ECONOMIC HARDSHIP AND THE EMOTIONAL HEALTH OF FAMILY CAREGIVERS

by

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Research Purposes: Multiple studies have quantified the direct and indirect costs of cancer care; however, there is little attention to how concerns about costs impact the emotional health of family caregivers. The purpose of this study, using the Pittsburgh Mind Body Center Model, was to evaluate how perceptions of economic hardship influence burden, anxiety, and depressive symptoms in caregivers of persons with a primary malignant brain tumor.

Methods: Data were from an ongoing, longitudinal study (NCI R01CA118711). Caregiver (CG)/care recipient (CR) dyads (n=33) were recruited within a month of the CR's diagnosis; data were collected at the point of diagnosis and 4 months later. CRs were questioned using the Neurocognitive Status Exam (NCSE) and CGs completed questionnaires to determine perceptions of economic hardship, burden (Caregiver Reaction Assessment), anxiety (POMS), and depressive symptoms (CES-D). Linear regression was used to examine relationships among variables.

Results: Perceived economic hardship had a significant effect on two CG burden subscales: feelings that providing care negatively affected one's schedule, and feelings of abandonment. Economic hardship did not predict CG burden due to schedule at baseline, but did significantly (p<.01) predict burden 4 months later. Alternately, economic hardship predicted burden due to feelings of abandonment at the time of diagnosis (p<.01), but not 4 months into the care situation. CG depression was predicted by economic hardship 4 months after diagnosis (p=.05), but not at the initial interview. Economic hardship predicted CG anxiety at both the time of diagnosis and at the second interview (p<.01).

Conclusions: Results suggest that caregivers' perception of economic hardship may be an important yet variable aspect of the burden, anxiety, and depression caregivers feel at the time of diagnosis and throughout the care situation.

Public Health Significance: Caregivers of persons with a chronic disease such as cancer face financial pressure that may have negative emotional consequences. Although it may not be feasible to alleviate economic hardship, interventions may be effective in decreasing associated feelings of burden and anxiety during the care situation, and preventing the escalation of depressive symptoms.

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PREFACE

I would like to express my eternal gratitude to Dr. Paula Sherwood and the Family Care team at the School of Nursing. Dr. Sherwood has been an invaluable mentor and role model to me throughout my time at the University of Pittsburgh, and her guidance and friendship helped me navigate the murky thesis process. Those on the Family Care team, including Allison Hricik, Alyssa Newberry, Jean Kuo, Allison Walker, and Sara Snyder, were a tremendous source of help, support, and encouragement. This document is truly the result of collaboration with this great group.

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1.0 INTRODUCTION

Research has shown that persons undergoing treatment for cancer face many expenses over and above the direct costs of care, such as co-payments and deductibles for prescription medications and hospital stays, and loss of income. Due to care demands and rising expenses, many caregivers leave or reduce paid employment, leading to a loss of earnings in addition to those lost by the patient. It is clear that cancer is a costly disease, both for persons diagnosed and their caregivers, and while studies have reported work on quantifying the costs of cancer care, little research has explored how these costs impact the caregiver's perceived economic hardship and subsequent depressive symptoms, anxiety, and burden. Over the past several decades much research has documented the toll that providing care has on the emotional and physical health of the caregiver. However, to date, no research has examined whether economic burden contributes to these changes in emotional health. There is also a paucity of research describing how the perception of economic burden changes over time, as the care recipient's disease and treatment progress. Finally, almost no research to date has focused on the financial impact of cancer care on caregivers of persons with a primary malignant brain tumor (PMBT), a population that faces challenges due to both patients' neurological dysfunction and treatment side-effects. The purposes of this study were to: 1) explore the extent to which perception of economic hardship contributes to the emotional consequences of providing care, and 2) explore the extent to which perceived economic hardship changes during the first four months following diagnosis.

1.1 FAMILY CAREGIVING

Whether due to illness or injury, at some point in their lifetime many people find themselves having to care for a loved one. The term caregiver refers to anyone who provides assistance to a person who is incapacitated to some degree. The type of care may range from physically moving a person who is non-ambulatory, to helping someone dress or fill out paperwork, to providing emotional support and accompaniment to doctors' visits. Formal caregivers are trained professionals, however the majority of caregivers are informal and therefore receive no compensation for their role. These caregivers are most often family members of the care recipient, but may also be a friend or neighbor.

Approximately 28.8 million adults in the United States are family caregivers, a number that is expected to rise to 37 million by the year 2050 [Spillman and Black, 2005]. For many reasons, caring for a loved one is a stressful experience. Caregivers face worry and anxiety over the well-being of their loved one, they may be confronted with unremitting time demands, and they may be forced to assume new roles within the family and/or learn new skills. The pressure of the caregiving role leaves many individuals at risk for negative emotional consequences. Due to the large number of family members providing care in the home, much research has focused on the emotional health of these men and women.

A large portion of this research has highlighted the negative psycho-behavioral responses that may result from caring for someone with an illness, the majority of which is found in the areas of cancer and dementia care. Negative psycho-behavioral responses that have been found in caregivers include anxiety [Marsh et al., 1998; Marsh et al., 1998], depressive symptoms [Kozachik et al., 2001; Watanabe et al., 2000], and overall emotional distress [Sparks et al., 1998; Vedhara et al., 2000]. Caregiving has also been linked to an increased risk for nervousness and difficulty sleeping [Clipp and Moore, 1995; Carter, 2002]. In addition, caregivers tend to engage in more risky health behaviors such as alcohol and tobacco use, they are less likely to make and keep routine medical visits, and they have worse perceptions of their health [Beach et al., 2000].

Because the population of persons providing care for a loved one is so large, it is important to understand clearly all the consequences this demanding experience can trigger. In particular, negative psycho-behavioral responses may lead to negative biological responses, but may also be moderated by professional interventions. Therefore, understanding the factors that fuel and mediate caregivers' negative psycho-behavioral responses is critical. However, to gain a more clear picture of the factors involved in this response, a small subset of caregivers should first be examined.

1.1.1 Caregivers of Persons With a PMBT

Persons diagnosed with a PMBT are faced with a unique and challenging set of circumstances that affects not only them but those close to them as well. Approximately 17,000 people are diagnosed with a PMBT each year, of which the majority are men and are aged in their 50's [Ries et al., 2006; Sherwood et al., 2007]. Diagnosis frequently follows a traumatic event such as a seizure or loss of consciousness, and rarely occurs without significant changes in personality and neurologic status [Greenberg et al., 1999]. Neurologic dysfunction in the patient forces caregivers of persons with a PMBT to face stressors similar to those of caregivers of persons with dementia, a subset of caregivers who have been shown to suffer from negative psycho-behavioral responses such as depressive symptoms, anxiety, and difficulty sleeping [Pinquart and Sorensen, 2003; Sherwood et al., 2007; Vitaliano et al., 2003].

Besides neurologic dysfunction, caregivers of persons with a PMBT must also grapple with oncologic issues, such as the diagnosis of a potentially terminal illness and the side effects of cancer treatment. Because PMBTs are aggressive and can be therapy-resistant, effective treatment is limited, as illustrated by a 1-year survival rate of just 29% following diagnosis of the most common type of PMBT, glioblastoma multiforme [Central Brain Tumor Registry, 2000]. Therefore, these caregivers are also at risk for negative outcomes similar to those of caregivers for persons with other types of cancer or dementia. They have been shown to be at risk for psycho-behavioral responses such as depressive symptoms, anxiety, and burden [Given et al., 2004; Kozachik et al., 2001; Sherwood et al., 2007].

Two reports describe the turmoil that family members undergo when learning that a loved one has a PMBT [Salander et al., 1996; Wideheim et al., 2002]. Anxiety, helplessness, and fear are common as family members try to maintain routine activities while facing the possibility of their loved one’s mortality. If the patient survives initial surgery or treatment, family members often become aware of neurological and functional deficits that may prevent the care recipient from fulfilling previously held obligations. At this point, family members often become caregivers, assuming responsibility for duties previously performed by the patient, and coordinating and even delivering care. They are then at risk for negative psycho-behavioral responses such as anxiety, depressive symptoms and caregiver burden.

1.1.2 Caregiving Model

To better understand the interactions and influences of factors such as disease and personal characteristics, and social and sociodemographic attributes, evaluation of biological and behavioral markers of distress can be done through the application of a mind body model. These models suggest that psychological, behavioral, and biological responses to an event are interrelated and are all part of the body's stress response. In doing so, mind body models provide a visual framework for evaluating hypothesized relationships and exploring how psychological, behavioral, and biological responses interact over time. Therefore, a mind body model can be used to help delineate the relationships between stressors, such as the care recipient's functional status or perceived economic hardship, and caregiver psychological responses.

A multidisciplinary team of investigators proposed the Pittsburgh Mind Body Center Model to examine interactions between biologic and behavioral responses to a stressor [Matthews, 2003]. Using research from the areas of oncology and dementia caregiving, this model can be adapted to describe how disease characteristics of a PMBT may trigger psycho-behavioral and subsequent biologic responses in caregivers, ultimately leading to changes in overall physical health [Sherwood et al., 2007].

Disease characteristics are viewed as the primary external stressor and encompass variables related to the care recipient and his or her disease trajectory. Disease characteristics such as tumor type and the patients' neurological status can lead to caregivers' psycho-behavioral responses, such as depressive symptoms and anxiety [Sherwood et al., 2007]. Caregivers' personal characteristics can either lead directly to psycho-behavioral responses or moderate the relationship between patients' disease characteristics and caregivers' psycho-behavioral responses. Then, psycho-behavioral responses can lead to biologic responses, which may impact overall health [Sherwood et al., 2007]. All of these interactions occur over time. See Figure 1 for details.

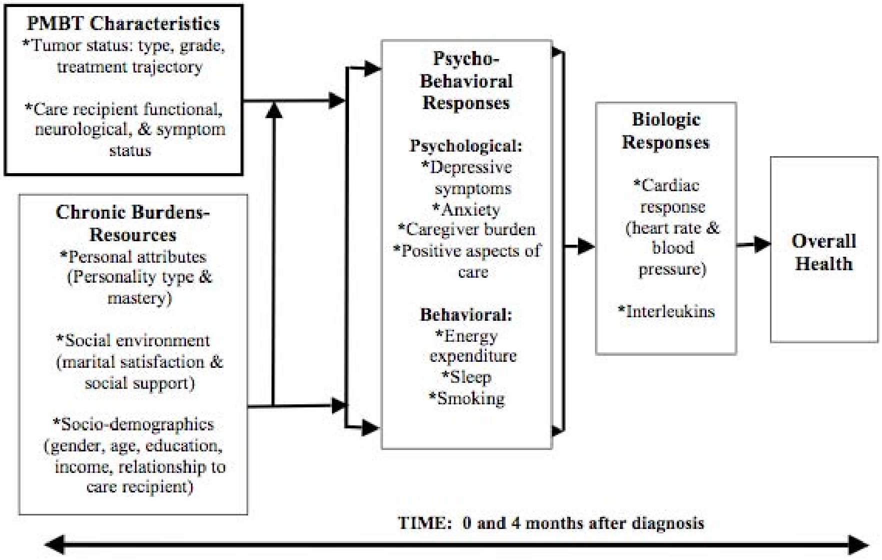


Figure 1. Pittsburgh Mind Body Model

While it is known that caregivers with lower income are more likely to suffer negative psycho-behavioral responses to the care situation [Pinquart and Sorensen, 2003; Nijboer et al., 2001; Gaugler et al., 2000], no research to date has explored whether financial concerns affect caregiver depressive symptoms, anxiety, and burden. High treatment costs and care demands take their toll on many caregivers, but the impact of these variables on the caregivers' emotional responses have not been delineated. The Pittsburgh Mind Body Model, therefore, can be used as a guide in this exploration, and provides a framework for discussion on the matter.

The Pittsburgh Mind Body Model may be used to examine the extent to which perceived economic hardship contributes to the emotional consequences of providing care, and how this relationship changes over time. Perception of economic hardship may both moderate caregiver response to the patient's disease characteristics, and provide a new stressor to which the caregiver must respond. However, caregivers' psycho-behavioral responses are not solely dependent upon the presence of a stressor, but are also dependent upon the amount of distress the caregiver associates with that stressor. Therefore, it is not so much the amount of financial resources present, but rather the caregiver's perception of economic hardship that must be examined.

This perception of economic hardship may be moderated by personal attributes and the caregiver's social environment. Persons with very different amounts of financial resources may have similar perceptions of their level of economic hardship due to personality type or support from family and friends, etc. It is the perception of economic hardship then that facilitates the caregiver's psycho-behavioral response. Perception of economic hardship may have some effect on caregivers' negative psychological response to the care situation, however, to date this relationship has not been examined. In addition, the interaction between perception of economic hardship and caregivers' psychological response occurs over time, although no research to date has examined this timeline and the potentially changing responses. Therefore, the purposes of this study were to 1) explore the extent to which perceived economic hardship contributes to the emotional consequences of providing care, and 2) explore the extent to which perception of economic hardship changes during the first four months following diagnosis.

1.1.3 Psycho-behavioral Responses to Caregiving

Caring for a loved one is a uniquely stressful experience; the potentially overwhelming nature of the role leaves family caregivers at risk for depressive symptoms. Depressive symptoms often manifest as loss of interest or pleasure in activities, low feelings of self worth, low energy, and poor concentration [Kozachik et al., 2001; Radloff, 1977]. In caregivers of persons with dementia, oncology, and other chronic illnesses, depressive symptoms have been closely linked with the patient's disease characteristics [Pinquart and Sorensen, 2003; Hinton et al., 2003], and functional status [Cohen et al., 2002].

In addition to depressive symptoms, the stress caused by the care situation causes many caregivers to feel burdened. Caregiver burden represents the impact of providing care on various aspects of the caregiver's life, such as schedule, self-esteem, health, finances, and feelings of abandonment [Given et al., 1992]. Past research has shown that feelings of caregiver burden are linked to disease characteristics such as the patient's neurological function [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000], tumor type [Gaugler et al., 2005], and symptom status [Andrews, 2001]. A meta-analysis supported the findings that when the care recipient has both functional and neurological impairments, the functional deficit has less of an influence on caregiver psycho-behavioral outcomes than the neurological decline [Pinquart and Sorensen, 2003].

Within the caregiving situation, there are many possible causes for these psycho-behavioral responses. As alluded to, and as illustrated in the Pittsburgh Mind Body Model, a possible cause for these responses are the patient's disease characteristics, which have been shown to influence the caregiver's emotional response to the care situation. Disease characteristics are defined as variables in the caregiving situation related to the tumor and treatment progression that may influence the quantity and severity of care demands, and therefore the degree to which the caregiver may exhibit negative psycho-behavioral responses to the care situation [Sherwood et al., 2007]. These characteristics include variables such as tumor type and grade, which may be indicative of the patient's expected survival and has been shown to impact psycho-behavioral responses [Ergh et al., 2003; Sherwood et al., 2007]. Tumor type and grade are also the basis for selecting specific treatment regimens, which may significantly impact the patient's functional, neurological, and symptom status. Surgery, radiation, and chemotherapy can lead to loss of motor and sensory function, fatigue, difficulty walking, pain, difficulty swallowing, and headache, which may in turn cause changes in the patient's functional status [Armstrong et al., 2005; Hoang-Xuan et al., 2003; Schmidinger et al., 2004]. Disturbance of the patient's functional status has been associated with reports of caregiver burden, anxiety, and sleep disruption.

Persons diagnosed with a PMBT face not only oncologic effects, but also neurological consequences. These have the potential to affect caregiving demands [Armstrong et al., 2005; Filley and Kleinschmidt-DeMasters, 1995; Irle et al., 1994]. Neuropsychiatric symptoms can include irritability, apathy, memory deficits, and hallucinations. A recent study by Sherwood et al. showed that more than one-third of caregivers stated that the care recipient had problems with short-term memory and decision-making regarding activities of daily living (ADLs) [Sherwood et al., 2006]. ADLs are self-care tasks done in daily living, such as bathing, dressing, and eating. Additionally, 88% of caregivers reported that the patient had at least one neuropsychological symptom, which has been linked with caregiver depressive symptoms, burden, and sleep disturbances in other caregiver populations [Sherwood et al., 2006].

Research has shown that more aggressive tumor grades, worsening functional and neurologic status, and more severe treatment-related symptoms in the patient can lead to greater reports of caregiver depressive symptoms, burden, anxiety, and sleep disturbances [Chio et al., 2005; Chumbler et al., 2003]. This suggests that disease characteristics, by dictating care demands and the patient's life expectancy, affect the caregiver's psycho-behavioral responses. However, these characteristics are not the sole determinant of caregiver response to the care situation.

Not all caregivers demonstrate a negative psycho-behavioral response to disease characteristics, suggesting that caregiver personal characteristics help moderate this response. Personal characteristics include factors such as personality type and mastery, defined as the perception of control over the care situation, and have been linked with caregivers' emotional responses [Mullan, 1992; Skaff et al., 1996]. Bookwala and Schulz showed that high levels of neuroticism are linked with burden and depressive symptoms in caregivers of patients with Alzheimer's disease [Bookwala and Schulz, 1998]. These researchers also suggested that neuroticism moderates the relationship between disease characteristics and caregivers' psycho-behavioral response, such that caregivers with high levels of neuroticism are at greater risk for depressive symptoms when a patient has neurological deficits, when compared to a caregiver with low levels of neuroticism [Bookwala and Schulz, 1998].

