people come to understand and deal with their cancer experience. These women had a strong belief that many cancer patients have no support and were experiencing a much more difficult time than they were themselves.

> ...when I was in the hospital, I don't know if I was in shock or what, but when [volunteer] came up to see me and told me where she was from and told me how many years since her operation, that gave me the biggest boost of all. I made up my mind, no matter what I had to do I had to do something to help someone else, cause I knew right then there [were] a lot of people out here who had had cancer, and I thought 'boy, they need someone.'

In comparing themselves to other cancer patients, they viewed themselves as having a much more positive experience with cancer than was generally the case. As one woman indicated:

> There she was with cancer, no husband and two children. Now how is that for not being as lucky as me...

and another,

> I began to feel guilty that I had survived and hadn't done anything to help anybody else...It makes me feel very lucky. A lot of the members, even though they are still surviving, have gone through so much more than I have.

This comparison leads these women to conclude that generally people have a very difficult time with cancer. Sometimes this belief comes from their own experience, which they generalize to other cancer patients:

> I would have loved to have a support group back when I had my cancer. So for me, I think I did it because it's a need. I feel like I'm young enough, that I look healthy enough, that I can bring someone hope.

The perception that these women develop is that there is a large number of cancer patients who are experiencing difficulties coping with their illness, a need for social support from individuals who have shared the experience, and that family and friends are often unable to provide needed support. Consequently, they feel an obligation to provide support to those they see as less fortunate than themselves.

Similarly, the men who had joined Cancermount indicated the same beliefs as the women. They too shared the belief that a lot of cancer patients are having a difficult time dealing with their illness and that they could be a source of social support providing information and comfort. As one man indicated:

> I joined the thing, the group, because there's a lot of people that don't know what cancer is, or how to deal with it. I thought I'll get involved with Cancermount because there's a lot of people who are having a tough time with it, trying to focus on the positive, and seeing somebody who has been through it and still surviving is a whole lot better than hearing about how everybody dies of cancer.

Although these men did not talk about openly comparing their experience with other cancer patients, it can be assumed that they have done so in order to conclude that others are having a much more difficult time.

> ...I see a lot of people hurting, and they don't know how to go for help. I personally feel that

> if you have the answer it doesn't hurt to talk to other people...

While offering support to others they perceive to be in need, these interviewees also benefited from the contact they had with those cancer patients they were helping. Both the men and the women who spoke about offering support to others as their reason for joining a cancer support group, also spoke about how they felt when they did provide others with what they perceived to be much needed support. As a male member of Cancermount indicated:

> It enriches my life. I cannot buy or put a dollar value on it. They give me strength and comfort, but I also provide strength and comfort for others. It's a two-way process.

A woman member of Cancermount spoke of the satisfaction she gained:

> I do prefer visiting patients because it gives you such a wonderful feeling. It's worth more money than anything to be told that I helped somebody.

In the very action of providing others with support, these people received support from those they talked to over the telephone or visited in the hospital. They indicated that such activity made them feel needed and valued, as well as enriching and fulfilling their lives. The feedback they received as "visitors" increased their feelings of self-esteem and self-worth. In this interaction cancer is transformed from a negative event in their lives to an opportunity to do something significant for others, to give something back.

Six of the women members of the support groups indicated that they participated in order to receive support from the group members. They felt it assisted them by providing positive attitudes, understanding, information and the opportunity to make new friends. The perception is the group gives them the opportunity to change their lives for the better. For example, one woman member of Reach to Recovery stated:

> Well, I kind of think of them as a life-line. It's through them it was a turnaround for me.

Similarly, the woman who was a member of both Cancermount and Reach to Recovery, indicated Cancermount made a difference in how she lived her life:

> I deal better, not so much with cancer, as with the old habits that I can still fall back into, that I spent all those years falling into. And the Cancermount group are just that stabilizing force. The Cancermount group is a reminder of how much I've learned and how much I don't want to go back to the way I was and how I've handled things.

When she talked about her participation in Reach to Recovery she emphasized the emotional aid she received:

> I just found that I had too rich a framework of people here. There was no way I could walk away from that. I didn't and it was the first group of people ever where I could say 'I feel sorry for myself.' Never before in my life had I been able to say to a group of people I feel sorry for myself or I feel like crying and with this group I can. They know I'm hurting when I say I'm hurting. Even if I say it in rather a strange fashion, they still know I hurt and they're there. So that's why I stay in it.

