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THE UNIVERSITY OF ALBERTA

THE ROLE OF FORMAL AND INFORMAL SOCIAL SUPPORT IN ADVANCED CANCER PATIENT WELL-BEING

BY

© LORETTA HALLGREN

A THESIS

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE ROLE OF FORMAL AND INFORMAL SOCIAL SUPPORT IN ADVANCED CANCER PATIENT WELL-BEING, submitted by LORETTA HALLGREN in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY in THE PLANNING AND EVALUATION OF HEALTH CARE.

(Supervisor)

Michael W. Gillespie

Charles Hobart

Date: December 18, 1987

Dedicated to my friend Sheila who, in the conduct of her everyday life and especially in her battle with cancer, continues to exemplify all of those qualities only to be found in one who is truly a "Lady of Substance."

ABSTRACT

The purpose of this study was to examine the relationships between formal and informal social support and the functional status and self-esteem aspects of the well-being of advanced cancer patients while paying specific attention to selected sociodemographic and contextual factors which may affect these relationships. The findings suggest that variations in the social support--well-being relationships are a function of several factors including (1) the type of outcome measure used, (2) the effects of sociodemographic and contextual variables, (3) the measurement of different aspects of social support and (4) the method of scoring social support measures. Overall, it was found that both formal and informal types of support were significantly related to functional status and self-esteem, however, some aspects of formal support were found to be negatively related to both functional status and self-esteem.

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Last, but not least, I wish to thank my husband, Bob, and my children, Shaina and Shaun, for their patience, understanding and unconditional love.

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CHAPTER I

INTRODUCTION

The purpose of this study was to examine the relationships between formal and informal social support and the functional status and self-esteem aspects of the well-being of advanced cancer patients while paying specific attention to selected factors which may affect these relationships. Justification for the study derived from two separate issues. First, while much of the empirical literature supports the predominant theoretical assumption that social support enhances well-being, there is also evidence which suggests that social support may have little, if any, or even a negative effect on well-being variously indexed, particularly within the context of severe illness. It is suggested that these contradictory findings may be a function of (1) differences in outcome measures of well-being and/or (2) failure to systematically examine or account for the effects of factors such as gender, age, marital status, socioeconomic status, time since initial diagnosis and individual differences in level of religious commitment, illness severity and support need, each of which may serve to strengthen or suppress the social support--well-being relationship.

The second justification for the study derived from a paucity of research examining the effects of formal support on individual well-being despite the fact that formal support now assumes a major role in the lives and care of cancer victims. Researchers have tended to focus on the role of informal support neglecting systematic and simultaneous examination of the effects of both formal and informal social support on various aspects of individual well-being.

In order to address these issues, two specific research questions were formulated and examined. The research questions were:

1. What is the nature of the relationships between formal and informal social support and the functional status and self-esteem aspects of advanced cancer patient well-being?
2. Under what circumstances do these relationships vary? That is, how are the social support--well-being relationships influenced by (1) sociodemographic factors such as gender, age, marital status and socioeconomic status, (2) length of time since initial diagnosis, (3) level of religious commitment, (4) severity of illness and (5) relative need for social support?

In summary, this study was conducted to address contradictory findings and a paucity of research regarding (1) the nature of the relationships between both formal and informal social support and advanced cancer patient well-being and (2) the effects of factors such as gender, age, marital status, socioeconomic status, time since initial diagnosis, religious commitment, illness severity, and support need on the social support--well-being relationship.

CHAPTER II

LITERATURE REVIEW

Overview of Chapter

The purpose of this chapter is to review the literature relevant to the study of social support and its relationship to individual well-being. Prior to examining the literature specific to social support and cancer, an overview of the general social support literature is provided in order to highlight major issues and trends which are expected to influence future research directions and enhance understanding of this complex social phenomenon. Within these two separate but related areas of the literature it will be shown that (1) integration of findings is difficult due to wide variation in the theoretical and methodological approaches used to study social support, (2) findings on the nature and strength of the social support--well-being relationship are inconsistent, (3) few studies have examined variations in social support and well-being due to sociodemographic and contextual factors and (4) there is a paucity of research examining the relationship of formal support to individual well-being.

The Social Support Literature

The concept of social support emerged as a popular focus of inquiry in the 1970's with the recognition of its potential significance as a mediating factor in the stress-illness relationship and general widespread acknowledgement of the important role played by the social environment in human health and well-being. Since that time, a sizeable body of literature, comprised of contributions from many social science and health-related disciplines, has developed to document theoretical formulations and empirical evidence of the benefits of social support and the detriments of its absence. With few exceptions, the evidence suggests that persons encountering stressful life circumstances are protected from potential declines in their physical and emotional well-being by the presence of supportive relationships (for example, Cassel, 1976; Cobb, 1976; Dean and Lin, 1977; DiMatteo and Hayes, 1981). Support systems are often viewed as acting as a preventive (preceding) factor which contributes to better mental health (Andrews et al., 1978; Henderson et al., 1980; Warheit, 1979), lower incidence of physical illness (Cassel, 1974; Wallston et al., 1983) and decreased risk of mortality (Berkman and Syme, 1979). Support systems are also viewed as a buffer (intervening factor) which moderates the effects of stressful life circumstances. The buffering model has emerged as a prominent theoretical orientation and has been broadly applied across a variety of stressful phenomena ranging from normal life transitions (Cobb, 1979); to undesirable life events such as unemployment (Gore, 1978) and occupational stress (House, 1981); and to crisis events such as rape (Burgess and Holmstrom, 1978), natural disasters (Baum et al., 1983; Murphy, 1987), bereavement (Walker et al., 1977), serious illness (Fiore et al., 1983; Weisman, 1979) and terminal illness (Carey, 1974). In almost all instances, social support has been shown to be a significant factor in successful adaptation or coping and for general health and well-being variously indexed. Despite the impressive accrual of evidence demonstrating a positive link between social support and well-being, findings have not gone unchallenged. A number of critical reviews suggest that issues surrounding the conceptualization and measurement of social support as well as theoretical clarification of the social support--well-being relationship are yet to be resolved (Barrera and Ainlay, 1983; Depner et al., 1984; Gore, 1984; Shumaker and Brownell, 1984; Thoits, 1982; Turner, 1981, 1983; Wortman, 1984). This review will focus primarily on emerging issues surrounding the wide variations found in the nature and strength of the relationship between social support and well-being. The specific issues discussed include (1) the conceptualization and measurement of social support; (2) the effects of sociodemographic, contextual and personal resource factors and (3) variation in outcome measures of well-being.

Conceptualizations of social support, although diverse and lacking in consensual agreement, commonly focus on the helping elements and processes of the social-relational systems in which individuals are located (Eckenrode and Gore, 1981; Gore, 1980). One of the most important trends toward clarification of the nature and measurement of social support is the movement away from considering it as a unitary or global concept. Recognition of the multidimensional nature and functions of social support is reflected in several recent definitions. For example, Kaplan et al. (1977) describe support as the degree to which an individual's needs for affection, approval, belonging and security are met by significant others. These needs may be met by the provision of socio-emotional aid such as affection, sympathy, understanding, acceptance and praise or through instrumental aid in the form of advice, or information, financial or practical task assistance. Similarly, House (1981) recognizes four distinct categories of social support including (1) emotional involving empathy, love and trust, (2) instrumental which encompasses behaviors that directly aid the person in need, (3) informational comprised of knowledge or advice useful in coping with personal and environmental problems and, finally, (4) appraisal support involving information relevant to self-evaluation or social comparison. Other frequently cited definitions such as those of Walker et al. (1977) and

Weiss (1974) similarly reflect the multidimensional nature of social support.

The basis for the trend toward recognition of the multidimensionality of social support is justified by evidence that not all sources or types of social support are equally effective in achieving desirable outcomes (Eaton, 1978; House, 1981; Walker et al., 1977) and, as Wellman (1981) has argued, not all social ties possessed by individuals are necessarily supportive and, in fact, some may be sources of stress rather than support (see studies by Fiore et al., 1983; Rook, 1984; Tilden and Galyen, 1987). Similarly, Broadhead et al., (1983) have pointed out that studies examining the dynamics of social support within the context of person-environment fit theory, suggest that the effectiveness of support varies according to the extent to which it facilitates the match between individual needs and the resources available to satisfy those needs.

Observations of the differential effectiveness of social support has prompted researchers not only to consider the amount of support available but also the type and source, and, perhaps most importantly, the extent to which the recipient perceives or experiences it as helpful. As Cobb (1976) and House (1981) have suggested, social support is likely to be effective only to the extent that it is perceived to exist. Thus, it is advocated that the cognitive appraisal of social support become the central target of support measurement (Barrera, 1981; Barrera and Ainlay, 1983).

An important implication of this trend is that, currently, at least two major dimensions of social support are implied by the definitions and corresponding measures employed: structural or network and functional or perceptual. Structural properties are typically examined using social networks measures which focus on indicators such as size, density, access, stability, etc. of the support system (Gottlieb, 1981; Heller and Mansbach, 1984; Tolsdorf, 1976; Walker et al., 1977). Examination of the functional properties focuses on the perceptual (qualitative) aspects of the support system such as perceived adequacy, quality, and need satisfaction (Andrews et al., 1978; Dean and Ensel, 1982; Husaini et al., 1982; Norbeck et al., 1981, Procidano and Heller, 1983; Sarason et al., 1983). Most studies, however, have focused on one dimension or the other and only occasionally have combined both in a single summary index (for example, Lin et al., 1979; Schaefer et al., 1981). When both types of measures have been compared, studies have generally found that perceived support is a stronger predictor of health outcome (Funch et al., 1986; Schaefer et al., 1981).

Despite the tendency to more adequately capture the multidimensionality of social support by examining its structural and functional dimensions, researchers continue to employ a wide range of measures to represent social support within these dimensions. This and other problems such as widespread failure to report reliability and validity or to replicate measures have resulted in relatively few attempts to develop standardized measures of social support. Present day researchers are, therefore, faced with a myriad of social support measures and the task of striking a balance between precision and generalizability in order to account for the unique dynamics of the particular situation under investigation and, at the same time, contribute to a more generalized theory of social support.

Another issue raised by observations of the differential effectiveness of social support is the importance of considering contextual factors which may influence the conditions under which support is effective or ineffective. Eckenrode and Gore (1981), who have elaborated on the importance of considering contextual factors for adequate explanation of the social support--well-being relationship, suggest that situational factors may strongly affect the provision as well as acceptance and effectiveness of social support. For example, studies have suggested that social support may be more beneficial to those in poor health (Berkman and Syme, 1979) and that certain groups of patients with certain illnesses and conditions might be expected to benefit more from social support (Broadhead et al., 1983). Contextual factors may assume particular importance in the case of severe illness as is discussed later in the review of literature specific to support and cancer.

Closely related to the differential effectiveness of social support observed within context-specific situations are suggestions that variations in the social support--well-being relationship may be a function of sociodemographic characteristics such as gender, age, marital status, socioeconomic status and ethnicity. While many studies have focused on specific groups, few have actually compared support levels and effects across subgroups within these populations. Based on a relatively comprehensive review of studies which have examined variations in support associated with gender, age and ethnicity, Vaux (1985) notes that more studies are available on gender than any other social status dimension. Although findings are disparate and may be due, in part, to methodological variations, particularly in the measurement of social support, Vaux does draw some tentative conclusions. According to his analysis, gender differences are most likely to emerge (1) when emotional rather than other types of support are measured, (2) among adolescents and college students rather than adults, (3) when focusing on support from friends rather than family, and (4) during stressful experiences more than at other times. Finally, many researchers have found that even though women report receiving more support than men, they do not necessarily report less distress. It has been hypothesized that this may be due to greater exposure to stress (Burke and Weir, 1978), less effective support (Cauce et al., 1982), higher expectations of support or some other undetermined vulnerability factor (Stokes and Wilson, 1984).

Few studies have examined variations in support associated with age although it has been reported that some aspects of support, such as network resources and support from friends, decrease across the adult life cycle (Heller and Mansbach, 1984; Zautra, 1983). In addition, a person's roles, needs and circumstances change with age and experience, as does the cumulative effect of experience on one's skills or abilities to mobilize support. Hence, the distribution and effects of social support might be expected to vary with age (Broadhead et al., 1983). Some studies, however, have found that the association between support and well-being does not vary with age (Cauce et al., 1982; Zautra, 1983).

Studies which have compared support characteristics across ethnic groups report some differences in sources and types of support but interpretation of these findings is complex since differences may also vary with age, gender and socioeconomic status.

Many studies have documented differential levels of distress, mental illness and general morbidity and mortality in low and high socioeconomic status groups but explanations of the link between social class and well-being are contradictory and complex. Increasingly, it is suggested that social support is a significant mediating factor since greater distress in low socioeconomic status groups is only partially explained by differences in exposure to stress (Kessler, 1983; Liem and Liem, 1978; Turner and Noh, 1983). The issue of whether support has direct or buffering effects remains unresolved but most evidence suggests that it has direct effects on distress among the middle class and stress-buffering effects among the lower class.

The separate or interaction effects of other social status variables such as marital status and education have received little attention although marital status has frequently been used as a proxy measure of social support. Two studies which have examined variation in the distribution of social support, by marital status, report a gradient of available support with the married receiving the most, followed by the never married, the widowed and then the divorced (McFarlane et al., 1981; Stephens et al., 1978). Broadhead et al. (1983) suggest that education may interact with social support so that the least educated receive the greatest benefit. Explanations of why the relative benefits of informal support are reduced for the well-educated include the possibility that effects are nullified by greater interpersonal skills and abilities resulting in the development of a broader range of supportive relationships or alternatively, the higher earning power of these individuals may result in the buying of necessary assistance and support.

A final set of variables posited as potentially important for more adequate explanation of the relationship between social support and well-being is variously referred to as vulnerability, risk or intrapersonal resource factors. A wide range of these factors including sense of control (Turner and Noh, 1983), uncertainty (Mishel and Braden, 1987), self-efficacy (Murphy, 1987), conflicted support (Sandler and Barrera, 1984) and coping strategies have been studied primarily as mediators in the stress-illness and/or social support--well-being relationship. Findings regarding the effects of these factors, however, remain tentative since they account for a small percentage of the total variance in outcome measures and hypotheses are often only partly supported.

Social support has been theoretically and empirically linked to a wide variety of physical, psychological and social aspects of well-being. Among these, psychological aspects have been the most commonly used outcome measures of well-being. Findings of the strength of the association between social support and psychological status are, however, inconsistent and appear to depend, at least partly, on the measures of social support used. For example, studies using elaborate measures of perceived support report zero order negative correlations of 0.20 to 0.45 between support and levels of anxiety or depression (Fiore et al., 1983; Funch and Metlin, 1982; Lin et al., 1979) whereas network measures of support are only weakly related to various aspects of psychological status (r = 0 to 0.20) (Funch and Metlin, 1982; Wilcox, 1981). No consistent association between various support measures and physical status has been documented. While some studies have found a positive relationship between support and measures of physical health or decreased mortality (Berkman and Syme, 1979; Gore, 1978; Wallston et al., 1983) others have failed to find any association (Funch and Metlin, 1982). Similarly, no consistent association between support and social aspects of well-being has been documented. Clearly, there is a need for further clarification of the impact of social support on various aspects of health and well-being.

The issues and trends discussed thus far have considerably broadened our understanding of the complexity and differential effects of social support; however, the affective/emotional component which formed the basis of the original conceptualizations of social support continues to be viewed as the most important. This would seem to justify the emphasis in the literature on the natural or informal support system since it presumably performs the most significant function, that of providing emotional or affective support. The notion of the primacy of the informal support system to individual well-being is rooted in long-standing sociological and social psychological theories and concepts. For example, Durkheimian anomie theory postulates that psychological well-being is maintained by social integration, a process whereby the traditions and rules of conduct of socially cohesive groups give members a sense of security, certainty and purpose in life (Durkheim, 1951). Thus, social support which is an aspect of social integration, protects against uncertainty and despair in the face of difficult life circumstances.

In the symbolic interactionist tradition, self evaluations and social identities are believed to originate in social interaction (Mead, 1934). Since social identity and self evaluation are important aspects of well-being and derive from social relationships, these relationships perform a supportive function by helping to maintain individual self-esteem and social identity.

Primary group theory which also speaks to the importance of human relationships and social bonds, suggests that morale and a sense of well-being are sustained by membership in primary groups. Withdrawal from these contacts, which provide a supportive milieu, is viewed as potentially harmful to individual cognitive and emotional states (Weiss, 1974). Lynch (1977) provides some evidence of this harmful effect in the case of physical illness and concludes that there is a biological basis for our need to form loving human relationships and if that need is unfulfilled, our health is in peril.

While there are sound theoretical reasons and an abundance of empirical evidence to support the assumption that the informal support system is of prime importance to human well-being, there are also good reasons why one should consider the role of formal support systems in contemporary societies. According to some prominent theorists, under conditions of urbanization and industrialization, kinship units have become highly specialized and other institutional structures have taken over functions commonly performed by family members in nonindustrialized societies (Ogburn, 1934; Parsons, 1943). Others, however, contend that the extended family remains a viable resource and provide some evidence that, in times of crisis, individuals still turn to family and friends (Litwak, 1960; Sussman and Burchinal, 1962).

Studies which have examined the patterns and relative contributions of formal and informal support systems are extremely rare and difficult to compare. Croog et al. (1972) examined the support role of the kin network, non-family such as friends and neighbors, and institutions in 345 men recovering from a myocardial infarction. They report that, in the case of severe illness,

(1) individuals have available to them and utilize a larger circle of resources than the family alone,

(2) support provided by neighbors and friends was viewed as of equally or greater benefit than that provided by the kinship group, and

(3) support services provided by formal institutions and agencies was perceived as helpful during the acute phase of illness but of limited importance during the recovery phase.

Other studies have focused on patients' and families' perceptions of support from health care professionals. They indicate that, although most support is obtained from families and friends, most patients and their families feel that more support from professionals would be beneficial (Bullough, 1982; Morrow et al., 1982; Nikolaisen and Williams, 1980). Irvin and Meier (1973), in studying perceptions of professional supportive behaviors among relatives of the terminally ill, found that the most supportive behaviors were information giving, encouragement, physical assistance, positive attitudes and being available.

A paucity of research on the role and effectiveness of formal social support prohibits the making of any general conclusions. It would appear that studies of this particular source of support may serve to provide a more rational basis for the design of support systems to serve the support needs of those for whom they are intended.

Social Support and Cancer

Social support has not been extensively studied within the specific context of the cancer experience; however, two important observations are evident in the relevant literature. The first is that evidence of the beneficial effects of social support is equivocal. While some studies do provide evidence of a positive link between support and various indicators of well-being throughout the cancer experience, others suggest that some types of social support are ineffective, and in some cases, even detrimental. Secondly, examination of the role of formal support systems is conspicuously absent despite their increasing prominence and assumed salience in cancer patient well-being. Each of these observations and their implications are examined.

Interest in the development of social support systems for cancer victims has evolved primarily as a result of widely documented evidence of the severe impact of cancer on the lives of those it touches, their families and communities, and society in general. However, while cancer has become the most widely researched disease entity from the perspectives of etiology, therapeutics, and psychosocial impact, relatively few studies have focused on the role of social support. Consistent with findings in the general literature, some of the available research suggests that social support may play a role in the etiology (Fox, 1978; Cox and Mackay, 1982), survival time (Funch and Marshall, 1983; Marshall and Funch, 1983), recovery (Funch and Metlin, 1982) and various psychosocial outcomes of cancer under the general rubrics of adaptation, coping and well-being (Mishel et al., 1984; Wortman, 1984). Of particular interest here is the social support - psychosocial outcome relationship.

A common theme in the psychosocial research on cancer populations has been the search for predictors or correlates of successful psychosocial adaptation. Although psychological factors have been the primary focus of investigation (for example, Derogatis et al., 1979; Hinton, 1975; Holland and Mastrovito, 1980; Rogentine et al., 1979; Stavraky, 1968), some attention has been given to the role of social support.

Mages et al., (1981), in examining a large number of variables (70), presumed to be related to psychosocial functioning, found three sets of variables, namely, degree of physical illness and impairment, previous psychological stability and social support to be the strongest predictors of a wide range of outcomes related to psychosocial status and functioning. Of particular interest was the finding that social support was significantly important during the initial crisis of the disease but became nonsignificant in subsequent follow up assessments as the disease progressed over a one year period. At that time physical factors became the strongest predictors of outcome. In a similar comprehensive study, Weisman (1979) provides convincing evidence that those who experience little social support and have severe physical disability have poorer psychosocial outcomes such as high anxiety, depression and low ego strength. Supporting the importance of contextual factors, these investigators estimate that half of the explained variance in emotional distress can be accounted for by disease-related variables, the remainder by a combination of psychological and social support variables.

Evidence regarding the efficacy of social support at various stages of the disease process is controversial. Some investigators suggest that support is most critical during the initial crisis phase following diagnosis (Mages et al., 1981; Weisman and Worden, 1976) while others suggest that recurrence following a period of disease control (Silberfarb et al., 1980), advanced disease (Holland, 1977) or terminality (Carey, 1974) constitute the stages at which social support will have the most positive and significant impact on psychosocial well-being.

Many studies of the role of social support in cancer patient outcomes have used relatively global, nonspecific or proxy measures of social support which may, in part, account for the diversity in findings. Some preliminary attempts to more precisely define sources and types of support and their effects are, however, beginning to emerge. For example, Holland (1977) found that, among advanced cancer patients, emotional support and reassurance were more effective than medication in dealing with anxiety and depression. Among the terminally ill, Carey (1974) found that higher quality interpersonal relationships, interpreted as concern shown by nearest next of kin and one's clergyman, was related to high emotional adjustment. At the same time, perceived quality of interpersonal relationships with other kin and physicians showed low correlations with adjustment.

The trend toward measuring multiple dimensions of social support is evident in a study by Bloom (1982) who examined the relationship of four types of support and adjustment to breast cancer. These included a measure of emotional support specified as perception of family cohesiveness, two measures of social affiliation including social contacts and involvement in social activities and a measure of social feedback operationalized as availability of a confidant. Each measure was related to three measures of adjustment, self concept, sense of power and psychological distress while controlling for marital status, age, employment, socioeconomic status and recent concurrent stressors. All social support measures were strong predictors of adjustment but explained little of the variance in self concept or sense of power. Social status and employment were the strongest predictors of these outcomes. A possible explanation for this finding is that both higher social status and employment may be important proxy measures of social support in that they provide opportunity for social contacts and a broader network of potential supporters. Higher socioeconomic status may also affect the qualitative features of interaction between the patient and health care providers. The higher socioeconomic status group may benefit most from informational support since there is some indirect evidence that those who are perceived to be more intelligent and educated are given more and clearer information relative to diagnosis, treatment and prognosis (Bloom, 1981).

In a more recent study, Bloom and Spiegel (1984) focused on the relationship of two dimensions of social support and the psychological well-being and social functioning of 86 women with advanced breast cancer. They found some evidence that the emotional dimension of support primarily affected psychological functioning whereas the social activity dimension was predictive of level of social functioning. Family support, normally assumed to provide emotional support, was found not to be positively related to social functioning but was positively correlated with psychological well-being. French and Metlin (1982) examined three somewhat different support forms, social, professional and financial, and their relationships to physical recovery and psychological adjustment in a sample of 151 breast cancer patients. A significant positive relationship was found between social support, interpreted as perceived degree to which network members (spouse, children, relatives and friends) could be relied upon and talked to, and psychological adjustment, conceptualized as positive affect. However, the relationship between professional support, interpreted as satisfaction with care, ability to talk to physician and extent of information received; and positive affect was found to be equally positive and significant. Financial support, measured according to socioeconomic status indicators, was the only support form found to be positively related to physical recovery. These findings provide some support for the assertion that different forms of support have unique effects on specific aspects of well-being and, therefore, consideration of various support forms and sources may contribute to a better understanding of the variation in cancer patient outcomes.