Research also suggests that caregivers with high levels of mastery are able to face the challenges of providing care and are able to problem-solve to meet care demands [Bookwala and Schulz, 1998]. This suggests that a feeling of mastery may help determine how well caregivers believe they can fulfill the care role. This in turn may affect their susceptibility to depressive symptoms [Skaff et al., 1996; Bookwala and Schulz, 1998].

In addition to disease and personal characteristics, social attributes also influence caregivers' psycho-behavioral responses. In caregivers of persons with chronic illness, marital satisfaction has been shown to influence anxiety, depressive symptoms, and burden [Beach et al., 2000; Tsai and Jirovec, 2005; Edwards, 2002]. In addition, the availability and willingness of friends and family to provide emotional support to the caregiver, the caregiver's social support, has been shown to moderate burden [Nabors et al., 2002]. One study found that when care demands were high, caregivers with low levels of social support were at greater risk for depressive symptoms than those with high levels of support [Cannuscio et al., 2004].

Lastly, in addition to disease characteristics, personal characteristics, and social support, sociodemographic attributes of the caregiver have also been linked with caregiver psycho-behavioral responses. In general, caregivers who are female, young, of lower income status, and who are spouses of the patient have been shown to be at higher risk for feelings of caregiver burden, depressive symptoms, anxiety, and sleep disturbances [Zarit et al., 1986; Pinquart and Sorensen, 2003; Nijboer et al., 2001; Gaugler et al., 2000; Blood et al., 1994].

Caregivers' psycho-behavioral responses do not solely depend on the presence of a stressor, but also depend on the amount of distress the caregiver associates with that stressor. As illustrated by the Pittsburgh Mind Body Model, personal characteristics, and social and sociodemographic attributes help to moderate the caregiver's response to the stressor, the patient's disease characteristics. For example, personality type and mastery help to shape the caregiver's attitude towards the care situation, while marital satisfaction and social networks provide emotional support to decrease the stress of providing care. Together, these factors help determine the degree to which the caregiver shows negative psycho-behavioral responses. Some factors, such as financial concerns, have not been well-studied, but may play a role in determining psycho-behavioral response to the care situation.

1.2 FINANCIAL CONCERNS IN ONCOLOGY

It is predicted that over 1.4 million people in the United States will be diagnosed with cancer in 2007 [American Cancer Society, 2007]. Advances in diagnosis and treatment have extended survival making some cancers, even in advanced stages, a chronic, rather than immediately life threatening, illness. While improved treatment has enabled Americans to live with cancer longer, it has also caused the national cost of the disease to balloon to over $206 billion in 2006. Of this, only $78 billion, or roughly one third of the total cost, is spent on direct medical costs; the other two-thirds are incurred as indirect costs due to factors such as lost productivity [ACS, 2007]. Direct costs are expenses related to cancer treatment, and include costs such as bills for clinic visits or hospital stays, transportation, and childcare. These costs may be fully or partially covered by third party payers. Indirect costs, on the other hand, are often due to opportunities lost because of cancer treatment, such as loss of income, used savings that were earmarked for another purpose, and canceled vacations [Moore, 1999]. These indirect expenses are absorbed by patients and their families. These expenses can be significant, and have real impact on patients and their loved ones.

Although over 15% of the United States population is uninsured, even insured persons face the threat of medical-related financial strain [DeNavas-Walt et al., 2004]. With healthcare costs rising and increased shifting of costs from employer to employee, financial hardship stemming from the diagnosis and treatment of cancer is likely to increase. In the United States, personal bankruptcy claims have been closely linked with medical costs, even when health insurance is present at the time of diagnosis [Himmelstein et al., 2005]. These trends suggest that financial strain may be compromising optimal cancer care and creating a new source of disparity in the healthcare setting.

In addition to the cost of cancer incurred by society as a whole, the cost to the individual patient and his or her family has the potential to be exorbitant. In a study of breast cancer patients published in 1999, Moore found that monthly out of pocket expenses ranged from $36 to $1224 [Moore, 1999]. Arozullah et al. reported on 156 insured breast cancer patients and found that women's average expenses totaled $1455 per month [Arozullah et al., 2004]. This total included both out-of-pocket costs for medication, transportation, doctor visits, and meals, and lost income (60% of the employed respondents reported cutting back on hours worked). On average, 50% of the women's financial burden was due to lost income, 41% was due to non-reimbursed direct medical costs such as prescription medications and physician visits, and the remaining 9% was due to direct non-medical costs such as transportation and childcare [Arozullah et al., 2004]. Although the studies are limited by sample homogeneity, both illustrate the out of pocket costs that can occur as a result of cancer diagnosis and treatment.

Illustrating the magnitude of lost income and time spent at work, Chang et al. reported that persons with cancer and their caregivers suffered a loss of 2 workdays and 5 short-term disability days per month [Chang et al., 2004]. Over the course of a long illness this has the potential to cause significant loss of income and productivity.

The high costs of medical care can also have considerable consequences for the family of a person with cancer. Covinsky et al. reported on persons and family caregivers faced with a life threatening disease (N=2,129) including congestive heart failure, metastatic lung cancer, and metastatic colon cancer [Covinsky et al., 1994]. Of these individuals, more than half reported at least some financial burden, and almost one third reported losing most or all of their savings. The study found that many families had to make adjustments including moving to a less expensive home or putting off medical care. Although the study describes adjustments made by persons and families with a life threatening disease in the face of financial concerns, it stops short of evaluating the effects these adjustments have on the mental and physical health of the patients or their families.

A recent report by Bradley et al. suggested that the costs related to cancer treatment have a significant impact on patients and their families [Bradley et al., 2007]. This descriptive, qualitative study examined responses from 20 participants who had been diagnosed with a primary malignant brain tumor (PMBT), and who were asked about the financial impact of their care. The analysis made clear that these patients felt that their treatment- and cancer-related costs were causing repercussions for their family and friends [Bradley et al., 2007]. Participants also verbalized the anxiety and distress that financial concerns were causing them, leading one patient to comment that, “I can’t just worry about the fact that I’m sick and I have cancer, I have to worry about how I’m going to get my medicine and get the tests” [Bradley et al., 2007]. Although it is limited by participant self-selection, this study suggests that worries over cancer costs are affecting not just the patient but also his or her family and caregivers.

Knowing that their diagnosis and treatment is financially affecting the patients’ loved ones appears to cause negative feelings. A 2007 study found that cancer patients who reported high levels of financial strain were more likely to report being a burden to their caregivers [Simmons, 2007]. This study did not, however, examine the caregivers’ reports of burden or financial strain. Along these same lines, Siegel et al. reported that persons with cancer who have financial hardship report higher numbers of unmet needs than those without [Siegel et al., 1991]. This may impact patient quality of life, but it is not known how this affects caregiver psycho-behavioral responses.

1.2.1 Financial Concerns in Neurology

With the exception of the recent work by Bradley et al. [2007], much of the research on the impact of cancer costs has focused on persons affected with some of the most common types of cancer, such as breast, colon, and lung, while comparatively little has focused on persons with a PMBT. However, these persons may face neurological challenges similar to those faced by persons with dementia or Alzheimer's disease, and therefore, caregivers of patients in these separate populations may confront like obstacles. In the area of neurology, much work has been done with not only the persons diagnosed, but also their caregivers.

In the past, research has shown that the families and caregivers of ill patients experience financial strain. A study by Wimo et al. in 1998 showed that family caregivers of dementia patients experienced financial burden. The study suggested that this may have played a role in the families' decision to enroll the patients in day care [Wimo et al., 1998]. A large study of male dementia patients and their female caregivers illustrated that the largest component of cost to the caregiver is lost earnings [Moore et al., 2001]. The average lost earnings was calculated to be $10,709 per year. These dementia caregivers also spent a significant amount of valuable time with their subsequent patients, and used their own resources to pay for care-related goods and services. Moore et al. estimated this cost to be approximately $360 per month [Moore et al., 2001]. The findings of the study suggested that as the disease progressed, caregivers were spending more time providing care, and therefore informal costs increased with disease progression [Moore et al., 2001]. To date, no study has been done, however, that explores how and if caregiver perception of economic hardship changes as time passes.

A 1997 paper by William Haley suggests that caregivers of persons with Alzheimer's disease may spend as many as 60 hours per week on care responsibilities. As a result, many of these caregivers must leave or reduce paid employment in order to provide care [Haley, 1997]. Similarly, a study of over 5,000 dementia patients and their primary caregivers by Covinsky et al. showed that the caregivers spent an average of 89 hours per week on care-related activities, and a significant number of caregivers had to reduce or halt paid employment [Covinsky et al., 2003]. However, it remains to be seen whether these financial pressures cause negative caregiver psycho-behavioral responses.

1.2.2 Consequences of Financial Concerns

It is clear that persons undergoing treatment for cancer and/or for a neurological condition may be faced with concerns and worry about finances. It is also apparent that these costs affect not only the patient, but also that person's caregivers and family. Research done in the past decade has also shown that financial concerns and perceived economic hardship can have an affect on physical health.

Barrera and colleagues defined financial hardship as the degree to which individuals experience distress as a result of an imbalance between appraised needs and available resources [Barrera et al., 2001]. Financial hardship begins with the realization that economic resources are inadequate to meet the demands on those resources, which is often followed by a change in behavior to maximize use of resources. Finally, inability to meet financial demands may result in a negative outcome, such as depressive symptoms or anger. There have been reported associations between financial hardship and mood in women caring for young children [Reading and Reynolds, 2001], persons with asthma [Janson-Bjerklie et al., 1993], and older adults [Chou and Chi, 2001]. However, little attention has been paid to persons with cancer.

In previously healthy persons, financial concerns have been shown to have an impact on health. In a prospective study of 1,759 men, Kubzansky et al. showed that men who worried more were at greater risk for coronary heart disease. In particular, subjects who report high levels of worry about social conditions or financial concerns had an increased risk for myocardial infarction and angina [Kubzansky et al., 1997].

Financial worry may also affect an individual's perception of his or her health. A Swedish study from 1995 of over 2,400 adolescents showed that participants who frequently or constantly worried about their families' finances were more likely to report that they believed they were in poor health [Hagquist, 1998]. To date, no additional research has explored this finding in other populations.

While these past studies suggest that financial worry may have an effect on physical health, no research to date has explored how perceived economic hardship caused by cancer diagnosis and treatment effects emotional health. In particular, no research to date has evaluated the impact that perceived economic hardship has on levels of caregiver anxiety, depressive symptoms, and burden. In addition, no study has examined changes in economic hardship over time, as the patient's disease and treatment progresses, and no study has explored whether any relationship between perception of economic hardship and psycho-behavioral responses changes over time. Therefore, this study used the Pittsburgh Mind Body Model to begin to explore the extent to which perceived economic hardship influences the negative caregiver psycho-behavioral responses of anxiety, burden, and depressive symptoms. This relationship was examined both at the time of patient diagnosis, and four months into the care situation. In addition, caregiver perception of economic hardship at diagnosis was compared to that perception four months into the care trajectory in order to evaluate the degree of change.

2.0 METHODS

2.1 DESIGN

This is a descriptive, longitudinal, pilot study (N=33) to explore the extent to which economic hardship contributes to the emotional consequences of providing care, and to explore the extent to which economic hardship changes during the first four months following diagnosis. This pilot study was part of an ongoing NIH funded study (NCI R01CA118711; Sherwood, PI).

2.2 ELIGIBILITY CRITERIA

Caregivers were denoted by the care recipient as the person who would be providing the majority of support (including emotional, financial, and physical support) to the patient. It was not a requirement of the study that caregivers be legally related to or live with the care recipient.

Caregiver: (1) Primary non-professional, non-paid caregiver, identified as such by the care recipient; (2) 21 years of age or over; (3) telephone access; (4) able to read and speak English; (5) did not currently consider self to be a primary caregiver for anyone else other than children under 21.

Care recipient: (1) Over 21 years of age; (2) newly (within one month) diagnosed with a PMBT verified via pathology report.

2.3 SETTING

Recruitment and data collection for the caregiver/patient dyad took place in a private room in either the neuro-oncology clinic at the University of Pittsburgh Cancer Institute (UPCI) or the neurosurgery clinic at the University of Pittsburgh Medical Center-Presbyterian (UPMC). UPCI is a NCI-designated Comprehensive Cancer Center serving western Pennsylvania. UPMC Presbyterian is an adult medical/surgical referral center, and is one of the flagship hospitals of UPMC, a premier health system that serves over 4 million people.

2.4 RECRUITMENT

Potential subjects were identified through referral from clinic staff. Only potential subjects who had consented for placement on a research registry were approached. Details of participation were explained to each dyad; it was explained that both caregiver and care recipient had to agree to participate in order for the other to be eligible and that data collection would be performed twice, once at baseline and once in 4 months. For their participation, care recipients were reimbursed $25 at each time point, and caregivers were reimbursed $75 at each time point. The care recipient consent form is available in Appendix A, and the caregiver consent is in Appendix B.

2.5 DATA COLLECTION

Data were collected separately from each member of the dyad so that they felt comfortable answering questions honestly. The dyad was given a choice of completing data collection either during their routine clinic appointment or in their homes (caregiver data for this portion of the larger study were collected during telephone interviews). The majority of care recipient data were collected while patients were in the private examination room awaiting a routine clinic appointment with their health care provider. Caregiver data were typically collected during a telephone interview at the subject's convenience, but within 72 hours of data collection with the care recipient. Interviews lasted approximately 60 – 90 minutes. All caregiver measures were administered by a trained member of the research team who recorded responses to instrument items in order to ensure completeness of data (a description of all measures is provided in the following measurement section). Following interview completion, all participants' responses were entered into a password protected SPSS database by a member of the research team. Every participant's data was verified by another member of the research team by comparing written responses with entered data for the purpose of quality assurance.

2.6 MEASURES

The following instruments (listed below in Table 1; full questionnaires available in Appendix C) were employed in the interviews:

Table 1. Instruments Used for Assessment of Caregiver and Care Recipient Factors

Concept (Specific Aim)	Measure Name (# of items)	Psychometrics [reference]
PMBT Characteristics		
Neuropsychological Status	Neurobehavioral Cognitive Status Exam (55)	0.93 [Engelhart et al., 1994]
Tumor Type	Pathology report	N/A
Chronic burdens/resources		
Economic Hardship	Economic Hardship Questionaire (20)	0.82-0.87 [Lempers et al., 1989]
Sociodemographics	Sociodemographic Questionnaire (22)	
Personality type	Goldberg's Adjective Scale (25)	0.82-0.90 [Goldberg, 1992]
Social support	Interpersonal Support Eval. List (12)	0.88-0.90 [Cohen et al., 1985]
Psychological		
Depressive symptoms	Reduced CES-D (10)	0.84-0.91 [Given et al., 7/99-6/02; Sherwood, 8/02-8/04]
Anxiety	Reduced POMS, anxiety subscale (3)	0.76-0.92 [Usala and Hertzog, 1989]
Caregiver burden	Caregiver Reaction Assessment (24)	>.80 [Given et al., 7/99-6/02; Sherwood, 8/02-8/04]

Note: CES-D = Center for Epidemiologic Studies-Depression; POMS = Profile of Mood States

2.6.1 PMBT Characteristics

The care recipients' neuropsychological status was measured by the Neurobehavioral Cognitive Status Examination (NCSE) [Kiernan et al., 1987]. Subjects answered questions and performed tasks that indicated disability in the following domains: level of consciousness, attention, language, constructional ability, memory, calculations, and reasoning. Scores were generated for each domain via algorithm (average ability=0, mild impairment=1, moderate impairment=2, and severe impairment=3); an overall score was calculated by summing the scores for each domain. The NCSE has a sensitivity of 0.93 in a population of non-psychiatric adults [Engelhart et al., 1994]. Reliability in this study was .43 at the first interview, and .76 at the second interview four months into the care situation. The care recipient's neuropsychological status (cognitive and neuropsychiatric symptoms) have been consistently linked to caregiver burden and depressive symptoms in the Alzheimer's disease caregiver population [Fillit et al., 2000; Kaufer et al., 2000] and have begun to be identified as a correlate of distress in the cancer, and particularly neuro-oncology, caregiving populations as well [Sherwood, 8/02-8/04; Sherwood et al., 2004].

Tumor type was assessed by a member of the research team, who reviewed the care recipient's pathology report via medical records and noted the tumor type and grade.

2.6.2 Chronic Burden/Resource Measures

Economic hardship was measured using Barrera et al.'s Economic Hardship questionnaire [Barrera et al., 2001]. Participants rated their perception of economic burden in the areas of Financial Strain, Inability to Make Ends Meet, Not Enough Money for Necessities, and Economic Adjustments/Cutbacks. Reliability of each subscale reported by Barrera et al. as well as the reliability obtained in this study is as follows: Financial strain, 0.73; Inability to makes ends meet, 0.70 - 0.76; Not enough money for necessities, 0.80 -0.85; and Economic adjustments, 0.70 - 0.73. Construct validity has been established in prior research [Barrera et al., 2001]. Individual items were summed to produce an overall score for each subscale, with higher scores indicating higher levels of economic hardship. In this study the reliability of this summary measure was .95 at the time of diagnosis, and .92 four months later.

