A PATH MODEL ANALYSIS OF THE CANCER EXPERIENCE: PATIENT DEPRESSION AND CAREGIVER RESPONSES AMONG HUSBANDS AND WIVES CARING FOR A SPOUSE WITH CANCER

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ABSTRACT

A PATH MODEL ANALYSIS OF THE CANCER EXPERIENCE: PATIENT DEPRESSION AND CAREGIVER RESPONSES AMONG HUSBANDS AND WIVES CARING FOR A SPOUSE WITH CANCER

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The purpose of this study is to describe husbands and wives responses to caring for a spouse with cancer using a path model analysis. Specifically, the focus of this research is to examine patients' functional physical status, duration of care, and depression and analyze the causal relationships on caregivers' depression and their responses to the impact of care on their health, daily schedule, and finances.

Data utilized were collected among 238 caregivers and their spouses with cancer over the phone and self-administered questionnaires. Using ordinary-least squares regression, a three-equation model was employed to reflect the relationships in models depicting the three burdens under study. Findings revealed patients' functional status affects caregivers' burden responses primarily because it influences patients' and then caregivers' mental health. Only in the case of impact on schedule does there appear to be a direct effect of patient's functional status on caregiver burden.

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CHAPTER I

INTRODUCTION

Background of Problem

The incidence of cancer in America has become a startlingly common occurrence. Consider the following facts: About 985,000 people were newly diagnosed as having cancer in 1989 (not including the incidence of non-melanoma skin cancer, which is estimated at 500,000 new cases annually). About 75 million Americans now living will eventually have cancer, or about 30% of the present total population. This means that cancer can be expected to strike in approximately three out of four families (American Cancer Society, 1989). Present trends in the delivery of health care services, such as shorter hospital stays, are likely to necessitate the need for increasing family involvement in the care for ill family members. The family is usually the first line of defense and the mainstay of support throughout the course of the disease. Exactly how caring for a family member with cancer affects the family member providing care is not fully understood at this time. The need to examine how spouses react to the caregiving role when their partner has cancer, as well as some of the contingencies which may affect their reaction (e.g. the patient's response to the cancer experience), is the focus of this research.

Family care for cancer patients will be discussed in terms of the patient's need for care and the impact of care by family caregivers. When illness such as cancer strikes in a family it commands a response from the entire family. Family stress theory (McCubbin, Joy, Caudle, Comeau, Patterson, & Needle, 1980) focuses attention on the ways in which the family is able to manage the illness and cope with their responses. Olsen (1970) described the impact of serious illness on the families as one of crisis and resulting stress. This event can throw the family system into disorder and disequilibrium as one member may no longer be able to function at his or her usual ability, thus placing new demands on the family as a unit.

The family care is conceptualized in terms of the informal support that caregivers provide. Indeed, the family is a critical element in the delivery of health care services for cancer patients (Northouse & Northouse, 1987). The prevailing use of prospective reimbursement schemes and Diagnostic Related Groupings (DRG's) in inpatient medical care has prompted earlier hospital releases and a greater dependence on the utilization of outpatient services. One effect of this is that health care professionals must rely on the availability of family members to provide many of the services which are necessary for adequate cancer treatment and follow-up. Transportation to outpatient cancer treatments, rehabilitative and assisted self-care efforts in the home, emotional support, and physical care are just some of the major activities carried out by families providing care in the home (Stetz, 1987; Lewis, 1983; Grobe, Ilstrup, & Ahmann, 1982; Welch, 1980).

Purpose of the Study

In view of what has been discussed in this brief introduction, the present study is designed to examine the factors which contribute to caregiver burden responses, with specific attention to the effect of patient and caregiver depression, physical dependency, and the duration of need for care. In this study, caregiver burdens are viewed as the subjective response to specific dimensions of impact to the role of providing care. These responses are also conceived to be influenced by the affect of caregiver depression.

The primary goal of this research is to describe and analyze the effect of those factors which influence the outcomes of caregiver burden to better understand the effect of cancer caregiving on the spouse. A secondary goal, to be discussed following the analysis, includes identifying those factors which may prove most salient to possible intervention designs which might assist those burdened caregivers.

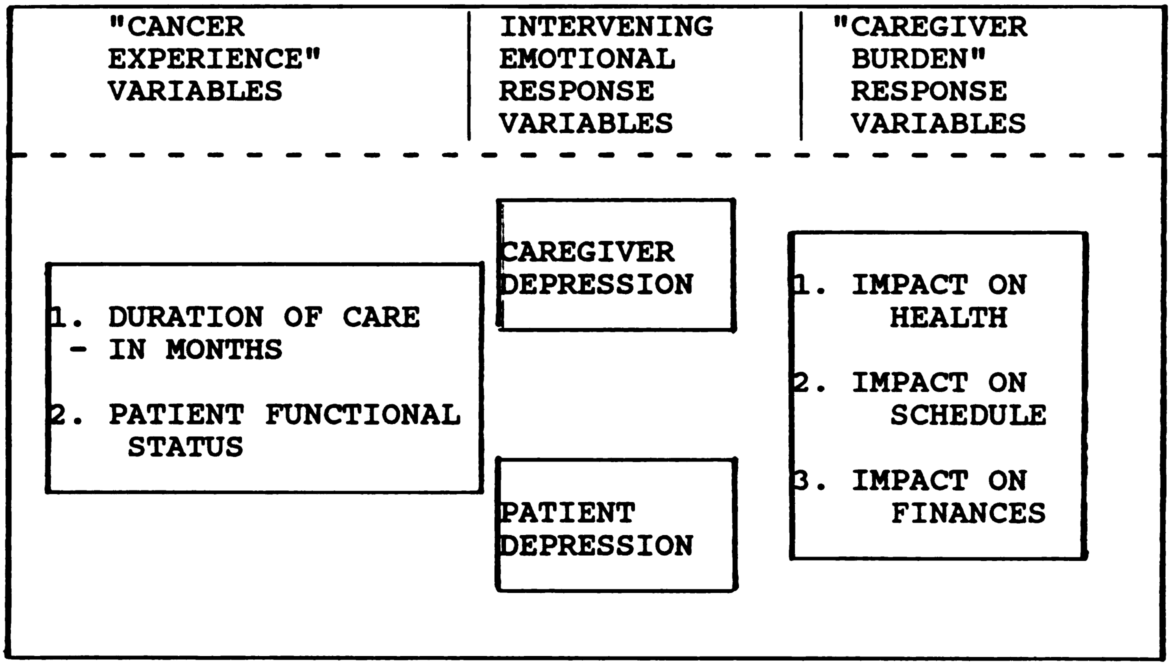
Research Questions

The general question that is being addressed in this research is: "how do selected factors of the cancer experience and patient depression affect the outcomes of spouse-caregiver burden responses?" More specifically the present study attempts to deal with the following questions: 1) to what extent do specific characteristics of the cancer care experience influence caregiver burden responses; and 2) do patients' emotional responses to the cancer experience, such as depression, help to explain the relationship to better predict caregivers' burden responses? Figure 1 depicts the variables under study as they are conceptualized in the path model.

General Conceptual Framework

A family systems framework (Broderick & Smith, 1979) will serve to guide the development of a path model of cancer caregiver burden responses. Following a brief introduction to the theoretical perspective guiding this research, the major variables to be examined will be discussed along with the proposed path model illustrating the relationship of the variables under study.

The cancer experience, as it will be referred to here, is framed in a family systems perspective which suggests that a variety of cancer care characteristics will influence caregiver burden. Specifically, the path model (Figure 1) posits particular characteristics of the care experience which are likely to influence patients' and caregivers' levels of depression which, in turn, are suggested to influence caregivers' burden responses. The negative impacts of care upon the primary caregiver are conceptualized in terms of the role strains associated with living and coping with the physical demands of direct care, disruption of the caregivers' daily schedule in attending to the physical and psychological needs of the patient, and financial strain likely to result from lost opportunity costs and additional expenses related to medical care activities, equipment and supplies.



<u>FIGURE 1</u> - Proposed Path Model Depicting the Cancer Experience, Intervening (Depression), and Caregiver (Burden) Response Variables

A family systems perspective of the cancer care experience implies that a variety of inputs to the family system are viewed as influencing patients' and caregivers' affective intervening states of depression which, in turn, is posited to influence caregivers' outcome responses to their role in care.

Definitions of Variables

The following conceptual definitions will help guide the reader through the selected review of research and further elaboration of the family systems framework guiding this research.

Patient. Patient is defined as the identified spouse with new or recurrent cancer diagnosis.

Caregiver. Caregiver is defined as the spouse who is self-identified as the person who provides the most care for a family member with cancer.

Depression. Depression is defined as a general mood state of non-psychiatric, depressive symptomatology, which includes cognitive, affective, and behavioral features. Depression in this study will be measured by the Center for Epidemiologic Study - Depression scale (CES-D 20), for both patient and caregiver.

Cancer Care Experience. The cancer care experience is defined as characteristics of the cancer which account for the need for care. Specifically, a) duration of care, measured in months, and b) the physical functional status of the patient, measured by the Karnofsky Performance Scale, will serve to operationalize the concept of cancer care experience for both patient and caregiver.

Caregiver Burden Responses. Caregiver burden responses are defined as caregivers' perceptions and self-appraisal of the impact of their role in care on the following dimensions: A) physical health; B) daily schedule; and C) finances.

Assumptions

Assumptions made in this research include:

1. The measures are appropriate to the concepts identified and sensitive to accurately appraise patients' and caregivers' depression and caregiver burden responses.
2. The causal ordering in the proposed model is logical and appropriate to test an exploratory predictive model of caregiver burden.

Limitations

Limitations of this research include:

1. Subjects who agreed to participate in this study may be very different from those who chose not to participate. Therefore, it is quite likely that the findings are not

representative of all cancer caregiver dyads. Reliance on a convenience sample may conceivably select out those truly depressed or burdened patient/caregiver dyads who elect not to participate in research studies.

2. All characteristics of the cancer experience are not explored (i.e. specific patient dependency, patients' symptom experience and distress, or specific caregiver attributes such as care involvement).
3. Additional characteristics of the dyad and family system, which may influence both patient and caregiver depression and the caregivers' perception of burden in care, are not explored (i.e. history and quality of the relationship, or other sociodemographic variables).

A final issue that may be considered a limitation of this study concerns the exclusion of variables related to the family and individuals' social-psychological and life-cycle development. It bears noting that inclusion of these potentially critical variables was beyond the scope of the present research.