While these studies do provide evidence of a positive link between social support and physical and psychosocial well-being, it may be that some findings are an artifact of several factors such as the conceptualization and measurement of social support, the outcome measures used, and lack of consideration of contextual variables such as demographic and disease-related characteristics which have been shown to confound the support--well-being relationship. Certainly, the evidence suggests that the link is not as simplistic as assumed in the early social support literature.

Recent theoretical formulations and empirical evidence have raised some critical questions relative to the nature, functions and effects of social support within the context of the cancer experience. Observers have long suggested that cancer is surrounded by unusual social phenomena and paradoxes but the implications of these factors for social support are only beginning to be considered. It is widely assumed that a life-threatening illness such as cancer elicits a uniquely desperate need for social support; however, it also often elicits an equally desperate need on the part of others to avoid the patient. Several theorists, including Cobb and Erbe (1978), Dunkel-Schetter (1984), Dunkel-Schetter and Wortman (1982), Weisman and Worden (1976) and Wortman and Dunkel-Schetter (1979), attribute this phenomenon to the stigma of cancer which is associated with both myths and painful realities. They suggest that cancer is surrounded by intense fear, assumptions of painful, wretched death and mutilation and the images of contamination and uncleanliness all of which evoke physical aversion and disgust in others leading to avoidance behavior and withdrawal of support.

Peters-Golden (1982) has recently provided empirical evidence which supports the theory that a diagnosis of cancer leads to support withdrawal and/or the non-materialization of expected support. Perceptions of social support relative to the illness experience of breast cancer were examined among 100 cancer patients and 100 disease-free individuals. Within the disease-free group, 61% admitted that they probably would avoid contact with someone they knew had cancer. When asked on whom they would rely for support if they had cancer, 42% cited a combination of family, friends and professionals, 29% felt they would rely primarily on themselves, 13% on their spouse and 13% on their doctor. Neither other patients nor self-help or community agencies were cited. An overwhelming majority (67%) believed that the physical aspects of the disease would be of greater concern than the social aspects. Among the patient sample, 72% reported that they were treated differently after people knew they had cancer. Of these, 72% said they were misunderstood as evidenced by inappropriate behavior and comments, particularly those which emphasized the loss of a breast instead of the life-threatening potential of the cancer. Fifty-two percent felt they were avoided by others, 14% felt they were pitied and 3% thought people were nicer to them. The majority felt that social interactions and relationships were strained due to avoidance behavior, false cheerfulness and optimism and general discomfort with how to rea[illegible] or what to say to a cancer victim. Thirty-three percent of the patients stated that they relied on 'no one' for support, 22% depended on their spouse, 18% on a combination of family and professionals, 10% on religion, 8% on themselves, 5% on other cancer patients and 4% on their doctors. Only half assessed the support they received as adequate to meet their needs. Twenty-six percent felt they received inadequate support and 9% deemed their support to be inconsistent. Those with recurrent disease and currently undergoing chemotherapy felt least adequately supported. Clearly these findings have important implications relative to the nature and efficacy of social support for cancer victims.

Social misconceptions and fears about cancer lead to a lack of fit between interactive and support needs as identified by patients, and the quality of support provided by the social network. Communication barriers and avoidance are obviously a source of distress but interaction is often as equally disturbing and may undermine the potential benefits of social support. When support is offered, it is often done so conditionally, much in the same way that social interaction is offered, that is, contingent upon patients' acceptance of their new and different status as a cancer victim (Peters-Golden, 1982).

Other explanations have been offered to account for support withdrawal or perceived inadequacy of support among cancer victims. Heller (1979) has suggested that people who are poorly adjusted or in ill health may underestimate the amount of support available to them. Such individuals may also unwittingly create discomfort in others by making them feel vulnerable to a similar fate (Coates et al., 1979). Finally, it is suggested that the very ill or poorly adjusted may lack social competence which may result in the poorer levels of adjustment reported for unsupported individuals and also account for the lower levels of support they receive (Heller, 1979; Silver and Wortman, 1980).

Closely related to the phenomenon of withdrawal or non-materialization of social support among cancer victims are the assertions that social support may be ineffective or even harmful. Some theorists have suggested that social support may undermine the patients' self-esteem to the extent that it reflects his/her status as an impaired person (DiMatteo and Hayes, 1981). Patients are often distressed by the emotional, physical and/or financial burdens that are placed on loved ones as a result of illness. Tangible and even psychological support are often seen by patients as infringements on others' time and energy. Acceptance of support may also accentuate the reality that the very ill are unable to reciprocate the help given to them, arousing feelings of inadequacy, guilt and helplessness. Thus, it is suggested that social support itself may constitute a source of stress which ultimately renders support ineffective or harmful.

Some empirical support for the hypothesis that social support may have harmful effects is offered by Revenson et al. (1983). They examined the relationships of six specific supportive behaviors commonly provided by family and friends and six measures of psychological adjustment, in a sample of breast cancer patients. The relationships were examined while controlling for the particular contextual conditions of treatment type and degree of functional disability. For those not undergoing any special cancer treatment, the receipt of support was found to be significantly related to increased negative affect, lowered self esteem and mastery, and greater difficulty in acceptance of death while not significantly related to decreased acceptance of the patient role. In contrast, for those undergoing special cancer treatments, supportive behaviors lost their negative impact but remained generally unrelated to adjustment. While controlling for degree of physical disability, supportive behaviors were again found to be related to poorer adjustment but only for the highly disabled. Among those minimally disabled, support was not significantly associated with adjustment. Social support has also been found to be detrimental in other illness conditions, such as myocardial infarction (Garrity, 1973), chronic disability (Hyman, 1971) and congestive heart failure (Lewis, 1966).

Although findings of the detrimental effects of social support are relatively few and should be interpreted cautiously due to the relatively small sample sizes on which findings are based, they nonetheless raise critical questions about the nature and effects of social support within the situational context of the cancer experience.

While much of the literature emphasizes the importance of informal support to individual health and well-being, it is suggested that under particular circumstances, such as the cancer experience, these systems may not fulfill their normal helping functions. Although research lags behind theorizing in this area, there is some evidence to support the notion that cancer disrupts social relationships and environments resulting in diminished availability and effectiveness of support (Dunkel-Schetter and Wortman, 1982). These observations, along with substantial knowledge of the impact of cancer in all life dimensions (Freidenbergs et al., 1980), have prompted institutions, community service agencies and the lay public to mount massive support efforts on behalf of the cancer victim. These efforts have assumed many forms ranging from psychotherapy, counseling, education and information dissemination to the provision of instrumental aid in such forms as transportation, housing, equipment and meals, and peer support and interaction. Generally, the objective of these programs and services is to enhance, supplement or, in cases of absence, replace the natural support system. Despite the fact that these formal support efforts have become an integral part of cancer care, their effectiveness has rarely been questioned or assessed.

In summary, this review has provided evidence that both the general social support literature and that specific to cancer have evolved as increasingly critical and questioning of the complex relationship between social support and individual well-being. The primary focus of the review was issues surrounding variation in the nature and strength of the association between social support and individual well-being. It is suggested that (1) increased precision in the conceptualization and measurement of social support, (2) examination of the effects of sociodemographic, contextual and personal resource factors on the social support--well-being relationship, (3) further study of the relationship between social support and different outcome measures of well-being, and (4) increased study of the effects of formal sources of social support as well as acknowledgement of the unique support dynamics in particular situations such as cancer will enhance future knowledge and understanding of the role of social support in individual well-being.

While the findings in the literature strongly suggest that social support plays a role in the etiological, treatment and recovery aspects of disease and illness as well as the maintenance of health and well-being, the precise nature, extent and dynamics of that role are still relatively poorly understood. This state of knowledge is due primarily to various unresolved theoretical and methodological issues which continue to surround the study of social support. Clearly the diversity and scope of these issues prohibits addressing them in a single study. Therefore, for the purposes of this study, two specific research questions reflecting the issues of the nature of the relationship between social support and different aspects of well-being, and variations in that relationship due to sociodemographic and contextual factors were formulated and corresponding hypotheses derived and tested. Again, the research questions were:

1. What is the nature of the relationships between formal and informal social support and the functional status and self-esteem aspects of advanced cancer patient well-being?
2. Under what circumstances do these relationships vary? That is, how are the social support--well-being relationships influenced by (1) sociodemographic factors such as gender, age, marital status and socioeconomic status, (2) length of time since initial diagnosis, (3) level of religious commitment, (4) severity of illness and (5) relative need for social support?

The following three hypotheses relating to the first research question were tested.

Hypothesis 1 - Controlling for gender, age, marital status, socioeconomic status, time since initial diagnosis, level of religious commitment, severity of illness and support need, individuals with high levels of formal support will report higher levels of functional status and self-esteem than those with low levels of formal support.

Hypothesis 2 - Controlling for gender, age, marital status, socioeconomic status, time since initial diagnosis, level of religious commitment, severity of illness and support need, individuals with high levels of informal support will report higher levels of functional status and self-esteem than those with low levels of informal support.

Hypothesis 3 - Formal and informal levels of social support will combine (either additively or interactively) to predict levels of functional status and self-esteem.

Turning to the second research question, the final hypothesis was:

Hypothesis 4 - The social support--well-being relationships will vary within the subgroups of (1) males and females, (2) young and old, (3) married and nonmarried, (4) high and low socioeconomic status, (5) longer and shorter times since diagnosis, (6) high and low religious commitment (7) more and less seriously ill and (8) high and low support need.

CHAPTER III

METHODOLOGY

Overview of Chapter

The aim of this study was to examine the relationships between both formal and informal sources of social support and two analytically distinct measures of advanced cancer patient well-being--functional status and self-esteem. In addition, eight selected control variables including gender, age, marital status, socioeconomic status, time since initial diagnosis, level of religious commitment, illness severity and individual differences in support need were assessed to determine their individual effects on the social support--well-being relationships.

The purpose of this chapter is to describe the methodological and analytical procedures used in the study. More specifically, the purpose is to describe (1) the patients selected for inclusion in the study, (2) the procedures used for subject recruitment and interviewing (3) the measures used to assess the functional status and self-esteem of individual patients (the dependent variables), (4) the conceptualization and measurement of individual levels of formal and informal social support (the independent variables), (5) the scoring method used for the independent variable measures, (6) the procedures by which the sociodemographic characteristics (gender, age, marital and socioeconomic status) and individual differences in time since initial diagnosis, level of religious commitment, severity of illness and support need were measured (the control variables), (7) the instrument validation procedures, and (8) the methods of analysis.

Description of Respondents

The two hundred cancer patients[1] selected for inclusion in the study met the following criteria which were set in order to control for potential sources of bias.

(1) All had advanced stage disease which was defined as locally advanced or metastatic disease being treated for palliative rather than curative purposes.

(2) All had any type of cancer with the exception of sex-specific cancers (breast, ovarian, uterine, prostate or testicular) and brain tumors. Sex-specific types were eliminated due to concentration of one sex or the other and the possible unique psychological impact of these cancers. Individuals with brain tumors were eliminated due to increased risk of mental

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[1] The sample size of 200 represents approximately 22% of the estimated 900 patients meeting the eligibility requirements of the study and living in Edmonton at any given period in time (Mortality By Age at Death and Sex, Alberta Cancer Board, 1985).

con[illegible] decreased levels of mental alertness.

(3) All resided in the City of Edmonton, Alberta to facilitate respondent access and to control for possible differences due to geographic location.

(4) All were Caucasian, English-speaking, of European extraction and of "mainstream" Protestant, Catholic or Jewish religion. Inasmuch as other groups would be infrequently represented in the study population, patients of these rarer groups were not studied and no attempt was made to study, indepth, the effects of race, ethnicity or religious type.

Respondents were referred for participation in the study on the basis of the above mentioned eligibility requirements. However, eligibility was confirmed using a series of screening items on the interview questionnaire. (See items G,H,I and P of the Background Information section of the Social Support Questionnaire, Appendix 1). Since respondents may not have been able to accurately report their disease stage for various reasons such as lack of knowledge or denial, medical records were checked in the case of questionable cases. Otherwise the word of the physicians and nurses who acted as referral sources was accepted.

Recruitment and Interviewing Procedures

Due to the unavailability of an adequate sampling frame listing cancer patients according to stage of disease, eligible respondents were identified and accessed through three separate referral sources. These included physicians practicing out of the (1) Royal Alexandra Hospital, a 950 bed acute care facility, (2) the Cross Cancer Institute, a specialized oncology treatment center and (3) nurses employed by the Edmonton Palliative Home Care Program, a service provided by the Edmonton Board of Health for individuals suffering from any form of terminal illness, including cancer. These three referral sources were selected in order to:

(1) generate an adequate number of respondents over a four month time period beginning November 15, 1986 and ending March 15, 1987

(2) access patients who were representative of a variety of levels of support, particularly formal support, and

(3) reduce the possibility of self-selection bias.

Following ethical and scientific approval of the study by the respective institutions and organizations involved, appropriate physicians and nurses were informed of the nature and purpose of the study and cooperation in providing the names of potentially eligible subjects was sought (Appendix II). Each subject referred was approached individually in person, or by telephone, and invited to participate in the study. All participants were personally interviewed at their convenience by the author or one of two other professional interviewers carefully selected on the basis of previous experience with medical subjects, personal rapport and stability. The majority of interviews (85%) were conducted in the patient's homes and the remainder in hospital or out-patient departments.

In accordance with ethical clearance procedures, all subjects were required to sign a consent form prior to the interview in order to ensure as much as possible; the subject's (1) understanding of the nature and purpose of the study (2) voluntary participation and (3) understanding of how confidentiality and anonymity would be maintained (Appendix 3). In addition, all participants received the Patient Information Form outlining the nature and purpose of the study (Appendix 4).

Although an initial attempt was made to systematically select every nth person, following a random start, from the lists provided by the referral sources, this procedure had to be abandoned due to the slow accrual of adequate numbers of subjects and the rapid loss of subjects due to death. The sampling procedure, therefore, was to approach all subjects referred who met the eligibility requirements. In other words, the study group constitutes a convenience sample and may not necessarily be representative of the cancer population of interest.

Description of Dependent Variable Measures

Assessment of Functional Status

For the purposes of this study, two distinct aspects of advanced cancer patient well-being were assessed. The first, functional status was assessed using the Functional Living Index - Cancer (FLIC) developed by Schipper et al., (1984), (Appendix 5). The index is cancer-specific, that is, specific enough to the cancer population to detect functional differences among patients with diagnoses of cancer. It was designed to measure overall functional quality of the cancer patient's day-to-day life and is sufficiently sensitive to detect degrees of dysfunction between patients with varying extents of disease and intensities of therapeutic intervention. The 22 item questionnaire is a multidimensional scale representing physical, psychological and social components of life functioning. Participants are required to rate their present level of functioning on a 7 point scale for each item. The overall score is derived by summing scores on all questions. The score range for the index is 22-154 with 22 indicating a very low level of functional status.

The questionnaire has been tested on over 1000 cancer patients representing diverse cancer populations and is reported to be reliable and valid. Reliability estimates using Cronbach's alpha coefficient vary from .90 to .94 on each of the subscales across different data sets.

Relatively vigorous validity testing has shown adequate levels of content, concurrent and construct validity. Evidence of concurrent validity is reported as relatively high correlations between the physical and psychological dimensions of the scale and other established measures. For example, the phys[illegible]al subscale of the FLIC correlates highly with the Karnofsky Scale (.76) and the psychological subscale correlates highly with the Beck Depression Scale (.77), the psychological subscales of the Goldberg General Health Questionnaire (.72) and the Spielberger State Anxiety Scale (.63). Evidence of construct validity is reported as factor analytic stability across several data sets (Schipper et al., 1984).

Assessment of Self-Esteem

The second outcome measure of well-being used for this study was self-esteem which, in comparison to functional status, is viewed as an analytically distinct or contrasting measure. Whereas the psychological functioning subscale of the FLIC is largely a measure of mood disturbance, self-esteem taps a measure of self-appraisal. The latter was assessed using the Rosenberg Self-Esteem Scale (Appendix 6), a 10 item unidimensional scale that measures the self-acceptance (liking or approval) component of self-esteem (Rosenberg, 1965). Each item is rated on a four point scale ranging from strongly agree to strongly disagree with some items reversed to prevent response set. Scores on each item are summed for the total scale score which ranges from 10 to 40 with 10 indicating a very low level of self-esteem. The scale has been widely used with reported reliability estimates comparable to those originally reported by Rosenberg using a sample of 5,024 high school students (reproducibility coefficient = .92). Rosenberg (1965) and others have also provided evidence of construct validity by adequately demonstrating that self-esteem represents a distinct aspect of psychological well-being. For example, it has been shown to be analytically distinct from measures of mood disturbance such as fear, anxiety and depression.

Description of Independent Variable Measures

Conceptualization and Measurement of Social Support

It has been previously noted that, despite the fact that social support has been widely studied, major discrepancies in the conceptualization and measurement of this complex phenomenon continue to exist. Since no widely accepted definition or measures of the concept have emerged, instruments designed to measure individual levels of both formal and informal social support were developed for the population of interest in this study.

Following Kaplan et al. (1977), social support is defined as the degree to which an individual's needs for affection, approval, belonging and security are met by significant others. Conceptually, in order for formal and/or informal support systems to fulfill their functions, that is to meet the individual's needs as listed above, it was determined that there must be evidence of (1) support resource availability, (2) support utilization and (3) the perception or experience of being supported. Therefore, for the purposes of this study and in accordance with recent trends in the conceptualization and measurement of social support, social support is viewed as a multidimensional construct with at least three measurable facets: available resources, utilization behaviors and subjective appraisal of social support.

Available support resources refer to relationships or interactions with others who are perceived by the individual as potentially available sources of support in time of need. Typically, support resources are measured by focusing on variables which define the properties or structure of the individual's social environment (Funch et al., 1986; Heller and Mansbach, 1984; Tolsdorf, 1976; Vaux and Harrison, 1985).

Support utilization behaviors involves the measurement of specific acts or attitudes presumed to provide evidence that the individual actually receives or utilizes support from others. Typically measured behaviors include listening to, comforting, helping with chores and seeking out or being provided with advice, information, materials or contact with others (Barrera and Ainlay, 1983; Norbeck et al., 1981;

Shumaker and Brownell, 1984; Stokes and Wilson, 1984).

Finally, subjective appraisal of social support involves evaluation of the amount, content or quality of support received from certain relationships or interaction with others. Appraisal measures of social support are the most variable and range from the evaluation of specific attitudes or behaviors which lead the individual to experience, or fail to experience, love, belonging, security, etc. (Norbeck et al., 1981; Porritt, 1979) to more general measures of satisfaction with the amount, type or efficacy of supportive interactions or behaviors (Brandt and Weinart, 1981; Procidano and Heller, 1983; Sarason et al., 1983).

In this study, both formal and informal support levels were conceptualized and measured according to (1) resource availability, (2) support utilization behaviors and (3) subjective appraisal of social support. A series of questionnaire items or corresponding indicators of these three aspects of social support were developed separately for the Formal (Appendix 7) and Informal Social Support Indexes (Appendix 8).

Formal Social Support Index

1. Support resource availability, which is an estimate of the number and type of persons in the health care system perceived by the respondent as potentially available to provide support in time

of need, was measured by items 1, and 4 (Appendix 7).

Support utilization was measured by items 2, 3, 5 and 6 which ask the respondent to indicate the extent to which they actually utilized and/or mobilized the support of those perceived as potentially available to them in time of need. In addition, item 9 (subitems 1A through 14A) requires respondents to indicate whether or not they have recently, or are currently utilizing a series of social or health care services and/or programs available to cancer patients.

3. The subjective appraisal of social support was tapped by items 7 and 8 which require a general appraisal of the adequacy of the amount of support and the appropriateness of support respectively, received from persons in the health care system. Whereas item 7 is an appraisal measure of the adequacy of the amount of support received, item 8 is a measure of the extent to which support is perceived as the right type or appropriate to the specific needs of the individual. In addition, item 9 (subitems 1B through 14B) requires appraisal of whether or not specific programs or services indicated as used in subitems 1A through 14A have been helpful

The Formal Social Support Index contains a total of 36 items including the subitems of question 9. Items 1 through 8 are rated on a four point scale with 1 indicating a very low level of support. When items 2, 3, 5 and 6 were inapplicable due to the response on a previous question, a score of 0 was given. The 14 A and B subitems of question 9 were dichotomously scored as 1 or 0 (Part A, Services Utilized: Yes = 1, No = 0, Part B, Services Helpful: Yes = 1, No = 0). If a service was not utilized (Part A), then the corresponding Part B was considered inapplicable and an automatic score of 0 was given. For items 3, 4 and 6, actual numbers were recoded according to a four point scale. A score of 1 was given if the actual number was 0 or 1, a score of 2 if the number was 2 or 3, a score of 3 if the number was 4 or 5 and a score of 4 if the actual number was 6 or greater. When items 3 and 6 were originally recorded as inapplicable, they were scored as 0.

Informal Social Support Index

The Informal Social Support Index was constructed in a way similar to that of the Formal Social Support Index using indicators corresponding to the resource availability, utilization and subjective appraisal dimensions of social support. Items 1, 3, 5 and 9 (Appendix 8) were designed to estimate the number and type of potentially available supporters, items 2, 4, 7, 11 and 12 to measure actual utilization of support as well as supportive behaviors exhibited by supportive persons and items 14 and 15 to obtain an appraisal of the adequacy and appropriateness, respectively, of received support. An additional four items (6, 8, 10 and 13) were added to this particular index to estimate changes in support since the onset of illness. Whereas formal support is likely to increase with disease chronicity and severity, it has been found that informal support may decrease generally among the chronically ill and particularly within the context of cancer where interpersonal relationships are strained and disrupted (Dunkel-Schetter, 1982).

Each index item was rated on a four point scale with the exception of subitems A to G of item 5 which are each scored on a scale from 0 to 2. The actual number responses for the seven subitems of this question were collapsed according to the three point scale (0 to 2) as follows. A score of 0 was given if the actual number was 0, a score of 1 if the actual number was 1 and a score of 2 if the actual number was 2 or more. For items 3, 7, 9, 11 and 12, actual numbers were collapsed to a four point scale in the same manner described for the Formal Social Support Index.

Since the social support indexes are multidimensional and the scoring method involved some arbitrary weighting of the individual items, several methods of operationalizing the indexes were examined in order to select a scoring method which maximized the predictive power of each index. Variations observed in the predictive power of the social support indexes using alternate methods of scoring are discussed in the next section.

Scoring of the Independent Variable Measures

The scoring method selected for the Formal and Informal Social Support indexes was derived through a series of analytical procedures which compared the predictive power of the indexes using four alternate methods of scoring. These included 1) a summative composite score using all questionnaire items, 2) a scale disaggregated by dimensions and derived by summing items[1] specific to the respective dimensions of each scale, 3) a summative composite index of significant predictor items only, and 4) a nonsummed index using individual significant predictor items. These four alternate scoring methods were examined due to possible weighting problems inherent in the scoring method used for each index (that is, not all items were similarly scored nor were there an equal number of items representing the respective support dimensions included in each index). It was possible, therefore, that either overweighting or underweighting of certain items and/or dimensions (subscales) may have resulted in a composite summative score

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[1] Significant predictor items refers to those items which explained a significant proportion of the variance in the dependent variable after controlling for the effects of all other items (independent variables). The criteria for significance was based on the t test which determines the significance of the unstandardized regression coefficients. Only those items with b values with a probability of 0.5 or less were retained as significant predictors.

which reduced the overall predictive or explanatory power of the social support indexes.

