

The Impact of Health Care Provider Communication on Self-Efficacy and Caregiver Burden in
Older Spousal Oncology Caregivers

by

Joyce J. Grater, MSW

BA, Indiana University of Pennsylvania, 1971

MSW, University of Pittsburgh, 1979

Submitted to the Graduate Faculty of

University of Pittsburgh School of Social Work in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

University of Pittsburgh

2005

UNIVERSITY OF PITTSBURGH
GRADUATE SCHOOL OF SOCIAL WORK

This dissertation was presented

by

Joyce J. Grater, MSW

It was defended on

August 11, 2005

and approved by

Dissertation Advisor:
Esther G. Sales, Ph.D., Chair
Professor
School of Social Work
University of Pittsburgh
Gary Koeske, Ph.D.

Wynne Korr, Ph.D.
Professor
Dean, School of Social Work
University of Illinois at Urbana

Catherine Bender, Ph.D.
Assistant Professor
Health and Community Services
School of Nursing
University of Pittsburgh

Gary Koeske, Ph.D.
Professor
School of Social Work
University of Pittsburgh

THE IMPACT OF HEALTH CARE PROVIDER COMMUNICATION ON SELF-EFFICACY AND CAREGIVER BURDEN IN OLDER SPOUSAL ONCOLOGY CAREGIVERS

Joyce J. Grater, PhD

University of Pittsburgh, 2005

This study explored how health care provider communication was related to self-efficacy and caregiver burden in older spousal caregivers of oncology patients. A convenience sample of 66 older (over 60 years of age) spousal caregivers of patients with advanced disease, completed a self-administered questionnaire. The questionnaire included measures of health care provider communication, social support, self-efficacy, and caregiver burden. The communication and self-efficacy measures were developed for this study. A factor analysis was done on both measures and both had good validity ($\alpha > .90$). A multiple regression analysis was performed to test for predictors to caregiver burden. Neither communication, nor self-efficacy were significant predictors of caregiver burden. Nor was communication a predictor to self-efficacy. Gender and social support were the predictors of burden. Bivariate analyses had shown a correlation between a caregivers health status and increased burden. One major finding was that, although this was a group of caregivers caring for spouses with advanced or terminal disease, very few had seen a social worker and none had been referred to a hospice or palliative care program. No caregivers were using any community social services. Implications for social work include early assessments of older caregivers to help identify at-risk caregivers, and to provide

appropriate referrals to alleviate burden. Other research implications include further testing of the communication and self-efficacy measures.

Key word/phrases: caregiver burden, self-efficacy, health care provider communication, oncology family caregiving

TABLE OF CONTENTS

ACKKNOWLEDGMENT.....	ix
1. INTRODUCTION	1
1.1. CANCER AS A CAUSE OF DISABILITY AND MORTALITY	1
1.2. NATIONAL TRENDS IN INFORMAL CAREGIVING	5
1.3. JUSTIFICATION FOR STUDY	7
1.4. RELEVANCE TO SOCIAL WORK.....	9
1.5. PROBLEM STATEMENT.....	10
2. THEORETICAL FRAMEWORKS.....	14
2.1. ROLE THEORY.....	14
2.2. STRESS-COPING MODEL.....	16
2.3. SELF EFFICACY.....	21
3. ONCOLOGY CAREGIVING AND COMMUNICATION IN CANCER CARE: A REVIEW OF THE LITERATURE	25
3.1. THE TRAJECTORY OF CANCER CARE	25
3.1.1. Primary and Adjuvant Treatment.....	25
3.1.2. Advanced Cancer.....	26
3.2. ONCOLOGY CAREGIVING	32
3.3. COMMUNICATION BETWEEN HEALTH CARE PROFICERS AND PATIENTS/CAREGIVERS	37
3.3.1. Communication Triads.....	42
3.3.2. Barriers to Communication.....	45
3.4. STUDY VARIABLES.....	49
3.4.1. Independent, Mediating and Dependent Variables.....	49
3.4.2. Contextual Variables.....	50
3.5. RESEARCH HYPOTHESES	51
4. METHOD	53
4.1. STUDY PARTICIPANTS AND PROCEDURES	53
4.2. PROCEDURES FOR FOCUS GROUP.....	55
4.3. PRETEST OF COMMUNICATION QUESTIONNAIRE	57
4.4. MEASURES	57
4.4.1. Communication.....	57
4.4.2. Self-efficacy.....	60
4.4.3. Caregiver Burden.....	61
4.4.4. Social Support Scale Data.....	63
4.4.5. Other Resource Variables	64
4.4.6. Other Variables	65
4.4.7. Data Analysis.....	66
5. FINDINGS.....	67
5.1. DESCRIPTIVE DATA.....	67

5.1.1.	Illness Data.....	68
5.1.2.	Descriptive Measurement Data.....	71
5.1.3.	Bivariate Analyses	74
5.2.	TEST OF MODEL.....	78
5.2.1.	Multiple Regression Analysis: Predictors to Caregiver Burden	78
5.2.2.	Analyses Testing Social Support as a Moderator	82
6.	DISCUSSION.....	86
6.1.	STUDY LIMITATIONS AND STRENGTHS.....	91
6.2.	CONCLUSION.....	92
	APPENDIX A: FOCUS GROUP DISCUSSION ITEMS.....	93
	APPENDIX B: SURVEY PACKET	97
	BIBLIOGRAPHY	110

LIST OF TABLES

Table 1. Caregiver age, gender, race, education, and income	68
Table 2. Diagnosis	70
Table 3. Descriptive Data of Burden, Social Support, HCP Communication, and Self-Efficacy Scores	72
Table 4. Descriptive Data of HCP Communication Measure.....	73
Table 5. Intercorrelations of Burden, Self-Efficacy, HCP Communication, and Social Support Variables.....	75
Table 6. Intercorrelations of Selected Variables and Demographics. (Rs).....	77
Table 7. Summary of Hierarchical Regression Analysis for Variables Predicting Caregiver Burden in Oncology Spousal Caregivers (N=66)	78
Table 8. Multiple Regression Analysis for Medical Subscale of HCP Communication Measure. Predicting to Caregiver Burden (DV)	80
Table 9. Multiple Regression Analysis for Supportive Communication Subscale of HCP Communication Measure, Predicting to Caregiver Burden (DV).....	81
Table 10. Multiple Regression Analysis for “Financial Problem” Subscale of CRA as the DV	84

LIST OF FIGURES

Figure 1. Main Research Model.....	47
------------------------------------	----

ACKKNOWLEDGMENT

First, I want to thank Dr. Esther Sales, my chair, for her infinite patience, guidance, and mentoring throughout the dissertation process.

I want to thank my committee members: Drs. Gary Koeske, Wynne Korr, and Catherine Bender for their expertise, advice and support.

Also thanks to my good friend, Kay Lowmaster, who deserves an honorary Ph.D. Her oncology social work skills helped me think through my research every step of the way.

And finally, many thanks also to Paul, Cait, Liz, and Sunny for their encouragement, love, and support all along the way. You got me to the finish.

I am grateful for the financial support from the American Cancer Society's Pre-doctoral grant in Oncology Social Work.

1. INTRODUCTION

Caregiver burden is an increasing problem with oncology patients surviving longer, but often with more complicated care and treatment, much of that care falling to family caregivers. While research has identified patient and caregivers variables associated with caregiver burden, less research has focused on how communication with health care providers might affect caregiver burden. This study investigates how communication with health care providers affects a caregiver's self-efficacy in caregiving, and if that competency then affects caregiving burden.

1.1. CANCER AS A CAUSE OF DISABILITY AND MORTALITY

Cancer is a major cause of disability and mortality in older Americans (NCI, 1991). The risk of developing any kind of cancer for persons age 65 and older is 11 times that for those under 65, and has increased 28.4% from 1,707 (per 100,000) in 1974 to 6,004 in 1997 (Ershler; 2003; NCI, 1997b). Cancer mortality is also higher in the elderly, with 70% of all deaths in persons aged 65 and over due to malignant tumors.

The lifetime risk of cancer is higher in males than females (559.6 per 100,00 vs. 420.1 per 100,00) (Ershler, 2003). Most sex related differences in the incidence of cancer occur after 64 years of age. Lung cancer is the most common fatal cancer in both sexes over 60 years and accounts for approximately 30% of cancer deaths in that group. In the

age group 60 to 79 years the second and third ranked fatal cancers in women are breast and colorectal; in men they are colorectal and prostate cancers.

Because cancer is more comprehensively screened for, detected earlier, and more aggressively treated in older adults, the five -year survival rate for all sites has improved for those over 65, from 45.9% for those diagnosed between 1981-86 (NCI, 1990) to 55.4% for those diagnosed between 1986-93 (NCI, 1997a). In spite of this increased survival rate, there is strong evidence of a pattern of under-treatment among elderly cancer patients, leading to poorer outcomes, which appears to be independent of their health status (Balducci, 2003). A strong effect of age on how cancer is treated has been seen in lung, breast, colorectal cancers and non-Hodgkin's lymphoma (Dale, 2003). Because the studies on undertreatment have been retrospective, it is not possible to capture the complexity of reasons for the use of less than standard treatments, such as patient preference or clinicians' assumptions about the ability of the patient to tolerate treatment.

While the role of bias and undertreatment is significant in understanding cancer treatment in older adults, it is also necessary to consider the risks of chemotherapy toxicity in elder patients with cancer. Older patients are at greater risk of chemotherapy induced myelosuppression than younger patients, particularly neutropeni,a that is the primary dose- limiting toxicity of chemotherapy (Dale). The incidence and severity of the toxicity of chemotherapy are greater in older patients (Balducci, 2000). The occurrence of myelosuppression, cardiosuppression, peripheral neuropathy, and central neurotoxicity can complicate treatment (Repetto, 2003). Effective management of toxicity induced by chemotherapy is crucial along with appropriate supportive care in the

elderly population in order to give them the best chance of cure and survival, or to provide palliation. It seems critical for caregivers to be educated about chemotherapy induced toxicity, so that the caregivers can monitor changes in a patient before the problems become too severe.

In addition to chemotherapy related toxicities, persons 65 years of age and older have three different diseases on average (Fried, Bandee-Roche, et al., 1999; Overcash, 1998). Comorbidities have a negative effect on survival in patients with cancer (Repetto, 2003). Common comorbidities include cardiovascular disease, hypertension, chronic bronchial obstruction, arthritis, benign prostatic hypertrophy, and depression.

Because of these comorbidities, polypharmacy and high drug use are common in older patients, and the drugs used to treat other health problems may interact with the chemotherapy drugs (Repetto, 2003). Another consideration is that the toxicities of chemotherapy may be exacerbated by the side effects of the drugs being used to treat comorbidities. Thus, drug interactions are a particular concern in the treatment of elderly cancer patients and caregivers of these patients should be educated to understand possible drug interactions and know when to get medical attention in a timely fashion.

As mentioned above, depression is a common comorbidity in the elderly. There is in fact an expanding body of research documenting the occurrence of depression in older adults in conjunction with medical illness (Caine, Lyness, & Holland, 1993). Older adulthood is a stressful time when life events and changes cluster and the incidence of physical illness and disability can increase. Psychosocial resources are often diminished while financial constraints may expand with advancing age. Given these developmental trends, a diagnosis of cancer and its subsequent treatment demands may present

significant adaptive challenges to both patients and their elderly caregivers (Raveis, 1999).

One of the changes that occurs in families when there is a life threatening diagnosis is that roles of family members shift and new roles are created. It is within that context that the caregiver role emerges. Broadly defined, the caregiver role is behavior that is expected or characteristic of an individual who occupies a particular position within the social system (Berg-Weger & Rubio, 1995). More specifically, the caregiver becomes immersed in the role through the performance of tasks or duties which are of extended duration and change in response to the patient's needs.

Providing care to oncology patients at home challenges families' physical, emotional, and material resources. Some groups of caregivers are more at risk for physical and emotional problems. Elderly spousal caregivers are especially at risk for their own physical and mental health. Some researchers have shown that spouses have continued to have more emotional problems than the patients at 2, 3, and 6 months follow-up (Oberst & James, 1985) and that elderly spouse caregivers of cancer patients experience more depression than their ill spouses (Gilbar, 1994). Others have examined types of elder impairment (physical or cognitive) and the impact on caregiver health outcomes for depression and change in health status among caregivers (Goode, Haley, Roth, & Ford, 1998; Ho, Irwin, & Grant, 1997; Neary, 1993; Shaw, Patterson, Semple, Williamson, Shaffer, Schulz, 1998).

Despite the burgeoning research in the area of family caregiving, there is still a paucity of research examining how caregiver burden may be affected by the quality of the interactions between the caregiver and the health care providers. There is abundant

research, to be sure, in the area of doctor-patient communication (Cooper-Patrick et al, 1999; Finset, et al, 1997; Kaplan, et al, 1989; Kaplan, et al, 1996; Marvel, et al, 1999; Ruckdeschel et al., 1999). However, the provision of health care is no longer, if it ever was, of a dyadic nature, especially in chronic illness and the elderly, where it is likely that the caregiver has her own set of health problems. For the care of the chronically ill patient to be optimal, not only the doctor, but also other types of medical professionals must interact with both the patient and the caregiver, and often with other members of the patient's family. With family caregivers expected to take on medical and nursing care at home, health care providers must communicate effectively with the caregivers as well as with the patients.

1.2. NATIONAL TRENDS IN INFORMAL CAREGIVING

It is estimated that 70 to 80% of supportive care to the elderly is provided by family members and, of those who are married, the wife most often is the primary caregiver (Staight & Harvey, 1990). It is well known that there are many sequelae to caregiving, including physical and psychological illness (Schulz and Beach, 1999). The cumulative stresses of caregiving lead to different types of caregiving endpoints. These endpoints may be the decision to institutionalize, social role changes, and psychiatric and physical morbidity (Biegel, Sales, & Schulz, 1991).

It seems especially salient now, in these times of great changes in health care delivery in the United States, to examine family caregiving in a context that recognizes caregiving as a viable medical component of a changing health care delivery system. It is estimated that as of 1997 there were 27.6 million caregivers providing assistance to non-

institutionalized adults in the United States (Arno, Levine, & Memmot 1999). Arno, et al.(1999) studied the economic value of informal caregiving and, using the National Family Caregiving Survey, estimated that the average caregiver provides 17.9 hours of informal caregiving per week. Applying this figure to the number of estimated caregivers yields approximately 22 to 26 billion hours of caregiving per year, nationwide, with the midrange estimate of 24 billion hours. Using this midrange figure and calculating the hourly rate at \$8.18 per hour, the national economic value of informal caregiving was \$196 billion in 1997

To see this in another light, the national expenditures for formal home health care was \$32 billion and nursing home care was \$83 billion in 1997 (Arno, 1999). Because informal caregiving lies outside the market economy, it is socially and politically invisible. But if it were a part of national health care expenses, it would be equivalent to approximately 18% of those expenditures. Some researchers have begun to investigate the economic impact of caregiving for certain chronic diseases, such as cancer (Sarna & McCorkle, 1996; Stommel, Given, & Given, 1993), Alzheimer's Disease (Ernst and Hay, 1994; Leon, Cheng, & Neumann, 1998), Parkinson's Disease (Whetton-Goldstein, et al., 1997), and AIDS (Turner, Catania, & Gagnon, 1994), among other chronic illnesses.

As the baby boomer population ages, interest in caregiving research will increase. In particular, government long-term care policies may be influenced by the outcomes of this research, or alternatively, existing long term care policies should be researched to determine the effects of policies on the targeted populations. With the aging of the baby boomer cohort, caregiving will be a significant social welfare and public policy issue. Projections as to the numbers of elderly who will require any type of long term care

varies, but there is consensus among health policy makers that, in the future, caregiving for the elderly will be problematic and expensive (Feder, 1998; Moon, 1996).

The AMA (1993) recognizes the importance of family caregivers in their policy statement (H-210.986) calling for a model of partnership for physicians and family caregivers. It calls for education of physicians in the development of interpersonal skills to better facilitate and manage caregiver burden. It also calls for further research on the role of physicians and other health care providers in supporting family caregivers. This policy statement acknowledges the link between formal and informal care.

1.3. JUSTIFICATION FOR STUDY

Older patients with cancer are cared for by family members who are frequently unprepared for the challenges of cancer caregiving (Haley, 2003). Older cancer patients have diverse needs and may need assistance with medication, transportation for treatment, activities of daily living, and social support. Caregivers of elderly cancer patients may have to accurately assess and report symptoms, especially if the patient has depression, dementia, or hearing loss, so education of the caregiver for this role is critical (Haley). Also, caregivers may have to participate in stressful end-of-life decisions, such as whether to use a hospice or other palliative care programs, or even whether to terminate life support while still being a source of emotional support to the patient (Haley). Older spousal caregivers may be more vulnerable to the negative effects of caregiving, such as fatigue and sleep disruption, because of their own old age, poor health, and willingness to suffer to provide care for their partner (Haley). Healthcare

professionals, including nurses, social workers, and psychologists, can have a positive effect on caregivers' well-being by providing information and support.

When one is chronically ill with cancer, health care professionals become an important support network for patients and their families. One way that the quality of that support can be defined is in the communication that occurs between patient, health professional, and family caregiver. For the health care providers to be a support network, they must support the family and patient through the illness experience. For this reason it is important for the patient and the caregiver to have optimal communication with health care providers so that caregivers have adequate preparation and knowledge to provide care confidently at home. This includes assistance with psychosocial concerns and appropriate referrals to community agencies. Healthcare professionals can help identify and prioritize caregivers' problems and develop problem-solving strategies. Behavioral interventions such as teaching new coping behaviors may help reduce caregiver distress and can be taught in individual sessions or in formal educational programs on cancer and caregiving (Haley, 2003). For example, after caregivers attended a 6 hour Family Caregivers Cancer Education Program that taught communication skills, symptom management, and resource identification, participants reported feeling more knowledgeable, less overwhelmed, and better able to cope with caregiving (Barg, et al, 1998).

Blanchard, et al (1995), in a review of selected studies of the role of social support in adaptation to cancer and survival, propose that a closer consideration of the role of support in the relationship between health care professional and patient is warranted. They also argue that studies should be more specific about the categories of health care

professionals who are considered to be sources of social support. One could argue that the role of social support is also important between healthcare providers and caregivers, especially with elderly caregivers who are more at risk for health problems secondary to caregiving than younger caregivers. Communication is increasingly acknowledged as a crucial component of an effective and socially responsible cancer care system (Thorne, 1999). A growing body of research reveals patterns in the way professional health care providers interact with patients and families and links these patterns with the illness experience as well as with quality of life (Blanchard, Albert, Ruckdeschel, Grant, & Hemmick, 1995; Sales, 1992; Thorne, 1999). It confirms that communication makes a quality of life difference throughout the continuum of the cancer illness (Blanchard, et al.; Thorne). Good quality means providing patients with appropriate and technically competent care, with good communication, shared decision-making, and cultural sensitivity (Thorne).

1.4. RELEVANCE TO SOCIAL WORK

Health related issues that impact families are central to the practice of oncology social work. Social workers practice from an ecological perspective, understanding the systems framework and how family functioning is affected at all levels by events that occur both within and external to the family. Ecological systems theory posits that individuals are engaged in constant interactions with systems in their environment and that these other systems and persons reciprocally influence each other (Hepworth, Rooney, & Larsen, 1997). Therefore, adequate assessments of human problems and plans of interventions should consider this reciprocal impact of people and environmental systems. From this perspective, the satisfaction of human needs

and mastery of developmental tasks require the availability of adequate resources in the environment and positive transactions between persons and their environment (Hepworth, et al.)

Cancer and its sequelae are such issues. Knowledge gained from this research would contribute to the caregiving literature in oncology by providing some understanding of the linkage between caregivers and oncology health care providers. Although there is an abundance of research in the caregiving field, there is little research connecting caregiving with variables beyond the individual and family system. Because oncology patients see many different types of specialists over the course of many years, it is important to understand the impact of interactions with these specialists on caregiving outcomes.

1.5. PROBLEM STATEMENT

Elderly patients with cancer differ greatly in physiologic age, frailty, and cognitive ability. The degree of physical impairment due to the disease and its treatment differs, so the caregiving demands range from minimal assistance with activities of daily living to complete care of debilitated patients. It may involve administering medications, managing side effects, providing appropriate nutrition, providing emotional support, and accurately assessing symptoms.

Cargivers are frequently unprepared for their role and need guidance and support from healthcare professionals in preparing for and managing caregiving, the disease, and its treatment, its symptoms, and medications (Haley). Caregivers do not necessarily know what community resources are available which may help both the patient and caregivers in having their needs met. Healthcare professionals, including, but not limited to, doctors, nurses, and social workers can help caregivers identify and prioritize problems and develop strategies to assist in solving them.

The specific aim of this dissertation is to determine how communication with health care providers impacts a caregiver's feeling of competency to provide care, or their self-efficacy, which, in turn, affects caregiver burden in elderly caregivers of oncology patients. It is hypothesized that communication with health care providers will impact a caregiver's feelings of competency in providing care. In turn, this feeling of competency will have a direct effect on caregiver burden experienced by elderly spousal caregivers. That is, it is expected that caregivers with a negative experience with providers will feel less competent in caregiving and will experience greater caregiver burden. Health care professionals will include physicians, nurses, and social workers. Although it is usually the doctor-patient relationship that is viewed as critical in the literature on communication in health care, it is important to acknowledge that patients and families develop important relationships with other members of the health care team. It is possible that a consistent and caring relationship with other members of the interdisciplinary team could offset a less than satisfactory relationship with a physician and could sustain a caregiver throughout the caregiving experience.

To reiterate, positive interactions with health care professionals can be viewed as a form of social support, which is known to have a buffering effect on stress (Biegel, et al, 1991). Support may include, but is not limited to, teaching caregivers how to provide particular kinds of care, managing symptoms, providing information, making appropriate referrals to community agencies, assisting patients and caregivers in decision-making, and helping caregivers and patients understand and cope with their feelings and circumstances. As noted above, elderly people often have a diminished social support system as well as being more likely to have health problems. Thus having a sense of being supported and cared for by medical professionals may be even more important for elderly caregivers than for a younger age group.