Organization of Chapters

The presentation of this study in organized into five chapters. Information in Chapter I is the introduction, purpose of the study, general research questions and orientation to the conceptual framework, definitions of the variables under study, proposed path model, and the basic assumptions and limitations of this research. In Chapter II a selected review of research and conceptual framework will be presented. The review of research will link this analysis with the work others have done regarding the impact of cancer in families and their responses to the cancer experience. Following this brief review, concepts relevant to family systems theory are integrated in a conceptual framework that is basis for generating the proposed model and hypotheses for this study. In Chapter III the methods of research used to conduct this study are described. Data and analyses are presented in Chapter IV. Finally, in Chapter V a summary and discussion of the findings, implications for family therapy, and directions for future research are discussed.

CHAPTER II

REVIEW OF RESEARCH AND THEORETICAL FRAMEWORK

Family Cancer Care Concepts & Issues

The purpose of this chapter will be to present a selected review of the current research on cancer care and the responses of both the patient and family caregiver. Following a description of the patient's need for care and the caregiver's involvement with that care, a family systems perspective will be employed to frame the issues of patient and caregiver emotional responses to the cancer experience, as well as caregivers' burden responses to the role of caregiving. The ways in which family caregivers are involved with and affected by the needs of family members with cancer, as well as the occurrence of depression among cancer patients and caregivers, will be surveyed in the following review of research.

In the following review of research, caregiver may be concurrently defined as 'family.' Caregiver burden responses are considered in light of the general caregiving research since very little is known about the burdens specific to cancer care.

Typically, family members provide over eighty percent of the necessary in-home care and health services (Hooyman &

Lustbader, 1986). The types of assistance that families provide range from frequent or episodic supportive contact to more routine aid for a family member's instrumental and physical daily living needs. While the stage and site of the disease typically determines the amount and degree of needed assistance, family response to diagnosis and treatment information seems to vary and often determines their plan of action (Gotay, 1985; Welch, 1980). The services that families provide for cancer patients, the care needs they meet, and the stresses they experience in shouldering a variety of family roles are of crucial importance to the total care picture when considering the adequacy of cancer care delivery (Oberst, Thomas, Gass, & Ward, 1989; Oberst & Scott, 1988; Northouse & Northouse, 1987).

Cassileth (1979) notes that families serve as primary sources of support for patients, and also as important resources to health care professionals. Family members often act to coordinate the necessary contacts with appropriate care agencies, as well as to monitor and carry information about the patient's day to day physical and psychological status. Researchers have attempted to examine and describe the process of care in terms of the emotional strain and psychosocial needs of family members in cancer care situations (Parkes, 1975); the informational needs (Googe & Varrichio, 1981), as well as the educational and support needs of caregivers (Skorupka & Bohnet, 1982).

Other studies have indicated that spouse caregivers report feeling alone and stressed (Cooper, 1984), needing extended family support (Chekryn, 1984), or experiencing "exhaustion crisis" (Oberst & James, 1983). Whether these types of strains lead to caregivers' feelings of burden in cancer caregiving is not clearly known, but would seem likely to contribute to such negative outcomes as impacts on health, daily schedule and finances. Also, other outcomes of care have been studied relative to the negative impact on the family caregiver's work role (Wellisch, Jamison, & Pasnau, 1978), the physical demands of care (Lewis, Ellison, Woods, 1985) and other reactions to lifestyle changes (Welch, 1981; Gotay, 1984) associated the impact of cancer on the family.

Researchers have shown that families want to be involved in the process of home care for a family member with cancer (Vess, Moreland, Schwebel, & Kraut, 1988; Edstrom & Miller, 1981) but often lack the skills necessary to provide care, and are ill prepared for the impact that cancer and home care may entail (Holmes, 1987; Krouse & Krouse, 1982). Most importantly, families want to know how to effectively provide the needed care and comfort for the patient (Skorupka and Bohnet, 1982). In Grobe, Ahmann, & Ilstrup (1982), families expressed a desire to be involved in such activities as monitoring symptoms and progress, basic caring for activities, providing equipment, and transporting their family member to cancer treatments and general transportation. Welch (1981) found that families often thought that formal supportive services were inadequate in meeting the care needs of the family. With this brief review, a portrait emerges as to the tasks and activities which families are engaged in providing for a family member with cancer.

The negative impacts of care upon the primary caregivers are generally conceptualized in terms of the role strains associated with living and coping with the physical demands of direct care, financial strain, medical emergencies, and the psychological and social consequences of providing emotional support for the patient and perhaps other family members. Very few researchers have specifically examined the impacts of family caregiving for cancer patients, therefore only a brief review of the cancer caregiver stress and burden is available. A description of the more general family caregiving literature (i.e for elderly or Alzheimers' patients) will help to guide the reader through the concepts under study.

The appraisal of stress associated with the emotional strains and demands of physical care among the identified primary caregiver, are noted in a few family cancer investigations (Oberst & Scott, 1988; Oberst, Thomas, Gass, and Ward, 1989; Northouse, 1988). Lewis (1986), in her review of the impact of cancer on the family, identified eleven major issues which have been empirically associated with cancer families experiences. Issues relevant to the present study include emotional strain and physical demands of care, altered roles and family lifestyle, and financial press.

The most commonly reported responses to caregiving are the subjective burdens and negative psychological reactions. In a study of caregivers for the physically impaired elderly, depression was found to dominate perceptions of burden across five dimensions (Stommel, Given & Given, 1990). Poulshock and Deimling (1984) argue that burden should only refer to subjective perceptions of and reactions to the experience of caregiving. Thus, the event activity or circumstance of caregiving should be considered as a burden only when the caregiver views it that way. Whether depression is an antecedent emotional state or condition in caregiving or if it emerges from the context of, is not clear. Again, the present study posits depression as an intervening emotional response to cancer, and not simply a negative outcome of caregiving.

Specific predictors of caregiver burden have generally focused on characteristics of the patients (i.e. physical and cognitive health status), characteristics of the caregiving process (i.e. activities of involvement and available support), and characteristics of the caregiver (i.e. sociodemographic background, attitudes, and health status). While depression could be viewed as a burden or outcome of caregiving, it is difficult to assess when or if depression emerges from involvement in the caregiving environment because no studies exist which document pre-caregiving measures.

There is a great deal of inconsistency therefore, in the identification of relevant predictors for caregiver burden responses. Whether those same burden models of caregiving hold for cancer families is unknown. Questions yet remain as to whether a caregiver burden framework developed for the elderly is appropriate for the cancer care experience. This exploratory study aims to shed light on that question.

Because of its symbolic meaning, as well as its threat of dire physical consequences, cancer can impose major changes in the family role structure, unsettle the emotional balance, and disrupt the family's patterns of interaction and relationships (Vess, Moreland & Schwebel, 1985) Thus, generalizations about the impact of cancer and the responses of family members remain quite tenuous. There are, as yet, no studies that have examined the family reactions across different disease attributes, or conclusively linked patient specific disease characteristics with particular family strains or burden reactions.

There are many important psychosocial factors in the complex web of family relations and influences which could be examined to understand patient and family caregivers' response to cancer (Spiegel, Bloom, & Gottheil, 1983). The role of depression, however, seems most compelling in terms of its influence in the potential responses to the event of cancer as well as the role of care (Farber, Weinerman, & Kuypers, 1984; Friedenbergs, Gordon, Hibbard, Levine, Wolf, & Diller, 1981-82).

Depression among cancer patients has been a critical variable under study in several psychosocial oncology investigations (Frank-Stromberg & Wright, 1984; Plumb & Holland, 1977). Goldberg & Cullen (1985) examined the evidence concerning psychosocial adjustment in cancer and noted certain specific cancer sites which seem to be associated with psychiatric problems that have a biological basis. Holland (1987) reported depression as the most common psychiatric problem encountered among cancer patients. In a study examining the prevalence of psychiatric disorders among cancer patients (Derogatis, Morrow, Fetting, Perman, Piasetsky, Schmale, et. al., 1983), eighty-five percent of the cancer patients who received a DSM-III diagnosis evidenced some type of psychiatric disorder with depression or anxiety as the major symptom, with the majority of those diagnoses (68%) constituting adjustment disorder related to the cancer. Thus, it appears likely that patients' depression would conceivably influence caregivers' mental health and their response to the role of care.

Oberst & Scott (1988) examined the temporal facets of patient and spouse responses to hospital discharge after cancer surgery and adjustment at home. They found that spouse anxiety and distress persisted or was elevated over time, well after the patient's mood states and adjustment patterns had stabilized. Other researchers (Cassileth, Lusk, Brown, & Cross, 1985) have documented similarity in the mood state patterns of cancer patients and their attending relative seen in an outpatient clinic. Patients and family members showed the greatest mood disturbance when they received palliative, as opposed to active treatment. Also, complete bedridden status was associated with greater mood disturbance in patients and their matched relative. The finding of functional impairment and parallel mood disturbance provide some support for the direction for the present research and underscore the importance of examining the influence of mood states (i.e. depression) in cancer patients and family members. Determining the mutuality of patients' and caregivers' depression is not possible in this study.

There are, of course, significant clinical differences between reactive and major depression, and between psychogenic and biogenic causes of depression. Indeed, some degree of an acute stress response is normal to the cancer patient. Snaith (1988) describes the states of grief and loss, hopelessness, or demoralization in the face of illness and adversity, and frustration at one's thwarted ambition, and the like as likely psychogenic causes of depression. He suggests these should not be viewed as homogeneous disorders of mood, but rather as reaction and response to the diagnosis and threat of life disruption. Since the focus of this research is not directed to identifying the causes or concomitant influences on depression, the present review is restricted to noting the relevance of depression as an intervening and more enduring variable in the causal path model of caregiver burdens.

Goldberg (1988) notes depression as one of the two most common psychiatric disorders in cancer patients (delirium being the other), and delineates the medical basis for evaluating depression and psychosocial distress. He notes that the physical consequences of cancer and treatment can account for disturbance of mood and thoughts that are often indistinguishable from other concomitant sources of distress (e.g. psychological, social, or existentially mediated). Thus, with regard to the patient, it becomes difficult to disentangle what might be biologically based depression and what is reactive despair from the complex web of antecedent physical assault of cancer and the concomitant psychosocial and emotional experiences. For example, an aggressive chemotherapy regime could impact a patient's mental state thus intensifying their concern or perhaps despair over job loss, family role disruption, or a host of other social impacts. Patients' mental state of depression is then posited to strongly influence the caregivers' overall emotional response to the cancer experience.