Tables 1 and 2 provide a comparative summary of the regression coefficients and the amount of variance explained in functional status and self-esteem, respectively, using the four alternate methods of scoring for the Formal Social Support Index while controlling for the effects of the eight control variables studied (that is, gender, age, marital status, time since diagnosis, socioeconomic status, religious commitment, severity of illness and support need). Focusing on the coefficients of determination (R^2) in each table, it is evident that the summative composite scoring methods (1 and 3) considerably reduce the amount of variance explained in the dependent variables as compared to the disaggregated by dimension (2) and nonsummed (4) methods of scoring. The same pattern is observed in Tables 3 and 4 when functional status and self-esteem are respectively regressed on alternate methods of scoring the Informal Social Support Index. Again the amount of variance explained in the dependent variables is considerably reduced using the summative composite (scales 1 and 3) methods of scoring. In three of the four tables (1, 3 and 4 but not 2) the nonsummed methods using only individual significant predictor items ($p = .05$) for each dependent variable explains the largest amount of variance after controlling for the effects of gender, age, marital status,

Table 1

Regression of Functional Status on
Formal Support Using Alternate Scoring Methods[1]
(N = 199)

Scoring Method	Regression Coefficients b	Regression Coefficients B	R^2
1. Summative Composite (all items)	-1.14***	.28	.06
2. Disaggregated by Dimension:			.52
a) Availability	4.00***	.17	
b) Utilization	-3.39***	-.52	
c) Appraisal	3.78***	.35	
3. Summative Composite (significant predictor items only)	-.01	-.00	
4. Nonsummed (individual significant predictor items)			.54
Item 2	-6.25***	-.20	
Item 3	-3.74*	-.15	
Item 7	5.[illegible]	.18	
Item 8	4.59	.16	
Item 9(2A)	-.95	-.02	

1. All reported values are after controlling for the effects of the eight control variables (gender, age, marital status, socioeconomic status, time since diagnosis, religious commitment, illness se[illegible]ity and support need).

*** significant at the .001 level

** significant at the .01 level

* significant at the .05 level

Table 7

Regression of Self-Esteem on Formal Support Using Alternate Scoring Methods[1]
(N = 199)

Scoring Method	Regression Coefficients b	Regression Coefficients B	R^2
1. Summative Composite (all items)	.14**	.19	.01
2. Disaggregated by Dimension:			.33
a) Availability	.93***	.22	
b) Utilization	-.50***	-.42	
c) Appraisal	.87***	.44	
3. Summative Composite (significant predictor items only)	.60***	.25	
4. Nonsummed (individual significant predictor items)			.31
Item 2	-.97*	-.17	
Item 7	1.12*	.20	
Item 8	1.42**	.27	

1. All reported values are after controlling for the effects of the eight control variables.

*** significant at the .001 level

** significant at the .01 level

* significant at the .05 level

Table 3

Regression of Functional Status on Informal Social Support Using Alternate Scoring Methods[1]

Scoring Method	Regression Coefficients b	Regression Coefficients B	R^2
1. Summative Composite (all items)	.70***	.22	.05
2. Disaggregated by Dimension:			.23
a) Availability	.88	.10	
b) Utilization	.22	-.03	
c) Appraisal	1.76	.10	
d) Support Changes	1.67**	.13	
3. Summative Composite (significant predictor items only)	1.86***	.21	
4. Nonsummed (individual significant predictor items)			.42
Item 2	-2.46	-.10	
Item 8	.44	.02	
Item 9	3.98**	.16	
Item 13	2.41	.10	
Item 15	5.28**	.17	

1. All reported values are after controlling for the effects of the eight control variables.

*** significant at the .001 level

** significant at the .01 level

Table 4

Regression of Self-Esteem on Informal Social Support Using Alternate Scoring Methods[1]

Scoring Method	Regression Coefficients b	Regression Coefficients B	R^2
1. Summative Composite (all items)	.18***	.31	.18
2. Disaggregated by Dimension:			.29
a) Availability	.06	.03	
b) Utilization	-.03	-.02	
c) Appraisal	.98***	.31	
d) Support Changes	.26	.11	
3. Summative Composite (significant predictor items only)	.53***	.30	
4. Nonsummed (individual significant predictor items)			.34
Item 7	-.59*	-.15	
Item 13	.71*	.16	
Item 14	1.64**	.27	
Item 15	.81	.14	

1. All reported values are after controlling for the effects of the eight control variables.

*** significant at the .001 level

** significant at the .01 level

* significant at the .05 level

socioeconomic status, time since diagnosis, religious commitment, severity of illness and support need. The only exception is in Table 2 where the disaggregated by dimension summed scoring method for the Formal Social Support Index explains slightly more of the variance (R^2 = .33) in self-esteem than the nonsummed method (R^2 = .31).

Given that, overall, the summative composite methods of scoring considerably reduced the predictive power of the social support measures and that the reliability of the subscales in the disaggregated by dimension (see Table 10 in Chapter IV) method was low or of borderline acceptability, the nonsummed method using only significant predictor items was selected as the method of choice for all subsequent correlation and multiple regression analyses.

The procedures for selecting the best formal and informal support predictor items of functional status and self-esteem included 1) examination of frequencies to eliminate items with low variability 2) examination of bivariate correlations to eliminate redundant items and finally 3) stepwise regression of the remaining items of each index to explain variance in functional status and self-esteem.

With respect to the Formal Social Support Index (Appendix 7), items 1, 9 (3A, 4A, 5A, 6A, 9A, 11A, 12A, 13A, and 14A) and all 9B items, with the exception of 7B, were selectively eliminated on the basis of low variability. No further items were eliminated due to redundancies observed in the bivariate correlations among the remaining items. Finally, stepwise regressions of the retained formal support items were performed to select those items which best explained the variance in functional status (Table 5) and self esteem (Table 6). Table 5 shows that five items emerged as significant predictors (p = .05 or less) and accounted for 54% of the explained variance in functional status. Of those items, three (2, 3 and 9(2A) are measures of support utilization and two (7 and 8) are measures of support appraisal. Table 6 shows that three items emerged as significant predictors accounting for 31% of the explained variance in self-esteem. One item (2) is a measure of support utilization and the remaining two (7 and 8) are measures of support appraisal.

Repeating the same procedures to select the significant informal social support predictors of functional status and self-esteem, item 1 was eliminated due to low variability and item 5 (subitems A to G) were additively combined due to redundancy in the bivariate correlations with all other items (Informal Social Support Index, Appendix 8). Finally, stepwise regressions of the remaining items were performed to select those which were significant predictors (p = .05) of functional status and self-esteem. Table 7 shows that five items emerged as significant predictors and accounted for 42% of the explained variance in functional

Table 5

Stepwise Regression of Individual Formal Social Support Items To Explain Variance in Functional Status

Step No.	Questionnaire Item No.	Questionnaire Item Description	Regression Coefficients b	Regression Coefficients B	R^2
1.	3.	Number of contacts with specific health care person over past two weeks.	-7.98***	-.33	.28
2.	8.	Is support from health care system appropriate for your needs?	6.92**	.24	.45
3.	2.	How frequently do you rely on one specific person in the health care system?	-9.18***	-.29	.50
4.	7.	Is support from health care system enough for your particular needs?	8.01**	.26	.53
5.	9(2A)	Have you used the Aids to Daily Living program?	-6.73**	-.13	.54

*** significant at the .001 level
** significant at the .01 level

Table 6

Stepwise Regression of Individual Formal Social Support Items To Explain Variance in Self-Esteem

Step No.	Questionnaire Item No.	 Description	Regression Coefficients b	 B	 R^2
1.	8.	Is support from health care system appropriate for your needs?	1.63**	.31	.24
2.	2.	How frequently do you rely on one specific person in the health care system?	-1.31***	-.24	.28
3.	7.	Is support from health care system enough for your particular needs?	1.48**	.26	.31

*** significant at the .001 level
** significant at the .01 level

Table 7

Stepwise Regression of Individual Informal Social Support Items To Explain Variance in Functional Status

Step No.	Questionnaire Item		Regression Coefficients		
	No.	Description	b	B	R^2
1.	13.	Do you see friends more, less or the same as before your illness?	7.29***	.29	.24
2.	15.	Is the support you receive from family and friends appropriate for your needs?	11.11***	.35	.29
3.	2.	How frequently do you rely on one particular person for help?	-6.82***	-.27	.36
4.	9.	How many friends do you have living nearby?	5.24***	.21	.40
5.	8.	Do you see your family more, less or the same as before your illness?	-3.88**	-.15	.42

*** significant at the .001 level
** significant at the .01 level

status. Among the significant predictor items, there is one item measuring each of the support availability (9), utilization (2), and appraisal (15) dimensions and two items (8 and 13) measuring the support change dimension of informal social support. When stepwise regression of the same items was performed to select the best predictor items of self-esteem, Table 8 indicates that four significant predictors emerged (p = .05 or less) accounting for 33% of the explained variance in self-esteem. Among these items, one is a measure of support utilization (7), two are measures of support appraisal (14 and 15) and one (13) a measure of support changes.

Given the above findings, it is suggested that the summative methods of scoring the social support indexes reduced the importance or effects of individual items in the explanation of functional status and self-esteem. Further, the disaggregated by dimension summed method resulted in inadequate levels of reliability of the subscales (see Table 10 in Chapter IV) as well as decreased predictive power. The scoring method of choice, therefore, was a nonsummed version of each social support index using only significant predictor items of each dependent variable.

Description of Control Variable Measures

It has been previously suggested that variations found in the social support--well-being relationship may be due to

Table 8

Stepwise Regression of Individual Informal Social Support Items To Explain Variance in Self-Esteem

	Questionnaire Item		Regression Coefficients		
Step No.	No.	Description	b	B	R^2
1.	15.	Is the support you receive from family and friends appropriate for your needs?	1.08*	.19	.23
2.	13.	Do you see your friends more, less or the same as before your illness?	1.14***	.25	.30
3.	14.	Is the support you receive from family and friends adequate for your needs?	1.96**	.32	.32
4.	7.	How many visits from family members over past two weeks?	-.58*	-.14	.33

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

the failure of researchers to systematically examine or account for the effects of certain factors which may, theoretically, enhance or suppress the relationship. In order to address this issue, the separate effects of (1) gender, (2) age, (3) marital status, (4) socioeconomic status, (5) time since initial diagnosis, (6) level of religious commitment, (7) severity of illness and (8) relative need for social support on the social support--well-being relationships of interest here were examined. The primary interest was in determining whether these relationships varied within the subgroups of (1) males and females, (2) young and old, (3) married and nonmarried, (4) high and low socioeconomic status, (5) longer and shorter times since initial diagnosis, (6) high and low religious commitment, (7) more and less seriously ill and (8) high and low support need.

The items used to measure these variables are found on the Background Information questionnaire in Appendix 1. The sociodemographic factors of gender,[1] age, marital

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[1] Since gender is a nominal variable it was coded Male = 0, Female = 1 and entered as a dummy variable in regression analysis.

status[1] and socioeconomic status were measured by items A, B, C, D, E and F respectively. Socioeconomic status was measured using a composite index (summed standardized scale scores) of years of education, annual household income and occupational status rated on a seven category, Canadian census-based scale.[2] While this occupational status scale is not an occupational prestige scale, it was similarly derived using a rank order method reflecting socioeconomic position within the structure of the labor force in Canada (Pineo, 1985). Although these scale categories are, at least, ordinal in nature they can be treated as interval without undue risk to derive standardized scores (Bohrnstedt and Knoke, 1982). Female respondents who did not work outside the home were categorized according to the husband's occupation which was assumed to more adequately reflect their social status.

The effect of time since initial diagnosis was assessed due to previously mentioned issues such as waning of support

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[1] Marital status was coded Married = 1, Nonmarried = 0 and also entered as a dummy variable in regression analyses.

[2] The seven categories of (1) unskilled, (2) semi-skilled, (3) skilled crafts and trade, (4) middle management, (5) semi-professionals and technicians (6) employed professionals and (7) self-employed professionals were derived by collapsing the 16 major socioeconomic categories of the revised Standard Occupational Classification used for the Canadian census (Pineo, 1985).

over the course of lengthy or chronic illness and/or adaptation to chronic or life threatening illness. This item (G) was scored on a scale from 0 to 10 representing actual number of years that had passed between the initial diagnosis of cancer and the time of the study.

Despite the fact that, by most objective standards, the population of interest would be considered very seriously ill, a composite index of four commonly used indicators presumed to be sufficiently sensitive enough to detect differences in levels of illness severity was developed. These included (1) amount of pain experienced (item Q), (2) frequency of pain medication (item R), (3) amount of assistance required to manage daily personal care (item S) and (4) amount of day bed confinement (item T). Each item was scored on a four point scale with 0 indicating less and 3 indicating greater illness severity. A composite score was derived by summing the individual item scores resulting in a possible score range of 0 to 12.

Evidence regarding the effects of religiosity on both social support and levels of well-being are inconclusive. However, in the case of a life threatening illness such as cancer, it has been suggested that level of religious commitment may serve to directly or indirectly affect the social support--well-being relationship primarily by affecting perceptions of levels of social support or well-being, or both. In order to assess the effects of level of religious commitment, the social support--well-being relationships were examined for differences between subgroups with high and low levels of religious commitment. Level of religious commitment was measured using a composite index of six items assumed to tap the belief system (items J and K), feelings of closeness to God (item L), religious behaviors including praying (item M) and contact with a clergyman (item N), and the importance of religion in dealing with illness (item O). Depending on the number of response categories, individual items were scored on either a 3 or 4 point scale with 0 indicating a low level of religious commitment. Individual item scores were standardized and then summed for the composite score used in subsequent analysis.

The final variable assessed for possible effects on the social support--well-being relationships was individual need for social support. Although it has been acknowledged in the literature (for example, DiMatteo and Hayes, 1981) that there is likely wide variation in individual support need, no empirical evidence of this aspect of social support can be found. In this study, differences in individual need for social support were measured by items U and V which require the respondent to rank on a seven point scale how likely they are, in general, to seek out and use support from (1) family, friends or neighbors and (2) the health care system when they have a problem. General willingness to seek out and use support is assumed to tap differences in support need since those with a low score (that is, very unlikely to seek out and use support) are also more likely to exhibit characteristics such as independence and self-reliance and also to attach less importance to interpersonal relationships than those very likely to seek out and use support, (DiMatteo and Hayes, 1981; Dunkel-Schetter, 1984; Rook, 1984). The support need score was derived by adding the scores of items U and V.

Instrument Validation Procedures

Prior to the data collection phase of the study, all questionnaires were submitted to a panel of experts and pretested on a sample of 20 advanced cancer patients to establish face and content validity. The panel of experts which included a nurse, physician, psychologist, sociologist and cancer patient were instructed to examine the questionnaires for clarity, interpretability and representativeness of the selected measures. This procedure resulted in (1) the addition of three items to measure religious commitment, (2) the addition of the list of services available to cancer patients (item 9 of the Formal Social Support Questionnaire) and (3) the inclusion of length of time since initial diagnosis as a control variable.

The pretesting procedure was conducted primarily to assess the (1) clarity of questionnaire items (2) sensitivity of items in detecting individual differences (3) ease of administering the structured interview format (4) length and feasibility of administration time and (5) ability of respondents to complete the interview without undue physical or emotional stress. It was found that the average completion time for the interview was 25 minutes and that respondents were willing participants, able to tolerate the interview well and had no difficulty understanding the questions. The only exception was respondents who were in the very terminal stage of cancer and on continuous intravenous pain medication. Since the mental alertness of these individuals was questionable, they were subsequently added to the list of ineligible participants to avoid collecting unreliable data.

The pretesting procedure also resulted in three questionnaire item changes. The annual household income categories were changed so that the upper limit of the lowest category (that is, under $12,000 per year) more adequately reflected the income of those living solely on social security benefits.[1] Original items measuring illness

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[1] See Revised Schedule of Social Security Benefits Government of Alberta Social Services, September, 1986.

severity and support need were replaced due to insufficient sensitivity in detecting differences within the sample.

Following administration of the questionnaires to a sample of 200 patients, further estimates of reliability and validity were made. Reliability estimates using Cronbach's alpha coefficient as a measure of internal consistency were calculated for the Formal and Informal Social Support Indexes, the Functional Living Index - Cancer and the Self-Esteem Scale. Original intentions to estimate test-retest and inter-rater reliability had to be abandoned in order to comply with the requests of ethics review committees who reasoned that the scientific gains did not, warrant the extra burden placed on respondents by these procedures. It was also found that the test-retest procedure was not feasible due to the rapid loss of subjects from death. The highly structured format of the interview diminished the concern for inter-rater discrepancies. This was, at least partially, confirmed during the interviewer training sessions where identical ratings were obtained by two interviewers on ten different subjects. Based on this evidence and the structured interview format, it is suggested that high inter-rater reliability would have occurred for the remaining subjects.

Beyond the content validation procedures described earlier, the construct validity of the Formal and Informal Social Support Indexes was estimated using factor analytic techniques to examine the underlying structure of these measures. Since the validity of the Functional Living Index - Cancer and the Rosenberg Self-Esteem Scale has been adequately established in the literature, no further validity estimates were calculated for these measures.

Methods of Analysis

First, the means, standard deviations and frequencies were calculated for all variables used in the study. Second, bivariate correlations were used to identify significant relationships between (1) levels of formal and informal support and well-being (functional status and self-esteem), (2) levels of formal and informal support and the control variables: gender, age, marital status, socioeconomic status, time since initial diagnosis, religious commitment, severity of illness and support need and (3) the control variables and patients' functional status and self-esteem. Finally, multiple regression analyses were used to test the four hypotheses stated in Chapter I.

Hypotheses 1 and 2 which predicted that individuals with higher levels of (1) formal and (2) informal support would report higher levels of functional status and self-esteem, controlling for selected variables, were tested by examining the unstandardized regression coefficient (b_1)

for the social support variable in each of the following regression runs:

1. Regression of functional status on formal support and the control variables.[1]
2. Regression of self-esteem on formal support and control variables.
3. Regression of functional status on informal support and control variables.
4. Regression of self-esteem on informal support and control variables.

To test for the significance of b_1 in each equation (that is, to determine whether b_1 differed significantly from zero) a t value was computed.[2] If the observed t value was larger than the critical value required with k degrees of freedom and alpha set at .01, then the null hypothesis that $b_1=0$ was rejected.

For hypothesis 3, which suggests that interaction effects may be operating in the explanation of functional

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[1] The control variables gender and marital status were entered as dummy variables, in all regression analysis, (Female = 1, Male = 0, Married = 1, Nonmarried = 0).

[2] The t test statistic is automatically computed in multiple regression analyses using the SPSS X statistical package.

status (Y_1) and self-esteem (Y_2), F tests[1] were computed to determine the significance of changes in the coefficient of determination (R^2). To determine whether formal and informal support combine either additively or interactively to predict functional status and self-esteem controlling for selected variables, the R^2 of the regression equation with the interaction term (formal support X informal support) included ($R_2{}^2$) was compared with the R^2 of the equation with the interaction term omitted ($R_1{}^2$). The F test was used to determine whether $R_2{}^2$ was significantly larger than $R_1{}^2$. If the null hypothesis H_o: $R_2{}^2 - R_1{}^2 = 0$ is rejected, then it can be concluded that there are interaction effects.

Similarly, hypothesis 4, which predicts that interaction effects between formal/informal support and each of the eight control variables may be operating in the prediction of functional status and self-esteem, was tested

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[1] F tests for determining the significance associated with the coefficient of determination were derived by

$$F(K_2 - K_1), (N - K_2 - 1) = \frac{R_2{}^2 - R_1{}^2/(K_2 - K_1)}{(1 - R_2{}^2)/(N - K_2 - 1)}$$

Where: K_2 = The number of independent variables in the equation used to estimate $R_2{}^2$.
K_1 = The number of independent variables in the equation used to estimate $R_1{}^2$.

(Bohrnstedt and Knoke, 1982, 391)

using F tests to determine whether the coefficient of determination differed significantly in equations with interaction terms from those without interaction terms. For each control variable, regressions with and without the interaction terms were calculated and compared. The procedure was repeated for each dependent variable with each independent variable. In each regression, the order of entry was the independent variable first (that is, either formal or informal support) followed by the particular control variable under investigation and, finally, the interaction term derived by multiplying the particular independent and control variable under consideration (for example, formal support X gender).

In the above example, if the coefficient of determination is significantly different with the addition of the interaction term as determined by the F test, then one can conclude that gender differences are operating in the explanation of the relationship between formal support and functional status or self-esteem.

Missing values were handled using the listwise deletion procedure which removes all cases that have missing values on any of the variables. This option was selected because there were few missing values and in order to avoid the problem of changes in the size of N due to variation in the number of cases available from correlation to correlation.

Limitations of the Study

Recognizing that the particular subjects selected for this study were, for the most part, physically and/or emotionally distressed, the instruments used to measure the independent and dependent variables had to be carefully selected to obtain adequate information without overtaxing the patient. One limitation of the study, therefore, is that the instruments chosen may not have been sufficiently sensitive or comprehensive enough to assess levels of social support and/or well-being. While the instruments chosen to measure functional status and self-esteem (the dependent variables) have been shown in previous research to be reliable and valid across several general and cancer specific populations, no such measures of social support exist. A wide range of measures have been utilized to represent social support but little information on their reliability and validity is available. The same measures have seldom been implemented more than once and those which appear to be reasonably valid contain large numbers of questions requiring considerable administration time. Funch et al. (1986), however, have recently provided some evidence that short multidimensional scales, such as those developed for this study, offer greater ease of administration than more elaborate scales without compromising reliability and validity.

Another limitation of the study is that only two outcome measures of patient well-being were used. Individual well-being is a complex, multidimensional phenomenon comprised of physical, psychological, social and spiritual factors. It is possible, therefore, that the social support--well-being relationships observed in this study may not be valid for other aspects of well-being.

Closely related to the limitations posed by utilizing a limited number of outcome measures is the number and type of control variables studied for possible effects on the social support--well-being relationship. Absent are psychological and personality related factors which have been previously implicated as vulnerability or buffering factors in studies of the stress-illness relationship. However, since the [illegible]ts of these factors which include for example, negative affect (alienation, anger, depression), personality-based hardiness (Kobasa, 1982), locus of control (Rotter, 1966) and sense of coherence (Antonovsky, 1987), remain inconclusive and in order to keep the study of manageable size, they were not studied.

A final limitation of the study concerns the extent to which the findings can be generalized. Since only advanced stage cancer patients residing in one urban center in Alberta were studied, generalization to individuals in a different disease stage or residing in other urban and/or rural areas must remain tentative. Further, the convenience sample used may not necessarily be representative of the population studied.

Summary

In summary, the purpose of this study was to examine the relationships between formal and informal social support and the functional status and self-esteem of advanced cancer patients while paying specific attention to selected factors which may affect these relationships. This section described (1) the study design, (2) the conceptualization, measurement and scoring methods of social support (the independent variables), (3) the methods by which the dependent and control variables were measured and (4) the methods of data analysis.

