STRESS, COPING, AND HEALTH IN SPOUSES OF CANCER PATIENTS

DISserTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy to the Graduate School of the Ohio State University

By

Chantal K. Hunt MS, RN

*****

The Ohio State University
2004

Dissertation Committee:

Professor Emeritus, Carol Kennedy, Chair
Professor Bonnie Garvin
Professor Barbara Andersen

Approved by

___________________________

Adviser
College of Nursing Graduate Program
Many studies document the negative biopsychosocial effects associated with providing care for an ill relative or friend. The increased costs of health care, emphasis on outpatient care, and the resultant increased demand for informal caregiving make it imperative that nurses understand the impact of caregiving and how best to assist caregivers and positively influence caregiving outcomes. The overall purpose of this dissertation research was to increase the understanding of biopsychosocial factors affecting health in young caregivers of cancer patients. The aims of this research were to: identify competing conceptualizations of the effects of caregiving, to present a multidimensional framework with which to examine the caregiver experience from a biopsychosocial perspective, and to test the feasibility of a methodology for studying relationships among contextual, intervening, and outcome variables related to stress and health outcomes in spouses of patients with cancer. Literature was reviewed to form the basis of a concept analysis and theory construction. These were used as the basis for the design of the pilot study. The framework for this study combines aspects of the Transactional Model of Stress, Appraisal, and Coping with Psychoneuroimmunology (PNI). A descriptive, cross-sectional design was used. The convenience sample consisted of spouses of patients with a non-recurrent, non-terminal diagnosis of cancer who were diagnosed within the previous 12 months. The couples were all parents with at
least one dependent child. Measures included both self-report and physiological measures of stress, health, and immune function. Physiologic stress was measured by salivary cortisol assay, and immune function by salivary secretory IgA. Data were analyzed by Pearson, Spearman and eta correlations, and the size and direction of correlations were analyzed according to theoretical expectations and previous research. In addition, the feasibility of the study methodology was evaluated. The sample included 13 subjects, and was 61.5% female. Results of the correlational analyses revealed a mean morning cortisol level of 0.9036 ug/dL (SD = 0.1825 ug/dL), and mean sIgA level of 299.97 ug/ml (SD = 320.66 ug/ml). Potential problems with including salivary assays in research are discussed. It is uncertain whether sIgA is a good measure of the effects of chronic stress on immune function because acute stressors may be a confounding variable. Gender had a positive relationship with general health in this sample, with women having lower general health scores than men. Individuals with larger family incomes reported better general health, had higher sIgA levels and, unexpectedly, also had higher cortisol levels than lower income individuals. Further, lower income individuals reported higher perceived stress. High perceived stress was associated with lower general health scores regardless of occupational status or gender. Number of hours worked outside the home was a strong predictor of the physiologic stress and immune responses in this sample, with fewer working hours being associated with higher cortisol and higher sIgA. Spouses working fewer hours were also more likely to perceive less
support from family. Positive caregiver esteem was associated with lower cortisol levels. Notwithstanding the small sample size, the number and magnitude of the correlations found between the variables suggest that the proposed model has promise for guiding future work in this area. Future investigations of stress, coping and health in spouses of cancer patients should address potential interventions tailored to the caregiver’s contextual characteristics and physiological health outcomes. In particular, young spouses with dependent children remain an understudied group. This study serves as a basis for future large-scale, interventional, multivariate research in the area of cancer caregiver stress, coping and health outcomes.
Dedicated to my parents, my husband, and my children.
ACKNOWLEDGMENTS

I wish to thank my advisers Carol Kennedy and Nancy Ryan-Wenger for their intellectual support, advice, and encouragement, without which this project would not have been possible.

I thank Bonnie Garvin for her never-ending support and encouragement, and for her willingness to step in at the last minute when needed.

I thank Barbara Andersen for stimulating ideas related to the topic at hand and for giving me an opportunity to see a wonderful research team at work. Also, I thank Terrie Lennie and Barbara Given for their input early in this work.

I thank my parents, James and Nicole Anderson for the sound foundation they gave me. I am sorry they are not alive to see this accomplishment.

I would like to thank Sheik Wisel, Melissa Hunter, Hamdy Hassanain, Clay Marsh for the use of their laboratories and skills.

Most of all, I thank my husband Dirk and our children Kayla, Kennon, and Kylar for their love and patience throughout this process.

This research was supported by grants from the Walther Cancer Institute, Sigma Theta Tau Epsilon, the OSU Alumni Grants for Graduate Research and Scholarship, and by a scholarship from the Critical Difference for Women, sponsored by Ruth Smart.

*I can do all things through Him who strengthens me (Phil. 4:13).*

vi
VITA

January 19, 1967……………………………Born – Detroit, Michigan, USA

1991………………………………………B.S. Agriculture, The Ohio State University

1998………………………………………B.S. Nursing, The Ohio State University

2001………………………………………M.S. Nursing, The Ohio State University

1998-2003………………………………Graduate Research and Teaching Associate,

The Ohio State University

PUBLICATIONS

Scholarship, 35: (1), pp. 27-32.

FIELDS OF STUDY

Major Field:  Nursing
# TABLE OF CONTENTS

| Abstract | ii |
| Dedication | v |
| Acknowledgments | vi |
| Vita | vii |
| List of Tables | ix |
| List of Figures | x |

**Chapters:**

1. Introduction .................................................. 1

2. Concepts used in Caregiver Research: A Review of the Literature ........... 9


4. Stress and Health in Spouses of Cancer Patients: A Pilot Study ........... 60

References ............................................................ 122
### LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 4.1</td>
<td>Measures and their conceptual and operational definitions</td>
<td>80</td>
</tr>
<tr>
<td>Table 4.2</td>
<td>Descriptive statistics for saliva cortisol and sIgA</td>
<td>93</td>
</tr>
<tr>
<td>Table 4.3</td>
<td>Relationships among demographic variables and outcomes</td>
<td>94</td>
</tr>
<tr>
<td>Table 4.4</td>
<td>Relationships among demographic variables, esteem, support and perceived stress</td>
<td>94</td>
</tr>
<tr>
<td>Table 4.5</td>
<td>Coping Processes and outcome variables</td>
<td>100</td>
</tr>
<tr>
<td>Table 4.6</td>
<td>Demographic variables and Coping Processes</td>
<td>101</td>
</tr>
<tr>
<td>Table 4.7</td>
<td>Esteem, Support, Perceived Stress and Outcome Variables</td>
<td>102</td>
</tr>
<tr>
<td>Table 4.8</td>
<td>Summary of correlation magnitudes and directions</td>
<td>105</td>
</tr>
<tr>
<td>Figure</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>Figure 3.1</td>
<td>Biopsychosocial model of caregiver stress</td>
<td>37</td>
</tr>
<tr>
<td>Figure 3.2</td>
<td>Block of contextual variables</td>
<td>38</td>
</tr>
<tr>
<td>Figure 3.3</td>
<td>Block of Mediating Processes</td>
<td>45</td>
</tr>
<tr>
<td>Figure 3.4</td>
<td>Block of Health outcome variables</td>
<td>48</td>
</tr>
<tr>
<td>Figure 3.5</td>
<td>Theoretical Framework</td>
<td>50</td>
</tr>
<tr>
<td>Figure 4.1</td>
<td>Multidimensional model of stress and health in spouses of cancer patients</td>
<td>77</td>
</tr>
<tr>
<td>Figure 4.2</td>
<td>Family Developmental Stage</td>
<td>89</td>
</tr>
<tr>
<td>Figure 4.3</td>
<td>Household Income</td>
<td>89</td>
</tr>
<tr>
<td>Figure 4.4</td>
<td>Education</td>
<td>90</td>
</tr>
<tr>
<td>Figure 4.5</td>
<td>Occupational Status</td>
<td>90</td>
</tr>
<tr>
<td>Figure 4.6</td>
<td>Percent of spouses meeting each inclusion criterion</td>
<td>91</td>
</tr>
<tr>
<td>Figure 4.7</td>
<td>Subjects consented, not responding, declined</td>
<td>92</td>
</tr>
<tr>
<td>Figure 4.8</td>
<td>Relationship between gender and general health</td>
<td>94</td>
</tr>
<tr>
<td>Figure 4.9</td>
<td>Developmental Stage and Health</td>
<td>95</td>
</tr>
<tr>
<td>Figure 4.10</td>
<td>Relationships among income &amp; positive reappraisal and cortisol &amp; sIgA</td>
<td>96</td>
</tr>
<tr>
<td>Figure 4.11</td>
<td>Relationships among occupational status, intervening variables, and cortisol</td>
<td>97</td>
</tr>
<tr>
<td>Figure 4.12</td>
<td>Occupational status, intervening variables, and sIgA</td>
<td>98</td>
</tr>
</tbody>
</table>
CHAPTER 1

INTRODUCTION

Cancer has rapidly developed into a chronic health problem because of increased incidence, improvements in diagnosis and treatment, and the resultant longer survival times (Miaskowski, Kragness, Dibble, & Wallhagen, 1997; Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999a & 1999b). The prevalence of cancer makes it a major health issue in the United States (Jensen & Given, 1991). The probability that a male will develop cancer in his lifetime is about 43% while the lifetime prevalence for women is 38.1% (Ries, Kosary, Hankey, Miller, Clegg, & Edwards, 2001). Estimated new cancer cases for 1999 were over 1.2 million (Ries et al.). As has been the trend in the last twenty years, more and more patients with cancer will be treated on an outpatient basis or in the home—mostly in an effort to decrease the costs of care (Hileman, Lackey, & Hassanein, 1992; Oberst, Gass, & Ward, 1989). Although cost effective, the increased reliance on family members to provide care exposes them to high levels of chronic stress—contributing to physical and psychological morbidity in the caregiver.
Significance

It is imperative that health care providers understand the factors contributing to poor health outcomes in caregivers of oncology patients and have knowledge of the informational, support, and coping assistance needs of this population (Harrington & Gates, 1996; Hileman et al.). Nursing, in its role as a patient and family advocate and holistic approach to care, is in a position to address the needs of the ever-growing population of family caregivers. Understanding the concepts related to the caregiving experience and the relationships between them will enable nurses to meet these needs.

Although it is widely acknowledged that cancer diagnosis can be a stressor for the patient (e.g., Harrison, Haddad, & Maguire, 1995; Kurtz, Given, Kurtz, & Given, 1994) it must be recognized as a source of stress and burden for the caregiver as well (e.g., Chan & Chang, 1999; Chwalisz, 1996; Northouse, Templin, Mood & Oberst 1998; Weitzner, Jacobsen, Wagner, Friedland & Cox, 1999; Weitzner, McMillan, & Jacobsen, 1999). An informal caregiver is an unpaid person, usually a family member, who helps the patient with physical care and/or with coping with the illness (Hileman et al., 1992). This arrangement often requires the caregiver to place the needs of the patient ahead of his or her own needs (Jones, 1996). Many studies document the negative biopsychosocial effects associated with providing care for an ill relative or friend. Caregiver burden is defined as the negative consequences of the activities involved with providing necessary direct care to a relative or friend that result in observable and perceived costs to the caregiver (Nijboer et al., 1999b). Research suggests that caregivers who report a larger amount of burden are at higher risk for negative health sequelae (e.g., Chwalisz, 1996; Nijboer et al.; Weitzner et al., 1999; Given & Given, 1992). It has been reported that 30
to 48% of family caregivers will experience significant psychological distress as a result of their role (Harrison et al., 1995; Hinds, 1992). Furthermore, caregivers may be at even greater risk for psychological distress than the patients they care for (Baider, Koch, Esacson, & De-Nour, 1997). The increased costs of health care, the emphasis on outpatient care, and the resultant increased demand for informal caregiving make it imperative that nurses understand the impact of caregiving and how best to assist caregivers and positively influence caregiving outcomes (Swanson, Jensen, Specht, Johnson, & Maas, 1997).

While most researchers will agree that caregiving is a multidimensional construct, many continue to examine only the “multiple dimensions” of the negative aspects while ignoring the positive aspects of caregiving (Kramer, 1997a; Morano, 2001). However, several studies have demonstrated the presence and benefits of the positive aspects of caregiving. How well-prepared the caregiver feels, the level of caregiving self-esteem, or how well he or she feels about the situation have been shown to be positively related to improved outcomes in caregivers of cancer patients (Given et al., 1992; Kurtz et al., 1995; Nijober et al., 1999a). Thus, if one is to examine caregiving from an holistic perspective, it is clear that both positive and negative appraisals of caregiving should be addressed.

Similarly, there is a need for more studies on the biophysiological sequelae of caregiving to gain a more complete understanding of this complex phenomenon. The central nervous system, the endocrine system, and the immune system all participate in the response to transient, repeated, and chronic psychological stress. Therefore, physical health may be changed as a result of the caregiving experience (Hansen-Grant, Pariante,
Further, otherwise healthy individuals have been shown to have adverse physiological sequelae from exposure to chronic stress (e.g., Kiecolt-Glaser & Glaser, 1992). In relatively healthy caregivers, measures thought to be more objective for health status—such as utilization of mental and physical health services—may not address this factor. Because of this, physiologic measures of stress and health should be compared with these other measures. It is expedient for the progressive nurse researcher to examine stress and health from both psychological and physiological perspectives. By measuring physiological indicators of stress and immune function that is closely related to health, we can improve the richness of measurement of constructs related to caregiver stress and health. This can easily be accomplished by including simple yet precise measures of the physiologic stress and immune response.

Finally, by examining stress from a biobehavioral perspective, one can better identify possible areas for intervention. A few studies have examined the impact of caregiving on the caregiver’s physiologic health (e.g., Kiecolt-Glaser & Glaser, 1994). However, the knowledge base needs to be expanded to include different kinds of caregiving situations and to include caregivers of both genders, diverse races, and from younger age groups.

**Research Problem and Purpose**

If the caregiver is to be able to continue caring for an ill family member, health care providers need to understand the biopsychosocial factors contributing to poor health outcomes and have knowledge of caregivers’ informational, support, and coping assistance needs. Understanding the concepts related to the caregiving experience and the relationships between them will enable nurses to more comprehensively meet these
needs. In particular, examining both positive and negative aspects of caregiving and using both physiologic and psychological measures, will better enable these goals to be met.

The President’s Cancer Panel and the National Institute of Nursing Research both emphasize the need for research on supporting family caregivers in an effort to improve quality of care and quality of life for both patients and family caregivers. There is a virtual absence of literature on these factors in the context of young families where a parent has cancer and the other parent is the primary caregiver for the ill spouse. Health care providers need to be aware of these factors, be able to accurately assess caregivers’ needs in these areas, and effectively intervene when warranted in order to improve caregiver outcomes. The overall purpose of this research is to increase the understanding of biopsychosocial factors affecting health in young caregivers of cancer patients.

Chapter two will present the concepts relevant to the experience of caregiving, based on the author’s recently published manuscript. Chapter three will present the theoretical basis for the study based on a submitted manuscript in revision. A fourth chapter will present a report of the research including a literature review, study design and methods, data analyses, results, and a discussion of the implications of the results.
References


CHAPTER 2

CONCEPTS USED IN CAREGIVER RESEARCH:
A REVIEW OF THE LITERATURE

Many studies document the negative biopsychosocial effects associated with providing care for a relative or friend. The negative effects of caregiving have been conceptualized in a number of ways in the literature. Common concepts include: caregiver burden (e.g., Zarit, Reever, & Bach-Peterson, 1980) caregiver strain, (e.g., Archbold, Stewart, Greenlick, & Harvath, 1990) and caregiver stress (e.g., Nolan, Grant, & Ellis, 1990; Pearlin, Mullan, Semple, & Skaff, 1990). Others have examined caregiving from a more positive, or at least neutral, perspective. For example, positive aspects of the caregiver experience have been conceptualized as caregiver esteem (Given et al., 1992; Nijboer et al., 1999a; Nijboer et al., 2001), uplifts of caregiving (Kinney, Stephens, Franks & Norris, 1995; Wallsten & Snyder, 1990), caregiver satisfaction (Lawton et al., 1991), finding or making meaning through caregiving (Ayres, 2000; Farran, Miller, Kaufman, Donner, & Fogg, 1999; Farran, 1997; Farrran, Miller, Kaufman, & Davis, 1997; Folkman, 1997), gain in the caregiving experience (Kramer, 1997a; 1997b), and caregiver appraisal (e.g., Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Oberst, Gass & Ward, 1989). Understanding the concepts related to the caregiving experience and the relationships among them will enable nurses to better address the needs of caregivers. The presence of multiple terms used to describe the effects of
caregiving may lead to confusion in the synthesis of caregiving literature. The aims of
this analysis are to identify the competing conceptualizations of the effects of caregiving
in an effort to clarify and delineate useful concepts for use in nursing research and
practice with individuals in the role of caregiver to chronically-ill family members.
Literature reviewed was obtained via searches of CINAHL, MEDLINE, and PsychInfo
computerized databases through mid-2002. Keywords used to search included caregiver,
caring, family caregiving, caregiver burden, and caregiver appraisal. Articles
reporting both earlier reviews of literature and of original research are included in this
review.