In summary, there is empirical evidence to suggest that cancer affects more than just the person with the diagnosis, and that in family caregiving situations the primary care provider is often at risk to be negatively affected by responses of the family member with cancer, and by the demands of care. Exactly what factors account for the contingencies of this relationship is not clearly understood in the cancer family care process.

In spite of the considerable abundance of research on the attributions of family caregiver burden and the impact of caring for the dependent elderly and family members with Alzheimer's Disease, very little is known about the reactions and burden responses to cancer caregiving. It seems plausible that reports of caregivers' experience of burden or impact will be colored by their subjective perceptions and personal interpretations of the contexts of care (Poulshock & Deimling, 1984). Thus, the cancer caregiver's report of burdens will be influenced by the contextual issues of the cancer experience and by the caregiving responsibilities with which they are faced.

It was the purpose of the preceding review to highlight some of the cancer family care issues and concepts and to provide a background from which the present analysis will emerge. A family systems framework will serve to guide the development of the proposed path model of cancer caregiver burden responses (See Figure 1).

Theoretical Framework

The health, age, sex, relationship, and a whole host of characteristics can affect the outcome of reactions to the caregiving role. Thus, while family caregiving is more or less viewed as a normative family process (Brody, 1985), it remains poorly understood. There are few descriptions of the home care process and caregiver reactions in the cancer literature. Investigation of the impact of family caregiving for cancer patients has only recently become a salient focus in cancer research. Cassileth, et. al. (1985) assert the impact of cancer on the family is of major concern in psychosocial oncology, and also in clinical family therapy practice (Quinn & Herndon, 1986).

Most of the current research is lacking a theoretical model which can link the study results beyond descriptive analysis into a broader interpretive structure (Weisman, 1979). Vess, et. al., (1985), examined the impact of cancer on the family's psychosocial environment and the reallocation of roles from a developmental perspective. However, such an explicit conceptual framework is not common in current psychosocial cancer research. The present research proposes a broadly interpreted general systems family framework (Broderick & Smith, 1979). Since the conceptualized variables place emphasis on caregivers' perceptions and self-appraisal of the burden impacts associated with the role of caregiving, elements of role strain and interactionist perspective (Burr, Leigh, Day, & Constantine, 1979) are encompassed in the framework.

A general systems framework provides a conceptual linkage by focusing the present research questions on the influence of the cancer patient's functional status and depression on the spouse caregivers' depression and their responses to the impact of the caregiving role upon their health, daily schedule, and finances. Characterized as a stress event (Giacquinta, 1977), cancer in the family can produce a change in the system's boundaries, structure, goals, purposes, rules, and values. A family systems perspective then posits that a change in one component of the family will affect a change in that entire family system (Minuchin, 1974).

Specific questions and hypotheses to be examined in this exploratory research are related to the theoretical as follows. The first question concerns the description of the specific cancer experience variables and the relationship between that experience and patient's and their caregiving spouse's depression. The second question relates to the cancer experience variables, patient's and caregiver's depression, and the potential contributions each make to the prediction of burden responses among spouses' providing care. The specific caregiver burden responses to be examined are the perceived impacts of caregiving on caregivers' health, daily schedule, and finances. The focus of this research is to propose a predictive model of caregiver burden responses. Specifically, the analysis may clearly depict the causal relationship of patient's mental state of depression upon caregiver's depression and, consequently, the effect of depression upon the specific caregiver burden responses to cancer care.

Research Hypotheses

Based on the review of literature and predicted path diagram, the following hypotheses are proposed for the present analysis of husbands and wives. The researcher wanted all subjects to be from comparable dyadic relationships, thus, all of the following hypotheses will center on the variable relationships among husbands and wives.

The first hypothesis is intended to examine the causal relationship between the cancer experience and caregiver burden. Six sub-hypotheses were developed to examine the relative importance of the cancer care experience variables on the three separate caregiver burden responses. Theoretically, the following hypotheses relate to cancer as an input in the family system which the well-spouse must respond to and accommodate the role as family caregiver. The first set of sub-hypotheses follows from the view that as duration of care persists over time caregivers' will perceive greater burdens.

Hypothesis 1_{1-3}: There is a positive causal relationship between duration of care in months and the burden response (A) impact on health, (B) impact on daily schedule, and (C) impact on finances.

Similarly, the next series of sub-hypotheses posits that as patients' functional status declines, a probable need for more care would result, and caregivers' would perceive greater burdens.

Hypothesis 1_{4-6}: There is a positive causal relationship between patients' functional dependency and caregiver's burden response (A) impact on health, (B) impact on daily schedule, and (C) impact on finances.

The second hypothesis proposed emerges from the theoretical consideration of the systemic assault of the cancer experience on patients' emotional mood state. In order to assess the extent and strength of the relationship between the selected characteristics of the cancer experience and patient depression, two sub-hypotheses were developed. Again, these hypotheses are based on the view that as duration of care (or need for care as result of the cancer disease) persists over time patients' will likely become or remain depressed, and that as patients' functional status declines they are more likely to be depressed. The two sub-hypotheses are stated as follows:

Hypothesis 2_1: There is a positive causal relationship between the duration of care and patients' depression.

Hypothesis 2_2: There is a positive causal relationship between patients' functional dependency and patients' depression.

The systems theory framework put forth in this study holds that a change in one component of the system will affect a change in the entire system. Thus, if cancer patients are prone to depressive moods, for whatever reasons, then their mood state would consequently affect the mental health of their caregiving spouse. The third hypothesis, proposed to examine the correlation between patients' and caregivers' depression, is stated as follows:

Hypothesis 3: There is a positive causal relationship between patients' depression and caregivers' depression.

The effect of caregiver's depressed mood state on their perception of the burdens associated with cancer care is the focus of the next hypothesis. Caregivers are more likely to perceive greater burden as a result of their depressed mood. Thus, in a systems theory framework, the final hypothesis emerges from the influence of the cancer experience upon the patients' and then caregivers' mental health will influence caregivers' perception of burdens. The fourth and final hypothesis then is designed to examine the relationship between caregivers' depression and the three specific caregiver burden responses.

Hypothesis 4: There is a positive causal relationship between caregiver depression and the specific caregiver burden responses of the impact on: A) health, B) schedule, and C) finances.

Based upon the selected review of research and conceptual framework, the above stated hypotheses emerge from the proposed path diagram. The research design, methods, and data analysis strategy for the present stated hypotheses will be discussed in the following chapter.

CHAPTER III

METHODS AND PROCEDURE

Description of the methods, including study design, sampling, data collection, and analysis strategy are presented in this chapter.

Research Design

In order to describe the family cancer experience and determine the causal relationships between patient depression, caregiver depression, and caregiver burden responses of married cancer patient/caregiver dyads, a secondary analysis of cross-sectional data was conducted. This study was carried out in conjunction with, and support from, Dr. Barbara A. Given and Dr. Charles W. Given, Principal Investigators for the following grants: NCNR, "Family Homecare for Cancer - A Community-Based Model" (#1 R01 NR01915-01) and ACS, "Family Home Care For Cancer Patients" (#PBR-32). Both are one year longitudinal panel studies.

The data reported here are taken from the first wave of a panel study of family caregivers of new and recurrent cancer patients.

Sample Selection

The researchers identified available and willing family cancer dyads for the proposed study design resulting in a convenience sample. Patients and their family caregivers were introduced to the study by nurses in community-based cancer care settings. Subjects were recruited via card back system and then screened according to clinical, cancer specific, and functional health criteria. The cancer patient/caregiver dyads were selected for screening using the following criteria: adult patients between 20 and 85 years of age; diagnosed with new or recurrent solid tumor or lymphoma; symptomatic or with some physical impairment/limitation in Activities of Daily Living or Instrumental Activities of Daily Living; and currently under medical treatment. The primary family caregiver was the person identified as the individual who provides the most care in the home for their family member with cancer.

Subject rights were guaranteed the protection accorded them under the human subjects review approval of the study from which it is drawn from. This included voluntary participation, withdrawal from the study at any time without penalty, and all information obtained to be held in strictest confidence, with no individual identity linked in any way to the results.

Two hundred thirty-eight married cancer-caregiver dyads were drawn from the first wave data set. Analysis was conducted with 190 cases for which responses of both the patient and caregiver were obtained. Spouse caregivers were self-identified as the person who provided the most care. Cancer patient selection is described below.

Sample Description

Data from 238 cancer patients and their caregiving spouses residing in the lower peninsula of Michigan were collected. The age of the patient and caregiver respondents ranged from 22 to 83 years old, with a mean age of 58 and 57 years for patients and caregivers, respectively (See Table 1 for sample description). The primary sites of cancer in this sample (e.g. female breast, colon-rectum, lung, and lymphoma) reflect the highest prevalence of reported cancer sites elsewhere in the U.S. (ACS, 1989).

The cancer patient/caregivers were selected for the study by use of a screening instrument which employed the following inclusion criteria: patients diagnosed with new or recurrent cancer within the last two years; some physical impairment/limitation, as evidenced by an activity performance status rating of 2 or more; and the caregiver's report of the patient's symptoms which necessitate his/her receipt of care and assistance in the home.

Data Collection

Data for the major variables under study were collected via a self-administered mailed questionnaire booklet to each patient and caregiver dyad. Data on the patient's diagnosis, tumor site, and the duration of caregiving were gathered from the caregiver over the telephone using a study eligibility screening instrument.

Operational Definitions of Major Variables

In the following discussion, the major variables under study will be described and operationally defined. Depression, as noted previously, is conceptually defined as a non-clinical and primarily psychogenic state, with cognitive, affective, and behavioral depressive features. Patient and caregiver depression were measured by the (CES-D) scale (Radloff, 1977).

The CES-D is a 20 item, Likert-type, self-report scale designed to assess depressive symptoms experienced over the past month. (Appendix A). This scale has been widely used as a state measure of current emotional distress and depressive mood (symptomatology) within a general, non-psychiatric population (Devins & Orme, 1985). Found to correlate only modestly with clinical diagnoses of depression, this instrument can be used for screening persons for symptomatology related to depression (Meyers and Weisman, 1980), or at risk for clinical depression (Roberts and Vernon, 1983).