CHAPTER IV

FINDINGS

Overview of Chapter

This chapter is divided into two main parts for the purpose of describing the (1) quantitative and (2) qualitative results of the data analysis. In the quantitative section, findings relevant to the reliability and validity estimates of the independent and dependent variable measures are presented first. Second, descriptive findings of (1) individual patient characteristics, (2) the independent and (3) dependent variable measures are presented. Third, the significant bivariate correlations among the independe[illegible]ependent and control variables are discussed. Finally, the results of the hypotheses tests as determined by multiple regression analysis are discussed.

The purpose of the qualitative section is primarily to supplement the quantitative findings by providing a more indepth view of the major issues and concerns surrounding social support as identified by this particular group of advanced cancer patients. The qualitative findings are presented in two parts in order to distinguish between (1) formal and (2) informal social support issues.

Quantitative Findings

Reliability and Validity Estimates of the Independent and Dependent Variable Measures

Table 9 presents a summary of the reliability estimates, as determined by Cronbach's alpha,[1] of the dependent variable measures used in the study. In addition to the Functional Living Index - Cancer (FLIC) and the Self-Esteem Scale, reliability estimates were calculated for the physical (FLICA)[2] and psychosocial (FLICB)[3] subscales of the FLIC. Given the magnitude of the alpha coefficients, the measures are judged to be sufficiently reliable. Table 10 provides a comparative summary of the reliability estimates for the Formal and Informal Social Support Scales using alternate scoring methods. While the alpha coefficients of the composite scales derived by summing all items on each scale are of sufficient magnitude, the coefficients for the particular dimensions (subscales) of each scale drop to below acceptable levels with the exception of the support appraisal dimension of the Informal

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[1] Cronbach's alpha is a measure of the internal consistency of a set of items and is based on the average intercorrelation among the items and the number of items that comprise the index.

[2] The physical functioning subscale is comprised of items 1, 3, 6, 8, 10, 12, 13, 16, 17 and 18.

[3] The psychosocial functioning subscale is comprised of items 2, 4, 5, 7, 9, 11, 14, 15, 19, 20, 21 and 22.

Table 9

Reliability Estimates of the Dependent Variable Measures

Index	Cronbach's Alpha
Functional Living Index - Cancer (FLIC)	.95
Physical Subscale of FLIC	.93
Psychosocial Subscale of FLIC	.90
Self-Esteem	.90

Table 10

Reliability Estimates of the Independent Variable Measures Using Alternate Scoring Methods

Scale	Cronbach's Alpha	
	Formal Social Support	Informal Social Support
Composite (Summative - all items)	[illegible]	.80
Disaggregated by Dimension		
1. Support Availability	.28	.53
2. Support Utilization	.69	.67
3. Support Appraisal	.52	.87
4. Support Change	--	.35
Composite (Summative - significant predictor items only)	.57	.71

Social Support Scale. Similarly, the alpha coefficients for the composite scales using only significant predictor items for each scale suggest that these scales are insufficiently reliable. These findings as well as others presented later in the preceding chapter, were used to determine the optimal scoring method for the social support scales.

Given that the validity of the dependent variable measures (functional status and self-esteem) has been adequately established in the literature, no further validity estimates were undertaken in this study. With respect to the independent variable measures (formal and informal social support), validity estimates beyond the face and content procedures described earlier were difficult due to the developmental state of the construct of social support. It was not possible, for example, to establish the concurrent validity of these measures since no established or criterion measures of social support exist to date. However, factor analysis which can be conceived as a construct validity tool[1] was used to determine the

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[1] Kerlinger (1973), in justifying factor analysis as a construct validity tool, makes the point that, since the main preoccupation of factor analysis is common-factor variance and, by definition, validity is common-factor variance, then factor analysis is firmly tied to measurement theory. Further, he notes that construct validity seeks the "meaning" of constructs through their relations with other constructs which, essentially, is what factor analysis does. That is, it constitutes a constitutive-meaning method by enabling the researcher to study the constitutive meanings of constructs and thus their construct validity.

underlying structure or patterning of the variables according to hypothetical factors for each social support measure.

Factor analysis was performed using the SPSS-X (Statistical Package for the Social Sciences) program. The initial method of factoring selected was principal component analysis which extracts the maximum amount of variance as each factor is calculated in order to determine the single best summary of linear relationships exhibited in the data. Factors with eigenvalues greater than one were retained and rotated to a final solution using the varimax (orthogonal) method. Table 11 shows the varimax rotated factor loadings of the Formal Social Support Index items. Four factors with eigenvalues greater than one emerged and, as indicated by the magnitude of the factor loadings, a significant proportion of the variance in each variable (item) was accounted for by the respective factors. A distinct patterning of the variables along the four factors or dimensions of the index is evident. Items 4, 5, and 6 which relate to the available number, the frequency of reliance on and number of contacts with persons in the health care system other than one particular person identified as the primary care giver, load significantly on Factor 1. Factor 2 accounts for a significant amount of the variance observed in the two variables pertaining to the utilization and perceived helpfulness of support services and programs.

Table 11

Varimax Rotated Factor Loadings of
Formal Social Support
Index Items

Item	* Factor 1	2	3	4
1. Availability of a particular health care professional?	–	–	–	.73
2. Frequency of reliance on this person?	–	–	–	.89
3. Number of contacts with this person?	–	–	–	.67
4. How many other health care persons relied on?	.84	–	–	.36
5. Frequency of reliance on these persons?	.86	–	–	–
6. Number of contacts with	.79	–	–	–
7. Overall adequateness of help?	–	–	.88	–
8. Overall appropriateness of help?	–	–	.90	–
9. Services utilized?	–	.96	–	–
10. Services helpful?	–	.96	–	–

* Factor eigenvalues were: Factor 1 = 3.73, Factor 2 = 2.06, Factor 3 = 1.36, Factor 4 = 1.06

Note: Only significant loadings equal to or greater than 0.3 are recorded.

Factor 3 is comprised of the two items relating to the cognitive appraisal of the overall adequateness and appropriateness of formal support. Finally, factor 4 accounts for a significant proportion of the variance observed in items 1, 2, and 3 which relate to the availability, reliance on and number of contacts with one particular person in the health care system. On the basis of the relatively large factor eigenvalues listed in Table 11, the significant loadings of the items on their respective factors and the clear clustering of variables, it is concluded that the Formal Social Support Index is comprised of four distinct underlying dimensions. Factors 1, 2, and 4 can be labelled according to distinct sources of support and factor 3 as the overall appraisal of formal social support.

Table 12 shows the varimax rotated factor loadings of the Informal Social Support Index items. Again, four factors with eigenvalues greater than one emerged. However, they accounted for a smaller proportion of the variance in their respective items and the resulting factor solution was not as clearly interpretable as that for the formal social support measure. The strongest factor was comprised of items 1, 2, 14 and 15 which represent the availability of a spouse or one particular person to provide support, the frequency of reliance on this person and an overall appraisal of informal support adequacy and appropriateness.

Table 12

Varimax Rotated Factor Loadings of Informal Social Support Index Items

Item	* Factor 1	2	3	4
1. Availability of spouse or particular other person?	.58	—	—	—
2. Frequency of reliance on this person?	.57	—	—	—
3. How many others counted on for help?	—	.35	.33	.39
4. Frequency of reliance on these persons?	.35	—	—	.36
5. Relatives residing near:				
A Spouse	—	.34	—	—
B Parents	—	—	—	.54
C Children	—	.70	—	—
D Siblings	—	—	—	.33
E In-laws	—	.72	—	—
F Grandchildren	—	.61	—	—
G Close others	—	-.40	—	—
6. Number of relatives residing near changed?	—	—	—	—

cont'd

Table 12 (cont'd)

	Item	* Factor			
		1	2	3	4
7.	Number of family visits?	—	.52	—	—
8.	See family more, less, same?	—	.32	—	.37
9.	Number of close friends residing near?	—	—	.66	—
10.	Number of friends residing near same, more, less?	—	—	.54	—
11.	Number of visits from friends?	—	—	.51	—
12.	Number of telephone calls from friends?	—	—	.55	—
13.	See friends more, same, less?	—	—	.72	—
14.	Overall adequateness of help?	.86	—	—	—
15.	Overall appropriateness of help?	.81	—	—	—

* Factor eigenvalues were: Factor 1 = 4.80, Factor 2 = 2.49, Factor 3 = 1.99, Factor 4 = 1.39

Note: Only significant loadings equal to or greater than 0.3 are recorded.

Items 5A, C, E, F, G, and 7 which loaded on the second factor pertain to the types of relatives living nearby and the number of family visits over the previous two week period. Factor 3 is comprised of five items all of which relate to indicators of support from friends. Finally, five items including the number of persons other than a spouse or significant other person available to provide support, the frequency of reliance on these persons, parents or siblings living nearby and changes in family contacts since the illness loaded most highly on factor 4. Item 6 which asked whether the number of relatives living nearby was more, less or the same as before the illness did not load significantly on any factor indicating that the variance observed for this variable could not be accounted for by any of the four retained factors.

Similar to the formal support measure, some patterning of the variables according to distinct sources of support such as spousal, other family members and friends is evident. However, the modest size of the item loadings on each factor may indicate that many of the items are factorially complex. That is, they are pervaded by other factors and thus are not factorially pure particularly in the case of items 3, 4, and 8 which load on two or more factors.

In conclusion, it can be said that the Formal and Informal Social Support Indexes are multidimensional in nature and that each is comprised of four relatively distinct underlying dimensions which measure the construct of social support. The four identified factors or dimensions account for 82.2% and 70.8% respectively, of the observed variances in the items on the formal and informal support indexes indicating that they are sufficiently valid measures of the social support construct.

Description of Individual Patient Characteristics

In this section, individual patient characteristics are described according to the sociodemographic and contextual (control) variables measured in the study.

Table 13 indicates that the majority of patients were referred for participation in the study by physicians from the Cross Cancer Institute (58.5%), followed by Royal Alexandra Hospital physicians (38%) and only a small percentage (3.5%) by nurses from the Edmonton Palliative Home Care Program. The major reason for the low number of referrals from this latter source was a lack of eligible respondents in the program at the time of the study.[1] A total of 209 patients were referred from all three sources

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[1] The Palliative Home Care Program is utilized by individuals with any type of terminal illness; therefore, the number of cancer patients in the program varies at any given time. Also, at the time of the study, many of the clients were suffering from breast cancer and were ineligible subjects.

Table 13

Description of Patients By Referral Source

Referral Source	Total Referred	Total Interviewed	% of Total Interviewed (N = 200)
Cross Cancer Institute	122	117[1]	58.5%
Royal Alexandra Hospital	80	76[2]	38.0%
Edmonton Palliative Home Care	7	7	3.5%

[1] Five of those referred were not interviewed due to refusal (2) and ineligibility (3)

[2] Four of those referred were not interviewed due to refusal (1) and ineligibility (3)

but six did not meet all eligibility requirements and three refused participation on the basis of poor health. The response rate of eligible respondents was 98.5% (200 out of 203).

Table 14 shows an almost even gender distribution with 96 males and 104 females participating in the study. The patients ranged in age from 20 to 85 years with a mean age of 59 years (Table 15). Table 16 indicates that the majority or 58.5% of the subjects were married with the remaining 41.5% distributed among the nonmarried categories. Dividing the standardized socioeconomic status scale scores into equal thirds, Table 17 shows that 47% were in the middle, 30% in the low and 23% in the high socioeconomic status group.

At the time of the study, 68% of the patients had initially been diagnosed with cancer two or less years ago, 28% three to five years earlier and only 4% had been diagnosed six or more years ago (Table 18). Table 19 indicates that 19% had a low level, most patients (47.5%) had a moderate level; and 33% a high level of religious commitment. With respect to the individual indicators of religious commitment (data not shown), 83% said they believed in God while only 32% believed in a form of life after death. Only 13.5% felt extremely close to God, 41% felt somewhat close and 39.5% reported feeling not very close or not close at all. Twenty four percent indicated

Table 14

Patient Distribution By Gender (N=200)

Gender	Number	Percent of Total
Male	*96*	*48*
Female	*104*	52

Table 15

Distribution of Patients By Age

Age	Number	Percent of Total
20-30	11	5.5
31-40	13	6.5
41-50	23	11.5
51-60	50	25.0
61-70	56	28.0
71-80	40	20.0
Over 80	7	3.5

Median Age - 61
Mean Age - 59
Standard Deviation 14.34
Range - 20 to 85 years

Table 16

Distribution of Patients By Marital Status

Marital Status	Number	Percent of Total
Married	117	58.5
Divorced/Separated	24	12.0
Single/Never Married	20	10.0
Widowed	33	16.5
Common Law	6	3.0

Table 17

Distribution of Patients By Socioeconomic Status[1] Group

Socioeconomic Status Group[2]	Number	Percent of Total
Low (Score range = -5.91 to -1.84)	60	30.0
Middle (Score range = -1.83 to 2.24)	94	47.0
High (Score range = 2.25 to 6.32)	46	23.0

1. Socioeconomic Status is a composite index derived by adding standardized scale scores for years of school completed, annual household income and occupational prestige.

2. Socioeconomic status groups were derived by dividing the total score range into thirds.

Table 18

Distribution of Patients By Years Since Initial Diagnosis

Years Since Initial Diagnosis	Number	Percent of Total
2 or less	136	68.0
3 - 5	56	28.0
6 or more	8	4.0

Range of Years Since Initial Diagnosis = 6 months to 10 years.

Table 19

Distribution of Patients By Level of Religious Commitment[1]

Score [2]	Number	Percent of Total
0 - 4	39	19.0
5 - 9	95	47.5
10 - 14	66	33.0

Mean = 7.71
Standard Deviation = 3.80

[1] Level of religious commitment is a composite score derived by adding individual scores on 6 items.

[2] Score categories are ranked from lowest to highest.

that they prayed very often, 13.5% never prayed and the remaining 63.5% prayed rarely or sometimes. Almost half (45.5%) reported no contact, 39% had occasional and 15.5% frequent contact with a clergyman. Thirty-nine percent of the respondents indicated that religion was not an important factor in dealing with their illness, 40% said it was somewhat important and 21% said it was very important.

Scores on the illness severity scale were distributed over the full range of the scale (0 to 12) with a mean of 5.2 and a standard deviation of 3.4 (see Table 20). These data suggest that the highest scores occurred for the frequency of pain medication and amount of pain indicators. When actual scores are divided at the midpoint of the illness severity scale (6.5), 60% of the respondents were classified as less severely and 40% as more severely ill.

Table 21 indicates that the respondents reported they were more likely, in general, to seek out and utilize help from formal sources within the health care system than from family and friends. This, however, may be a reflection of their health status rather than an indication of general, relative overall support need. When the two individual indicators were additively combined, the mean support need was 9.3 on a scale range of 2 to 14. If the support need scale is divided at the midpoint (8), 47% have a relatively low and 53% a relatively high support need.

Table 20

Characteristics of Patients By Illness Severity Indicators

Indicator	Mean	Standard Deviation
Amount of Pain (Range = 0 (none) to 3 (great deal))	1.7	0.9
Frequency of Pain Medication (Range = 0 (never) to 3 (daily))	1.9	1.2
Assistance with Daily Care (Range = 0 (none) to 3 (great deal))	.9	1.0
Daily Bed Confinement (Range - 0 (none) to 3 (all day))	.8	0.9

For Composite Scale (Range = 0 to 12):
Mean = 5.2
Standard Deviation = 3.4

Table 21

Characteristics of Patients By Support Need Indicators

Indicator	Mean	Standard Deviation
Likelihood of Seeking/ Using Help From Informal Sources (Range = 1 (very unlikely) to 7 (very likely))	4.0	1.7
Likelihood of Seeking/ Using Help from Formal Sources (Range = 1 (very unlikely) to 7 (very likely))	5.2	1.4
Combined Indicators (Range = 2 (low support need) to 14 (high support need))	9.3	2.6

Description of Independent Variable Measures

Levels of formal and informal social support were the independent variables used in the study. Using the summative composite scaling method for descriptive purposes, overall, the respondents reported relatively low levels of formal support and moderate levels of informal support as indicated in Table 22. Upon closer examination, the relatively low levels of formal support are primarily due to the small percentage of patients who actually utilized the various programs and services listed as available to cancer patients. Table 23 indicates that the most frequently used services were dietary counseling[1] (52.5%), followed by Aids to Daily Living[2] (38.5%) and counseling from a clergyman or pastoral care worker (34.5%). The remaining services were infrequently used but were generally found to be helpful when used. Although dietary counseling was the most frequently used service, it was also reported as the least helpful.

With respect to levels of informal support (data not shown), most patients reported having an adequate number of

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[1] Since nutrition is currently emphasized in cancer care and treatment, dietary counseling is fairly routinely provided.

[2] The Aids to Daily Living Program is a support service administered by the Local Board of Health for the purpose of providing a variety of physical aids/devices which assist disabled individuals to function in the home environment.

Table 22

Formal and Informal Support Levels[1]

Support Type	Mean	Standard Deviation
Formal Support (Range = 8 (low) to 61 (high))	23.7	6.4
Informal Support (Range = 12 (low) to 70 (high))	40.5	8.0

---

[1] The reported values are based on the summative composite scaling method.

Table 23

Utilization and Perceived Helpfulness of Formal Support Programs and Services

Program/Service	% Utilizing Program/Service	% of Users Who Found Service/Program Helpful
Home Care	16.0	97.0
Aids to Daily Living	38.5	98.0
Homemaker	11.5	96.0
Meals-On-Wheels	2.5	100.0
Self-Help Group	4.0	63.0
Volunteer Visits	5.0	80.0
Dietician	52.5	45.0
Clergyman/Pastoral Careworker	34.5	94.0
Psychiatrist/Psychologist/ Mental Health Nurse	9.5	100.0
Nurse/Social Worker	23.0	89.0
Legal/Financial	1.5	100.0
Relaxation/Stress Management	4.5	100.0
Pain Control	7.0	100.0
Other*	9.5	100.0

* Other reported services utilized were physiotherapy, respiratory therapy and home surgical supplies. In addition, a small number of patients paid for services such as housekeeping and child care.

family members who were available and provided support in time of need. However, the majority reported relatively low levels of support from friends in terms of availability and number of contacts. While 64% reported having the same number of close friends living nearby at present compared to before their illness, 52% reported seeing their friends less and 79% reported having two or fewer ~~visits~~ visits from friends over the previous two week period.

Table 24 compares perceptions of the overall adequacy (amount) and appropriateness of support received from formal and informal sources. While the majority of respondents reported both formal and informal support as frequently or always adequate and appropriate for their needs, appraisals of informal support were consistently higher. For example, informal support was reported as always adequate by 63% while only 35% reported formal support as always adequate. Similarly, while 41% of the subjects reported informal support as always appropriate, only 28% reported formal support as always appropriate. For both types of support, appraisals of support amount were higher than appraisals of support appropriateness indicating that although most patients felt they received enough support, it was not necessarily perceived as the right type of support for their particular needs.

Table 24

Appraisal of Support Adequacy and Appropriateness
By Support Source

Support Source	Perceived Adequacy % Reporting Rarely	 Sometimes	 Frequently	 Always	Perceived Appropriateness % Reporting Rarely	 Sometimes	 Frequently	 Always
Formal	3.0	20.5	41.5	35.0	4.0	34.0	34.0	28.0
Informal	3.0	6.5	27.5	63.0	3.5	14.0	41.5	41.0

Description of Dependent Variable Measures

Functional status and self-esteem which were perceived to be two distinct aspects of well-being, were the dependent variables in the study. Table 25 shows that moderate levels of both functional status and self-esteem were reported by the respondents with the greatest variability found in the functional status outcome measure. In order to more closely examine functional status, mean levels of functioning were calculated for individual items contained in the physical and psychosocial functioning subscales of the FLIC.

With respect to physical functional status, Table 26 indicates that the lowest mean scores or lowest levels of physical functioning were reported for amount of pain (mean = 2.6), extent to which pain interfered with daily activities (mean = 3.4), satisfaction with work (mean = 3.5) and ability to complete household tasks (mean = 3.8).

For the 12 items on the psychosocial functioning subscale, Table 27 indicates that the lowest areas of functioning were frequency of feeling depressed (mean = 3.0), extent to which cancer was a hardship personally as well as to significant others and time spent thinking about the illness, all of which had a mean of 3.8. Highest levels of functioning were reported for willingness to see and spend time with significant others (mean = 6.0), satisfaction with treatment (mean = 5.2) and ability to cope with everyday stress (mean = 4.7). Overall, the means for

Table 25

Mean Levels of Functional Status and Self-Esteem
(N = 200)

Characteristic	Mean	Standard Deviation
Functional Status (Range = 22 (lowest) to 154 (highest))	93.4	25.6
Self-Esteem (Range = 10 (lowest) to 40 (highest))	29.9	4.6

Table 26

Mean Levels of Physical Functional Status (Physical Functioning Subscale of FLIC)

FLIC Item Number	Item Description[1]	Mean	Standard Deviation
1	How well do you look?	4.3	1.4
3	Amount of pain related to cancer	2.6	2.1
6	How much nausea?	5.4	1.6
8	Able to complete household tasks?	3.8	2.0
10	Pain interfering with daily activities?	3.4	2.0
12	How comfortable today?	4.5	1.4
13	Satisfaction with work?	3.5	1.9
16	Able to do household chores?	4.1	2.1
17	How well do you feel today?	4.5	1.2
18	Nausea affecting daily functioning?	5.5	1.7

[1] Score range for all items is 1 (low functional status) to 7 (high functional status)

Table 27

Mean Levels of Psychosocial Functional Status
(Psychosocial Functioning Subscale of FLIC)

FLIC Item Number	Item Description[1]	Mean	Standard Deviation
2	Treatment satisfaction	5.2	1.4
4	Willingness to see friends	4.5	1.9
5	Frightened of future	4.5	1.5
7	Willingness to spend time time with those close	6.0	1.1
8	Cancer a personal hardship	3.8	2.0
11	Disruptiveness of cancer to those close	4.0	1.7
14	Feel discouraged	4.0	1.6
15	Cancer a hardship to those close	3.8	1.8

cont'd.

Table 27 (cont'd)

FLIC Item Number	Item Description[1]	Mean	Standard Deviation
19	Able to maintain leisure activities	3.2	1.9
20	Time spent thinking about illness	3.8	1.4
21	Ability to cope with everyday stress	4.7	1.3
22	How often depressed	3.0	0.6

[1] Score range for all items is 1 (low functional status) to 7 (high functional status)

the two subscales were almost identical with 4.16 for physical and 4.20 for psychosocial functioning.