Socioeconomic status is a contextual variable that affects both caregiver burden and communication. SES has been linked with many factors in health care both globally and more specifically. Poor doctor-patient communication in discussions of the effects of medications has been linked to a lower socioeconomic status (Rosenberg, et al, 1997). Less aggressive treatment of lung and breast cancer has also been correlated with lower socioeconomic status (Hewitt & Simone, 1999). Age related differences in healthcare costs vary depending on the treatment approach and may also differ across disease sites (Erschler, 2003). Since Medicare does not provide for prescription drug coverage, outpatient prescription drug costs can be prohibitive for elderly people on a fixed income if they do not have a coinsurance to cover the costs. Financial costs may contribute to caregiver burden in many elderly caregivers of cancer patients. Thus age and socioeconomic status are important demographic variables to account for in explaining the relationship between health care provider interaction, self-efficacy, and caregiver burden.

The literature on the direct impact of cancer-related variables related to caregivers suggests a number of illness factors that appear to affect caregiver adjustment: the illness stage and prognosis, caregiving demands, illness duration, cancer site, and patient distress (Biegel, et al, 1991). Other variables affecting caregiver distress include such contextual variables such as caregiver characteristics, for example age and gender, and social support (Biegel, et al). This study will include the usual demographic variables in the research model: gender, race, income level, education, insurance, and employment status. The study will also include a set of “illness variables,” the site of the cancer diagnosis, stage of disease, type of treatment the patient is currently receiving, length of time since diagnosis, if the patient is enrolled in a clinical trial, and if the patient has sought second and third opinions from other institutions. A third group of

contextual variables will be social support available to the caregiver and community resources being utilized, such as Home Health Care or Hospice.

The proposed research would add communication with health care providers as another key variable linking the caregiving experience to the health care environment. It is hypothesized that an elderly caregiver's communication with health care providers will contribute to the caregiver's feeling of competency in the caregiving role, leading to a decrease in caregiver burden. Findings from this research may have implications for the development of clinical programs and supportive services for older cancer caregivers.

2. THEORETICAL FRAMEWORKS

2.1. ROLE THEORY

Role theory establishes caregiving as a normative role in the family life cycle and helps explain the relationship between role assumption, the level of willingness to assume the role, and caregiver strain. Role theory frames roles as an assumed series of relationships and interactions (Berg-Weger, 1995). Goode (1960), one of the early role theorists whose work has implications for caregiver burden, suggested that caregivers are willing to assume a role for intrinsic gratification related to role tasks, protective gains and internal self reward/punishment, suggesting that caregivers strive to fulfill a normative expectation and/or avoid criticism by others (Berg-Weger, 1995).

The caregiving literature is rich in studies examining various facets of role strain: gender aspects (Baruch, & Spaid, 1989; Miller, 1990 ; Young & Kahana,1989), daughters as caregivers (Mui, 1992; Scharlach, 1987); from a race perspective (Mui,1992), and from a family burden perspective (Sales, 2003). Another major focus of caregiving research is role overload and role conflict, in particular, multiple roles of female caregivers (Christensen, Parris, Townsend, 1998; Doress-Worters, 1994; Franks, & Stephens, 1992; Scharlach, 1994; Stoller & Pugliesi, 1989; Stull, 1994). Providing care to a seriously ill spouse, parent, or other significant person can restrict a caregiver's personal and social life, employment and vocational opportunities, as well as create financial burdens. The outcomes of these strains are psychological distress, physical health problems, and psychological distress, and increased caregiver burden.

Role theory is also an important theoretical framework for the examination of family caregiving within the context of the health care system in which family caregiving occurs. Role

theory attempts to explain the ways in which a person's behavior is indirectly or directly influenced by the social environment (Davis, 1996). It is a theory consistent with social work's historical emphasis on person-in-the- environment framework. Generally, *role* refers to patterned behaviors enacted by persons in an interaction situation. Roles are classifications of behavior and do not exist in isolation, but are designed to have reciprocal functions in a relationship with others (Davis).

Caregiving performed by a family member, in this case an older spouse, is a social role, which has contained in it such relational qualities and expectations. Znaniecki (1965) defined a social role as a set of patterned and functionally interdependent social relations between a person and his/her social circle involving duties and personal rights. It requires that both the individual and the circle members must meet each other's expectations, so that there is role complementarity. This circle contains everyone toward whom the person's duties are directed and everyone who grants the rights which make it possible to perform their duties. The title of the role most often carries with it the culturally defined behavior, for example a doctor "doctors"; a mother "mothers", a caregiver "gives care", and so on. Lack of role complementarity may result from lack of knowledge of the role system; differing goals on the part of the role partners; disagreement as to the right of one of the partners to occupy that role; and absence of appropriate resources to aid in role performance (Davis, 1996). Lack of complementarity results in dissatisfactory relationships as well as individual and interpersonal stress.

The concept of role complementarity has relevance to the role of the oncology caregiver. There is nothing to prepare a caregiver for the emotional impact of a life threatening diagnosis or the complexity of the medical system. The medical system assumes that the primary caregiver will be a source of tangible and emotional support. Furthermore, it is assumed that the caregiver

will be responsible for providing care that has the potential for impacting the outcome of the treatment. For example, it is important for a caregiver to understand that chemotherapy causes immunosuppression and what the implications are for the patient's care. If the caregiver and the patient do not understand that the patient should not eat fresh fruits and uncooked vegetables and serves them anyway, this could have serious consequences for the patient. The medical system operates under certain assumptions about the role of the caregiver. First, there is the assumption that there is a caregiver. Then there are assumptions that the caregiver will automatically take on the role, and is capable of doing so. But these assumptions are not always conveyed to the caregiver in any standard way, depending, instead, on the communication style of the physicians and the time the medical and nursing staff has to attend to such needs. However, a caregiver must gain competency in the caregiving role through interactions with health care providers who convey information and instruction about diagnosis, treatment, prognosis, symptom management, and community resources. These are complex, stressful interactions requiring coping skills, problem solving skills, and role changes.

2.2. STRESS-COPING MODEL

The term “caregiver burden” is widely used in the caregiving literature to reflect the physical, emotional, social, and financial problems experienced by family members caring for physically and/or mentally ill adults (Staight & Harvey, 1990; Stuckey, et al, 1996; Wicks, et al, 1997). The traditional stress-coping model has been the dominant conceptual model for understanding the caregiving experience, providing a theoretical framework for interactions between the individual and the environment (Beigel, et al., 1991; Schulz, 1998). It assumes that the onset and progression of chronic illness is stressful for both the patient and caregiver, reflecting the

physical, emotional, social, and financial problems experienced by patients and families (Staight & Harvey, 1990; Stuckey, et al., 1996; Wicks, et al., 1997).

The stress-coping model is grounded in the work of Folkman and Lazarus. According to Folkman and Lazarus (1991), definitions of coping need to include the *efforts* made to manage stressful demands, independent of the outcome. The best coping changes the person-environment relationship for the better; an implicit corollary to definitions of coping is mastery over the environment, which is the coping ideal. Coping is seen as tantamount to problem solving. But Folkman and Lazarus' theory notes that sources of stress arising from managing emotions and maintaining self-esteem are not enough to master the environment or fit within a problem solving framework. Folkman and Lazarus' model has been adapted by researchers to examine the relationships among caregiving stressors, possible psychosocial resources, and caregiver well-being (Goode, et al, 1998; Yates, et al, 1999).

The basic stress model is comprised of four major components: stressors, mediators, outcomes, and contextual or background information (Biegel, et al, 1991; Goode, et al, 1998; Yates, et al, 1999). Stressors are generally interpreted as the environmental conditions to which the caregiver must adapt and are often operationalized as the physical, mental, or functional health status of the care receiver (Braithwaite, 1996). In more elaborate conceptualizations of the stress-coping model in caregiving, stressors arising directly from caregiving have been called primary stressors to distinguish them from stress that may arise secondary to caregiving within work and family roles (Goode, et al., 1998; Schulz & Quittner, 1998). Some examples of secondary stressors might include role conflict created by caregiving demands (Schulz & Quittner, 1998). For example, a caregiver may experience tension between work responsibility

and caregiving responsibility, or a caregiver may find it necessary to become an advocate for the patient, a role that may create increased stress for the caregiver.

Primary stressors constitute what is known as objective burden or caregiver workload and include the activities and responsibilities caregivers accept in order to promote the physical and mental well-being of their ill family member (Braithwaite, 1996). These are more task-oriented activities, such as providing assistance with daily activities, personal care, or any activities representing environmental demands of caregiving (Braithwaite, 1996). Subjective burden refers to the caregivers' perceptions of the impact of caregiving on their lives, physically, mentally, financially, and socially (Stuckey, et al., 1996). Several psychosocial resource factor variables that may moderate the effect of caregiving stressors on well-being have been identified. These include caregiver appraisals of primary stressors, coping responses, and social support. More specifically, better caregiver well-being has been found to be related to benign appraisals of primary stressors (lower stressfulness ratings and higher self-efficacy), greater social support, and coping responses characterized by more problem-focused coping than avoidance or emotion-focused coping (Goode, et al.). In short, almost all stressful events require one to assess the demands, challenges or threats the situation poses, and determine one's ability to cope (Lazarus, 1977). This is done by having someone to talk to about the situation, suggest coping strategies, and so on. Social support has been found to be a significant factor in the psychological adjustment of cancer patients and caregivers (Biegel, et al., 1991; Northouse, 1988).

Appraisal of caregiving stressors has garnered much attention in the caregiving literature and has been fully developed conceptually by Lawton and colleagues. Lawton drew upon the work of Lazarus and Folkman and their concept of cognitive coping processes, which is viewed as a continuing interpretation of the two-way processes of threat, coping, outcome, and

perception of outcome, which merge into the concept of “reappraisal”(Lawton, et al, 1989). Outcome variables have been conceptualized as the caregiver’s willingness to continue care, mental and physical health, and overall life satisfaction (Braithwaite, 1996). Even though the caregiving literature consistently demonstrates a moderate relationship between the level of patient disability and psychological health of the caregiver, there is much variability in caregiver outcomes that is thought to be mediated and/or moderated by many other factors (Schulz & Quittner, 1998). These factors may include available economic and social support resources, individual difference factors such as gender, personality traits, and coping strategies, and the relationship quality between the care recipient and caregiver (Schulz & Quittner). I am suggesting that the caregivers’ communications or interactions with health care providers are another such factor. Communicating with health care providers in a serious medical situation is usually a new experience for most lay people and learning to navigate this new environment is stressful.

Lawton (1991) and colleagues apply this concept of cognitive coping processes to caregiving appraisal and assert that cognitive caregiving appraisal represents an attempt to impose meaning on the caregiving process and the caregiver’s part in it; in turn, the imposition of meaning may lead to positive behavior in relation to caregiving demands. Lawton suggests that the term “caregiving appraisal” be used to describe the evaluation of any part of the caregiving process, the two most important of which are caregiving satisfaction and caregiving burden. Thus, in the experience of interacting with the health care providers of their loved ones, caregivers may, depending on the nature of those interactions, continually reappraise the nature of their caregiving experience. For example, if a caregiver is provided reassurance, appropriate explanations of diagnosis, and/or treatment, and timely teaching of caregiving tasks, it is possible

that the caregiver may appraise the caregiving experience as less stressful than it may have been without this interaction. Also, a positive interaction with health care providers may make it more likely that the caregiver would feel more comfortable asking questions or voicing concerns to the health care provider in the future, so that the caregiver will become more proficient and comfortable in the caregiving role. This is not to say that the care will be any easier or less emotionally draining, but that the caregiver may appraise the experience in a more positive light.

The caregiving stress model has been criticized for a number of reasons: that it focuses on the individual caregiver's coping mechanisms, that it does not recognize positive outcomes, and that it loses sight of the relationship between the caregiver and care recipient, as well as other family relationships (Yates, et al, 1999). The appraisal model has, however, attempted to understand these relational qualities and recognizes caregiving as a dynamic process involving caregivers, care recipients, and other environmental and psychosocial factors (Yates, et al., 1999).

This model too has been criticized mainly because some elements of appraisal overlap with elements of resources and coping strategies (Braithwaite, 1996a; Yates, et al, 1999). It is reasonable to assume that the appraisal model flows conceptually from the stress-coping model and that they both offer a strong basis for examining how caregiver burden is impacted by the caregiver's interactions with health care providers. In attempts to cope with the caregiving experience, a caregiver may appraise caregiving as less burdensome if interactions with health care providers are more positive than negative. The caregivers may feel more prepared for the task and feel more supported and validated by the health care providers as an important component of the patient's health care team, thereby increasing feelings of self-efficacy.

2.3. SELF EFFICACY

Self-efficacy is a key theoretical concept in this model, supporting the conceptual basis for this study. Because the caregiving literature frequently uses the concepts of mastery and self-efficacy interchangeably, it would be helpful to distinguish the two concepts. Self-efficacy is the expectation or belief that one can successfully perform behaviors to produce a desired outcome (Bandura, 1977). The concept was initially developed by Bandura (1977) as a construct in social learning theory, as well as playing a role in social cognitive theory (Bandura, 1986). Self-efficacy is considered to be an important determinant of behavioral change because it influences the initial decision to engage in a behavior (intention), the effort expended, and the persistence when facing difficulties (Bandura, 1977; 1986). Self-efficacy is derived primarily from the experience of personal mastery arising from one's own personal successful experiences. But efficacy expectations also originate from vicarious learning, such as seeing others perform threatening activities without adverse consequences; verbal persuasion where one is led through persuasive suggestion into believing they can cope successfully with what has overwhelmed them in the past; and through emotional arousal which can influence efficacy expectations in threatening situations (Bandura, 1977).

Mastery shares conceptual ground with self-efficacy, but it is more of a global concept of self rather than domain specific. Pearlin and Schooler (1978, p.5) define mastery as "the extent to which one regards one's life chances as being under one's own control in contrast to being fatalistically ruled." Lawton (1989) defines personal mastery as a stable view of the self that includes the expectation that one is capable of dealing with problems as they arise. But he further explains that personal mastery may manifest itself in different domains of behavioral competence and that the degree to which mastery is attributed to oneself may vary, depending on

which of the many domains of behavioral competence is being judged. Thus caregiving mastery corresponds to a belief in one's ability to provide appropriate care during the care giving process, representing another facet of caregiving appraisal. This concept of caregiver mastery is domain specific and appears closer to the concept of self-efficacy. This researcher believes that caregiver mastery describes the concept of self-efficacy in the caregiving context. The concept of self-efficacy links conceptually with role theory. Researchers who have studied the effects of role-specific mastery on caregivers' well-being have found that those caregivers with greater mastery in this role also experience less psychological distress (Franks & Stevens, 1992; Townsend, Noelker, Deimling, & Bass, 1989). Christensen et al's (1998) study of mastery in adult daughters providing care to impaired parents suggests that feelings of mastery in caregivers' additional roles may contribute to better mental health. In addition, their findings suggest that feelings of mastery as a wife may be especially important to women and so have a stronger effect on their psychological well-being. Miller, et al (1995) studied the relationships among race, psychological resources of sense of control and caregiver mastery, and distress outcomes of caregiver depression and role strain among 77 African American and 138 White spouse caregivers of persons with dementia. Caregiver mastery moderated the effects of stressors on depression and was the only significant psychological resource predicting lower role strain. All of this research provides an examination of the predictive value of caregiver mastery on caregiver distress.

The theoretical constructs framing this proposal help to explain the complexity of caregiving processes. Stress-coping theory explains the concept of caregiver burden and how a caregiver might appraise the strain of the caregiving experience. Self-efficacy provides an explanation for personal mastery derived not only from one's experiences, but also from learning vicariously

from others, through verbal persuasion, and through emotional arousal caused by stressful or threatening situations. Self-efficacy is used as a predictor that adds to or works together with other variables in predicting intention and/or behavior as well as acting as a mediating variable explaining the relationship between the independent (quality of care and satisfaction with care) and dependent (caregiver burden) variables. Finally, role theory helps explain the ways in which a person's behavior is influenced either directly or indirectly by the social environment. It is an important framework for examining family caregiving within the context of the health care system in which family caregiving occurs.

It is in that complicated health care system that family caregiving takes hold. Learning how to manage a loved one's care needs –from knowledge about the disease and treatment to daily hands on care- requires interactions with health care providers. How health care providers communicate with patients and their family members from the moment a person becomes a patient sets the stage for the illness experience for the patient *and the family*. For many people it is stressful to have to talk to doctors and other health professionals. Doctors are often seen as being too busy and family members often see themselves as disrupting the doctor's work. Unfortunately, health care providers often concur with this view. This researcher has found in her own work at a Cancer Information and Referral Service that patients and family members will often call to ask questions about treatment, prognosis, and side effects that are better directed to the treating oncologist. However the callers often say they “don't want to bother the doctor”. Some are confused by the different specialists attending their family member and don't know who is “in charge”. It is these observations over the years as an oncology social worker that have led to the view that communication between family members and health care providers is a critical variable in caregivers' adaptation and adjustment to the caregiving role, affecting

caregiver burden and the caregiver's own belief that she/he can successfully provide care to a family member.

3. ONCOLOGY CAREGIVING AND COMMUNICATION IN CANCER CARE: A REVIEW OF THE LITERATURE

3.1. THE TRAJECTORY OF CANCER CARE

In order to develop a broad-based foundation from which to examine the research questions, it is important to first offer some background about the advanced and terminal stages of the trajectory of cancer care. The trajectory of cancer care covers prevention, early detection, and screening; diagnosis and treatment of new cancer diagnoses; care of survivors; advanced care; and finally, terminal care and support for families. It is the advanced and terminal stages that are pertinent to this study.

As in other chronic illnesses, the efforts to diagnose and treat cancer are coordinated by individual physicians, health plans, and cancer care centers. Patients and their families must learn to function effectively as partners with the doctors, nurses, social workers, and others who provide and participate in their cancer treatment. Good communication with health care providers is critical to health outcomes such as symptom management.

After the discussion of the cancer trajectory, the major types of cancer treatments and who provides them will be discussed briefly. Following that will be a discussion of cancer caregiving research. Finally there will be a review of research relating to doctor -patient -caregiver communication, particularly in the provision of oncology care.

3.1.1. Primary and Adjuvant Treatment

Most cancers are treated with surgery, chemotherapy, radiation or some combination of the three (Hewitt, 1999). Surgery is the oldest and main treatment of primary solid tumors such as breast,

colon, and liver. Surgery is often curative, especially for tumors that are localized. Radiation is most often used as an adjuvant treatment to surgery. It may be external or internal. Either way, it is a localized treatment affecting cells in a specific area. Chemotherapy is a systemic treatment to eradicate any cancerous cells. It is most commonly given intravenously. It may also be given by mouth, by injection, topically, or through catheters, which may be placed in the chest, spine, or abdomen. Patients go home with catheters and caregivers are responsible for caring for them until they are removed.

Higher doses of chemotherapy and radiation are more effective than lower doses with most cancers, but they also produce serious side effects (Hewitt, 1999). Fatigue is a universal side effect, which can last for many months after treatment has stopped. Chemotherapy and radiation can compromise the immune system and can cause both cardiac and neurological toxicity (Hewitt, 1999).

3.1.2. Advanced Cancer

Advanced cancer refers to the stage where a person's cancer may start growing and spread to vital organs (ACS, 2003). Choices for further treatment become more limited as the cancer progresses. Cancer may recur at the site at which it began or it may appear as distant metastases. Advanced and incurable cancer may exist at the time of the original diagnosis or it may occur many years later. The type of treatment at this stage depends on the kind of cancer, how large it is, how it behaves biologically, and what previous therapy was given. It is not unusual for patients to seek medical opinions about experimental treatment at comprehensive cancer centers at this time. Unfortunately, the chance of curing a recurrent cancer is low, and often the goal of care is symptom relief (Hewitt, 1999).

Advanced and terminally ill cancer patients are increasingly being treated at home with the assistance of hospice or palliative care teams. This is an intense time both physically and emotionally for caregivers. Caregivers may also need to participate in stressful treatment and end of life decisions, such as whether a treatment should be stopped, whether to use hospice services, or whether to go on a clinical trial. These are considerations that require careful analysis of information in order to come to a decision. This information must come from clear communication and dialogue with the patient's health care providers

As choices for treatment become limited, palliative care increases and becomes the focus of care for the patient and the family (ACS, 2003). Palliative care refers to care that relieves suffering and improves the quality of a patient's life. It relieves symptoms caused by the cancer treatment or symptoms of the disease. Although palliative care may be given throughout all stages of cancer to some degree in order to relieve symptoms, it is more relevant to focus on this type of care in the last stages of the disease. This treatment is given during the last year of life.

Hospice care is palliative care provided near the end of life. Generally the requirements for admission to a hospice program is a life expectancy of six months or less and that the patient is no longer actively being treated. Unfortunately hospice referrals are often not made until last few weeks before death, so neither the patient, nor the family has the support and care of hospice services in a timely manner. This is an emotionally and physically exhausting time for caregivers. The caregiver must assume new tasks and provide emotional support to the patient as he or she copes with the process of dying (Sales, 1992). During this process, the patient begins to withdraw, and, unfortunately, so do friends and other family members. Caregivers experience isolation and loneliness.

End of life care involves all appropriate medical and psychosocial support services for the patient and the family as death nears. The hospice unit of care includes the family system as well as the patient. Social workers are often very involved at this time assisting with emotional support, counseling regarding advance directives, helping with respite and other services to relieve caregiver burden, and helping the family and patient to understand the consequences of aggressive life-extending treatments. End-of-life care includes spiritual, emotional, and psychological components. But too often physicians do not offer hospice referrals, or the patient refuses the services if it is offered. Also, it often happens that when a patient becomes terminal, the managed care plan refers the patient back to the Primary Care Physician instead of continued care under an oncologist. These physicians are less familiar with hospice services and terminal care needs than the medical oncologists.