Based on prior research documenting a relationship between caregivers' emotional health and certain sociodemographic variables [Pinquart and Sorensen, 2003; Nijboer et al., 2001; Gaugler et al., 2000], this information was collected including caregiver age, gender, level of education, ethnicity, income, relationship to the care recipient, and comorbid conditions.

Personality type was measured using the modified Goldberg Adjective Scale [Goldberg, 1992]. Subjects rated their level of agreement with statements regarding five personality types (extraversion, agreeableness, conscientiousness, emotional stability, and openness). Subscale scores for each personality type were generated by summing individual items; higher scores indicating stronger traits. The neuroticism portion of the Goldberg Adjective Scale, also known as the emotional stability scale, has an internal reliability of .82 - .88 [Goldberg, 1992], reliability in our study was .75. Certain personality types, e.g. high levels of neuroticism, have been consistently linked with both caregiver burden and depressive symptoms in Alzheimer's disease caregivers [Bookwala and Shulz, 1998; Jang et al. 2004]. Data suggest these relationships may also be present in cancer caregivers [Nijboer et al., 2001].

Social support was measured using the Interpersonal Support Evaluation List (ISEL) [Cohen et al., 1985]. Subjects rated the availability of three types of social support (appraisal, belonging, and tangible). Individual items were summed to produce an overall score for each subscale, higher scores indicating more social support. The ISEL has an internal reliability of 0.88 - 0.90 in the general population, and a validity of 0.62 [Cohen et al., 1985]. Reliability in this study was .85 at the first interview, and .87 at the second interview. Low levels of social support have been linked to increased caregiver burden and depressive symptoms in both neurologic and cancer caregivers [Goldstein et al., 2004; Goode et al., 1998].

2.6.3 Psychological Measures

Depressive symptoms were measured using the Reduced Center for Epidemiologic Studies-Depression (CES-D) [Radloff 1977]. [Note: Reduced measures of the CES-D and POMS anxiety scales were used in the study to reduce subject burden. These measures were obtained as a result of analysis from the REACH study (R. Schulz, personal communication) and data providing validity and reliability of the abbreviated measures are available upon request.]

Subjects indicated how often they experienced various symptoms. Individual items were summed to produce an overall score, higher scores indicating higher levels of depressive symptoms. Reliability estimates of the CES-D range from 0.76 to 0.92 [Radloff, 1977], reliability in this study was .87 at the time of diagnosis and .87 four months later. The CES-D has proven to be a valid measure of depressive symptoms in populations of healthy adults, cancer patients, and adolescents [Hann et al., 1999; Radloff, 1991]. High levels of depressive symptoms have been found in caregivers of persons with Alzheimer's disease, cancer, and PMBTs [Sherwood et al., 2006; Kozachik et al., 2001; Schulz et al., 2004]. In turn, depressive symptoms has been linked to dysfunction in endocrine and immune systems, which can manifest in worsening overall health for general populations and for Alzheimer's disease caregivers [Dentino et al., 1999].

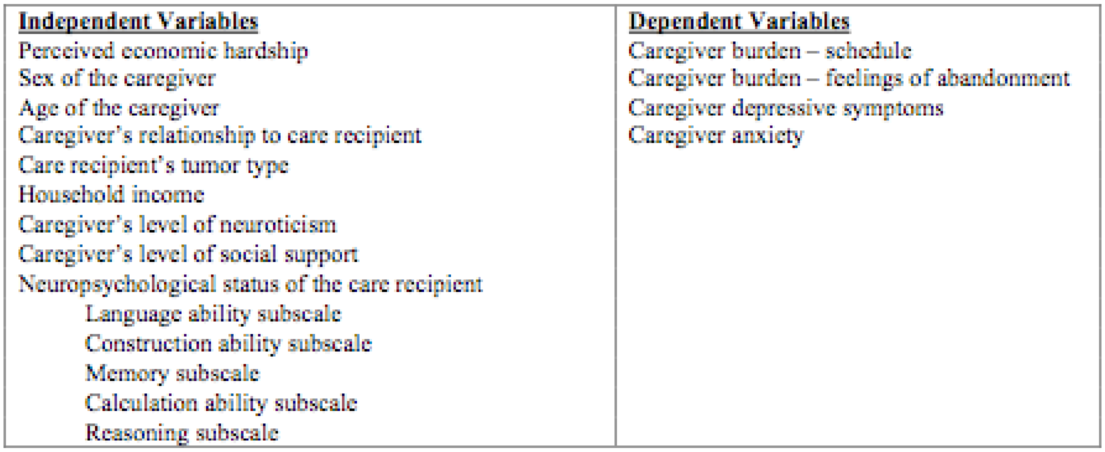
Anxiety was measured using an abbreviated anxiety subscale of the Profile of Mood States (POMS) scale [McNair and Lorr, 1964; Usala and Hertzog, 1989]. Individual items were summed to produce a total score, higher scores indicating higher levels of anxiety. Validity was found to be 0.61 in a sample of adults from the general population [Nyenhuis et al., 1999]; internal reliability has been reported as 0.64 [McNair and Lorr, 1964]. Reliability in this study was .94 at the first interview and .91 at the second interview.

Caregiver burden is a multidimensional concept and was therefore measured via two subscales of the Caregiver Reaction Assessment, which asks caregivers to indicate the impact of providing care on their schedules and feelings of abandonment [Given et al., 1992]. The schedule subscale consists of five items that assess the impact of providing care on the caregiver's usual activities, including whether providing care has forced them to eliminate activities and interfered with relaxation. The abandonment subscale measured the ability of the family to support the caregiver and work together in the care situation (including the caregiver's perception of being 'abandoned'). Subscale scores resulted from summing individual items, and greater caregiver burden was indicated by higher scores. Reliability of each subscale has been reported as follows: schedule, 0.78 - 0.84 [Given et al., 1992; Nijboer et al., 1999], reliability in this study was .77 at the time of diagnosis and .90 four months later; feelings of abandonment, 0.62 - 0.90 [Given et al., 1992; Nijboer et al., 1999], reliability in this study was .72 at the first interview and .87 at the second interview. Caregiver burden has been linked to overall morbidity and physical health outcomes [Schulz et al., 1999].

2.7 STATISTICAL ANALYSIS

All statistical analyses were done using the SPSS statistical package. See Table 2 for all independent and dependent variables used in subsequent analyses.

Table 2. Variables used in statistical analyses

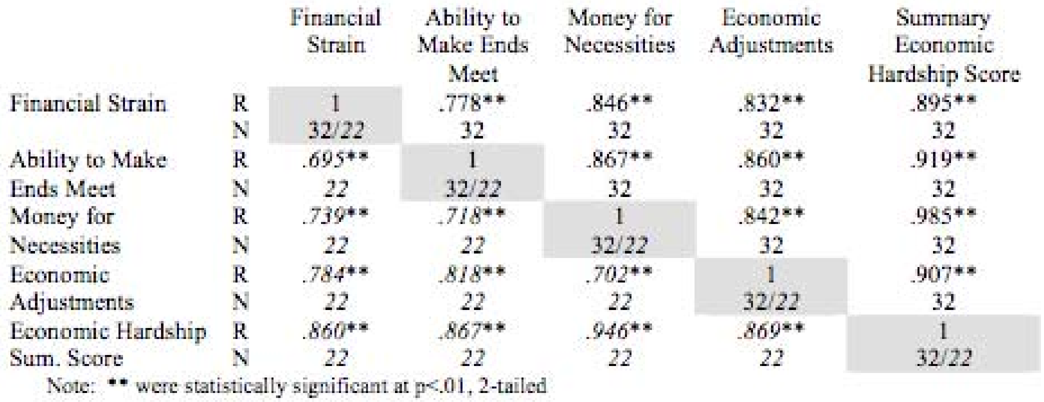


Independent Variables	**Dependent Variables**
Perceived economic hardship	Caregiver burden – schedule
Sex of the caregiver	Caregiver burden – feelings of abandonment
Age of the caregiver	Caregiver depressive symptoms
Caregiver's relationship to care recipient	Caregiver anxiety
Care recipient's tumor type	
Household income	
Caregiver's level of neuroticism	
Caregiver's level of social support	
Neuropsychological status of the care recipient	
Language ability subscale	
Construction ability subscale	
Memory subscale	
Calculation ability subscale	
Reasoning subscale	

2.7.1 Study Purpose 1: To explore the extent to which perceived economic hardship contributes to caregiver depressive symptoms, anxiety, and burden.

Due to the small sample size and large number of potential predictors, an attempt was made to limit potential predictors within regression models. One potential independent variable was the care recipient's neuropsychological status, which was measured with an instrument that provides both summary scores and five domain specific scores. Another potential independent variable was the caregiver's perception of economic hardship, which was measured with an instrument that also provides both summary scores and specific domain scores. High pair-wise correlations between Economic Hardship subscales and between the subscales and the summary measure (see Table 3) suggested that the summary measure could be used alone in subsequent analyses of the dependent variables (Table 2).

Table 3. Correlations among measures of Economic Hardship at the time of diagnosis (top half), and 4 months after diagnosis (bottom half).

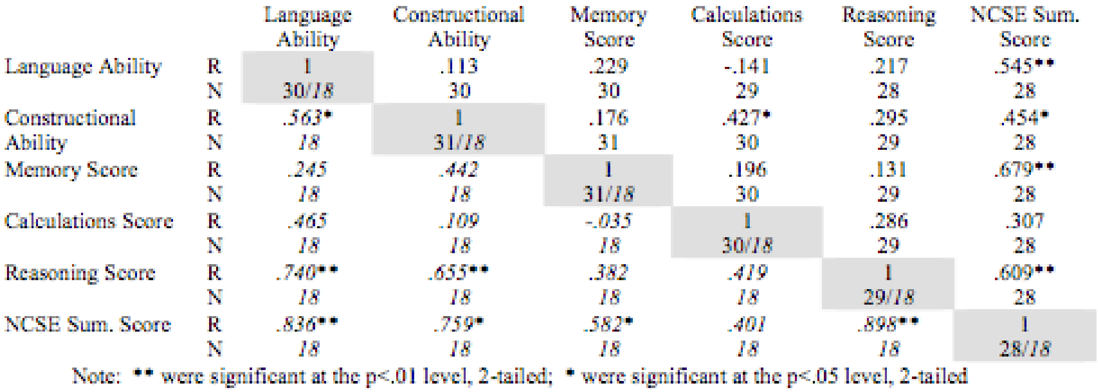


		Financial Strain	Ability to Make Ends Meet	Money for Necessities	Economic Adjustments	Summary Economic Hardship Score
Financial Strain	R	1	.778**	.846**	.832**	.895**
	N	32/22	32	32	32	32
Ability to Make Ends Meet	R	_.695_**	1	.867**	.860**	.919**
	N	_22_	32/22	32	32	32
Money for Necessities	R	_.739_**	_.718_**	1	.842**	.985**
	N	_22_	_22_	32/22	32	32
Economic Adjustments	R	_.784_**	_.818_**	_.702_**	1	.907**
	N	_22_	_22_	_22_	32/22	32
Economic Hardship Sum. Score	R	_.860_**	_.867_**	_.946_**	_.869_**	1
	N	_22_	_22_	_22_	_22_	32/22

Note: ** were statistically significant at p<.01, 2-tailed

Correlational analyses were also utilized to explore the relationships among Economic Hardship subscales and Neuropsychological Status subscales (domains). Neuropsychological subscales did not exhibit statistically significant correlations with each other or with the summary score (see Table 4), and so separate measures were used in subsequent analyses of the dependent variables of interest.

Table 4. Correlations among NCSE domain scores at the time of diagnosis (top half), and four months later (bottom half)

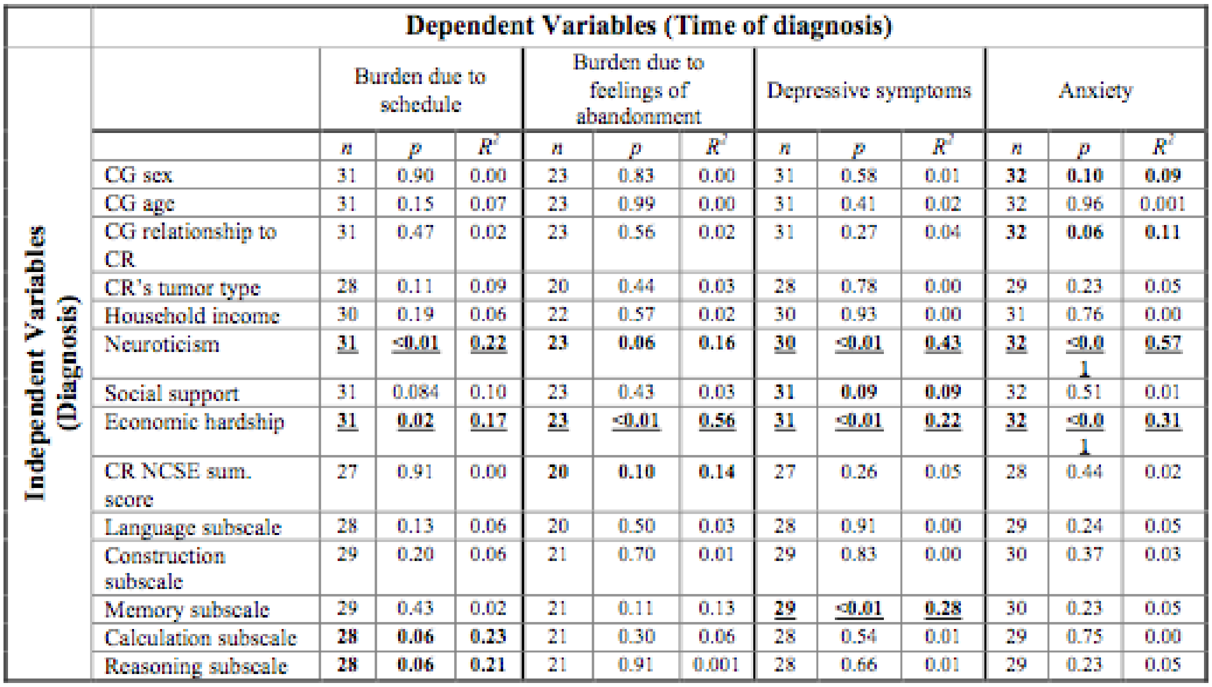


		Language Ability	Constructional Ability	Memory Score	Calculations Score	Reasoning Score	NCSE Sum. Score
Language Ability	R	1	.113	.229	-.141	.217	.545**
	N	30/*18*	30	30	29	28	28
Constructional Ability	R	*.563**	1	.176	.427*	.295	.454*
	N	*18*	31/*18*	31	30	29	28
Memory Score	R	*.245*	*.442*	1	.196	.131	.679**
	N	*18*	*18*	31/*18*	30	29	28
Calculations Score	R	*.465*	*.109*	*-.035*	1	.286	.307
	N	*18*	*18*	*18*	30/*18*	29	28
Reasoning Score	R	*.740***	*.655***	*.382*	*.419*	1	.609**
	N	*18*	*18*	*18*	*18*	29/*18*	28
NCSE Sum. Score	R	*.836***	*.759**	*.582**	*.401*	*.898***	1
	N	*18*	*18*	*18*	*18*	*18*	28/*18*

Note: ** were significant at the p<.01 level, 2-tailed; * were significant at the p<.05 level, 2-tailed

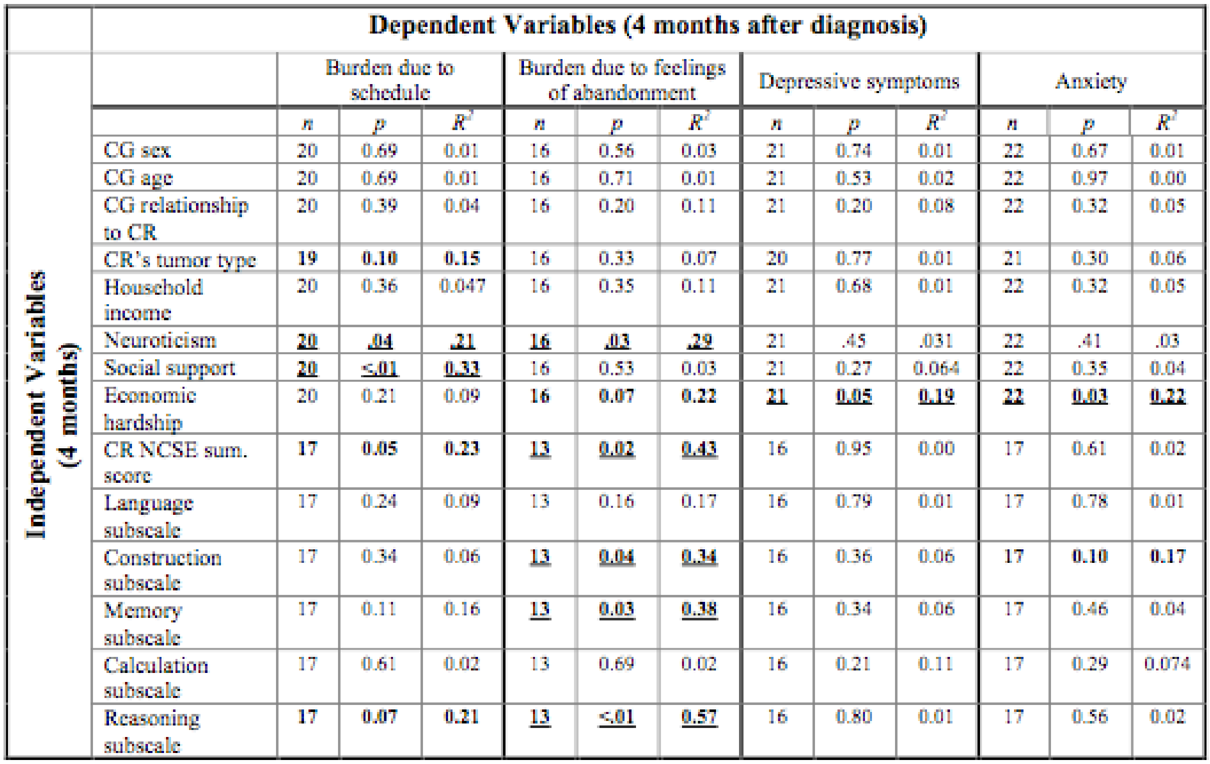
Although the primary goal of this study was to determine the impact of economic burden on caregivers' emotional health, other variables, such as age and caregivers' level of neuroticism, have been consistently associated with caregivers' emotional health in the literature, yet sample size prohibited concomitant evaluation of all factors. For this reason, the first step in each analysis was to perform univariate regression analyses between potential independent variables and each dependent variable of interest. From these univariate analyses (Table 5, 6), any potential independent variable that demonstrated a relationship with a statistical significance of p<0.10 was included as a potential predictor in multiple linear regression models.