For two of the women, the positive attitudes displayed by group members were an important component of their

participation in group meetings:

> ...everybody is so up there, it keeps me up.

And,

> It was neat to see people who were upbeat and had a positive attitude and things. Just to look at these ladies and realize how upbeat.

Three of the women indicated multiple reasons for participating; for example, one member of Reach to Recovery stated:

> I'm glad I went because it gave me more information. They took away some of the scary parts about cancer, because even the people who had so much worse, they had it very bad, still had a very positive, very optomistic attitude. It took away some of the dark corners that I was still worrying about.

Another woman talked about the positive feedback received and friends she had developed in Cancermount:

> I get a lot of positive feedback through those contacts...It's been a wonderful source of friendship. The cameraderie there is just marvelous.

Each of these six women was able to draw from Cancermount or Reach to Recovery those elements of support that she felt was most helpful to herself.

II. Nonparticipation

At the time of the interviews, five women and 13 men did not belong to either Cancermount or Reach to Recovery. Their reasons were varied. Two women and seven men felt they had no need for a support group. Two of these people felt cancer was not as problematical as they first thought

it would be; consequently they had no need for a support group. As one man stated:

> I don't know what support I can get there, because it wasn't as disastrous as we thought it might be.

A woman stated:

> Like I say it's out of my mind most of the time. I like to say it was a nightmare while it lasted but it was caught early. I feel I'm cured but I don't know.

Seven felt they could deal with the crisis themselves, or believed they had sufficient support from family and friends negating the necessity for a support group. As one man said:

> I guess my biggest problem is myself, in that I've been on my own since I was 15 and consequently I take the attitude I'll look after this myself. So it's my problem and I'll look after it and maybe that's one reason why I haven't contacted anyone.

A single woman living alone emphasized her independence:

> I wish I had but I understand why I didn't. One, because I'm sure, I remember saying to my mother I'm sure they'd probably consider me really obnoxious because I have that attitude that I'm going to do this all by myself, and I'm wonderful and, of course, no one could believe it.

Two people (one woman and one man) did not feel they were ready to join a support group. The woman looked upon a support group not as a support for herself but as an opportunity to provide support to others. As a consequence, although she was thinking about joining Reach to Recovery as a volunteer at a later date, she did not feel she was prepared to take on that responsibility at the time of the

interview. The man who was not ready to join stated:

> I just was not ready for it. I cannot really explain to you why I did not feel comfortable talking about myself in a group. I don't know. I guess I am more comfortable talking about it now.

For this man, joining a support group mean he would lose some of his privacy, and he would be faced with a situation whereby he would be compelled to disclose his experience.

Each of the remaining seven men and women had different reasons for not joining a support group. These reasons were as follows:

1) a lack of knowledge of support groups for cancer patients,
2) knowledge of cancer support groups but waiting to be contacted rather than contacting them,
3) concerns about confidentiality,
4) a negative experience when first contacting a support group,
5) a negative idea of what support groups are about,
6) still thinking about whether or not to join a support group,
7) appreciating the help received but not even thinking about joining.

Reasons for not joining a cancer support group seem to be varied and individualistic. The most often stated reason for not participating is that this type of support is not needed by some individuals. However, out of 18

nonparticipants, only nine indicated this reason. An equal number of nonparticipants indicated a wide variety of reasons for nonparticipation.

Summary

This chapter has discussed the participation of interviewees in two cancer support groups, Cancermount and Reach to Recovery. For the most part, it can be stated that the most significant reason, or the reason most often stated for not participating in a cancer support group, is the feeling that it is not necessary. Those who felt the support group was not necessary for their own well-being believed themselves capable of handling the crisis on their own, or were receiving sufficient support from family and friends.

The men and women who participated in Cancermount and Reach to Recovery indicated that they joined for one of two reasons. They joined to either provide support for other cancer patients, or to receive support from people who shared their experience. In the provision of support to others, members of these support groups are also receiving support in return. Their self-esteem and feelings of self-worth are increased in the very activity that they believe is directed at others. Participation in Cancermount and Reach to Recovery is therefore an attempt to draw from a social support group that form of support that is most

needed by an individual. Support may come in the form of meeting new friends, gaining information, developing a positive attitude, or increasing self-esteem through helping other cancer patients believed to be in need of support.