When it is apparent that a person's cancer is growing and treatment choices become limited, the cancer care team can begin to make some predictions about end of life. Treatment may still continue, but the goal may be to control symptoms caused by the cancer rather than to cure the cancer (ACS, 2003). Common symptoms that are controlled or relieved by palliative care include: pain, breathing difficulties, loss of appetite and weight loss, fatigue, weakness, problems sleeping, anxiety and depression, and confusion (ACS). Caregivers need to be alerted to these symptoms of distress so that they can help the patient get help. Cancer related fatigue is a very debilitating symptom affecting one's quality of life. Rest does not always relieve it. It is defined as an "unusual and persistent sense of tiredness that can occur with cancer or cancer treatment" (ACS, p. 6). It affects all aspects of a person's life, including being with family and friends and doing any of one's normal activities. It can even impair one's ability to follow the cancer treatment plan.

As mentioned earlier, there is a greater incidence of toxicities and comorbidities in older patients, which translates into more supportive care needs. Comorbidities may also influence what chemotherapy regimen is prescribed. For example, some treatments with high cardiotoxicity would be contraindicated in older patients with cardiovascular disease. The demands of caregiving range from minimal assistance with the activities of daily living to the complete care of greatly debilitated patients, depending on the degree of physical impairment. Caregiving may involve administering medications, managing side effects of the treatment and disease, and providing appropriate nutrition.

For example, older persons undergoing chemotherapy are at greater risk for myelosuppression, the major dose limiting toxicity of modern chemotherapy regimes, which can lead to febrile neutropenia and require hospitalization (Erschler, 2003). These patients may be more susceptible to mucosal cystitis, gastritis, and stomatitis, which can lead to severe diarrhea. These symptoms require prompt treatment to prevent life threatening dehydration leading to failure of vascular support (Balducci, 2003; Repetto, 2003). Thus it is important that older patients and their caregivers should be taught to recognize the symptoms of diarrhea, cystitis, gastritis, and stomatitis.

How a medication is delivered, orally or intravenously, can be influenced by nonmedical factors, especially in the elderly. For example, oral anticancer drugs can be conveniently administered at home, but nonadherence and incorrect usage are potential problems (Balducci, 2003). On the other hand, intravenous administration can assure correct dosage, but traveling to a treatment center might be a hardship for elderly patients and their caregivers. In addition, prolonged fluid administration can cause discomfort or require hospitalization and it is contraindicated in patients with cardiac decompensation (Mofards, 2002).

Since cancer and its treatment are associated with functional impairment and psychological sequelae such as depression and anxiety, elderly patients require much psychological support. Whether the patient has a caregiver, as well as the health and competence of the caregiver, is a critical consideration in developing treatment or palliative care plans (Haley, 2003).

Anxiety and depression can hinder one's ability to follow a treatment plan, too. About 25% of people with cancer are clinically depressed (ACS, 2003). Caregivers need to be alerted to the symptoms of depression for their loved one, and themselves as well. They need to know that help is available in the form of medications, counseling, or a combination of both.

Cancer related pain is a common problem that affects more than two thirds of patients with advanced cancer (ACS, 2003). Chronic pain is prevalent in the elderly generally (Davis & Srivastava, 2003). Pain has repercussions for all aspects of a patient's life, impeding their activities, ability to do self-care, sleeping and eating problems, and more.

Pain often goes untreated due to barriers such as abnormal presentation, patient reluctance to report it, difficulty in communication, cultural aversion to narcotics, and the inability to pay for medication (Davis & Srivastava, 2003). Elderly patients with advanced or terminal cancer may have several underlying sources of pain including a chronic non-malignant pain that predates the cancer, pain from the cancer itself, and pain from the treatment.. Unrelieved pain can affect patients' memory, attention span, sleep patterns, energy levels, and overall physical functions, as well as increase depression and mood disturbance .

Breathing difficulties arise from many sources, including chronic lung diseases such as emphysema and other disease not cancer related, obstruction of the airway, pneumonia, pain, anemia, fluid in the lungs, the cancer itself, and more (ACS, 2003). Breathing problems may arise as life expectancy decreases. Treatment are most often opiod medications, anti-anxiety

medicines to reduce cough and distress caused by shortness of breath, and other medicines to help reduce lung secretions and reduce anxiety (ACS).

Nutrition is a great concern for patients and caregivers all through their treatment. Good nutrition can help patients feel better and stay stronger. When cancer becomes advanced, patients may lose weight and have little appetite. Malnutrition is prevalent in the elderly, especially those who have been hospitalized or institutionalized (Balducci, 2003). Impaired nutrition, including reductions in body protein is correlated with a greater risk of severe hematotoxic effects of chemotherapy. Thus it is critical for caregivers to be taught about chemotherapy and nutrition and to make sure they understand the importance of adequate and proper nutrition as a compliment to their loved one's treatment.

Confusion is another symptom that patients with advanced cancer may experience. Sometimes this is experienced as trouble thinking and acting normally. For example, a patient may not know where they are or what day it is. This can be frightening to caregivers as well as patients. Confusion may be caused by liver disease, bowel or bladder blockage, drugs or cancer that affects the central nervous system or brain, and medicine withdrawal (ACS, 2003).

It is common for a patient with terminal disease to display little emotion or become restless, anxious, irritable, depressed, or angry. These are more like the signs of a more advanced state of confusion referred to as delirium (ACS, 2003). In this state sometimes patients may see things that are not there. It is important for caregivers to be aware of signs of confusion and report it to the physician.

It is against this backdrop that researchers examine the interactions of caregivers and the health care providers of their family member and how this interaction impacts the outcome of caregiver burden.

3.2. ONCOLOGY CAREGIVING

Recognition of the burden that the diagnosis and treatment of cancer imposes on family caregivers has appeared in the literature since the 1980's, when several researchers examined the needs of caregivers of cancer patients and identified that caregivers perceived that they were not provided with enough education to care for terminally ill family members and that they experienced at least one unmet psychosocial need (Grobe, et al, 1980; Houts, et al, 1986). Since then there has been an abundance of cancer caregiving studies approaching the area from many domains, including the impact of stage of disease, age and gender of caregivers, relationships, treatment types, psychosocial variables such as effects of support patterns, effects of home care, and financial burdens. The greatest concentration of studies appear to be on caregiving in end of life issues and terminal care, perhaps because this stage is the most intense emotionally and physically demanding for caregivers.

Numerous studies examining the burdens of caring for older patients focus more on aged psychiatric patients or patients suffering from Alzheimer's disease who are severely handicapped, requiring intensive caregiving (Biegel & Schulz, 1999). While some of these findings may be generalized across caregiving populations in a global sense, they do not contribute to an understanding of the needs of particular patient population groups. Generally, significant caregiving problems reported by many family caregivers center around emotional, physical, and sometimes financial burden (Biegel & Schulz, 1999; Kinsella, 1998). Researchers have identified major caregiving problems including: coping with the increased needs of the care receiver caused by physical and/or mental illness; coping with disruptive behaviors; restrictions on leisure and social activities; lack of privacy; disruption of daily routines; conflicting role

demands; lack of support and assistance from other family members; and lack of assistance from community agencies (Biegel & Schulz, 1999).

Some researchers have examined the impact of the phases of cancer on the family (Sales, 1991). The phase of cancer as used here draws upon and expands the work of Northouse (1984). Northouse identified three phases of illness, the initial, adaptation, and terminal phases. She then identified central problems for families in each of these phases. In the *initial phase*, families (1) felt excluded from the focus of medical care, (2) felt frustrated in attempts to communicate with the medical staff and others, and (3) had difficulties managing their emotions. Key concerns of the *adaptation phase* were (1) adjusting to role and life changes, (2) meeting the needs of other well family members, and (3) living with uncertainty. In the *terminal phase*, Northouse identified the central family issues as (1) the need to provide care and support for the dying, (2) the need for family members to communicate with one another about death, and (3) the need to deal with feelings about separation and loss.

Based on an analysis of additional studies assessing the family impact of different stages of illness since Northouse, Sales (1991) expanded these stages of illness. The three stages were expanded into six categories: diagnostic, hospital, post hospital, adjuvant treatment, recurrence, and terminal. Building within this framework, some researchers have examined family caregiving needs during specific treatment phases. Stetz, et al. (1996) described some of the challenges facing caregivers whose family member has undergone bone marrow transplantation. Five major themes emerged from a qualitative analysis of caregiver focus group interviews: (1) Preparing for Caregiving, (2) Managing the Care, (3) Facing Challenges, (4) Developing Supportive Strategies, and (5) Discovering Unanticipated Rewards and Benefits. Each of these themes contained subcategories.

One of the purposes of this research was to determine the informational needs of family caregivers of patients undergoing a bone marrow transplant. An expressed need of family caregivers within each of these five themes was better communication with healthcare professionals, including doctors, nurses, and social workers. For example, the category Preparing for Caregiving contained subcategories of (1) seeking and acquiring health care, (2) obtaining information and materials, and (3) evaluating the validity of information (Stetz, et al., 1996). Obtaining information and materials included not only information about diagnosis and treatment but also information on services and resources.

Many caregivers felt ineffective in dealing with healthcare professionals and said they felt that the healthcare professionals did not really listen to them or acknowledge them or their knowledge about the patient. They complained of feeling treated like children and excluded from discussions and decision making with respect to the welfare of the patient. Many complained that they did not get the information they needed and felt they could not ask. They also spoke about the need for appropriate timing of information, stating they preferred to receive the information before they actually needed it and that too much medical jargon was used (Stetz, et al.).

Although the findings from the Stetz study centered around communication difficulties with healthcare providers, another study with this same population of bone marrow transplant patients and their families did not report any difficulty communicating effectively with healthcare professionals, although the study indicated that family members typically did not recall specific details of the treatment information (Zabora, et al., 1992). However, this lack of recall may possibly be interpreted as communication difficulty since healthcare professionals know that patients and families need to be provided with information a number of times for the information

to be absorbed. It is notable that the Stetz study used a cross-sectional, descriptive focus group methodology to collect data, whereas participants in the Zabora study responded only to quantitative instruments.

Other researchers have underscored the need for cancer caregivers to acquire information regarding disease and treatment-related expectations from healthcare providers so that the caregiver can anticipate potential problems and know how to provide optimal care (Given, et al., 2001). Patients with advanced cancer may be treated aggressively, perhaps on clinical trials, and with considerable side effects. Alternatively, the goal of treatment may shift from cure to palliation or comfort measures. Either way, the patient is likely to experience symptoms from the treatment an/or from the disease itself.

At this point, the patient may continue to be treated by the oncology specialist or the patient may be referred back to the primary care physician. This may place caregivers in a difficult situation because there is not a consistent health care provider to turn to for advice and direction regarding the patient's care. Also, these transitions come at a time when families may be experiencing not only anger, shock, and depression at realizing the treatments are no longer effective, but they may also have increased care responsibilities (Given, et al., 2001). So at a time when communication with health care providers is crucial to the family caregiver, the avenues to communication may be diminished instead.

In a review of the cancer caregiving literature, Given, et al. (2001) stress the importance of education and information if family caregivers are to provide effective home care patients. Families often find themselves giving care by trial and error. There are many reasons why caregivers of patients with advanced disease do not have adequate information to provide care. Sometimes caregivers are not included in physician-patient conferences. If they are included,

their perspectives and questions are often not acknowledged or addressed. Many caregivers lack the ability to ask questions or feel intimidated by the physician. Sometimes caregivers are too overwhelmed with the situation and not know what questions to ask.

Some researchers have examined how the patterns of the cancer caregiving experience might change over time. Nijboer, et al. (2000) studied newly diagnosed colorectal cancer patients who had a prognosis of at least six months and who lived with a partner. The aim of the study was to describe overall patterns of cancer caregiver experiences in the partners of patients over time; across different groups with regard to gender, age, and SES; and within individuals. Patterns of caregiver experiences appeared to vary between subgroups. Women, younger caregivers, and caregivers with higher SES experienced caregiving more negatively (Nijboer, et al.).

Other researchers have also examined the demographic variables of age, sex, and SES as contributing to the burden borne by the spouses of cancer patients (Mor, et al., 1987; Wellisch, et al., 1983). Age is one of the most important variables. Mor et al. (1987) demonstrated that young caregivers have to contend with more financial problems than older people in similar situations; however, older spouses cannot shoulder the burden of caregiving as well as a younger person. Gilbar (1994) examined the burden of elderly cancer caregivers as perceived by the patients and their spouses. The spouses perceived caregiving as more burdensome than did the patient.

It is common in the oncology caregiving literature to examine the terminal phase of illness, probably because this is often the most labor intensive and is emotionally charged. Some of the areas of exploration in this phase dealt with how caregivers are assisted by other family members, paid caregivers, and volunteers (Emanuel, et al., 1999), economic burden (Emanuel, et

al., 2000), the emotions and coping strategies of caregivers (Grbich, et al., 2001), and involving family members in cancer care (Speice, et al., 2000). In both the Grbich and the Speice studies, caregivers indicated a need for emotional support from health care professionals throughout the cancer trajectory, and wanted explicit conversations with healthcare providers in order to provide optimum care.

To summarize, caregiving in cancer care covers multiple phases over time, so that caregiving needs change and shift with changes in the patient's course of disease, the type of cancer diagnosis, treatments, and side-effects. The one theme that runs through these studies is that caregivers all voice a need for better communication with healthcare providers. Given the ubiquitous nature of this need, it is surprising that no one, at least to the author's knowledge, has explored any link between communication with healthcare providers and caregiver burden.

The following section will review literature that examines communication between health care providers and caregivers. Literature that describes the nature of communication between doctors and their patients will first be reviewed, since this is the basic dyadic relationship in healthcare and has been linked with outcomes such as patient compliance. Following that will be a review literature that has examined the caregivers (of usually elderly patients) as an important component of the medical encounter. Finally, more limited literature that has identified the caregiver as a part of the oncology caregiving system will be reviewed.

3.3. COMMUNICATION BETWEEN HEALTH CARE PROFICERS AND PATIENTS/CAREGIVERS

Much of the cancer communication research has focused on the actual mechanics and dynamics of the consultation between physician and patient. This research documents that constructive

relationships between physicians and patients are related to better coping and satisfaction with treatment protocols, information exchange, and accrual to clinical trials (Thorne, 1999). Research suggests that the physician remains the most critical person in the perception of cancer patients, and that communication problems between physicians and patients are likely to create the greatest distress (Thorne, 1999). Various types of physician-patient communication patterns have been associated with patient anxiety levels and with patient satisfaction with care (Buckman, et al, 1991).

A broad perspective on the impact of communication in cancer care is the research linking outcomes to patient-physician communication. Constructive and positive communications in cancer care have been linked with a sense of control, active information-seeking behavior, disclosing feelings, and a search for meaning (Halldorsdottir & Hamrin, 1997). Stewart (1995), in a review of randomized controlled trials including, but not limited to, cancer, confirmed that it was possible to demonstrate a significant impact of communication on emotional health, symptom resolution, function, physiologic measures, and pain control. Similar linkages were found by Simpson, et al (1991), correlating the quality of health care communication on specific illness-related outcomes. More specifically, they asserted that explaining and understanding patient concerns, even unresolvable ones, results in decreased anxiety; that greater participation results in better compliance; and that better information results in decreased psychological stress. Thorne (1999) points out that this type of research challenges health care researchers to consider outcomes beyond the traditional mortality and morbidity measures and to recognize that there are other relevant outcomes in cancer care.

Some studies of communication of oncologists and their patients (and family members if present) indicate that one of the major factors determining whether patients will successfully be

enrolled in cancer clinical trials is the quality of the communication occurring between patient and doctor (Ruckdechel, Albrecht, Blanchard, and Hemmick, 1996). The longer-term relationship between the patient and the oncologist is one of “alliance building” that the oncologist and patient use to confront the uncertainty in the disease process and the outcome of the treatment (Ruckdechel et al.). Finset, Smedstad, and Ogar (1997) found that coping strategies tend to remain an implicit subject in physician-patient interactions in oncology care and that some patients find emotional components of the oncologists’ behavior to be significant for their coping.

Rosenberg et al. (1997) conducted a review of original research about physician-patient communication. They found research supportive of the fact that physicians’ communication patterns impacted the quality of history-taking and diagnostic skill, patient health benefits, and patient compliance. They concluded that there was a consistency across studies that led them to believe that certain ways of communicating with patients will improve the quality of medical care. They describe a communication style that encourages patients to play a more active role in the interaction and they acknowledge that an assertive, active patient will change the role of the physician as well.

Thorne (1998) also analyzed existing research-based knowledge in the cancer communication literature and determined that constructive relationships between patients and physicians are correlated with better coping and satisfaction with treatment, information exchange, and accrual to clinical trials. The listening skills of physicians are especially important to improved rapport and patient understanding (Thorne). It is the physician who is the most critical of all relationships in the perception of cancer patients. Thus, communication problems between patient and physician are likely to be the most problematic (Thorne).

One of patients' and families' common complaints about communication with physicians and other health care providers concerns the use of medical jargon. Bourhis et al. (1989) surveyed 40 physicians, 40 student nurses, and 40 patients regarding the usage and evaluation of medical and everyday language in a hospital setting. Medical language use, as might be expected, was felt to be a source of problems with patients, while everyday language was viewed as promoting better understanding (Bourhis, et al.). It is important to note that in the last ten years, patients and families have become very resourceful in information seeking, especially by using the Internet. Having such increased knowledge can help mitigate the inequality between patient and physician, at least from the medical jargon perspective.

Much patient-physician communication research has centered around patient characteristics, such as age or gender. The variable of age, especially with regard to the elderly, is common in the research literature and is salient to this proposal. Beisecker et al., (1996) studied the attitudes of medical students and primary care physicians regarding the input of older and younger patients in medical decisions. This is an important area because it is becoming more common for patients to demand significant input into many kinds of treatment decisions, including when to stop treatment. This is different than the historical model where the physician is the paternalistic benefactor.

Ninety percent of medical students, residents, and fully trained physician respondents believed that physicians want stronger input into making clinical decisions than patients (Beisecker, et al, 1996). Whether this is translated into physician behavior is unknown because it was only a survey of attitudes. The researchers found that although age had somewhat of an effect on the degree to which doctors believe patients should have medical decision input, the relationship is complex, involves other variables, and requires further study. Physician gender

and training/experience also affected physicians' attitudes and willingness to have patients play a more active role in decision making. Furthermore, physicians indicated they wanted greater decision-making authority under certain conditions and for some types of medical encounter.

Greene, et al. (1987) also compared the interactions of doctors with their old and young patients in regard to psychosocial concerns in the medical encounter. Doctors were most likely to raise medical issues with both older and younger patients. However, they were much more likely to raise psychosocial issues with younger patients than with older ones. When psychosocial issues were raised by the patient, doctors responded significantly better in the interviews with younger patients. Perhaps older patients did not have many psychosocial issues to raise or were afraid to raise them.

The broad literature on communication in the physician-patient relationship is enlightening and provides a context to examine communication issues with a third person present in the medical encounter. More specifically, communication is increasingly acknowledged as a crucial component of an effective and socially responsible cancer care system (Thorne, 1999). A growing body of research reveals patterns in the way professional health care providers interact with patients and families and links these patterns with the illness experience as well as with quality of life (Sales, 1992; Thorne). It confirms that the ways in which health care providers communicate makes a quality of life difference throughout the continuum of the cancer illness by providing patients with appropriate and technically competent care, with good communication, shared decision-making, and cultural sensitivity (Thorne). Finally, because physicians have most often focus on the patient, ancillary fields such as nursing and social work, which have long focused on families in hospital settings, have recognized the strain and burden of caregiving for families (Sales, 2002).

3.3.1. Communication Triads

Researchers have begun to consider the physician-companion-patient triad in medical encounters, recognizing that the triad is distinctly different and more complex than the dyadic relationship, and also recognizing the triad as a common occurrence, especially in older, chronically ill adults. Given that one of the most identified needs of caregivers in the caregiving literature was good communication with health care providers, one would expect that there would be an abundance of information about caregiver-doctor communication. While there is some research in this area, especially regarding the role of a companion in physician encounters with the elderly, the area is only starting to be examined more fully. One can extrapolate information from the physician-patient communication literature, but that is limiting in attempting to understand families' experiences communicating with health care providers of their loved ones because the relationship changes from a dyadic to a triadic one. The following section will examine literature focusing on the companion-patient-physician relationship, including literature that is oncology- related as well as more general medically oriented.

Once there are three participants rather than two, the encounters involve coalitions between the patient, or family member, and the physician (or nurse or social worker). A coalition is defined as "an effort by two members of the triad to achieve a mutually desired goal despite the (active or passive) resistance of the third member" (Coe & Pendergast, 1985, p. 241). Studies of coalitions involving doctors, patients, and companions reveal that often there is more than one coalition within an encounter, and that common themes within the encounter include seeking information and compliance issues (Coe & Pendergast). Physician-initiated coalitions were more likely to be successful, particularly in gaining accurate information or obtaining adherence to treatment recommendations (Coe & Pendergast).

Beisecker and Moore (1994) found that oncologists identified four types of coalitions during medical encounters with patients and their companions: (1) patient and companion, (2) patient and oncologist, (3) companion and oncologist, and (4) internal coalitions within a family against other family members. Coalitions have been found to affect patients' attitudes, their interactions with their physician, and their medical outcome (Prohaska & Glasser, 1995). Companions reported that the occasions on which they accompany their family member to the oncologist appointment were at the beginning of treatment, when test results were to be discussed, when decisions had to be made, and when they had special concerns or questions (Beisecker, et al., 1996). The oncologist provides more information when the family is present, particularly under conditions of potential uncertainty such as when the patient has symptoms (Labrecque, et al., 1991). Adelman, et al. (1987) also recognized the significance of a third person companion accompanying an elderly patient to a doctor visit. They conceptualized a research agenda to be addressed in this area. They considered the basic and important initial issues to be centered around how the third person affects the doctor-patient relationship in areas such as content of the medical encounter, trust, patient satisfaction, and influence on physicians' evaluation (Adelman et al., 1985). In both Coe and Pendergast and Adelman, et al. it appears that the third person in the medical encounter may be viewed more as an intrusion in the physician-patient relationship. But what is important is that there is recognition of the significance of the third person in the medical encounter between doctors and elderly patients. It is very common that this third person is an elderly spouse who is providing care to his/her chronically ill partner.