Significant Correlations Among Dependent, Independent and Control Variables

In this section, Pearson correlation coefficients among the (1) independent and dependent, (2) independent and control and (3) dependent and control variables are presented. First, Pearson correlation coefficients among the significant formal and informal support predictor items (independent variables) and the two dependent variables are shown in Tables 28 and 29. Table 28 shows that all formal support variables are significantly correlated (at the .001 level) with functional status. With respect to self-esteem, two formal support variables (32 and 33) are significantly correlated at the .001 level, one (variable 28) at the .01 level and two (variables 27 and 35A) at the .05 level. The negative correlations between three of the formal support variables (27, 28 and 35A) and functional status indicate that lower levels of functional status are associated with increased reliance on as well as increased number of contacts with a particular health care person and utilization of special services. This is to be expected since, ordinarily, formal support is increased as functional status deteriorates with disease progression. It is also noted that the same formal support variables are negatively correlated with self-esteem suggesting that increased

Table 28

Pearson Correlation Coefficients Among the Formal Social Support Significant Predictor Items (Independent Variables) and the Dependent Variables
(N = 200)

	Independent Variables					Dependent Variables	
Variable	V27	V28	V32	V33	V35A	Functional Status	Self-Esteem
Frequency of reliance on a particular health care person (V27)	1.00	.62***	.18**	.11	.15*	-.45***	-.16*
No. of contacts with one particular health care person (V28)		1.00	.06	.01	.22***	-.53***	-.18**
How often is help from health care system enough? (V32)			1.00	.68***	-.11	.39***	.46***
How often is help from health care system appropriate? (V33)				1.00	-.10	.41***	.49***
Current or recent utilization of Aides to Daily Living Program (V35A)					1.00	-.30***	-.12*
Functional Status						1.00	.59***
Self-Esteem							1.00

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

Table 29
Pearson Correlation Coefficients Among the Informal Social Support Predictor Items and the Dependent Variables
(N = 200)

Variable	V49	V54	V55	V56	V60	V61	V62	Functional Status	Self-Esteem
	Independent Variables					Dependent Variables			
V49 Frequency of reliance on a particular person	1.00	.33***	.29***	.13*	.08	.53***	.42***	-.11	.20**
V54 No. of family visits in past two weeks		1.00	.43***	.14*	.05	.43***	.26***	-.10	.05
V55 See family more, less or same as before illness			1.00	-.01	-.10	.31***	.17**	.20**	-.02
V56 How many friends living nearby				1.00	.41***	.30***	.29***	.40***	.33***
V60 See friends more, less or same as before illness					1.00	.28***	.34***	.49***	.40***
V61 Support from family, friends enough						1.00	.97***	.25***	.47***
V62 Support from family, friends appropriate							1.00	.37***	.49***
Functional Status								1.00	.59***
Self-Esteem									1.00

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

utilization of formal support is associated with lower levels of self-esteem, which is again, perhaps more a function of disease progression than an indication of the failure of the formal support system.

Table 29 shows that most of the informal support variables are also significantly correlated with both dependent variables with the exception of variable 54 (number of family visits over past two weeks) which is not significantly associated with either functional status or self-esteem, variable 55 which is not significantly related to self-esteem and variable 49 which is not significantly related to functional status. The significant positive relationships (other than the above noted exceptions) between the informal support variables and the dependent variables suggests that higher levels of informal support are associated with higher levels of functional status and self-esteem.

Although there are significant relationships between several of the individual formal and informal support variables (see Tables 28 and 29, respectively) they are not of sufficient magnitude to cause concerns about multicollinearity. With respect to the two dependent variables (functional status and self-esteem), the moderately high correlation (.59) was expected since both were presumed to be a measure of the well-being construct. However, since the correlation was only moderately strong, it can be said that they are not redundant measures of exactly the same thing.

Second, Tables 30 and 31 show the Pearson correlation coefficients between the independent variables (formal and informal support significant predictor items, respectively) and the control variables. Table 30 indicates that there are several significant correlations between the individual formal support items and the control variables. The most consistent correlations are between the individual formal support variables and illness severity where all correlations are significant at the .001 level. The only control variable which is not significantly associated with any of the formal support variables is time since initial diagnosis. Table 31 shows that, overall, the individual informal support variables are significantly correlated with more of the control variables than are the formal support variables (Table 30). All individual informal support variables are significantly correlated with marital status (with the exception of variable 55) and illness severity. Only one informal support variable (V54) is significantly correlated with the time since diagnosis control variable. Although there are several significant correlations between the individual formal and informal support variables and the control variables, none are of sufficient magnitude to cause concerns associated with multicollinearity.

Table

Pearson Correlation Coefficients Among the Formal Support Significant Predictor Items and the Control Variables
(N = 200)

Independent Variables (Formal Support Significant Predictor Items)	Control Variables Gender (Female)	Age	M.S. (Married)	SES	Time Since Diagnosis	Relig. Commitment[1]	Illness Severity	Support Need
V27 Frequency of reliance on particular health care system	.13*	.01	-.01	-.00	.04	.03	.43***	.13*
V28 No. of contacts with one particular health care person	.17**	.04	.05	-.01	.03	.04	.48***	.04
V32 Is support from health care system enough	.03	.19**	.12*	-.00	.06	.04	.48***	-.04
V33 Is support from health care system appropriate	.04	.21***	.05	-.12*	.09	.30***	-.23***	.05
V35A Current or recent utilization of Aides to Daily Living Service	.27***	.23***	.04	-.00	.01	.04	.41***	.04

[1] Calculations are based on summed standardized scale scores.

*** significant at the .001 level

** significant at the .01 level

* significant at the .05 level

Table 31.

Pearson Correlation Coefficients Among the Informal Support Significant Predictor Items and the Control Variables
(N = 200)

Independent Variables	Control Variables							
(Informal Support Significant Predictor Items)	Gender (Female)	Age	M.S. (Married)	SES	Time Since Diagnosis	Relig. Commit- ment	Illness Severity	Support Need
V49 Frequency of reliance on one particular person	-.01	.01	.43***	.18**	.02	.22***	.15*	.12*
V54 No. of family visits in past two weeks	.06	.15*	.19**	.05	.19**	.02	.25***	.19**
V55 See family more, less or same as before illness	-.10	-.11	.11	.03	.07	.08	.28***	.02
V56 How many friends living nearby	-.19**	.04	.24***	.19**	.07	.06	-.28***	.05
V60 See friends more, less or same as before illness	-.02	.00	.19**	.08	.03	.22***	-.45***	.14*
V61 Support from family, friends enough	-.06	.12	.31***	.11	.03	.24***	-.13*	.09
V62 Support from family, friends appropriate	-.10	.13*	.25***	.04	.04	.22***	-.25***	.06

1. Calculations are based on summed standardized scale scores.
*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

Table 32 shows the correlations between the dependent and control variables. With the exception of severity of illness and support need, none of the control variables are significantly correlated with the functional status dependent variable. The high negative correlation (-.73) between severity of illness and functional status was not unexpected since as severity of illness increases, functional status normally decreases. By contrast, many of the control variables were significantly correlated with the self-esteem dependent variable. Significant correlations are observed between self-esteem and severity of illness (-.30), religious commitment (.27) and income (.23) which are all significant at the .001 level, occupation (.20), overall socioeconomic status (.19) and marital status (.19) which are significant at the .01 level, and age (.15) which is significant at the .05 level.

These findings suggest that self-esteem was more likely than functional status to be related to the selected control variables. Further, the large number of observed significant correlations underline the importance of the need to control for selected factors when examining the relationships between social support and well-being.

Results of Hypothesis Tests

In this section, results of the multiple regression analysis used to test each of the four hypotheses are presented. Hypotheses 1 and 2 state that:

Table 32

Pearson Correlation Coefficients Among the Dependent and Control Variables

Control Variable	Dependent Variables	
	Functional Status	Self-Esteem
Gender (Female)	-.06 (N=200)	-.04 (N=200)
Age	.07 (N=200)	.15* (N=200)
Marital Status (Married)	-.01 (N=200)	.19** (N=200)
Education	-.01 (N=200)	.10 (N=200)
Income	.01 (N=192)	.23*** (N=192)
Occupation	-.01 (N=192)	.20** (N=200)
Socioeconomic Status[1]	-.01 (N=192)	.19** (N=192)
Time Since Diagnosis	-.06 (N=200)	-.09 (N=200)

cont'd.

Table 32 (cont'd)

Control Variable	Dependent Variables	
	Functional Status	Self-Esteem
Religious Commitment	.07 (N=200)	.27*** (N=200)
Severity of Illness	-.73*** (N=200)	-.30*** (N=200)
Support Need	.16** (N=200)	.11 (N=200)

1. Summed standardized scale scores for education, income and occupation.
*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

> Individuals with higher levels of (1) formal and (2) informal support will report higher levels of functional status and self-esteem controlling for gender, age, marital status, socioeconomic status, time since diagnosis, religious commitment, illness severity and support need.

For each hypothesis, separate regressions were run for each dependent variable with each independent variable[1] for a total of four runs. These were:

(1) Regression of functional status on formal support and the control variables (hypothesis 1)

(2) Regression of self-esteem on formal support and the control variables (hypothesis 1)

(3) Regression of functional status on informal support and the control variables (hypothesis 2)

(4) Regression of self-esteem on informal support and the control variables (hypothesis 2)

For each equation, the independent variable (that is, formal or informal support) was forced to enter on the first step followed by the block entry of the eight control variables on the second step. The unstandardized multiple regression coefficient for the independent variable (b_1) was then examined and tested for significance in each run.

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[1] For this and all subsequent multiple regression analysis the scoring method for the independent variables (formal and informal social support) is the nonsummed method using individual significant predictor items.

Tables 33 and 34 show the results of regressing [illegible] functional status and (2) self-esteem on formal support and the control variables. Focusing on the unstandardized regression coefficients for the formal support variables in each table, it is noted that the corresponding t values for all formal support items are significant with the exception of variable 35A in Table 33. Where the observed t statistics exceed the required critical values, the null hypothesis that $b_1 = 0$ is rejected. However, hypothesis 1, which predicts that the higher the formal support level, the higher the functional status and self-esteem is only partly supported since for both functional status and self-esteem, support utilization (items 1 and 2, Table 33 and item 1, Table 34) has negative effects but support appraisal (items 3 and 4, Table 33 and items 2 and 3, Table 34) has positive effects.

When functional status was regressed on informal support and the control variables, Table 35 indicates that the unstandardized regression coefficients for the informal support variables are significant for two of the five predictor variables: 56 (number of friends living nearby) and 62 (appropriateness of support from family and friends) which are both significant at the .01 level. These findings suggest that when informal support availability (variable 56) and support appraisal (variable 62) aspects of informal

Table 33

Regression of Functional Status on Formal Support and the Control Variables

Variable	Regression Coefficients b 1	B	R 2 2
Formal Support Items			
1. V27 Frequency of reliance on particular health care person	-6.25***	-.20	
2. V28 No. of contacts with one particular health care person	-3.74**	-.15	
3. V32 Is support from health care system enough	5.59*	.18	
4. V33 Is support from health care system appropriate	4.59*	.16	
5. V35A Current or recent utilization of Aides to Daily Living Program	-.95	-.02	.54
Gender	-1.01	-.02	
Age	.24**	.14	
Marital Status	-[illegible].59	-.05	
Socioeconomic Status	.16	.02	

cont'd

Table 33 (cont'd)

Variable	Regression Coefficients b[1]	 B	 R^2[2]
Time Since Diagnosis	-.59	-.04	
Religious Commitment	-.16	-.03	
Severity of Illness	-3.79***	-.50	
Support Need	1.51***	.15	.72
Constant	131.18*	--	

1. Recorded values are after controlling for the effects of all other variables

2. Recorded values are those observed after Step 1 and Step 2 of the regression procedure.

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

Table 34

Regression of Self-Esteem on Formal Support and the Control Variables

Variable	Regression Coefficients b[1]	 B	 R^2[2]
Formal Support Items:			
1. V27 Frequency of reliance on particular health care person	-.97**	-.17	
2. V32 Is support from health care system enough	1.17*	.20	
3. V33 Is support from health care system appropriate	1.42*	.27	.31
Gender	-.50	-.05	
Age	.06**	.19	
Marital Status	.87	.09	
Socioeconomic Status	.46***	.26	

cont'd

Table 34 (cont'd)

Variable	Regression Coefficients		
	b[1]	B	R^2[2]
Time Since Diagnosis	.16	.05	
Religious Commitment	.11	.11	
Severity of Illness	-.17	-.13	
Support Need	.12	.07	.43
Constant	7.49	--	

1. Recorded values are after controlling for the effects of all other variables
2. Recorded values are those observed after Step 1 and Step 2 of the regression procedure.

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

Table 35

Regression of Functional Status on Informal Support and the Control Variables

Variable	Regression Coefficients		
	b [1]	B	R^2 [2]
Informal Support Items:			
1. V49 Frequency of reliance on one particular person	-2.46	-.10	
2. V55 See family more, less or same as before illness	.44	.02	
3. V56 How many friends living nearby	3.98**	.16	
4. V60 See friends more, less or same as before illness	2.41	.10	
5. V62 Support from family and friends appropriate	5.28**	.17	.42
Gender	-.72	-.01	
Age	.32***	.18	
Marital Status	-4.79	-.09	

cont'd

Table 35 (cont'd)

Variable	Regression Coefficients		
	b [1]	B	R^2 [2]
Socioeconomic Status	-.04	-.00	
Time Since Diagnosis	-.62	-.04	
Religious Commitment	.08	.01	
Severity of Illness	-4.69***	-.62	
Support Need	1.09*	.11	.67
Constant	120.48*	--	

1. Recorded values are after controlling for the effects of all other variables

2. Recorded values are those observed after Step 1 and Step 2 of the regression procedure.

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

social support are measured, then hypothesis 2 which predicts that individuals with higher levels of informal support will have higher levels of functional status is supported. However, when utilization (variable 49) or support change (variables 55 and 60) aspects of informal support are measured controlling for support availability and appraisal, then the same hypothesis is rejected.

In Table 36, it is observed that when self-esteem is regressed on informal support and the control variables, the unstandardized regression coefficients for the informal support variables are all significant with the exception of variable 62 (appropriateness of support from family and friends). However, again, the hypothesis that individuals with higher levels of informal support will have higher levels of self-esteem is only partially supported since, while support changes and appraisal have a positive effect on self-esteem, support utilization has a negative effect.

It should be noted that in Tables 33, 34, 35, and 36, the reported levels of statistical significance may be slightly biased since there is some correlation among the independent variables (formal support, informal support and controls) and, therefore, the t ratios used to test for significance are not independent of each other. Also, the standard errors of the regression coefficients are affected by the degree of intercorrelation among the independent variables. Therefore, in order to determine (1) whether the

Table 36

Regression of Self-Esteem on Informal Support and the Control Variables

Variable	Regression Coefficients		
	b [1]	B	R^2 [2]
Informal Support Items:			
1. V54 No. of family visits in past two weeks	-.59*	-.15	
2. V60 See friends more, less or same as before illness	.71*	.16	
3. V61 Support from family, friends enough	1.64**	.27	
4. V62 Support from family, friends appropriate	.81	.14	.33
Gender	-.16	-.02	
Age	.08***	.24	
Marital Status	.40	.04	
Socioeconomic Status	.35**	.20	

cont'd

Table 36 (cont'd)

Variable	Regression Coefficients b [1]	 B	 R^2 [2]
Time Since Diagnosis	.28	.10	
Religious Commitment	.11	.11	
Severity of Illness	-.21*	-.16	
Support Need	.06	.04	.42
Constant	-5.82	--	

1. Recorded values are after controlling for the effects of all other variables

2. Recorded values are those observed after Step 1 and Step 2 of the regression procedure.

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

reported levels of statistical significance were sufficiently biased to cause practical concern and (2) if multicollinearity existed, the intercorrelations among all independent variables used in the regression equations were examined. Previously, Table 30 and 31 indicated that none of the correlation coefficients among the formal/informal support and the control variables were sufficiently large enough to cause concern regarding biased levels of significance or multicollinearity.[1] Similarly, Table 37 indicates that the correlations among the control variables used as independent variables in the multiple regression analyses were not of sufficient magnitude to cause concern.

Hypothesis 3 which states that formal and informal support will combine (either additively or interactively) to predict functional status and self-esteem was also tested using multiple regression analysis. To test for interaction effects,[2] a product term for formal and informal support was

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[1] The risk of multicollinearity exists if correlations of 0.80 or higher are observed among the independent variables (Bohrnstedt and Knoke, 1982, 384).

[2] An interaction effect is present if the effect of X_1 on Y depends on the level of X_2 (which implies, symmetrically that the effect of X_2 on Y depends on the level of X_1).

Table 37

Pearson Correlation Coefficients Among the Control Variables

Variable	1	2	3	4	5	6	7	8
1. Gender (Female)	1.00	.04	.20**	-.01	.03	.23***	.10	.30***
2. Age		1.00	.05	-.37***	-.03	.03	.21***	-.08
3. Marital Status (Married)			1.00	-.35***	-.10	.00	.10	-.02
4. Socioeconomic Status				1.00	-.05	.03	-.09	.14*
5. Time Since Diagnosis					1.00	-.11	-.06	-.05
6. Religious Commitment						1.00	-.00	.21***
7. Severity of Illness							1.00	-.08
8. Support Need								1.00

Note: All correlations are calculated on N=200 with the exception of those related to Socioeconomic Status where N=192.

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

added to the linear multiple regression equation for each dependent variable as follows:

$$Y_1 \text{ or } Y_2 = a + b_1X_1 + b_2X_2 + b_3X_1X_2$$

where Y_1 = functional status, Y_2 = self-esteem, X_1 = formal support and X_2 = informal support. For each regression equation, the independent variables were entered first followed by the interaction terms. Table 38 shows the coefficients of determination (R_2) and the R square changes observed when functional status was regressed on formal support, informal support and the interactive terms. Similarly, Table 39 shows the result of regressing self-esteem on formal support, informal support and the interactive terms. For each regression equation, it is noted that the addition of the interactive terms does not significantly change the amount of variance explained in the dependent variable as determined by the F test of significance. Therefore, it is concluded that formal and informal support combine additively, but not interactively, to predict functional status and self-esteem.

In order to determine whether the social support--well-being relationship varied among certain subgroups in the population (hypothesis 4), multiple regression analyses were performed to test for interaction effects between the independent variables (formal and informal support) and each of the control variables under investigation. Stated in the full form, the specific hypothesis tested was: the social

Table 38

Regression of Functional Status on Formal Support, Informal Support and the Formal X Informal Support Interaction Terms (N = 199)

Step	Independent Variable	Additive Equation R^2	Additive Equation R^2 Change	Interaction Equation R^2	Interaction Equation R^2 Change	F^1
1	Formal Support (Variables 27,28,32, 33,35A)	.54	.54			
2	Informal Support (Variables 49,55,56, 60,62)	.62	.18			
3	Formal Support X Informal Support[2]			.65	.03	.62(NS)

1. F tests the significance of the R^2 change between the additive and interaction equations.

2. Represents all possible interaction terms between the individual formal and informal support variables. All 25 interaction terms were entered as a block.

Table 39

Regression of Self-Esteem on Formal Support, Informal Support and the Formal X Informal Support Interaction Terms
(N = 199)

Step	Independent Variable	Additive Equation		Interaction Equation		
		R^2	R^2 Change	R^2	R^2 Change	F^1
1	Formal Support (Variables 27,32,33)	.31	.31			
2	Informal Support (Variables 54,60,61,62)	.41	.10			
3	Formal Support X$_2$ Informal Support[2]			.42	.01	.31(NS)

1. F tests the significance of the R^2 change between the additive and interaction equations.

2. Represents all possible interaction terms between the individual formal and informal support variables. All 12 interaction terms were entered as a block.

support--well-being relationship will not vary for (1) male and female, (2) young and old, (3) married and nonmarried, (4) high and low socioeconomic status individuals or persons with (5) longer and shorter times since initial diagnosis, (6) high and low levels of religious commitment, (7) lesser and greater illness severity and (8) high and low support need. Separate regressions were run for each control variable representing the eight pairs of subgroups listed above with each dependent variable. In each run, the dependent variable was regressed on the formal and informal support significant predictor items, the control variable under investigation and the interaction terms represented by the products of each independent variable item and the particular control variable under investigation (for example, individual formal support items X gender, individual informal support items X gender). In each case, the order of entry into the regression equation was the two independent variables, followed by the control variable and finally, the interactive terms.

To test for interaction effects, that is, to determine whether differences were operating within the subgroups in the prediction of functional status and self-esteem, the coefficient of determination for the equation with the interactive terms included (R_2^2) was compared with the coefficient of determination for the equation with the interactive terms omitted (R_1^2). If R_2^2 was significantly larger than R_1^2 as determined by the F statistic, then it was concluded that differences were operating and the null hypothesis was rejected. Table 40 indicates that, in the prediction of functional status, all null hypotheses were retained with the exception of that relating to marital status. In this case the F statistic is significant at the .05 level suggesting that the relationship between informal support and functional status varies for the married and nonmarried. Similarly, in the prediction of self-esteem, Table 41 shows that the relationship between informal support and self-esteem varies significantly (at the .05 level) only according to marital status. Based on these findings it can be concluded that the social support--well-being relationships do not vary for (1) males and females, (2) young and old, (3) high and low socioeconomic status individuals or persons with (4) longer and shorter times since diagnosis (5) high and low levels of religious commitment, (6) lesser and greater illness severity, or (7) high and low support need. It can also be concluded that the effects of informal support on both functional status and self-esteem vary for the married and nonmarried although the effects of formal support were not affected by marital status.

In order to more closely examine the interaction effects between informal support and marital status, further regression analyses were performed to determine (1) which

Table 40

Tests For Interaction Effects Between the Independent and Control Variables in the Prediction of Functional Status (N = 199)

	Formal Support			Informal Support		
Control Variable	R^2_1 [1]	R^2_2 [2]	F	R^2_1	R^2_2	F
Gender	.54	.55	.83	.42	.43	.67
Age	.54	.55	.83	.42	.43	.67
Marital Status	.54	.55	.83	.42	.46	2.75*
Socioeconomic Status	.54	.55	.83	.42	.44	1.33
Time Since Diagnosis	.55	.55	.00	.43	.43	.00
Religious Commitment	.54	.55	.83	.42	.44	1.33
Illness Severity	.68	.69	1.18	.63	.63	.00
Support Need	.57	.58	.91	.44	.46	1.38

1. R^2_1 represents the additive equation comprised of the independent variables (that is, either the formal or informal support individual items) and the control variable under investigation.

2. R^2_2 represents the additive regression equation with the interaction terms added (that is, the product terms of each formal or informal support variable and the control variable under investigation.

* significant at the .05 level

Table 41

Tests For Interaction Effects Between the Independent and Control Variables in the Prediction of Self-Esteem (N = 199)

Control Variable	Formal Support			Informal Support		
	R^2_1[1]	R^2_2[2]	F	R^2_1	R^2_2	F
Gender	.31	.33	2.00	.33	.34	.71
Age	.31	.32	.92	.35	.37	1.52
Marital Status	.34	.35	.97	.34	.38	3.03*
Socioeconomic Status	.37	.39	2.09	.36	.36	.00
Time Since Diagnosis	.31	.31	.00	.34	.34	.00
Religious Commitment	.32	.33	.94	.35	.36	.74
Illness Severity	.31	.32	.92	.34	.35	.74
Support Need	.32	.34	1.91	.34	.36	1.47

1. R^2_1 represents the additive equation comprised of the independent variables (that is, either the formal or informal support individual items) and the control variable under investigation.

2. R^2_2 represents the additive regression equation with the interaction terms added (that is, the product terms of each formal or informal support variable and the control variable under investigation.

* significant at the .05 level

specific individual informal support variable(s) were interacting significantly with marital status in the prediction of functional status and self-esteem and also to determine (2) the nature of the effect of marital status on the informal support--well-being relationship. First, it should be noted that in Tables 40 and 41 the R_1^2s (additive equation) for both formal and informal support and the respective control variables represent the total R^2s of all individual formal and informal support significant predictor items plus the control variable under investigation. At the same time the R^2_2s (interactive equation) represent the block entry of all possible interaction terms represented by the individual formal or informal support items and the particular control variable under investigation. Therefore in the case of the significant interaction effect found in Table 40 between informal support and marital status, there were five possible interaction terms which may have produced the interaction effect. Table 42 shows the results of the tests for interaction effects between the individual informal support items and marital status. It is observed that when the interaction effects are examined separately for each informal support item and marital status (married), all are significant suggesting that the relationship between each informal support variable and functional status varies between the married and nonmarried groups.