Responses are measured on a four point scale describing the frequency of occurrence (i.e. "almost all of the time" to "rarely or none of the time") for each depressive symptom item. The scale has shown consistently good psychometric properties, with moderate convergent validity with other depression measures. High internal consistency has been noted in previous reports (Radloff, 1977; 1986), with Cronbach's alphas reported between .84 to .90. Reliabilities in this study show similarly high alpha coefficients (.91 to .88, for caregivers and patients, respectively) in the total sample (N=268) from which the present study subjects were drawn. Reliability and validity will be discussed further in the following chapter.

The other major outcome variables are collectively described as Caregiver Burden Responses, also noted previously, and conceptually defined as caregivers' self appraised impacts of care on: A) physical health; B) daily schedule; and C) finances. Operationally, these burden responses to caregiving will be measured by the Caregiver Responses Inventory (Given & Given, 1987). (Appendix B) This inventory was constructed to tap the subjective impact reactions to the specific processes and situations of caregiving. An initial pool of 111 items was reduced to 40 items with 5-point Likert response scales. From these items five distinct subscales were found measuring perceived caregiving burdens in the following areas: impact on health, impact on schedule, impact on finances, feelings of family abandonment, and a sense of entrapment. The factor structure of these scales has been confirmed on two additional independent samples of caregivers of the physically impaired elderly and of Alzheimer's patients. All five scales are reliable with Cronbach's alpha ranging from .76 to .84 in the present sample. The current research focused only on the three burden subscales of impact (e.g. health, schedule, and finances) because of their empirical relevance to possible interventions.

The cancer care experience is operationalized by asking two specific questions which address first, the length of time care has been provided to the patient and second, the functional physical dependency of the patient. Duration of care is measured by asking the caregiver to report in months "how long have you been providing care?" for this cancer patient.

Patients' functional physical dependency is measured by the Karnofsky Performance Status Scale (KPS) (Appendix C). The KPS is a multidimensional construct reduced to a unidimensional one. This scale, a standard measure in oncology research and practice, is a functional performance tool that appraises a patient's symptomatology and ability to carry on normal activity (Heinrich & Schag, 1987). It is the most widely used method of quantifying functional status of cancer patients. It is reported to possess good construct validity and has been compared well with Katz's ADL Index and other quality of life measures. High inter-rater reliability (.97) was found among non-clinicians using the scale.

In this study, the measure was administered over the telephone by asking the caregivers to report, based on the five-point scale, the gross functional performance or activity status. Conceptually, this measure may evidence the patient's need for care.

Other data, such as the type of cancer and whether patients were undergoing active cancer treatments, were collected to further illustrate the cancer experience and patients' likely need for care. However, these are nominal data and were not employed in the path model but only reported here as background variables and descriptors of the sample under study.

In the next section the strategy for analyzing the proposed path model is discussed.

Analysis Strategy

The researcher analyzed the variables under study by the following methods. The first stage of the analysis involved calculating the descriptive statistics which describe the characteristics of the sample, the responses on the major variables (means, standard deviations), frequency distributions, psychometric properties of the major scales used, and the inter-correlations of the major variables and outcome measures utilizing Pearson product-moment correlation coefficient.

The second stage of analysis employed a recursive path model, derived from the theoretical considerations outlined earlier. The proposed path model presents a graphic depiction of the direct and indirect effects of the variables on the outcome measures and predictive inferences related to the strength of the effects of the variables. While the path model yields a method for decomposing and interpreting linear relationships among a set of variables that are assumed to have a prior causal ordering, an initial step in the path analysis was to indicate the causal ordering of the variables. The focus of such causal ordering was as follows: a) the selected cancer experience variables and depression; b) depression and the specific caregiver burden reactions; and c) the cancer experience and caregiver burden reactions. The statistical technique employed for the path analysis was ordinary-least-squares regression.

Estimates of the standard error of the observed sample correlation allowed the researcher to judge if the predicted population correlation could have generated the observed sample correlation. This allowed one to test the goodness-of-fit of the model for predicting cancer caregivers' burden responses. Presentation of data and analysis will be examined next.

CHAPTER IV

PRESENTATION OF DATA AND ANALYSIS

Overview

In this chapter data analysis and interpretation of the study findings are presented. Reliability measures and descriptive statistics are presented for the measures and subscales used in this research. Data relevant to the study questions and hypotheses are presented to examine the strength of the relationships between the variables. Regression equations were formulated to examine the variance that can be explained and to derive the standardized beta coefficients and depict the direct and indirect effects of the variables in the path model.

Sample Characteristics

The sample consisted of 238 caregivers and their spouses with cancer. Table 1 presents the socio-demographic characteristics of the subjects, including caregiver age, gender, race, and eduction. Table 2 presents patient age and gender. The subject characteristics are not entered into the later analysis, but are only presented for description of the study sample.

Table 1. Caregiver Sociodemographic Data

Caregiver Age

$\bar{X}$ = 57 Years
SD = 11
Min. = 23
Max. = 81

Gender	N	%
Male	98	41
Female	140	59
Total	238	100

Race	N	%
Caucasian	229	96
Black	5	2
Hispanic	1	.5
Other	1	.5
Total	236	99

Missing Cases = 2

Education	N	%
Grade School or Less	11	5
Some High School	31	13
High School Graduate	83	35
Some College	72	30
College Graduate	20	8
Graduate/Prof. Degree	21	9
Total	238	100

The sample of caregivers consist of 140 women and 98 men, with a mean age of 57 years (S.D. = 11). Ninety-six percent of these caregivers are white, 86% have graduated from high school, and 48% have some college or higher education experience. Since only spouse caregivers are included, patient gender complements that of the caregivers. Mean age of patients is more than 58 years (S.D. = 11).

Table 2. Patient Sociodemographic Data

Patient Age	Gender	N	%
$\bar{X}$ = 58	Male	140	59
SD = 11	Female	98	41
Min. = 22			
Max. = 83	Total	238	100

Table 3a and 3b presents cancer specific data regarding primary tumor site and primary mode of treatment. The cancer related data reveal the most frequent tumor sites to be the female breast (23%), lung (16%), lymphoma (13%), and colon-rectal (12%). Most patients were undergoing active treatment for their cancer, the most frequent being chemotherapy (83%).

Table 3a. Cancer Specific Data

Primary Tumor Site	N	%
Bladder	5	2
Breast	55	23
Colon/Rectal	28	12
Gastro-intestinal	23	10
Gynecological	9	4
Lung	39	16
Prostate	16	7
Lymphoma	31	13
Head/Neck	6	2
Other	26	11
Total	238	100

Characteristics of the Cancer Experience

The mean, standard deviation, and frequency distribution of the two identified independent variables, patient physical functional dependency and the duration of care, are presented in Table 4 and 5, respectively.

Table 3b. Cancer Specific Data

Treatment	N	%
Chemotherapy	196	83
Radiation	9	4
Hormone	5	2
Surgery/Other	12	5
None	14	6
Total	236	99

Missing Cases = 2

Table 4 presents data for the Karnofsky Performance Scale. Mean scores for this measure of patients' physical functional dependency, is 2.44 (S.D. = .87) on a 5 point scale. Only 10% of the caregivers reported their patients were fully active in all activities. Fifty-two percent of the caregivers said their patient was fully active in only light activities, indicating some functional impairment, while 23% say their patient is symptomatic but in bed less than half the day, and 15% report physical functional limitation to the extent that their patient is in bed more than half the day.

Table 5 shows data on caregivers' duration of involvement in care, reported in months, and reveals that 61% have only been providing care for twelve months or less.

The mean number of months of duration in care is nearly 25 (S.D. = 47), but the median duration of care is 9 months.

Table 4. Characteristics of the Cancer Care Experience[1]

Activity Status*	Frequency	Percent
(1) Fully active - all activities	24	10
(2) Fully active - light activities	123	52
(3) In bed < 50% of day	54	23
(4) In bed > 50% of day	36	15
(5) Bedridden/unable to care for self	1	--
Total	219	100

Mean = 2.44 S.D. = .88
* Karnofsky Performance Scale

The case reporting 480 months duration was excluded from the analysis of the major variables. The groupings of months in Table 5 is presented for descriptive purposes only. Analysis for was performed on duration as a continuous interval variable.

Table 5. Characteristics of the Cancer Care Experience[2]

Duration of Care (in months)	N	%
1-3	45	19
4-6	53	22
7-9	29	12
10-12	15	6
13-24	30	14
25-36	21	10
37-48	8	4
49-60	8	4
61-62	2	--
73 or more	18	7
Total	237	99.

$\bar{X}$ = 25 months
Med. = 9 months
SD = 47
Min. = 1
Max. = 480

Missing cases = 1

Description and Reliability of Measures

Reliability coefficients for the CES-D 20 depression measure and caregiver burden subscales are presented in Table 6. Reliability refers to the internal consistency of the scale and the extent to which all the items in the scale are equally good indicators of the concept or attribute in question. It is generally understood, the higher the coefficient alpha score the stronger the internal consistency of the scale, meaning that the items in the scale are consistently measuring the same concept. The alpha coefficient scores presented in Table 6 reflect acceptable to high levels of internal consistency of the measures. When a scale is shown to possess repeatedly high reliability scores it possesses reproducibility and scale scores are less likely to be influenced by error.

Table 6. Reliabilities of Caregiver Burden Subscales and (CES-D) Depression Measures (N = 268)

Scale	N of Items	Alpha Coefficient
Caregiver Depression	20	.91
Patient Depression	20	.88
Impact on Health	5	.77
Impact on Schedule	5	.84
Impact on Finances	3	.80

Descriptive statistics for the depression measures and he caregiver burden subscales are presented in Table 7. Examination of the caregiver depression measure reveals a moderate positive skew and somewhat higher kurtosis, reflecting a slightly asymmetric and more peaked distribution than that of a normal curve. While most caregiver depression scores cluster around the sample mean, a few have extreme high values.

Recursive Path Model Analysis

Analysis of the path model is presented in two stages. First, the bivariate correlations among all variables are presented. Second, three recursive path models will be presented to depict each of the three caregiver burden outcomes as the dependent variable: impact on health, impact on schedule, and impact on finances.