Beisecker et al (1994, 1996) studied the role of a companion in medical appointments of cancer patients, both from the perspective of the patient and the companion (Beisecker et al., 1996) and from the perspective of the oncologist (Beisecker et al, 1994). Companions (most

often a spouse) attend medical appointments to provide support and companionship, increase patient understanding, provide transportation, and ask questions. Companions saw themselves as more active than the patients saw them (Beisecker, et al., 1996). In the study of oncologists' perceptions of companions, physicians were overwhelmingly in favor of having a companion present during the medical appointment. The physicians noted "coalitions" occurred when companions were present, but many noted this term denoted conflict and preferred the term "alliance".

Prohaska and Glasser (1996) also studied patients' views of family involvement in medical care encounters and medical decisions with elderly patients. Their study was designed to examine the role of the third person at three points in the medical care decision process of older patients: before the medical encounter, during the medical encounter, and after the medical encounter. Accompanied patients were compared to unaccompanied elderly patients. The spouse was the most frequent companion. Their findings showed that individuals who accompany the older patient to the medical appointment are involved in the health care decisions leading to the medical visit, and that the older patients recognize the caregiver or companion involvement in the medical decision process. One of the main reasons for the presence of a companion was to make sure the patient understood the doctor's recommendations and prescriptions. Thus the authors recommend that there should be a focus on patient-education for the patient and the caregiver as well as support for the caregiver. A caregiver involved in decision making should be informed and supported in that role.

Labrecque's research (1991) focused on oncology patients, but underscored the findings of Prohaska. One salient finding was that physicians discussed both future treatments and the

patient's current medical status more often when family members were present. Physicians also provided more information when companions were present.

This research links the role of companion, mostly a family member, with the role of health care provider. It also links the family system with the health care system. It is this linkage that provides the context for examining caregiving and how caregiving is impacted by the larger social system, how the roles of the family member prepare the caregiver for the role of health care provider, and how the physician's role impacts caregiving in the family.

3.3.2. Barriers to Communication

There is also a growing body of literature indicating that racial and ethnic differences between patients and physicians are often barriers to communication (Cooper-Patrick et al., 1999; Hayward, Bernard, & Freeman, Corey, 1990; Kleinman, Eisenberg, & Good, 1978; Mull, 1993). Cooper-Patrick et.al. suggests that a number of physician factors may account for these communication barriers. One, doctors may incorporate such biases as racial and ethnic stereotypes into their interpretations of patient's symptoms, predictions of patient's behaviors, and medical decision- making. Second, they may simply lack understanding of the patient's ethnic and cultural disease models or naming of symptoms. Third, physicians are often not aware of or have expectations for the visit that are different from the patient's expectations.

Other factors such as low literacy, language barriers, and lack of self-esteem in regard to managing one's health may be more prevalent in ethnic minorities (Cooper-Patrick et al.). Physicians and patients belonging to the same race or ethnic group are more likely to share cultural beliefs, values, and experiences in society, which leads to more effective communication because they feel more comfortable with one another (Cooper-Patrick, et al). Racial differences in oncology mortality and morbidity rates have highlighted these issues in the prevention and

early detection of cancer (Hewett, 1999). Although it is not the main purpose of this study to focus on this area, it is, nevertheless, important enough to include as part of the contextual picture of caregiving and it contributes to the public policy aspects of caregiving.

In summary, researchers have noted that from the perspective of the patient, encounters with health care professionals seem to play an important role in shaping the illness experience (Halldorsdottir, et al, 1997). It seems reasonable to assume that these same encounters would shape the illness experience for the patient's caregiver as well. Furthermore, it would seem that the illness experience for the patient is of a triadic nature rather than a dyadic one, and this must ultimately have some consequences for the patient's health outcomes (e.g. compliance) and for caregiver effects (e.g. caregiver burden). These encounters with health care providers then are centered on how well or how badly the communication, both verbal and non-verbal, is perceived by all parties involved. While these interactions may not be as important in routine medical encounters, they are very important in the chronic illness experience. Constructive relationships between physicians and patients are linked with better coping and satisfaction with treatment protocols (Speigel, 1997), information exchange (Rosenblum, 1994), and accrual to clinical trials (Ruckdeschel et al, 1996). More specifically, the listening skills of physicians have been linked to improved rapport and patient understanding (Ruckdeschel et al, 1996). Do these same skills then lead to positive outcomes for the primary caregiver as well? Does the family feel supported by the medical care team in caring for their family member? Does the caregiver feel prepared by the health care providers to perform such functions as monitor symptoms, change dressings, understand when to call a doctor and when it is not necessary, understand the emotional turbulence both the patient and the caregiver will have, etc.? In the following section the research model proposed for this study along with the research questions which center on the

caregiver's communication with health care providers will affect caregiver burden either directly or indirectly through the mediating variable of self-efficacy will be discussed.

As noted earlier, stress-coping theory, the concept of self-efficacy, and role theory provide the foundations for the theoretical model used in this study. The relevant aspects of these constructs have been previously outlined, but will be summarized here. The proposed model for the study is shown in Figure 1.

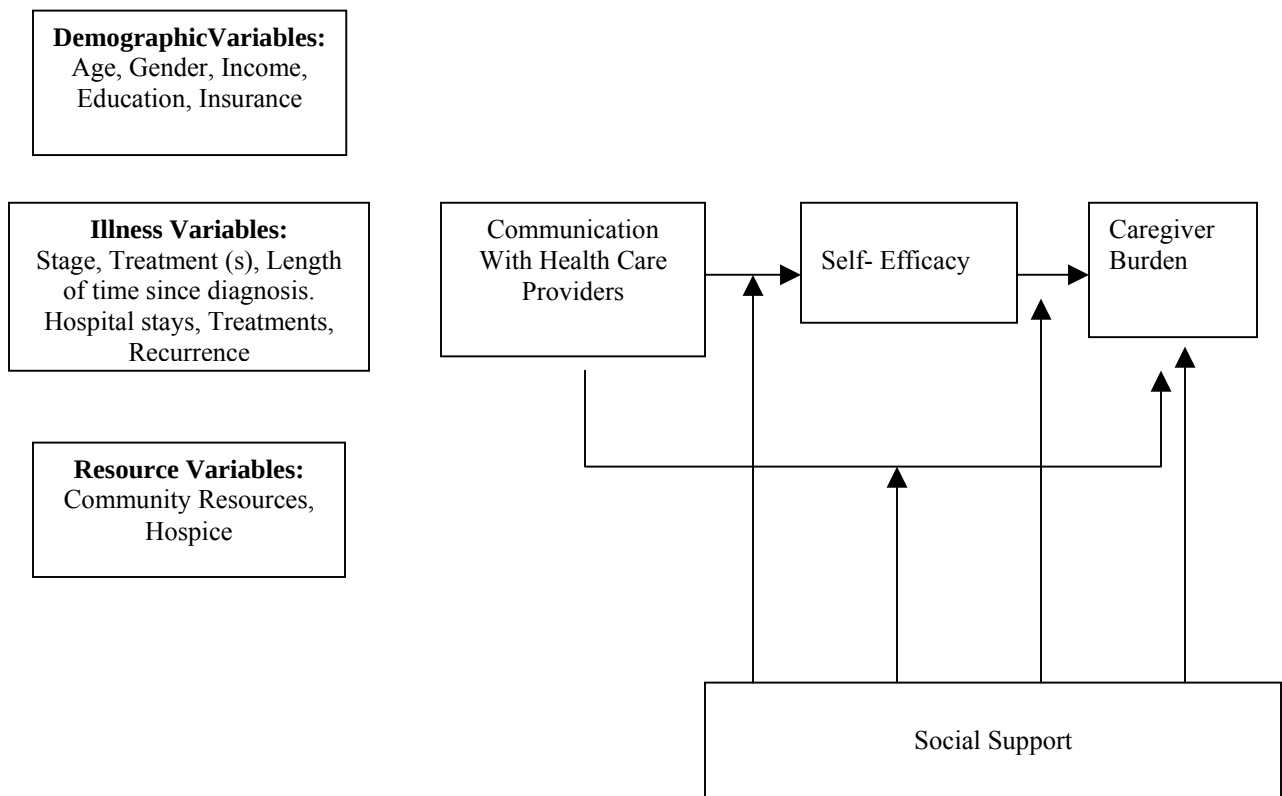


Figure 1. Main Research Model

The major research question: is how does a caregiver's communication with health care providers affect self-efficacy in caregiving, thereby impacting caregiver burden in older spousal caregivers of oncology patients? The stress-coping model offers a construct for understanding

the caregiving experience by providing a theoretical framework for interactions between the individual and the environment. It also provides a construct for the possible buffering effects of social support as a coping resource in communicating with health care providers, in learning to provide competent care to a loved one (self-efficacy) in dealing with the stresses of caregiving. In the model for this study, communications with health care providers is seen as one of the stressful components of caregivers' responsibility. The stress of these interactions may come from fear of hearing bad news, fear of talking to health care professionals, not knowing what questions to ask, not understanding information that is being discussed, being expected to take on responsibilities that might be too much to handle, participating in decision making, etc. Yet, in order to prepare for and to carry out caregiving responsibilities, it is important for a caregiver to be actively involved in interactions with health care professionals who are treating their loved one. The caregiver's communication with health care providers may well impact the caregiver's belief that she or he is competent (or not) to carry out these responsibilities both emotionally and physically.

The concept of self-efficacy, or, caregiver mastery, is viewed in this model as a mediating variable. Self-efficacy as discussed earlier refers to the belief that one is capable of performing behaviors required to produce a desired outcome (Leganger, et. al., 2000). It is expected that communication with health care providers will influence the caregiver's self-efficacy or feelings of competency in the caregiving role. While self-efficacy stems partially from the experience of a more global construct of personal mastery, efficacy expectations also originate from vicarious learning and verbal persuasion as well (Leganger, et. al.). A caregiver's interactions with the health care team may well result in learning about their loved one's disease and treatment, and the caregiver should also feel supported in their role by the health care team. So "verbal

persuasion” could be defined as education, encouragement and support for the caregiver in the caregiving role by the health care providers.

Role theory, as noted earlier, explains the ways in which a person’s behavior is influenced by the social environment. In this case, the social environment is conceptualized as the medical environment that both the patient and caregiver have now entered. If interactions with the health care team are positive, then the caregiver should be, through those interactions, prepared more thoroughly for caregiving than if those interactions were negative. Role theory also contributes to an understanding of caregiver burden as a form of role overload or role strain. It is hypothesized that self-efficacy will mediate the effects of communication on caregiver burden. The study variables will be discussed more fully in the following section.

3.4. STUDY VARIABLES

3.4.1. Independent, Mediating and Dependent Variables

In this model, communication is conceptualized as the quality of interpersonal care, based on health providers’ behaviors as perceived by the caregivers. This independent variable is hypothesized to bolster self-efficacy in caregiving, thereby influencing the caregiving positively or negatively.

Self-efficacy, as mentioned above, is the caregiver’s feelings of competency for caregiving and is viewed as a mediating variable for this model. It is hypothesized that health care provider communication (verbal and non-verbal behaviors) will impact self-efficacy, and that it is the feeling of caregiver competency that will mediate the effects of these verbal and non-verbal communications on caregiver burden.

The dependent variable in this model is caregiver burden. It is hypothesized that burden will be impacted by self-efficacy in caregiving.

3.4.2. Contextual Variables

Contextual variables have been divided into three categories, which have been discussed or mentioned in the literature review: demographic, illness, and resource variables. The demographic variables include age, gender, income, and education, type of insurance, race, and employment status. All of these variables are known to influence health related outcomes.

The illness variables include: the type of cancer diagnosis (i.e., breast, lung, colon, etc.), the stage of disease, treatment, length of time since the diagnosis was made, if the patient is participating in a clinical trial, and if the patient had been treated elsewhere before coming to the current treatment facility. All of these illness variables have the potential to influence caregiver burden, as well as having a possible correlation with communication with health care providers. These variables may have implication for future research within any of these particular areas.

Resource variables include social support and utilization of any community resources such as Home Health Care, Meals on Wheels, Adult Services, etc. As noted earlier, social support has been found to be a significant factor in the psychological adjustment of cancer caregivers. The social support framework explains how informal social networks of family members and friends moderate, or protect an individual from the stressors of caregiving (Bass, et al. 1996). In this model, social support is believed to moderate the effects of the stressors of learning new caregiver competencies from health care providers and the stressors of carrying out those responsibilities in their caregiving role.

3.5. RESEARCH HYPOTHESES

1. Communication with health care providers will relate to decreased caregiver burden.
2. Communication with health care providers will impact self-efficacy in caregiving. It is predicted that good communication with health care providers will positively affect self-efficacy in caregiving.
3. Self-efficacy will relate to caregiver burden. It is predicted that higher self-efficacy will relate to decreased caregiver burden.
4. Self-efficacy mediates the effects of quality of communication on caregiver burden. It is predicted that positive communication with health care providers will increase self-efficacy in caregiving, which will lead to a decrease in caregiver burden.
5. Higher social support will relate to lower caregiver burden.
6. Social support will moderate the relationship between self-efficacy and caregiver burden. It is expected that the relationship between self-efficacy and caregiver burden will be lower for caregivers with more social support.
7. Social support will moderate the relationship between communication and caregiver burden. It is expected that the relationship between communication and caregiver burden will be lower for caregivers with more social support.
8. Social support will moderate the relationship between communication and self-efficacy. It is expected that the relationship between communication and self-efficacy will be higher for those with more social support.

In summary, it is predicted that more positive communication will lead to increased self-efficacy in caregiving and that a caregiver with higher self-efficacy will experience less caregiver burden. It is hypothesized that self-efficacy will explain or account for the relationship between communication and caregiver burden. It is hypothesized that social support will have a buffering effect on the relationship between self-efficacy and burden, between communication and burden, and between communication and self-efficacy. Based on the literature, it is predicted that the demographic variables of age and socioeconomic status and social support will have a direct effect on caregiver burden. The following chapter will discuss the methodology for this study.

4. METHOD

This is a hypothesis testing study using a cross sectional design. A convenience sample of caregivers was recruited from the Hillman Cancer Center of the University of Pittsburgh Cancer Institute, an outpatient facility.

4.1. STUDY PARTICIPANTS AND PROCEDURES

Caregivers for this study were spouses who were at least 60 years old and caring for a spouse with an advanced or terminal cancer diagnosis. The patient may have been newly diagnosed or progressed over time to a recurrence and more advanced disease. Caregivers of leukemia patients were not eligible due to the more acute onset and intensive treatment than other cancer diagnoses. A caregiver caring for a spouse with a major co-morbid condition such as Alzheimer's Disease or a major psychiatric illness was ineligible. Finally, the caregiver had to speak and read English.

After the development of the self-efficacy and communication questionnaires, the main study model was approved by the IRB. Initially the goal was to aim for a recruitment of 100 caregivers in order to ensure an adequate representation of ages, diversity of disease sites and stages. However, recruitment was more difficult and slower than what had been anticipated. I had discussed this study with several oncology social workers who had agreed to identify potential participants following IRB approval. This did not result in any participants.

I discussed the study with nurses and several medical oncologists at the UPMC Cancer Centers outpatient clinic. A nurse identified an appropriate caregiver, told them about the study, and asked if they were interested. If they were agreeable, then the nurse introduced the

researcher to the caregiver. Caregivers and patients (if they were present) were assured of confidentiality and that none of the information would be shared with any health care providers. They were advised that the surveys only had a number, which corresponded to their name and which was kept separate from the surveys. They were informed that the completed surveys, as well as their name with corresponding number, would be kept in a locked file. The caregivers often would complete the survey while they were awaiting their loved one's treatment to finish. If they took the survey home, they were given a stamped, addressed envelope with which to mail it back, but I did not have their addresses and phone numbers to make follow up calls if they were not returned in a timely manner. This strategy has resulted in 66 completed surveys out of 82. Upon return of the completed survey a \$10.00 grocery store gift certificate was either given personally or mailed out. A grant from the American Cancer Society made the reimbursement feasible.

This was the only strategy that slowly resulted in accruing 66 caregivers (out of 82 identified) who agreed to participate in the study over the last year. The nurses identified potential caregivers, briefly discussed the study, and introduced me to the caregiver if he/she was interested. I spent a day a week in the outpatient clinic so I would be available to see caregivers identified by the nurses. My presence in the clinic was a reminder to the staff that I was there for study recruitment. This is a high volume clinic and the nurses are extremely busy, so if I was not visible, I would have had few referrals. In addition, there were other researchers in the clinic looking for study participants with the assistance of the nursing staff also. So there was some competition for participants. Finally, after a few months of making myself available in the clinic, I began to see more returning patients and families than new patients. This was to be expected, but it made accrual much slower.

4.2. PROCEDURES FOR FOCUS GROUP

A focus group was conducted for the purpose of developing a self-efficacy scale in oncology caregiving. IRB approval for the focus group to develop the self-efficacy scale and the Caregiver-Health Care Provider Communication Scale was granted. Bandura (1977), a leading theorist on the construction of self-efficacy scales, recommends focus group methodology for particular areas of expertise. Initially the researcher contacted a University of Pittsburgh Cancer Institute (UPCI) oncologist who had agreed to help with focus group recruitment by identifying appropriate caregivers and having them contact the researcher if they were interested. His research protocol nurse also agreed to assist with this recruitment as well. However, this strategy resulted in no referrals. This was a time of flux for the UPCI, as the Institute was in the process of moving to a new facility. Because of this, the researcher chose to pursue a different means of recruitment for this small group.

The minister of the researcher's local church was approached about this group. The church has a large population of older members, so it seemed reasonable to expect that there were some caregivers who might be willing to participate in the group. He agreed to contact some older caregivers to see if they were interested in participating in a focus group about caregiving. He also gave permission to hold the group at the church, so the participants did not have to travel. Five caregivers contacted the researcher to express their interest. They were given more information about the study, including the fact it would be audio taped, and were agreeable to participation. An afternoon time was agreed upon and the group meeting took place September 23, 2002 at the researcher's community church.

Four out of five participants showed up for the focus group. The group was given ground rules for the meeting:

- Participants would be advised each time the tape machine was turned on and off.
- No names of any health care providers would be permitted.
- The group was advised to stay focused on the discussion topics as provided in the handout.
- Confidentiality was stressed. Participants were assured that no information in the discussion would be shared outside the group and no information would be shared with any health care provider.

A list of the focus group discussion items is in the appendices. The results of the focus group discussion generated a list of items that the caregivers felt were especially important in feeling confident as a caregiver. For example, these caregivers all felt strongly that it was important to keep a written record of any types of changes they observed in their loved one's health. Some other areas identified as helping to provide a sense of competency in caregiving was being able to use appropriate community resources, taking their own needs into account as well as those of their loved ones, being organized about caregiving tasks, being able to judge the seriousness of a problem, dealing with role changes, making sure their loved one was comfortable, advocating for their loved one without alienating the health care providers, and being persistent about obtaining resources, among other items. These became items in the Self-Efficacy scale, which is listed in the appendices.

4.3. PRETEST OF COMMUNICATION QUESTIONNAIRE

The communication questionnaire was developed using items culled through the literature on communication and caregiving in health care, the researcher's own experience as an oncology social worker, the experience of other oncology social workers and nurses, and some aspects of the Quest Scale (Quality of End of Life Care and Satisfaction with Treatment) developed by Sulmasy, et al (in press). The questionnaire was given to a convenience sample of 14 colleagues, who asked caregivers they knew to provide feedback on comprehension and readability of the survey. Fifteen surveys were distributed and fourteen of them were returned. Adjustments were made based on the feedback. Originally the researchers attempted to recruit caregivers from the UPCI outpatient division for the pretesting. However, as with the focus group recruitment problem, this strategy failed and it was necessary to resort to other means of recruitment.

4.4. MEASURES

4.4.1. Communication

The issue of communication has been conceptually troubling. The term is used freely in the literature, as in "doctor-patient communication". When conducting a Medline search on this topic, multiple terms such as "physician-patient relation," "communication," "physician-patient-family communication" and "medical encounter" were used. The range of topics was vast. Some of the studies described taped interviews of the segments of visits to physicians and counted how long patients spoke before being interrupted or how doctors launched into their own

agendas without asking the patient whether there were any new concerns (Rosenberg, et.al., 1997). Some of the articles on communication that came up had to do with satisfaction with care, which is a consequence of good communication (Walker, et al., 1996). It became clear that the actual behaviors that occur in interactions with health care providers that make patients and families feel listened to and a part of their loved one's care was how the term "communication" would be operationalized. This would include, for example, a physician making time to explain things to families such as treatment issues or including the spouse in decision making discussions. These kind of behaviors, which are both verbal and non-verbal, are indicators of what we know as good communication skills, i.e., empathy, open-ended questions, focusing on the patient, paraphrasing, furthering responses, etc. In addition, these behaviors include how health care providers communicate to patients and caregivers what they need to know about the illness, treatment and side effects, psychosocial reactions, and so forth, leading to at least some preparedness about caregiving needs.

However, finding a measure that addressed communication as it was conceptualized in this study was difficult. There were many patient satisfaction instruments that measured how satisfied patients were with care that included communication aspects, but not the behaviors alone. Through the efforts of Dr. Robert Arnold at the University of Pittsburgh School of Medicine the researcher was made aware of preliminary work on the Quest Scale (Quality of End-of-Life Care and Satisfaction with Treatment), discussed below, being conducted by Sulmasy and his colleagues (Sulmasy, et al, 2002).