Negative Conceptualizations of Caregiving

Caregiver Burden

A caregiver is an unpaid person who helps the patient with physical care or
coping with the disease process (Hileman, Lackey, & Hassanein, 1992). Similarly,
Pearlin and colleagues define informal caregiving as, "Activities and experiences
involved in providing help and assistance to relatives or friends who are unable to
provide for themselves" (1990, p. 583). The Merriam-Webster Dictionary (2001)
definition of caregiver is as "a person who provides direct care as for children or the
chronically ill" (no pagination). "Burden" is defined by the same source as, "Bearing of a
load" or "Something that is oppressive or worrisome". Therefore, caregiver burden could
be stated as the oppressive or worrisome load borne by individuals providing direct care
for the chronically ill.
Many definitions of caregiver burden have been posited in the literature. Caregiver burden may be defined as the consequences of the activities involved with providing necessary direct care to a relative or friend that result in observable and perceived costs to the caregiver (Jones, 1996; Maurin & Boyd, 1990; Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999b; Nolan et al., 1990). It is the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver (Zarit et al., 1980), or, "the negative subjective experience of the caregiver" (Chwalisz, 1996). Braithwaite (1992) defined caregiver burden as the extent to which meeting caregiving demands conflicts with the basic needs of the caregiver. Finally, caregiver burden may be defined as "an external demand or potential threat that has been appraised as a stressor" (Lawton et al., 1989, p. 61).

The idea of observable versus perceived costs relates to a commonly accepted division between subjective and objective types of caregiver burden. Early conceptualizations of caregiver burden failed to distinguish between these conceptually distinct domains (e.g. Zarit et al., 1980). Objective burden is the observable, concrete, tangible cost to the caregiver resulting from the loved-one's illness (Jones, 1996; Maurin & Boyd, 1990). Subjective burden refers to the positive or negative feelings that may be experienced when giving care (Nijboer, et al., 1999a). Subjective burden may also be defined as the individual’s personal appraisals of the situation (Maurin & Boyd, 1990). Research suggests that caregivers who report a larger amount of subjective burden are at higher risk for negative health sequelae such as depression, and that it is this subjective aspect of burden that is important in predicting outcomes (e.g., Given et al., 1992; Nijboer et al., 1999a; Weitzner et al., 1999).


**Hassles of Caregiving**

The concept “hassles” has been examined in regard to caregivers along with the concept “uplifts” (see below; Kinney & Stephens, 1989; Kinney et al., 1995). Hassles may be defined as minor events appraised as threatening to the individual’s well-being, or as annoying or troublesome concerns (Lazarus & Folkman, 1984; Merriam-Webster, 2001). Hassles may exert little or no influence individually. However the accumulation of numerous hassles may have a significant effect on health. In other words, there may be a cumulative effect of these minor stressors producing chronic stress for the affected individual. Hassles are the actual stressors involved in being a caregiver (e.g., assistance with ADL, etc), which must be appraised by the caregiver as being a hassle in order to exert negative effects (Kinney & Stephens, 1989).

**Caregiver Strain**

"Strain" has several definitions appropriate to the concept at hand. It is, "An act of straining or of being strained: as excessive or difficult exertion or labor", "excessive physical or mental tension", or "an unusual reach, degree or intensity" (Merriam-Webster 2001, no pagination). Thus, caregiver strain might be stated as the unusually excessive physical or mental exertion required of, and the resultant tension experienced by individuals providing direct care for the chronically ill.

In the caregiving literature, caregiver strain has been defined as both a stressor and as perceived stress. For example, Pearlin (1994) defines it as "enduring problems one experiences as an incumbent of a particular role or status" (p. 10). It exists because of the occurrence of simultaneous multiple demands. Others describe caregiver strain as
the impact of caregiving on the caregiver (Ory et al., 1999). Strain has also been referred to as the "felt difficulty in performing the caregiver role" (Archbold et al., 1990, p. 376).

**Caregiver Stress**

The dictionary definitions of stress are "constraining force or influence", "a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation", and "a state resulting from stress--especially one of bodily or mental tension resulting from factors that tend to alter existent equilibrium" (Merriam-Webster, 2001, no pagination). Therefore, like strain, stress can be seen as both a cause and a result of a phenomenon--such as caregiving--that alters equilibrium. Cohen and colleagues defined perceived stress as, 'the degree to which situations in one’s life are appraised as stressful’ (Cohen, Kamarck, & Mermelstein, 1983, p.387). Nolan and colleagues (1990) define caregiver stress as the result of a cognitive imbalance between the perceived nature of the demand and the perceived capabilities of the individual. This definition is based on a transactional view of stress as put forth by Lazarus and Folkman (1984). From the transactional perspective, stress is a process rather than merely a response to an environmental stimulus. This definition of stress emphasizes relationships among the person, his or her characteristics, and the environmental event presented. The authors define psychological stress as, “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p.19). From this perspective it is the subjective or perceived stress that is important rather than the actual stressor.

All of the above concepts recognize a division between the objective and the subjective aspects of caregiving. Caregiver burden, hassles, strain, and stress all imply a
negative connotation to being a caregiver. There is an imbalance between demands and the caregiver’s ability to cope with the demands. Caregiver stress and subjective burden may result from caregiver strain, hassles, or objective burden. The caregiver’s appraisals of the hassles, strains, or objective burdens of caring determine the degree of perceived caregiver stress and/or subjective caregiver burden.

Positive Conceptualizations of Caregiving

While most researchers will agree that caregiving is a multidimensional construct, most continue to examine only the “multiple dimensions” of the negative aspects while ignoring the positive aspects (Kramer, 1997a; Morano, 2001). However, several studies have demonstrated the presence of and positive influence of the positive aspects of caregiving.

Caregiver Esteem

Caregiver esteem is the extent to which performing caregiving informs the caregiver’s self esteem. Self-esteem is the confidence or satisfaction one has for oneself (Merriam-Webster, 2001). Therefore caregiver esteem can be defined as the confidence or satisfaction the caregiver derives as a direct result of caregiving. Given and colleagues found that caregiver esteem was inversely related to depression in samples of caregivers of both elderly and cancer patients (1992). Nijboer and colleagues found that caregivers with high levels of caregiver self-esteem reported the lowest levels of depression (1999a; 1999b). Further, it was found that caregiver esteem decreases over time in the caregiving role, and female caregivers are more likely than males to report decreased caregiver esteem over time (Nijboer, Triemstra, Tempelaar, Mulder, Sanderman & Van den Bos, 2000).
Uplifts of Caregiving

The dictionary definition of uplift is ‘to improve the spiritual, social, or intellectual condition of (an individual)” (Merriam Webster 2001). In an examination of the uplifts and hassles of caregiving, Kinney and Stephens (1989) defined uplifts as events that make one feel good, make one joyful, or make one glad or satisfied or, ‘uplifts are daily events that evoke feelings of joy, gladness or satisfaction’ (Kinney et al., 1995). Researchers interested in the uplifts of caregiving generally examine the caregiver's appraisals of a list of daily tasks as either ‘uplifts’ or ‘hassles’. Uplifts are hypothesized to buffer the effects of hassles (Kinney & Stephens, 1989). In an examination of the uplifts and hassles of caregiving, it was found that when uplifts outweighed hassles, caregivers reported less distress (Kinney et al., 1995).

Caregiver Satisfaction

Satisfaction is defined as ‘the quality or state of being” or, ‘a source or means of enjoyment” (Merriam-Webster, 2001; no pagination). Satisfaction is one of the most common terms used to address the positive aspects of caregiving (Kramer, 1997a). An early definition of caregiver satisfaction was posed by Lawton and colleagues as ‘the benefits accruing to the caregiver through his or her own efforts” (1989, p. P64). This research group later defines satisfactions as, ‘Subjectively perceived gains from desirable aspects of or positive affective returns from caregiving’ (Lawton et al., 1991, p. P182). And again later, caregiving satisfaction was defined as, ‘the result of caregiving experiences that give life a positive flavor” (Lawton, Rajagopal, Brody, & Kleban, 1992, p. S157). These authors and others seem to have trouble defining what exactly is meant by satisfaction. However, satisfaction has been shown to be related to positive affect and
to burden, and may have differential effects in predicting negative and positive affective sequelae in caregivers (Lawton et al., 1989; Lawton et al., 1991). This research suggests that even burdensome or stressful activities may be associated with satisfaction for the caregiver.

**Finding or Making Meaning through Caregiving**

Qualitative researchers were the first to identify the construct “finding meaning” in caregiving. Farran and colleagues conducted a study of dementia caregivers and found six major themes that led to the conceptualization of finding meaning as a positive psychological resource variable in caregiving (1991). These qualitative data were later used to construct a quantitative scale—the Finding Meaning through Caregiving Scale—for use in assessing positive aspects of and ways of finding meaning through caregiving (Farran et al., 1999). An earlier study by this group found that subjects who were able to find higher levels of meaning had lower depression scores (Farran et al., 1997). One other researcher recently examined the construct of meaning in caregivers in a qualitative study (Ayers, 2000). This study employed thematic and narrative analyses to describe the processes used by caregivers in making meaning and how these are related to the caregivers’ more general ideas about themselves. Caregivers used the process of making meaning to make sense of caregiving and to interpret both the caregiving experience and their own affective responses. The process involved expectations (predictions about events), explanations (reasoning to account for discrepancies among expectations and actual events), and strategies (actions taken to actualize expectations). Ayers suggests that studies need to be designed to measure which methods of making meaning predict risk for negative outcomes in caregivers, rather than merely describing the process.
Gain in the Caregiving Experience

Caregiver gain is defined as, “The extent to which the caregiving role is appraised to enhance an individual’s life space and be enriching” (Kramer, 1997a, p. 219). It may include any positive return to the caregiver as a result of the caregiving experience. The concept of caregiver gain was posited by Kramer after a critical review of literature on the positive aspects of caregiving. The author poses a model of caregiver adaptation in which ‘appraisal of role gain’ is an intervening process through which background and contextual variables act to influence well-being outcomes. There also is a relationship between caregiver resources (e.g. coping and social support) and gain. However, Kramer suggests that the nature of the relationship has not been clearly explicated in the literature. In a recent study of caregiver strain and gain, gain was found to moderate the relationship between stress and negative affect, and the effects of gain were independent of negative appraisals of strain (Rapp & Chao, 2000).

One conceptual issue noted by Kramer (1997) in a recent review of the caregiving experience is that gain in caregiving is often conceptualized as appraisal. However, in the true sense of the Transactional Model, appraisal can be positive, negative, or benign (Lazarus & Folkman, 1984). Also, gain has been conceptualized as both an event-specific and a role-related construct. Event-specific gain includes responses to specific caregiving tasks while role-specific gain pertains to more general appraisals of the caregiving role (Kramer). Researchers should be careful to delineate which conceptualization of gain they are attempting to measure. Lastly, strain and gain are often treated as opposites on a continuum when they may actually be differentially related to outcomes (Kramer).
Caregiver Appraisal: A Neutral Conceptualization

To "appraise" is to "set a value on", "estimate the amount of", or "to evaluate the worth, significance, or status of" something (Merriam-Webster, 2001, no pagination).

Therefore, caregiver appraisal may refer to the process by which a caregiver estimates the amount or significance of caregiving. Oberst and colleagues (1989) defined appraisal as the caregiver’s assessment of both the nature of the stressor and his or her resources for coping with it. Caregiving appraisal may be positive, negative, or neutral (Kinsella, Cooper, Picton, & Murtagh, 1998) and consists of subjective cognitive and affective appraisals of the potential stressor and the efficacy of one’s coping efforts (Lawton et al., 1989). Caregiver appraisal is a neutral term in that it can imply positive, neutral, or negative feelings about the caregiving situation. However, one attribute of most caregiving situations is that the caregiver is required to place the needs of the care receiver above his own needs (Kinsella et al.). This implies an imbalanced relationship.

There is some sort of expectation that the caregiver should provide care to the individual who is sick. Care is given without compensation or pay. There are observable and perceived costs (or gains) to the caregiver from providing care. There are present chronic, repeated stressors leading to increased role expectations of the caregiver.

However, not all imbalanced relationships are negative (e.g., parent-child, teacher-student, etc.). While the above attributes may be present, there is a transaction between the environment and the individual influencing the evaluation and outcomes of caregiving. Thus caregiver appraisal may be the most useful concept for exploring the
caregiving experience—especially from a transactional perspective—because appraisal is part of the transaction between the individual and the environment (Lazarus & Folkman, 1984).

Appraisals of the caregiver concerning his or her abilities and of the caregiving situation in general have been proposed as mediators of burden and outcomes. For example, a group of Dutch researchers found that the caregiver’s appraisal is a direct indication of their psychological distress regardless of such factors as coping and social support (Pot, Deeg, & van Dyck, 2000). Distress from negative appraisals of the caregiver may result in the inability of the caregiver to continue caring for the patient—therefore a change in social functioning of the caregiver (Weitzner et al., 1999).

However, positive appraisals of the caregiver also have been proposed as mediators of outcomes. For example, how well-prepared the caregiver feels, the level of caregiving self-esteem, and how well he or she feels about the situation have been shown to be positively related to improved psychological outcomes in caregivers of frail elders (Archbold et al., 1990; Lawton et al., 1989), and in caregivers of cancer patients (Given et al., 1992; Kurtz, Given, Kurtz & Given, 1994; Kurtz, Kurtz, Given, & Given, 1995; Nijboer, et al., 1999a & b). Not all caregivers will perceive their role as stressful or burdensome and the demand to provide care is not in and of itself a stressor (Lawton et al., 1989). Whether caregiving is stressful is determined by the subjective appraisal of the individual. For instance, a recent study of caregivers of advanced cancer patients in Australia suggested that the caregiver’s appraisals were a more important determinant of outcomes than objective indicators such as patient symptoms or dependence (Aranda &
Examining reactions to caregiving from an appraisal standpoint will allow the reaction of the caregiver to dictate whether (or not) burden, stress, gain (etc.) are present in the caregiving role.

Few well-designed instruments have been developed by nurses to measure the concept of caregiver appraisal. One of these is the Caregiver Reaction Assessment (CRA) developed by Given and colleagues (1992). The scale consists of 24 items that describe five components or subscales of the caregiving experience. The scale aims to assess caregiver appraisals in each of these domains: daily schedule, finances, relationships with others, physical health, and self-esteem. These subscales tap into several of the attributes of caregiving appraisal, including: needs of care receiver placed above needs of caregiver, imbalanced relationship, observable and perceived costs, chronic and/or repeated stressors, increased role expectations, and the transactional process between the caregiver and the environment. This instrument has been widely used both in the United States and abroad (e.g., the Netherlands and Australia), and internal consistency, and construct validity have been reported as adequate (e.g., Aranda & Hayman-White 2001; Nijboer et al., 1999a). Further, the CRA has been widely used with partners of cancer patients and exhibits factorial invariance across different types of caregivers (e.g., Nijboer et al., 1999a).

Another instrument for measuring caregiver appraisal is the Appraisal of Caregiving Scale (ACS; Oberst et al., 1989). This is a 53-item self-report instrument with which to measure the meaning of caregiving in terms of four dimensions of
appraisal: harm/loss, threat, challenge, and benign. The instrument can be used to measure the same attributes as the CRA. For a review of other available instruments, the reader is referred to Kinsella et al., 1998.

Discussion

Several things have become clear over the past two decades concerning family caregiving. Early descriptive studies documented the negative psychological and physiological health effects associated with caregiver burden (e.g., Barusch, 1988; Oberst et al., 1989; Robinson, 1989). Caregiver burden has been conceptualized and measured in a number of different ways in the literature (Chwalisz, 1996). Chwalisz concluded from a 1992 review of the literature that caregiver burden is best described as the negative subjective experience of the caregiver.