Table 7. Scale Means for Patient and Caregiver Depression and Caregiver Burden Responses (N = 190)

	Mean	S.D.	Min	Max	Skew	Kurt	N
1.	1.71	.41	1.00	3.20	.648	.591	192
2.	1.72	.42	1.00	3.55	.911	1.993	220
3.	2.07	.62	1.00	4.20	.619	.870	220
4.	2.93	.94	1.00	5.00	-.051	-.669	220
5.	2.33	.86	1.00	5.00	.823	.415	220

1. Patient Depression (1-4)
2. Caregiver Depression (1-4)
3. Impact on Health (1-5)
4. Impact on Schedule (1-5)
5. Impact on Finances (1-5)

Table 8 contains the Pearson r linear correlation coefficients for all predictor and outcome variables in the proposed path model. Since duration of care did not correlate with the other predictor variable, patient performance status (r = -.10), the intervening variables of patient and caregiver depression (r = .04, -.03, respectively), nor with any of the three burden outcome measures of impact on health, schedule, and finances (r = .09, .05, 06, respectively), it was not expected to contribute significantly to the model explaining caregiver burden reactions. Thus, duration of care was dropped from the subsequent path models.

<u>Table 8</u>. Pearson Linear Correlation Coefficients of All Predictor and Outcome Variables (N = 190)

	1	2	3	4	5	6	7
1	1.0						
2	-.098	1.0					
3	.040	.289***	1.0				
4	-.025	.224***	.399***	1.0			
5	.088	.151*	.304***	.547***	1.0		
6	.047	.424***	.481***	.518***	.567***	1.0	
7	.055	.062	.233***	.317***	.273***	.196**	1.0

1. Duration of Care
2. Functional Status (Karnofsky)
3. Patient Depression
4. Caregiver Depression
5. Impact on Health
6. Impact on Schedule
7. Impact on Finances

* $p \leq .05$
** $p \leq .01$
*** $p \leq .001$

The finding of non-significant correlations for the duration of care variable may have resulted from possible problems in measurement, likely to result from respondents having to remember an often ill-defined onset of illness. The finding of non-significance and subsequent decision to exclude this variable from the model will be discussed further in the next chapter.

Patients' functional status is shown to moderately correlate with patients' reported levels of depression ($p < .001$). Correlations among the dependent variables indicate that the impact of caregiving on health, schedule and finances are highly related to each other. They also correlate with patients' and caregivers' levels of depression. Thus, assuming that depression is the more enduring state, these correlations appear to suggest that caregivers' level of depression may influence their perception of how caregiving impacts their lives.

Two of the three caregiver burden responses (excluding finances) appear to be moderately related ($p \leq .05$) to the measures of patients' physical functional status and their reported level of depression. Whether these effects are direct or mediated through caregivers' affective state (i.e. their own level of depression) will be explored through the path models. The recursive path diagram (Figure 2) depicts the proposed model and how the variables are thought to be related to each other, with caregiver burden reactions conceptualized as the outcomes. Three separate path figures will be analyzed to examine the three specific caregiver burden reactions (i.e. impact on caregiver health, schedule, and finances, respectively).

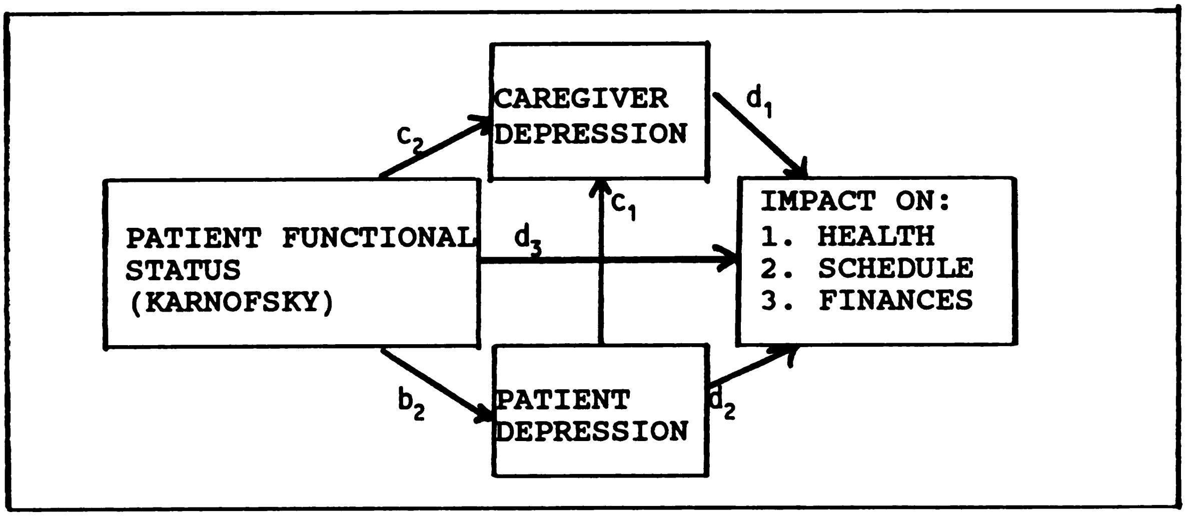


Figure 2. Recursive Path Diagram of Caregiver Burden

The proposed path model was generated to depict the relationships between the variables suggested by the research questions. Patient depression is treated as an intervening variable, influenced by patients' physical functional status. Caregiver depression is also conceptualized as intervening, influenced by patients' functional dependency and by patients' depression. All the proposed paths are recursive. Which is to say, that all causal impacts are assumed to be unidirectional and without feedback loops (Land, 1969).

Regression Equations for Path Analysis

The path coefficients are derived using a three equation model for each of the three caregiver burden impacts.

1. $\text{Pdep} = b_2(\text{pfs})$
2. $\text{Cdep} = c_1(\text{pdep}) + c_2(\text{pfs})$
3. $\text{Imp}_{a,b,c} = d_1(\text{cdep}) + d_2(\text{pdep}) + d3(\text{pfs})$

Figure 3. Regression Equations for Path Coefficients

The first two regression equations calculate the beta coefficients and amount of variance explained in the intervening variables. The third regression computes the proposed direct effects of all predictor and intervening variables on the caregiver burden outcome variables. In Figure 3, the three regression equations computed in the path are presented.

Results of the first stated regression equation are presented in Table 9. The first regression analysis revealed that patient functional status was significant ($p < .001$) in explaining the relatively small proportion ($R^2 = .08$) of the variance found in patient depression. Recall that in Table 8 the Pearson Correlation coefficients for the two variables were only moderately correlated (.289, $p < .001$).

Table 10 presents results of the second regression run with patient functional status and patient depression entered in the equation to predict caregiver depression. Table 10 reveals a significant beta coefficient, .358 (p.<.001), for patient depression. Nearly 17 percent (R^2 = .1684) of the variance in caregiver depression can be explained and accounted for by the variable patient depression.

<u>Table 9</u>. Regression of Patient Functional Status with Dependent Variable Patient Depression

<u>Predictor Variable</u>	<u>Beta</u>	<u>T Signif</u>
Patient Functional Status	.28942	.0000 *
Multiple R	.2894	
R^2	.0838	
F	17.2785	
F Significance	.0000	

The results of the first two regression equations are reflected in the beta coefficients for patient functional status and patient depression.

<u>Table 10</u>. Regression of Patient Functional Status and Patient Depression with Dependent Variable Caregiver Depression

<u>Predictor Variables</u>	<u>Beta</u>	<u>T Signif</u>
Patient Functional Status	.12203	.0807
Patient Depression	.35805	.0000*
Multiple R	.4103	
R^2	.1684	
F	19.0325	
F Significance	.0000	

The beta coefficients for patient depression on patient functional status (.289, in Table 9) and for caregiver depression on patient depression (.358, in Table 10) will be displayed in each of the three path figures depicting their influence on the specific caregiver burden, impact on health (Figure 4).

Table 11a presents the results of the third regression equation examining the amount of variance explained by the predictor and intervening variables for the caregiver burden response of impact on health. When entering the predictors of patient functional status and the intervening variables of patient and caregiver depression into the regression run, it appears that only caregiver depression (.503) is significant ($p < .001$) in explaining the variation in the burden response impact on caregiver health.

Table 11a. Regression of Patient Functional Status, Duration of Care, Patient Depression and Caregiver Depression with Dependent Variable Impact on Health

Predictor Variables	Beta	T Signif
Patient Functional Status	.00821	.8984
Patient Depression	.10296	.1315
Caregiver Depression	.50257	.0000*

Multiple R	.5534
R^2	.3063
F	27.5230
F Significance	.0000*

The beta coefficient (.503) for caregiver depression is then added to the path diagram depicting the causal relationships of all variables with impact on health. As shown in Figure 4, there are no direct effects of patient functional status on impact on caregiver health, but only the indirect effects through patient depression and caregiver depression. Nor are there direct effects of patient depression on caregivers' perceived impact on health. The reader should note that only significant beta coefficients are depicted. Nearly thirty-one percent of the variance ($R^2 = .306$) in the dependent variable, impact on health, can be explained in this path model.

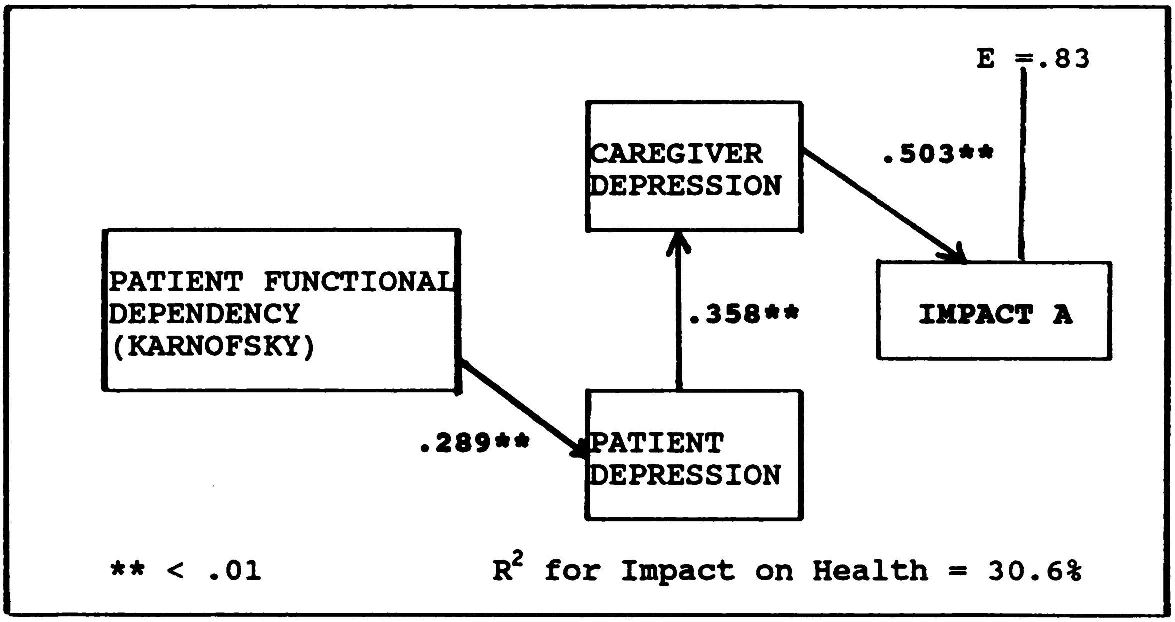


Figure 4. Path Model Coefficients for Impact on Health

The next phase of the path analysis then is to determine if the causal model can help to better predict the relationship between patient functional status and caregiver impact on health. By taking into account the additional factors of patient and caregiver depression, which were posited to influence caregiver burdens, the path model allows the researcher to determine the combined effects of the variables on the ultimate dependent variable, impact on health.