Table 5. Results of exploratory univariate analyses of each independent variable separately with each dependent variable at time of diagnosis.



		Dependent Variables (Time of diagnosis)											
Independent Variables (Diagnosis)		Burden due to schedule			Burden due to feelings of abandonment			Depressive symptoms			Anxiety		
		n	*p*	R^2	*n*	*p*	R^2	*n*	*p*	R^2	*n*	*p*	R^2
	CG sex	31	0.90	0.00	23	0.83	0.00	31	0.58	0.01	**32**	**0.10**	**0.09**
	CG age	31	0.15	0.07	23	0.99	0.00	31	0.41	0.02	32	0.96	0.001
	CG relationship to CR	31	0.47	0.02	23	0.56	0.02	31	0.27	0.04	**32**	**0.06**	**0.11**
	CR's tumor type	28	0.11	0.09	20	0.44	0.03	28	0.78	0.00	29	0.23	0.05
	Household income	30	0.19	0.06	22	0.57	0.02	30	0.93	0.00	31	0.76	0.00
	Neuroticism	**31**	**≤0.01**	**0.22**	**23**	**0.06**	**0.16**	**30**	**≤0.01**	**0.43**	**32**	**≤0.01**	**0.57**
	Social support	31	0.084	0.10	23	0.43	0.03	**31**	**0.09**	**0.09**	32	0.51	0.01
	Economic hardship	**31**	**0.02**	**0.17**	**23**	**≤0.01**	**0.56**	**31**	**≤0.01**	**0.22**	**32**	**≤0.01**	**0.31**
	CR NCSE sum. score	27	0.91	0.00	**20**	**0.10**	**0.14**	27	0.26	0.05	28	0.44	0.02
	Language subscale	28	0.13	0.06	20	0.50	0.03	28	0.91	0.00	29	0.24	0.05
	Construction subscale	29	0.20	0.06	21	0.70	0.01	29	0.83	0.00	30	0.37	0.03
	Memory subscale	29	0.43	0.02	21	0.11	0.13	**29**	**≤0.01**	**0.28**	30	0.23	0.05
	Calculation subscale	**28**	**0.06**	**0.23**	21	0.30	0.06	28	0.54	0.01	29	0.75	0.00
	Reasoning subscale	**28**	**0.06**	**0.21**	21	0.91	0.001	28	0.66	0.01	29	0.23	0.05

Table 6. Results of exploratory regression analyses of each independent variable separately with each dependent variable 4 months after diagnosis.



	Dependent Variables (4 months after diagnosis)												
		Burden due to schedule			Burden due to feelings of abandonment			Depressive symptoms			Anxiety		
		n	p	R^2	n	p	R^2	n	p	R^2	n	p	R^2
Independent Variables (4 months)	CG sex	20	0.69	0.01	16	0.56	0.03	21	0.74	0.01	22	0.67	0.01
	CG age	20	0.69	0.01	16	0.71	0.01	21	0.53	0.02	22	0.97	0.00
	CG relationship to CR	20	0.39	0.04	16	0.20	0.11	21	0.20	0.08	22	0.32	0.05
	CR's tumor type	**19**	**0.10**	**0.15**	16	0.33	0.07	20	0.77	0.01	21	0.30	0.06
	Household income	20	0.36	0.047	16	0.35	0.11	21	0.68	0.01	22	0.32	0.05
	Neuroticism	**20**	**.04**	**.21**	**16**	**.03**	**.29**	21	.45	.031	22	.41	.03
	Social support	**20**	**≤.01**	**0.33**	16	0.53	0.03	21	0.27	0.064	22	0.35	0.04
	Economic hardship	20	0.21	0.09	**16**	**0.07**	**0.22**	**21**	**0.05**	**0.19**	**22**	**0.03**	**0.22**
	CR NCSE sum. score	**17**	**0.05**	**0.23**	**13**	**0.02**	**0.43**	16	0.95	0.00	17	0.61	0.02
	Language subscale	17	0.24	0.09	13	0.16	0.17	16	0.79	0.01	17	0.78	0.01
	Construction subscale	17	0.34	0.06	**13**	**0.04**	**0.34**	16	0.36	0.06	**17**	**0.10**	**0.17**
	Memory subscale	17	0.11	0.16	**13**	**0.03**	**0.38**	16	0.34	0.06	17	0.46	0.04
	Calculation subscale	17	0.61	0.02	13	0.69	0.02	16	0.21	0.11	17	0.29	0.074
	Reasoning subscale	**17**	**0.07**	**0.21**	**13**	**≤.01**	**0.57**	16	0.80	0.01	17	0.56	0.02

After identifying potential predictors through univariate analyses, this subset of independent variables was included in an initial multiple linear regression model for each dependent variable at each time point. In addition, each model was also forced to caregiver age, relationship to care recipient, and sex, due to the overwhelmingly consistent relationship between these factors and caregiver anxiety, depressive symptoms, and burden. Because it was the primary variable of interest, economic hardship was also forced in each model. Next, a backwards stepwise regression analysis was performed in which the least significant of the independent variables was removed one at a time from each model. Independent variables were removed until all variables in the model, had a significance of 0.10 or lower (with the exception of economic hardship), and the overall model produced acceptable fit indices.

2.7.2 Study Purpose 2: To determine whether caregiver perception of economic hardship changes from the time of diagnosis to four months later.

A paired t-test was used to examine the change in economic hardship between subjects' scores at baseline and 4 months.

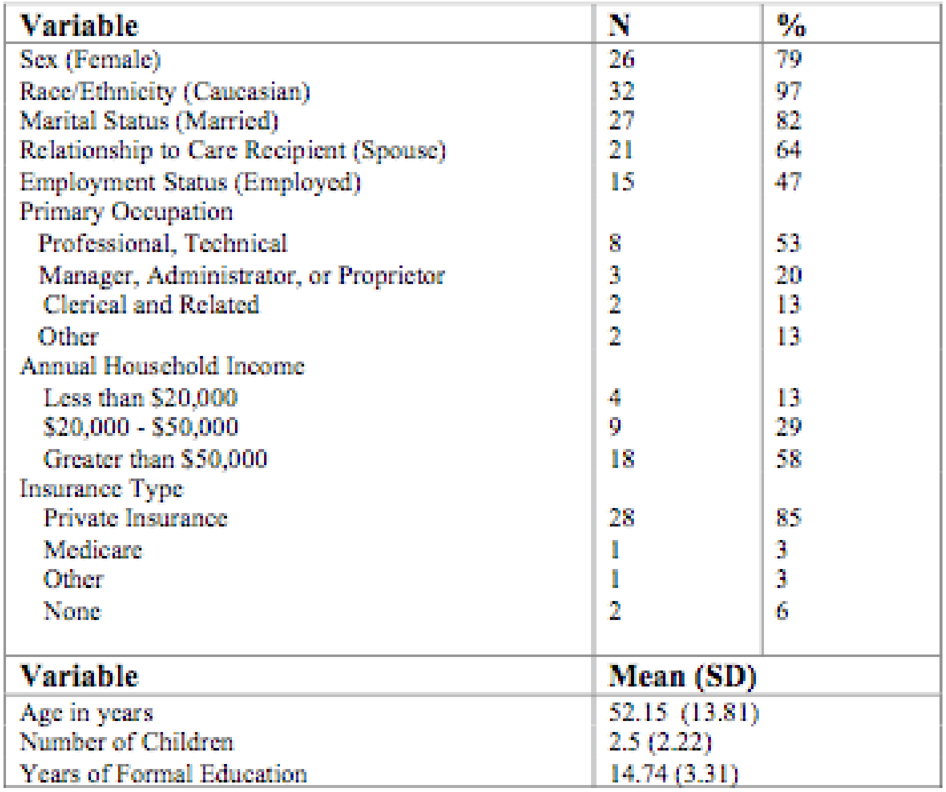
3.0 RESULTS

3.1 DESCRIPTION OF SAMPLE

A total of 33 caregiver/care recipient dyads were recruited for the project. As illustrated in Table 7, the majority of caregivers were Caucasian (n=32, 97%), women (n=26, 79%), and were spouses (n=21, 64%) of the care recipient. The mean age of the sample was 52.15 years (SD=13.81), and the caregivers had a mean number of children of 2.5 (SD=2.22) children. At the time of the first interview, approximately one-half of the caregivers were employed (n=15, 47%). Of those who were employed, 53% (n=8) worked in a professional or technical profession. The caregivers had an average length of formal education of 14.74 years (SD=3.32), indicating that many had at least some post-secondary education. The caregivers reported an annual household income of less than $50,000 in 42% (n=13) of the cases. A majority (85%, n=28) of the caregivers held private health insurance, while 2 caregivers reported they did not have health insurance.

As seen in Table 8, the majority of the care recipients were men (n=23, 70%) with a mean age of 52.51 years (SD=18.02). Most of the care recipients' tumors were classified as either astrocytomas grade I-III (n=7, 21%) or astrocytoma grade IV (glioblastoma multiforme) (n=19, 58%). Many of the care recipients (n=15, 45%) underwent at least one craniotomy and of those known to have received chemotherapy, Temodar was the most common drug received (n=22, 67%). Seventy percent (n=23) of the care recipients were known to have had radiation as part of their treatment regimen.

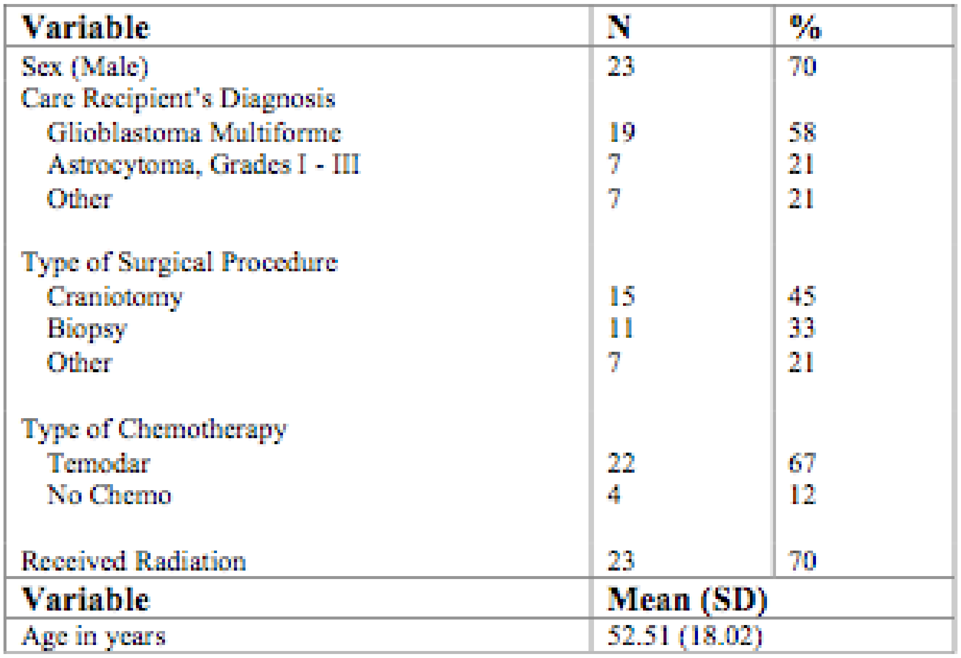
Table 7. Characteristics of caregivers in sample



Variable	N	%
Sex (Female)	26	79
Race/Ethnicity (Caucasian)	32	97
Marital Status (Married)	27	82
Relationship to Care Recipient (Spouse)	21	64
Employment Status (Employed)	15	47
Primary Occupation		
Professional, Technical	8	53
Manager, Administrator, or Proprietor	3	20
Clerical and Related	2	13
Other	2	13
Annual Household Income		
Less than $20,000	4	13
$20,000 - $50,000	9	29
Greater than $50,000	18	58
Insurance Type		
Private Insurance	28	85
Medicare	1	3
Other	1	3
None	2	6

Variable	Mean (SD)
Age in years	52.15 (13.81)
Number of Children	2.5 (2.22)
Years of Formal Education	14.74 (3.31)

Table 8. Characteristics of care recipients in sample



Variable	N	%
Sex (Male)	23	70
Care Recipient's Diagnosis		
Glioblastoma Multiforme	19	58
Astrocytoma, Grades I - III	7	21
Other	7	21
Type of Surgical Procedure		
Craniotomy	15	45
Biopsy	11	33
Other	7	21
Type of Chemotherapy		
Temodar	22	67
No Chemo	4	12
Received Radiation	23	70
Variable	**Mean (SD)**	
Age in years	52.51 (18.02)	

3.2 BASELINE RESULTS

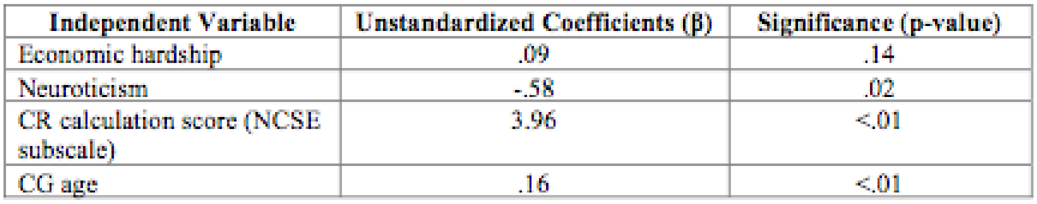
3.2.1 Study Purpose 1: To explore the extent to which perceived economic hardship contributes to caregiver burden, depressive symptoms, and anxiety.

3.2.1.1 Time of diagnosis

Caregiver burden was measured by two subscales – the impact of providing care on caregivers' schedule and the impact of providing care on caregivers' feelings of abandonment. At baseline (see Table 9), caregiver burden related to the caregivers' schedule was predicted by caregiver neuroticism (p=.02), caregiver age (p<.01), and the care recipient's ability to perform calculations (p<.01), which is a component of the care recipient's neuropsychological function.

Caregivers with higher levels of neuroticism and those who were older had higher levels of burden. When care recipients had higher functioning in their ability to perform calculations, reports of caregiver burden were higher.

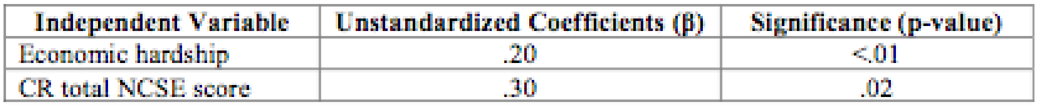
Table 9. Multiple regression analysis of factors influencing caregiver burden due to schedule at the time of diagnosis (N = 28; p < .01; R2 = .50)



Independent Variable	Unstandardized Coefficients (β)	Significance (p-value)
Economic hardship	.09	.14
Neuroticism	-.58	.02
CR calculation score (NCSE subscale)	3.96	<.01
CG age	.16	<.01

Caregiver burden due to feelings of abandonment at baseline was significantly predicted by perceived economic hardship (p < .01), and the care recipient's total neuropsychological functioning (p = 0.02)(Table 10). Caregivers who perceived a high level of economic hardship and those who were caring for persons with high levels of neuropsychological dysfunction reported higher levels of burden related to feeling abandoned.

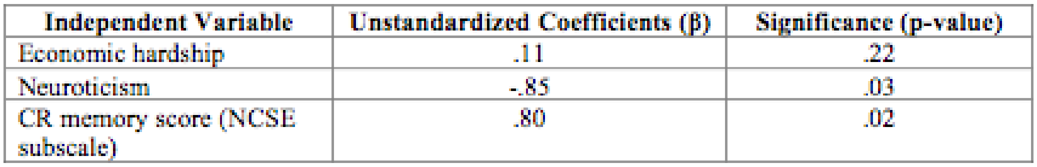
Table 10. Multiple regression analysis of factors influencing caregiver burden due to feelings of abandonment at the time of diagnosis (N = 20; p < .01; R2 = .63)



Independent Variable	Unstandardized Coefficients (β)	Significance (p-value)
Economic hardship	.20	<.01
CR total NCSE score	.30	.02

Regarding depressive symptoms, at the time of diagnosis, depressive symptoms were significantly predicted by neuroticism (p = .03) and the care recipient's ability to remember short and long term events (a component of the care recipient's neuropsychological function) (see Table 11). Caregivers with higher levels of neuroticism and those who were providing care for persons with higher levels of neuropsychological dysfunction reported higher levels of depressive symptoms.