More recent studies examined both negative and positive appraisals of the caregiver (e.g., Given et al., 1992; Nijboer et al., 2001; Kinney et al., 1995; Lawton et al., 1991; Farran et al., 1999). As stated by Kinney in her 1997 review, “..there is more to mental health than the absence of pathology, and people experience both positive and negative emotions” (p. 218). Thus, if one is to examine caregiving from a holistic perspective, both positive and negative appraisals of caregiving should be addressed. A very recent review of caregiver intervention studies lists several recent contributions to knowledge, including the identification of research design, measurement, and sampling issues, and the conduct of descriptive research on cultural issues and positive aspects of caregiving (Farran, 2001). Methodologically, much of the information on the positive aspects of caregiving has resulted from qualitative studies. The richness of the qualitative data thus far suggest that quantitative instruments may not be able to adequately tap the
positive aspects of the caregiving experience (Kramer, 1997). Further, research into the
effects of interventions on the positive aspects of caregiving need to be conducted
(Farran, 2001).

**Current Research Priorities**

Considering the advances in knowledge related to caregiving thus far, several
suggestions can be made with regard to future studies. The President’s Cancer Panel and
the National Institute of Nursing Research both emphasize the need for research on
supporting family caregivers in an effort to improve quality of care and quality of life for
both patients and family caregivers. In light of the identified concerns in the 1990's,
added attention to cultural and gender differences in caregiver research is needed (Farran,
2001). Interventions will need to be examined that provide more flexibility for the
working caregiver, and for caregivers in rural settings. In addition, there is a need for
more longitudinal studies of caregivers over the course of years. Another possible area
for study is the use of computers and other technologies for provision of caregiver
support. A description of these and other current research priorities is presented
succinctly in the review by Farran (2001).

Last, there is a need for more studies on the biophysical sequelae of caregiving.
The central nervous system, the endocrine system, and the immune system all participate
in the response to transient, repeated, and chronic psychological stress and therefore,
physical health may be changed as a result of caregiver appraisal (Hansen-Grant,
Pariante, Kalin, & Miller, 1998). A few studies have examined the impact of caregiving
on the caregiver's physiologic health (e.g., Kiecolt-Glaser and Glaser, 1994). However,
these studies need to be expanded to include different kinds of caregiving situations,
different types of physiological measures of the impact of caregiving, and an examination
of the effects of caregiver interventions on caregiver health. Self-report data are
commonly used for measurement of mental and physical health outcomes. These
measures may fail to give an accurate picture of the psychological distress and physical
health effects of the caregiving role (Dura & Kiecolt-Glaser, 1990; Robinson & Austin,
1998; Schulz, Visintainer, & Williamson, 1990). Caregivers tend to underreport
problems both out of denial and out of a lack of awareness of the effects of caregiving on
their mental and physical health (Robinson & Austin). Furthermore, caregivers who are
mentally distressed are likely to seek out medical health services rather than mental
health services and to present with multiple somatic complaints (Schulz et al., 1990).
Also, some measures of mental health may not be sensitive enough for relatively healthy
caregiving subjects. Further, those with the greatest burden may be less able to obtain
health services for themselves than those with the least burden. Therefore, measures
thought to be more objective for health status—such as utilization of mental and physical
health services—may not even be valid for this population. By using both self-report and
physiologic indicators of stress and health, a more accurate picture of the health outcomes
of caregivers can be obtained. In addition, examining interactions among objective
stressors, caregiver appraisals, and outcomes in a multivariate fashion may provide
insight as to why caregiver research has produced varying results in different contexts
(Braithwaite, 1996). Also, by examining the stress from a biobehavioral perspective, one
can better identify possible areas for intervention.
Conclusion

Many patients with chronic illnesses are treated on an outpatient basis or in the home. Although this is financially cost effective for the health care system, the increased reliance on family members exposes them to high levels of chronic stress—contributing to physical and psychological morbidity in the caregiver. These costs have rarely been examined. If the caregiver is to be able to continue caring for their ill family member, health care providers need to understand the biopsychosocial factors contributing to poor health outcomes and have knowledge of caregivers’ informational, support, and coping assistance needs. Understanding the concepts related to the caregiving experience and the relationships among them will enable nurses to address these needs. In particular, examining both positive and negative aspects of caregiving and using both physiologic and self-report measures, will better enable these goals to be met.
References


instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*: 55-63.

CHAPTER 3

CAREGIVING IN THE CONTEXT OF TRANSACTIONAL STRESS AND PSYCHONEUROIMMUNOLOGY: A BIOPSYCHOSOCIAL MODEL OF CAREGIVER STRESS

An informal caregiver is an unpaid person, usually a family member, who helps a patient with physical care and/or with coping with his or her illness (Hileman, Lackey, & Hassanein, 1992). This arrangement often requires the caregiver to place the needs of the patient ahead of his or her own needs (Jones, 1996). Many studies document the negative biopsychosocial effects associated with providing care for an ill relative or friend. It has been reported that 30 to 48% of family caregivers will experience significant psychological distress as a result of their role (Harrison, Haddad & McGuire, 1995; Hinds, 1985). Furthermore, caregivers may be at even greater risk for psychological distress than the patients they care for (Baider, Koch, Esacson & De-Nour, 1997). The increased costs of health care, the emphasis on outpatient care, and the resultant increased demand for informal caregiving make it imperative that nurses understand the impact of caregiving and how best to assist caregivers and positively influence caregiving outcomes (Swanson, Jensen, Specht, Johnson, & Maas, 1997).

There is a need for more studies on the biophysiological sequelae of caregiving in order to gain a more holistic understanding of this complex phenomenon. The central nervous system, the endocrine system, and the immune system all participate in the
response to transient, repeated, and chronic psychological stress and therefore, physical health may be changed as a result of the caregiving experience (Hansen-Grant, Pariante, Kalin, & Miller, 1998). Further, otherwise healthy individuals have been shown to have adverse physiological sequelae from exposure to chronic stress (e.g., Kiecolt-Glaser & Glaser, 1992). Because of this, the progressive nurse researcher should examine caregiver stress and health from both psychological and physiological perspectives. A few studies have examined the impact of caregiving on the caregiver’s physiologic health (e.g., Kiecolt-Glaser & Glaser, 1994). However, the knowledge base needs to be expanded to include different kinds of caregiving situations and to include caregivers of both genders, diverse races, and from younger age groups. Finally, by examining the stress from a biobehavioral perspective, one can better identify possible areas for intervention. It is imperative that health care providers understand the factors contributing to poor health outcomes in spousal caregivers.

Nursing, with its role as a patient and family advocate and holistic approach to care, is in a position to address the needs of the ever-growing population of family caregivers. Understanding the concepts related to the caregiving experience and the relationships between them will enable nurses to meet these needs. This paper presents a multidimensional framework with which to examine the caregiver experience from a biopsychosocial perspective. The framework presented combines aspects of the Transactional Model of Stress, Appraisal, and Coping (Lazarus & Folkman, 1984) with the principles of Psychoneuroimmunology (Ader, 2001).
Transactional Model of Stress, Appraisal, and Coping

The transactional model of stress, appraisal, and coping is a framework for addressing appraisal and coping as they relate to stress and its outcomes (Lazarus & Folkman, 1984). This model views the person in a bi-directional, dynamic, mutually reciprocal relationship with the environment. The interaction between the individual’s appraisals and the environment helps determine the level of stress experienced, subsequent appraisals of the situation, and future stress in similar contexts. The focus is primarily on the psychological and social processes involved in stress and an integrative theoretical analysis of these.

The practical purpose of the theory is to examine the causes of psychological stress in different people. The authors define psychological stress as, “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19). They sought to “provide a theoretical and methodological framework within which to think about the processes that mediate psychological stress and its relationship to health and adaptation” (pp. 19-20). The theory came about partly because Lazarus and Folkman felt that a strict stimulus-response definition of stress is inadequate because it does not include the relationship of the person with the environment and defines stress only in terms of the individual’s response to it. An overall purpose of the theory is to gain an understanding of the relationships among stress, appraisal, coping and the short and long-term adaptational outcomes of these
processes such as social functioning, morale, and physical health. In general, causal antecedents such as values and beliefs precede mediating processes such as appraisal and coping efforts. These, in turn, precede immediate and long-term effects.

The relational meaning of a stressor goes above and beyond the mere interaction of personalogical and environmental variables. Transaction is a term that can distinguish the relational meaning from the interaction and adds the individual’s connotation of the event to the perception of the event (or the ability to see through the event to its implications). Appraisal occurs when the person goes through the process of evaluating and constructing the relational meaning of the stimulus, or when a person evaluates the significance of an event to his or her well-being. Appraisal continues in a circular or feedback fashion until the situation is resolved.

The transactional model of stress appraisal and coping is very useful for nursing research. There are many instruments which can be used to operationalize the concepts that have been tested extensively throughout the course of the development of the theory. This theory does not discriminate the subject matter of nursing. In fact, this being a theory from psychology, it does not even discriminate the knowledge as strictly psychology. This theory is broad and middle-range in scope. In other words, this framework can be applied in a number of settings with varying amounts of complexity of the research designs, questions or hypotheses. Although this theory is complex, it is also parsimonious. Extensive testing and research has identified variables (concepts) of import to this area of study. The framework provides a useful “map” by which to
navigate the various concepts. One is able to see which concepts will be related to which other concepts. The framework also helps to explain observable interactions between individuals and the environment and gives insight into why patients react as they do.

**Psychoneuroimmunology**

The principles of *psychoneuroimmunology* complement the Transactional Stress Model. *Psychoneuroimmunology* (PNI) is the study of the relationships among brain, behavior and immunity and of the effects of stress on immune and endocrine function (Ader, 2001; Baum & Poluszyński, 1999). While the transactional model is most useful for studying stress from the psychological perspective, it can and has been adapted for use by researchers interested in the social and physiological aspects. Psychoneuroimmunologists are studying the links between the physiological and psychological dimensions and sociologists those between the social and psychological dimensions using this theory as a basis (e.g., Kiecolt-Glaser & Glaser, 1995; Lacey, Zaharia, Griffiths, et al., 2000; Lerman & Glanz, 1997).

Hans Selye, in the 1940’s, first described the General Adaptation Syndrome—the relationships between stress, adaptation, and activation of the adrenal cortex (Lerman & Glanz, 1997; Nelson, 2000; Sapolsky, 1992; Tewes, 1999). The perception of a stressor or appraisal of threat, danger, or challenge from the stressor, can activate both psychological and biological systems and is accompanied by activation of the Hypothalamic-Pituitary-Adrenocortical (HPA) system and the release of stress hormones such as cortisol from the adrenal cortex (Baum & Poluszyński, 1999). This arousal is a primary mechanism for the effects of stress on health. In general, the stress response is adaptive. However, long-term stress responses can be maladaptive and can lead to
decreased immune function (Ader, 2001; Baum & Poluszny; Hucklebridge, Clow & Evans, 1998). Organisms generally respond to stressors by upregulation of sympathetic output and the release of stress hormones (Benschop, & Schedlowski, 1999; Carlson, 2001; Chrousos, & Gold, 1992; Nelson, 2000; Sapolsky, 1992; Tewes, 1999). In humans, cortisol is the principal stress hormone and is released from the adrenal cortex in response to stress. If everything is working, cortisol completes a feedback loop once a threat is perceived to be over. One function of cortisol is to prevent excessive immune system activation in a crisis, and there is evidence that cortisol levels rise in response to increased immune activity, possibly to exercise some control over it (van Eck & Nicholson, 1994). This is an inhibitory activity that may allow glucocorticoids to protect from overactivity of the immune system—preventing inflammatory diseases and autoimmune reactions. Various physical and psychological stressors, including trauma, exercise, hypoglycemia, anxiety, and depression can increase cortisol levels.

In general, cortisol enhances physiological adaptation to stress and therefore serves an adaptive function. However chronic high levels of cortisol can be maladaptive and have been implicated in depression, anorexia nervosa, anxiety disorders, Alzheimer’s disease, and post-traumatic stress disorder (PTSD; Hansen-Grant et al., 1998). Evidence from animal studies suggests that if the stress system is not shut down, too much cortisol is produced, which eventually will damage the hippocampus—the brain site of emotion, consolidated memory, and learning. This damage impairs the hippocampus’ ability to inhibit the HPA axis, throwing its response to stress out of whack, causing it to go into
overdrive and to secrete more glucocorticoids that further damage the hippocampus. Hippocampal atrophy has been noted in patients with depression, PTSD and schizophrenia (Hansen-Grant, et al.).

Exposure to the chronic stressors of caregiving places family members at risk for poor physical and mental health outcomes and may result in the inability to continue caring for the patient (e.g., Nolan, Grant & Ellis, 1990; Oberst, Gass & Ward, 1989; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999; Weitzner, McMillan & Jacobsen, 1999). In addition, the central nervous system, the endocrine system, and the immune system all participate in the response to transient, repeated, and chronic psychological stress (Hansen-Grant, et al., 1998). Since caregivers are exposed to high levels of long-term stress of a multidimensional nature, examining the relationships among context, mediators, and outcomes using both the transactional stress and psychoneuroimmunology frameworks will result in a more comprehensive understanding of the effects of caregiving.

The aim of this theory construction is to provide a theoretical framework with which to examine the relationships between contextual factors, mediating variables, and caregiving outcomes in spousal caregivers. Blalock’s (1969) method of theory construction is used. A block non-recursive system will be used to organize variables and identify the relationships between them. Since a very complex set of relationships exists between variables in the experience of caregiving, a preliminary literature review was conducted in order to select variables to include in the model (Gray, 1995).
From this review, the writer was able to organize the numerous variables into three blocks of variables to be included in the framework (Figure 3.1). Each block will be described including the variables and relationships within them, and evidence for the relationships between the blocks will be given.

The philosophical basis of knowledge obtained through such a framework is based on an analytic/empirical model similar to the primary academic model used in most nursing research. This pattern of knowing is akin to Carper’s empirics, or the science of nursing (1978). This pattern uses observation, classification, quantification, and measurement to explain, predict, or control phenomena in an objective or “value-free” manner (Wolfer, 1993). This perspective may be evaluated (not incorrectly) by some as reductionistic. However, if one is to study health and illness from a holistic approach, it is often necessary to take a reductionist view in order to include physiological phenomena in one’s ‘holistic’ research (Holden, 1996).
Theoretical Block of Contextual Antecedents

Description of the Block

Contextual antecedents form an exogenous block that describes the life and caregiving situation of the spousal caregiver. Caregiver race and gender, family developmental stage, disease-related variables, and other demographic variables are the identified contextual antecedents. These variables impact the caregiver’s ability to endure the stressors of the caregiving role. The contextual antecedents form an exogenous block with the relationships between the variables shown in Figure 3.2.

![Diagram of contextual variables](image)

Figure 3.2: Block of contextual variables

Demographic Variables

Research findings have suggested that numerous caregiver, patient, and family, characteristics have an influence on caregiver experiences. These include factors such as race (Knight, Silverstein, McCallum, & Fox, 2000), gender, (Hagedorn, Buunk, Kuijer et al., 2000; McFarland, & Saunders, 1999), age of the patient and caregiver (Barsevick,
Much, & Sweeney, 2000; Dellman-Jenkins, Blankenmeyer, & Pinkard, 2001), and family relationship and development issues (Barsevick et al., 2000; Bradley, Given, Given, & Kozachik, 2000; Dellman-Jenkins et al.).

*Caregiving and race.* Most of the literature on caregiving, stress, and immune function used White subjects or did not examine the effects of race on caregiver burden and health (Knight, Silverstein, McCallum, & Fox, 2000). Race may be defined as a social status category reflecting biology, geographical origin, and culture (Williams, 1997). It is important to examine race in health outcomes studies because it may reflect differential risk-factor exposure which can ultimately affect health via biological pathways. For example, by 1996 estimates for the 20-54 year-old age group, the incidence rates for breast, lung, colorectal, and prostate cancers are higher for Blacks than for Whites (U.S. Census Bureau, 2001). Given the high incidence of cancer and other chronic illnesses in Black Americans, it is useful to examine relationships among race and the other variables. Cultural differences between Whites and Blacks can directly affect the appraisal of caregiving and indirectly affect health via differences in variables such as coping and social support (Knight et al., 2000). For example, Black spouse caregivers were found to appraise their caregiving experience more favorably and to report lower levels of psychological distress than White caregivers despite their pre-existent lower levels of health (Farran, Miller, Kaufman, & Davis, 1997; Wallsten, 2000). Others have found that Black caregivers used fewer coping strategies and were more likely than Whites to perceive the caregiving role as expected and natural (Haley,
West, Wadley et al., 1995). Black caregivers are more likely to report using emotion focused coping, to be younger than White caregivers, and to report poorer subjective health (Knight et al.).