Taylor et al. (1988) suggested that cancer patients join self-help groups because the reactions of family and friends are such that social support is inappropriate or unavailable. This undermining of social support leads the cancer patient to turn to outside sources in order to receive the support they find necessary. However, as indicated by this research, cancer patients may also join because they view their own cancer experience in positive terms, and feel that they can provide less fortunate cancer patients with some positive support.

CHAPTER SEVEN

CONCLUSIONS

The interpretation of stressful life events is dependent upon the meaning that individuals construct through interactions with their social support network. Family, friends, neighbours, as well as the medical and helping professions are an integral part of the development of strategies when adjusting to such stress. The past decade has seen a rapid growth in research in the area of social support, emphasizing the importance of social support to the maintenance of health. Recent research has suggested that social support has been found to be critical to individuals coping with major life stressor events (see Andrews et al. 1978; Sokolovsky et al. 1978; Lin et al. 1979; Kuo and Tsai 1986; Parry 1986). Studies of social support and illness have focussed their attention on the the question of social support as a main effect or buffer against significant life changes. To date, this research has been unable to confirm or disprove either the buffering or main effect of social support (Thoits 1982). House et al. (1988) suggests it would profit social support research to move away from such an unsolvable question and refocus efforts on the processes of social support.

In addition, studies of social support have centred their

attention on the receipt of support by individuals undergoing stress. The provision of support by individuals undergoing a health crisis has not been a component of this literature. This view does not take into account the complex nature of social support itself. Social support is an interplay of receipt of support and provision of support by both the social support network and the individual undergoing the stressor event. This thesis has examined this bidirectional nature of social support. Specifically, through 46 interviews (27 women and 19 men) with people who have experienced cancer, this thesis examined the supportive transactions that occurred during this major life stressor event. Interactions between cancer patients and their family, friends, and neighbours, as well as participation in social support groups, were explored. It is argued that social support is bidirectional in nature, that is, not only do people receive support during a major life stressor event, but they also provide support to others in their support network. Men are concerned with the receipt and provision of instrumental support. Women, on the other hand, focus on expressive support and are concerned with the well-being of others.

I. Narratives of Social Support

Recently, Dr. Arthur Frank was preparing to present a paper to the Tom Baker Cancer Centre on the incorporation of narratives in psycho-social oncology research. The objective

of this paper was the reclamation of the individual story within research. Although Dr. Frank speaks in terms of psycho-social oncology, he suggests that social scientific research could benefit from "...reclaiming the primacy of hermeneutic description over administrative science" (1990, p. 12). Similar to this suggestion, the presence of interviewees has been maintained throughout this thesis, through direct quotes, in an attempt to ensure that these people do not become lost in the analysis.

The 27 women and 19 men interviewed for this study clearly shared similarities in their experiences, but each person also had a unique story to tell. By allowing interviewees to speak for themselves, an attempt has been made to ensure that they do not become mere pieces of data.

During the writing process interviews reconstructed themselves. Sometimes interviews were painful, sometimes joyful, but always satisfying. These people have gone through a frightening and at times frustrating experience, that they believe has allowed them to better appreciate each additional day they gain. To take away their voice, and just turn them into pieces of data, would be to deny their experience, and their humanity.

The most prominent characteristic of the sociological literature on social support is its quantitative nature. The question becomes, what does this type of research tell us about social support? Schwartz and Jacobs (1979) argue:

> Quantitative methods allow for the clear, rigorous, and reliable collection of data and permit the testing of empirical hypotheses in a logically consistent manner. (p. 5)

Quantitative methods would allow the researcher to test theories in order to confirm or reject these same theories. The purpose of this research was, on the other hand, the development rather than testing of theory, through the exploration of the processes of social support. Consequently, for the purposes of this research, the number of times a person visits another does not truly indicate a supportive transaction. The number of services provided by one person to another does not indicate a supportive transaction. The quality of the visit, or the manner in which the service is provided for another is more likely an indicator whether or not social support is part of the interaction. Counting instances of support transactions does not really tell us what is going on.

In order to understand the nature of social support, people had to be put back into the research. The context of a master's thesis demands that the researcher demonstrate the ability to accomplish an appropriate scientific project. It became necessary to adopt a research method that would accomplish these two goals. Theoretically, symbolic interactionism presented the opportunity to allow cancer patients to speak for themselves. Methodologically, grounded theory ensures that categories are not forced upon the "data" but instead categories remain true to the interviews

themselves. Although this may not be the ideal way to return the individual to the research, it was at the time the best approach and still remain "scientific." The heavy emphasis on direct quotations from interviewees hopefully lends a sense of how these people felt, and conceived their cancer experience, so that the reader might develop an understanding of these people's lives.