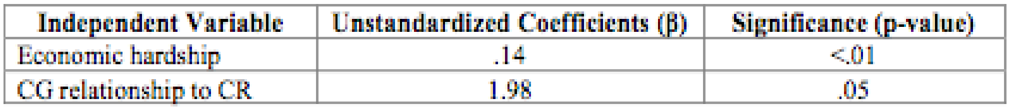
Table 11. Multiple regression analysis of factors influencing caregiver depressive symptoms at the time of diagnosis (N = 29; p <.01; R2 = .50)



Independent Variable	Unstandardized Coefficients (β)	Significance (p-value)
Economic hardship	.11	.22
Neuroticism	-.85	.03
CR memory score (NCSE subscale)	.80	.02

The final analysis of caregiver emotional health at the time of diagnosis was performed to identify predictors of caregiver anxiety. Perception of economic hardship (p<.01) and relationship to the care recipient (p=.05) significantly predicted anxiety (see Table 12). Caregivers with higher levels of economic hardship and caregivers who were also spouses reported higher levels of anxiety.

Table 12. Multiple regression analysis of factors influencing caregiver anxiety at the time of diagnosis (N = 32; p <.01; R2 = .36)

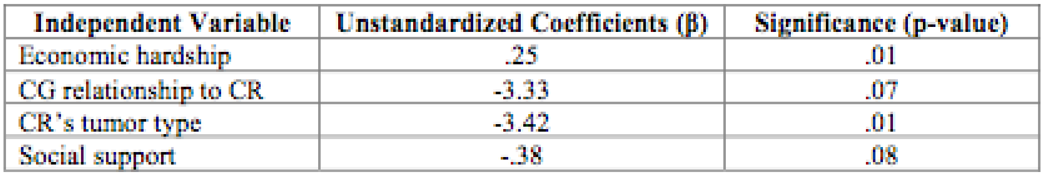


Independent Variable	Unstandardized Coefficients (β)	Significance (p-value)
Economic hardship	.14	<.01
CG relationship to CR	1.98	.05

3.2.1.2 Four months after the care recipient's diagnosis

The second set of analyses were performed to identify whether predictors of caregivers' emotional health changed at 4 months following diagnosis. At this time point, caregiver burden related to schedule was predicted by economic hardship (p<.01) and the care recipient's tumor type (p=.01)(see Table 13). Caregivers with higher levels of perceived economic hardship and caregivers of persons with a glioblastoma multiforme (the most aggressive brain tumor) reported higher levels of caregiver burden. There was also a trend for caregivers who were spouses (p=.07) and those with lower levels of social support (p=.08) to report higher levels of burden related to schedule.

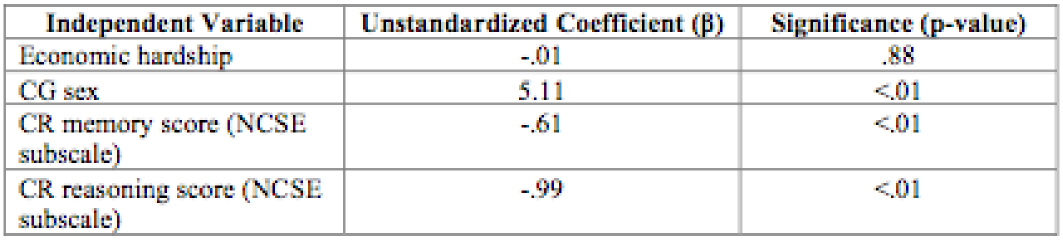
Table 13. Multiple regression analysis of factors influencing caregiver burden due to schedule at 4 months after diagnosis (N = 19; p <.01; R2 = .58)



Independent Variable	Unstandardized Coefficients (β)	Significance (p-value)
Economic hardship	.25	.01
CG relationship to CR	-3.33	.07
CR's tumor type	-3.42	.01
Social support	-.38	.08

At 4 months following diagnosis, caregiver burden related to feelings of abandonment was predicted by caregiver sex (p<.01), and two components of the care recipient's neuropsychological function – the care recipient's ability to remember short and long term events and the care recipient's ability to reason(see Table 14). Female caregivers and caregivers of persons who had higher levels of dysfunction in memory and reasoning were more likely to report higher levels of burden due to abandonment.

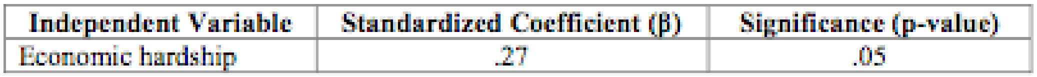
Table 14. Multiple regression analysis of factors influencing caregiver burden due to feelings of abandonment at 4 months after diagnosis (N = 13; p<.01; R2 = .91)



Independent Variable	Unstandardized Coefficient (β)	Significance (p-value)
Economic hardship	-.01	.88
CG sex	5.11	<.01
CR memory score (NCSE subscale)	-.61	<.01
CR reasoning score (NCSE subscale)	-.99	<.01

Four months after the care recipient's diagnosis, perception of economic hardship was the only statistically significant predictor of caregiver depressive symptoms (p = .048). As caregivers had higher levels of economic hardship, they also reported more depressive symptoms (see Table 15).

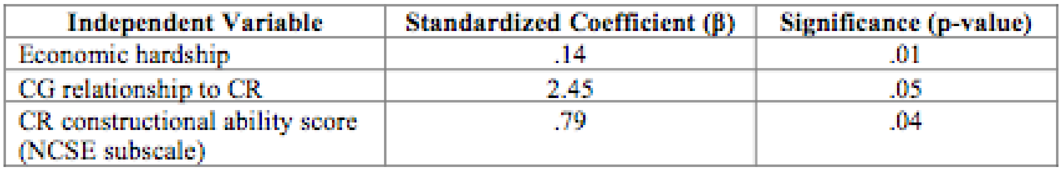
Table 15. Multiple regression analysis of factors influencing caregiver depressive symptoms at 4 months after diagnosis (N = 21; p = .05; R2 = .15)



Independent Variable	Standardized Coefficient (β)	Significance (p-value)
Economic hardship	.27	.05

Finally, caregiver anxiety at 4 months following diagnosis was predicted by caregivers' perception of economic hardship (p=.01), caregivers' relationship to the care recipient (p=.05), and the care recipient's ability to perform constructional tasks (p=.04), a component of care recipients' neuropsychological function (see Table 16). Caregivers who reported higher levels of perceived economic hardship, who were spouses of the care recipient, and who were providing care for someone with difficulty with constructional ability reported higher levels of anxiety.

Table 16. Multiple regression analysis of factors influencing caregiver anxiety at 4 months after diagnosis (N = 17; p <.01; R2 = .52)

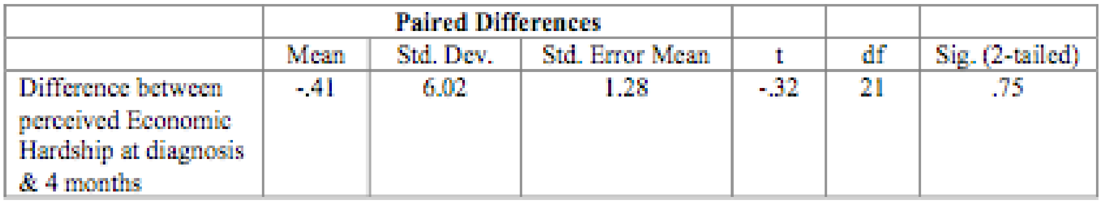


Independent Variable	Standardized Coefficient (β)	Significance (p-value)
Economic hardship	.14	.01
CG relationship to CR	2.45	.05
CR constructional ability score (NCSE subscale)	.79	.04

3.2.2 Study Purpose 2: To determine whether caregiver perception of economic hardship changes from the time of diagnosis to four months after diagnosis.

Paired t-tests showed no statistically significant difference (Table 17) between caregivers’ reported economic hardship at the time of diagnosis and economic hardship 4 months into the disease trajectory. The mean score for Economic Hardship at diagnosis was 28.66 (SD=12.62) and 4 months later was 29.14 (SD=11.02). Paired sample correlation between Economic Hardship at the time of diagnosis and four months later was high ($R^2 = 0.87$).

Table 17. Difference in perceived economic hardship between diagnosis and 4 months later



	Paired Differences					
	Mean	Std. Dev.	Std. Error Mean	t	df	Sig. (2-tailed)
Difference between perceived Economic Hardship at diagnosis & 4 months	-.41	6.02	1.28	-.32	21	.75

4.0 DISCUSSION

Cancer is a costly disease, both for those diagnosed and their family members. Research has shown that undergoing treatment for cancer results in many expenses over and above the direct costs of care, the impact of which is often felt by family members, such as spouses, who serve as family caregivers. For example, due to caregiving demands and rising expenses, many persons caring for a loved one with cancer must leave or reduce paid employment, leading to a loss of earnings in addition to those lost by the care recipient. While studies have reported work on quantifying the costs of cancer care, and a separate body of literature has shown that financial concerns affect emotional health in healthy adults, little research has explored how the costs of cancer impact caregivers' burden, depressive symptoms, and anxiety. There is also a scarcity of research describing how the perception of economic hardship changes over time, as the care recipient's disease and treatment progress. Therefore, the purposes of this study were to: 1) explore the extent to which perceived economic hardship contributes to the emotional consequences of providing care to a person with a PMBT, and 2) explore the extent to which the perception of economic hardship changes during the first four months following diagnosis.

4.1 STUDY PURPOSE 1: TO EXPLORE THE EXTENT TO WHICH PERCEIVED ECONOMIC HARDSHIP CONTRIBUTES TO CAREGIVER BURDEN, DEPRESSIVE SYMPTOMS, AND ANXIETY.

For this study caregiver emotional health was operationalized as caregiver burden, depressive symptoms, and anxiety. Because caregiver burden is a multi-dimensional concept, two subscales of the CRA were used. The schedule subscale assessed the impact of providing care on the caregiver's usual activities, including whether providing care has forced them to eliminate activities and interfered with relaxation. The abandonment subscale of the CRA measured the ability of the family to support the caregiver and work together in the care situation (including the caregiver's perception of being 'abandoned' by family and friends).

4.1.1 Burden Due to Schedule

At the time of diagnosis, caregiver feelings of burden due to schedule were predicted by caregiver neuroticism, the care recipient's calculation ability, and the age of the caregiver. Neurotocism predicted burden due to schedule in such a manner that persons who were more neurotic reported higher levels of burden, data which supports work in caregivers of persons with Alzheimer's disease and persons with cancer [Nijober et al., 2001; Bookwala and Schulz, 1998]. Research in other caregiving populations has also suggested that caregivers caring for patients with more neuropsychological dysfunction tend to feel more burdened in the care situation [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000], and that the caregiver's level of neuroticism may help moderate this relationship [Bookwala and Schulz, 1998]. However, in this study the care recipients' ability to perform calculations predicted burden due to schedule such that when care recipients were better able to perform calculations, caregivers reported higher levels of burden related to schedule. This discrepancy may be an artifact of the changing nature of the relationship between the care recipient’s calculation ability and the caregiver’s level of burden due to schedule - this relationship no longer existed four months into the care situation. In addition, most studies have used overall neuropsychological functioning, rather than domain specific functioning, as a predictor of caregiver outcomes. In fact, when univariate analyses were performed, there was no relationship between overall NP performance and caregiver burden related to schedule. Finally, it may be that patients with higher abilities in calculations were employed in jobs that necessitated high degrees of cognitive functioning. Given that the majority of the care recipients stopped working during the course of their initial diagnosis and treatment, it may be that caregivers of this group felt more acutely stressed and burdened due to their schedule.

A similarly discordant result compared to prior literature was seen when caregiver age predicted burden due to schedule in a manner such that older caregivers were more likely to report feeling burdened. In general, studies have suggested that younger caregivers were more likely to feel burdened [Pinquart and Sorensen, 2003; Zarit et al., 1986; Blood et al., 1994]. This finding could have been affected by the sample size. For example, the majority of our caregivers were spouses, who would be significantly older than adult children, the next most common group. As spouses typically display higher levels of burden [Pinquart and Sorensen, 2003] caregiver age could have been masking this effect. Conducting analysis to examine the interaction between age and relationship to the care recipient would help to elucidate these findings, but was prohibited by sample size restrictions. At the time of diagnosis, the perception of economic hardship did not predict caregiver burden due to schedule.

Four months after diagnosis, caregiver burden due to schedule was predicted by perception of economic hardship such that participants reporting higher levels of economic hardship were more likely to report feeling burden related to their schedule. Caregivers who were spouses of the care recipients were more likely to report feeling burdened (supporting the previously suggested hypothesis that older caregivers were more likely to feel burdened because they were spouses), a finding supported in the meta-analysis of dementia caregivers performed by Pinquart and Sorensen in 2003. In addition, caregivers of care recipients with higher-grade tumors were more likely to report feeling burdened due to their schedule. Tumors of higher grade may indicate a poorer prognosis for the patient and has been shown to influence the psycho-behavioral response of the caregiver [Ergh et al., 2003; Sherwood et al., 2007]. In addition, the caregivers' level of social support predicted burden due to schedule such that participants with lower levels of social support reported greater burden. Similarly, Nabors et al. [2002] found that in their study population of caregivers of patients with traumatic brain injuries, caregivers with less social support and more unmet family needs tended to report higher levels of burden.

Economic hardship had a greater influence on caregiver burden due to schedule four months into the care situation than at the time of diagnosis. By this point in the treatment trajectory, the care recipients and their families have likely received bills for their initial hospital stays, surgeries, biopsies, radiation, and/or chemotherapy. The care recipient has likely missed a great deal of work, and the caregiver has probably missed at least some days as well. It may be hypothesized that caregivers feel more burdened due to their schedule at four months following diagnosis because they are worried about missing too much work, and how that loss will affect their family financially. Since it appears that positive social support may alleviate the caregivers' feelings of burden, perhaps encouraging caregivers to reach out to friends and family for help and support may be one strategy that could help decrease these feelings of burden. This may be particularly important for caregivers who are spouses of their respective patients, and for caregivers of care recipients with high-grade tumors.

4.1.2 Burden Due to Feelings of Abandonment

At the time of diagnosis, caregiver burden due to feelings of abandonment was predicted by economic hardship, such that caregivers who reported greater levels of economic hardship reported higher levels of burden. Similarly, caregivers caring for patients with higher overall scores on the NCSE, and therefore had higher levels of neuropsychological function, were more likely to report feeling burdened due to feelings of abandonment. This is a similar relationship to that seen between burden due to schedule and calculation ability, however differs from the studies that report a trend of increasing caregiver burden with decreasing neurological functioning in the patient [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000]. Perhaps, at the outset of the care situation, caregivers of higher functioning persons do not receive as much help from friends and family members. Because the care recipient seems to be doing well, friends and family may not think it necessary to offer support and assistance to the caregiver.

Four months after the care recipient's diagnosis, however, caregiver burden due to feelings of abandonment was predicted by care recipient memory and reasoning such that caregivers caring for patients with worse memory and reasoning were more likely to report feeling burdened. This is the expected relationship as reported by previous studies [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000], but differs from that seen in this study at the time of diagnosis. This finding provides evidence for the hypothesis that the relationship between care recipient neurological function and caregiver burden and depressive symptoms is a changing one. This study has also provided evidence that different types of neuropsychological functioning (the NCSE subscales of language, constructional ability, memory, calculations, and reasoning) in the care recipient may affect caregiver burden and depressive symptoms in different ways. Perhaps, as it appears here, lower functioning influences burden and depressive symptoms more as the care situation progresses.

Four months after the care recipient's diagnosis caregiver burden due to feelings of abandonment was predicted by caregiver sex, such that female caregivers were more likely to report feeling burdened. This finding is supported by previous work, in particular a meta-analysis of 84 studies of family caregivers of older, frail adults performed by Pinquart and Sorensen in 2003. This information may be helpful in the future when deciding which caregivers to approach with interventions designed to alleviate or prevent feelings of burden.

Although at the time of diagnosis economic hardship was a significant predictor of caregiver burden due to abandonment, it was not four months later. It may be hypothesized that at the time of diagnosis the caregiver may worry about many things, but one stressor may be the looming bills and financial pressures. These worries may cause the caregiver to feel alone and without support, particularly if the care recipient, who used to help shoulder financial burden, is no longer able to do so. At four months into the care situation, however, the caregiver is likely to have received help from others in caring for the patient, so that he or she may go to work and fulfill other responsibilities. It may also be hypothesized that some of these caregivers are finding that their ill loved ones are able to return to work and are therefore sharing in the financial load. Further work is needed to evaluate this relationship, and may include analyzing employment patterns of both patients and caregivers and how this relates to caregiver burden. Knowing that these caregivers are feeling burdened at the outset of the care situation, however, may indicate a crucial timepoint for intervention. Stopping or alleviating caregiver burden early in the care situation may help prevent some negative emotional consequences from occurring down the line.