**Caregiving and gender.** As many as 27% of caregivers are male. However, most studies used small samples of male caregivers or did not examine gender effects. Several studies have documented that female caregivers experience greater burden or more psychological distress than male caregivers (e.g., Hagedorn et al., 2000; Northouse, Mood, Templin et al., 2000). Men have shown fewer depressive symptoms and rated their everyday caregiving experiences more favorably than women (Wallsten, 2000). Conversely, other researchers have found male caregivers experiencing more strain or greater burden than females (Gilbar, 1999; Schumacher, Dodd, & Paul, 1993). Gender differences in distress may be due to both biological and gender socialization factors (Hagedorn et al., 2000). Women tend to be more emotionally connected in relationships than are men and may focus more on the emotional aspects of caregiving than do men, who tend to be more task-oriented (McFarland, & Saunders, 1999). Further, when men are caregivers, they are less likely to help their wives with traditionally “female” tasks and are more likely to have help from others than female caregivers (Allen, 1994).

**Caregiving and family developmental stage.** Families, like individuals, go through stages of development (Duvall, 1977). Depending on the developmental stage, the effects of illness on family dynamics may vary. For example, dividing families into young families (couple with infant and/or preschool children), and the middle family (couple with school-age and/or teenage children), based on Duvall’s conceptualization of family life cycle, the capacity to maintain normalcy in family routines may be more
important for young families than for middle families where degree of independence of
the children and flexibility in reallocating roles and responsibilities may be more
important (Barsevick, Much, & Sweeney, 2000). One of the main concerns cited by
spousal caregivers is management of the disruptions of life caused by the disease
(Northouse & Peters-Golden, 1993). These caregivers may have to take on more
household and work responsibilities while managing altered schedules for work, child-
care, domestic, and social activities. Therefore, information about the family’s
developmental stage should be included when studying spousal caregiving.

*Disease-related variables.* Disease-related variables refer to the patient’s
psychological, physiological, and behavioral manifestations that are either a direct result
of the disease or result from the treatment of the disease. These variables can directly
affect the caregiver’s outcomes. For instance, Weitzner, Jacobsen and colleagues (1999)
found that caregiver quality of life was negatively correlated with the patient’s functional
performance and in general, the caregiver’s well being was related to the patient’s
condition. Furthermore, it appears that patient depression is predictive of caregiver
depression (Kurtz et al., 1995).

*Relationships within the Block*

Demographics ($X_1$) and family developmental stage ($X_2$) have a reciprocal
relationship (Figure 3.2). For example, demographic variables such as the age of the
couple would have a relationship with the number and ages of children in the home.
Also, the family developmental stage could have a relationship with the socioeconomic
status of the family (e.g., families with infants more likely to have only one income).
Demographics ($X_1$) are related to disease and treatment variables ($X_3$) in that variables such as race, gender, and age are related to the risk for certain types of cancer, dying from cancer, and chances of early detection of cancer. The relationship between disease-related variables ($X_3$) and demographics ($X_1$) is depicted with a broken arrow because while race and gender are fixed, income and occupational status may be affected by severity of the disease or its associated treatments.

Theoretical Block of Mediating Processes

Description of the Block

According to the Transactional Model of Stress and Coping, the interaction between the individual’s appraisals and the environment helps determine the level of stress experienced (Lazarus & Folkman, 1984). In the context of caregiving, perceived stress, social support, coping, and positive caregiver esteem may influence appraisal of the effects of external stressors thereby intervening between them and health outcomes (Figure 3.3).

Perceived stress. The definition of stress posed in the 1984 work by Lazarus and Folkman emphasizes a relationship between the person, his or her characteristics, and the environmental event presented. The authors define psychological stress as, “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p.19). Cohen and colleagues defined perceived stress as, “the degree to which situations in one’s life are appraised as stressful” (Cohen, Kamarck, & Mermelstein, 1983, p.387). Perceived stress from tasks may affect the individual’s effective use of mediators such as coping or may decrease the positive esteem of the caregiver (Nijboer et al., 1998).
Social support. Social support has been shown to decrease perceived stress and to improve health outcomes in caregivers (e.g., Chwalisz, 1996). Although research has shown that, in general, social support can positively influence outcomes, its impact can vary depending on such factors as timing, type, and perception. For example, while greater amounts of instrumental support may be effective in reducing burden for caregivers of cognitively impaired family members, it may actually exacerbate burden in caregivers of patients who are cognitively alert (Bass, Tausig, & Noelker, 1988). One study examined the effects of the presence of minor children on received support in spousal caregivers of oncology patients (Stommel & Kingry, 1991). The authors concluded that the presence of minor children was associated with more received support from family members. It is possible that, although the quantity of family help was higher in families with small children, the effects of the support may or may not have been positive because the presence of family support does not always ease burden related to caregiving or increase coping effectiveness (Brennan, 2001; Nijboer et al., 2001).

Coping. Coping is defined as, ‘Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus & Folkman, 1984, p. 178). Two types or functions of coping are identified: problem-focused and emotion-focused. Problem-focused coping aims to manage or alter the problem while emotion-focused coping aims to address the person’s emotional response to the problem. Emotion-focused strategies may be best when the stressor is not changeable, and tends to be associated with poorer health outcomes (e.g., Folkman & Moskowitz, 2000; Lerman & Glanz, 1997). Problem-
focused strategies may work best when the stressor is changeable, and the person can focus attention on tasks, or generate a sense of mastery, positive esteem, or control (Folkman & Moskowitz, 2000).

*Caregiver esteem.* The positive appraisals of the caregiver concerning his or her abilities, or of the caregiving situation in general, have been proposed as a mediator of caregiving outcomes. For example, how well-prepared the caregiver feels, the level of caregiving esteem, how well he or she feels about the situation, and the ability to attribute meaning to the situation have been shown to be positively related with improved outcomes in caregivers (Given et al., 1992; Nijboer et al., 1999; Nijboer et al., 2001). Given and colleagues found that caregiver esteem was inversely related to depression in samples of caregivers of both the elderly and cancer patients. Nijboer and colleagues found that caregivers with high levels of caregiver self-esteem reported the lowest levels of depression.

*Relationships within the Block*

Many complex relationships exist within this block (Figure 3.3). Perceived stress (X₄) has a reciprocal relationship with all the other variables in the block. For example, Oberst et al. (1989) found that their sample of family caregivers showed positive correlations among measures of perceived burden, and appraisal of threat, harm or loss. Kinsella, Cooper, Picton, and Murtagh (2000) have proposed a model of caregiving stress in which perceived stress has a reciprocal relationship with self esteem, and suggest that social support may lead to better recognition of the positive aspects of caregiving by the caregiver (i.e., caregiver esteem). Social support has been shown to decrease perceived
stress (e.g., Chwalisz, 1996). Further, anxiety, a construct similar to perceived stress, was predicted by caregivers’ perception of available social support (Raveis, Karus, & Pretter, 1999).

![Diagram of mediator processes](image)

**Figure 3.3: Block of Mediating Processes**

*Theoretical Block of Caregiver Outcome Variables*

**Description of the Block**

The outcome variables block consists of three caregiver outcomes of interest (Figure 3.4). These include health status, physiologic stress response, and immune function. Exposure to the chronic stressors of caregiving places family members at risk for poor physical and mental health outcomes. Because of relationships among brain behavior and immunity, physical health may be changed as a result of caregiver appraisal (Hansen-Grant et al., 1998). Harrison et al. (1995) reported a 48% psychological morbidity rate for depression and anxiety in their sample of cancer caregivers. However,
self-report measures alone may be inadequate for assessing health status in caregivers who are relatively healthy. Caregivers may tend to underreport problems both out of denial and out of a lack of awareness of the effects of caregiving on their mental and physical health (Dura & Kiecolt-Glaser, 1990; Robinson & Austin, 1998). In addition, some measures of mental health may not be sensitive enough to detect risk for psychological morbidity in relatively healthy caregiving subjects (Schulz et al., 1990). By utilizing both self-report and physiologic indicators, a more accurate picture of the health outcomes of young spousal caregivers can be obtained.

*Health status.* Health may be defined as a state characterized by soundness of physical and mental functioning, including physical, psychological, and social aspects (Orem, 1971). The World Health Organization (WHO) defines health as, ‘a state of complete physical, mental, or social well-being and not merely the absence of disease or infirmity’ (2001). Mental health is not only the absence of mental illness, but also the adjustment of an individual to his or her environment such that he or she is comfortable with his or her life situation, while being able to live in such a way that his or her behavior is not in conflict society (Thomas, 1989). Physical health encompasses the more objective physiological aspects of well-being—including both illness and wellness—and includes the constructs somatic symptoms and ambulation (Parkerson, Broadhead, & Tse, 1990 and 1991). Social health consists of self-concept regarding personal relationships and the quantity of social activities an individual is involved in (Parkerson et al.). General (overall) health status, based on the WHO definition of health includes the constructs mental, physical and social health (Parkerson et al., 1990; 1991).
Physiologic stress response. Physiologic stress may be defined as the physiologic response pattern in response to a stimulus that includes an alarm phase, physiologic resistance to defend against damage, followed by either adaptation or exhaustion (Selye, 1956). In humans, cortisol is the principal glucocorticoid released from the adrenal cortex (Benschop, & Schedlowski, 1999; Carlson, 2001; Nelson, 2000; Sapolsky, 1992; Tewes, 1999). As mentioned above, in general, cortisol enhances physiological adaptation to stress and therefore serves an adaptive function. However, chronic high levels of cortisol can be maladaptive and may decrease immune function.

Immune function. Immune function is the body’s recognition of and reaction to foreign or non-self antigens with the purpose of neutralizing or eliminating any threat they may cause the host (Thomas, 1989). Several studies have documented a link between stress, emotion, and antibody levels (e.g., Deinzer & Schuller, 1998). Individuals who react highly to stress will show higher cortisol levels and may have long-term immune system effects such as decreased antibody levels (Deinzer & Schuller; Hucklebridge, Clow, & Evans, 1998; Kiecolt-Glaser & Glaser, 1995).

Relationships within the Block

As should be evident from the above definitions, reciprocal relationships exist between all variables in this block (Figure 3.5). For example, depressed patients often have altered HPA function and tend to have elevated levels and altered circadian rhythms of cortisol (Hagerty, 1995; O’Toole & Johnson, 1997). Also, stress may play a role in the progression of disease by influencing viral replication, immune response, and health-related behaviors (Robinson, Matthews, & Witek-Janusek, 1999 & 2000). Conversely,
the diagnosis of a disease in itself may introduce psychological and physiological stressors, thereby constituting a chronic stressor itself (Robinson et al.).

Figure 3.4: Block of Health outcome variables.

In a series of studies, Ronald Glaser, Janice Kiecolt-Glaser, and their colleagues studied the role of stress on the health of caregivers of Alzheimer’s patients (e.g., Kiecolt Glaser & Glaser, 1992). Compared with controls, the caregivers had poor antibody and T-cell responses to an influenza virus vaccine. More recently, they have shown that psychological stress can affect wound healing in Alzheimer’s caregivers with caregivers taking 24% longer to heal the same size wound than control subjects. Levels of interleukin-2 (IL-2), an important cytokine for wound healing, were significantly lower in cells from the caregivers as compared to the controls. Therefore, otherwise healthy individuals have been shown to have adverse physiological sequelae from exposure to stressors.
Theoretical Framework

The multiple variables involved with the caregiver experience are blocked to allow conceptual discrimination between the different relationships (Schwirian, 1981). Figure 3.5 depicts a conceptual framework for use in examining the relationships between the variables and between the blocks of variables identified by the author as important to the study of stress in spousal caregivers. The relationships between the blocks will be discussed to further describe the phenomenon of caregiver appraisal.

Impact of Contextual Antecedents Block on Mediating Processes Block (R1)

Contextual antecedents can influence the perceived stress, social support, coping, and esteem of the caregiver. For example, contextual factors such as disease and treatment variables (e.g. Gilbar, 1999; Harrington, Lackey & Gates, 1996; Kurtz et al., 1995), gender (Gilbar, 1999, Miaskowski, Kragness, Dibble, & Wallhagen, 1997), and age of the patient and caregiver (e.g., Kurtz et al., 1994) have been shown to affect perceived stress and coping in caregivers. Results of a study on the effects of social support on caregiver strain showed that while greater amounts of instrumental support may be effective in reducing burden for caregivers of cognitively impaired family members, it may actually exacerbate burden in caregivers of patients who are cognitively alert (Bass, Tausig, & Noelker, 1988).
Figure 3.5: Theoretical Framework


Key for Variables in Model

<table>
<thead>
<tr>
<th>Contextual Factors:</th>
<th>Mediating Processes:</th>
<th>Caregiver Outcomes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>X1 = Demographic Variables</td>
<td>X4 = Perceived Stress</td>
<td>X8 = Health Status</td>
</tr>
<tr>
<td>X2 = Family Development</td>
<td>X5 = Social Support</td>
<td>X9 = Physiologic Stress</td>
</tr>
<tr>
<td>X3 = Disease Related Variables</td>
<td>X6 = Coping</td>
<td>X10 = Immune Function</td>
</tr>
<tr>
<td>X7 = Caregiver Esteem</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Impact of Contextual Antecedents Block on Outcomes Block (R2)

Exposure to the chronic stressors of caregiving places family members at risk for poor physical and mental health outcomes (Nolan et al., 1990; Oberst et al., 1989; Weitzner, Jacobsen et al., 1999 & Weitzner et al. 1999). For example, Weitzner, Jacobsen and colleagues (1999) found that caregiver quality of life was negatively correlated with the patient’s functional performance and, in general, caregivers’ well being was related to the patient’s condition. Furthermore, it appears that patient depression is predictive of caregiver depression (Kurtz et al., 1995). Also, health outcomes are related to variables such as race and gender as a function of differential risk-factor exposure.

Impact of Mediating Processes Block on Outcomes Block (R3)

The mediators coping and social support have been shown to improve health outcomes in caregivers (e.g., Baider et al., 1998; Chwalisz, 1996; Pearlin, Mullan, Semple & Skaff, 1990; Steele & Fitch, 1991). Another proposed mediator of the outcomes of stress are the positive appraisals of the caregiver concerning his or her caregiving abilities, which have been shown to be positively related to improved outcomes (Archbold et al., 1990; Given, Given, Stommel et al., 1992; Kurtz et al., 1995; Lawton, Kleban, Moss et al., 1989; Nijober et al., 1999). Chwalisz (1996) found that while problem focused coping was associated with a decrease in perceived stress in spouse caregivers of persons with brain injuries, emotion focused coping was associated with both an increase in perceived stress and, interestingly, an improvement in mental health status. Emotion-focused strategies may be best when the stressor is not changeable, while problem-focused strategies work best when the stressor is changeable.
(Lerman & Glanz, 1997). How well-prepared the caregiver feels, the level of caregiving self-esteem, and how well he or she feels about the situation have been shown to be positively related to improved outcomes in caregivers of frail elders (Archbold, et al., 1990; Lawton et al., 1989), and in caregivers of cancer patients (Given, et al., 1992; Kurtz, et al., 1995; Nijboer et al., 1999).

**Impact of Outcomes Block on Mediating Processes Block (R4)**

Because of the transactional nature of the stress-appraisal-outcome process, a feedback loop exists between the outcomes and the mediating processes. For example, poor health outcomes in the caregiver may increase the perception of the stress of caregiving, may lead to decreases in coping ability, and may decrease the esteem of the caregiver.

**Conclusion**

Many patients with chronic illnesses are treated on an outpatient basis or in the home, and spouses are often called on to provide informal care. The increased reliance on family members exposes them to high levels of chronic stress—contributing to physical and psychological morbidity in the caregiver. If caregivers are to effectively continue caring for their ill family members, health care providers need to understand the biopsychosocial factors contributing to poor health outcomes in caregivers. Understanding the factors that can affect the caregiver’s health outcomes and the relationships between these factors will enable nurses to better meet the needs of both patients and caregivers. In particular, attention to factors related to the caregiving context, mediating processes, and biopsychosocial health outcomes will better enable health care providers to assess and intervene with spousal caregivers.
References


CHAPTER 4

STRESS AND HEALTH IN SPOUSES OF CANCER PATIENTS: A PILOT STUDY

Cancer has become a chronic (as opposed to acute) health problem because of increased incidence, improvements in diagnosis and treatment, and the resultant longer survival times (Miaskowski, Kragness, Dibble, & Wallhagen, 1997; Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999a & 1999b). The prevalence of cancer makes it a major health issue in the United States. The probability that a male will develop cancer in his lifetime is about 43% while the lifetime prevalence for women is 38.1% (Ries, Kosary, Hankey, Miller, Clegg, & Edwards, 2001). Estimated new cancer cases for 1999 were over 1.2 million (Ries et al.).