The Quest Scale (Quality of End-of-Life Care and Satisfaction with Treatment) measures quality of care of interpersonal interactions between caregivers and health care professionals in an Intensive Care Unit population. Of particular interest was a 9 item section of the instrument

measuring quality of care. These items focused on how often particular behaviors or styles of care were true of physicians or nurses – a five point scale from never, to always --regarding the doctors or nurses taken as a whole over the last two days. In this study participants were asked to assess these behaviors for physicians, nurses, and social workers collectively, as a health care team, over the time frame since the diagnosis was made, rather than the two days. It is believed that an assessment of collective behaviors over time may capture the caregiver's perceptions of how often behaviors occurred throughout the illness experience, not only when there is a particular crisis or incident that may color that moment in time, but the whole of the illness time frame. The Quest instrument concentrates upon the interpersonal aspects of care delivered by health care professionals that have been noted in the literature as important for caregivers. Items include how often doctors or nurses "spent enough time with __," "arrived late when they promised to come see _____ or you," "been hard to reach in time of need," "seemed distracted," "been willing to take time to listen," "treated _____ more as a disease than as a person," "showed personal concern about __," " ignored _____ your feelings," and "responded quickly in time of need."

However, this scale was not comprehensive enough for purposes of this study, so other items that the researcher identified through personal experience with oncology patients and families, through discussions with physicians and nurses, and through the oncology caregiving literature were added to this communication questionnaire. Some sample items included: How often the health care team has "taught you how to give medication properly", "given you information about tests and procedures ordered for your loved one", and "asked you about how you are managing care at home". The responses were "never", "rarely", "sometimes", "usually", and "always".

There were a total of 45 survey items related to communication with health care providers. After the survey was developed, the researcher asked colleagues who had older relatives caring for spouses to test the survey for comprehension and content. Changes were made according to their feedback. This scale was tested for reliability and validity. The final scale contained 34 items ($\alpha = .94$). This scale had two subscales, derived by factor analysis. One group of 19 items that asked about how providers informed caregivers of medical information, the "medical information subscale", had an alpha of .92 ($n = 45$). Some sample items from this subscale were "taught you about pain and symptom management", explained to you the risks and benefits of treatment", "made sure you understood the risks and benefits of treatment", and taught you how to give medication properly". The second subscale consisted of 15 items that asked about how providers interacted with caregivers in providing that information. This subscale is referred to as a "supportive communication subscale" and had an alpha of .82. Some sample items from this subscale were "asked how you were managing care at home", asked you about what help you might need", "listened to what you had to say", and "been willing to take time to listen.

4.4.2. Self-efficacy

Bandura (2001) maintains that self-efficacy scales must be tailored to activity domains and they must assess the many ways in which efficacy beliefs operate within the selected domain. Furthermore, it is recommended that preliminary work identify the forms that challenges and impediments take within a selected domain. This is done by asking people, in open-ended interviews and pilot questionnaires, to describe things that make it hard to perform required activities regularly. The identified challenges or impediments are built into the efficacy items. Participants judge their ability to meet the challenges or to surmount impediments in the formal

scale. Pretests are then conducted to ensure that the efficacy items contain sufficient gradations of difficulty (Bandura). So in accordance with Bandura's guide for constructing self-efficacy scales, a focus group was utilized for the items and later pre-tested for readability and clarity as described above.

Bandura states that self-efficacy scales should have face validity and should measure what they say they measure. The construct of self-efficacy is embedded in a theory that should explain a network of relationships among different factors. Caregiving is comprised of a series of activities, both physical and emotional. Having a sense of competency in as many of these activities as possible would logically increase one's self-assessment of caregiving ability. The items for the self-efficacy scale reflected preparedness for the process of caregiving, such as feeling able to judge the seriousness of a problem or symptom, being able to try different ways to find a solution to caregiving problems, feeling able to weed out inaccurate or wrong information regarding their loved one's care, etc. There were a total of 19 items for this scale. The respondents were asked how often – never, sometimes, often, very often, and always- they felt competent in different aspects of their caregiving routine. A higher score reflects a higher level of self-efficacy. This measure was tested for reliability and validity and had an alpha of .89 (n=59).

4.4.3. Caregiver Burden

Caregiver burden was operationalized within a subjective framework., using the Caregiver Reaction Assessment by Given and Given (1992), which is a tool commonly utilized in oncology caregiving research. Subjective measures were operationalized by how caregivers

feel (from strongly disagree to strongly agree) about caring for the patient. The measurement for caregiver burden will be discussed in the following section.

The Caregiver Reaction Assessment developed and tested by Given et al. (1992), is a 24-item tool used to measure both positive and negative reactions to the experience of caring for aged persons with chronic physical impairments, Alzheimer's disease, and cancer. Initially forty items were administered to a sample of 377 caregivers of persons with physical impairments and Alzheimer's disease. Five dimensions of caregiver's reactions were identified through an exploratory factor analysis. Using confirmatory factor analysis on an independent sample (n=377), these dimensions were tested for factorial invariance across spouse and non-spouse caregivers of persons with cancer and those caring for persons with Alzheimer's disease. The five distinct subscales are (a) impact on schedule, (b) caregiver esteem, (c) lack of family support, (d) impact on health, and (e) impact on finances. Each of the 24 items are rated on a 5-point scale from "strongly agree" (5) to "strongly disagree". Higher scores indicate higher burden. (1). Some sample items are "I feel privileged to care for___," "Others have dumped caring for ___onto me," "I have eliminated things from my schedule since caring for___," and "I enjoy caring for___."

The researchers correlated the five subscales of the CRA with the number of patient dependencies in activities of daily living and caregivers' level of depression. Patient dependencies in ADL and caregiver depression were selected because of the way in which they relate to indicators of burden in conceptual models used to explain the impact of caregiving on family members. Internal consistency of coefficients for the five subscales ranged from .80 for the impact on health subscale to .90 for the caregiver esteem subscale. A finding of a modest correlation between CRA scores and measures of dependency and depression gave evidence of

construct validity. Correlations are in the expected directions (Given et al., 1992). I was given permission by Dr. Given's research center at Michigan State to utilize the CRA.

The coefficient alpha reliability for the Caregiver Reaction Assessment (CRA) for this study sample, was .83. The reliability for the subscales was sufficient with the lowest internal consistency being found for the subscale of health ($\alpha = .59$), compared with .80 in the Given (1993) research. In Nijboer, et al's (1999) work assessing the psychometric qualities of the CRA, the alpha coefficient for the health scale was .68, which is closer to the current study. The standardized Cronbach's alphas for the other subscales were: .62 for disrupted schedule, .81 for financial problems, .73 for family support, and .83 for self-esteem. By comparison, the Given, et al study alphas were: .82 for schedule .90 for self-esteem, .85 for family support, .80 for health, and .81 for finance.

4.4.4. Social Support Scale Data

In a review of the role of social support in adaptation to cancer and to survival, Blanchard et al. (1995) determined that there was no consensus about the instruments that are most appropriate to measure social support or assess outcomes. This study will utilize the MOS Social Support Survey which is a short, simple 18 item instrument developed for patients in the Medical Outcomes Study (MOS) a two year survey that was developed for patients with chronic conditions, but may be appropriate for use with other populations (Sherbourne & Stewart, 1991)). The instrument measures four functional dimensions of social support: emotional/informational, tangible, affectionate, and positive social interaction. All scales are reliable (alphas $>.91$) and are stable over time. Selected construct validity hypotheses were

supported. The coefficient alphas for this study sample were also all above .91. This instrument is written for a ninth grade level and above. It takes 2-3 minutes to complete.

Sample items include the availability of “someone you can count on to listen when you need to talk,” someone to help with daily chores if you were sick,” “someone who shows you love and affection,” and “someone to get together with for relaxation.” Responses range from “none of the time” to “all of the time.” There is one additional item , “someone to do things with to help you get your mind off things”, which was not used because it seemed to repeat other items on the measure. Also, it did not fit in any of the scales four subscales. To obtain a score for each subscale, the average of the scores for each item in the subscale is calculated. To obtain an overall support index, the average is calculated for the scores for all 18 items in the four subscales. A higher score reflects higher support. The survey is published through the RAND Health Communications and is free.

4.4.5. Other Resource Variables

In addition to social support, other resource variables include and community resources, such as Home Health Care, Meals on Wheels, Adult Services, etc. These variables could provide a moderate the caregiving experience, impacting caregiver burden, in particular, but perhaps self-efficacy as well, especially in an older population. For example, having a Visiting Nurse may well help a caregiver learn more about how to care for their loved one, making them feel more competent, and also making them feel more supported in their caregiving experience. Or perhaps, having ACCESS for assistance with transportation might help caregivers and patients in their daily needs. Thus, having community services to assist with the medical and non-medical aspects of care can be looked upon as a dimension of social support. Health care and personal

care services appear to offset the impact that disability and problem behavior of care recipients have on caregivers (Bass, Noelker, Rechlin, 1996). Information was asked as to whether the patients and/or the caregivers are currently utilizing any of this help and how many types.

4.4.6. Other Variables

The survey included demographic information: the age of the caregiver and their spouse, education level, income category, employment status, and race. Caregivers were also asked if they had any chronic disorders that might affect their own daily living activities, and how they would rate their own health (poor, fair, good, or excellent).

In addition to demographic information, caregivers were also asked questions about their spouses' cancer diagnosis and treatment. These are referred to as "illness variables" and included: the name of the diagnosis, i.e. colon cancer, lung cancer, etc.; the stage of the cancer and how long, in months since the diagnosis. They were asked if this diagnosis was a recurrence of a previously diagnosed cancer and if the disease was in a more advanced stage at the time of the original diagnosis. There were several items inquiring about the number of medical opinions their loved one received prior to beginning treatment, if their loved one was treated somewhere else prior to coming to the cancer center, and if there had been any hospitalizations in the last year, and if so, how long was the longest hospital stay. In addition, caregivers were also asked what treatments, if any, their loved one was receiving, i.e. chemotherapy, radiation, and if their loved one was enrolled in a clinical trial. One question asked if the caregiver's spouse had any other health problems besides a cancer diagnosis. The last question asked what type of insurance plan the patient was enrolled in. Any of these items may have a correlation with the three main variables for this study. The researcher believed these variables were important in understanding

the cancer caregiving experience more completely. However, because there were only 66 respondents, not all of the illness variables were used as controls in the multivariate model, so as to have sufficient power.

4.4.7. Data Analysis

Data was analyzed utilizing Statistical Package for Social Sciences (SPSS). Because there are several hypothesized predictors of the dependent variable of caregiver burden, a multiple regression approach was used. Sample means, standard deviations, and zero-order coefficients for all major variables were obtained. Caregiver burden (DV) and health care providers communication (IV) are hypothesized to be mediated by self-efficacy. That is, self-efficacy may account for the observed relationship between communication and a positive caregiving experience.

5. FINDINGS

5.1. DESCRIPTIVE DATA

Out of 82 surveys given out, a total of 66 were returned, for a return rate of 80%. Of those returned, 42 (64%) were delivered in person and 24 (36%) were sent back by mail. Approximately half (51.5%) of the respondents were 69 years or younger, and the remaining were 70 or over, with the oldest age being 87. The mean age of the caregivers was 68.8 years (median = 69 years) and the mean age of the spouse they were caring for was 69.7 (median= 70 years). Forty- four (67%) of the caregivers were females and 22 (33%) were males. Sixty- four caregivers (97%) were white, while one caregiver (1.5%) identified as an African American and one other (1.5%) responded as “other”.

The majority of the caregivers (n=35 or 53%) had a high school education or less; 36% (n= 24) had some college or were college graduates, and 10% (n=7) had a post graduate education. Twenty-two percent (n = 13) of the caregivers had incomes over fifty thousand dollars a year. Forty-eight percent (n = 28) had incomes between twenty thousand and fifty thousand dollars a years, and thirty percent (n = 17) had less than twenty thousand dollars per year. Most of these caregivers (n = 53 or 80%) did not work outside the home, but 9 caregivers (14%) worked part time and 4 caregivers (6%) worked full time. Table 1 presents the demographic data.

Table 1. Caregiver age, gender, race, education, and income

	Number/Caregiver (%)
Age	
60-69	34 (51.5%)
70-79	27 (40.9%)
>80	5 (7.5%)
Gender	
Female	44 (67%)
Male	22 (33%)
Race	
White	64 (97%)
African-American	1 (1.5%)
Other	1 (1.5%)
Education	
High School or less	35 (53%)
Some College/College	24 (46%)
Post Graduate	7 (10%)
Income	
<20,000	17 (30%)
20,000-50,000	28 (48%)
>50,000	17 (30%)

5.1.1. Illness Data

Illness variables, as mentioned previously, are: diagnosis (Table 2), stage of the disease (advanced or terminal), type of treatment the patient is currently (chemotherapy, radiation, biological therapies), if the patient is participating in a clinical trial, length of time since diagnosis, and if the patient has been treated at more than one institution (oncology patients often seek second and third opinions at different hospitals).

The caregivers rated themselves as being in fairly good health overall. Twelve caregivers (18%), said their health was “excellent”; thirty-seven (56%) rated their health as “good”; fifteen

caregivers (23%) said their health was “fair”; and only two (3%) said they had “poor” health. This corresponds with the survey question asking if the caregivers had any chronic health problems. Twenty-nine percent of the caregivers ($n = 19$) said they had a chronic condition that affected their daily living activities.

The mean number of medical opinions sought by patients prior to starting treatment was two (SD .86). Fifty-four percent had two opinions, 15% had three opinions, and 9% sought more than three opinions. The majority of the patients (61%) started their treatment at the Cancer Institute. The mean number of hospitalizations in the last year was two (SD.72). The mean length of time in months from the time of diagnosis was 30.7 (SD. 42.2). The range here was wide, from a minimum of 2 months to a maximum of 180 months from time of diagnosis. This range is significant in and of itself. It indicates that some patients most likely had advanced disease at the time of diagnosis, while others had either progressed to an advanced stage or perhaps had treatment successful at slowing the progression of an advanced diagnosis.

Although the patients referred for this study all had documented advanced disease, fifty three percent of the caregivers ($n=35$) said they did not know the stage of the their spouse’s cancer. In the present sample thirty seven percent ($n=24$) said the cancer was advanced and ten percent ($n=7$) said the disease was terminal. Forty- one percent of the caregivers ($n=27$) identified the cancer as a recurrence of a previously diagnosed cancer and fifty- nine percent ($n=39$) said it was a new diagnosis.

The caregivers in this non -random sample were caring for a heterogeneous group of cancer patients. Table 2 presents the diagnosis data. Lung cancer ($n = 25$ or 38%) was the predominant diagnosis. There are a number of lung cancer studies at the Cancer Center and many people with this diagnosis come here for second opinions. This diagnosis also tends to be more advanced at

the time of diagnosis. Thus many advanced lung cancer patients are seen for evaluation. Colon cancer (n =8) and melanoma (n = 8) each represented 12% of the diagnoses. Other cancers represented were head and neck (n = 2 or 3%). There was one case each of brain, breast, bladder, unknown primary, and sarcoma (1.5% each). Other diagnosis represented were pancreatic (n = 5, 7.6%), non Hodgkin's Lymphoma (n = 3, 4.5%), prostate (n = 4, 6.1%), and esophagus (n = 3, 4.5%). Three people (4.5%) indicated they did not know the diagnosis or put "stage 4" as a name.

Table 2. Diagnosis

	N	%
Lung Cancer	25	38%
Colon Cancer	8	12%
Melanoma	8	12%
Pancreas	5	6.1%
Lymphoma	3	4.5%
Prostate	4	4.5%
Esophagus	3	3.7%
Bladder	1	1.2%
Unknown Primary	1	1.2%
Don't Know	3	3.7%

Only 4 (6%) of the patients were receiving radiation; 67% (n=44) were receiving chemotherapy. Seventeen patients (26%) were enrolled in a clinical trial. Thirteen patients (20%) were currently not being treated. Ten patients (15%), were on new treatment regimes after previous treatments failed. Thirty-one (47%) of the patients had other health problems in addition to cancer.

Although this cohort of patients had advanced disease, only seven (11%) patients were receiving home care; one was in a home hospice program. None had been, nor was currently, in

an extended care facility hospice program. One patient had spent some time in an extended care facility. None were receiving Meals on Wheels. Forty-eight percent of the caregivers reported that their loved one's health care providers never or rarely offered any referrals to community services. Because of the almost non-existent use of these resource variables, they were not included as control variables in the hierarchical regression. Also, almost half the caregivers (48%) said they had never or rarely seen a social worker, which is the likely source of linkage with community resources. Health care insurance did not appear to be a problem in this sample. All were covered by private insurance, or Medicare with supplemental coverage and none were on Medicaid.

5.1.2. Descriptive Measurement Data

Data available for the social support measure were not normally distributed. Consequently, this variable was transformed by squaring the social support mean score resulting in a decrease in skewness. All other main variables were normally distributed.

Table 3 presents the overall scale data for the Caregiver Reaction Assessment (CRA), self efficacy, health care provider communication, and social support. The mean score for caregiver burden, as measured on a five -point scale, with a higher score indicating higher burden, by the Caregiver Reaction Assessment, (CRA) was moderately low, ($M = 2.2$; $SD .45$), regarding the negative aspects of the caregiving experience. The CRA is comprised of 5 subscales: self-esteem, disrupted schedule, family support, financial problems, and health problems. The mean scores for the current study for these subscales were as follows: 1.77 for low self-esteem, 3.0 for disrupted schedule, 1.88 for low family support, 2.22 for financial problems and 2.31 for health problems. Caregivers reported moderate social support ($M=3.9$; $SD. 1.0$) as measured by the

five- point scale of the Social Support Scale of the Medical Outcomes study (MOS), with 1 being low social support and 5 being high social support. They reported having fair communication with health care providers as measured by a 5 point scale (never, rarely, sometimes, usually, always), with 5 being the highest level of satisfaction with communication behaviors of health care providers ($M = 3.8$; $SD = .64$). Self efficacy, also measured on a five point scale, with the higher score indicating higher self efficacy in caregiving, had a mean score of 3.8 ($SD = .07$).

Table 3. Descriptive Data of Burden, Social Support, HCP Communication, and Self-Efficacy Scores

	X	SD	Alpha
Caregiver Reaction Assessment (CRA)	2.19	.45	.83
• Self Esteem Subscale	1.77	.64	.83
• Disrupted schedule	3.00	.68	.62
• Family Support Subscale	1.85	.75	.73
• Financial Problems	2.19	.78	.81
• Health Problems Subscale	2.31	.75	.59
Social Support Scale	3.91	1.0	.96
• Emotional/informational Support Subscale	3.74	1.2	.95
• Tangible Support Subscale	3.69	1.35	.93
• Affection Subscale	4.31	1.16	.91
• Positive Social Interaction Subscale	4.08	.95	.97
Health Care Provider Communication	3.80	.66	.94
• HCP Subscale: Supportive Communication	3.64	.59	.83
• HCP Subscale: Medical Information	3.92	.77	.92
Self Efficacy	3.84	.07	.88

Descriptive data for the individual items in the HCP Communication measure, developed for this study, are described in Table 4. These items were on a 1-5 scale with 5 reflecting good communication and being the lowest. Negatively worded items were reverse scored. Some of the highest mean items were related to giving medical information. These included: giving

information about a loved one's illness and treatment, giving information about medication, and giving information about tests and procedures. There were also high mean items in the Supportive Communication subscale as well. These included: answering all your questions about a loved one's illness and treatment, including you in decisions about your loved one's illness and treatment, listened to what you had to say, and made you feel cared about as a person. Several items had sufficiently low scores that could indicate communication problems for the caregiver. The lowest means were for asking about financial problems, asking about the need for community resources, and offering referrals to community services. These items have implications for social work intervention. Social workers are usually the professional who makes the appropriate referrals in social services related issues. Several other items had only slightly higher means: explaining what to expect in terms of emotional and relationship issues, asking about what help one might need, teaching about pain and symptom management, and asking how the caregiver is managing care at home.

Table 4. Descriptive Data of HCP Communication Measure

Item	X	SD
Given information about loved one's illness and treatment. (MC)	4.56	.56
1. Included you in decisions about your loved one's illness and treatment. (SC)	4.44	.80
2. Answered all your questions about your loved one's illness and treatment. (SC)	4.60	.52
3. Listened to what you have to say (SC)	4.72	.45
4. Made you feel cared about as a person. (SC)	4.60	.56
5. Given you their full attention. (SC)	4.53	.64
6. Asked how you are managing care at home. (SC)	2.98	1.4
7. Seemed distracted by other things when they talked to you. (SC)	1.29	.56
8. Been willing to take time to listen. (SC)	4.53	.92
9. Treated your loved one more as a disease than as a person. (SC)	1.38	.80
10. Responded quickly in time of need. (SC)	4.53	.73

Table 4 Cont'd

11. Given you information about medication (MC)	4.51	.71
12. Discussed control of your loved one's discomfort. (MC)	4.30	.95
13. Discussed the way decisions are made about admitting your loved one to a hospital (MC)	3.60	1.54
14. Taught you how to give medication properly. (MC)	3.64	1.64
15. Explained to you the risks and benefits of treatment. (MC)	4.25	1.21
16. Offered to make a referral to community services (SC)	1.98	1.43
17. Taught you about nutrition. (MC)	3.47	1.50
18. Taught you about side effects. (MC)	3.88	1.36
19. Given you information on tests and procedures ordered for your loved one (MC)	4.50	.88
20. Taught you how to monitor any changes in the health status of your loved one. (MC)	3.60	1.52
21. Explained what to expect in terms of emotional/relationship issues related to illness. (SC)	3.00	1.58
22. Asked about what help you might need (SC)	2.55	1.47
23. Asked about financial/insurance problems due to illness. (SC)	1.97	1.26
24. Talked to you about community resources that might help. (SC)	2.67	1.52
25. Taught you about pain and symptom management. (MC)	2.66	1.53
26. Given you written information on your loved one's disease. (MC)	3.95	1.29
27. Given you written information on your loved one's treatment. (MC)	4.02	1.29
28. Given you written information on your loved one's care needs at home. (MC)	3.20	1.57
29. Taught you when it is necessary to call a doctor. (MC)	3.64	1.49
30. Discussed goals of treatment and made sure you understood. (MC)	4.24	1.00
31. Explained to you who all health care providers are who see your loved one. (SC)	3.26	1.53
32. Discussed other options/alternatives to treatment with you. (MC)	3.50	1.51
33. Made sure you understood risks and benefits of treatment. (MC)	4.22	1.26

Medical Communication Subscale = MC

Supportive Communication = SC

5.1.3. Bivariate Analyses

There was no relationship found between communication and self-efficacy as had been predicted. In the bivariate correlational analyses presented in Table 5, the relationship of self

efficacy to caregiver burden was significant ($r = -.27$, $p = .03$) in the expected direction; a higher level of self efficacy was correlated with lower burden scores.