4.1.3 Depressive Symptoms

Caregiver depressive symptoms were predicted by personality type such that caregivers with higher levels of neuroticism were more likely to report higher levels of depressive symptoms. This is a finding that is supported in studies of caregivers of persons with Alzheimer's disease and persons with cancer [Nijober et al., 2001; Bookwala and Schulz, 1998]. In keeping with some of the findings reported in previous sections, the care recipient's score on the memory subscale of the NCSE predicted depressive symptoms such that care recipients with better memory tended to have caregivers who reported more depressive symptoms. Several past studies have found the opposite effect, that caregivers were more likely to report depressive symptoms, and feel burdened and anxious when caring for poorly functioning patients [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000]. It is possible that the discrepancies found in this study in terms of the relationship between the neurological functioning of the care recipient and caregiver burden and depressive symptoms may be partly a function of the timing of the interviews. It may be that caregivers of highly functioning patients feel greater dread about the inevitable decline of their loved one, which may in turn affect their levels of burden and depressive symptoms. Again, this is a finding that should be re-examined in a larger sample size, and at several time points over a longer treatment trajectory.

At the time of diagnosis, economic hardship did not predict caregiver depressive symptoms, however four months into the care situation it was the only significant predictor of these symptoms. This study found that caregivers who reported higher economic hardship were more likely to report having depressive symptoms. Depressive symptoms can, in turn, influence a person’s lifestyle choices that can impact physical health. It is important to try to stop or prevent this process from occurring, and this may be possible through the implementation of targeted interventions. While it may not be feasible to directly change a patient’s financial status, it may yet be possible to indirectly alter the perception through financial advisement and counseling. Such actions, taken soon after the patient is diagnosed and before the caregiver feels too many negative emotional consequences, may help empower the caregiver in a situation in which he or she may otherwise feel helpless.

4.1.4 Anxiety

At the time of diagnosis and four months into the care situation, caregivers who were spouses of the care recipients were more likely to report feeling anxious. This finding is supported in the literature in studies of caregivers of persons with cancer and persons with dementia [Pinquart and Sorensen, 2003; Nijboer et al., 2001; Gaugler et al., 2000].

Caregivers caring for patients with higher scores on the construction subscale of the NCSE, and therefore more ability in this area, were more likely to report feeling anxious in the care situation four months after the diagnosis. It is unusual to hear reports of higher care recipient functioning leading to more caregiver anxiety. In fact, previous studies have actually found the opposite to be true in the areas of oncology and dementia care [Chumbler et al., 2003; Pinquart and Sorensen, 2003; Bookwala and Schulz, 2000; Gaugler et al, 2000]. While constructional ability approached significance as a predictor in the initial univariate analysis at four months, no other neuropsychological domain significantly predicted anxiety at either four months or the initial time of diagnosis. Prior studies that have examined the relationship between care recipient functioning and caregiver emotional response have used broader measures of neuropsychological status, such as the total NCSE score, and therefore may not have seen different affects from separate types of functioning. This relationship should be examined further in a larger sample, and at multiple time points over a longer treatment trajectory.

Economic hardship predicted caregiver anxiety both at the time of diagnosis and four months into the care situation, suggesting that this relationship may be constant. In general, caregivers who reported higher levels of economic hardship were more likely to report feeling anxious. This makes sense intuitively, and it is therefore likely that any future interventions that decreased economic hardship may also alleviate some anxiety.

4.2 STUDY PURPOSE 2: TO DETERMINE WHETHER CAREGIVER PERCEPTION OF ECONOMIC HARDSHIP CHANGES FROM THE TIME OF DIAGNOSIS TO FOUR MONTHS LATER.

There was no difference between the levels of economic hardship reported by the caregivers at the time of diagnosis and economic hardship four months into the care situation. This suggests that, at least in the early stages of the treatment trajectory, perceptions of economic hardship do not change. However, even though it may not change, perceived economic hardship does appear to influence this population of caregivers in a negative way.

4.3 CONCLUSIONS

These results suggest that perceived economic hardship may play an important role in caregivers’ emotional health. However, it appears that the nature of this relationship changes over time, even though the actual perception of economic hardship may not. These data may be useful in identifying caregivers at risk for burden, depressive symptoms, and anxiety, and suggest possible timing of and avenues for future interventions with this population. In addition, this study helps identify additional areas of research that are needed in order to better understand the impact of family caregiving on the physical and mental health of persons serving in this role.

4.3.1 Implications for Public Health

Due to the high numbers of family caregivers and the proven impact of providing care on caregivers’ emotional, and subsequently physical health, it is vital that we determine predictors of emotional and physical dysfunction. Public health implications as a result of identifying those predictors include:

- If caregivers’ emotional and physical health deteriorates, there will be a greater demand on the nation’s health system, a factor that should not be taken lightly when considering the number of family caregivers in the U.S.

- Caregivers who are have poor emotional or physical health may be less able to deliver high quality care to the care recipient, which could potentially lead to more patient hospitalizations and institutionalization [Schulz et al., 1999; Schulz et al., 2004].

4.3.2 Implications for Clinical Practice

- Quality cancer care should go beyond care of the tumor and help patients and their families deal with secondary issues, such as economic concerns.
- Clinicians should consider implementing financial planning services at the time of diagnosis to help the family cope with economic concerns.
- Clinicians should assess, and regularly reassess, patients' and caregivers' perception of economic hardship and evaluate its potential impact on emotional health and treatment decisions.

4.3.3 Implications for Future Research

This study has begun to explore the effect economic hardship has on caregiver emotional health. However, further research is needed in several areas, including:

Descriptive

- How does perceived economic hardship influence patient adherence to treatment regimens?
- Does perception of economic hardship differ between populations of persons with other types of cancer (prostate, colon, etc.)?
  - Other chronic illnesses?

- How does perceived economic hardship influence patient outcomes, such as symptom severity and quality of life?
- What impact does caring for a loved one have on caregivers' work productivity?
- How do religious faith and/or spiritual beliefs affect the emotional health of caregivers?
    - Do these beliefs mediate the relationship between perceived economic hardship and emotional health?
- How does caregiver perception of economic hardship change after the care situation is over?
    - How does it change throughout a long-term care situation?

Interventions

- Financial planning assistance at the time of patient's diagnosis.
    - Does financial planning assistance at the time of diagnosis alleviate perceived economic hardship?
    - Does it limit the effect that economic hardship has on caregiver burden, depressive symptoms, and anxiety?
    - Is it feasible to offer financial planning assistance?
    - Who should it be offered to? How should eligible patients and their families be identified?
- Would psychosocial counseling with family caregivers reduce the impact of economic hardship on emotional health?
- What would the impact of a public education intervention regarding health insurance options have on the perceived economic hardship of caregivers of persons with chronic diseases?

4.3.4 Limitations

This study is limited by its relatively small sample size of 33 participants. Also, the majority of participants in the sample were Caucasian. Although this is representative of the way in which the disease occurs, it precludes generalization to other ethnic groups where other avenues of financial and family support may vary. In addition, participants were recruited solely from medical clinics serving the Pittsburgh and Western Pennsylvania region. It is possible that economic concerns facing persons living in this area may differ from those living in other areas of the country. Finally, although persons with differing annual household incomes were represented in the sample, there were more persons with incomes above $50,000 than any other category, which may limit generalization.

APPENDIX A. CARE RECIPIENT CONSENT FORM

University of Pittsburgh
School of Nursing
Acute and Tertiary Care Department
336 Victoria Bldg, 3500 Victoria St
Pittsburgh, PA 15261 Phone: 412-624-4722

University of Pittsburgh
Institutional Review Board
Approval Date:06/05/2007
Renewal Date:04/25/2008
IRB #:074007

CONSENT TO ACT AS A SUBJECT IN A CLINICAL STUDY
CARE RECIPIENT

TITLE: Stress and aging: Caregiver outcomes in neuro-oncology

PRINCIPAL INVESTIGATOR:
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Alyssa Newberry, Student Worker, Sch of Nsg, U of Pgh, 15261, (412) 624-1316
SOURCE OF SUPPORT: University of Pittsburgh Cancer and Aging Program; Oncology Nursing Society

Why is this research being done?

The purpose of this research study is to identify factors that are involved in caring for someone with a brain tumor and to examine the stress that can go along with a family member's treatment.

Who is being asked to take part in this study?

You have been invited to participate in this research study because you are over 21 years of age and you have been diagnosed with a brain tumor. You will be one of 120 persons who will be studied.

What procedures will be performed for research purposes?

If you decide to take part in this research study, you will undergo the following procedures that are not part of your standard medical care. This study will require four, 15 minute visits either in your home or at your clinic visit.

Screening procedures: We will review your medical records to verify your diagnosis. No additional procedures will be necessary to determine if you are eligible to take part in this research study.

Participant's Initials_____

Experimental procedures: If you qualify to take part in this research study, you will undergo the following procedures:

Monitoring your physical and neurological function (e.g. your ability to remember and do things for yourself). A member of the research team will ask you questions to see how your thinking is and to see how you are able to do things for yourself. Answering these questions will take approximately 20 minutes. The research team member will do this 4 times – once at your initial visit and again at your 4, 8 and 12 month follow up visit. These questions will help us get a better of idea of any help you may need at home.

What are the possible risks, side effects and discomforts of this research study?

You may feel uneasy about sharing personal information. You may choose not to answer any question that makes you uneasy. In addition, you may choose to withdraw from the study at any time.

What are the possible benefits from taking part in this research study?

There will be no direct benefit from participating in this study.

If I agree to take part in this research study, will I be told of any new risks that may be found in the course of the study?

You will be promptly notified if any new information develops during the conduct of this research study which may cause you to change your mind about continuing to participate.

Will I or my insurance provider be charged for the costs of any procedures performed as a part of this research study?

You and/or your insurer will not be billed for research only services. The study will pay for the research only costs. You and/or your insurer will be billed for routine care services and you will be responsible for any applicable copays, coinsurances and deductibles.

Will I be paid if I take part in this research study?

You will be paid $25 for each time we interview you (possibly four times).

Who will know about my participation in this research study?

Records pertaining to your involvement in this research study will be stored in locked file cabinets within the department of the principal investigator. A case number will indicate your identity on these records and specimens. This information will only be accessible to the investigators and their research study staff listed on the first page of this document. Your personal research results will not be put in your medical record. University of Pittsburgh policy requires that research records be kept for a period of not less than five years.

Participant's Initials_____

Is my participation in this research study voluntary?

Your participation in this research study, to include the use and disclose of your identifiable information for the purposes described above, is completely voluntary. (Note, however, that if you do not provide your consent for the use and disclosure of your identifiable information for the purposes described above, you will not be allowed, in general, to participate in the research study.) Whether or not you provide your consent for participation in this research study will have no affect on your current or future relationship with the University of Pittsburgh. Whether or not you provide your consent for participation in this research study will have no affect on your current or future medical care at a UPCI treatment center or affiliated health care provider or your current or future relationship with a health care insurance provider.

Your doctor may be an investigator in this research study, and as an investigator, is interested both in your medical care and in the conduct of this research. Before agreeing to participate in this research study or at any time during your study participation, you may discuss your care with another doctor who is in no way associated with this research study. You are not under any obligation to participate in any research study offered by your doctor.

May I withdraw, at a future date, my consent for participation in this research study?

You may withdraw, at any time, your consent for participation in this research study, to include the use and disclosure of your identifiable information for the purposes described above. (Note, however, that if you withdraw your consent for the use and disclosure of your identifiable information for the purposes described above, you will also be withdrawn, in general, form further participation in this research study). Any identifiable research or medical record information recorded for, or resulting from your participation in this research study prior to the date that you formally withdrew your consent may continue to be used and disclosed by the investigators for the purposes described above. Should you decide to withdraw, you may choose to have your specimens returned to you or destroyed.

To formally withdraw your consent for participation in this research study you should provide a written and dated notice of this decision to the principal investigator of this research study at the address listed on the first page of this form.

Your decision to withdraw your consent for participation in this research study will have no affect on your current or future relationship with the University of Pittsburgh. Your decision to withdraw your consent for participation in this research study will have no affect on your current or future medical care at a UPCI treatment center or affiliated health care provider or your current or future relationship with a health care insurance provider.

Under what circumstances might I be withdrawn from the study?

You will be withdrawn from the study if your caregiver wishes to withdraw from the study.

Participant's Initials_____

Any information about you obtained from this research will be kept as confidential (private) as possible. You will not be identified by name in any publication of research results unless you sign a separate form giving your permission (release). In unusual cases, your research records may be released.

Will this research study involve the use or disclosure of my identifiable medical record information?

We will record the following information from your clinic chart – your diagnosis, treatment plan, any changes to your tumor over the course of your participation in the study, and any side effects from treatment noted over the course of your participation in the study. This information will be identified by a study ID number only and will be kept in a locked office in the project area.

Who will have access to identifiable information related to my participation in this research study?

In addition to the investigators listed on the first page of this authorization (consent) form and their research staff, the following individuals will or may have access to identifiable information related to your participation in this research study:

Authorized representatives of the University of Pittsburgh Research Conduct and Compliance Office may review your identifiable research information for the purpose of monitoring the appropriate conduct of this research study. In unusual cases, the investigators may be required to release identifiable information related to your participation in this research study in response to an order from a court of law. If the investigators learn that you or someone with whom you are involved is in serious danger or potential harm, they will need to inform, as required by Pennsylvania law, the appropriate agencies.

Authorized representatives of the University of Pittsburgh Cancer Institute (UPCI) or other affiliated health care providers may have access to identifiable information related to your participation in this research study for the purpose of (1) fulfilling orders, made by the investigators, for hospital and health care services (e.g., laboratory tests) associated with research study participation; (2) addressing correct payment for tests ordered by the investigators; and /or (3) for internal hospital operations (i.e. quality assurance).

Other members of the research team may have access to data or samples collected as part of this research study in order to complete specimen testing and data analysis. We will be happy to provide you with a list of these members at your request.

May I have access to my information that results from my participation in this research study?

In accordance with the UPCI Notices of Privacy Practices document that you have been provided, you are permitted access to information contained within your medical records filed with your health care provider.

For how long will the investigators be permitted to use and disclose identifiable information related to my participation in this research study?

The investigators may continue to use and disclose, for the purposes described above, identifiable information related to your participation in this research study indefinitely.

Participant's Initials_____

Who will pay if I am injured as a result of taking part in this research study?

University of Pittsburgh researchers and their associates who provide services at the UPCI recognize the importance of your voluntary participation in their research studies. These individuals and their staffs will make reasonable effort to minimize, control, and treat any injuries that may arise as a result of this research. If you believe that you are injured as the result of the research procedures being performed, please contact immediately the Principal Investigator or one of the co-investigators listed on the first page of this form.

Emergency medical treatment for injuries solely and directly relating to your participation in this research will be provided to you by hospitals of the University of Pittsburgh Medical Center (UPMC). It is possible that the UPMC may bill your insurance provider for the costs of this emergency treatment. Any co payments or deductibles will remain the responsibility of the insured party. If your research-related injury requires medical care beyond this emergency treatment, you will be responsible for the costs of this follow-up care unless otherwise specifically stated below. There is no plan for monetary compensation. You do not, however, waive any legal rights by signing this form.

VOLUNTARY CONSENT:

All of the above has been explained to me and all of my current questions have been answered. I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that such future questions will be answered by the researchers listed on the first page of this form. Any questions I have about my rights as a research participant will be answered by the Human Subject Protection Advocate of the IRB Office, University of Pittsburgh (1-866-212-2668). By signing this form, I agree to participate in this research study. A copy of this consent form will be given to me. I further certify that no research component of this protocol was begun until after this consent form was signed.

________________________________ ___________________________
Participant's Signature Date

____
Participant's Name (Print)

CERTIFICATION of INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise.

______________________________ ___________________________
Printed Name of Person Obtaining Consent Role in Research Study

_________________________________ ________________________________
Signature of Person Obtaining Consent Date

____
Participant's Name (Print)

is unable to provide direct consent for study participation because

____

Therefore by signing this form, I give my consent for his/her participation in this research study.

______________________________	________________________
Representative's Name (Print)	Representative=s Relationship to Participant
______________________________	________________________
Representative's Signature	Date/Time

Verification of Explanation

I certify that I have carefully explained the purpose and nature of this research study to the above named participant in appropriate language. He/she has had an opportunity to discuss it with me in detail. I have answered all his/her questions and he/she has provided affirmative agreement (i.e., assent) to participate in this study.

___________________________	__________________________________
Investigator's Signature	Date

CONSENT FOR CONTINUED RESEARCH PARTICIPATION:

I understand that I am currently participating in a research study. I further understand that consent for my participation in this research study was initially obtained from my authorized representative as a result of my inability to provide direct consent at the time that this initial consent was requested. I have now recovered to the point where it is felt that I am able to provide direct consent for continued participation in this research study.

All of the above has been explained to me and all of my current questions have been answered. I understand that I am encouraged to ask questions about any aspect of this study and that future questions will be answered by the researchers listed on the first page of this form. I also understand that any questions I have about my rights as a research participant will be answered by the Human Subject Protection Advocate of the IRB Office, University of Pittsburgh (866-212-2668). By signing below, I agree to continue my participation in this research study. A copy of this consent from will be given to me.