Table 42

Tests For Interaction Effects Between Individual Informal Support Items and Marital Status[1] in the Prediction of Functional Status
(N=199)

Interaction Terms	Additive Equation R^2_1	Interaction Equation R^2_2	F
1. Frequency of reliance on one particular person x Marital Status (V49 x V04)	.41	.45	13.79***
2. See family more, less or same as before illness x Marital Status (V55 x V04)	.41	.43	6.60*
3. How many friends living nearby x Marital Status (V56 x V04)	.41	.44	6.89**
4. See friends more, less or same as before illness x Marital Status (V60 x V04)	.41	.44	6.89**
5. Is support from family, friends appropriate x Marital Status (V62 x V04)	.41	.45	13.79***

[1] Calculations are based on Marital Status (V04: Married = 1, Nonmarried = 0)

*** significant at the .001 level
** significant at the .01 level
* significant at the .05 level

To determine which individual informal support item(s) were interacting with marital status in the prediction of self-esteem the same procedure was repeated. Table 43 indicates that among the four interaction terms, only one (see friends more, less or same as before illness) was significant at the .05 level.

In order to examine the nature of the effect of marital status on the informal support--well-being relationship, the mean well-being scores for the married and nonmarried subgroups with high and low levels of informal social support were examined. For the functional status measure of well-being, Table 44 indicates that the mean functional status scores for both high and low levels of informal support were higher among the married than the nonmarried. Similarly, Table 45 shows that the mean self-esteem scores were higher among the married than the nonmarried for both high and low levels of informal support. These findings suggest that while the effects of informal support on functional status and self-esteem were positive for both the married and nonmarried, the effects were stronger among the married subgroup.

Given that interaction effects between social support and the selected control variables were largely undetected in the prediction of functional status or self-esteem (with the exception of those found between informal support and marital status), each subscale of the functional status

Table 43

Tests For Interaction Effects Between the Individual Informal Support Variables and Marital Status[1] in the Prediction of Self-Esteem (N=199)

Interaction Terms	Additive Equation R^2_1	Interaction Equation R^2_2	F
1. No. of family visits over past two weeks x Marital Status (V54 x V04)	.34	.35	2.94
2. See friends more, less or same as before illness x Marital Status (V60 x V04)	.34	.36	6.25*
3. Is support from family, friends enough x Marital Status (V61 x V04)	.34	.34	.00
4. Is support from family, friends appropriate x Marital Status (V62 x V04)	.34	.35	2.94

1. Calculations are based on Marital Status (V04: Married = 1, Nonmarried = 0)

* significant at the .05 level

Table 44

Comparison of Mean Functional Status
Scores For Married and Nonmarried Subgroups
With High and Low Informal Support Levels
(N = 200)

Informal Social Support Level	Married	Nonmarried
	Mean	Mean
High Support	97.3	90.6
Low Support	93.5	87.4

Table 45

Comparison of Mean Self-Esteem Scores For Married and Nonmarried Subgroups With High and Low Informal Support Levels

(N = 200)

Informal Social Support Level	Married	Nonmarried
	Mean	Mean
High Support	32.8	28.5
Low Support	29.5	26.6

measure (FLIC) was also examined for interaction effects. Based on previous research findings that social support is usually unrelated to physical well-being but positively related to psychosocial well-being, it was reasoned that a different pattern of interaction effects may emerge by examining the physical and psychosocial subscales of the FLIC. This reasoning was supported by the study (data not shown). No significant interaction effects were found between formal or informal support and the control variables in the prediction of physical functional status (subscale A). By contrast, significant interaction effects (at the .01 level) between formal support and gender and between informal support and (1) gender (significant at the .01 level) as well as (2) support need (significant at the .05 level) occurred in the prediction of psychosocial functional status (subscale B). With respect to the interaction effect between formal support and gender, it was found that the two support appraisal items (enough and appropriate support from the health care system) interacted significantly with gender in the prediction of psychosocial functional status. This finding suggests that the effects of formal support appraisal on psychosocial functional status vary according to gender. The significant interaction effect between informal support and gender also occurred for the support appraisal items (enough and appropriate help from family and friends). Similarly, the significant interaction effect between informal support and support need also occurred between the two support appraisal items and support need where the interaction effects were significant between those with high support need (a score equal to or greater than the mean of 6.5 on the support need scale) and those with low support need (a score less than the mean).

With respect to differences in the social support--psychosocial functional status relationship within the subgroups described above, no further analyses of these differences were undertaken for two reasons. First, of a total of 126 interaction terms examined, only three were found to be significant. Since a few might be expected to be significant by chance, the finding of three significant interaction terms should be interpreted cautiously. Second, the amount of additional variance explained by the significant interaction terms was relatively small (the largest R^2 increase was 3%) suggesting that the additive model was the most parsimonious in the explanation of the social support--psychosocial functional status relationship.

Summary

The quantitative findings of the study are summarized according to the central questions and purposes of the research. First, the nature of the relationships between both formal and informal sources of social support and the functional status and self-esteem aspects of cancer patient well-being were examined due to (1) contradictory findings in the literature which have suggested that social support has positive, null and even negative effects on various aspects of well-being and (2) a paucity of research on the effects of formal social support on cancer patient well-being. Further, it was suggested that the contradictory findings regarding the effects of social support on individual well-being may be a function of 1) differences in outcome measures of well-being and 2) the failure of researchers to systematically examine the effects of various sociodemographic and contextual factors which may enhance or suppress the social support--well-being relationship.

With respect to the nature of the relationship between social support and cancer patient well-being, the hypotheses that, controlling for the effects of gender, age, marital status, socioeconomic status, time since initial diagnosis level of religious commitment, illness severity and support need, individuals with higher levels of (1) formal and (2) informal support would experience higher levels of functional status and self-esteem were only partially supported. The nature of the relationship (that is, positive, negative or null) between levels of social support and levels of functional status or self-esteem was found to vary according to (1) which aspect of social support was measured (that is, availability, utilization or appraisal of adequacy and appropriateness of social support) and (2) the outcome measure used.

When the relationships between formal support and the two outcome measures of well-being were examined, it was found that while higher levels of support appraisal were associated with higher levels of both functional status and self-esteem, support availability and utilization were associated with lower levels of functional status and self-esteem. Thus, while support appraisal was positively related to the outcome measures, support availability and utilization were negatively related to the same outcome measures. In the case of the relationships between informal support and the two outcome measures, higher levels of informal support appraisal and availability were associated with higher levels of functional status but higher support utilization was associated with lower levels and support changes not associated with functional status. With respect to the self-esteem outcome measure, higher levels of support appraisal were associated with higher levels of self-esteem but higher levels of support utilization were associated with lower levels of self-esteem. Levels of support availability and support changes were unrelated to self-esteem.

These findings support both theoretical formulations and other empirical findings that the perception or experience of feeling supported (that is, positive appraisal) is the most important predictor of well-being. Further, they support the contention that discrepancies found in the nature of the social support--well-being are, at least in part, a function of the type of well-being outcome measure used and also what aspect of social support is measured.

Some support for the contention that discrepancies found in the nature of the social support--well-being may be a function of the failure to systematically account for various sociodemogrpahic and contextual factors was found. For example, age and illness severity were found to be significant factors in the explanation of the variance observed in functional status. Similarly, age, severity of illness and socioeconomic status were significant predictors of self-esteem. Based on these findings, it is suggested that failure to account for the effects of these factors may result in overestimation of the relative effects of social support on various aspects of well-being.

The second major question addressed in the study was whether or not the social support--well-being relationship varied among certain sub-groups in the population. The findings indicate that the effects of formal support on functional status and self-esteem did not vary for (1) males and females, (2) married and nonmarried, (3) young and old, (4) high and low socioeconomic status or among those with (5) longer and shorter times since initial diagnosis, (6) high and low levels of religious commitment, (7) greater and less severity of illness or (8) high and low support need.

Similarly, the effects of informal support on functional status and self-esteem were not found to vary among any of these subgroups with the exception of the married and nonmarried.

Overall, the dependent and independent variable measures used in the study were determined to be sufficiently reliable and valid. Of considerable importance to future social support research was the finding that alternate methods of scoring the social support indexes produced considerable variation in their predictive power. Specifically it was found that using individual significant predictor items (nonsummed) resulted in a substantial increase in the predictive power of the indexes as compared to summed scoring methods.

Qualitative Findings

Although the primary emphasis of this study was to examine the social support--well-being relationship among advanced cancer patients using quantitative methods, a considerable amount of data beyond that obtained from the structured interview format were also incidentally collected. These data, which were largely unsolicited, derived mainly from the elaboration of responses to questions contained in the structured interview or, in most cases, from an apparent need of the subjects to "unburden" themselves to someone they possibly perceived to be an outside, objective observer. The findings presented in this section are, therefore, based on a content assessment of this qualitative data and should be viewed as a secondary or supplementary form of analysis. The primary emphasis is on issues and concerns raised by the subject in relation to various aspects of (1) formal and (2) informal social support.

Formal Social Support

In this section, findings relevant to the subjects' experiences with the formal social support system are presented according to selected major themes that emerged. For the most part, these themes center on issues relating to the perceived adequacy of the amount and type of support experienced from the health care system.

Overall, perhaps the most striking finding in this data was the wide variation observed in both the subjects' expectations and actual receipt of formal support. Approximately one third of the subjects expressed considerable gratitude and satisfaction with their care and implied that their support expectations had been fully met. The remaining two thirds, however, expressed varying degrees of dissatisfaction, disappointment and unfulfilled expectations. Those who were most satisfied tended to be patients who were (1) hospitalized or in the palliative home care program as opposed to those on self-care in the home setting, (2) older than the average age of participants and

(3) male versus female. With respect to the care setting, those who were hospitalized or in the palliative home care program typically expressed satisfaction in terms of the perception that their needs were more fully met than when they remained in the home setting. The most frequently cited example of satisfaction by these particular subjects was the achievement of pain control. Many subjects stated that adequate pain control could not be achieved in the home setting due to the reluctance of physicians to prescribe medication of sufficient strength or amount for use without professional supervision or monitoring. The importance of pain control in terminally ill cancer patients is perhaps best captured by the frequently heard statement, "When the pain is under control, it is possible to put all other things in their proper perspective." An extreme example of the inability to put things into proper perspective when pain is severe and uncontrolled was the offer of money to the interviewer to obtain and administer a lethal dose of medication by three different subjects. Another frequently heard statement reflecting the despair associated with uncontrolled pain was, "All I want is for this to end as soon as possible."

The observation that older than average subjects tended to more readily express satisfaction with care than their younger counterparts appeared to derive primarily from an acceptance of their dying state. For example, many of these subjects talked at length about their past "good times" and accomplishments indicating that their lives had been rich and full and they were now willing to accept that the end was near. With this acceptance also came acceptance as well as increased appreciation or gratitude for the type of care they were receiving. By contrast, the considerable difficulty of younger subjects in accepting their impending death was reflected in common remarks such as, "There must be something more that could be done for me", "Why are the doctors so slow in starting my treatment?", "If I had been treated earlier, I wouldn't be in this situation" and "Why is this happening to me?"

The tendency of males to more readily express satisfaction with care appeared to derive primarily from differences in male and female expectations of the type and amount of care provided by health care professionals. For example, typical statements of dissatisfaction by female subjects included, "I have to wait days for the doctor to return my phone calls.", "I think it is unreasonable to expect patients in my condition to wait hours to see the doctor in his office or in the outpatient departments", "The nurses take forever to answer my call light, change my dressings, take me to the bathroom, etc." and "I need to see the doctor more often than every two weeks." Male subjects, on the other hand were more likely to express satisfaction with their care by statements such as, "I am confident that the doctors/nurses are competent and are doing everything they can" or "The doctors and nurses work very hard and under very stressful, difficult circumstances."

By far the most frequently expressed area of dissatisfaction in terms of type of expected support from health care professionals, was the lack of information provided. At least 80% of those who felt dissatisfied mentioned that lack of information regarding various aspects of their disease created anxiety, fear, frustration and a general feeling of ineptness in handling their daily care.

The most needed types of information cited were related to a better understanding of (1) the nature and progression of the disease, (2) the side effects and expected outcomes of various treatments including radiation, chemotherapy and pain medication, (3) the physical limitations imposed by the disease and, particularly, (4) the management of day to day problems such as pain control, nausea and disrupted dietary, elimination and sleeping habits. Many patients emphasized that more knowledge in these specific areas was important in maintaining a degree of self-care for as long as possible.

The issue of self-care was viewed as an important means of maintaining a sense of independence and control which, in turn contributed to an improved sense of emotional well-being. This type of information was also frequently mentioned as important to the primary care giver (usually a spouse, son, daughter or close friend), whom the patients sensed felt overwhelmed, anxious and inept at handling the responsibilities of caring for a cancer victim. Distress of the primary care giver was perceived to derive from both a deficiency of information and a lack of reassurance that they were doing all that was possible under the circumstances.

Another type of needed information, cited primarily by the young adults in the study, was related to new treatment advances. Many in this particular group, aged 20-45, felt that their physicians were too reluctant to discuss leading-edge therapies available in other parts of the world. As a result, many spent considerable time, energy and money searching on their own for new hopes and chances of cure. Although most understood physician skepticism about unproven or unconventional therapies, they nonetheless felt they had the right to make their own decisions and choices and even felt compelled to try any form of treatment regardless of its scientific status.

While no statistics are available on the use of nonconventional therapies, it is suspected that the practice may be relatively widespread. A total of 20 persons or 10% of those interviewed for this study admitted that they had, or were currently, using some nonconventional form of therapy. Ten of these had travelled to Mexico to obtain various drugs unavailable in most other parts of the world while the remaining ten said they had used other forms of treatment such as vitamin or herbal therapy, transcendental meditation and acupuncture. Given that most patients do not readily admit to the use of these therapies, it is suspected that the 10% cited here is a conservative estimate of actual use.

Similar to other research findings (for example, Dunkel-Schetter, 1984; Gardner and Wheeler, 1987), many of the subjects expressed disappointment in the failure of health care professionals to provide emotional support particularly in the form of understanding, empathy, reassurance and availability. While expectations of receiving this type of support were lower than for informational support, most felt it would be beneficial. Reasons cited for the general unavailability of emotional support were insensitivity and lack of time due to heavy work loads, or, reluctance of the patients themselves to burden health care professionals with problems other than those directly related to medical or physical aspects of the disease. Reluctance to raise personal problems stemmed from perceptions of health care professionals as hurried, distracted, distant, and disinterested, and the need of many patients to present themselves in the best possible light. For example, many felt that they didn't want physicians or nurses to know they were fearful or anxious or, in general, give the impression they were unable to handle their own personal problems.

Many of the subjects cited typical comments of health care professionals which made them reluctant to disclose their fears and concerns. These included, "Don't worry about it, you're doing very well, you look great, I'm very pleased with your progress, this is a common problem/complication and is to be expected given your condition." Judging from the conversations surrounding these types of comments, it would appear that the exposure of personal problems and fears evoked increased feelings of vulnerability, loss of control and failure.

Some evidence of the widespread emotional difficulties experienced by cancer patients along with the reluctance to expose these types of problems to doctors and nurses, was the large number who commented that psychological counseling would be helpful. When subjects were questioned about the utilization of various support programs and services, counseling from a psychologist was the most frequently mentioned needed service but only 9.5% (Table 23) had actually received this service. Further, patients clearly stated that, although they thought a psychologist would be helpful, they would not consider seeing a psychiatrist. Upon further questioning, the basis for this comment was not due to the perception that problems were of insufficient magnitude to warrant the help of a psychiatrist but, rather, the stigma or fear attached to being labelled "crazy".

Generally patients were found to be unaware of, and expressed surprise at, the actual number and variety of support services and programs available to cancer victims. Among those who were knowledgeable or had actually utilized services, some had very positive experiences while others expressed frustration with long waiting times, eligibility requirements and the coordination of various services. Obviously different patterns of service utilization were apparent for those who were hospitalized and/or in the palliative home care program and those who were not. Those who were hospitalized or in a home care program received far more services and experienced higher levels of satisfaction than those who were not. In many cases those who obviously could have benefited from various support programs simply lacked the knowledge, energy or, in some cases, the extra financial resources required to obtain them.

Informal Social Support

In this section, findings related to the major issues and concerns surrounding informal social support are discussed. Generally, it was found that patients more consistently and readily discussed issues related to formal support than informal support. It was also found, however, that informal support problems were perceived to be of greater intensity and impact.

Most of the concerns raised about informal social support centered on the phenomenon of strained or disrupted interpersonal relationships which were directly attributable to the cancer experience. Approximately 50% of the patients interviewed reported some degree of strain in their personal relationships particularly with close loved ones and, to a lesser degree, with friends. The most common reason cited for strained relationships with loved ones was the inability to discuss innermost fears and the issue of impending death. Some blamed themselves for strained relationships resulting from avoidance behaviors, uncertainty of others' reactions and the desire not to burden, upset or evoke feelings of pity in others. Others felt that relationships were strained due to the reactions and unsupportive behaviors of loved ones.

Behaviors cited as unsupportive and/or causing strained relationships were false cheerfulness, giving unsolicited advice, citing the positive experiences of other cancer patients, being overly emotional and avoiding contact. These same unsupportive behaviors were reported for friends; however, patients generally found that friends were most likely to avoid contact. Expectations of support from friends were unmet in many cases and as one patient said, "Having cancer certainly weeds out those who are only fair weather friends." Some patients also suggested that they, themselves, were partially responsible for strained or severed relationships with friends due to a lack of physical and emotional energy to divert to maintaining or improving social relationships and/or guilt feelings about their inability to reciprocate the help extended by friends.

These observations appear to support the emerging acknowledgment that the social interactions which form the basis of social support are not always free, benevolent or beneficial and, in some cases, result in more cost than benefit in terms of conflict, disappointment and unfulfilled expectations. Perhaps the most dramatic examples of failed interpersonal relationships and nonmaterialization of expected support were the incidents of physical and emotional abuse reported by the study subjects.

A total of nine patients openly admitted abusive situations and it was suspected in three additional cases. Four of the nine reported cases involved relatively young adults who lived at home in a blended family situation. In each case, the spouse of the natural parent was reported to be resentful of the burden and disruptions created by having to care for a cancer victim. This resentment was manifest primarily by emotional and, in one case, physical abuse. The remaining five cases involved older persons two of which were abused by an alcoholic spouse, and three by a son or daughter who had assumed primary responsibility for their care. The most severe case involved a female patient in her 70s who had been effectively isolated from all outside contacts by her daughter and left to die from starvation in squalid living conditions. Although most abused patients did not provide a detailed account of the history or dynamics of their interpersonal relationships with the abuser, it was suspected that, in most cases, cancer served to exacerbate already potentially problematic family situations.

Another group of patients who were highly distressed about the quality of family interpersonal relationships was young to middle-aged adults who had young children and adolescents living at home. Generally these patients expressed overwhelming feelings of helplessness in dealing with the tragedy of younger children watching a parent slowly die. In describing their childrens' reactions, a typical pattern of withdrawal and pulling away from the parent with cancer was observed. Although this behavioral pattern likely constitutes a defense or coping mechanism or even a form of bereavement that occurs with the anticipated death of a loved one, most patients viewed it as a personal failure. Acknowledgement of their own inability to deal with the situation led many to suggest the urgent need for professional counseling or support groups for this particular age group.

An interesting observation was the generally negative attitude toward self-help groups exhibited by the study participants and the fact that only 4% had actually utilized this type of support (Table 23). While self-help groups are founded on the assumption that exposure to others in a similar situation fulfills a need to learn more about, or clarify, the meaning and appropriateness of various personal reactions and behaviors through social comparison, most patients did not perceive them as appropriate for their particular needs or circumstances. Most felt that they could not discuss emotional feelings openly and freely with strangers other than professionals who were knowledgeable about their disease and expressed an interest in them as individuals.

Summary

In summary, it is concluded that the foregoing content assessment of the qualitative data obtained in the study has served to provide a somewhat different perspective of the nature and dynamics of social support within the context of advanced cancer. With respect to formal social support, the failure of health care professionals to consistently provide adequate and appropriate information was viewed as the major unfulfilled support expectation. Within their context of informal social support, while some patients had exceptionally sensitive families and friends with whom they could communicate openly without fear of rejection or avoidance, most experienced some communication barriers, strained interpersonal relationships and difficulties in receiving or accepting social support.

CHAPTER V

DISCUSSION

Overview of Chapter

In this chapter, findings relevant to the central research questions of the study are discussed. These include, (1) the nature of the relationships between formal and informal social support and the functional status and self-esteem of advanced cancer patients and (2) the circumstances under which these relationships vary. In addition, the theoretical and practical implications of the study findings are explored.

Discussion of Findings

In light of contradictory findings reported in the literature regarding the effects of social support on various aspects of individual well-being and a paucity of research on the effects of formal social support, the central purpose of this study was to examine the effects of both formal and informal social support on two analytically distinct aspects of advanced cancer patient well-being.

With respect to informal social support, the data support the predominant finding that social support is positively and significantly related to psychosocial aspects and, to a lesser degree, physical aspects of well-being. The findings also suggest, however, that the nature and strength of the relationship between informal support and well-being varies as a function of (1) the type of well-being outcome measure used, (2) the effects of various sociodemographic and contextual factors, (3) the aspect of social support measured and (4) the method of scoring social support measures. Each of these variations are discussed in the following paragraphs.

Findings from both the correlation and multiple regression analyses indicate that, consistent with other findings, informal support is more strongly related to psychosocial than physical aspects of well-being. The zero-order correlations between the individual informal support variables and functional status which is, in part, a physical status measure, ranged from .10 to .49 which is higher than the generally reported range of 0 to .25. The higher correlations found here are, in part, a function of the scoring method used. When a summative composite rather than an individual significant predictor item scoring method was used, the correlation between formal support and functional status was .22 which falls within the generally reported range. The zero-order correlations between the informal support items and self-esteem ranged from .20 to .49 which is only slightly higher than the range of .20 to .45 reported by other investigators (Funch et al., 1986). When the effects of informal support on functional status and self-esteem were examined using multiple regression analysis, it was found that the effects of informal support remained more significant in the prediction of self-esteem (a psychosocial measure of well-being) than functional status after controlling for various sociodemographic and contextual factors.

Overall, these data support the observation that reported variations in the effects of informal social support are, in part, a function of the type of outcome measure used. Explanations of the differential effects of social support on psychosocial and physical aspects of well-being derive from both methodological and theoretical observations.

From a methodological perspective, some investigators have noted that many studies which have reported higher correlations between social support and physical status have used physical status measures which include psychophysiological symptoms or somatic complaints which may overlap with psychological functioning producing an inflated estimate of the effects of support on physical status (Broadhead et al., 1983; Funch et al., 1986). However, since the physical status measure used here (that is, the physical functioning subscale of the FLIC) does not appear to be contaminated with these types of items, an alternate methodological explanation of variation in social support effects seems more plausible. It is suggested that, among ill populations, physical status is largely a function of the nature and severity of the illness. Since disease-related factors such as degree of physical limitation, amount of pain, chronicity, likelihood of recovery and threat to survival have been conclusively linked to physical status, they are likely to be the strongest predictors of physical status. Failure to account for these factors may, therefore, also result in overestimation of the effects of social support on physical status. Thus, reported variations in the association between social support and physical status, in particular, are likely a function of methodological weaknesses.