Table 5. Intercorrelations of Burden, Self-Efficacy, HCP Communication, and Social Support Variables

	Caregiver Burden	HCP Communication	Self-Efficacy	Social Support
Caregiver Burden	--	-.09	-.27*	-.24*
HCP Communication		--	.09	.34**
Self-Efficacy			--	.23*

* $p < .05$ level

** $p < .01$ level

As presented in Table 5, social support was correlated with self- efficacy ($r = .23$, $p < .05$), that is, a higher level of social support was correlated with a higher level of self- efficacy. There is also a correlation between communication and social support ($r = .34$, $p < .01$) The HCP communication measure includes supportive communication, thus this may be confounded with social support.

Table 6 presents intercorrelations of central variables and demographics. Spearman's correlations were performed because at least some of these background variables were not normally distributed. Self-efficacy was also correlated with self reported health status of the caregiver ($r_s = .32$, $p = .008$). Caregivers with higher self- efficacy reported better health. In addition, caregivers who had been in the role of caregiver for a longer time reported higher self efficacy. These correlations are useful in establishing construct validity for the self-efficacy measure. Caregivers with higher levels of burden reported a poorer health status ($r_s = -.35$, $p = .01$). Additionally, caregivers of spouses who were treated somewhere else prior to treatment in the current facility reported more burden ($r_s = .26$, $p = .04$). Age was correlated negatively with the medical communications subscale of the communication measure ($r_s = -.31$, $p = .01$). The

older the caregiver, the less likely the caregiver would have satisfactory communication with health care providers about medical information. There was also a correlation between communication and the caregiver's education level ($r_s = -.32$; $p = .0$),

There were several other relationships that are relevant to the main study variables and which also capture some salient issues these caregivers were dealing with. In the demographic questions, caregivers were asked about their own health as well as questions regarding some aspects of their spouses' medical treatments. An independent sample t-test was done to examine if being treated somewhere else (coded "yes" or "no") and if this was a recurrence (coded "yes" or "no") of a previously diagnosed cancer had any relationship to caregiver burden. There was no relationship between recurrence and burden.

However, the difference in means was significant for being treated somewhere else and burden, but in an unexpected direction. Caregivers who had spouses treated somewhere else had a lower mean burden score ($M = 2.05$) than those not treated somewhere else ($M = 2.29$), which was a significant difference ($p = .04$). It may be that those who had been treated somewhere else and then made a decision to be seen at a comprehensive cancer center coped better than the other group, or just had been dealing with the situation longer than the other group and so were more adapted to the caregiving role. Male caregivers in this sample had a lower mean burden score ($M = 2.03$) than female caregivers ($M = 2.28$) which was a significant difference ($p = .03$).

Also, caregiver burden was correlated positively with the number of hospitalizations a patient had experienced in the last year ($r = .26$ $p = .04$), the more hospitalizations, the greater the burden. Self-efficacy was correlated with how a caregiver rated his/her own health ($r = .32$, $p = .01$), so that a poorer health status was associated with greater burden.

Table 6. Intercorrelations of Selected Variables and Demographics. (Rs)

	HCP Communication	HCP Medical Subscale	Self- efficacy	Burden	Recurrence
1. Age	-.26*	-.31*	-.05	.07	.28*
2. Education	-.32**	-.35**	.12	.69	.59
3. Length of time as caregiver	.37	.57	.26*	.02	-.53**
4. Self reported health status	.07	.14	.32**	-.31*	.26
5. Treated somewhere else	-.15	-.17	.00	.20*	.37**
6. Recurrence	-.20	-.13	.12	.14	.37**
7. Number of medical opinions	.34**	.33**	.12	.13	-.22
8. Number of hospitalizations	.09	.09	-.22	.26*	.04
9. HCP medical subscale	---	---	.09	-.12	-.18
10. CRA: Health status subscale	---	---	-.33**	.72**	.03
11. CRA Financial Problem subscale	---	---	-.46*	.28*	---

*p<.05

**p<.01

I also did a bivariate analysis of the subscales of the CRA in order to explore if any subscales were especially revealing of how burden might have been experienced in this sample. Both the financial problem subscale and the health problem subscale were correlated with self -efficacy. Caregivers with lower self efficacy had more financial problems ($r_s = -.4$). Also caregivers with more health problems (in the health problem subscale) had lower self -efficacy ($r_s = -.33$; $p = .01$).

Overall the bivariate analyses yielded correlations which shed some light on self-efficacy and caregiver burden. The correlation between burden and self-efficacy ($r = -.27$, $\rho = .03$) is significant. The higher the self-efficacy, the lower the burden.

5.2. TEST OF MODEL

5.2.1. Multiple Regression Analysis: Predictors to Caregiver Burden

Table 7 summarizes the multiple regression analysis of the main model. In this model, the dependent variable was caregiver burden and the independent variables entered were self efficacy (Step 2) and health care provider communication (Step 3). Social support, caregiver age, illness variables, and education were entered as control variables. The control variables contributed 38% (R Square=.38) to caregiver burden.(Table 7). In this model , social support (p = .01), gender (p = .03, and education (p = .03) were significant predictors of burden. Self-efficacy, added in the second part of the model, contributed an additional 4% to burden along with the control variables. The significant predictors in model 2 were gender (p = .03) and social support (p = .03). In part 3 of the model, HCP communication was added, which contributed an additional 1% to caregiver burden. Gender was again a significant predictor of burden (p = .01), as was social support (p = .01). Model 2, self-efficacy, along with the control variables , were significant predictors of burden. (p = .04) in this hierarchical regression.

Table 7. Summary of Hierarchical Regression Analysis for Variables Predicting Caregiver Burden in Oncology Spousal Caregivers (N=66)

Step 1	B	β	R .61	R2 .38	F Change 1.9	DF 12	Significance .07
Predictors:							
Recurrence	-.03	-.04					.83
Time since diagnosis	.003	.25					.13
Advanced disease	.10	.10					.47
Stage of cancer	-.07	-.15					.34
Chemotherapy	.15	.15					.39

Table 7 Cont'd

New Treatment	-.06	-.05	.78
Not being treated	-.06	-.17	.34
Radiation Therapy	-.46	-.05	.77
Gender	.30	.31	.03*
Age	.01	.12	.43
Social Support	-.03	-.40	.01**
Education	0.14	-.36	.03*
Step 2			
Edictors:			
Recurrence	-.004	-.004	.98
Time since diagnosis	.004	.29	.08
Advanced disease	.04	.04	.78
Stage of cancer	-.05	-.10	.50
Chemotherapy	.15	.15	.36
New treatment	.06	.05	.76
Not being treated	.02	.01	.54
Radiation therapy	-.17	-.10	.48
Gender	.35	.37	.01**
Age	.01	.10	.51
Social support	-.02	-.33	.03*
Education	-.11	-.30	.06
Self-efficacy	-.20	-.26	.10
Step 3			
Predictors:			
Recurrence	.01	.01	.96
Time since diagnosis	.004	.32	.07
Advanced disease	.06	.03	.83
Stage of cancer	-.04	-.07	.65
Chemotherapy	.17	.17	.31
New treatment	.04	.04	.82
Not being treated	.03	-.12	.87
Radiation therapy	-.14	-.09	.56
Gender	.34	.36	.02*
Age	.01	.11	.45
Social support	-.02	-.37	.01**
Education	-.09	-.25	.15

Table 7 Cont'd

Self-efficacy	-.21	-.28	.09
HCP communication	.08	.11	.54

*p<.05

**p<.01

A secondary regression analysis was also done testing the two subscales of the communication measure. One subscale measured HCP communications that were more supportive in nature. The second subscale measured communications that focused on providing teaching or instruction involving treatment, disease process, care needs, etc., so these communications were more medical in nature. Using the dependent variable of burden, I tested the contributions of self-efficacy, age and education for each communication subscale separately (Tables 8 & 9). Since the illness variables were not significant predictors in the main model, I chose to only use social support, age, gender, and education in this sub-analysis. Social support and gender were significant predictors of burden in the all steps of the model. On the model with the subscale of medical communication, social support and gender were predictors of burden. One might conclude that caregivers who have help from family and friends would feel more supported and more competent in their caregiving role.

Table 8. Multiple Regression Analysis for Medical Subscale of HCP Communication Measure. Predicting to Caregiver Burden (DV)

	B	β	R	R²	F Change	DF	Significance
Model 1			.42	.18	3.2	4	.02
Predictors:							
Age	.01	.09					.46
Gender	.29	.32					.02*
Education	-.05	-.19					.13
Social support	-.02	-.26					.01**

Table 8 Cont'd

Model 2			.47	.22	3.32	5	.01
Gender	.30	.11					.01**
Self-efficacy	-.16	-.23					.07
Social support	-.02	-.01					.05*
Age	.01	.07					.58
Education	-.05	-.13					.32
Model 3			.48	.23	2.9	6	.02
Age	.00	.03					.82
Gender	.34	.33					.01**
Education	-.06	-.16					.23
Social support	-.02	-.22					.09
Self-efficacy	-.15	-.22					.08
HCP medical subscale	-.08	-.13					.33

*p<.05

**p<.01

Table 9. Multiple Regression Analysis for Supportive Communication Subscale of HCP Communication Measure, Predicting to Caregiver Burden (DV)

	B	β	R	R2	F Change	DF	Significance
Model 1			.40	.16	2.88	4	.03
Predictors:							
Age	.01	.07					.52
Gender	.26	.28					.03*
Education	-.08	-.19					.18
Social support	-.02	-.32					.01**
Model 2			.45	.21	2.30	5	.02
Gender	.29	.31					.01**
Self-efficacy	-.15	-.22					.09
Social support	-.02	-.25					.05*
Age	.00	.06					.61
Education	-.08	-.16					.66

Table 9 Cont'd

Model 3			.45	.21	2.46	6	.04
Age	.00	.06					.62
Gender	.30	.31					.01**
Education	-.05	-.13					.32
Social support	-.02	-.25					.06
Self-efficacy	-.15	-.22					.09
HCP supportive subscale	-.01	-.02					.89

*p<.05

**p<.01

I had conceptualized self efficacy as a mediator variable in this study. I believed that if health care providers took the time to make sure that caregivers knew what to expect and what to do in their caregiving role that this would make them more confident caregivers, and thus they would experience a low degree of caregiver burden. So HCP communication should have been a predictor of self efficacy in caregiving. But this was not the case. Since there was no direct relationship found either between communication and self efficacy, communication and caregiver burden, or between self-efficacy and caregiver burden, no test of mediation was done.

5.2.2. Analyses Testing Social Support as a Moderator

Social support was predicted to be a moderator variable between the major variables in this study. A multiple regression analysis was done to test three models. The first model tested social support as a moderator between self -efficacy and caregiver burden. In this model self-efficacy, social support, and a created variable of the interaction between self-efficacy and social support were tested, with burden as the dependent variable. These variables contributed 10% to

burden. Although all three variables had significant intercorrelations, there were no significant predictors in the model.

The second model tested the interactive effect of HCP communication and social support, HCP communication, and social support on caregiver burden. These variables contributed 6% to burden and there was no significant predictor in this model.

The last model tested the predictors of communication, social support, and the interaction of communication and social support on self-efficacy. Both social support ($\beta = 1.02$, $p=.03$) and the interactive term ($\beta = -.935$, $p=.05$) had a correlation with self efficacy at the .05 level. They contributed 7% towards self efficacy, but there were no significant predictors.

Because the bivariate analysis of the CRA subscales revealed a correlation between the financial problem subscale and self-efficacy, I performed a regression analysis with the CRA financial problem subscale as the dependent variable and the independent variables of self efficacy and HCP communication. Age, gender, education, , and social support were entered as control variables. The control variables contributed 21% to this aspect of burden; the regression analysis was significant at .01. Education ($p=.01$)and self-efficacy ($p = .01$) were the most significant predictor variables in this model (Table 10.). Since education is often a proxy for socio-economic status, it is not surprising that the lower one's education, the more likely one is to be in a lower income category. This may explain the relationships among the financial problem subscale, education, and self-efficacy. And it is reasonable to think that self-efficacy, or one's feeling of competency in caregiving, might be a predictor of the burden of financial problems related to caregiving, in the sense that higher feelings of competency might be intimately related to one's lack of worry over financial problems, especially as those finances might relate to illness needs and services.

Table 10. Multiple Regression Analysis for “Financial Problem” Subscale of CRA as the DV

	B	β	R	R²	F Change	DF	Significance
Model 1			.46	.21	3.2	4	.01
Predictors:							
Age	.01	.11					.32
Social support	-.03	-.27					.03*
Gender	-.20	-.12					.30
Education	-.31	-.44					.00*
Model 2			.47	.22	3.3	5	.01
Age	.01	.08					.44
Education	-.24	-.36					.00*
Self-efficacy	-.43	-.35					.00*
Social support	-.02	-.18					.14
Gender	-.14	-.08					.45
Model 3			.48	.23	2.9	6	.02
Age	.01	.12					.31
Gender	-.17	-.10					.37
Education	-.22	-.32					.01
Social support	-.02	-.21					.09
Self-efficacy	-.39	-.32					.01**
HCP communication	.16	.14					.29

*p<.05

**p<.01

In conclusion, the data did not confirm the predictions of the study. Nevertheless, there were some patterns in both the bivariate and regression analyses that capture and /or confirm some trends that impact the caregiving experience of older caregivers. Self-efficacy was correlated positively with social support, caregiving experience over longer periods of time, and the

caregiver's health status. Burden was correlated negatively with self-efficacy. Communication was correlated with social support, education, and with the age of the caregiver (in the HCP subscale of medical communication). Financial problems also appeared to correlate with self-efficacy, as did caregiver's health status. Education was surprisingly correlated with higher caregiver burden, but it was also a predictor, along with social support, of self-efficacy. The following section discusses some of the factors that may have contributed to these findings.

6. DISCUSSION

One of the most stated needs of caregivers in the literature is the need for information, support, and better communication with healthcare providers. There has been an abundance of studies examining caregiver burden. This researcher's experience in oncology social work led to an interest in the possible relationships between health care provider communication, self-efficacy in caregiving, and caregiver burden. Would caregivers who felt they had obtained adequate knowledge and support from healthcare providers experience more preparedness in the caregiving role? If they felt better prepared to care for a spouse with advanced cancer, would they then experience less caregiver burden? The data, however, did not confirm my predictions. Thus, I will discuss some of the factors that might have contributed to the patterns found.

The overall CRA score for the caregivers in this study was rather moderate (M=2.2 on a 5 point scale)), meaning that as a group, this sample experienced moderate burden. Possibly those who agreed to complete this survey were doing somewhat better at that particular time than those who were not interested in completing the survey, so there is possibly a selection bias here. Also, as a group, these participants seemed to have good communication with health care providers (M=3.8 on a 5 point scale). However, as discussed earlier in the descriptive analysis of the communication measure, there were some items that were lacking in the communication with health care providers, and these could affect both self-efficacy and burden. For example, lack of communication regarding referrals to community services, or hospice care, lack of teaching about pain and symptom management, and lack of HCPs asking about a caregiver is managing care at home may impact burden and self-efficacy. Finally, these participants seemed to feel

relatively competent in their caregiving abilities ($M=3.8$ on a 5 point scale). It is also possible that communication is not relevant here after all for either self-efficacy or burden.

In the review of the literature discussion of advanced cancer, two studies focusing on the needs of the family caregivers of bone marrow patients were discussed. One study by Stetz, et al (1987) found that communication with health care providers was problematic, with caregivers feeling that they were not listened to and not acknowledged by health care providers. Stetz used a descriptive focus group methodology to collect data as contrasted to the second study of the needs of caregivers of bone marrow patients. In this second study conducted by Zabora, et al (1992) participants responded to quantitative instruments, the same as this present study. In the Zabora study caregivers did not report any difficulties in communicating with health care providers. So it is possible that the methodology for this study might have limited the participants' ability to adequately reveal their in-depth experience of communication with their loved one's health care providers.

It is also possible that caregivers in this sample truly had enough information as a whole. As mentioned earlier, Prohaska and Glasser (1996) found that individuals, usually family members of older patients, who accompany their loved one to a medical appointment, are involved in the health care decisions leading to the medical appointment and that older patients recognize the caregiver or companion involvement in the medical decision process. A second study by Labrecque, et al (2001) underscored Prohaska's and Glasser's findings. This study focused on oncology patients and the results concluded that physicians discussed both future treatments and the patient's current medical status more often if a family member was present. This information may help explain the relatively positive communication that caregivers had with health care providers in this study. Many of the Cancer Institute's patients come from great distances and

almost always come with at least one family member; often times, they come with multiple family members. But even patients who live locally almost always come with a family member. Sometimes the patient is too sick to come alone, but even if that is not the case, family members still accompany loved ones. So perhaps this sample of caregivers had all the information they needed to be competent caregivers.

I found it notable that there was a positive correlation between the number of medical opinions patients had prior to treatment and communication with health care providers. It may be indicative of a sample that feels strongly that one should seek a second or third opinion when one has a serious diagnosis. Although this may seem like good common sense, there are still many patients who feel they will offend their physicians if they seek another opinion. But there has been much information through the media about the efficacy of a second opinion in serious illness and perhaps people are simply learning that this is now common and acceptable.

Interestingly, there was a negative correlation with education and health care provider communication, i.e., more educated caregivers had less positive communication with health care providers. This finding is supported in the literature. Nijboer, et al (2001) found that caregivers with a higher socioeconomic status experienced caregiving more negatively. It may be that people with a higher education are more likely to seek information on their own about a disease, standard and alternative treatments, and clinical trials. They may be more prepared to question physicians about these issues. At times, when emotions run high, these questions are posed more as a confrontation rather than a dialogue.

In spite of the positive HCP communication in this sample, caregivers still did not seem to know some basic facts about their spouses' illness. For example, 38% of caregivers (n=31) indicated that they did not know the stage of their loved one's disease. Perhaps they did not

understand what "stage" meant. If this is so, then I made an assumption about caregivers' knowledge of their loved one's illness as well as assuming that everyone would understand what I realize now is a medical term. It is also possible that the patient was told the stage, but did not communicate this information to the caregiver. In a nationwide telephone survey of 1800 family caregivers about family experiences with hospital care, 40% of family caregivers said they were not asked enough about their views on the patients' treatment and 20% reported they were not as involved as much as they would have liked with decision making about the patients' care (von Eigen, Walker, Edgman-Levitan, Cleary, & Delbanco, 1999). This lack of attention to the role of a caregiver could likely lead to the caregiver's lack of appropriate information about the patient's condition, treatment and expectations of the treatment, prognosis, and care needs.

Self-efficacy was the strongest predictor of caregiver burden. Caregivers who had been at caregiving the longest felt more confident as caregivers. Interestingly, there was *not* a correlation between how long one had been a caregiver and caregiver burden, nor was there a correlation with HCP communication. Caregivers whose spouse had been treated somewhere else before their current treatment experienced more burden. One explanation for this, as mentioned earlier, is that many of the patients who have been treated elsewhere and are now being treated at the Cancer Center come from long distances. Many of them stay at hotels or Family House through the treatment. This is both costly and tiresome for the caregivers.

One of the more striking incidental findings was that no one had been referred to a hospice or palliative care program even though this was a sample of advanced or terminal cancer patients. Clearly doctors are not broaching this subject in a timely manner and patients and family caregivers are without a valuable resource. Also, only a small subset had any home care involvement and no one had any community service involvement. Along with that was the

finding that social workers were not especially involved with these patients. It had been this researcher's experience, based on discussions with the two oncology social workers at the Cancer Center, that most of their referrals are patients and families with serious financial problems, such as no insurance, poor insurance, lost insurance, lost a job due to illness, etc. This sample of caregivers and their loved ones did not seem to have serious financial issues, and insurance was not a problem. There was not one patient who had Medicaid in this sample.

There is one major social work implication here. One of the functions of oncology social workers is as a gatekeeper for various community resource referrals. However, caregivers in this sample did not see a social worker very often ($X = 2.82$, $SD = 1.73$). Older caregivers of advanced and terminal patients should be evaluated to determine needs for community resources and to assess for financial problems that may ease some of the burden of caregiving. The financial problems associated with illness are devastating not only to the patient, but extends to the caregiver as well. Older patients and caregivers live on fixed incomes and often pay a substantial amount of their monthly income on prescription drugs. Many of the caregivers in this study indicated they had their own medical problems. This may create additional stress for the caregiver. A social work assessment on all older spousal caregivers of oncology patients could help in the early identification of financial concerns and other health related caregiving concerns. Social workers can assist caregivers in working through the maze of Medicare and supplemental insurances, as well as other related issues. Social workers can also educate caregivers about the emotional and relationship issues related to illness and treatment and assist them in dealing with those issues.

While assisting with the more tangible needs of the older caregivers, social workers can also assess other caregiver needs such as the health of the caregiver and any limitations on ADLs,

what he/she understands about the spouse's illness and treatment, available support from family and friends coping abilities, etc. This information can be communicated to the patient's physicians and nurses, so that care is taken to educate and support the more vulnerable caregivers.