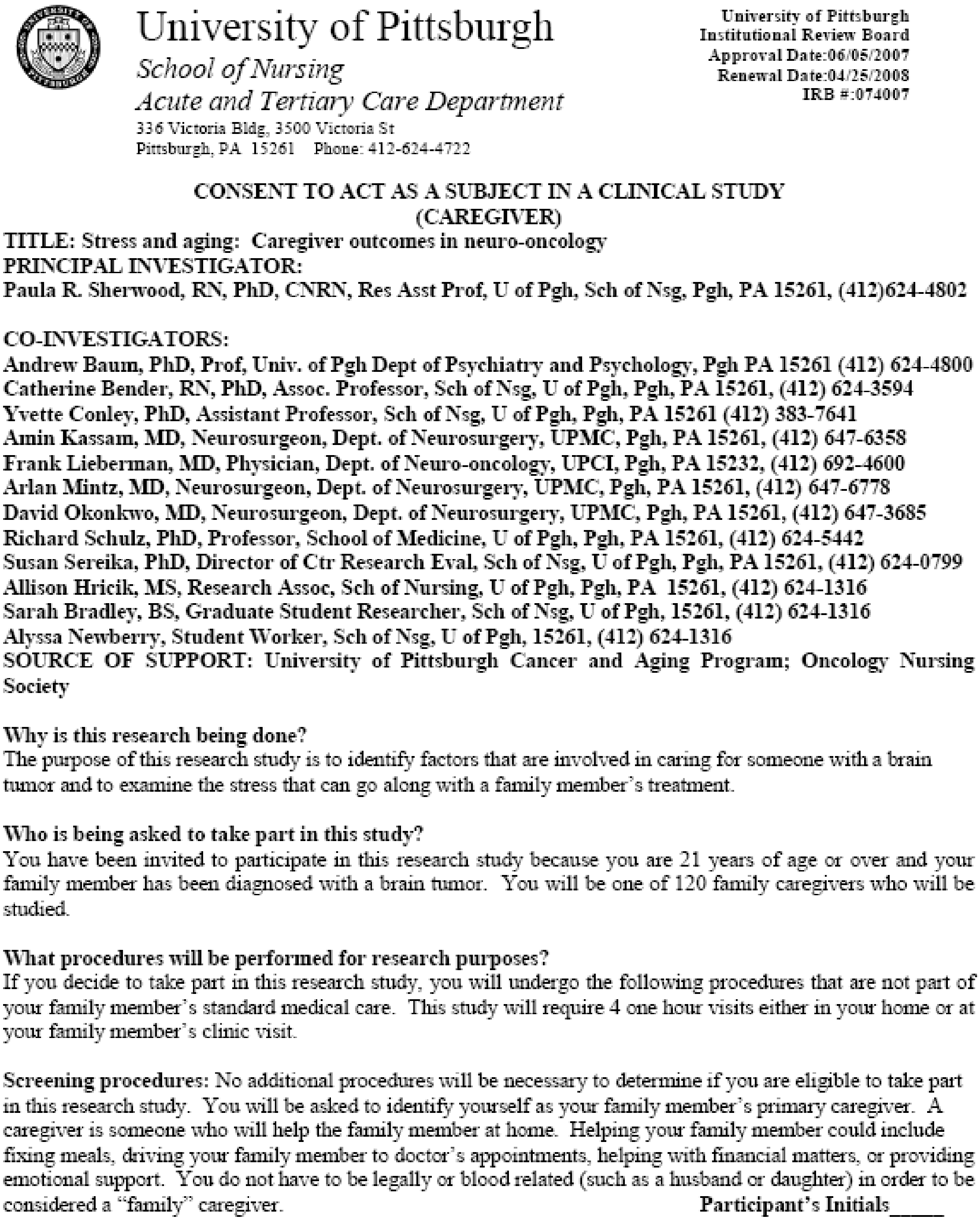
______________________________	___________________________
Participant's Signature	Date

VERIFICATION OF EXPLANATION

I have explained the purpose and nature of this research study to the above named participant in appropriate language. He/she has had an opportunity to discuss it with me in detail. I have answered all his/her questions and he/she has provided affirmative agreement (i.e., assent) to participate in this study.

______________________________	___________________________
Investigator's Signature	Date

APPENDIX B. CAREGIVER CONSENT FORM



University of Pittsburgh
School of Nursing
Acute and Tertiary Care Department
336 Victoria Bldg, 3500 Victoria St
Pittsburgh, PA 15261 Phone: 412-624-4722

University of Pittsburgh
Institutional Review Board
Approval Date:06/05/2007
Renewal Date:04/25/2008
IRB #:074007

CONSENT TO ACT AS A SUBJECT IN A CLINICAL STUDY (CAREGIVER)

TITLE: Stress and aging: Caregiver outcomes in neuro-oncology
PRINCIPAL INVESTIGATOR:
Paula R. Sherwood, RN, PhD, CNRN, Res Asst Prof, U of Pgh, Sch of Nsg, Pgh, PA 15261, (412)624-4802

CO-INVESTIGATORS:
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David Okonkwo, MD, Neurosurgeon, Dept. of Neurosurgery, UPMC, Pgh, PA 15261, (412) 647-3685
Richard Schulz, PhD, Professor, School of Medicine, U of Pgh, Pgh, PA 15261, (412) 624-5442
Susan Sereika, PhD, Director of Ctr Research Eval, Sch of Nsg, U of Pgh, Pgh, PA 15261, (412) 624-0799
Allison Hricik, MS, Research Assoc, Sch of Nursing, U of Pgh, Pgh, PA 15261, (412) 624-1316
Sarah Bradley, BS, Graduate Student Researcher, Sch of Nsg, U of Pgh, 15261, (412) 624-1316
Alyssa Newberry, Student Worker, Sch of Nsg, U of Pgh, 15261, (412) 624-1316
SOURCE OF SUPPORT: University of Pittsburgh Cancer and Aging Program; Oncology Nursing Society

Why is this research being done?

The purpose of this research study is to identify factors that are involved in caring for someone with a brain tumor and to examine the stress that can go along with a family member's treatment.

Who is being asked to take part in this study?

You have been invited to participate in this research study because you are 21 years of age or over and your family member has been diagnosed with a brain tumor. You will be one of 120 family caregivers who will be studied.

What procedures will be performed for research purposes?

If you decide to take part in this research study, you will undergo the following procedures that are not part of your family member's standard medical care. This study will require 4 one hour visits either in your home or at your family member's clinic visit.

Screening procedures: No additional procedures will be necessary to determine if you are eligible to take part in this research study. You will be asked to identify yourself as your family member's primary caregiver. A caregiver is someone who will help the family member at home. Helping your family member could include fixing meals, driving your family member to doctor's appointments, helping with financial matters, or providing emotional support. You do not have to be legally or blood related (such as a husband or daughter) in order to be considered a "family" caregiver.

Participant's Initials_____

Experimental procedures: If you qualify to take part in this research study, you will undergo the following procedures:

1. Blood collection for analysis. Samples of your blood will be tested for substances that may tell us about the stress you are undergoing.A blood sample (approximately 1 ½ tablespoons) will be collected four times – once at your initial visit and once at your 4, 8 and 12 month follow up visits. The blood sample will be obtained by inserting a needle into your arm. This blood will be used to identify specific markers that may be related to stress.
2. Monitoring your energy expenditure and heart rate. A lightweight armband will be placed on your upper arm for 72 hours. You will be asked to wear the armband at all times except when you take a bath or shower. You will also be given a sheet of paper to record your general activities over those three days. You will be asked to wear the armband a total of four times – once at your initial visit and again at your 4, 8 and 12 month follow up visits. At your initial visit, we will teach you how to put the armband on and give you a preaddressed prepaid box to use in mailing the armband back in 72 hours. For your follow up visit, we will mail the armband and recording sheet to you and call you 72 hours before your follow up visit to remind you to put the armband on. You will take the armband off when you come back for your follow up visit. The armband will be used to measure your energy expenditure (the amount of calories you spend every day) and your heart rate, which will tell us more about the amount of stress you are under.
3. Monitoring your blood pressure. You will be given an automatic blood pressure machine and asked to take your blood pressure within one hour of waking up every morning for three mornings. You will be asked to monitor the armband a total of four times – once at your initial visit and again at your 4, 8 and 12 month follow up visits. At your initial visit, we will teach you how to check your blood pressure and give you a preaddressed prepaid box to use in mailing the blood pressure monitor back in 72 hours. For your follow up visit, we will mail the blood pressure monitor and recording sheet to you and call you 72 hours before your follow up visit to remind you to start recording your blood pressure. You will bring the blood pressure monitor with you when you come back for your follow up visit.
4. Questionnaires. We will ask you questions from several questionnaires during your initial and three month follow up visit. Answering these questions will take approximately 1 ½ to 2 hours. During the visit, trained research study personnel will ask you questions to determine what kinds of activities you are doing for your family member and how those activities are impacting your life. If you are unable to keep either of these appointments, a member of the research team may come to visit you or you will receive a telephone call in order to ask you these questions. You will answer questions at the initial visit and at the 4, 8 and 12 month follow up visits. We will be asking you questions in a private conference room. A member of the research team will be available to sit with your family member while you answer questions if you would prefer.
5. Interviews. With your verbal approval, we will be audiotaping random interviews for quality assurance purposes. If your interview is chosen for audiotaping and you agree, the tape will not include your last name and will be kept in a locked cabinet in the project office under the direction of the interviewer and the principal investigator (Dr. Sherwood). After being reviewed by the Dr. Sherwood, the audiotape will be erased. Audiotapes will not be provided to secondary investigators not listed on the current research document.
6. For all participants, we will audiotape your responses to several questions that ask about how caregiving has affected you and your family. Your responses will be written down word for word, all identifying information will be removed, and your responses will be kept in a locked cabinet in the project office under the direction of the interviewer and the principal investigator (Dr. Sherwood).

Participant's Initials_____

What are the possible risks, side effects and discomforts of this research study?

1. One risk of participating in the study is the possible discomfort, soreness, bruising, dizziness, fainting, and rarely infection associated with blood sampling. This risk is considered rare (occurs in < 1% or < 1 out of 100 patients).
2. You may feel uneasy about sharing personal information. You may choose not to answer any question that makes you uneasy. In addition, you may choose to withdraw from the study at any time.
3. You may feel pressure on your arm when the automatic blood pressure cuff inflates. You may choose not to check your blood pressure at any time. In addition, you may choose to withdraw from the study at any time.
4. You may feel slight pressure on your arm from the armband used to measure energy expenditure and heart rate. You may choose not to wear the armband. In addition, you may choose to withdraw from the study at any time.
5. As with any investigational study, there may be adverse events or side effects that are currently unknown and it is possible that certain of these unknown risks could be permanent, serious or life-threatening.

What are the possible benefits from taking part in this research study?

There may be no direct benefit from participating in this study. The general benefit will be for future caregivers of persons with a brain tumor.

If I agree to take part in this research study, will I be told of any new risks that may be found in the course of the study?

You will be promptly notified if any new information develops during the conduct of this research study which may cause you to change your mind about continuing to participate.

Will I or my insurance provider be charged for the costs of any procedures performed as a part of this research study?

You and/or your insurer will not be billed for research only services. The study will pay for the research only costs. These studies include the blood testing for markers of stress done as a part of the research protocol.

Will I be paid if I take part in this research study?

You will be paid $75 for each time we interview you (possibly four times). At the completion of the baseline, 4 and 8 month interviews, $75 will be mailed to you after we receive the armband and blood pressure monitor from you. For the final 12 month visit, you will be paid at the end of the interview. At the end of the study, you will also receive an automatic blood pressure monitor.

Participant's Initials_____

Who will know about my participation in this research study?

Records pertaining to your involvement in this research study will be stored in locked file cabinets within the department of the principal investigator. Your biologic samples will be under the control of the principal investigator of this research project. To protect your confidentiality, all personal identifiers (i.e., name, social security number, birth date) will be removed (de-identified) and replaced with a specific code number. The information linking these code numbers to the corresponding subjects' identities will be kept in a separate, secure location. The investigators on this study will keep the samples indefinitely. Your biologic samples may be given to investigators outside of UPMC or may be utilized in future studies.

Any information about you obtained from this research will be kept as confidential (private) as possible. You will not be identified by name in any publication of research results unless you sign a separate form giving your permission (release). In unusual cases, your research records may be released.

Will this research study involve the use or disclosure of my identifiable medical record information?

This research study will not involve the recording of current and/or future identifiable medical information from your hospital and/or other health care provider (e.g., physician office) records.

Who will have access to identifiable information related to my participation in this research study?

In addition to the investigators listed on the first page of this authorization (consent) form and their research staff, the following individuals will or may have access to identifiable information related to your participation in this research study:

Authorized representatives of the University of Pittsburgh Research Conduct and Compliance Office may review your identifiable research information for the purpose of monitoring the appropriate conduct of this research study. In unusual cases, the investigators may be required to release identifiable information related to your participation in this research study in response to an order from a court of law. If the investigators learn that you or someone with whom you are involved is in serious danger or potential harm, they will need to inform, as required by Pennsylvania law, the appropriate agencies.

Authorized representatives of the University of Pittsburgh Cancer Institute (UPCI) or other affiliated health care providers may have access to identifiable information related to your participation in this research study for the purpose of (1) fulfilling orders, made by the investigators, for hospital and health care services (e.g., laboratory tests) associated with research study participation; (2) addressing correct payment for tests ordered by the investigators; and /or (3) for internal hospital operations (i.e. quality assurance).

Other members of the research team may have access to data or samples collected as part of this research study in order to complete specimen testing and data analysis. We will be happy to provide you with a list of these members at your request.

Participant's Initials_____

May I have access to my information that results from my participation in this research study?

In accordance with the UPCI Notices of Privacy Practices document that you have been provided, you are permitted access to information contained within your medical records filed with your health care provider.

For how long will the investigators be permitted to use and disclose identifiable information related to my participation in this research study?

The investigators may continue to use and disclose, for the purposes described above, identifiable information related to your participation in this research study indefinitely.

Is my participation in this research study voluntary?

Your participation in this research study, to include the use and disclose of your identifiable information for the purposes described above, is completely voluntary. (Note, however, that if you do not provide your consent for the use and disclosure of your identifiable information for the purposes described above, you will not be allowed, in general, to participate in the research study.) Whether or not you provide your consent for participation in this research study will have no affect on your or your family member's current or future relationship with the University of Pittsburgh. Whether or not you provide your consent for participation in this research study will have no affect on your or your family member's current or future medical care at a UPCI treatment center or affiliated health care provider or your or your family member's current or future relationship with a health care insurance provider.

Your family member's doctor may be an investigator in this research study, and as an investigator, is interested both in your family member's medical care and in the conduct of this research. Before agreeing to participate in this research study or at any time during your study participation, you may discuss your family member's care with another doctor who is in no way associated with this research study. You are not under any obligation to participate in any research study offered by your family member's doctor.

May I withdraw, at a future date, my consent for participation in this research study?

You may withdraw, at any time, your consent for participation in this research study, to include the use and disclosure of your identifiable information for the purposes described above. (Note, however, that if you withdraw your consent for the use and disclosure of your identifiable information for the purposes described above, you will also be withdrawn, in general, form further participation in this research study). Any identifiable research or medical record information recorded for, or resulting from your participation in this research study prior to the date that you formally withdrew your consent may continue to be used and disclosed by the investigators for the purposes described above. Should you decide to withdraw, you may choose to have your specimens returned to you or destroyed.

To formally withdraw your consent for participation in this research study you should provide a written and dated notice of this decision to the principal investigator of this research study at the address listed on the first page of this form.

Participant's Initials_____

Your decision to withdraw your consent for participation in this research study will have no affect on your or your family member's current or future relationship with the University of Pittsburgh. Your decision to withdraw your consent for participation in this research study will have no affect on your or your family member's current or future medical care at a UPCI treatment center or affiliated health care provider or your or your family member's current or future relationship with a health care insurance provider.

Under what circumstances might I be withdrawn from the study?

You will not be withdrawn from the study unless you desire to end participation in the study.

Who will pay if I am injured as a result of taking part in this research study?

University of Pittsburgh researchers and their associates who provide services at the UPCI recognize the importance of your voluntary participation in their research studies. These individuals and their staffs will make reasonable effort to minimize, control, and treat any injuries that may arise as a result of this research. If you believe that you are injured as the result of the research procedures being performed, please contact immediately the Principal Investigator or one of the co-investigators listed on the first page of this form.

Emergency medical treatment for injuries solely and directly relating to your participation in this research will be provided to you by hospitals of the University of Pittsburgh Medical Center (UPMC). It is possible that the UPMC may bill your insurance provider for the costs of this emergency treatment. Any co payments or deductibles will remain the responsibility of the insured party. If your research-related injury requires medical care beyond this emergency treatment, you will be responsible for the costs of this follow-up care unless otherwise specifically stated below. There is no plan for monetary compensation. You do not, however, waive any legal rights by signing this form.

Future studies:

In addition, you are being asked to consent to being contacted by the investigators regarding your willingness to participate in future studies. If you do not agree to be contacted for future studies, you will not be excluded from this study as agreeing to this future contact is optional.