Although each of the interviewees had an experience with cancer, this was a thesis about social support. Cancer was chosen as vehicle to examine the processes of social support, since it is an extreme example of a crisis that would necessitate the activation of a social support network. As discussed in Chapter One, Wethington and Kessler (1986) suggest that the processes of social support would be made much more explicit through an investigation of particular life event rather than generalized surveys. A life event that carries the cultural meanings that are evident with cancer, as discussed in Chapter Three, provides the opportunity to examine social support from both positive and negative experiences. As stated in Chapter One, expectations of social support may be altered by the significance of a crisis. The cultural meanings attached to cancer increase the significance of the crisis to both the cancer patient and the social support network. As stated by Frank:

> Critical illness offers the experience of being taken to the threshold of life, from which you can see where your life could end. From that vantage point you are both forced and allowed to think in new ways about the value of your life. (1990:1)

Another crisis, for example a heart attack, may not result in the same interactions with the social support network that would be brought about as a consequence of the cultural meanings surrounding cancer.

How did these people perceive the support they received during their illness? By focussing on actors' perceptions of support they would receive should they need it, the literature implies that actors are passive receivers of support after they activate the support network. However, the interviewees in this study clearly indicated that they were not passive but active participants in a bidirectional process. As central actor in these supportive transactions, interviewees controlled information provided to their support network. They decided who to tell and what to tell to family, friends, and neighbours. As indicated by the disappointment of those who did not receive what they felt was appropriate support from family and friends, they held expectations of the roles that others should play in providing support. When these expectations were not met, the interactions became confused, and interviewees no longer could control the flow of information.

In Chapter One of this thesis, the stated expectation of this research was the demonstration that should gaps appear in

a person's familial support network, friends would fill those gaps, thus providing the necessary support. For those interviewees who were disappointed with the reaction of their family, friends did provide support. However, the very nature of the family prevents friends from standing in as proxies. Yes, they turned to friends for support, but the disappointment with the lack of family support remained. For those who felt their family members had provided adequate support, friends became a supplemental source of support. Overall, friends were not a replacement for family members, but instead increased the level of support available to interviewees.

The bidirectional nature of social support could be most clearly seen in interactions with family members and participation in cancer support groups. Those interviewees who chose to, acted as caregivers to family members and other cancer patients. Family stress was alleviated, and roles that would create an atmosphere of normal family life were either maintained or developed. Most of the women, and a few of the men became volunteers with either Cansurmount or Reach to Recovery in order to provide assistance to other cancer patients. Thus interviewees were not only recipients of support, but also providers of support.

These interviewees were also attempting to make sense of their cancer experience. To accept cancer as a random event would be to admit that it could happen again, that one has no

control over one's life circumstances. By redefining their experience, taking responsibility for cancer, and acting as social support to family members and other cancer patients who need their expertise, these cancer patients gained control over their disease. This control makes it possible for interviewees to acquire a sense of self-worth. These people did not passively sit by and allow events to act upon them. They took action and in that action were able to make sense of what could have been a senseless life event.

II. Research Limitations

Any research project has weaknesses as well as strengths. There are areas that limit this research. Although Corbin and Strauss (1990) suggest that criteria used to assess quantitative research should not be applied to qualitative research, the development of new criteria may continue the debate over the merits of quantitative versus qualitative research rather than providing a resolution to the problem. Consequently, the following discussion will focus on the traditional criteria for assessing the credibility of this research: reliability, validity, and generalizability.

Shaffir, Stebbins and Turowetz (1980) present an excellent summarization of the problems of validity and reliability in qualitative research. Problems of validity centre on whether or not "...an accurate or true impression of the phenomenon under study" (p. 11) is attainable. Hand in

hand with validity is the problem of reliability, which focusses "...on the replicability of observations" (p. 12). Can another researcher come to the same conclusions if she/he shares the same methodological training, has the same sensitivity to the research domain, and is able to develop similar rapport with the subjects? Shaffir et al. (1980) suggest these two problems fall into three categories:

> 1) reactive effects,
> 2) selective perception and interpretation,
> 3) limitations on the researcher's ability to witness all relevant aspects of the phenomenon in question. (p. 12)

Reactive effects are those behaviours or responses that interviewees make in reaction to the researcher's presence. Interviewees may attempt to present themselves in a role or provide answers to questions that they believe will make a favourable impression on the researcher. People will attempt to cast themselves in the best light possible in order to gain the approval of others. Their answers are also constrained by their ability to recall past events. This is a problem that will always be a component of social science research, and one solution is to attempt to reduce these effects if at all possible. Interviewees were aware that the researcher had also had an experience with cancer. As a result of a mutual understanding of the feelings and problems that surround cancer and its subsequent treatment, reactive effects may have been somewhat reduced.