6.1. STUDY LIMITATIONS AND STRENGTHS

This study was limited by the fact that the measures were done only once. Also, the sample size was small, which restricted power for the analysis. Future studies in this area should follow caregivers over time to track changes in communication, self-efficacy, and social support. Strengths of the study were the communication measure and the self-efficacy measure, developed and tested for this study. Both measures had very good reliability. Further refinement of these measures, with a bigger sample size that is tested and retested over time, are necessary. But both may contribute to the oncology caregiving and communication literature.

Also the study was limited by the source of the caregiver sample, which was a comprehensive cancer center. This is a different sample, I believe, than caregivers from community hospitals, who do not get referred to a comprehensive cancer center, do not choose to go to one, or whose insurance will not cover them at such an institution. Future studies in this area might also include in depth interviews with caregivers as well as the quantitative measures. Future studies might also include how people get their medical information in addition to their health care providers. Do they get it from the Internet, from blogs, (which may also be a source of social support for some)? Also, in this study, the patients were quite ill, yet there was very little talk of hospice or palliative care. Future studies should examine this lack of

communication. Other future studies might want to look at these same issues but in a younger population, who often have less insurance coverage than the elderly, or with a group of subjects with the same diagnosis. Finally, future studies may want to look at a different outcome, other than caregiver burden, such as depression or anxiety, for example.

6.2. CONCLUSION

Social workers in outpatient oncology centers should make it a priority to work with nurses and physicians to screen older caregivers in order to assess their overall needs as caregivers, so that appropriate referrals and assessments can be made, in a timely way. If older caregivers are in an environment that allows them to ask questions about their loved one's treatment, disease, prognosis, etc, then over time, as the disease progresses, they may feel more comfortable discussing hard issues, such as stopping treatment or advanced directives, with both their loved one and the health care providers.

APPENDIX A: FOCUS GROUP DISCUSSION ITEMS

The following is a list of possible indicators of skill in the caregiving process. Each category has a list of behaviors that some researchers consider important to be a competent caregiver. We will discuss these areas and also see if there are other caregiving skills you think are important, but are not listed here.

Monitoring:

1. Notices subtle changes.
2. Notices verbal and non-verbal indicators of patient's well-being.
3. Uses instruments, such as a thermometer, for monitoring when it seems appropriate.
4. Makes accurate observations.
5. Keeps a written record when appropriate.
6. Notices patterns, for example, sleep and eating patterns, or certain times of the day when a patient might be more uncomfortable than at other times.

Interpreting

1. Recognizes when something is "different" or "wrong" from the expected course of disease or treatment effects.
2. Judges the seriousness of a problem.
3. Seeks explanations for unexplained signs and symptoms.
4. Asks detailed questions for the purpose of developing an explanation.

5. Can use a reference point in making sense of an observation. For example, when a new symptom first became obvious.
6. Considers multiple explanations for an observation.

Making Decisions

1. Takes into account multiple illness demands.
2. Weighs the importance of conflicting priorities.
3. Attends to multiple care issues at once.
4. Thinks ahead about possible consequences of a given action.

Taking Action

1. Recurring actions are done on a regular schedule.
2. Caregiver takes own needs into account in making a caregiving schedule.
3. Can develop routines to manage complex tasks.
4. Can organize illness care tasks so that the patient can be involved if appropriate.
5. Has a system for remembering when it is time to perform certain actions.
6. Has the ability to take action on multiple issues at one time.

Making Adjustments

1. Adjusts amount of food, prn medications, rest, exercise, etc. until optimum comfort and symptom management is achieved.
2. Modifies long-standing routines to accommodate the illness situation.
3. Tries different strategies until a solution to caregiving problems are found.

4. Accessing Resources
5. Seeks resources as appropriate.
6. Uses advice judiciously.
7. Seeks authoritative resources when appropriate.
8. Weeds out inaccurate, wrong, or inadequate advice.
9. Persists in finding resources until what is needed is found.
10. Figures out which health providers are most helpful, accessible, and knowledgeable.
11. Can make own needs known.
12. Takes initiative in seeking resources.

Providing hands on care

1. Performs procedures safely.
2. Pays attention to patient's comfort.
3. Takes the time needed with procedures to get the best results.

Working together with the patient

1. Perceives when to take a more active role in illness care.
2. Perceives when to step back.
3. Provides care in a way that is meaningful to the patient given his/her personal history and identity.

Negotiating the Health Care System

1. Evaluates care received in the health care system.

2. Advocates for the patient and/or self when necessary.
3. Seeks assistance from health care providers in a timely way.

APPENDIX B: SURVEY PACKET

February 25, 2003

To: Oncology Caregivers

You have been asked to participate in a research study that is looking at how communication with health care professionals-doctors, nurses, and social workers- affects your caregiving experience. Enclosed is a group of questionnaires asking about different aspects of your caregiving experience plus some basic information about you and your spouse's illness. It will take about 20 minutes of your time to complete the questionnaires. A stamped, addressed return envelope is enclosed.

The questionnaires will only be used by the principal investigator. It will not be shared with any other health care professional or any other researchers. Your participation is completely voluntary and your participation or non-participation will not affect the care of your spouse at a UPMC facility.

As a thank you, all respondents who mail back completed questionnaires will be mailed a \$10.00 gift certificate to Giant Eagle.

If you have any questions about your rights as a research participant, you can call the Human Subject Protection Advocate of the Institutional Review Board (IRB) at the University of Pittsburgh at 412-578-8570. If you have questions about the questionnaire study, you can call the principal investigator, Joyce Grater, at 412-623-4788.

There are minimal risks associated with this study. Completing this questionnaire may elicit feelings of sadness, anger, or other emotions. However, the benefit of participation is that you are helping health care professionals better understand what caregivers need from them in order to feel more confident in caregiving. Enclosed is a University of Pittsburgh Cancer Institute brochure with an 800 number. If you have any concerns or questions about caregiving, you can call this number and speak to an oncology nurse or social worker.

Thank you for your time and for your expertise as a caregiver.

Sincerely,

Joyce Grater, LCSW
Principal Investigator

I would like to know about how your health care team (all the doctors, nurses, and social workers) has *communicated with you* throughout your loved one's cancer care. Think of these health care providers as a group and give an over all rating of how the health care providers communicated with you. Check the box that best describes how often these interactions or behaviors occurred in the course of your loved one's illness.

How often has the health care team:

	Never	Rarely	Sometimes	Usually	Always
1. used words that you can understand?					
2. given you information about your loved one's illness and treatment?					
3. included you in decisions about your loved one's illness and treatment?					
4. answered all your questions about your love one's illness and treatment?					
5. listened to what you have to say?					
6. made you feel cared about as a person?					
7. given you their full attention?					
8. asked you about how you are managing the care at home?					
9. disagreed with you about your loved one's care					
10. spent enough time with your loved one?					
11. arrived late when they promised to come see you or your loved one?					
12. been hard to reach in time of need?					
13. seemed distracted by other things when they talked to you?					
14. been willing to take time to listen?					
15. treated your loved one more as a disease than as a person?					
16. ignored you or your loved one's feelings?					
17. responded quickly in time of need?					

	Never	Rarely	Sometimes	Usually	Always
18. given you information about medication?					
19. discussed control of your loved one's discomfort?					
20. discussed the way decisions are made about admitting your loved one to a hospital?					
21. taught you how to give medication properly?					
22. taught you about nutrition?					
23. taught you about side-effects?					
24. given you information about tests and procedures ordered for your loved one?					
25. taught you how to monitor any changes in the health status of your loved one.					
26. explained what to expect in terms of emotional and relationship issues related to the illness and treatment?					
27. asked you about what help you might need?					
28. asked about financial/ insurance problems due to the illness and/or treatment?					
29. talked to you about community resources that might help support you and your loved one?					
30. taught you about pain and symptom management?					
31. discussed under what circumstances your loved one might be admitted to an intensive care unit?					
32. given you written material on your loved one's disease?					
33. given you written material on your loved one's treatment?					
34. given you written information on your loved one's care needs at home?					

	Never	Rarely	Sometimes	Usually	Always
35. taught you when it is necessary to call a doctor .					
36. discussed the goals of treatment and made sure you understood?					
37. explained to you who all the different health care providers are who see your loved one while hospitalized?					
38. discussed other options and/or alternatives to treatment?					
39. explained to you the risks and benefits of treatment ?					
40. made sure you understood about the risks and benefits of treatment??					
41. discussed advanced directives (durable power of attorney and living wills) <i>with you</i> ?					
42. made sure <i>you</i> understood about advanced directives?					
43. offered to make a referral to community services ?					
44. discussed advanced directives <i>with your loved one</i> ?					
45. made sure your loved one understood about advanced directives?					
46. I see my loved one's doctor(s)					
47. I see my loved one's nurse(s)					
48. I see the oncology social worker(s)					

MOS Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone you can count on to listen to you when you need to talk	1	2	3	4	5
2. Someone to give you information to help you understand a situation	1	2	3	4	5
3. Someone to give you good advice about a crisis	1	2	3	4	5
4. Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
5. Someone whose advice you really want	1	2	3	4	5
6. Someone to share your most private worries and fears with	1	2	3	4	5
7. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
8. Someone who understands your problems	1	2	3	4	5
9. Someone to help you if you were confined to bed	1	2	3	4	5
10. Someone to take you to the doctor if you needed it	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
12. Someone to help with daily chores if you were sick	1	2	3	4	5
13. Someone who shows you love and affection	1	2	3	4	5
14. Someone to love you and make you feel wanted	1	2	3	4	5
15. Someone who hugs you	1	2	3	4	5
16. Someone to have a good time with	1	2	3	4	5
17. Someone to get together with for relaxation	1	2	3	4	5
18. Someone to do something enjoyable with	1	2	3	4	5

Self-Appraisal Scale in Caregiving

This is a list of different kinds of responsibilities and tasks that other caregivers, through trial and error, have identified as important to caregiving. Please answer according to your own experience as a caregiver. Place an “X” besides the response that best describes your own experience.

	Never	Sometimes	Often	Very Often	Always
1. I notice small changes in my loved one's condition.					
2. I keep a written record or diary of medications, symptoms, changes in conditions, dietary needs, etc. on a regular basis.					
3. I feel able to judge the seriousness of a problem or symptom.					
4. I ask questions so I can get an explanation about my loved one's medical situation.					
5. I feel able to juggle all the different things I have to do now that my loved one is ill.					
6. If something unexpected happens during my loved one's course of illness, I feel able to handle it.					
7. I take my own needs into account as well as my loved one's needs.					
8. I am able to get into a routine to manage all my responsibilities.					
9. I am able to change my longstanding routines to make new routines for caregiving.					
10. I am able to try different ways to find a solution to caregiving problems.					
11. I am able to find out about useful resources to help me in caring for my loved one.					
12. I know when to step back and let my loved one be more active in his/her own care.					
13. I feel able to weed out inaccurate or wrong information regarding my loved one's care.					

14. I persist in getting the resources I need to help me and my loved one.					
15. I feel confident that I can do "hands on" care.					
16. I know what to do or to look for when it comes to my loved one's comfort needs.					
17. I know when to take a more active role in my loved one's care.					
18. I do what my loved one's doctors and other health care providers tell me to do.					
19. I seek help from doctors and other health care providers in a timely way.					

Caregiver Reaction

These questions are about how you feel **right now** about your experience as a caregiver. There are no right or wrong answers. Your answers are confidential. Check the response that best describes how you feel now.

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I feel privileged to care for my loved one					
2. Others have dumped caring for my loved on me.					
3. My financial resources are adequate to pay for things that are required for caregiving.					
4. My activities are centered around care for my loved one.					
5. Since caring for my loved one it seems like I am tired all of the time.					
6. It is very difficult to get help from my family in taking care of my loved one.					
7. I resent having to take care of my loved one.					
8. I have to stop in the middle of work					
9. I really want to care for my loved one.					
10. My health has gotten worse since I've been caring for my loved one.					
11. I visit family and friends less since I have been caring for my loved one.					
12. I will never be able to do enough caregiving to repay my loved one.					
13. My family works together at caring for my loved one.					
14. I have eliminated things from my schedule since caring for my loved one.					
15. I have enough physical strength to care for my loved one.					
16. Since caring for my loved one, I feel my family has abandoned me					

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
17. Caring for my loved one makes me feel good.					
18. The constant interruptions make it difficult to find time for relaxation.					
19. I am healthy enough to care for my loved one.					
20. Caring for my loved one is important to me.					
21. Caring for my loved one has put a financial strain on the family.					
22. My family (brother, sister, and children) left me alone to care for my loved one..					
23. I enjoy caring for my loved one.					
24. It's difficult to pay for my loved one's health needs and services.					

Please either write in an answer or check a line for each item. **These questions are about you, the caregiver.**

1. _____ Age

2. _____ Male _____ Female

3. Race

_____ White

_____ African-American

_____ Hispanic

_____ Asian

_____ Other (please specify)

4. Education

1. _____ Some high school

2. _____ High School Graduate

3. _____ Some college

4. _____ College Graduate

5. _____ Post graduate

5. Income:

1. _____ Less than 20,000

2. _____ 20,000 to 29,999

3. _____ 30,00 to 39,999

4. _____ 40,000 to 49,999

5. _____ Over 50,000

6. Employment:

1. _____ Currently working full time

2. _____ Currently working part time

3. _____ Not working

7. Do **you** have any chronic disorders that affect your daily living activities?

1. _____ yes

2. _____ No

8. How would you rate your own health?

- 1. ☐ poor
- 2. ☐ fair
- 3. ☐ good
- 4. ☐ excellent

Please either write an answer or check a line for each item. **These questions are about your loved one.**

9. ☐ Loved one's age

10. ☐ Male ☐ Female

11. Race

- ☐ White
- ☐ African-American
- ☐ Hispanic
- ☐ Asian
- ☐ Other (Please specify)

12. Diagnosis:

1. What is the name of the kind of cancer your loved one is diagnosed with?

2. What is the stage that the cancer is in, if you know it?

- ☐ Advanced
- ☐ Terminal
- ☐ Don't know

3. Is this a recurrence of a previously diagnosed cancer? ☐ Yes ☐ No

4. Was the disease already in a more advanced stage at the time of the original diagnosis?
☐ Yes ☐ No

13. How long, in months, has it been since your loved one was diagnosed? _____

14. How many medical opinions did your loved one get from other doctors before starting treatment?

- 1. ☐ None
- 2. ☐ Two
- 3. ☐ Three
- 4. ☐ More than three

15. Was your loved one treated somewhere else before being treated at his/her current treatment facility?

- 1. ☐ Yes
- 2. ☐ No

16. How many hospitalizations has your loved one had in the last year, if any?

1. ☐ None

2. ☐ 1-2

3. ☐ 3-4

4. ☐ Over 4

17. How long was your loved one in the hospital for his/her longest stay?

☐ less than 1 week

☐ over 1 week, but less than 2

☐ more than 2 weeks

18. Is your loved one (Check all that apply):

1. ☐ Currently getting radiation

2. ☐ Currently getting chemotherapy

3. ☐ Currently enrolled in a clinical trial

4. ☐ Is on a new treatment regimen because the first kind of treatment didn't work

5. ☐ Currently not being treated

6. ☐ Other, please explain

19. Services your loved one may be receiving(check all that apply):

1. ☐ Home Care

2. ☐ Hospice at home

3. ☐ Hospice in an extended care facility

4. ☐ Community home health aids

5. ☐ Meals on wheels

6. ☐ Other, please specify

20. Has your loved one spent any time in an extended care facility: Yes ☐, No ☐.

If yes, how long?

21. Does your loved one have other health problems besides a cancer diagnosis?

1. ☐ Yes

2. ☐ No

22. What type of insurance does your loved one have(check all that apply):

1. ☐ HMO (where you have a primary care physician)

2. ☐ BC/BS or other private insurance

3. ☐ Medicare HMO (such as Security Blue)

4. ☐ Medicare (not an HMO plan)

5. ☐ Medicaid (or a Medicaid HMO, for example, BEST)

6. ☐ Other (Please write in)

23. If there is anything else you would like to add about yourself or your loved one that would help in understanding your caregiving situation better, please write about it here.

BIBLIOGRAPHY

- Adelman, R.D., Greene, M.G., & Charon, R. (1987). The physician-elderly patient companion triad in the medical encounter: the development of a conceptual framework and research agenda. *The Gerontologist*, 27(6), 729-734.
- American Cancer Society (2003). *Facts and Figures*.
- Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18 (2), 182-189.
- Back, A.; Baile, W.(2003).Communicating skills: Myths, realities, and new developments. *Journal of Supportive Oncology*. 1 (3), 169-171.
- Bakas, T., Lewis, R., & Parsons, J. (2001). Caregiving tasks among family caregivers of patients with lung cancer. *Oncology Nursing Forum*, 28 (5), 847-854.
- Balducci, L. (2003). New paradigms for treating elderly patients with cancer: the comprehensive geriatric assessment and guidelines for supportive care. *The Journal of Supportive Oncology*, 1(supplement 2), 30-37.
- Balducci, L., (2003). Management of cancer pain in geriatric patients. *The Journal of Supportive Oncology*, 1 (Supplement 2), 175-191.
- Balducci, L., The elderly patient with cancer: New approaches for improved outcomes. *The Journal of Supportive Oncology*, 1 (Supplement 2), 3-4.
- Bandura A. (2001). Guide for constructing self-efficacy scales
- Barg, F.K., Codey, M., Pasacrete, J., Senay, B., & McCorkle, R. (1995). Development of a self-administered psychosocial cancer screening tool. *Cancer Practice*, 2 (4), 288-296.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- Baruch, A. & Spaid, W. (1989). Gender differences in caregiving: why do wives report greater burden? *The Gerontologist*, 29 (5), 667-676.
- Bass, D. M.; Noelker, L.S.; & Rechlin, L. R. (1996). The moderating influence of services use on negative caregiving consequences. *Journal of Gerontology*. 51B (3), S121-S131.
- Bass, D.M., Noelker, L.S., & Rechlin, L.R. (1996). The moderating influence of service use on negative caregiving consequences. *Journal of Gerontology*, 51B (3), S121-S131.

- Belansky, E.S., & Boggiano, A.K. (1994). Predicting helping behaviors: the role of gender and instrumental/expressive self-schemata. *Sex Roles*, 30 (9/10), 647-661.
- Benson, J. & Britten, N. (1996). Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semi-structured interviews with patients. *British Medical Journal*, 313(7059). 729-731.
- Beisecker, A.E., Brecheisen, M.A., Ashworth, J., & Hayes, J. (1996). Perceptions of the role of cancer patients' companions during medical appointments. *Journal of Psychosocial Oncology*, 14 (4), 29-45.
- Beisecker, A.E., Murden, R.A., Moore, W.P., Graham, D. (1996). Attitudes of medical students and primary care physicians regarding input of older and younger patients in medical decisions. *Medical Care*, 34 (2), 126-137.
- Beisecker, A.E. & Moore, W.P. (1994). Oncologists' perceptions of the effects of cancer patients' companions on physician-patient interactions. *Journal of Psychosocial Oncology*, 12 (1/2), 23-39.
- Beisecker, A.E. (1988). Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. *The Gerontologist*, 28 (3), 330-335.
- Berg-Weger, M. & McGartland-Rubio, D. (1995). Role induction and caregiver strain: a structural equation approach. *Journal of Social Service Research*, 21 (2), 33-51.
- Biegel, D.E. & Schulz, R. (1999). Caregiving and caregiver interventions in aging and mental illness. *Family Relations*, 48, 345-354.
- Biegel D.E., Sales, E., & Schulz, R. (1991). *Family Caregiving in Chronic Illness*. Sage Publications, Newbury Park, California.
- Bisconti, T.L., & Bergeman, C.S. (1999). Perceived social control as a mediator of the relationships among social support, psychological well-being, and perceived health. *The Gerontologist*, 39 (1), 94-103.
- Blanchard, C.G., Albrecht, T.L., Ruckdeschel, J.C., Grant, C.H., & Hemmick, R.M (1995). The role of social support in adaptation to cancer and to survival. *Journal of Psychosocial Oncology*. 13(1/2) 75-95.
- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, 19(4), 668-675.
- Boland, D. & Sims, S. (1996). Family caregiving at home as a solitary journey. *Image- the Journal of Nursing Scholarship*, 28(1), 55-58.

- Bourhis, R.Y., Roth, S., & MacQueen, G. (1989). Communication in the hospital setting: a survey of medical and everyday language use amongst patients, nurses, and doctors. *Social Science and Medicine*, 28 (4), 339-346.
- Braithwaite, V. (2001). Contextual or general stress outcomes: making choices through caregiving appraisals. *The Gerontologist*, 40 (6), 706-717.
- Braithwait, V. (1996) a. Understanding stress in informal caregiving: is burden a problem of the individual or of society?. *Research on Aging*, 18 (2), 139-174.
- Braithwaite,V. (1996)b. Between stressors and outcomes: can we simplify caregiving process variables? *The Gerontologist*, 16 (1), 42-53.
- Breckler, S.J. (1995). Psychosocial resource variables in cancer research: statistical and analytical consideration. *Journal of Psychosocial Oncology*, 13 (1/2), 161-176.
- Bucher, J.A., Houts, P.S., Maguth, C., & Nezu, A. (1999). Improving problem-solving skills of family caregivers through group education. *Journal of Psychosocial Oncology*, 16 (3/4), 73-84.
- Caine, E.O. Lyness, J.M., & King, D.A. (1993). Reconsidering depression in the elderly. *The American Journal of Geriatric Psychiatry*, 46, 199-212.
- Chapman, K., Abraham, C., Jenkins, V., & Fallowfield, L. (2003). Lay understanding of terms used in cancer consultations. *Psycho-Oncology*, 12, 557-566.
- Christensen, M., Parris-Stephens, M.A., & Townsend, A.L. (1998). Mastery in women's multiple roles and well-being: adult daughters providing care to impaired parents. *Health Psychology*, 17 (2), 163-171.
- Coe, R.M. & Pendergast, C.G., (1985). The formation of coalitions: interaction strategies in triads. *Sociology of Health and Illness*, 7, 236-247.
- Cooper-Patrick, L., Gallo, J., Gonzales, J., Hong, T., Powe, N., Nelson, C., & Ford, D. (1999), Race, gender, and partnership in the patient-physician relationship. *Journal of the American Medical Association*, 282(6), 583-589.
- Council on Scientific Affairs, American Medical Association (1993). Physicians and family caregivers: a model for partnership. *Journal of the American Medical Association*, 269 (10), 1282-1284.
- Dale, D.C., (2003). Poor prognosis in elderly patients with cancer: the role of bias and undertreatment. *The Journal of supportive Oncology*, 1 (Supplement 2), 11-17.
- Daley, J.G., & Bostock, D.J. (1998). A world view model of health care utilization: the impact of social and provider context on health care decision-making. *Journal of Health and Social Policy*, 9 (4), 67-82.