From a theoretical perspective, a possible reason for the observed differential effects of social support on psychosocial and physical aspects of well-being is that, unlike physical status, the link between social support and psychosocial status is strongly rooted in social support theory. Whereas it is the essential component of social support (that is, the presence of significant, emotionally supportive relationships) that is responsible for most of the documented relationships between social support and various indicators of psychological and social well-being, it is biological and physiological factors that largely determine physical aspects of well-being particularly in the case of documented, life-threatening disease.

Data from this study provide evidence that variations found in the effects of social support are not only a function of the type of outcome measure used but, also, of various sociodemographic and contextual factors which have not been systematically or comprehensively examined in previous research. Data from this study provide evidence that several of these factors have a significant effect on both functional status and self-esteem. For example, Table 35 showed that age and illness severity were significant factors in the explanation of the observed variance in functional status. However, [illegible] illness severity predicted lower levels of well-being, increased age was not associated with lower levels of well-being. Similarly, Table 36 showed that age, socioeconomic status and illness severity were significant factors in the explanation of self-esteem. In this case, while illness severity predicted less self-esteem increased age and socioeconomic status predicted more self-esteem. These findings underscore the importance of examining the effects of various sociodemographic and contextual factors in order to more accurately document the relative effects of informal support on various aspects of well-being. Failure to do so is likely to result in biased estimates of the relative effects of social support.

Data from this study provide some evidence to support the contention of other researchers that variations found in the social support--well-being relationship are also a function of the type of social support measure used. Evidence from this study suggests that the measurement of different aspects of social support such as availability, utilization and cognitive appraisal may result in differential effects on the various outcome measures. For example, within the context of informal support, the most significant predictors of functional status were items measuring support changes (2), support appraisal (1), support utilization (1) and support availability (1). Thus, it is concluded that various aspects of social support are important in the explanation of functional status but that measures of support change are likely to account for the greatest proportion of explained variance. On the other hand, the most significant informal support predictors of self-esteem were items measuring support appraisal (2), support changes (1), and support utilization (1) with the support appraisal items accounting for almost 73% of the total variance in self-esteem explained by the informal support items.

To date, little attention has been paid to variations in the social support--well-being relationship resulting from differences in the scoring methods for social support measures. Data from this study suggest that aggregated scoring methods may severely underestimate the predictive power of social support. Clearly it is important that researchers carefully examine the effects of alternate scoring methods for social support measures.

Turning to findings relative to the relationships between formal social support and the functional status and self-esteem of advanced cancer patients, a somewhat different pattern of results emerged. First, unlike informal support, several of the formal support variables were significantly but negatively related to both functional status and self-esteem (see Table 28). Second, while the effects of the informal support variables on functional status were largely nonsignificant, the effects of the formal support variables remained significant after controlling for the effects of several selected variables. However, in the case of self-esteem, the effects of formal support were significant as were the effects of informal support. The failure to find unconditional support for the hypothesis that individuals with higher levels of informal support will experience higher levels of functional status was unexpected since it is commonly assumed that higher levels of informal support effectively enhance most aspects of well-being. The finding of negative relationships among several of the formal support variables and functional status was also unexpected since it is commonly assumed that (1) since informal or natural social support enhances well-being, then support achieved through formal supportive interventions will have a similar positive effect and (2) since formal support interventions are purposefully designed to meet the unique support needs of specific populations, then those interventions will enhance well-being. Given the empirical evidence of this study and theoretical formulations of other researchers, it would appear that these commonly held assumptions cannot remain unchallenged.

There are several reasons why formal support may not parallel the positive effects of informal support. In a theoretical analysis of social support, Gottlieb (1983) has reasoned that natural (informal) support differs fundamentally from professional (formal) support by virtue of (1) its natural accessibility, (2) its congruence with local norms about when and how support ought to be expressed, (3) its rootedness in longstanding peer relationships, (4) its variability, ranging from the provision of tangible goods to simple companionship, and (5) its freedom from financial and psychological (stigmatizing) costs incurred when professional resources are used. Evidence that these features detract from, or suppress the effectiveness of formal support was provided by the qualitative data obtained in this study. Patients clearly indicated that formal support was not easily accessible, lacked expected substance and incurred costs in terms of emotional stress due to lack of information, communication barriers and environments nonconducive to the discussion of personal problems.

Other possible explanations for the negative effects of formal social support as observed in this study include (1) the fact that, overall, the subjects reported relatively low levels of support and, (2) the formal support measure may not have been sufficiently sensitive to detect differences in levels of support resulting in a lower bound estimate of the effects of support. In light of these theoretical and empirical explanations, the finding that several formal social support variables were negatively related to the functional status and self-esteem status of cancer patients should be interpreted cautiously. While there are both theoretical reasons and empirical evidence to support the finding that [illegible]s of formal support were negative, the same relationship between formal support and well-being may not be found among other distressed or ill populations or others living in different communities where the nature of formal support may be different.

It should also be noted that the illness itself will tend to mobilize the formal support system and as the severity of illness increases, mobilization also increases; hence the negative relationship between formal support and functional status. Supporting evidence of this interpretation is offered by Dunkel-Schetter (1984) who, in examining the relationship between social support and physical well-being, found that support was associated with physical condition among poor prognosis patients so as to indicate that the physical effects of advanced cancer may elicit support. It is also possible that levels of functional status may be even lower without formal support, however, the design of the study precludes the testing of this possibility.

An additive statistical model provided the best description of the association between formal and informal social support and the outcome measures used in this study. The finding that no interaction effects between formal and informal social support were operating in the explanation of functional status or self-esteem was somewhat unexpected. The expectation of interaction effects was based on the commonly held assumption that the primary purpose of formal supportive interventions is to enhance or sustain individual well-being by enhancing or supplementing the informal system in situations of inadequacy or absence. What was actually found was that the absence of both formal and informal support is problematic while the presence of both is most beneficial; more so than one would expect by simply adding up the separate effects of each. Why, then, were formal and informal support found to combine additively rather than interactively in the explanation of functional status and self-esteem?

While there are no other known studies available for a comparative analysis of the additive versus interactive effects of formal and informal support, findings from other studies which have examined the interactive effects of social support in general do provide some insights. From a, statistical perspective, several investigators including House (1981), Thoits (1982), and Turner (1983), have argued that failure to detect interaction effects may be a function of (1) small sample size, (2) cross-sectional study design, (3) weak or insignificant effect of social support on the outcome measure used or, (4) invalidity of the social support measure. Based on the evidence from this study, it is suggested that interaction effects were undetected primarily due to (1) the cross-sectional design, (2) the relatively low correlations among the formal and informal support variables resulting in independent rather than dependent effects on the outcome measures and (3) the observation that low levels of informal support did not bring forth increased levels of formal support or, in other words, both the levels and effects of formal support remained relatively constant despite variations in informal support levels.

The next section of the chapter will address findings relating to the question of whether the effects of social support on functional status and self-esteem aspects of well-being vary according to certain sociodemographic and contextual factors. The primary interest was in determining whether the effects of social support operated differently among subgroups represented by the various control variables selected for study.[1]

With respect to the functional status outcome measure, the finding that the effects of social support did not vary for any of the subgroups, with the exception of the married and nonmarried was somewhat unexpected (see Table 40). While the effects of social support on functional status would not necessarily be expected to vary according to factors such as gender, socioeconomic status, religious commitment, support need or even time since diagnosis, they might be expected to vary according to factors such as age and particularly severity of illness. Since severity of illness is generally found to be the strongest predictor of functional status among populations who are already ill, it was expected that the effects of social support on functional status would differ among the more and less severely ill. The finding that the effects of informal support on functional status varied according to marital status was not surprising since there is a large literature which supports the argument that being married enhances well-being. This is likely due to the fact that married

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[1] These findings are based on the analysis of interaction terms which demonstrate only that the effects of support and/or the control variable are conditional on each other. They do not indicate the precise nature of the conditional relationship.

persons generally receive higher levels of support due to increased availability, utilization and more favorable appraisal of the amount and appropriateness of support all of which may enhance the effects of informal support on functional status.

The effects of informal support on self-esteem were also found to vary among the married and nonmarried. Mean levels of self-esteem were found to be higher among the married than the nonmarried subgroup for both high and low levels of informal support. A possible explanation is that, since one of the important observed functions of social support is self-identity maintenance and enhancement and, support exchanges serve to validate a person's sense of own value and adequacy (self-esteem) then, it would follow that married and nonmarried persons are likely to vary in terms of available resources and exchanges relevant to the enhancement of self-esteem. For example, married persons are more likely to have access to supportive resources relevant to the enhancement of self-esteem such as affirmation of worth, approval, praise and expression of respect for the recipient.

The finding that the effects of formal support on functional status and self-esteem did not vary among any of the subgroups studied was somewhat unexpected since, as was the case with informal support, variations were expected particularly among the more and less severely ill. However, since the sample was comprised of advanced cancer patients it is possible that interaction effects were undetected due to the failure of the illness severity measure to detect sufficient variability. It is also possible that the fact of death as the inevitable outcome for all of these terminally ill individuals, served as a homogenizing or overriding factor which suppressed the detection of variations among the various subgroups studied.

Evidence of variations in the effects of social support on different outcome measures as well as variations in the effects of support among different subgroups was [illegible] by examining two additional outcome measures--the physical functioning and psychosocial functioning subscales of the FLIC. No significant interaction effects between the formal or informal support variables and the control variables were found for physical functioning. However, interaction effects not previously detected were found when psychosocial functioning was used as the dependent variable measure. As was previously noted, these particular interaction effects were not further examined since they were comparatively few in number (3 out of a possible 126) and, therefore, may have occurred by chance. Also, the amount of additional variance explained in the outcome measures by the interaction terms was relatively small (3% or less).

Summary and Implications

In summary, the study data provided evidence, which is supportive of the predominant finding in the literature that informal social support has a significant influence on the self-esteem but little effect on the functional status of advanced cancer patients. Evidence also suggested that the relative effects of informal support vary as a function of (1) the type of well-being outcome measure used, (2) controlling for the effects of factors such as gender, marital status, support need and severity of illness, (3) the aspects of social support measured and (4) the scoring method for the support measure. Further, there was some evidence of variation in the effects of informal support on functional status and self-esteem among married and nonmarried subgroups in the population.

The examination of formal social support provided evidence that this type of support differs somewhat from informal social support in terms of its nature and effects on cancer patient well-being. Unlike informal support, some aspects of formal support were found to be negatively related to the functional status and self-esteem of the cancer patients studied. It was also found that these outcome measures were significantly affected by other factors, particularly, the patient's level of illness severity. Although no variations in the effects of formal support on functional status or self-esteem were detected among the subgroups studied, it was found that the effects of formal support on psychosocial functional status varied according to gender.

The effects of formal and informal support on the outcome measures were found to vary according to the measurement of different aspects of social support. Several aspects of support including utilization, appraisal and support changes were found to be significant predictors of functional status. Formal and informal support appraisal items were found to be the strongest predictors of self-esteem followed by support utilization in the case of formal support and by support changes in the case of informal support.

While there is considerable confidence in the validity of the findings of the study, it should also be noted that, due to certain inherent limitations, the findings should be interpreted cautiously. First, since some of the total variance observed in functional status and self-esteem, remained unaccounted for by the independent variables, there are obviously other unmeasured factors influencing the outcome measures. It is suggested that, foremost among these factors, are those relating to personality characteristics of the subjects which have been previously discussed in terms of their potential influence on both social support and well-being (see page 72). A further, closely related, limitation is that only two outcome measures of well-being were examined. Clearly, the relative effects of social support vary as a function of the type of outcome measure used. Therefore, findings of the effects of social support, as reported here, may vary according to other measures of well-being.

Third, the cross-sectional design of the study prohibits any conclusion of the direction of causality. However, while there is no single study which persuasively documents causal direction, the total body of available evidence suggests that much of the causal flow is between social support and well-being rather than vice versa (House, 1981:51). It might be argued, however, that this particular direction of causality is most likely when psychosocial rather than physical measures of well-being are examined. Data from this study suggest that, in the case of the formal support--functional status relationship, the direction of causality may be reversed since the illness mobilizes formal support.

A final limitation of the study is the relatively unproven reliability and validity of the social support measures used. Since the measures were specifically developed to assess the support levels of a specific population, it is unknown whether the reliability and validity estimates reported here would remain constant for other populations.

To conclude this chapter, some of the important theoretical, as well as practical, implications of the study findings are explored. First, from a theoretical perspective, the findings further enhance the observation that social support is a multidimensional, conditional and changing phenomenon which, despite many years of relatively intense study, still requires further theoretical elaboration and methodological refinement. The focus of this discussion will, therefore, be on issues requiring further clarification and suggested directions of future research.

While there is general theoretical consensus and supporting empirical evidence that social support is a significant factor in maintaining health and reducing the consequences of illness, there are still many unanswered critical questions about social support. For example, it is not conclusively known (1) what the essential or potent ingredients of social support are, (2) why it is differentially effective (3) under what circumstances effectiveness is likely to vary or (4) how it should be structured to obtain optimal effectiveness. The findings of this study have provided tentative answers to some of these questions, however, more basic research is required for further clarification. More specifically, it is suggested that future research should focus on the following:

1. The development of standardized measures of social support with well-defined psychometric properties and which simultaneously measure both structural and

perceptual aspects of support is critically needed not only to facilitate integration of research findings but also more adequately document the relationships between specific types of support and specific aspects of well-being.

It is increasingly advocated that measures of social support should include negative aspects of support in order to account for observed anomalies in support effects and, particularly, the apparent paradox that close social ties are both sources of support and stress (Tilden and Galyen, 1987). The traditional emphasis on the positive aspects of social support has, [illegible] part, contributed to the failure to adequately document the conditions under which social support effectiveness is enhanced or suppressed. Consideration of the negative aspects of social support is expected to gain importance in future research in light of recent evidence that problematic aspects of support have more potent effects on well-being than positive aspects (Rook and Dooley, 1985). Although negative aspects of social support were not explicitly measured in this study, the qualitative analysis provided evidence that cancer patients experience costs and conflicts within their support systems. An interesting and fruitful area of future research would be an examination of the relative impact of positive and negative aspects of social support on individual well-being. An equally important area of future research would be identification of the negative aspects of social support among various ill as well as well populations. For example, to what extent do strained and disrupted relationships occur among other ill populations or is this phenomenon cancer-specific or exacerbated by life threatening illnesses?

The elaboration of present research models is required to further clarify the circumstances under which support levels and effects are expected to vary. Specifically, models should account for the influence of various demographic, personal and environmental factors which have been implicated for their effects on both social support and well-being. The relative as well as combined effects of these factors are largely unknown and may serve to clarify conflicting evidence of the positive, negative and null effects of social support.

Clearly the dearth of studies on formal support necessitates the need for more research in this area. The findings of this study suggest that, while formal support has a significant effect on the well-being of cancer patients, that effect may not necessarily be positive. While this finding may challenge some of the major underlying assumptions of the nature and effects of formal support, it should also be noted that more research regarding the absence of formal support is needed since, without any formal support, levels of well-being may be affected even more negatively.

The final section of this chapter will focus on the practical implications of the study findings. At the outset of this discussion, it is suggested that while formal support interventions have considerable potential to enhance the well-being of the ill, two underlying, inherent problems should be acknowledged. The first, which is not unique to social support, is the problem of integrating the analytical and applied research traditions. Formal supportive interventions have often proceeded without the benefit of adequate scientific-based knowledge. In their efforts to enhance well-being and alleviate human suffering, health care professionals may have been too willing in their uncritical acceptance of social support as the new panacea for improving human well-being. In addition, they may have underestimated the complexity of social support by viewing it as a natural extension of the type of help provided by service professionals.

The second major underlying problem, which follows from the first, relates to the essentially unchallenged assumptions surrounding formal supportive interventions as well as the, perhaps, unrealistic expectations of the benefits of these interventions. The fact that formal support is fundamentally different from informal support in that it does not occur spontaneously and is essentially artificial support grafted on to natural support, significantly increases the probability of ineffectiveness or negative effect.

Further, there is also the critical question of how much natural support systems can be altered or supplemented by formal or professional intervention. Individuals, themselves, must be willing to accept the need for change as well as help ~~from~~ outsiders. However, it may not be possible to easily reshape the beliefs and values necessary to achieve these changes. A final word about supportive interventions in general, is that they are often shaped by social and political forces rather than scientific research making modifications and changes difficult.

Keeping the caveats imposed by the above mentioned problems in mind, some specific suggestions regarding supportive interventions within the context of the cancer experience are made. First, since the positive and significant effects of informal social support on individual well-being are well documented, the primary focus of formal interventions should be to enhance or supplement rather than supplant the natural helping system. The patients in this study clearly indicated they could not only identify specific areas where ~~professional~~ intervention was required but also a general willingness to accept help if professionals expressed an interest in them as individuals and demonstrated some degree of sensitivity to their problems and needs. Therefore, it is suggested that professionals use their advantageous position of having a captive audience to more carefully assess the support needs of their clients.

A second recommendation derived from the findings of this and other studies is that professionals should more consistently provide informational support. This is the type of support desired most but received the least. It is also likely the easiest and most cost effective type of supportive intervention to administer. The wide variations observed in the amount and type of information provided by individual professionals might best be addressed by developing standard, comprehensive information pamphlets specifically for advanced cancer patients. This may help to ensure that giving adequate and appropriate information is not conditional but, rather, a matter of standard procedure.

Of particular interest was the findings that the cancer patients studied lacked knowledge and were generally unaware of most of the support services and programs presumed to be available to cancer patients. This suggests that, although a sufficient number and variety of support services may be in place, they are generally unknown and are, therefore, probably not reaching those who need them most. Clearly the availability of these programs must be made more widely known for optimal utilization. A related finding of interest was that those services most widely used were also perceived as least helpful. For example, patients fairly routinely received dietary counseling but reported receiving little benefit from it. This may be a function of the often inherent problems associated with cancer such as lack of appetite, nausea and digestive upset, or, it may be a function of the type of information given and, possibly, the attitude that dietary concerns are of little relevance among the dying. Another frequently provided but not necessarily appreciated or helpful service was pastoral care. Many patients resented the imposition of this type of support and expressed the desire to make their own choices about certain services.

Overall, the patients in this study reported generally low levels of formal support resulting from a combination of lack of essential information to assist them in managing the physical and emotional aspects of their disease and underutilization of support services due to lack of knowledge. The general impression was that supportive interventions were lacking in certain basic forms (information) and coordination.

Certainly there is considerable potential for formal support systems to enhance various aspects of individual well-being. However, it is time to critically evaluate these systems and to challenge certain underlying assumptions that presently provide the rationale for the basis and purposes of formal support if optimal effectiveness is to be achieved.

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APPENDIX 1

SOCIAL SUPPORT QUESTIONNAIRE

PART I - BACKGROUND INFORMATION

A. Sex

1) ______ Male
2) ______ Female

B. Age

______ Years

C. Marital Status

1) ______ Married
2) ______ Divorced/Separated
3) ______ Single, (Never Married)
4) ______ Widowed
5) ______ Common Law/Living Together

D. Years of School Completed

______ Years

E. Present Annual Household Income

1) ______ Under 12,000
2) ______ 12 - 21,999
3) ______ 22 - 31,999
4) ______ 32 - 41,999
5) ______ 42,000 or more
6) ______ Refused
7) ______ DK

F. Occupation ___________
(when employed)

If housewife, what is husband's occupation?

____

G. With what type of cancer were you first diagnosed and when?

Type____________________ When? Month_________ Year__________

H. What is your ethnic origin or origins?____________________

I. To which religious group, if any, do you belong? _________

____

Some people find religion to be a source of help or comfort particularly during difficult times. The next few questions are to determine the extent to which religion is a source of support to you personally.

J. Do you believe in the existence of a supreme being?

Yes _____ No _____ Not Sure _____

K. Do you believe in a form of life after death?

Yes _____ No _____ Not Sure _____

L. If you believe in God, how close do you feel to Him most of the time?

Extremely Close _____ Somewhat Close _____ Not Very Close _____ Not Close At All _____

M. About how often do you pray?

Very Often _____ Sometimes _____ Rarely _____ Never _____

N. About how often do you usually have contact with a clergyman?

Frequently _____ Sometimes _____ Never _____

O. How important is religion in helping you to deal with your illness?

Very Important _____ Somewhat Important _____ Not Important _____

P. Race (Observed) ____________________

Q. Over the past two weeks, how much pain have you experienced?

A Great Deal _____ A Moderate Amount _____ Very Little _____ None _____

R. Over the past two weeks how frequently have you taken pain medication?

Daily _____ Frequently _____ Occasionally _____ Never _____

S. At the present time would you say you are able to manage your daily personal care (that is bathing, dressing, toileting, eating)

Unassisted___ With Minimal Assistance___ With Moderate Assistance___ With a Great Deal of Assistance___

T. At the present time, how much of the day are you confined to bed?

All Day _______ Most of the Day _____ Part of the Day _____ Very Little or None of the Day ______

U. People differ in their willingness to seek out and use help or support from others when they have problems. On a scale from one to seven, how likely are you, in general, to seek out and use the support available to you from family and friends when you have a personal problem?

1 2 3 4 5 6 7

Very Unlikely Very Likely

V. Using the same scale from one to seven, in general how likely are you to seek out and use help from the health care system when you have a medical problem?

1 2 3 4 5 6 7

Very Unlikely Very Likely

APPENDIX 2

942 Rice Road
Edmonton, Alberta
T6R 1A1
Phone: 430-6128

November 18, 1986

Dear

I am writing to inform you of a research study I am conducting on advanced cancer patients and to appeal for your help in identifying eligible subjects who might be approached for participation. The purpose of the study which is being conducted for my doctoral thesis, is to determine whether the formal (health care) and informal (family and friends) support levels of cancer patients has any relationship to their level of well-being. The rationale for the study derives from 1) the fact that findings in this area of study are extremely contradictory and 2) a paucity of research on the effects of formal support despite the fact that formal support services have assumed a major role in cancer care.

Originally I had intended to obtain lists of eligible subjects from the medical records of appropriate institutions such as the Royal Alex Hospital and the Cross Cancer Institute. Although the Ethics Review Committees have approved the study, I have been advised that due to legal implications, a list of names cannot be obtained from this source. It has been suggested therefore, that the only alternative is to ask individual physicians to contribute to a list of potentially eligible respondents.

For the purposes of the study, eligible respondents are defined as:

1. adults with advanced cancer (locally advanced or metastatic disease and being treated for palliative versus curative purposes.
2. having any type of cancer with the exception of sex-specific types (breast, ovary, uterus, prostate) and brain tumours which have resulted in mental impairment (disorientation, decreased alertness, etc.).
3. white, English-speaking and residing in Edmonton.

A total of 200 patients will be interviewed once using a structured questionnaire. The types of questions asked, the extent of participation and patient rights are outlined in the Patient Information Form enclosed. In addition, each participant will sign an approved consent form.

I regret this imposition but find I have no alternative for obtaining a list of subjects which is, of course, critical to the study. Your assistance is most sincerely appreciated and if you have further questions or concerns, please contact me. Please be assured that all subjects will be approached and interviewed with utmost sensitivity. If you have even one eligible subject please contact me by telephone or, if you prefer, a list of names and telephone numbers could be mailed to me.

Thank you for your cooperation.