A second problem area lies in the bias that may enter a

study through selective perceptions and interpretations on the part of the researcher. Researchers do not live in a vacuum and are influenced not only by their own personal views but also by the theoretical perspectives of other scholars in the same area of research. A strategy that is recommended by Shaffir et al. (1980) in order to reduce this problem is "...to play back one's observations to one's subjects either in verbal or written form" (p. 14). In addition to "playing back" observations to an interviewee, several graduate students were enlisted in reviewing and discussing interviews, problems of data analysis and subsequent interpretations. Expanding on this type of assistance, the findings of this study were also discussed with an individual who is experiencing health problems stemming from a chronic disease other than cancer. The comments of these people have been helpful in determining the validity of the findings and conclusions.

Ideally grounded theory should be a research team effort in order to reduce bias that results from selective perceptions. Each member of the team can contribute different perspectives and insights that can provide a depth of analysis that may not be available to the solo researcher. Team research, however, is a guideline rather than a rule rigidly adhered to by grounded theorists. Grounded theory is pursued by both solo researchers and teams of researchers. For example Glaser has completed grounded theory research both

as a solo researcher (1976) and as a member of a team (Glaser and Strauss 1965, 1968, 1971). In addition, Strauss (1990), lists 20 other solo researchers utilizing grounded theory effectively (xii). As Strauss notes, the conditions of graduate work do not facilitate research in team settings. Indeed, most graduate students studying with Dr. Strauss learn their skills as solo researchers (1990:284). The suggestion made is to enlist the aid of other graduate students to share ideas and discuss problems encountered. As indicated previously, this has been an integral part of the data analysis process for this research.

In addition to validating findings and conclusions by enlisting the aid of others, there is the problem of whether or not patterns exist. Quantitative sociology has carefully designed statistical methods that "...rule out every possible alternative explanation for an observed relationship before finally accepting it" (Schwartz and Jacobs 1979, p. 312). While this eliminates the possibility of Type I error occurring, that is concluding there is a pattern when one does not exist, it enhances the chance of Type II error. Type II error is failing to detect a pattern that does exist. Qualitative sociology is more likely to detect previously overlooked patterns that may have been unavailable to rigorous statistical methodologies. Through a grounded theory approach, qualitative research can expose those previously overlooked patterns of social interaction, while maintaining

a rigorous methodology that might also reduce the chance of Type I error. Since this qualitative methodology is grounded in the everyday experiences of participants, the theory is constructed to fit the data and, consequently, should withstand tests of validity. For example, the bidirectional nature of social support should become apparent in future research incorporating the concept.

The final category of problems relating to validity and reliability discussed by Shaffir et al. (1980) are limitations on the researcher's ability to access all pertinent information. Authorities that control the field "...may affect access because of what the subject or agency represents to the larger group" (p. 13). The original intent of this research was to interview cancer patients who were still in the treatment phase of their illness. This was not possible, as discussed in Chapter Two. Consequently, alternative sampling methods were developed. Despite this problem, a number of interviewees still in the treatment phase or just completing treatment did participate (12). The remaining 34 interviews were retrospective. Selective recall might become problematic. However, cancer is not a short-term disease. Usually, patients do not stop being patients when treatment is completed. For at least five years, the cancer patient remains under the scrutiny of the medical profession, returning for check-ups and blood tests at regular intervals. Cancer is viewed as a chronic rather than a curable disease,

so the patient is never told she or he is cured. The resulting uncertainty about the future might lead cancer patients to maintain a high level of supportive interactions with their network. In addition, this is a significant event in people's lives and, as a result, memories may be much clearer in comparison to a less traumatic occurrence. However, this is a problem with any research inquiring into circumstances surrounding an event. It remains unsolvable because researchers cannot observe or know everything that is germane to a study.