The combined indirect effects of the significant variables in the path equation must be less than or equal to the observed correlation (r = .151) between patient functional status and impact on health, as expressed in the following equation:

$$r \geq (d_1 \times c_1 \times b_2) \quad \text{or, } r\ (.151) \geq .052$$

(Recall) <u>Figure 3</u>.

1. $Pdep = b_2(pfs)$
2. $Cdep = c_1(pdep) + c_2(pfs)$
3. $Imp_a = d_1(cdep) + d_2(pdep) + d_3(pfs)$

In the three-equation model for the impact on caregiver health, patient functional status is only indirectly related to caregivers' perceived impact on health. This relationship is depicted by the multiplicative term of $d_1 \times c_1 \times b_2$, and amounts to .052. This is less than the observed correlation (r = .151) between patient functional status and the impact on caregiver health. In order to accept the model as reasonably fitting the observed data, the standard error on the sample correlation was computed. This allows one to test if the observed correlation in the sample differs from the one hypothesized on the basis of the path model to such a degree that it is unlikely that the proposed path model fits the sample data.

The formula to test for a significant difference between the observed and predicted r was calculated in the following way:

$$\frac{\text{observed sample r} - \text{hypothesized population r}}{\text{SE r}}$$

or

$$\frac{(.151) - (.052)}{\text{SE } .0719}$$

The result, 1.38, indicates the observed correlation is not significantly different (i.e. more than 2 standard deviations away) from the correlation hypothesized for the population, and the model predicting caregiver impact on health can be accepted.

The second caregiver response, impact on schedule, was then analyzed in the same manner as the impact on health. Table 11b presents the regression results when all variables are entered upon the second outcome measure.

As the findings from Table 11B show, there are a number of significant beta coefficients to be added in the second path figure (Figure 5) First, there appears to be a significant (p < .0001) direct effect of patient functional status on impact of caregivers' schedule (beta coefficient = .269). Second, there is a significant effect of patient depression (beta coefficient = .263).

Table 11b. Regression of Patient Functional Status, Patient Depression and Caregiver Depression with Dependent Variable Impact on Schedule

Predictor Variables	Beta	T Signif
Patient Functional Status	.26890	.0000*
Patient Depression	.26284	.0000*
Caregiver Depression	.35340	.0000*
Multiple R	.6501	
R^2	.4226	
F	45.6273	
F Significance	.0000	

The direct and indirect effects of patient functional status on impact on schedule can be derived from Figure 5 which illustrates the direct paths (or direct causal relationships) upon the second outcome, perceived impact on caregivers' schedule.

As with the first path, the next phase of analysis involved determining if the causal model can help to better predict the relationship between the predictor variables and caregiver impact on schedule. The combined effects of the variables in the path equation must be less than or equal to the observed correlation (r = .424) between patient functional status and impact on schedule.

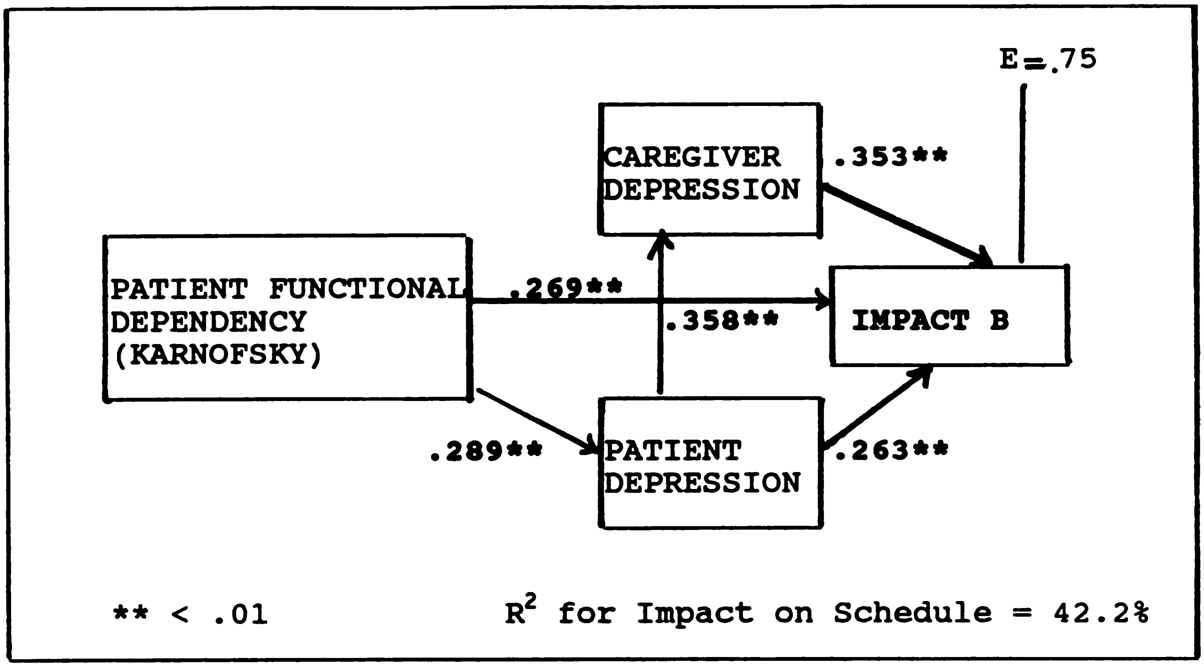


Figure 5. Path Model Coefficients for Impact on Schedule

By adding the combined effects of the variable beta coefficients, the formula can be expressed in the following equation:

$$r \geq d_1 + (d_2 \times b_2) + (d_1 \times c_1 \times b_2) \quad \text{or, } r\ (.424) \geq .382$$

Similarly with the test of the model for impact on health, the standard error of the observed correlation was computed. Again, the calculated standard error was entered in the following equation:

$$\frac{\text{sample } r(.424) - \text{hypothesized population } r\ (.382)}{\text{SE } r\ (.0659)}$$

The result, .64, reveals no significant difference (i.e more than 2 standard deviations away) from the correlation found hypothesized for the population. Therefore, based on the standard error estimate for the predicted r, the path model predicting caregiver impact on health can be accepted.

Table 11c presents the regression results for the third outcome measure, impact on finances. As with the regression results for impact on health, among all the variables only caregiver depression appears to have a significant effect in explaining the variance on the caregiver burden of impact on finances.

There is not a large amount of variation in the dependent variable that can be explained by the other variables entered in the equation ($R^2 = .117$, $p < .001$). While caregivers' perceptions of the impact of care on finances may be influenced by other relevant factors, such as socioeconomic resources, it does appear that some effect can be explained by their affective state of depression, which in turn appears to be influenced by patient depression.

The beta coefficient for caregiver depression (.275) is then added to the next path diagram (Figure 6) as a direct effect of caregiver depression on impact on finances (and an indirect effect of patient depression). Figure 6 depicts the causal path of the variables on the third outcome under investigation. Similar to the model for impact on health, there are no apparent direct effects of the predictor variables on impact on finances, but only the indirect effects through the intervening variables of caregiver and patient depression.

Table 11c. Regression of Patient Functional Status, Patient Depression and Caregiver Depression with Dependent Variable Impact on Finances

Predictor Variables	Beta	T Signif
Patient Functional Status	-.04132	.5709
Patient Depression	.13766	.0746
Caregiver Depression	.27472	.0003*
Multiple R	.3417	
R^2	.1167	
F	8.1932	
F Significance	.0000	

As with the two previous path models, the next phase of analysis involved determining if the causal model can help to better predict the relationship between the predictor variables and caregiver impact on finances.

The combined effects of the variables in the path equation must be less than or equal to the observed correlation (r = .062) between patient functional status and impact on finances. By adding the combined effects of the variable beta coefficients, the formula can be expressed in the following equation:

$r \geq (d_1 \times c_1 \times b_2)$ or $r\ (.062) \geq .028$

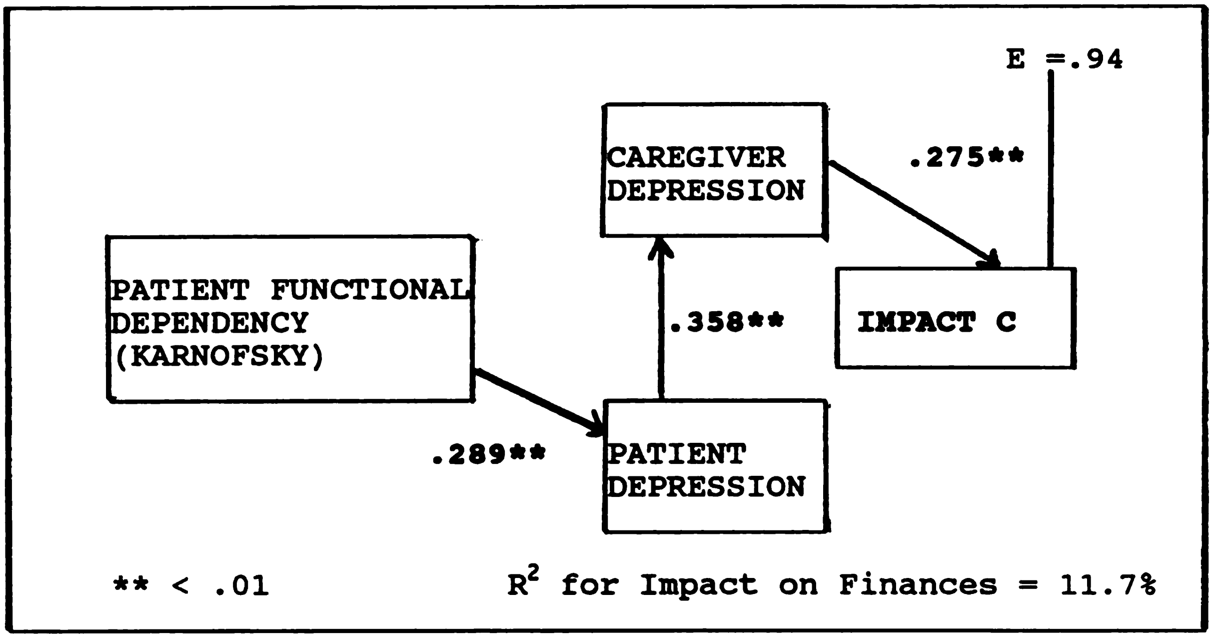


Figure 6. Path Model Coefficients for Impact on Finances

Again, in order to test whether the model can help to predict the depicted causal relationships in the population involves the calculating the standard error score for the predicted correlation. Thus, the following equation is calculated to determine the standard error of the predicted correlation, based on the model:

$$\frac{\text{sample } r\ (.062) - \text{hypothesized population } r\ (.028)}{\text{SE } r\ (.0726)}$$