In the last twenty-five years, there has been a trend toward more patients being treated on an outpatient basis or in the home—mostly in an effort to decrease the costs of care (Hileman, Lackey, & Hassanein, 1992; Oberst, Gass, & Ward, 1989). Although cost effective, the increased reliance on family members to provide care exposes them to high levels of chronic stress—contributing to both physical and psychological morbidity in the caregiver. Although it is widely acknowledged that cancer diagnosis can be a stressor for the patient (e.g., Harrison, Haddad, & Maguire, 1995; Kurtz, Given, Kurtz, & Given, 1994) it must be recognized as a source of stress and burden for the caregiver as well (e.g., Chan & Chang, 1999; Chwalisz, 1996; Northouse, Templin, Mood & Oberst 1998;
Weitzner, Jacobsen, Wagner, Friedland & Cox, 1999; Weitzner, McMillan, & Jacobsen, 1999). It is imperative that health care providers understand the factors contributing to poor health outcomes in caregivers of cancer patients and have knowledge of the informational, support, and coping assistance needs of this population (Harrington & Gates, 1996; Hileman et al.).

The impact of caring is physical, emotional, financial and social, is often considerable, and may be negative (Hudson, Aranda, & McMurray, 2002). Caregiver burden is defined as the negative consequences of the activities involved with providing necessary direct care to a relative or friend that result in observable and perceived costs to the caregiver (Nijboer et al., 1999b). Research suggests that caregivers who report a larger amount of burden are at higher risk for negative health sequelae (e.g., Chwalisz, 1996; Nijboer et al.; Weitzner et al., 1999; Given & Given, 1992). It has been reported that 30 to 48% of family caregivers will experience significant psychological distress as a result of their role (Harrison et al., 1995; Hinds, 1985). Furthermore, caregivers may be at even greater risk for psychological distress than the patients for whom they care (Axelsson, & Sjoden, 1998; Baider, Koch, Esacson, & De-Nour, 1997; Baider, Walach, Perry, & Kaplan De-Nour, 1998).

The increased costs of health care, the emphasis on outpatient care, and the resultant increased demand for informal caregiving make it imperative that health care providers understand the impact of caregiving and how best to assist caregivers and positively influence caregiving outcomes (Swanson, Jensen, Specht, Johnson, & Maas, 1997). Since the spouse plays a central role in the well-being of the patient receiving treatment for cancer, it is important to attend to their caregiving experience. However,
the needs of the caregiver are often overlooked in favor of concerns about the patient’s needs (Hudson, 2003). More research is needed to identify which factors may be important when assessing partners’ needs and developing interventions to improve quality of life of both patients and partners.

While most researchers will agree that caregiving is a multidimensional construct, many continue to examine only the ‘multiple dimensions’ of the negative aspects while ignoring the positive aspects of caregiving (Kramer, 1997a; Morano, 2001). However, several studies have demonstrated the presence and benefits of the positive aspects of caregiving. How well-prepared the caregiver feels, the level of caregiving self-esteem, or how well he or she feels about the situation have been shown to be positively related to improved outcomes in caregivers of cancer patients (Given, Given, Stommel et al., 1992; Kurtz, Kurtz, Given & Given, 1995; Nijober et al., 1999a). Thus, if one is to examine caregiving from a holistic perspective, both positive and negative appraisals of caregiving need to be addressed.

Similarly, there is a need for more studies on the biophysiological sequelae of caregiving to gain a more holistic understanding of this complex phenomenon. The central nervous system, the endocrine system, and the immune system all participate in the response to transient, repeated, and chronic psychological stress and therefore, physical health may be changed as a result of the caregiving experience (Hansen-Grant, Pariante, Kalin, & Miller, 1998). Further, otherwise healthy individuals have been shown to have adverse physiological sequelae from exposure to acute and chronic stress (e.g., Kiecolt-Glaser & Glaser, 1992; Kiecolt-Glaser, Newton, Cacioppo, et al., 1996). In relatively healthy caregivers, measures thought to be more objective for health status—
such as utilization of mental and physical health services—may not address this factor. Because of this, physiologic measures of stress and health should be compared with these other measures. By measuring a physiological indicator of stress or immune function that is closely related to health, we can improve the richness of the measurement of constructs related to caregiver stress and health. This can easily be accomplished by including simple yet precise measures of the physiologic stress and immune response.

Finally, by examining stress from a biobehavioral perspective, one can better identify possible areas for intervention. A few studies have examined the impact of caregiving on the caregiver's physiologic health (e.g., Kiecolt-Glaser & Glaser, 1994). Illness-specific investigations of caregiving have been largely focused on caregivers of patients with cognitive disorders, stroke, and traumatic brain injury. There is a much smaller body of research on caregivers of cancer patients, particularly in younger caregiver-patient dyads.

The purpose of this research was to test the feasibility of a methodology for studying relationships among contextual, intervening, and outcome variables related to stress and health outcomes in spouses of patients with cancer. A second aim was to collect preliminary data for future research in this area.

Literature Review

Definition of Caregiving

An informal caregiver is an unpaid person, usually a family member, who helps the patient with physical care and/or with coping with the illness (Hileman et al., 1992). This arrangement often requires the caregiver to place the needs of the patient ahead of his or her own needs (Jones, 1996). Similarly, Pearlin, Mullan, Semple and Skaff defined
informal caregiving as "activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves" (1990, p. 583). Many studies document the negative biopsychosocial effects associated with providing care for an ill relative or friend (e.g., Bakas, Lewis, & Parsons, 2001; Hudson, Aranda, & McMurray, 2002). There is some sort of expectation that the caregiver should provide care to the individual who is sick, care is given without compensation or pay, and there are observable and perceived costs to the caregiver from providing care (Hunt, 2003). There are present chronic, repeated stressors as a result of the needed care that lead to increased role expectations of the caregiver. Also, there is a transaction between the environment and the individual which influences the caregiver's evaluation of the caregiving situation and subsequent outcomes. Consequences of caregiving include any temporary or permanent conditions that arise from exposure to the role, such as a change in physical, psychological, and social functioning in the caregiver (Hunt).

Young Adults as Cancer Caregivers

Over 20% of incident cancer diagnoses occur in the 20-54 year-old age group, and cancer is among the leading causes of death for men and women within these ages (Murphy, 1998; Ries et al., 2001). Cancer incidence is substantial in the 35-54 year-old age group with a 17.6% incidence rate (Ries et al., 2001). This is an age cohort with a high likelihood of having minor children at the time of diagnosis. It is possible that the ages of children may be positively or negatively associated with the amount of family assistance received and the amount of competing stress endured by the caregiver (Stommel & Kingry, 1991). Much of the research on caregiving examines caregivers of older adults and focuses on caregiver emotional responses while neglecting other aspects.
of the impact of caregiving (Nijboer, Triemstra, Tempelaar et al., 1999b; Schulz, Visintainer, & Williamson, 1990). Harrison et al. (1995) reported a 48% psychological morbidity rate for depression and anxiety in their mixed-age sample of cancer caregivers. This rate was as high as 58% for caregivers in the 18 to 39 year-old age group. While research has improved knowledge in the area of caregiver burden in general, more studies on the multidimensional aspects of caregiving in younger adults are needed to gain a more complete picture of the dynamics of the role of caregiving for a spouse with cancer.

**Caregiver Stress and Appraisal**

Cohen and colleagues defined perceived stress as, “the degree to which situations in one’s life are appraised as stressful” (Cohen, Kamarck, & Mermelstein, 1983, p.387). Nolan and colleagues (1990) define caregiver stress as the result of a cognitive imbalance between the perceived nature of the demand and the perceived capabilities of the individual. This definition is based on a transactional view of stress as put forth by Lazarus and Folkman (1984). From the transactional perspective, stress is a process rather than merely a response to an environmental stimulus. This definition of stress emphasizes a relationship between the person, his or her characteristics, and the environmental event presented. The authors define psychological stress as, “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p.19). From this perspective it is the subjective or perceived stress that is important rather than the actual stressor.

The concept of caregiver appraisal is related to that of caregiver stress in that appraisal is part of the transaction between the individual and the environment (Lazarus
& Folkman, 1984). Caregiver appraisal may refer to the estimate of the amount or significance of caregiving by the caregiver. Oberst, et al. (1989) defined appraisal as the caregiver’s assessment of both the nature of the stressor and his or her resources for coping with it. Caregiving appraisal may be positive, negative, or neutral (Kinsella, Cooper, Picton, & Murtagh, 1998) and consists of subjective cognitive and affective appraisals of the potential stressor and the efficacy of one’s coping efforts (Lawton et al., 1989).

Caregiving and Gender

As many as 27% of caregivers are male. However, many studies used small samples of male caregivers or did not examine gender effects. Several studies have documented that female caregivers experience greater burden or more psychological distress than male caregivers (e.g., Hagedorn, Buunk, Kuijer et al., 2000; Langer, Abrams, and Syrjala, 2003; Northouse, Mood, Templin et al., 2000). Men have shown fewer depressive symptoms and rated their everyday caregiving experiences more favorably than women (Wallsten, 2000). Conversely, other researchers have found male caregivers experiencing more strain or greater burden than females (Gilbar, 1999; Schumacher, Dodd, & Paul, 1993). Morse and Fife (1998) found no differences in adjustment to cancer based on the gender of the partner in their multivariate analysis, but found that female partners experienced more psychological distress than males. Baider, Perry, Holland and colleagues (1995) found that female spouses of melanoma patients managed distress better than did male spouses. The authors suggest that women receive and use more types of social support than men, and are more likely to mobilize their social support networks in times of need.
One qualitative study explored reciprocity in relationships of 22 male caregivers of cognitively impaired older adults and suggested that when reciprocity was absent, men described giving care as an obligation and were more likely to have negative feelings about the role (Neufeld & Harrison, 1998). Many men who said they provided care because of obligation also stated feeling burdened, stressed, angry, alone, and frustrated. Women tend to be more emotionally connected in relationships than are men and may focus more on the emotional aspects of caregiving than do men, who tend to be more task-oriented (McFarland, & Saunders, 1999). Further, when men are caregivers, they are less likely to help their wives with traditionally “female” tasks, and when they do help with these, are more likely to have help from others, while female caregivers are less likely to have help (Allen, 1994). Compared to men, women are more likely to be the primary caregiver, to provide more intensive and complex care, to have more difficulty balancing care with other family and employment responsibilities, and to suffer from poorer emotional health secondary to caregiving (Navaie-Waliser, Spriggs, & Feldman, 2002). Langer, Abrams, and Syrjala (2003) found that female caregivers of patients receiving hematopoietic stem cell transplant were more depressed and anxious than males. The authors suggest that female caregiving activities are more “expected” and are thus less recognized as outside societal norms than when men are caregivers. In fact, men may have fewer caregiving responsibilities or a shorter duration of provision of caregiving because of an increased likelihood of the female patient doing more of the home responsibilities, or her mother will often step in to help. This finding has been reported by others as well (e.g., Navaie-Waliser et al., 2002).
Caregiving and Family Developmental Stage

Families, like individuals, go through stages of development (Duvall, 1977). Depending on the developmental stage, the effects of cancer on family dynamics may vary. For example, based on Duvall’s conceptualization of family life cycle, the capacity to maintain normalcy in family routines may be more important for young families than for middle families where degree of independence of the children and flexibility in reallocating roles and responsibilities may be more important (Barsevick, Much, & Sweeney, 2000). One of the main concerns cited by spousal cancer caregivers is management of the disruptions of life caused by the disease (Northouse & Peters-Golden, 1993). Spousal caregivers with families may have to take on more household and work responsibilities while managing altered schedules for work, child-care, domestic, and social activities. Therefore, family developmental stage is examined in this research in order to better understand the effects of caregiving in younger caregivers with families.

Mediating Processes

According to the Transactional Model of Stress and Coping, the interaction between the individual’s appraisals and the environment helps determine the level of stress experienced (Lazarus & Folkman, 1984). In the context of caregiving, subjective burden refers to the caregiver’s positive or negative appraisals of caregiving or the stress perceived by the caregiver. Perceived stress, social support, positive caregiver esteem and coping may mediate the effects of external stressors thereby influencing health outcomes.

Perceived stress. The definition of stress posed in the 1984 work by Lazarus and Folkman emphasizes a relationship between the person, his or her characteristics, and the
environmental event presented. The authors define psychological stress as, ‘a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being’ (p.19).

Cohen and colleagues defined perceived stress as, ‘the degree to which situations in one’s life are appraised as stressful’ (Cohen, Kamarck, & Mermelstein, 1983, p.387).

Perceived stress from tasks may affect the individual’s effective use of mediators such as coping or may decrease the positive esteem of the caregiver (Nijboer, Triemstra, Tempelaar et al., 1998). Thus, it will be useful to examine relationships among stress, appraisal, and health in this sample of caregivers.

**Social support.** Social support has been shown to decrease perceived stress and to improve health outcomes in caregivers (e.g., Chwalisz, 1996). In fact, a possible reason for the increased distress in caregivers (over patients) is that the patient has many individuals focusing on his or her needs, and the caregiver, while providing extensive support, may receive little support in return (Langer, Abrams, and Syrjala, 2003). Results of a recent qualitative study of family caregivers of patients receiving terminal palliative care at home suggest that support from both formal and informal sources is inadequate (Proot, Abu-Saad, Crebolder, Goldsteen, Luker & Widdershoven, 2003). The authors describe a phenomenon where the level of partnership between married couples decreases over time, requiring the partner (caregiver) to have to search for other people with whom to spend time or do things with, and from whom to seek emotional support. They also reported cases where caregivers experienced lack of support from family or friends when attention is paid only to the patient and no one inquires about the problems of the caregiver.
Although research has shown that, in general, social support can positively influence outcomes, its impact can vary depending on such factors as timing, type, and perception. For example, while greater amounts of instrumental support may be effective in reducing burden for caregivers of cognitively impaired family members, it may actually exacerbate burden in caregivers of patients who are cognitively alert (Bass, Tausig, & Noelker, 1988). One study examined the effects of the presence of minor children on received support in spousal caregivers of oncology patients (Stommel & Kingry, 1991). The authors concluded that the presence of minor children was associated with more received support from family members. It is possible that, although the quantity of family help was higher in families with small children, the effects of the support may or may not have been positive because the presence of family support does not always ease burden related to caregiving or increase coping effectiveness (Brennan, 2001; Nijboer, Tempelaar, Triemstra et al., 2001). In a study of immune response in caregivers of Alzheimer’s patients, caregivers with poorer immune response reported less social support and less positive social support, as well as more physician visits for infectious illness symptoms when compared with those who were high immune responders (Esterling, Kiecolt-Glaser, Bodnar et al., 1994). In a multi-step, multivariate analysis, Morse and Fife (1998) found that support from family members was the most important variable explaining the largest percentage of the variance in adjustment to cancer in spouses of cancer patients. The present study examines social support from family as a potential intervening variable between caregiving context and health outcomes of the caregiver.
Caregiver esteem. The positive appraisals of the caregiver concerning his or her abilities, or of the caregiving situation in general, have been proposed as a mediator of caregiving outcomes. For example, how well-prepared the caregiver feels, the level of caregiving esteem, how well he or she feels about the situation, and the ability to attribute meaning to the situation have been shown to be positively related with improved outcomes in caregivers (Given et al., 1992; Nijboer et al., 1999a; Nijboer et al., 2001). Caregiver esteem is the extent to which performing caregiving informs the caregiver’s self esteem, or the confidence or satisfaction the caregiver derives as a direct result of caregiving. Given and colleagues found that caregiver esteem was inversely related to depression in samples of caregivers of both the elderly and cancer patients. Nijboer and colleagues found that caregivers with high levels of caregiver self-esteem reported the lowest levels of depression. These samples included mixed caregiving contexts (i.e., not limited to spouse caregivers, included wide age ranges, patients with conditions other than cancer, etc.) and therefore, may not generalize to the specific context of cancer caregiving in young families.

Coping. Coping is defined as, ‘Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus & Folkman, 1984, p. 178). Problem-focused coping aims to manage or alter the problem while emotion-focused coping aims to address the person’s emotional response to the problem. Emotion-focused strategies may be best when the stressor is not changeable, and tends to be associated with poorer health outcomes (e.g., Folkman & Moskowitz, 2000; Lerman & Glanz, 1997). Problem-focused strategies may work best when the stressor is changeable, and the person can
focus attention on tasks, or generate a sense of mastery, positive esteem, or control (Folkman & Moskowitz, 2000). Active coping may be detrimental in cases where the partner can do little to influence the course of the illness (Morse & Fife, 1998). In such cases, attempting to influence it could cause increased distress. The ability to control emotional distress and to maintain a positive cognitive response may be particularly important to caregivers who have little control over the outcome of the illness. In a large sample of adults ages 18 to 65, Cobb and Steptoe (1996) found that the impact of stressful events on health outcomes—namely, susceptibility to upper respiratory infection—was buffered by avoidant coping style. Findings from another study suggested that escape-avoidance coping was the most significant predictor of immune changes in a sample of family members of patients undergoing BMT (Futterman, Wellisch, Zighelboim et al., 1996). In particular, less escape-avoidance coping was correlated with better immune functioning (higher T cell and CD4+ cells).