- Davis, L. V. (1996). Role theory and social work treatment, pp 581-600. From *Social Work Treatment : Interlocking Theoretical Approaches* (Turner, Francis, ed.) Free Press.
- Deimling, G., Boaz, K., Bowman, K., & Schaeffer, M. (2002). Cancer survivorship and psychological distress later in life. *Psycho-Oncology*, 11, 479-494.
- Dilworth-Anderson, P., Williams, S.W., & Cooper, T. (1999). The context of experiencing emotional distress among family caregivers to elderly African Americans. *Family Relations*, 48 (4), 391-396.
- Doress-Worters, P. (1994). Adding elder care to women's multiple roles: a critical review of the caregiver stress and multiple roles literature. *Sex Roles*, 31 (9/10), 597-613.
- Ellis, P.M. & Martin, H.N. (1999). How should doctors communicate the diagnosis of cancer to patients? *Annals of Medicine*, 31 (5), 336-341.
- Emanuel, E., Fairclough, D., Slutsman, J. Emanuel, L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers *Annals of Internal Medicine*, 132(6), 451-459.
- Emanuel, E., Fairclough, D., Slutsman, J. Alpert, H.; Baldwin, D.; Emanuel, L.(1999). Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *The New England Journal of Medicine*, 34 (13), 956-963.
- Erschler, W.B., (2003). Cancer: A disease of the elderly. *The Journal of Supportive Oncology*, 1 (supplement 2), 5-10.
- Estes, C.L. (1993). The aging enterprise revisited. *The Gerontologist*, 33 (3), 292-298.
- Feder, J. (1999). Improving public financing for long-term care: the political challenge. *Journal of Aging and Social Policy*, 10 (5), 1-6.
- Feinberg, L.F. & Newman, S.L. (2004). Family caregiver support: policies, perceptions and practices in 10 states since passage of the National Family Caregiver Support Program. *Gerontologist*, 44 (6), 760-769.
- Ferrel, B.R., Grant, M., Chan, J., & Ferrell, B.A. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncology Nursing Forum*, 22(8), 1211-18.
- Finset, A., Ekeberg, O, Eide, H., & Aspegren, K., (2003). Long term benefits of communication skills training for cancer doctors. *Psycho-Oncology*, 12, 686-693.
- Fobair, P.A. & Zabora, J.R. (1995). Family functioning as a resource variable in psychosocial cancer research: issues and measures. *Journal of Psychosocial Oncology*, 13 (1/2), 97-114.

- Forte, J.A. (1998). Power and role- taking: a review of theory, research, and practice. *Journal of Human Behavior in the Social Environment*, 1 (4), 27-56.
- Franks, M. & Stephens, M. Parris (1992). Multiple roles of middle-generation caregivers: contextual effects and psychological mechanisms. *Journal of Gerontology: Social Sciences*, 47, S123-129.
- Fry, P.S. (2003). Perceived self-efficacy domains as predictors of fear of the unknown and fear of dying among older adults. *Psychology of Aging*, 18 (3), 474-486.
- Galassi, J.P. Schanberg, R., & Ware, W. (1992). The patient reaction assessment: A brief measure of the quality of the patient-provider medical relationship. *Psychological Assessment*, 4(3) 346-351.
- Given, B., Given, C., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Journal for Clinicians*. 51(4), 213-231.
- Given, C., Given, B., Azzouz, F., Stommel, M., & Kozachik, S. (2000). Comparison of changes in physical functioning of elderly patients with new diagnoses of cancer. *Medical Care*, 38 (5), 482-493).
- Given, C.W., Given, B. Strommel, M., Collins, C. King, S. & Franklen, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health*, 15, 271-283.
- Gilbar, O. (1994). The elderly cancer patient and his spouse: two perceptions of the burden of caregiving. *Journal of Gerontological Social Work*, 21 (3/4), 149-157.
- Glajchen, M., The emerging role and needs of family caregivers in cancer care. *The Journal of Supportive Oncology*, 2 (2), 145-155.
- Gold, D.P., Franz, E., Reis, M., Sennerville, C. (1994). The influence of emotional awareness and expressiveness on care-giving burden and health complaints in women and men. *Sex Roles*, 31 (3/4), 205-223.
- Goode, K., Haley, W., Roth, D., & Ford, G. (1998). Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychology*, 17 (2), 190-198.
- Goodwin, J.S., Hunt, W.C. & Samet, J. M. (1991). A population-based study of functional status and social support networks of elderly patients newly diagnosed with cancer. *Archives of Internal Medicine*, 151, 366-370.
- Goold, S.D., Williams, B., Arnold, R.M. (2000). Conflicts regarding decisions to limit treatment: a differential diagnosis. *Journal of the American Medical Association*, 283, 909-914.

- Gove, W.R.; Ortega, S.T.; Style, C.B. (1989). The maturational and role perspectives on aging and self through the adult years: An empirical evaluation. *American Journal of Sociology*, 94 (5), 1117-45.
- Greene, M.G. & Adelman, R.D. (2003). Physician-older patient communication about cancer. *Patient Education and Counseling*, 50(1), 55-60.
- Greene, M.G., Hoffman, Charon, R., & Adelman, R.(1987). Psychosocial concerns in the medical encounter: a comparison of the interactions of doctors with their old and young patients. *The Gerontologist*, 27 (2), 164-168.
- Grembowski, D., Patrick, D., Diehr,P., Beresford, S., Kay, E., & Hecht, J.(2001). Self-efficacy and health behavior among older adults. *Journal of Health and Social Behavior*, 34 (2), 89-104.
- Haidet, P., Hamel, M.B., Davis, R.B., Wenger, N., Reding, D., Kussin, P.S., Alfred, F., Lynn, J., Weeks, J.C., & Phillips, R.S. (1998). Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. *The American Journal of Medicine*, 105 (3), 222-229.
- Haley, W. E., (2003). Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *Supportive Oncology*, 1(supplement 2), 25-29.
- Haley, W.E., LaMonde, L.A., Han, B., Narramore, S., Schonwetter, R. (2001). Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hospital Journal*, 15(4), 1-18.
- Haug, M.R. (1994). Elderly patients, caregivers, and physicians: theory and research on health care triads. *Journal of Health and Social Behavior*, 35 (March), 1-12.
- Halldorsdottir, S., & Hamrin E. (1997). Caring and uncaring encounters within nursing and health care from the cancer patient's perspective. *Cancer Nursing*, 20 (2), 120-128.
- Hayman, J.A., Langa, K.M., Kabeta, M.U., Katz, S.J., DeMonner, S.M., Chernew, M.E., Slavin, M.B., & fendrick, A.M. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, 18 (13), 3219-3225.
- Hepworth, D.H., Rooney, R.H.,& Larsen, J.A. (1997). *Direct Social Work Practice: Theory and Skills*, Brooks/Cole Publishing Company , Pacific Grove, California.
- Hewitt, M. & Simone, J.V. (1999). *Ensuring Quality Cancer Care*, National Academy Press, Washington. D.C.
- Jackson, A.P. & Huang, C. (2000). Parenting stress and behavior among single mothers of preschoolers: the mediating role of self-efficacy. *The Journal of Social Service Research*, 26 (4), 29-42.

- James, L.R. & Brett, J.B. (1984). Mediators, moderators, and tests for mediation. *Journal of Applied Psychology*, 69 (2), 307-321.
- Jepson, C., McCorcle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychological status. *Image: Journal of Nursing Scholarship*, 31 (2), 115-120.
- Kane, R., Reinardy, J., Penrod, J., & Huck, S. (1999). After hospitalization is over: A different perspective on family care of older people. *The Journal of Gerontological Social Work*, 31 (1/2), 119-141.
- Kaplan, S., Greenfield, S., Gandek, B., Rogers, W., Ware, J. (1996). Characteristics of physicians with participatory decision-making styles. *Annals of Internal Medicine*, 124(5), 497-504.
- Keefe, J. F., Ahles, T.A., Porter, L.S., Sutton, L.M., McBride, C.M., Pope, M.S., McKinstry, E.T., Furstenberg, C.P., Dalton, J.D., Baucom, D.H. (2002). The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain*, 103, 157-162.
- Kinsella, G. (1998). A review of the measurement of caregiver and family burden in palliative care. *Journal of Palliative Care*, 14(2), 37-45.
- Koeske, G.F. (1992). Moderator variables in social work research. From *Quantitative Methods in Social Work: State of the Art*, 159-178.
- Krant, M., & Johnston, L. (1978). Family members' perceptions of communications in late stage cancer. *International Journal of Psychiatry in Medicine*, 8 (2), 203-217.
- Kristjanson, L.J. (1993). Validity and reliability testing of the Famcare Scale: measuring family satisfaction with advanced cancer. *Social Science and Medicine*, 36 (5), 693-701.
- Kurtz, M., Kurtz, J., Stommel, M., Given, C., & Given, B. (2002). Predictors of depressive symptomatology of geriatric patients with lung cancer : a longitudinal analysis. *Psycho-Oncology*, 11, 12-22.
- Labrecque, M., Blanchard, C., Ruckdeschel, J., Blanchard, E. (1991). The impact of family presence on the physician-cancer patient interaction. *Social Science and Medicine*, 33(11), 1253-1261.
- Lawton, M.P., Rajagopal, D.R., Brody, E., & Kleban, M.H.(1992). The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology*, 47 (4), S 156-S164.
- Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology: Psychological Sciences*, 46 (4), 181-189.

- Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences*, 14 (3), 61-71.
- Leganger, A., Kraft, P., & Roysamb (2000). Perceived self-efficacy in health behavior research: conceptualization, measurement and correlates. *Psychology and Health*, 15, 51-69.
- Levine, C. (1999). Home sweet hospital: the nature and limits of private responsibilities for home health care. *Journal of Aging and Health*, 11 (3), 341-359.
- Martire, L.M., Stephens, M.A., & Townsend, A.I. (1998). Emotional support and well-being of midlife women: role-specific mastery as a mediational mechanism. *Psychology of Aging*, 13 (3), 396-404.
- Marvel, H.K., Epstein, R.M., Flowers, K., Beckman, H.B. (1999). Soliciting the patient's agenda. *Journal of the American Medical Association*, 281 (3), 283-287.
- Mechanic, D. (1998). Trust in the provision of medical care. *Journal of Health Politics, Policy, and Law*, 23 (4).
- Milberg A. & Strang, P. (2004). Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psycho-Oncology*, 13, 605-618.
- Miller, B.; Campbell, R. T.; Farran, C. J.; Kaufman, J. E.; Davis, L. (1995). Race, control, mastery, and caregiver distress. *Journal of Gerontology; Social Sciences*, 50B (6), S374-382.
- Miller, B. (1990). Gender differences in spouse caregiver strain: socialization and role explanations. *Journal of Marriage and the Family*, 52 (May), 311-321.
- Mills, M. & Davidson, R. (2002). Cancer patients' sources of information: use and quality issues. (2002). *Psycho-Oncology*, 11, 371-378.
- Moon, M. (1996). *Medicare Now and in the Future*. Urban Institute Press, Washington, D.C.
- Mui, A. (1992). Caregiver strain among black and white daughter caregivers: a role theory perspective. *The Gerontologist*, 32 (2), 203-212.
- National Cancer Institute (1990). Cancer statistics review: 1973-1987 (NIH Pub. No. 90-2789). Bethesda, Md.:
- National Cancer Institute (1991). Cancer statistics review. 1973-1988 (NIH Pub. No. 91-2789). Bethesda, Md.:
- National Cancer Institute (1997a). Cancer statistic review: 1973-1994 (NIH Pub. No. 97-2789). Bethesda, Md.

- National Cancer Institute (1997b). (SEER) Cancer Query System on the Web: 1973-1997. Accessed Nov.12, 2000,at the web site <http://www.seer.cancer.gov/PublicationsReportCard>.
- Neary, M.A. (1993). Type of elder impairment: Impairment on caregiver burden, health outcomes and social support. *Clinical Gerontologist*, 13(2), 47-59.
- Nezu, C.M., Nezu, A.M., Friedman, S.H., Houts, P.S., DelliCarpini, L.A., Bildner, C., & Faddis, S. (1999). Cancer and psychological distress: two investigations regarding the role of social problem-solving. *Journal of Osychosocial Oncology*, 16 (3/4), 27-40.
- Nijboer, C., Tempelaar, R.Triemstra, M., Van Den Bos, G., & Sanderman, R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer*, 91 (5), 1029-1039).
- Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. & Van Den Bos, G. (1998). Cancer and caregiving: the impact on caregiver's health. *Psycho-Oncology*, 7, 3-13.
- Oberst, M.T. Thomas, S.E., Gass, K.A., & Ward, S.E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12 (4), 209-15.
- Pasacreta, J., Barg, F., Nuamah, I., McCorcle, R. (2000). Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nursing*, 23 (4), 295-303.
- Pajared, F. Hartley, J. & Valiante, G. (2001). Response format in writing self-efficacy assessment: greater discrimination increases prediction. *Measurement and Evaluation in Counseling and Development*, 33, 214-221.
- Pearlin, L, Mullan, J. T., Semple, S. J., & Skaff, M. (1990). Caregiving and the stress process. *Gerontologist*, 30 (5): 583-594.
- Petersson, V.W., vonEssen, L., & Sjoden, P. (1998). Perceptions of caring: patients' and staff's associations to CARE-Q behaviors. *Journal of Psychosocial Oncology*, 16 (1), 75-96.
- Porter, L., Keefe, F., McBride, C., Polla, K., Fish, L., & Garst, J. (2002). Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: correspondence between patients and family caregivers. *International Journal for the Study of Pain*, 98, 169-178.
- Poulshock, W.S., & Deimling, G.T. (1984). Families caring for elders in residence: issues in the measurement of burden. *Journal of Gerontology*, 39 (2), 230-239.
- Prohaska, T.R. & Glasser, M. (1996). Patients' views of family involvement in medical care decisions and encounters. *Research on Aging*, 18 (1), 52-69.
- Rabow, M., Hauser, J., Adams, J. (2004). Supporting family caregivers at the end of life. *Journal of the American Medical Association*, 29 (1), 483-491.

- Raevis, V.H. & Karus, D.G. (1999). Elderly cancer patients: Correlations of depressive symptomatology. *Journal of Psychosocial Oncology*, 17(2), 57-77.
- Repetto, L. (2003). Greater risks of chemotherapy toxicity in elderly patients with chemotherapy. *The Journal of Supportive Oncology*, 1 (supplement 2), 18-24.
- Rogers, M. & Todd, C. (2002). Information exchange in oncology outpatient clinics: source, valence, and uncertainty. *Psycho-Oncology*, 11, 336-345.
- Rosenberg, E.E., Lussier, M.T., & Beaudoin, C. (1997) Lesson for clinicians from physician-patient communication literature. *Archives of Family Medicine*, 6(3), 279-283.
- Rubio, D.M. Berg-Weger, M., & Tebb, S.S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers. *Social Work Research*, 23 (1), 54-64.
- Ruckdeschel, J.C., Albrecht, T.L., Blanchard, C. & Hemmick, R.M. (1996). Communication, accrual to clinical trials, and the physician-patient relationship: Implications for training programs. *Journal of Cancer Education*, 11(2), 73-79.
- Ross, C.E. & Chia-ling, W. (1995). *American Sociological Review*, 60 (October), 719-745.
- Salander, P., Bergenheim, A.T., Bergstrom, P., & Henriksson, R. (1998). How to tell cancer patients: a contribution to a theory of communicating the diagnosis. *Journal of Psychosocial Oncology*, 16 (20), 79-91.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12 (Supplement 1), 33-41.
- Sales, E. (1992). Psychosocial impact of the phase of cancer on the family: an updated review. *Journal of Psychosocial Oncology*, 9 (4), 1-18.
- Sarna & McCorkle (1996). Burden of care and lung cancer. *Cancer Practice*, 4 (5), 245-251.
- Scharlach, A. (1994). Caregiving and employment: competing or complementary roles. *The Gerontologist*, 14 (3), 378-385.
- Scharlach, A. (1987). Role strain in mother-daughter relationships in later life. *The Gerontologist*, 27 (5), 627-631.
- Schieman, S. & Turner, H.A. (1998). Age, disability, and the sense of mastery. *Journal of Health and Social Behavior*, 39 (September), 169-186.
- Schulz, R. & Beach, S.R. (1998). Caregiving as a risk factor for mortality: the caregiver health effects study. *Journal of the American Medical Association*, 28 (23), 2215-2219.
- Schulz, R., & Quiltner, A. (1998). Caregiving for children and adults with chronic conditions: introduction to the special; issue. *Health Psychology*, 17 (2), 107-111.

- Schumacher, K. L., Stewart, B. J., Archbold, P. C., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: development of the concept. *Research in Nursing and Health*, 191-203.
- Sharp, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2004). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology*, 14, 102-114.
- Siminoff, L., Zhang, A., Sturm, C., Colabianchi, N. (2000). Referral of breast cancer patients to medical oncologists after initial surgical management. *Medical Care*, 38(7), 696-704.
- Silliman, R.A., Guadagnoli, E., Rakowski, W., Landrum, M.B., Lash, T.L., Wolf, R., Fink, A., Ganz, P.A., Gurwitz, J., Borbas, C., & Mor, V. (2002). Adjuvant tamoxifen prescription in women 65 years and older with primary breast cancer. *Journal of Clinical Oncology*, 30 (11), 2680-2688.
- Simpson, M. Buckman, R., Stewart, M., et al. (1991). Doctor-patient communication: the Toronto consensus statement. *British Medical Journal*, 303, 1385-1387.
- Smith, C. (1999). Caregiving effectiveness in families managing complex technology at home: replication of a model. *Nursing Research*, 48(3), 120-128.
- Soothill, K., Morris, S., Harman, J., Francis, B., & Thomas, C. (2001). Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care in the Community*, 9(6), 464-475.
- Staight, & Harvey, S. M. (1990). Caregiver burden: A comparison between elderly women as primary and secondary caregivers for their spouses. *Journal of Gerontological Social Work*, 15 (1/2), 89- 102.
- Steffan, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., & Bandura, A (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. *Journal of Gerontology: Psychological Sciences*, 57B (1), 74-86.
- Stetz, K.M. (1987). Caregiving demands during advanced cancer. *Cancer Nursing*, 10(5), 260-268.
- Stewart, M. A.. (1995). Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal*, 152 (9), 1423-33.
- Stoller, E.P., & Pugliesi, K.L. (1989). Other roles of caregivers :competing responsibilities or supportive resources. *Journal of Gerontology: Social Sciences*, 44 (6), S231-238.
- Stommel, M., Given, C., & Given, B.(1993). *The cost of cancer home care to families*. *Cancer*, 71 (5), 1867-74.
- Stommel, M. & Kingry, M. (1991). Support patterns for spouse-caregivers of cancer patients: the effect of the presence of minor children. *Cancer Nursing*, 14 (4), 200-205.

- Stuckey, J., Neundorfer, M., & Smith, K. (1996). Burden and well-being: the same coin or related currency? *The Gerontologist*, 36(5), 686-693.
- Stull, D. (1994). Women in the middle: a myth in the making? *Family Relations*, 43, 319-324.
- Sulmasy, D. P., McIlvane, J. M., Pasley, P. M., & Rahn, M. A scale for measuring patient perceptions of the quality of end-of-life care and satisfaction with treatment: the reliability and validity of QUEST. *Journal of Pain and Symptom Management*, 23 (6), 458-470.
- Thorne, S. (1999). Communication in cancer care: What science can and cannot teach us. *Cancer Nursing*, 22(5), 370-379.
- Toseland, R.W. & McCallion, P. (1997). Trends in caregiving intervention research. *Social Work Research*, 21 (3), 154-161.
- Walker, A.J., Acock, A.C., Bowman, S.R., & Fuzhong, L. (1996). *Journal of Gerontology: Psychological Sciences*, 51B (3), 130-142.
- Van Ryn M. & Burke, J. (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science and Medicine*, 50, 813-828
- Weitzner, M.; McMillan, S.; Jacobson, P. B.;(1999). Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management*, 17 (6), 418-428.
- Wingate, A.L. & Lackey, N.R. (1989). *Cancer Nursing*, 12 (4), 216-225.
- Wright, S.D., Lund, D. a., Caserta, M.S., & Pratt, C. (1991). Coping and caregiver well-being: the impact of maladaptive strategies. *Journal of Gerontological Social Work*, 17 (1/2), 75-90.
- Wright, K. & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. *Cancer Nursing*, October, 371-374.
- Yates, M.E., Tennstedt, S., & Chang, B. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Psychological Sciences*, 54B (1), P12-P22.
- Young, R. F. & Kahana, E. (1989). Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *The Gerontologist*, 29 (5), 660-666.
- Zabora, J.R., Smith, E.D., Baker, F., Wingard, J.R., & Curbow, B. (1992). The family: the other side of bone marrow transplantation. *Journal of Psychosocial Oncology*, 10 (1), 35-46.
- Zarit, S.H., Reever, K.R., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontology*, 20 (6), 649-655.