Another consideration of importance to any study is whether or not it can be replicated. Through careful replication of the conditions of a study a researcher should be able reproduce the same conclusions. Schwartz and Jacobs (1979) argue that the very nature of many sociological studies prevents their replication. Some studies are too expensive, time consuming, and require large numbers of personnel to complete. Others focus on activities and people that are not available to all researchers. Changes over time in the social, economic, or political milieu can irreversibly alter conditions, preventing any possibility of replicating a study. However, Schwartz and Jacobs also argue that "...many replication studies are feasible under comparable conditions" (p. 309). Qualitative research should, therefore, be replicable through an examination of comparable conditions. For example, a study of people who are experiencing another

life-threatening disease such as AIDS might produce the same conclusions as this study of cancer patients.

The objective of sociological research is to generalize to as wide a population as is possible. Grounded theory has limitations to its generalizability. The small sample size, in this instance 46 interviewees, the differing cancer experiences of men and women, the mean age of the sample (51.8), the number of interviewees with some post-secondary education (35), the high representation of individuals with an income exceeding $30,000 (35), and the limited geographical spread, predominantly residents of Calgary with a few interviews from smaller urban centres, suggests that this study is restricted in generalizability to this particular group. However, as Corbin and Strauss (1990) argue:

> A grounded theory is generalizable insofar as it specifies conditions that are linked through action/interaction with definite consequences. The more systematic and widespread the theoretical sampling, the more completely the conditions and variations will be discovered, permitting greater generalizability, precision, and predictive capacity. (p. 15)

The purpose of this study is to provide a starting point for continuing research in order to build upon social support theory. Therefore,

> If the original theory fails to account for variation uncovered through additional research, the new specifications can be used to amend the original formulation. (Corbin and Strauss 1990, p. 15)

Since this is an exploratory study, an expansion of this

project is intended in order to continue to improve the generalizability of the findings and further develop theory in the area of social support.

Because the focus of this thesis was family, friends, neighbours and cancer support groups, some areas of social support were left unexplored. Several people inquired why questions had not been asked about their medical treatment, or their relationship with physicians and other medical staff. This statement usually occurred after interviews had been completed. By the time it became apparent that this was an important part of their experience, most of the interviews had been completed and a thorough examination of this aspect of social support would be impossible. As a consequence, it was decided that the social support provided by medical practitioners would be incorporated into future research. Another unexplored area was the effect of cancer treatment on the provision and receipt of support. For example, bone marrow replacement puts restrictions on who can visit leukemia patients for extended periods of time; mastectomies may affect a woman's body image enough that the provision and receipt of social support may be significantly altered. Body image becomes an important aspect of cancer. "One wears cancer" (Frank 1990:92) and it's stigmatizing effect may constrain the processes of social support through the attitudes of not only the cancer patient but also the social support network.

There are a number of other areas that would have proven

to be fruitful avenues of investigation in this study. Interviews with members of interviewees' social support network could have provided insight into the process of providing and receiving support. Incorporating persons who suffer other chronic diseases that do not carry the same meaning, i.e. cancer is death, would have provided a point of comparison that might have provided insight into differential effects on the support network, and the amount and type of support provided. An examination of support transactions between network members would very likely have illuminated the effects of indirect support on cancer patients.

III. Theoretical Considerations

As stated earlier in Chapter One, network analysts are active in the area of social support research. The focus is on how social relationships are central to psychological and physical health outcomes. The perspective of network analysis is macrostructural, concentrating on the effects of the network structure upon the individual actor. Although social relationships are critical to the network approach, researchers are heavily dependent on "...mathematical models and statistical methodologies" (Fine and Kleinman 1983, p. 97) to the detriment of an examination of those relationships. Consequently, there is a predominance of counting social support transactions, rather than examining the quality of supportive interactions. This has lead some researchers to

label network analysis as atheoretical (Wallace and Wolf, 1986; Fine and Kleinman, 1983).

In Chapter One, it was noted that Fine and Kleinman (1983) argue that symbolic interactionism can restore to network analysis an examination of the relational nature of social support. In addition, if network analysis is viewed as atheoretical, symbolic interactionism can provide a theoretical perspective that is not inconsistent with the original intent of network analysis. Symbolic interactionism can return the concentration on the quality of interaction, and how those interactions shape and reshape the network structure. Network analysis can bring to symbolic interactionism the effect of the macrostructure on interactions between actors, and subsequent meanings constructed out of those interactions. As a consequence, by synthesizing network analysis and symbolic interactionism, it is possible to add to and enhance research in the social support area.