The result, .47, indicates that the path model prediction for the population correlation does not differ significantly from the observed sample correlation. However, since the observed correlation was not significant at the .05 level, it is unlikely that the population correlation differs from zero. Correspondingly, despite the significance of individual paths in the model, the path chain from patient functional status to impact on finances does not differ from zero.

In review of the preceding analysis, recall that in the path figure for impact on health, the path model depicting the causal relationships provide the reader with additional information not readily apparent by the Pearson r correlation analysis. That is, that the predictor variables do not by themselves explain a significant amount of the variance in the outcomes. However, indirectly, through patient depression and subsequently through caregiver depression, they do color the perception of caregivers' response in the impact of the care role on health.

As demonstrated in the preceding analysis, the impact on schedule is directly affected by patient functional status and also by patient depression. This seems fairly logical since the patients' physical health and psychological adjustment is likely to have implications for the caregivers' involvement in care, thus causing some impact on their daily schedule.

Table 12 presents a synopsis of the direct and indirect effects for each of the outcome caregiver burden response variables. As noted earlier, there are no apparent direct effects of patient functional health on caregiver impact on health or impact on finances, but the indirect effects through patient depression and consequently through caregiver depression. The hypothesized population correlations for the model are presented as the total effects. Standard error scores for the observed sample r are also shown in Table 12.

Table 12. Effects of Patient Functional Status on the Caregiver Burden Response to Impact on Health, Schedule, Finances

	Health	Schedule	Finances
DE	---	.269	---
IE $_1$	.052	.113	.028
TE$_2$	.052	.382	.028
Observed r	.151	.424	.062
SE Estimate$_3$	1.38ns	.64ns	.47ns

1 - Indirect Effects via Patient and Caregiver Depression
2 - Hypothesized total effect based on Path Model
3 - Deviation of the observed from hypothesized effects in terms of the standard error of the sample correlation
ns - non-significant

Table 13 presents a summary of the regression results of all three outcome burden responses on the independent variable, patient functional status, and the intervening variables, patient depression and caregiver depression. This table displays the beta coefficients for all variables, including the predicted amount of variance that can be explained by the independent and intervening variables for each caregiver burden.

Table 13. Summary Table of Caregiver Burden Responses Regressed on Cancer Experience and Depression Variables

	DEPENDENT VARIABLES		
INDEPENDENT VARIABLES	IMPACT ON HEALTH	IMPACT ON SCHEDULE	IMPACT ON FINANCES
Patient Functional Status	.01	.27*	-.04
Pt Depression	.10	.26*	.14
Cg Depression	.50*	.35*	.27*
TOTAL R^2	30.6%	42.6%	11.7%

*significant at p < .001

Analysis of Research Hypotheses

Given the results of the foregoing analysis, the first series of hypotheses may be discussed. Hypotheses 1_{1-6} reflect the causal relationships between the cancer experience variables, duration of care and patient functional status, and the three specific caregiver burden responses. Each hypothesis will be discussed in light of the correlations and the third regression equation determining the relative contribution of the predictor variable on the outcome of each of the caregiver burdens. The hypotheses concerning the relationship of the duration of care and burden can be summarized in the following:

Hypothesis 1_{1-3}: There is a positive causal relationship between duration of care in months and the burden response (A) impact on health, (B) impact on schedule, and (C) impact on finances.

Since only non-significant correlations were found relating duration and all other variables in the model, this variable could neither have direct nor indirect effects on the burden variables. Therefore, hypotheses 1_{1-3} stating the causal relationship between duration and the specific caregiver burden responses must be rejected.

The next hypotheses to be discussed relates to another dimension of the cancer experience, patients' physical functional status, on the impact on caregiver health.

Hypothesis 1_{4-6}: There is a positive causal relationship between patients' functional dependency and caregiver's burden response (A) impact on health, (B) impact on schedule, and (C) impact on finances.

The correlation for the cancer experience variable patient functional status reveal significant associations with the burden responses of caregiver impact on health and impact on schedule, Pearson r .151 ($p < .05$)) and .424 ($p < .001$), respectively. The impact on finances, however, revealed non-significant correlations. All three burden responses were regressed on patient functional status with patient and caregiver depression. Only impact on schedule yielded significant beta coefficients suggesting a direct causal link between the two variables. There were no direct causal relationships between the other two burden variables and patient functional status. But in the case of impact on health, patient functional health status has an indirect effect on the burden response variable mediated through the intervening variables of patient and caregiver depression.

The second set of hypotheses were intended to assess the extent and strength of the relationship between the selected characteristics of the cancer experience and patient depression. Two sub-hypotheses were developed:

Hypothesis 2_1: There is a positive causal relationship between the duration of care and patients' depression.

As with the Pearson correlation between duration and the caregiver burden responses, there was no significant relationship found between the variable duration of care and patients' depression (r .04 ns). Consequently, analysis did not reveal any effect (either direct or indirect) of duration of care.

The next stated hypothesis was intended to examine the causal effect of the second dimension of the care experience, patient functional status, on patients' depression.

Hypothesis 2_2: There is a positive causal relationship between patients' functional dependency and patients' depression.

The simple regression on patients' functional status for patients' depression revealed a significant beta coefficient (.289, p <.0001), evidencing a causal relationship. Since only 8% of the variation of patient depression can be explained by the variable patient functional status, other additional factors are likely to also influence patients' depression. However cautiously, the stated hypothesis can be accepted.

The third hypothesis proposed to examine the relationship between patient and caregiver depression. Pearson's r revealed a significant correlation (.399, p < .0001), suggesting the possibility a causal relationship may exist.

Hypothesis 3: There is a positive causal relationship between patients' depression and caregivers' depression.

Regressions were run for caregiver depression on patient depression and patient functional status and yielded a significant beta coefficient (.358, p <.0001) only on patient depression. Nearly 17% of the variation of caregiver depression could be accounted for by patient depression.

The fourth proposed hypothesis was designed to examine the relationship between caregivers' depression and specific caregiver burden responses.

Hypothesis 4: There is a positive causal relationship between caregiver depression and the specific caregiver burden responses of the impact on: A) health, B) schedule, and C) finances.

Results from the correlation and regression analyses on caregiver depression revealed significant and direct relationships, respectively, for each of the three caregiver burden responses. It appears that depression clearly influences the caregivers' perception of burden with regard to the impact on their health, schedule and finances. The largest caregiver depression beta coefficient was found for impact on health (.504, $p < .0001$), followed by impact on schedule (.353, $p < .0001$). The causal relationship between caregivers' depression and perceived impact on finances, while still significant ($p < .0001$), was the weakest in terms of the amount of variation explained (R^2 11.7%).

The test for the goodness-of-fit of each of the models was calculated by comparing the observed to the hypothesized correlation (derived from the path model) in terms of the respective standard errors. In each of the models predicting caregiver burden responses, the difference between observed and hypothesized correlations did not exceed two standard errors. Thus, all path models were accepted as reasonably fitting the data. Furthermore, while impact on finances had a non-significant observed correlation with patient functional status, a path chain also indicated that the effect of patient functional status on the burden response impact on finances was not likely to differ from zero.

Summary

To summarize, patient functional status affects caregiver burden responses primarily because of its influence on patient and then caregiver health. Only the burden response of impact on schedule reveals a direct effect from patient functional status. This finding may have relevance to the design of intervention strategies to assist in easing caregiver burdens by directing attention to the mental health state of the patient, as well as the caregiver.

In conclusion, other variables might be considered when formulating future models for which to predict specific burden responses, particularly for impact on caregivers' health and finances. A summary of the study and findings will be discussed in the next chapter. Implications for clinical intervention and possible directions for future research will also be discussed.

CHAPTER V

SUMMARY, CONCLUSIONS, AND DISCUSSION

Overview

A summary of the present study and research questions addressed in the hypotheses will be presented in this chapter. Conclusions derived from the study findings and implications for intervention will also be discussed. A discussion of directions for future research will conclude this chapter and study.

Summary of Study

The primary emphasis of the present research was to describe and analyze the effect of selected characteristics of the cancer experience, and the influence of patient and caregiver depression, on caregiver burden responses. Caregiver burdens were defined as the perceived impact of the caregiving role on caregivers' health, daily schedule, and finances. The present study was designed as an exploratory recursive path model analysis in an attempt to better understand the factors which may prove most salient as targets for intervention to assist burdened caregivers.

Based on examination of the research literature, the predicted path model of caregiver burden responses was proposed to depict the relevant variables under study. Since there was no specific theory of caregiver burden responses for cancer for which to test, the exploratory path analysis was designed to examine the effects of selected predictor and intervening variables on caregivers' perceived impact of care.

Nonetheless, causal ordering in the model was devised by the investigator and suggested by the review of research. Pearson linear correlations were used to determine the relationships among all the variables. Path coefficients were derived by employing three ordinary-least-squares regression equations.