**Health Outcomes of Caregiving**

Exposure to the chronic stressors of caregiving places family members at risk for poor health outcomes (Weitzner et al., 1999). The central nervous system, the endocrine system, and the immune system all participate in the response to transient, repeated, and chronic psychological stress and therefore, physical health may be changed as a result of caregiver appraisal (Hansen-Grant et al., 1998). Distress from negative appraisals of the caregiver may result in the inability of the caregiver to continue caring for the patient--therefore a change in social functioning of the caregiver (Weitzner, et al., 1999). There has been conflicting evidence about the effects of caregiving on health, which could be due to several factors (Schulz, Visintainer, & Williamson, 1990). Although valuable in
assessing perceived health, self-report measures alone may be inadequate for assessing health status in caregivers. Caregivers may tend to underreport problems both out of denial and out of a lack of awareness of the effects of caregiving on their mental and physical health (Dura & Kiecolt-Glaser, 1990; Robinson & Austin, 1998). In addition, some measures of mental health may not be sensitive enough to detect risk for psychological morbidity in relatively healthy caregiving subjects (Schulz et al., 1990).

*Definition of health.* Health may be defined as a state characterized by soundness of physical and mental functioning, including physical, psychological, and social aspects (Orem, 1971). The World Health Organization (WHO) defines health as, ‘a state of complete physical, mental, or social well-being and not merely the absence of disease or infirmity’ (2001). Mental health is not only the absence of mental illness, but also the adjustment of an individual to his or her environment such that he or she is comfortable with his or her life situation, while being able to live in such a way that his or her behavior is not in conflict with one’s associates or with society (Thomas, 1993). Further, mental health subsumes such constructs as emotional symptoms, personal self-esteem, and cognition (Parkerson, Broadhead & Tse, 1991). Physical health encompasses the more objective physiological aspects of well-being—including both illness and wellness. Physical health includes the constructs somatic symptoms and ambulation. Social health consists of self-concept regarding personal relationships and the quantity of social activities an individual is involved in. General (overall) health status, based on the WHO definition of health includes the constructs mental, physical and social health (Parkerson et al.) It is this construct, general health status, which is examined in this study.
Physiologic indicators of health. Physiologic stress may be defined as the physiologic response pattern in response to a stimulus that includes an alarm phase, physiologic resistance to deter damage, followed by either adaptation or exhaustion (Selye, 1956). In humans, cortisol is the principal glucocorticoid released from the adrenal cortex (Benschop, & Schedlowski, 1999; Carlson, 2001; Nelson, 2000; Sapolsky, 1992; Tewes, 1999). Cortisol secretion displays a marked diurnal pattern with highest concentrations early in the morning (just after awakening), moderate levels in the mid-afternoon, and low levels at the end of the day (van Eck & Nicholson, 1994). Further, individuals with high levels of perceived stress and trait anxiety show elevated cortisol levels throughout the day when compared with individuals with low stress and anxiety (van Eck & Nicholson). Cortisol is a physiological measure that can be easily obtained from saliva. An individual’s health may be affected by prolonged stress because increased cortisol levels decrease the body’s immune response by decreasing antibody formation, preventing release of inflammatory mediators, inhibiting the development of T-lymphocytes, and other actions (Ader, 2001; Hansen-Grant et al., 1998). Various physical and psychological stressors can increase cortisol levels. In general, cortisol enhances physiological adaptation to stress and therefore serves an adaptive function. However chronic high levels of cortisol can be maladaptive. One function of cortisol is to prevent excessive immune system activation in a crisis, and there is evidence that cortisol levels rise in response to increased immune activity, possibly to exercise some control over it (van Eck & Nicholson, 1994).

Immune function is the body’s recognition of and reaction to foreign or non-self antigens with the purpose of neutralizing or eliminating any threat they may cause the
host (Thomas, 1989). Findings of a recent prospective study of the effects of an intervention involving therapeutic back massage on both psychophysiological variables and immune function showed significant inverse relationships between natural killer cell activity and both mood and perceived stress (Goodfellow, 2003). Esterling, Kiecolt-Glaser, Bodnar et al. (1994) reported that both current and recently-bereaved caregivers of Alzheimer’s patients did not differ in NK cell response and had a significantly poorer response than non-caregiving controls. In addition, caregivers with poorer immune response reported less social support and less positive social support, as well as more physician visits for infectious illness symptoms when compared with those who were high immune responders. The authors suggest that the finding that past caregivers responded similarly to current caregivers may mean that chronic stress could have long-term consequences for the caregiver. Also, psychological stressors may contribute to increased susceptibility to infectious illness via reduction of both cytokine production, and the body’s ability to use available cytokines.

One measure of the effects of stress on immune function is salivary secretory Immunoglobulin A (sIgA; Hucklebridge, Clow, & Evans, 1998; Sanchez-Martin, Cardas, Ahedo, Fano, et al., 2001). Secretory IgA is the predominant immunoglobulin found in mucosal secretions and is considered part of the body’s first line of defense against infection (Sanchez-Martin et al.). Several studies have documented a link between stress, emotion, and sIgA levels (e.g., Deinzer & Schuller, 1998). Individuals who react highly to stress will show higher cortisol levels and may have long-term immune system effects such as decreased sIgA levels (Deinzer & Schuller; Hucklebridge, Clow,
Evans, 1998; Kiecolt-Glaser & Glaser, 1995). Further, sIgA secretion has been found to be lower in high-stress situations than in low stress situations (Deinzer & Schuller, 1998).

Specific Aims

The aims of this pilot work are:

1. To test the feasibility of a methodology for studying relationships among demographic variables, coping, perceived stress, social support, caregiver esteem, and health outcomes in a sample of young spousal caregivers who are also parents of dependent children.

2. To collect preliminary data to guide future research.

Theoretical Framework

By combining aspects of the Transactional Stress (Lazarus and Folkman, 1984) model and Psychoneuroimmunology (Ader, 2001), a model is proposed with which to study antecedent, intervening, and outcome variables related to stress and health in young spousal cancer caregivers. The contextual antecedents for this study included gender, family developmental stage, income, and occupational status. Intervening processes included perceived stress, social support, caregiver esteem, and coping. Proposed outcome variables are self-reported health status, physiologic stress response, and immune function. (Figure 4.1).
Research Design and Methods

Design. A descriptive, cross-sectional, correlational design was used to test the feasibility of a methodology for studying relationships among contextual, intervening, and outcome variables related to stress and health outcomes in spouses of patients with cancer. A second aim was to collect preliminary data for future research in this area.

Subjects and setting. The convenience sample consisted of spouses of patients with cancer diagnosed within the previous year. Included were spouses of patients with a non-recurrent diagnosis of cancer who were non-terminal (life expectancy > 6 months). The couples were all parents with at least one dependent child, and spousal caregiving was informal (unpaid).
Measures

Demographic questionnaire. Demographic data were collected on a written questionnaire and included: age of caregiver and patient, caregiver gender, ages and number of children, household income, race, caregiver's previous health history, years of education, occupational status, and spouse’s cancer site. Subject gender and family developmental stage were determined by self-report using this questionnaire. Family developmental stage was categorized by collapsing Duvall’s (1977) four categories of families with minor children into three categories: very young families (couple with infant and/or preschool children), young families (couple with school-age children), and middle families (those with adolescent children), and by adding a fourth category for families with non-minor (over 18) but still-dependent children. Families were categorized by the age of the oldest child. A summary of the measures used and their conceptual definitions is presented in Table 4.1 (page 81).

Perceived stress. Perceived stress was operationalized as the total score on the 10-item Perceived Stress Scale (PSS), a measure of the degree to which situations in one’s life during the past month are appraised as stressful (Cohen, Kamarck, & Mermelstein, 1983). Items consist of a 5-point Likert scale ranging from 0= “never” to 4= "very often”. Sample items include, “In the last month, how often have you felt that you were unable to control the important things in your life?” and, “In the last month, how often have you felt that things were going your way?” (Cohen et al., 1983, pp.394-95). Scores are reversed for seven of the items and then summed across the 14 items and can range from 0 to 40 with higher scores indicating higher perceived stress (Cohen et al.). The PSS can be administered in only a few minutes and is easy to score.
The PSS has been shown to be a reliable and valid measure of perceived stress in various samples with coefficient α reliabilities from 0.84 to 0.86 for these samples (Cohen, et al., 1983). A major rationale for using the PSS is the availability of normative data. The authors report norms for five age categories with means ranging from 18.3 to 21.1 and SD’s ranging from 7.1 to 8.1. Test-retest reliabilities of .85 and .55 were reported for test occasions of two days and six weeks apart respectively (Cohen, et al., 1983). The lower reliability at six weeks is expected due to the “state” nature of perceived stress. In all three original samples, the PSS showed small to moderate correlations (.20, .17, and .38; p<.01) with a measure of the number of life events. These correlations significantly increased (as expected) when the life events scale scores were weighted to account for the respondents’ perceptions of the impact of the events (.33, .24, and .49 respectively). Predictive validity was assessed by comparison with scores from a depressive symptomatology scale. Correlations of .76 and .65 (p<.001) were found for two student samples. The authors cite evidence through partial correlations that although these are high correlations, the PSS measures a different and independently predictive construct than depressive symptomatology. However, they state that the correlation between the PSS and depressive symptoms may by somewhat inflated by the similarity in the operational definitions of the two constructs. Predictive validity also was evidenced by significant correlation between PSS scores and changes in health center utilization. Further, the PSS was a valid predictor of social anxiety in the student samples. Divergent validity was assessed by comparing PSS scores with measures of life satisfaction (Cohen & Williamson, 1987). These measures were inversely related (high PSS scores correlated with reports of increased dissatisfaction), as expected, with r = .47 (p<.0001).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Definition</th>
<th>Instrument</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male or Female</td>
<td>Study specific Demographic Questionnaire</td>
<td>N/A</td>
</tr>
<tr>
<td>Family Devel. Stage</td>
<td>Infants/preschool; school age; adolescent; young adult.</td>
<td>Study Specific Demographic Questionnaire</td>
<td>Duvall, 1977</td>
</tr>
<tr>
<td>Coping</td>
<td>Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person</td>
<td>Ways of Coping Questionnaire (WAYS). <em>Eight subscales:</em> confrontive coping, distancing, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal.</td>
<td>Folkman &amp; Lazarus, 1988</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>A particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being</td>
<td>Perceived Stress Scale</td>
<td>Cohen, Kamarck, &amp; Mermelstein, 1983</td>
</tr>
<tr>
<td>Caregiver Esteem</td>
<td>The positive appraisals of the caregiver concerning his or her abilities, or of the caregiving situation in general</td>
<td>Caregiver Reaction Assessment</td>
<td>Given &amp; Given, 1992</td>
</tr>
<tr>
<td>Lack of Family Support</td>
<td>Perceived lack of social, emotional, or practical support from immediate or extended family.</td>
<td>Caregiver Reaction Assessment</td>
<td>Given &amp; Given, 1992</td>
</tr>
<tr>
<td>Perceived Health</td>
<td>General (overall) health status, based on the WHO definition of health includes the constructs mental, physical and social health</td>
<td>DUKE Health Profile</td>
<td>Parkerson et al., 1990</td>
</tr>
<tr>
<td>Physiologic Stress</td>
<td>Salivary cortisol level (ug/dL).</td>
<td>ELISA</td>
<td>Salimetrics State College, PA</td>
</tr>
<tr>
<td>Immune Function</td>
<td>Salivary secretory IgA (ug/mL)</td>
<td>ELISA</td>
<td>Salimetrics State College, PA</td>
</tr>
</tbody>
</table>

Table 4.1: Measures and their conceptual and operational definitions.
Social support. The Caregiver Reaction Assessment (CRA; Given et al., 1992) is a 24-item instrument that can be used to assess both positive and negative appraisals of the caregiving experience. The CRA consists of five subscales that assess caregiver appraisals in each of these domains: disrupted schedule, financial problems, social support from family, health problems, and caregiver self-esteem. The CRA family support subscale was used to assess social support from family (five items). All items on the scale are answered using a 5-point Likert scale from 1= "strongly disagree", to 5= "strongly agree". High scores on each subscale indicate negative reactions to caregiving except for the caregiver esteem subscale where higher scores indicate a positive reaction. The instrument can be completed in less than 10 minutes (Nijboer et al., 1999a). Internal consistency, and construct validity have been reported and are adequate with Cronbach’s \( \alpha \) coefficients from 0.80-0.90. Further, the CRA has been widely used with partners of cancer patients and exhibits factorial invariance across different types of caregivers (e.g., Nijboer et al., 1999a).

The social support subscale contains five items and assesses the extent to which the family supports and works with the caregiver (Given et al., 1992). Sample items include, ‘My family works together at caring for (my spouse)” (reversed), and ‘Others have dumped caring for (my spouse) onto me”. Alpha coefficients for internal consistency of the subscale ranged from 0.68 to 0.85 (Given et al., 1992; Nijboer et al., 1999a). Higher scores represent a greater lack of family support.

Caregiver esteem. Caregiver esteem was measured using the caregiver esteem subscale (seven items) of the CRA (above; Given et al.). The subscale is designed to measure the extent to which the caregiver derives self-esteem from caregiving. Sample
items are, ‘Caring is important to me”, and ‘I resent having to care for (my spouse)” (reversed; 1992, p. 276). Cronbach’s alpha reliabilities range from 0.73 to 0.90 for the esteem subscale (Given et al., 1992; Nijboer et al., 1999a). Higher scores on the subscale represent higher positive caregiver esteem.

*Coping.* Coping was assessed using the Ways of Coping Questionnaire (WCQ; Lazarus & Folkman, 1984). This is a 66-item questionnaire designed to assess coping strategies used in coping with demands resulting from a specific stressful situation. The measure uses a 4-point Likert scale ranging from 0= "does not apply/not used", to 3="usedagreatdeal". Cronbach’s α reliability ranges from 0.70 to 0.80. The WCQ has been validated with various samples such as cancer patients, and spouses of patients with Alzheimer’s disease. The WCQ measures coping processes, not coping styles (Folkman & Lazarus, 1988). Sample items include, “Stood my ground and fought for what I wanted”, and “I tried to keep my feelings to myself” (p. 31). Items on the WCQ fall into eight subscales: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. For conceptual definitions of each subscale, the reader is referred to Lazarus and Folkman (1998, p. 11).

*Health status.* Health status was measured using the general health score of the Duke Health Profile (DUKE; Parkerson et al., 1990). The 17-item DUKE was developed from an earlier instrument, the 63-item Duke-UNC Health Profile (DUHP; Parkerson, Gehlbach, Wagner et al., 1981). The DUKE was developed based on the WHO definition of health to include physical, mental, and social health dimensions (Parkerson et al., 1990). The instrument contains several subscales including physical health, mental
health, and social health, from which a general health score can be obtained. Physical health is measured with five items related to physical capacity for ambulation and physical symptoms. Sample items include, “Today would you have any physical trouble or difficulty walking up a flight of stairs?” and “During the past week, how much trouble have you had with getting tired easily?” (Parkerson, Broadhead, & Tse, 1991, p. 398). Mental health is measured with five items concerned with psychological symptoms, cognition, and personal self-esteem. Questions include, ‘I like who I am’, and ‘I have difficulty concentrating” (p.385). The social health subscale consists of five items related to participation in social activities and to social self-esteem. Sample items are, ‘I am not an easy person to get along with” and ‘During the past week, how often did you socialize with other people?’ (p. 385). Answers are given to 3-point Likert scales with responses ranging from 0= ”No, doesn’t describe me at all” to 2= ”yes, describes me exactly”, with some items reversed. Other questions use a 3-point Likert scale ranging from 0= ”A Lot” to 2= ”None”. Scores are summed and multiplied by 10 for each subscale to obtain scores ranging from 0 to 100 for each subscale. The combined general health subscale measures overall health by averaging the scores from the physical, mental, and social health subscales. The result is a self-report of symptoms, concepts, and capacity to perform that indicates health status in the positive sense of well-being (Parkerson et al., 1990). For each subscale and general health, a score of 100 indicates the best health status and zero the worst.

Alpha reliabilities range from 0.55 to 0.78 for the various subscales, with test-retest reliabilities ranging from 0.57 to 0.78 (Parkerson et al., 1990). However,
coefficient $\alpha$ and test-retest reliabilities were both adequate at 0.78 for the general health subscale, which combines scores from the physical, mental, and social health subscales.