Sincerely,

Loretta Hallgren

APPENDIX 3

PATIENT CONSENT FORM

This is to indicate that I have agreed to participate in a study conducted by Loretta Hallgren who is a Doctoral Candidate in the Faculties of Sociology and Health Services Administration at the University of Alberta. I have been informed of the nature of the study and it is my understanding that:

1) The purpose of the study is to determine whether the help received by cancer patients from family, friends and health care workers has any effect on their physical and emotional well-being.

2) An interviewer will ask me a series of questions relating to a) background information, b) the support or help I receive from family, friends and health care workers and c) my present state of physical and emotional health.

3) My participation in the study is voluntary and I have the right to a) refuse participation, b) terminate the interview at any time and c) refuse to answer any questions considered to be too personal without any consequences.

4) Any information I give will be strictly confidential and anonymous.

5) I may contact Mrs. Hallgren at 430-6128 if I have any questions or concerns related to the study.

Signature ______________________

Witness ______________________

Date ______________________

APPENDIX 4

PATIENT INFORMATION FORM

Dear Patient,

I would like to invite you to participate in a research study which attempts to determine how the support or help you receive from family, friends and health care workers affects your physical and emotional health. The results of the study will be used to help health care givers better understand how they might maximize the benefits of support systems to assist cancer patients to cope more effectively with their illness.

If you agree to participate in the study, an interviewer will ask you questions related to:

1) your background which includes questions such as your age, education, occupation, religion, etc.

2) the number and type of persons who are available to provide you with help and an appraisal of the amount and type of help you receive, and;

3) your present state of physical and emotional health.

The extent of your participation will be one interview which takes approximately 20 minutes. You have the right to refuse to participate, to terminate the interview at any time and to refuse to answer any questions you feel are inappropriate. Although I cannot assure you of any direct benefit from your participation, it is hoped that the information you provide will help to improve cancer patient care in the future. Any information you give will be confidential and your name will not appear on any document related to this study. If you have any questions or concerns regarding the study please feel free to contact Loretta Hallgren, the director of the study at 430-6128. Your valuable assistance as a study participant would sincerely be appreciated.

Thank You.

APPENDIX 5

FUNCTIONAL LIVING INDEX - CANCER

On a scale of one to seven, how would you rate each of the following:

INTERVIEWER: Define meaning of one and seven for each item

1. How well would you say you look today?

1 2 3 4 5 6 7

Extremely Poor — **Extremely Well**

2. Rate your satisfaction with the treatment you are currently receiving.

1 2 3 4 5 6 7

Very Unsatisfied — **Very Satisfied**

3. How much of your pain or discomfort over the past 2 weeks was related to your cancer?

1 2 3 4 5 6 7

None — **All**

4 Rate how willing you were to see and spend time with friends, in the past 2 weeks.

1 2 3 4 5 6 7

Unwilling — **Very Willing**

5. Rate the degree to which you are frightened of the future.

1 2 3 4 5 6 7

Constantly Terrified — **Not Afraid**

6. How much nausea have you had in the past [illegible] weeks.

1	2	3	4	5	6	7
None						A Great Deal

7. Rate how willing you were to see and spend time with those closest to you, in the past 2 weeks.

1	2	3	4	5	6	7
Unwilling						Very Willing

8. How much of your usual household tasks are you able to complete?

1	2	3	4	5	6	7
All						None

9. Rate the degree to which your cancer has imposed a hardship on you (personally) in the past 2 weeks.

1	2	3	4	5	6	7
Tremendous Hardship						No Hardship

10. How much is pain or discomfort interfering with your daily activities?

1	2	3	4	5	6	7
Not At All						A Great Deal

11. Rate in your opinion, how disruptive your cancer has been to those closest to you in the past 2 weeks.

1	2	3	4	5	6	7
Totally Disruptive						Not Disruptive

12. How uncomfortable do you feel today?

1	2	3	4	5	6	7
No Discomfort						A Great Deal of Discomfort

13. Rate your satisfaction with your work and your jobs around the house in the past month.

1	2	3	4	5	6	7
Not At All Satisfied						Very Satisfied

14. Rate how often you feel discouraged about your life.

1	2	3	4	5	6	7
Always						Never

15. Rate the degree to which your cancer has imposed a hardship on those closest to you in the past 2 weeks.

1	2	3	4	5	6	7
No Hardship						Tremendous Hardship

16. Do you feel well enough to make a meal or do minor household repairs today?

1	2	3	4	5	6	7
Very Able						Not Able

17. How well do you feel today?

1	2	3	4	5	6	7
Not At All Well						Extremely Well

18. Has nausea affected your daily functioning?

1 2 3 4 5 6 7

Not At All **A Great Deal**

19. Rate your ability to maintain your usual recreation or leisure activities.

1 2 3 4 5 6 7

Able **Unable**

20. How much time do you spend thinking about your illness?

1 2 3 4 5 6 7

Constantly **Never**

21. How well are you coping with your everyday stress?

1 2 3 4 5 6 7

Not Well **Very Well**

22. How often do you feel depressed?

1 2 3 4 5 6 7

Never **Continually**

APPENDIX 6

SELF-ESTEEM SCALE

For each statement below, place a check in the column that best describes your feeling or opinion.	Strongly Agree 1	Agree 2	Disagree 3	Strongly Disagree 4
1. On the whole, I am satisfied with myself.	____	____	____	____
2. At times I think I am no good at all.	____	____	____	____
3. I feel that I have a number of good qualities.	____	____	____	____
4. I am able to do things as well as most other people.	____	____	____	____
5. I feel I do not have much to be proud of.	____	____	____	____
6. I certainly feel useless at times.	____	____	____	____
7. I feel that I am a person of worth, at least on an equal basis with others.	____	____	____	____
8. I wish I could have more respect for myself.	____	____	____	____
9. All in all, I am inclined to feel that I am a failure.	____	____	____	____
10. I take a positive attitude toward myself.	____	____	____	____

APPENDIX 7

PART II - SOCIAL SUPPORT QUESTIONNAIRE

A. FORMAL SOCIAL SUPPORT INDEX

1. Do you have a particular person in the health care system such as a doctor, nurse, psychologist or volunteer worker whom you feel you can count on to help you when you are experiencing problems?

Yes ____ [illegible]
No ____ 1

2. Given your present state of health, how frequently would you say you rely on this person for help with problems you are experiencing?

Constantly ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1

3. How many contacts have you had with this person over the past two weeks?

Number ____ (1-4)
Not Applicable ____ 0

4. How many other persons in the health care system would you say you rely on for help at the present time?

Number ____ (1-4)

5. How frequently do you rely on these persons for help?

Constantly ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1
Not Applicable ____ 0

6. How many contacts have you had with these persons over the past two weeks?

Number ____ (1-4)
Not Applicable ____ 0

7. Overall, how often would you say that the help provided by persons in the health care system is enough for your particular needs?

Always ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1

8. How often would you say that the help you receive is appropriate for the particular problems you are experiencing?

Always ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1

9. Following is a list of services which some cancer patients have used. Please indicate which of these services you have recently (within the past month), or are currently using and if they have been helpful.

Service	A Used Yes	A Used No	B Helpful Yes	B Helpful No
1. Edmonton Home Care Program				
2. Aides to Daily Living				
3. Homemaker Services				
4. Meals-On-Wheels				
5. Self-Help or Mutual Aid Groups				
6. Visits from a Trained Volunteer				
7. Counselling from a Dietician				
8. Clergyman or Pastoral Care Worker				
9. Psychiatrist, Psychologist or Mental Health Nurse				
10. Nurse or Social Worker				
11. Legal or Financial Counsellor				
12. Relaxation or Stress Management Program				
13. Pain Control Program				
14. Others Not Listed a.				
b.				
c.				

APPENDIX 8

B. INFORMAL SOCIAL SUPPORT INDEX

Score

1. Do you have a spouse or one particular person whom you feel you can count on for help when you need it?

Yes	____	4
No	____	1

If answer to number 1 is yes,

2. How frequently would you say you rely on this person for emotional or practical help with problems you are experiencing?

Constantly	____	4
Frequently	____	3
Sometimes	____	2
Rarely	____	1
Not Applicable	____	0

3. How many other persons such as family members, friends or neighbors would you say you can rely on for help when you need it?

Number ____ (1-4)

4. How frequently do you rely on these persons for help with problems?

Constantly	____	4
Frequently	____	3
Sometimes	____	2
Rarely	____	1
Not Applicable	____	0

5. How many of the following relatives reside in the Edmonton area at the present time?

Spouse	Yes ____ (1)	No ____	(0)
Parents	Number	____	(0-2)
Children	Number	____	(0-2)
Brother/Sisters	Number	____	(0-2)
In-Laws (Mother, Father, Son, Daughter)	Number	____	(0-2)
Grandchildren	Number	____	(0-2)
Others such as aunts, uncles or cousins to whom you feel particularly close.	Number	____	(0-2)

6. Is the number of relatives living in the Edmonton area now more, less or about the same as before your illness?
More______(4)
Less______(1)
Same______(2.5)

7. How many visits from family members have you had over the past two weeks?
Number____(1-4)

8. Would you say you see your family more, less or about the same amount now as compared to before your illness?
More______(4)
Less______(1)
Same______(2.5)

9. How many good close friends do you have living in the Edmonton area at the present time?
Number ____(1-4)

10. Would you say you have more, less or about the same number of close friends living here now as compared to before your illness?
More______(4)
Less______(1)
Same______(2.5)

11. How many visits have you had from close friends over the past two weeks?
Number ____(1-4)

12. How many telephone calls have you had from friends over the past two weeks?
Number ____(1-4)

13. Would you say you see close friends more, less or about the same as before your illness?
More______(4)
Less______(1)
Same______(2.5)

14. Overall, how often would you say you receive enough help from you spouse, family members, friends and neighbors?
Always ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1

15. How often would you say the help received from these persons is appropriate for the type of problem you are experiencing?
Always ____ 4
Frequently ____ 3
Sometimes ____ 2
Rarely ____ 1

APPENDIX 9

CODE BOOK FOR ALL DATA

Columns	Variable	Description
Card 1		
1-3	V01	Subject I.D. Number
4	V02	Sex Male - 0 Female - 1
5, 6	V03	Age (Years) Not Reported - 99
7	V04	Marital Status Married - 1 Divorced/Separated - 2 Single (Never Married) - 3 Widowed - 4 Common Law (Living Together) - 5 Not Reported - 9 (2-5 recoded as 0 [dummy variable] for regression analysis)
8, 9	V05	Years of School Completed Not Reported - 99
10	V06	Present Annual Household Income Under 12,000 - 1 12 - 21,999 - 2 22 - 31,999 - 3 32 - 41,999 - 4 42,000 or more - 5 Refused - 9 Don't Know - 8
11	V07	Occupation Unskilled - 1 Semi-skilled - 2 Skilled Crafts, Trades - 3 Middle Management, Skilled Clerical, Sales, Service - 4 Semi-Professionals, Technicians - 5 Employed Professionals - 6 Self-employed Professionals - 7 Not Reported - 9

Columns	Variable	Description
12, 13	V08	Cancer Type Buccal Cavity, Pharynx - 01 Oesophagus - 02 Stomach - 03 Intestine - 04 Rectum - 05 Pancreas - 06 Gallbladder - 07 Larynx - 08 Trachea, Bronchus, Lung - 09 Melanoma - 10 Bladder - 11 Kidney - 12 Hodgkins - 13 Non-Hodgkins Lymphoma - 14 Multiple Myeloma - 15 Primary Site Unknown - 16 Liver - 17 Leukemia - 18 Bone, Connective Tissue - 19 Not Reported - 99
14, 15	V09	Month of Diagnosis January - 01 February - 02 March - 03 April - 04 May - 05 June - 06 July - 07 August - 08 September - 09 October - 10 November - 11 December - 12 Not Reported - 99
16, 17	V10	Year of Diagnosis Not Reported - 99

Columns	Variable	Description
18, 19	V11A	Ethnic Origin (1st) English - 01 Irish - 02 Scottish - 03 German - 04 Ukranian - 05 Polish - 06 Dutch - 07 Welsh - 08 Scandinavian - 09 Canadian - 10 Italian - 11 French - 12 Austrian - 13 Jewish - 14 Romanian - 15 Russian - 16 Not Reported - 99
20, 21	V11B	Second Reported Ethnic Origin Code Same as V11A
22	V12	Religion None - 0 Protestant - 1 Catholic - 2 Anglican - 3 Baptist - 4 Lutheran - 5 Presbyterian - 6 Jewish - 7 United - 8 Not Reported - 9
23	V13	Do you believe in the existence of a supreme being? Yes - 2 No - 0 Not Sure - 1 Not Reported - 9

Columns	Variable	Description
24	V14	Do you believe in a form of life after death? Yes - 2 No - 0 Not Sure - 1 Not Reported - 9
25	V15	If you believe in God, how close do you feel to him most of the time? Extremely Close - 3 Somewhat Close - 2 Not Very Close - 1 Not Close At All - 0 Not Applicable - 7 Not Reported - 9
26	V16	About how often do you pray? Very Often - 3 Sometimes - 2 Rarely - 1 Never - 0 Not Reported - 9
27	V17	About how often do you usually have contact with a clergyman? Frequently - 2 Sometimes - 1 Never - 0 Not Reported - 9
28	V18	How important is religion in helping you to deal with your illness? Very Important - 2 Somewhat Important - 1 Not Important - 0 Not Reported - 9
29	V19	Race (observed) White - 0 Other - 1

Columns	Variable	Description
30	V20	Over the past two week how much pain have you experienced? A Great Deal - 3 A Moderate Amount - 2 Very Little - 1 None - 0 Not Reported - 9
31	V21	Over the past two weeks how frequently have you taken pain medication? Daily - 3 Frequently - 2 Occasionally - 1 Never - 0 Not Reported - 9
32	V22	At the present time would you say you are able to manage your daily personal care Unassisted - 0 With Minimal Assistance - 1 With a Great Deal of Assistance - 2 With a Great Deal of Assistance - 3 Not Reported - 9
33	V23	At the present time, how much of the day are you confined to bed? All Day - 3 Most of the Day - 2 Part of the Day - 1 None of the Day - 0 Not Reported - 9
34	V24	On a scale from 1-7 how likely are you in general, to seek out and use the support available to you from family and friends when you have a personal problem? 1 2 3 4 5 6 7 Very Unlikely V[illegible]ely Not Reported - [illegible]

Columns	Variable	Description
35	V25	In general how likely are you to seek out and use help from the health care system when you have a medical problem? 1 2 3 4 5 6 7 Very Unlikely Very Likely Not Reported - 9

Formal Social Support Index

Columns	Variable	Description
36	V26	1. Do you have a particular person in the health care system such as a doctor, nurse, psychologist or volunteer worker whom you feel you can count on to help you when you are experiencing problems? Yes - 4 No - 1 Not Reported - 9
37	V27	2. (If yes to V26) Given your present state of health, how frequently would you say you rely on this person for help with problems you are experiencing? Constantly - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Applicable - 0 Not Reported - 9
38 & 39	V28	3. (If yes to V26) How many contacts have you had with this person over the past two weeks? Actual Number 0 or 1 - 1 (Recoded) 2 or 3 - 2 4 or 5 - 3 6 or more - 4 Not Applicable - 00 Not Reported - 99
40 - 41	V29	4. How many other persons in the health care system would you say you rely on for help at the present time? Actual Number 0 or 1 - 1 2 or 3 - 2 4 or 5 - 3 6 or more - 4 Not Reported - 99

Columns	Variable	Description
42	V30	5. (If response to V29 is NOT 0) How frequently do you rely on these persons for help? Code same as V27.
43 - 44	V31	6. (If response to V29 is NOT 0) How many contacts have you had with these persons over the past two weeks? Code same as V28.
45	V32	7. Overall, how often would you say that the help provided by persons in the health care system is enough for your particular needs? Always - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Reported - 9
46	V33	8. How often would you say that the help you receive is appropriate for the particular problems you are experiencing? Code same as V32.
47	V34A	Services Utilized and If Helpful Home Care Program (Used) Yes - 1 No - 0 Not Reported - 9
48	V34B	Helpful Yes - 1 No - 0 Not Applicable (If V34A is 0) - 7 Not Reported - 9
49	V35A	Aides to Daily Living
50	V35B	Code same as V34A & V34B
51	V36A	Homemaker Services
52	V36B	Code same as V34A & B

Columns	Variable	Description
53	V37A	Meals-On-Wheels
54	V37B	Code same as V34A & B
55	V38A	Self-Help or Mutual Aid Groups
56	V38B	Code same as V34A & B
57	V39A	Visits From A Trained Volunteer
58	V39B	Code same as V34A & B
59	V40A	Nutritional Counselling
60	V40B	Code same as V34A & B
61	V41A	Clergy or Pastoral Care Worker Counselling
62	V41B	Code same as V34A & B
63	V42A	Psychiatrist, Psychologist or Mental Health
64	V42B	Nurse Counselling
65	V43A	Nurse or Social Worker
66	V43B	Code Same as V34A & B
67	V44A	Legal or Financial Counselling
68	V44B	Code Same as V34A & B
69	V45A	Relaxation or Stress Management Program
70	V45B	Code same as V34A & B
71	V46A	Pain Control Program
72	V46B	Code same as V34A & B
		Others Not Listed
73	V47A	Number Used: 0 - 0 1 or more - 1
74	V47B	Number Helpful: 0 - 0 1 or more - 1
75	V47C	Number Not Helpful: 0 - 1 1 or more - 0
		Not Applicable (If V47A is 0) V47B and V47C are coded 7

Informal Social Support Index

Columns	Variable	Description
76	V48	1. Do you have a spouse or one particular person whom you feel you can count on for help when you need it? Yes - 4 No - 1 Not Reported - 9
77	V49	2. (If V48 is yes) How frequently would you say you rely on this person for practical or emotional help with problems you are experiencing? Constantly - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Applicable - 0 Not Reported - 9
78 & 79	V50	3. How many other persons such as family members, friends or neighbors would you say you can rely on for help when you need it? Actual Number 0 or 1 - 1 (Recoded) 2 or 3 - 2 4 or 5 - 3 6 or more - 4 Not Reported - 99
80	V51	4. (If response to V50 is not 0) How frequently do you rely on these persons for help? Constantly - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Applicable - 0 Not Reported - 9

Columns	Variable	Description
Card 2		
		5. How many of the following relatives reside in the Edmonton area at the present time.
1	V52A	Spouse - Yes 1 No 0
2	V52B	Parents 0 - 0 1 - 1 2 - 2
3, 4	V52C	Children 0 - 0 1 - 1 2 or more - 2
5, 6	V52D	Brother/Sisters Code same as V52C
7, 8	V52E	In-laws Code same as V52C
9, 10	V52F	GrandChildren Code same as V52C
11, 12	V52G	Others Code same as V52C Not Reported - 99
13, 14	V53	6. Is the number of relatives living in the Edmonton area now more, less or the same as before your illness? More - 40 Less - 10 Same - 25 Not Reported - 99
15, 16	V54	7. How many visits from family members have you had over the past two weeks? Code same as V50
17, 18	V55	8. Would you say you see your family more, less or about the same amount now as compared to before your illness? More - 40 Less - 10 Same - 25 Not Reported - 99

Columns	Variable	Description
19, 20	V56	9. How many good close friends do you have living in the Edmonton area at the present time? Code same as V50
21, 22	V57	10. Would you say you have more, less or about the same number of close friends living here now as compared to before your illness? More - 40 Less - 10 Same - 25 Not Reported - 99
23, 24	V58	11. How many visits have you had from close friends over the past two weeks? Code same as V50
25, 26	V59	12. How many telephone calls have you had from friends over the past two weeks? Code same as V50
27, 28	V60	13. Would you say you see your close friends more, less or about the same since your illness? More - 40 Less - 10 Same - 25 Not Reported - 99
29	V61	14. Overall, How often would you say you receive enough help from your spouse, family members, friends and neighbors? Always - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Reported - 9
30	V62	15. How often would you say the help received from these persons is appropriate for the type of problem you are experiencing? Always - 4 Frequently - 3 Sometimes - 2 Rarely - 1 Not Reported - 9

Functional Living Index

Columns	Variable	Description
31	V63	1. How well would you say you look today? 1 2 3 4 5 6 7 Extremely poor — Extremely well Not Reported - 9
32	V64	2. Rate your satisfaction with the treatment you are currently receiving. Code same as V63
33	V65 * Reverse Item Code	3. How much of your pain or discomfort over the past 2 weeks was related to your cancer. 1 2 3 4 5 6 7 None All 7 6 5 4 3 2 1
34	V66	4. Rate how willing you were to see and spent time with friends in the past 2 weeks. Code same as V63
35	V67	5. Rate the degree to which you are frightened of the future. Code same as V63
36	V68 * Reverse Item	6. How much nausea have you had in the past two weeks? Code same as V65
37	V69	7. Rate how willing you were to see and spend time with those closest to you in the past 2 weeks. Code same as V63
38	V70 * Reverse Item	8. How much of your usual household tasks are you able to complete? Code same as V65

Columns	Variable	Description
39	V71	9. Rate the degree to which your cancer has imposed a hardship on you (personally) in the past 2 weeks). Code same as V63
40	V72 * Reverse Item	10. How much is pain or discomfort interfering with your daily activities? Code same as V65
41	V73	11. Rate in your opinion, how disruptive your cancer has been to those closest to you in the past 2 weeks. Code same as V63
42	V74 * Reverse Item	12. How uncomfortable do you feel today? Code same as V65
43	V75	13. Rate your satisfaction with your work and your jobs around the house in the past month. Code same as V63
44	V76	14. Rate how often you feel discouraged about your life. Code same as V63
45	V77 * Reverse Item	15. Rate the degree to which your cancer has imposed a hardship on those closest to you in the past 2 weeks. Code same as V65
46	V78 * Reverse Item	16. Do you feel well enough to make a meal or do minor household repairs today? Code same as V65
47	V79	[illegible]. How well do you feel today? Code same as V63

Columns	Variable	Description
48	V80 * Reverse Item	18. Has nausea affected your daily functioning? Code same as V65
49	V81 * Reverse Item	19. Rate your ability to maintain your usual recreation or leisure activities. Code same as V65
50	V82	20. How much time do you spend thinking about your illness? Code same as V63
51	V83	21. How well are you coping with your everyday stress? Code same as V63
52	V84 * Reverse Item	22. How often do you feel depressed? Code same as V65

Self-Esteem Scale

(High Score (4) = High Self-Esteem
Low Score (1) = Low Self-Esteem)

Columns	Variable	Description
53	V85 * (Reverse Item)	1. On the whole, I am satisfied with myself Strongly Agree - 4 Agree - 3 Disagree - 2 Strongly Disagree - 1 Not Reported - 9
54	V86	2. At times I think I am no good at all Strongly Agree - 1 Agree - 2 Disagree - 3 Strongly Disagree - 4 Not Reported - 9
55	V87 * Reverse Item	3. I feel that I have a number of good qualities Code same as V85
56	V88 * Reverse Item	4. I am able to do things as well as most other people Code same as V85
57	V89	5. I feel I do not have much to be proud of Code same as V86
58	V90	6. I certainly feel useless at times Code same as V86
59	V91	7. I feel that I am a person of worth, at least on an equal basis with others. Code same as V86
60	V92	8. I wish I could have more respect for myself. Code same as V86

Columns	Variable	Description
61	V93	9. All in all, I am inclined to feel that I am a failure. Code same as V86
62	V94	10. I take a positive attitude toward myself. Code same as V85

* Reverse Item