Summary of Research Questions

The specific questions addressed in this research were: to what extent does duration of care and patients' functional status influence caregiver burden responses, and does patients' and caregivers' emotional-mental state of depression help to clarify the relationship to predict caregiver burden responses? The first series of hypotheses addressed the relationship between duration of care and each of the three burden responses, impact on caregivers' health, daily schedule, and finances. All hypotheses relating to duration of care were rejected because no significant relationship was found between it and the other variables under study.

While duration of care did not appear as a significant variable in the correlation and regression analysis, questions arise as to problems of measurement and conceptualization of the duration variable. Measurement problems were likely a result of subjects having to recall when care actually began, or the often ill-defined onset of the disease. Conceptually, it is quite possible that the further out in time patients and their caregivers get from the date of new or recurrent cancer, the more apt they are to adjust, normalize, or otherwise develop coping strategies to deal with the impact and stress of cancer and care. Thus, an important need exists to reassess and examine the relationship between duration of care and caregiver burden.

The second series of hypotheses were stated to assess the relationship between each of the burden responses and patients' functional status. There were significant correlations found between patients' functional status and two of the burden outcomes, as well as both intervening depression variables. Thus, patients' functional status was retained in the causal model and subsequent analysis. Results from the ordinary-least-squares regression analyses revealed only the burden response of impact on schedule was directly effected by the predictor, patients functional status.

The relationship between patients' functional status and patients' depression was the focus the next hypothesis. A significant correlation was found between the two variables and the beta coefficient (in this case, beta = r) derived from the simple regression was entered in the path figure.

A causal relationship was found between patient's depression and caregiver's depression, which attests to acceptance of the third hypothesis. A significant beta coefficient was derived from the second regression and added to the path figure.

The final hypotheses predicted a causal relationship between caregiver depression and each of the three burden responses. Significant beta coefficients were derived from each of the regressions in the third equation and entered in the path. Thus, the final hypotheses were accepted.

Testing of the path model was accomplished by calculating the standard error of estimate for the sample correlations. In order to assess the predictive power of the path model for the population a test of goodness-of-fit for each of the three burden models was calculated. It was found that, indeed, each of the three path models predicted population correlations consistent with the observed correlations, i.e. the sample correlations did not differ by more than two standard errors from the predicted population correlation. Therefore, each model could be accepted as partially predictive of the specific caregiver burdens under investigation.

Only the model for impact on caregivers' schedule was found to have both direct and indirect effects. It also had revealed a greater amount of explained variation than each of the models for impact on health and impact on finances. Thus, the model for impact on schedule could be accepted as better predictive than the models for impact on health and finances.

In summary, based on the path model, patient's functional status affects caregivers' burden responses largely because it influences patients' and then caregivers' mental health. Only in the case of impact on schedule does there appear to be a direct effect of patient's functional status on caregiver burden. An important implication of this finding relates to the aims in design of interventions to ease caregiver burdens, i.e. focussing on patients' and caregivers' mental health.

Primary Conclusions

The following conclusions may be made based upon the findings from the present study.

1. Duration of care, measured in months, is not a relevant variable in the proposed path model for caregiver burdens among spouse caregivers for cancer patients.
2. There is a direct causal relationship between patients' functional status and caregivers' burden impact on schedule.

3. Patients' functional status is an important factor which, if not predictive of, directly contributes to cancer patient's depression.
4. Among husbands and wives, there is a significant causal relationship between patients' depression and caregivers' depression.
5. There is a causal relationship between caregivers' depression and their burden responses to the impact on their health, daily schedule, and finances.
6. The causal effect of patients' functional status on caregiver burden responses is largely through its' influence on patients' and then caregivers' depression.
7. The observed sample correlations in this study did not differ significantly from predicted population correlations in each of the three path models. Thus, the models are found to be acceptable in delineating a limited number of predictive influences to cancer caregiver burden.

Implications for Interventions

As depicted in each of the path models, caregiver burden responses appear to be influenced primarily through patient's depression and then caregivers' depression. This finding has important implications to ease caregiver burdens. While caution should be noted to not deny the effect of patients' functional status, the psychosocial aspect of depression appears to exert a greater influence on caregivers' perception of the negative impacts of care. Since care is often characterized as a family event or family illness, strategies to address family reactions (i.e. spouse caregivers' burden or depression) should therefore take into account the family issues that are relevant to specific responses incurred by the family's experience of cancer. At the least, interventions should be designed to address the mental health needs and well-being of both the patient and his/her caregiver.

Identifying the goal to lower depression may be more efficacious to the easing burdens than would the design of specific programs to relieve the caregiver of specific activities of care (i.e. respite or in-home help). The critical point is that depression will likely color the perceived impact even if the specific burden impact is objectively relieved. Thus, caregivers may still feel the effects of the burden.

While this study did not seek to address the causes of depression, some of the intervention approaches may be appropriately aimed concurrently at the causes and symptoms of depression. For example, nursing strategies may promote activities which advance greater health locus of control, particularly with regard to symptom management and the control over side effects of cancer treatment protocols which could be influencing patients' depression.

Psychosocial interventions to address and treat family and marital problems related to the role disruption brought upon by cancer are another relevant area to broach in the ease of cancer care related stress and burden. Attention to the stress associated with the complementary roles of patient (care receiver) and the well spouse (caregiver) may be an important avenue to consider for clinical interventions with cancer caregiver dyads.

An additional issue not addressed by the present study, but which deserve mention as potentially critical factors in assessing the impact of cancer on the family, relates to the dynamic issues within the family system. Specifically, problems related to interruption of the family life-cycle or future family plans may influence both patients' and spouse caregivers' emotional reactions to cancer and care. Intrapsychic and world views toward death and spirituality may also come into play when clinical intervention is called for or initiated. The last issue, noted as both a clinically relevant area of concern and a direction for future research, involve the history and quality of the relationship as the potentially overriding influence upon depression and negative responses to cancer and care.

In summary, evidence from this study would suggest that caregiver depression and burden responses are separate dimensions of the family cancer experience. They must be treated separately in the design of interventions to ease the stress and burden of caregiving. Each of the burden responses may requires distinct and precise approaches to enable caregivers to experience any relief of burden.

However, as findings from this study indicate, depression appears to be the overriding variable influencing the perception of impact from care. Easing caregiver depression then should be considered as a primary aim of interventions to ease burden.

Implications for Future Research

Given that there is no arguably distinct or consistent theoretical model of family caregiver burden, nor a specific framework to guide an investigation of the stress encountered in family cancer care, the present study should be viewed as an exploratory and descriptive path model analysis of the cancer experience. The present model predicting cancer caregiver burden, while not rejected as significantly different from the population, does not cast an exceptionally persuasive theoretical breakthrough. The relevance of patients' depression, and then caregivers' depression, was identified as mediating variables in the causal path of caregiver burden responses. Thus, the modest aim of the present study was achieved.

The selection of different predictor "need for care" variables would be recommended to test for stronger and more direct causal relationships to the burden outcomes. Specifically, by selecting temporal ranges of the duration of care variable may help in selecting those families newly diagnosed, or diagnosed as newly recurrent, and reveal variant effects of duration upon burdens.

Other specific measures of patient functional status should be utilized for finer, more clearly distinct descriptions of patient dependency. The measure used in the present study, while presumably sensitive enough, did not provide remarkably thorough detail. While the measure served adequately for the current study, a more elaborate multidimensional indicator would have perhaps served the model better.

The current state of research in cancer caregiving is reflected in the relative infancy with which the theoretical groundwork has been laid. This study represents an attempt to examine only some of the relevant concepts germane to cancer family care. Further research in the general area of psychosocial aspects of cancer families, and caregiving for cancer patients in particular, is urgently needed. Specific research directions should address variable issues of the pre-caregiving environment.

Summary

In final summary, the present study stands as an effort to develop and test an exploratory model predicting the specific caregiver burden responses of impact on health, schedule, and finances. This study was designed to examine the influence of patient and caregiver depression as a mediating variable in the causal relationship between patient functional status and caregiver burden. Findings from this research reveal that, among husbands and wives, cancer patients' functional status affects caregiver burden largely because it influences patient depression and then caregiver depression. Only in the case of impact on schedule was there a direct effect of patients' functional status.

APPENDICES

APPENDIX A

CES-D SCALE

During the PAST MONTH, how much of the time ...

Rarely or of the Time	**Some of the Time**	**Most of the Time**	**Almost None All of the Time**
(1)	**(2)**	**(3)**	**(4)**

1. were you bothered by things that usually don't bother you?

2. have you not felt like eating; had a poor appetite?
3. have you felt that you could not shake off the blues, even with the help from family or friends?

4. have you felt that you were just as good as other people?

5. have you had trouble keeping your mind on what you were doing?

6. have you felt depressed?

7. have you felt that everything you did was an effort?

8. have you felt hopeful about the future?

9. have you thought your life has been a failure?

10. have you felt tearful?

11. has your sleep been restless?

12. were you happy?

13. have you talked less than usual?

14. have you felt lonely?

15. were people unfriendly?

16. have you enjoyed life

17. have you had crying spells?

18. have you felt sad?

19. have you felt that people disliked you?

20. could you not get "going?"

APPENDIX B

CAREGIVER BURDEN RESPONSES

Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)

A. **Impact on Health**:

1. I am healthy enough to care for ______. (reflect)

2. It takes all my physical strength to care for ____.

3. My health has gotten worse since I've been caring for ___.

4. I have enough physical strength to care for ____. (reflect)

5. Since caring for ____ it seems like I'm tired all the time.

B. **Impact on Daily Schedule**:

1. My activities are centered around care for _____.

2. I have to stop in the middle of my work to provide care _____.

3. I have eliminated things from my schedule since caring for _____.

4. The constant interruptions make it difficult to find time for relaxation.

5. I visit family and friends less since caring for ____.

C. **Impact on Finances**:

1. My financial resources are adequate to pay for things that are required for caregiving. (reflect)

2. Its difficult to pay for _____'s health needs and services.

3. Caring for ____ has put a financial strain on the family.

APPENDIX C

KARNOFSKY PERFORMANCE SCALE

Which of the following best describes your relative's physical functional performance status within the past month?

__ No symptoms, fully active and able to carry out all daily activities without restrictions (1)

__ Some symptoms, fully active and able to carry out light activities or sedentary activities (house or office work) (2)

__ Symptomatic, unable to carry out work activities and in bed less than 50% of the day (3)

__ Symptomatic, unable to care for self, in bed 50% or more during the day (4)

__ Symptomatic, unable to care for self, bedridden (5)

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