By examining social support from a relational perspective, this research has begun the process of synthesizing network analysis and symbolic interactionism. Although the concentration was on diadic interactions, how individuals interact with members of portions of their support network was partially laid bare. There is no need to "throw out the baby with the bath water." Symbolic interactionism has a quantitative tradition, as well as a qualitative

tradition. Consequently, it can accommodate the mathematical models and statistical methodologies of network analysis, as well as qualitative investigations that will expose the nature of supportive transactions.

IV. Implications for Social Support Research

Although social support interactions were categorized into instrumental and expressive interactions, as well as interactions with family, friends, neighbours and support groups, for the purposes of research, the lives of the people who participated must be seen as a whole. Relations with family, neighbours, friends, and cancer support groups are not separate compartmentalized bits of a person's life. Instead they are pieces of a whole that fit within the context of cancer. When social scientists dichotomize social support into expressive and instrumental help, it assists the researcher in determining who did what for whom. But for the cancer patient these supportive transactions are blurred. People don't just provide one type of social support and then disappear from the scene. In any given supportive transaction many kinds of support may be forthcoming. Instrumental support can also be expressive. For example, when driving a cancer patient to chemotherapy treatments is that simply instrumental, or are there expressive components to that same action? Do friends' constant offers of instrumental support become expressive support in the repetition, because they

demonstrate caring? Is expressive support just that or, because it raised the self-esteem of a cancer patient and therefore allowed him/her to continue working or caring for family members, does it become instrumental? These people would say yes.

In Chapter Two, social support was defined as "...the perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and confiding partners" (Lin et al. 1986, p. 18). However, research has focussed on expressive support, contending that self-esteem and identity develop out of social interaction, which then become important contributors to psychological well-being. As a consequence, social support should have a "...direct or main effect upon [the] psychological state" (Thoits 1982, p. 154). This concentration on the psychological effects of social support has led researchers to see instrumental support as secondary in importance.

Cancian (1986) suggested that because Western culture has feminized love, men's expressions of love are discounted. Has social support also been feminized? Men may appear more instrumentally oriented, but the relief of those who receive instrumental support may be expressive in nature. For example, was it instrumental or expressive support provided for the man whose boss told him not to worry, that his family would be taken care of while he went through cancer treatments? Yes it was instrumental, but the lifting of

concern over who would care for his family during his treatments was expressive in nature.

This blurring of boundaries between forms of support can be accommodated by combining both quantitative and qualitative methods of research. Supportive transactions can be counted to determine who does what for whom, but they can also be examined for the quality of that transaction. This also provides the opportunity for the researcher to retain the personal account within the research act. As stated previously, the synthesis of symbolic interactionism and network analysis can accommodate this perspective.

V. Future Directions for Research

There is no need here to emphasize the importance of further research in the area of social support. As the literature demonstrates, sociology has seen a rapid increase in this direction in the past decade. This is a relatively new area for sociology. Therefore, there is much to be investigated. However, researchers must not get bogged down in unsolvable questions, such as whether or not social support has a buffering or main effect on health outcomes. Instead, there is a need to return to the original inductive orientation of network analysis in the area of social support.

This research has demonstrated the effectiveness of qualitative analysis in the area of social support. The semistructured interviewing style, the broad questions that

were asked, the listening through talk as well as silences, allowed interviewees to provide new and important information about their social support interactions. If a quantitative method had been chosen instead, the bidirectional nature of social support would never have become apparent.

During the initial phases of this thesis it seemed that interviewees would identify the type of social support that was important to them, that friends would be instrumental in alleviating negative support from family members, and that participation in cancer support groups would be a result of lack of support from family and friends. These explanations did not fit interviewees' lived experiences. The qualitative approach means that such explanations can be set aside when new information suggests that another interpretation would result in a better fit between the data and the developing theory. The cancer patient as provider of social support, the blurring of types of support provided, and the regaining of control became more important ingredients in this thesis.

As previously stated, social support is a relatively new area of sociological research. This leaves much of the nature of social support unexplored. The above suggestions for possible investigation only scratch the surface, but have the power to provide new insight into the nature of social support.

One of the important characteristics of this research is the investigation of the process of social support during a

health crisis. Past sociological research has focussed on perceived support transactions that would be forthcoming should a crisis occur, or an investigation of everyday support transactions (Wellman and Wortley 1990). The examination of an actual crisis situation has provided new insight into the processes of social support.

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