Construct validity of the DUKE has been demonstrated by comparison of observed versus expected correlations with other health measures designed to elicit measurement of sickness-related dysfunction and depression. The Spearman rank-order correlation between the DUKE general health subscale and the Sickness Impact Profile (SIP; Gilson, Gilson, Berner et al., 1975) overall health score was acceptable at -0.70 (Parkerson et al., 1990). DUKE mental health scores compared with Zung depression scores (Zung 1965) produced a correlation of $r=-0.70$. DUKE scores were also compared for patients with either no known physical or mental health problems (i.e., being seen for health maintenance only), those with known physical health problems, and those with known mental health problems. As expected, those with no known health problems scored higher on all DUKE measures than those with physical or mental health problems, (Parkerson et al. 1990). Further, those with mental health problems scored lower on DUKE mental health, and those with physical health problems scored lower on DUKE physical health. Therefore, it appears that the DUKE is a valid and reliable instrument with which to assess health status in clinical and non-clinical samples.

**Physiologic stress and immune function.** Salivary cortisol and sIgA assays were used to assess the physiologic stress response and immune system function. This method is relatively inexpensive, non-invasive, safer than the collection and handling of blood samples, and is useful for collection outside of a clinical setting.

Physiologic stress was assessed by measuring salivary cortisol, which has been shown to correlate with unbound plasma levels with at $r=0.96$, $p<0.0001$ (Salimetrics,
Cortisol is excreted in a diurnal pattern and measurements may be affected by the pH of the sample, which is influenced by the consumption of food or drink (Edwards et al., 2001; Hucklebridge et al., 1998; Lovallo & Thomas, 2000; Salimetrics, Inc. 2001). Edwards and colleagues (2001) found that a single sample between three and twelve hours after awakening is relative to the mean cortisol produced throughout the day and is a reliable measure of background cortisol status when samples are synchronized to time of awakening. Therefore, one sample was collected from each subject at six hours post-awakening, and must occur at least one hour after the consumption of anything by mouth.

In addition, an early morning (post-awakening/peak) and a late evening (before bedtime/nadir) sample were collected to obtain an estimate of the overall cortisol secretion pattern for these subjects. Saliva was collected via passive drool into a salivette tube without cotton (Shirtcliff, Granger, Schwartz, & Curran, 2001). Samples were refrigerated and then centrifuged, divided into aliquots, and frozen at –80° until analyzed.

Cortisol level was analyzed by an Enzyme-linked Immunosorbent Assay (ELISA) kit (Salimetrics, State College, PA) designed specifically for salivary cortisol. The kit has a detection range of 0.007 to 1.80 ug/dl, with serum correlation of 0.96. Normals for saliva cortisol range from 0.1 ug/dL at the nadir (from late evening to early morning) to 1.8 ug/dL just prior to awakening (Lovallo & Thomas, 2000). The normal is expected to be between 0.6 and 0.8 ug/dL in the mid afternoon. The assay kit contains a built-in pH monitor, therefore allowing for exclusion of samples of high or low pH. Samples and standards are run in duplicate and optical density run on a microtiter plate reader (Bio Tek) at 450 nm using 590 nm as a reference. Sample concentrations were determined from the standards by a 4-parameter curve fit using Kinetic Calc software (BioTek).
Salivary IgA was measured by ELISA (Salimetrics, State College, PA) designed specifically for salivary sIgA. The kit has a minimum detection concentration of 2.5 ug/ml and the normal range of values is 90-900 ug/ml (Salimetrics, Inc. 2001). Sample collection, handling, and analysis procedures are similar to those for salivary cortisol (above). However, sample concentrations were determined from the standards by log-linear regression.

Procedures

Subjects were obtained in the outpatient chemotherapy and radiation oncology clinics at a large Midwestern university medical center affiliated with a large Comprehensive Cancer Center. Subjects were recruited directly by the investigator in the waiting and treatment rooms of the above outpatient areas. Potential subjects were approached by the investigator and asked to participate. A complete description of the study was provided verbally and in writing to subjects and informed consent and HIPAA authorization was obtained prior to data collection. Participants were told that their participation was not part of their spouse’s medical treatment and that refusal to participate would not alter their spouse’s treatment. As a token of appreciation for completing the study, subjects received $20.

Questionnaires and sample collection were completed at a site convenient for the subject (i.e., home, workplace, outpatient clinic). Saliva samples were collected immediately after awakening, six hours post-awakening, and immediately before bedtime. Participants were asked to complete questionnaires on the day after saliva samples were collected. Subjects were instructed to collect samples at least one hour after tooth-brushing, smoking, or consumption of anything by mouth to prevent
confounding of results due to microvascular bleeding or pH changes. Saliva was collected via passive drool into a salivette tube without cotton. Data collection required a total of less than one hour. Participants were given complete verbal and written instructions on how to provide saliva samples and how to fill out the questionnaires. Those who requested it were loaned a digital watch with an alarm to signal the 5-hour (one hour before sample collection) time when nothing may be taken by mouth and the 6-hour post-awakening saliva collection time (one hour later). A short questionnaire was included with the salivettes on which subjects were asked to record time of awakening, time of each sample collection, and time of last oral intake before giving the sample.

Subjects were instructed to refrigerate saliva samples after collection. The researcher collected refrigerated samples and transported them to the lab in an insulated cooler with a cold pack. Samples were centrifuged, divided into aliquots, and frozen at –80°C in the laboratory until analyzed. Samples and standards were run in duplicate to determine cortisol and sIgA levels. Optical density was read on a microtiter plate reader (BioTek) at 450 nm using 590 nm as a reference.

Data Analysis

The sample is described according to demographic characteristics with frequencies and percentages. The feasibility of the study methodology will be analyzed in the following manner:

1) Success of recruitment method is reported as frequencies and percentages of: patients screened; met age criterion, diagnosed < 1 year ago, married, had dependent children, spouse was contacted by investigator, spouse agreed to participate.

2) Participation of subjects was evaluated by presenting the following data in chart form:
percent of subjects who complied with data collection procedures: completion all forms.  

3) Procedures related to assays of samples were evaluated according to: time required to conduct assays; cost of assays; and, equipment and lab related issues. 

Relationships among selected contextual variables, mediating variables, and health were analyzed using SPSS 11.5 for Windows®. Pearson correlations were used for interval level variables, Spearman correlation for ordinal/interval variables, and eta correlation ratio for mixed level variables such as nominal and interval level variables. Appropriate data transformations were performed if necessary when the assumption of normality was not met. Correlation matrices among all variables were constructed. The size and direction of correlations were analyzed according to sample characteristics, theoretical expectations, and previous research. 

Results 

A total of 20 subjects were recruited. Seven subjects dropped out and thus the sample included 13 subjects. The sample was 61.5% female (8 females and 5 males). Mean age was 43.6 years (SD= 6.702), with a range from 34 to 53 years. Ten families had adolescents or young adult dependents (77%; Figure 4.2). Three had infants, preschool, or school age children (23%). Fifty-three percent had a household income over 40,000/year (Figure 4.3). Only one family (<8%) was earning less than 25,000/year. Three families (23%) earned over 70,000/year. This was a highly educated sample (Figure 4.4). Almost half of subjects (46.2%) had some college (n=6), and another 46.2% had bachelors (n=3), masters (n=2), or (n=1) doctoral degrees. All subjects had at
least a high school diploma. Almost half (46%) of spouses were working full-time (n=6; Figure 4.5). Another 4 were working at least half time but less than full-time (31%). The sample included 3 homemakers (23%).

Figure 4.2: Family Developmental Stage

Figure 4.3: Household Income
Figure 4.4: Education

Figure 4.5: Occupational Status
Recruitment and Subject Participation

A total of 977 patients were screened based on the following criteria: age 18 to 54 years; patient diagnosed with cancer less than one year ago; couple was married; couple had dependent children. Figure 4.6 illustrates the percentage meeting each inclusion criterion. Fifty-four spouses met all inclusion criteria (6%). Of these, 39 (72.2%) spouses were contacted, and 15 (27.8%) were unable to be contacted. Of the 39 spouses contacted, 20 (51%) consented to participate, 14 (36%) were contacted through the patient (i.e., advertisement given to patient to share with spouse), but did not respond, and 5 (13%) declined to participate (Figure 4.7). Thirteen of the 20 patients who agreed to participate completed data collection and returned all study materials.

Figure 4.6: Percent of spouses meeting each inclusion criterion.
Procedures related to Salivary Assays

Salivary cortisol and salivary secretory IgA assays were run in duplicate over a four day period (approximately 24 hours total time). Assay kits cost $140 each for cortisol plus $20 for cortisol controls; $270 each for sIgA; and Salivettes (Sartsedt) for sample collection cost $56.00 per 100. Thus, the total cost to include these assays was almost $900. Other necessary equipment and supplies included: several sizes of single and multi-channel precision pipettes, pipette tips, several disposable tubes, reagent reservoirs, many 12 x 75mm snap cap tubes, a vortex, plate rotator, microtiter plate reader, refrigerated centrifuge(s), and computer software for data reduction. Aside from the assay kits and reagents, the equipment and supplies used were available in the researcher’s college laboratory.

Table 4.2 presents the descriptive statistics for salivary cortisol and sIgA. Data presented are from the early morning samples as this timepoint had complete data, whereas many mid-day and evening samples were below the lower level of sensitivity for the assays. Data are reported for 12 subjects as one subject returned the saliva samples
after the assays were run, and it would not have been cost-effective to run the assay on only one subject’s samples. The mean morning sIgA level was 299.97 ug/ml (SD= 320.66 ug/ml), and the range was from 0.97 to 1033.0 ug/mL. A square root transformation was conducted on the raw sIgA scores to produce a distribution approximating normality. All analyses reported used the transformed sIgA data. The mean morning cortisol level for this sample was .9036 ug/dL (SD= .1825 ug/dL) and the range was from 0.52 to 1.22 ug/dL.

<table>
<thead>
<tr>
<th>Descriptive statistics for Cortisol and sIgA</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td>mean</td>
</tr>
<tr>
<td>median</td>
</tr>
<tr>
<td>std. deviation</td>
</tr>
<tr>
<td>minimum</td>
</tr>
<tr>
<td>maximum</td>
</tr>
</tbody>
</table>

Table 4.2: Descriptive statistics for saliva cortisol and sIgA.

**Relationships among Variables**

**Gender.** Gender had a positive relationship with general health (eta= .409). Women had lower general health scores than men (Figure 4.8). This relationship did not appear to be affected by coping process or perceived stress. No relationships existed between gender and either cortisol (eta= .109) or sIgA (eta=.090). See Table 4.3 for a summary of the correlations among demographic and outcome variables.
Figure 4.8: Relationship between gender and general health.

<table>
<thead>
<tr>
<th>Variable</th>
<th>General health</th>
<th>Cortisol</th>
<th>Sqrt sIgA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental stage</td>
<td>-.434*</td>
<td>0.282</td>
<td>-0.008</td>
</tr>
<tr>
<td>Income</td>
<td>.351*</td>
<td>.390*</td>
<td>.694**</td>
</tr>
<tr>
<td>Education</td>
<td>.455*</td>
<td>0.169</td>
<td>0.23</td>
</tr>
<tr>
<td>Occupational status</td>
<td>0.297</td>
<td>.548**</td>
<td>.750***</td>
</tr>
<tr>
<td>Gender</td>
<td>.394*</td>
<td>0.166</td>
<td>0.286</td>
</tr>
</tbody>
</table>

* small correlation (.30-.49)
** medium correlation (.50-.69)
*** large correlation (> .70)

Table 4.3: Relationships among demographic variables and outcomes.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Caregiver esteem</th>
<th>Lack of family support</th>
<th>Perceived stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental stage</td>
<td>rho= -.187</td>
<td>-0.098</td>
<td>-0.107</td>
</tr>
<tr>
<td>Income</td>
<td>rho= -.171</td>
<td>-0.271</td>
<td>-.445*</td>
</tr>
<tr>
<td>Education</td>
<td>rho= -.164</td>
<td>0.174</td>
<td>-0.053</td>
</tr>
<tr>
<td>Occupational status</td>
<td>eta= .621**</td>
<td>.477*</td>
<td>0.211</td>
</tr>
<tr>
<td>Gender</td>
<td>eta= .409**</td>
<td>0.105</td>
<td>0.09</td>
</tr>
</tbody>
</table>

* small correlation (.30-.49)
** medium correlation (.50-.69)
*** large correlation (> .70)

Table 4.4: Relationships among demographic variables, esteem, support and perceived stress.
**Developmental Stage.** No relationships existed between developmental stage and either cortisol (rho= .282) or sIgA (eta= -.008). However, developmental stage was negatively correlated with general health (rho = -.434). Thus, spouses at higher family developmental stages reported poorer general health. This may be an effect of higher age. Developmental stage had a low, positive correlation with distancing (rho= .403). Distancing is moderately correlated with poorer general health (r= -.570; Figure 4.9).

![Figure 4.9: Developmental Stage and Health](image)

**Income.** Income level was correlated with general health (rho= .351), salivary cortisol (rho= .390), and sIgA (rho= .694). Thus individuals with higher incomes reported better general health and had higher sIgA levels but, unexpectedly, also had higher cortisol levels than lower income individuals (Figure 4.10). The same relationship existed among Income, positive reappraisal and sIgA.
Figure 4.10: Relationships among income & positive reappraisal and cortisol & sIgA

Income was not correlated with distancing (rho= -.231), seeking social support (rho= .129), accepting responsibility (rho= -.258), or planful problem-solving (rho= -.259) types of coping, nor with a lack of family support (rho= -.271), or positive caregiver esteem (rho= -.171; Table 4.6). Income was associated with perceived stress (rho= -.445) with lower income individuals reporting higher perceived stress (Table 4.4).

Occupational status. Occupational status was operationalized as the number of hours worked outside the home, with full-time being coded as “1”, and zero hours as “5” with three levels in between (3/4 time, ½ time, less than half time). Therefore a positive correlation between occupational status and other variables indicates that the fewer hours worked outside the home the higher the value of the variable it is being correlated with.
No relationship existed between occupational status and general health.

Occupational status was positively correlated with both cortisol (rho = .548) and IgA (rho = .750; Figures 4.11 and 4.12). The fewer hours worked outside the home, the higher were both the cortisol and the sIgA level.
Further, occupational status was positively correlated with several of the potential intervening variables, all of which had a negative association with both cortisol and sIgA level (Figures 4.11 and 4.12). For example, spouses who worked the fewest hours were more likely to use distancing (eta= .404), seeking social support (eta= .549), planful problem solving (eta= .594), accepting responsibility (eta= .489), and positive reappraisal (eta= .609) as coping processes. In other words, working more hours outside the home was associated with less use of distancing, SSS, accepting responsibility, and positive reappraisal coping processes. Spouses working fewer hours were also more likely to perceive less support from family (eta= .477), while deriving higher caregiver esteem (eta= .621) than those who worked outside the home more.
Coping

Coping as measured by the WCQ falls into eight subscales (Tables 4.5 and 4.6). Escape-avoidance coping was negatively correlated with general health scores ($r = -.608$), regardless of developmental stage, occupational status, and gender. Seeking Social Support as a coping process was associated with lower cortisol levels ($r = -.516$), and the relationship appears to be independent of developmental stage, income, and gender. Accepting responsibility was associated with lower general health ($r = -.384$), independently of developmental stage, income, and gender. Planful problem solving was associated with lower general health ($r = -.314$) and lower cortisol ($r = -.651$). These relationships appear to be independent of developmental stage, income, and gender. Distancing as a coping mechanism is associated with both lower general health ($r = -.570$) and lower sIgA ($r = -.333$). This appears to be true regardless of income level and gender. Positive reappraisal was associated with lower cortisol ($r = -.682$) and lower IgA ($r = -.511$). These relationships appear to be true regardless of developmental stage.
<table>
<thead>
<tr>
<th>Variable</th>
<th>General health</th>
<th>Cortisol</th>
<th>Sqrt sIgA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontive coping</td>
<td>0.042</td>
<td>-0.229</td>
<td>-0.29</td>
</tr>
<tr>
<td>Distancing</td>
<td>-.570**</td>
<td>-0.238</td>
<td>-.333*</td>
</tr>
<tr>
<td>Self controlling</td>
<td>0.211</td>
<td>0.167</td>
<td>0.206</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>0.27</td>
<td>-.516**</td>
<td>-.315*</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>-.384*</td>
<td>-0.134</td>
<td>-.324*</td>
</tr>
<tr>
<td>Escape/avoidance</td>
<td>-.608**</td>
<td>-0.21</td>
<td>-0.164</td>
</tr>
<tr>
<td>Planful problem solving</td>
<td>-.314*</td>
<td>-.651**</td>
<td>-0.295</td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>0.251</td>
<td>-.682**</td>
<td>-.511**</td>
</tr>
</tbody>
</table>

* small correlation (.30-.49)
** medium correlation (.50-.69)
*** large correlation (> .70)

Table 4.5: Coping Processes and outcome variables

Confrontive coping was not associated with general health (rho = .042), cortisol (rho = .282), or sIgA (rho = -.008). Similarly, self controlling was not associated with general health (rho = .211), cortisol (rho = .167), or sIgA (rho = .206). Distancing and accepting responsibility were not associated with cortisol level (rho = -.238 and -.134, respectively). Escape-avoidance was not associated with either cortisol (rho = -.210) or sIgA (-.164).
Esteem

While positive caregiver esteem was not associated with general health ($r = .093$) or sIgA ($r = -.056$), it is associated with lower cortisol levels ($r = -.487$), and this relationship appears to be independent of developmental stage, income, and gender (Table 4.7). Also, spouses working fewer hours were more likely to have higher caregiver esteem ($\eta = .621$) than those who worked outside the home more.

<table>
<thead>
<tr>
<th>Variable</th>
<th>General health</th>
<th>Cortisol</th>
<th>sIgA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver esteem</td>
<td>0.093</td>
<td>-.487*</td>
<td>-.056</td>
</tr>
<tr>
<td>Lack of family support</td>
<td>-0.198</td>
<td>0.016</td>
<td>-.329*</td>
</tr>
<tr>
<td>Perceived stress</td>
<td>-.555**</td>
<td>-0.106</td>
<td>-0.035</td>
</tr>
</tbody>
</table>

* small correlation (.30-.49)
** medium correlation (.50-.69)
*** large correlation (> .70)

Table 4.7: Esteem, Support, Perceived Stress and Outcome Variables

Perceived Stress

Perceived stress was not associated with either cortisol ($r = -.106$) or sIgA ($r = -.035$). High perceived stress was associated with lower general health scores ($r = -.555$), and this was true regardless of occupational status or gender. Higher perceived stress was associated with lower income ($\rho = -.445$).

Perceived lack of Family Support

A high perception of lack of family support was not associated with cortisol level ($r = .016$), nor with general health ($r = -.198$). However, lack of support was associated
with lower sIgA (r= -.329), and this appears to be independent of developmental stage, income, and gender. Spouses working fewer hours were also more likely to perceive a lack of support from family (eta= .477).

Health Outcomes: General Health, Salivary Cortisol, and Salivary sIgA

**General health.** Mean GHS score was 65.65 (SD= 14.55) and the range of scores was 46.7 to 93.3. General health was not correlated with either cortisol (r= -.129) or sIgA (r= .095). Of the demographic variables examined, general health was not correlated with occupational status (eta= .297). General health also was not correlated with confrontive coping (rho=.042), self controlling (rho= .211), positive caregiver esteem (rho= .093), or perceived lack of support (rho= -.198).

**Salivary cortisol.** The mean morning cortisol level for this sample was .9036 ug/dL (SD= .1825 ug/dL) and the range was from 0.52 to 1.22 ug/dL. There was a moderate positive correlation between cortisol level and sIgA (r= .502). Salivary cortisol level was not correlated with developmental stage (eta=.282), gender (eta= .166), confrontive coping (rho=-.229), distancing (rho= -.238), accepting responsibility (rho= -.134), escape-avoidance (rho= -.210), lack of family support (r= .016), or perceived stress (r= -.106).

**Salivary sIgA.** The mean morning sIgA level was 299.97 ug/dL (SD= 320.66 ug/dL), and the range was from 0.97 to 1033.0 ug/dL. A square root transformation was conducted on the raw sIgA scores to produce a distribution approximating normality. All analyses reported used the transformed sIgA data.

As mentioned above, sIgA was correlated with salivary cortisol (r= .502). Salivary sIgA was not correlated with developmental stage (eta= -.008), gender (eta=
.286), confrontive coping (rho = -0.290), self controlling (rho = 0.206), escape-avoidance (rho = -0.164), planful problem solving (rho = -0.295), positive caregiver esteem (r = -0.056), or perceived stress (r = -0.035). Table 4.8 provides a summary of all correlation magnitudes and directions.
Discussion

This pilot study examined perceived and physiologic stress and health outcomes in spousal cancer caregivers and the relationships among these and gender, family developmental stage, income, occupational status, social support, coping, and caregiver esteem. The study was limited by a small sample size, use of a convenience sample, and the correlational design from which causal inferences cannot be made. Results can only be interpreted from an associational standpoint, and are only generalizable to younger spouses of cancer patients who also are parents of dependent children. Nevertheless, even with the small sample size, the number and magnitude of the correlations found between the variables suggest that the proposed model has promise for guiding future work in this area.

Several factors inherent to cortisol secretion and measurement make it necessary for the researcher to pay special attention to possible confounding variables. First, cortisol is excreted in a diurnal pattern with heightened activity in the early morning (acrophase or peak) and low activity late in the day (nadir; Hucklebridge, Clow, & Evans, 1998). Normals for saliva cortisol range from 0.1 ug/dL at the nadir (from late evening to early morning) to 1.8 ug/dL just prior to awakening (Lovallo & Thomas, 2000). Therefore, it is important to collect samples from all subjects at as near the same time of day after awakening as possible to avoid error related to normal rhythmic secretion of this hormone. Second, the pH of saliva is affected by consumption of food or drink which may lead to false results (Lovallo & Thomas, 2000; Salimetrics). In particular, low pH may artificially inflate results. The Salimetrics assay contains a built-in pH indicator and the manufacturer suggests that samples with a pH < 3.5 or > 9.0 may be falsely high or
low. None of the samples tested in this study exhibited high or low pH. Other factors which may confound results are regular use of medications with known effects on cortisol secretion (e.g. oral contraceptives, dexamethasone, etc.), immune system alterations, autoimmune disease, substance use or dependency, and psychiatric illness (Lovallo & Thomas, 2000). In addition, it was necessary to use only data from the early morning samples in this study because many of the collected mid-day and evening samples were below the lower level of sensitivity for the assays. Other potential problems with including salivary assays include, the increased cost of completing the study, increased subject and researcher burden, and potential for nonstandardized sample handling procedures which may increase error variance.

The mean morning cortisol level for this sample was .90 ug/dL. Morning cortisol levels were expected to be as high as 1.8 ug/dL. Therefore, this group of adults may have had a lower than normal awakening cortisol level, which was unexpected. All subjects who returned the sample time log reported having given the morning sample within 20 minutes of awakening except for one subject who reported a 30 minute post-awakening sample. Two subjects did not return or did not complete their logs. It is not clear whether time of morning sample was a factor in the morning cortisol levels since 25% of subjects did not report proper timing of their sample. Also, the mean morning sIgA level was about 300 ug/ml. The normal range of sIgA values can range from 90 to 900 ug/ml, and is likely to fall between 306 and 466 ug/ml in healthy adults (e.g., Childers, Greenleaf, Dasanayake, Powell, & Michalek, 2003). Therefore, it appears that this sample as a whole may have had lower than normal sIgA levels, which was expected, but was not consistent with their lowered cortisol level. However, sIgA was a highly variable
measure in this sample. This large range of values appears to be the norm, however, as Childers and colleagues measured values ranging from 48 to 1311 ug/ml in their sample of 20 healthy adults with a mean age of 33.8 years and ranging from ages 22 to 51 years (similar to the subjects in the present study). Recently, Sanchez-Martín et al. reported that while some authors found increases in sIgA with stress, others have found decreases in the production of sIgA with stress (2001). These authors speculated that the differences may be a result of differential effects of or pathways of various stressors (e.g., acute vs. chronic) on the immune response. Further, it has been reported that acute stressors may actually produce an elevation in sIgA level (Evans et al., 1994; White & Porth, 2000; Zeier et al., 1996). Therefore, it is possible that this sample’s sIgA data were affected by the nature of the acute stressors the spouses were faced with at the time of sampling, in addition to the chronic stressor of having a spouse with cancer. This could be an explanation of the unexpected moderate positive correlation between cortisol and sIgA in this sample.

Salivary cortisol and salivary secretory IgA assays were run in duplicate over a four day period (approximately 24 hours total time). Total cost for running the assays was approximately $900, including actual costs to the researcher for assay kits, control solutions, and salivettes. Aside from these costs, the equipment and supplies used were available in the College of Nursing laboratory. However, assays were run by the investigator in a lab outside the College in order to facilitate instruction in the required methods by experienced lab personnel. It is highly recommended that researchers without experience with ELISA obtain such training from the manufacturer of the assay kits, or consider sending the samples to an outside lab or a General Clinical Research
Center (if available on site) for analysis. It is this author’s contention that the cost associated with salivary cortisol assay is justified in light of the importance of understanding the links between stress and illness, and the usefulness of this information in evaluating the effectiveness of potential stress management interventions.

Gender had a positive relationship with general health in this sample, with women having lower general health scores than men. Based upon the correlational analyses, this relationship did not appear to be affected by coping process or perceived stress. Thus the women in this sample were less healthy than the men, regardless of what they did to cope, or how stressed they felt. It is not clear whether the women in the study were less healthy to begin with, or whether their caregiving experience was sufficiently more distressing than that of the men to cause them to have poorer self-reported health. This is an interesting finding that requires further study.

Individuals with larger family incomes reported better general health, had higher sIgA levels and, unexpectedly, also had higher cortisol levels than lower income individuals. Perhaps higher income individuals had more stressful combination of work and family stressors than did lower income individuals. Another possible explanation for this is that higher income individuals coped less often via positive reappraisal—a process that was associated with lower cortisol levels in this sample. Positive reappraisal is an emotion-focused coping process. Emotion-focused coping has been shown to be more adaptive in situations where the stressor is uncontrollable—such as when a spouse has cancer (Folkman & Lazarus, 1988). Lower income individuals, who were more likely to use positive reappraisal, may have benefited from this coping process by lowering of cortisol levels.
In the case of sIgA, positive reappraisal could potentially decrease some of the positive effects that having a higher income had on sIgA levels. More importantly, lower income individuals, who were more likely to use positive reappraisal, may have had an even more dramatic decrease in sIgA level via using this coping strategy. This relationship seems counterintuitive since positive reappraisal also had a positive effect on cortisol level. However, as mentioned above, it is uncertain whether sIgA is a good measure of the effects of chronic stress on immune function because acute stressors may be a confounding variable. However, these are interesting findings in light of the known health disparities associated with low socioeconomic status. Health care providers should be aware of these issues when assessing the need for intense intervention with caregivers having lower incomes. Further, lower income individuals reported higher perceived stress. High perceived stress was associated with lower general health scores regardless of occupational status or gender.

Number of hours worked outside the home was a strong predictor of the physiologic stress and immune responses in this sample, with fewer working hours being associated with higher cortisol and higher sIgA. Further, occupational status was correlated with several of the potential intervening variables. Spouses who worked the fewest hours were more likely to use distancing, seeking social support, planful problem solving, and positive reappraisal as coping processes, and these processes were correlated with lower cortisol and lower sIgA. In other words, working more hours outside the home was associated with less use of distancing, seeking social support, and positive reappraisal coping processes, and also higher cortisol and sIgA levels. Spouses working fewer hours were also more likely to perceive less support from family. Note that these
relationships were not gender specific, as occupational status was not correlated with gender in this sample. It is possible that working spouses may have more help from relatives due to their working status than spouses who must be home more often to care for the spouse who is ill. Alternatively, those spouses who can continue working longer hours may have relatively less-dependent spouses, and therefore do not need to provide much care, nor need to receive much outside help with care of their spouse with cancer.

Seeking Social Support as a coping process was associated with lower cortisol levels, and the relationship appears to be independent of developmental stage, income, and gender. In addition, lack of family support was correlated with lower sIgA level, apparently independently of the demographic variables examined. It is possible that the ages of children may be positively or negatively associated with the amount of family assistance received, with parents of younger children receiving more support (Stommel & Kingry, 1991). Therefore, future studies should examine the effects of interventions to encourage seeking social support, especially from family, in order to positively affect health outcomes in spouses of cancer patients.

Positive caregiver esteem was associated with lower cortisol levels, and this relationship may be independent of developmental stage, income, and gender. Spouses working fewer hours were more likely to have higher caregiver esteem than those who worked outside the home more. Perhaps spouses working outside the home were less likely to be doing much caregiving and could not therefore derive positive caregiver esteem. Nevertheless, based on these data, spousal caregivers could benefit from interventions aimed at increasing their positive esteem from the caregiving role.
Unexpectedly, neither perceived stress nor general health score were correlated with either cortisol or sIgA. Self-report data are commonly used for measurement of mental and physical health outcomes in caregivers. These measures may fail to give an accurate picture of the psychological distress and physical health effects of the caregiving role (Dura & Kiecolt-Glaser, 1990; Robinson & Austin, 1998; Schulz, Visintainer, & Williamson, 1990). Caregivers tend to underreport problems both out of denial and out of a lack of awareness of the effects of caregiving on their mental and physical health (Robinson & Austin). Therefore, measures of the physiological sequelae of stress may be more appropriate for caregivers, who may be unaware of the effects of the caregiving role on their mental, physical and social health.

Conclusions and implications for future research

Many patients with chronic illnesses are treated on an outpatient basis or in the home. Although this is financially cost effective for the health care system, the increased reliance on family members exposes them to high levels of chronic stress—contributing to physical and psychological morbidity in the caregiver. These costs have rarely been examined. If the caregiver is to be able to continue caring for their ill family member, health care providers need to understand the biopsychosocial factors contributing to poor health outcomes and have knowledge of caregivers’ informational, support, and coping assistance needs. Understanding the concepts related to the caregiving experience and the relationships among them will enable nurses to address these needs. In particular, examining both positive and negative aspects of caregiving and using both physiologic and self-report measures, will better enable these goals to be met.

While a large number of patients were screened, the design of the study hindered
accrual of enough subjects to perform the regression analyses originally proposed. Only 54 spouses met the inclusion criteria, and of these only 20 were enrolled, and only 13 completed data collection. Therefore, future studies should include spouses of patients who are recurrent, have been diagnosed for longer than one year, those with advanced cancer, and should include caregivers other than spouses in order to enhance both subject recruitment and the diversity of the sample. Also, future investigations of stress, coping and health in spouses of cancer patients should address potential interventions tailored to the caregiver's contextual characteristics and physiological health outcomes. In particular, young spouses with dependent children remain an understudied group.

Several lines of research have shown positive effects of psychological interventions on immunity. Natural killer cell activity (NKCA) was studied by Fawzy and colleagues who found positive effects of a structured group intervention on NKCA activity in cancer patients (Fawzy, Kemeny, Fawzy, et al., 1990; Fawzy, Fawzy, Hyun et al., 1993; Fawzy, Fawzy & Canada, 2001). Subjects receiving the structured group intervention also had lower rates of cancer recurrence and death than did control subjects (Fawzy et al., 1993). The authors suggested that such an intervention was easily offered and integrated into cancer patient care, and should be easy to replicate with other samples (see Fawzy et al, 2001 for a review).

Lymphocyte quantification is another method of examining the effects of interventions on immune function. For example, higher white blood cell and total lymphocyte counts have been found in malignant melanoma patients after a structured group intervention (Fawzy et al., 1990), and after relaxation training in Stage I breast cancer patients (Gruber, Hersh, Hall, et al., 1993).
A third measure of immunity, lymphocyte proliferation, is a measure of the actual functional capacity of lymphocytes when exposed to antigen or mitogen stimulation (Borysenko, 1987). One research group found that higher baseline stress lowered the proliferation of T cells when stimulated by PHA and CON-A—two mitogens that stimulate proliferation (Andersen, Farrar, Golden-Kreutz, Kutz, MacCallum, et al., 1998). Thus, lymphocyte proliferation shows promise as a measure of the effectiveness of stress-lowering interventions on immune function.

Examining interactions among objective stressors, caregiver appraisals, and outcomes in a multivariate fashion may provide insight as to why caregiver research has produced varying results in different contexts (Braithwaite, 1996). A few studies have examined the impact of caregiving on the caregiver’s physiologic health (e.g., Kiecolt-Glaser and Glaser, 1994). However, these studies need to be expanded to include different kinds of caregiving situations, different types of physiological measures of the impact of caregiving, and an examination of the effects of caregiver interventions on caregiver health (Hunt, 2003). This study serves as a basis for future large-scale, interventional, multivariate research in the area of cancer caregiver stress, coping and health outcomes.
References


REFERENCES