________Yes, I agree to future contact.

________No, I do not agree to future contact.

VOLUNTARY CONSENT:

All of the above has been explained to me and all of my current questions have been answered. I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that such future questions will be answered by the researchers listed on the first page of this form. Any questions I have about my rights as a research participant will be answered by the Human Subject Protection Advocate of the IRB Office, University of Pittsburgh (1-866-212-2668). By signing this form, I agree to participate in this research study. A copy of this consent form will be given to me.

______________________________	______________________________
Participant's Signature	Date

____

Participant's Name (Print)

CERTIFICATION of INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise. I further certify that no research component of this protocol was begun until after this consent form was signed.

______________________________	______________________________
Printed Name of Person Obtaining Consent	Role in Research Study
______________________________	______________________________
Signature of Person Obtaining Consent	Date

APPENDIX C. MEASURES

C.1 NEUROBEHAVIORAL COGNITIVE STATUS EXAM

The Neurobehavioral Cognitive Status Examination
(Neuropsychological functioning)

Start Time: ________

I. Level of consciousness:		
	Alert	
	Lethargic	
	Fluctuating	
Describe patient's condition:		
II. Orientation (Score 2,1,0)		
A. Person		
1. Name (0 points)	Response	Score
2. Age (2 points)	Response	Score
B. Place		
1. Current location (2 points)	Response	Score
2. City (2 points)	Response	Score
C. Time		
1. Date: month(1 point) day(1 point) year(2 points)	Response	Score
2. Time of day within one hour (1 point)	Response	Score
3. Day of week	Response	Total Score
III. Attention		
A. Digit Repetition	Graded digit repetition (Score 1 or 0; discontinue after 2 misses at one level).	
Level 1		
3-7-2	Response	Score
4-9-5	Response	Score
Level 2		
5-1-4-9	Response	Score
9-2-7-4	Response	Score
Level 3		
8-3-5-2-9	Response	Score
6-1-7-3-8	Response	Score
Level 4		
2-8-5-1-6-4	Response	Score
9-1-7-5-8-2	Response	Score
		Total Score
B. Four Word Memory Task	Give the four unrelated words: robin, carrot, piano, green. Have patient repeat the four words twice correctly and record the number of trials required to do this .	

IV. Language		
A. Speech Sample	Fishing Picture (record patient's response verbatim).	
B. Comprehension	(Be sure to have at least 3 other objects in front of the patient for this test). If a, b, and c are successfully completed, praxis for these tasks is assumed normal.	
Metric	(Score 1 or 0). If incorrect, describe behavior.	
a. Pick up then pen.	Response	Score
b. Point to the floor.	Response	Score
c. Hand me the keys.	Response	Score
d. Point to the pen and pick up the keys.	Response	Score
e. Hand me the paper and point to the coin.	Response	Score
f. Point to the keys, hand me the pen, and pick up the coin.	Response	Score
C. Repetition		
Metric	(Score 2 if first try is correct, 1 if second try is correct, 0 is incorrect).	
a. Out the window.	Response	Score
b. He swam across the lake.	Response	Score
c. The winding road led to the village.	Response	Score
d. He left the latch open.	Response	Score
e. The honeycomb drew a swarm of bees.	Response	Score
f. No ifs, ands, or buts.	Response	Score
D. Naming		
Metric	(Score 1 or 0).	
a. Shoe	Response	Score
b. Bus	Response	Score
c. Ladder	Response	Score
d. Kite	Response	Score
e. Horseshoe	Response	Score
f. Anchor	Response	Score
g. Octopus	Response	Score
h. Xylophone	Response	Score

		Total Score:
V. Construction Ability		
Metric	Design Constructions (Score 2 if correct in 0-30 seconds; 1 if correct in 31-60 seconds; 0 if correct in greater than 60 seconds or incorrect).	
Design 1	(Record incorrect attempts). Time:______	Score
Design 2	(Record incorrect attempts). Time:______	Score
Design 3	(Record incorrect attempts). Time:______	Score
VI. Memory		
(Score 3 if recalled without prompting; 2 if recalled with category prompt; 1 if recognized from list; 0 if not recognized)		
Words	Robin	
	Carrot	
	Piano	
	Green	
		Score
Category Prompt	Bird	
	Vegetable	
	Musical Instrument	
	Color	
		Score
List	Sparrow, robin, bluejay	
	Carrot, potato, onion	
	Violin, guitar, piano	
	Red, green, yellow	
		Score
		Total Score
VII. Calculations		
Metric	(Score 1 point if correct within 20 seconds). Problems may be repeated, but time runs continuously from first presentation.	
1. How much is 5+3?	Response	
	Time	Score
2. How much is 15+7?	Response	
	Time	Score
3. How much is 39/3?	Response	
	Time	Score
4. How much is 31-8?	Response	
	Time	Score
		Total Score

VIII. Reasoning		
A. Similarities	Explain: "A hat and a coal are alike because they are both articles of clothing." If a patient does not respond, encourage; if patient gives differences, score 0. (Score 2 if abstract; 1 if imprecisely abstract or concrete; 0 if incorrect).	
Metric		
a. Rose-Tulip	Flowers	
	Other Responses	Score
b. Bicycle-Train	Transportation	
	Other Responses	Score
c. Watch-Ruler	Measurement	
	Other Responses	Score
d. Corkscrew-Hammer	Tools	
	Other Responses	Score
		Total Score
B. Judgment		
Metric	(Score 2 if correct; 1 if partially correct; 0 if incorrect).	
a. What would you do if you woke up one minute before 8:00 am and remembered an important appointment downtown at 8:00?	Response:	Score
b. What would you do if you were walking beside a lake and saw a 2-year-old child playing alone at the end of a pier?	Response:	Score
c. What would you do if you came home and found that a broken pipe was flooding the kitchen?	Response:	Score
		Total Score
	End Time: ______	

C.2 SOCIODEMOGRAPHIC QUESTIONNAIRE

Sociodemographic Questionnaire

Interviewer:
"I'm going to start the interview by asking you some general questions."

1. What is your sex? ☐ Male (1) ☐ Female (2)

2. What is your date of birth? ____/____/______

3. What is your age? __________

4. Which one of the following best describes your current marital status?
   - ☐ Never married (1)
   - ☐ Currently married (2)
   - ☐ Living with partner/significant other (3)
   - ☐ Widowed (4)
   - ☐ Separated (5)
   - ☐ Divorced (6)
   - ☐ Other (7) (specify________________________)

5. How many years have you been at your current marital status? ____

6. Do you consider yourself to be Hispanic or Latino, that is, of Mexican, Puerto Rican, Cuban, Caribbean, or of Latin American descent?
   ☐ Yes (1) ☐ No (2) ☐ Do not know (3)

7. What is your race?
   - ☐ White (1)
   - ☐ Black or African American (2)
   - ☐ American Indian (3) – specify tribe_______________
   - ☐ Alaska Native (4)
   - ☐ Native Hawaiian or other Pacific Islander (5)
   - ☐ Asian (6)
   - ☐ Unknown (7)
   - ☐ Other (8) (specify_________________________)

8. Is English your primary language (the one you speak most often)?
   ☐ Yes (1) ☐ No (2)

9. Where do you live?
   Primary zip code ___________________
   Secondary zip code ___________________

10. In what type of area did you live most of your childhood?
    - ☐ Urban, large city (1)
    - ☐ Urban, small city (2)
    - ☐ Suburb of large city (3)
    - ☐ Suburb of small city (4)
    - ☐ Rural, farm (5)

☐ Rural, non-farm (6)
☐ Other (7), specify____

11. What is your educational background?

School	Number of years attended	Did you finish this school?	If earned degree, specify the major area of interest
Grade School Grade 1-8			
High School Grades 9-12			
Earned G.E.D.			
Vocational/ Technical school			
2 year college (Associate's level)			
4 year college Bachelor's Level			
Graduate school (Master's Level)			
Professional school (ex. MD, C.V.M, JD)			
Graduate school (Doctoral level) (ex: PhD., Ed.D.)			
Other, specify			

12. What is your current employment status?
- ☐ Full time (working at least 35 hours a week) (1)
- ☐ Part time (working less than 35 hours a week) (2)
- ☐ Laid off or unemployed, looking for work (3)
- ☐ Laid off or unemployed, not looking for work (4)
- ☐ Retired, not working at all (5)
- ☐ Retired, but working part or full time (6)
- ☐ Disabled/unable to work (7)
- ☐ Full time homemaker (8)
- ☐ Student (9)
- ☐ Other (10), (specify_________________)

13. Are you currently employed? ☐ Yes (1) ☐ No (2)
IF YES:
a.) What is your primary occupation?___________________________
b.) Has this been your primary occupation for most of your working life? ☐ Yes (1) ☐ No (2)
c.) If no, what was your primary occupation?________________________
d.) Did you change occupations since [patient name's] cancer? ☐ Yes (1) ☐ No (2)
  ☐ Yes, I changed because of the physical demands of my job (1)
  ☐ Yes, I changed because of the mental demands of my job (2)

IF NO:
e.) When you were employed, what was your primary occupation? ________________________
f.) When was the last year that you were employed? ______________
g.) Did you stop work because of [patient name's] cancer? ☐ Yes (1) ☐ No (2)
- ☐ Yes, I stopped because of the physical demands on my job (1)
- ☐ Yes, I stopped because of the mental demands on my job (2)
- ☐ Yes, I stopped for other reasons (3) (specify____)
- ☐ No, my stopping work was not because of [patient name's] cancer (4)

14. Do you have any children? ☐ Yes (1) ☐ No (2)
IF YES, specify number and ages of children____

15. How many people presently live in your household including yourself?
Adults:___________ Children:___________

16. Do you have a religious background or preference? ☐ Yes (1) ☐ No (2)
IF YES, please specify:
- ☐ Catholic (1)
- ☐ Jewish (2)
- ☐ Protestant (3)
- ☐ Other (4) (specify_________________________)

17. How important is religion or spirituality in your life?
- ☐ Not at all important (1)
- ☐ Somewhat important (2)
- ☐ Extremely important (3)

17a. To what extent do you follow the customs and practices of your religion?
- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Frequently (3)
- ☐ Always (4)
- ☐ N/A (5)

18. Do you have health care insurance? ☐ Yes (1) ☐ No (2)
IF YES, specify type:
- ☐ Medicare (1)
- ☐ Medicaid (2)
- ☐ SSI (3)
- ☐ Veterans Administration (4)
- ☐ Workers Compensation (5)
- ☐ Private health insurance (6) (specify____________________________)
- ☐ Other (7) (specify____)
- ☐ None (8)

IF YES, does insurance cover the cost of medication?
☐ Yes, all the cost (1)
☐ Yes, some of the cost (2); Specify:____
☐ No (3)

IF YES, does your insurance cover the cost of health care?
☐ Yes , all the costs (1)
☐ Yes, some of the costs (2); Specify:____
☐ No (3)

18-19. What are the sources of your own total gross annual income (select all that apply):
☐ Wages, salaries, commissions, bonuses, tips from all jobs
☐ Yes (1) ☐ No (2)
☐ Self employment income from farm or non farm business
☐ Yes (1) ☐ No (2)
☐ Interest, dividend, net rental income, royalty income, or income from estates or trusts
☐ Yes (1) ☐ No (2)
☐ Social security or railroad retirement
☐ Yes (1) ☐ No (2)
☐ Supplemental security income or other public assistance income
☐ Yes (1) ☐ No (2)
☐ Retirement, survivor, or disability pensions
☐ Yes (1) ☐ No (2)
☐ Other, please specify____
☐ Yes (1) ☐ No (2)

19a. If you are currently employed, please select your own gross annual income from wages only:
☐ Under $10,000 (1)
☐ $10,000-$14,999 (2)
☐ $15,000-$19,999 (3)
☐ $20,000-$29,999 (4)
☐ $30,000-$39,999 (5)
☐ $40,000-$49,999 (6)
☐ $50,000-$59,999 (7)
☐ $60,000-$69,999 (8)
☐ $70,000-$79,999 (9)
☐ $80,000-$99,999 (10)
☐ $100,000-$150,000 (11)
☐ Over $150,000 (12)
☐ Unknown (13)
☐ Refused (14)
☐ N/A (15)

19b. If you are not currently employed, but were employed in the past, please select your own gross annual income from wages from the last year you worked:
☐ Under $10,000 (1)
☐ $10,000-$14,999 (2)

☐ $15,000-$19,999 (3)
☐ $20,000-$29,999 (4)
☐ $30,000-$39,999 (5)
☐ $40,000-$49,999 (6)
☐ $50,000-$59,999 (7)
☐ $60,000-$69,999 (8)
☐ $70,000-$79,999 (9)
☐ $80,000-$99,999 (10)
☐ $100,000-$150,000 (11)
☐ Over $150,000 (12)
☐ Unknown (13)
☐ Refused (14)
☐ N/A (15)

20. What is the total gross annual income for your household from all sources (before taxes and deductions)

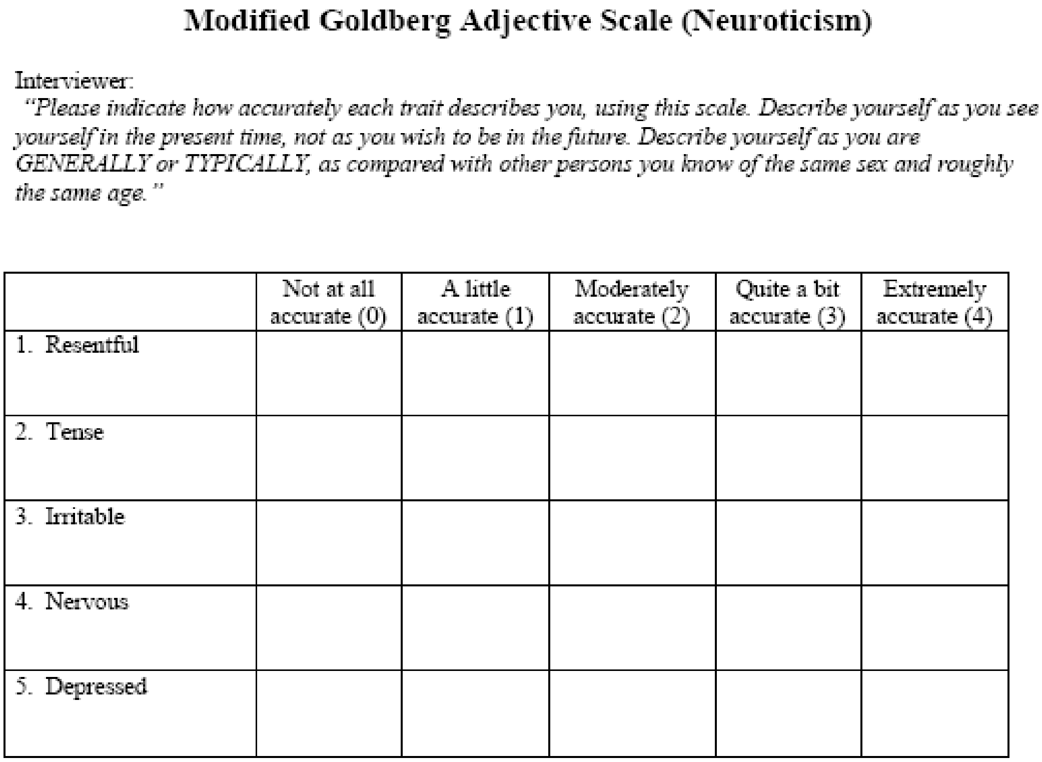
☐ Under $10,000 (1)
☐ $10,000-$14,999 (2)
☐ $15,000-$19,999 (3)
☐ $20,000-$29,999 (4)
☐ $30,000-$39,999 (5)
☐ $40,000-$49,999 (6)
☐ $50,000-$59,999 (7)
☐ $60,000-$69,999 (8)
☐ $70,000-$79,999 (9)
☐ $80,000-$99,999 (10)
☐ $100,000-$150,000 (11)
☐ Over $150,000 (12)
☐ Unknown (13)
☐ Refused (14)
☐ N/A (15)

21. Does your current household income meet your basic needs (such as food, housing, utilities, and health care)? ☐ Yes (1) ☐ No (2)

22. How difficult is it to pay for your basic needs?

☐ Not at all difficult (1)
☐ Somewhat difficult (2)
☐ Extremely difficult (3)

C.3 MODIFIED GOLDBERG ADJECTIVE SCALE



Modified Goldberg Adjective Scale (Neuroticism)

Interviewer:

"Please indicate how accurately each trait describes you, using this scale. Describe yourself as you see yourself in the present time, not as you wish to be in the future. Describe yourself as you are GENERALLY or TYPICALLY, as compared with other persons you know of the same sex and roughly the same age."

	Not at all accurate (0)	A little accurate (1)	Moderately accurate (2)	Quite a bit accurate (3)	Extremely accurate (4)
1. Resentful					
2. Tense					
3. Irritable					
4. Nervous					
5. Depressed					

C.4 SHORTENED CES-D

Shortened CES-D (Depressive Symptoms)

Interviewer:

"Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week."

	Rarely or None of the time (Less than 1 day) (0)	Some or a Little or the time (1-2 Days) (1)	Occasionally or a Moderate Amount of Time (3-4 days) (2)	Most or all of the Time (5-7 days) (3)
1. I was bothered by things that usually do not bother me.				
2. I had trouble keeping my mind on what I was doing.				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not get "going".				

C.5 ISEL

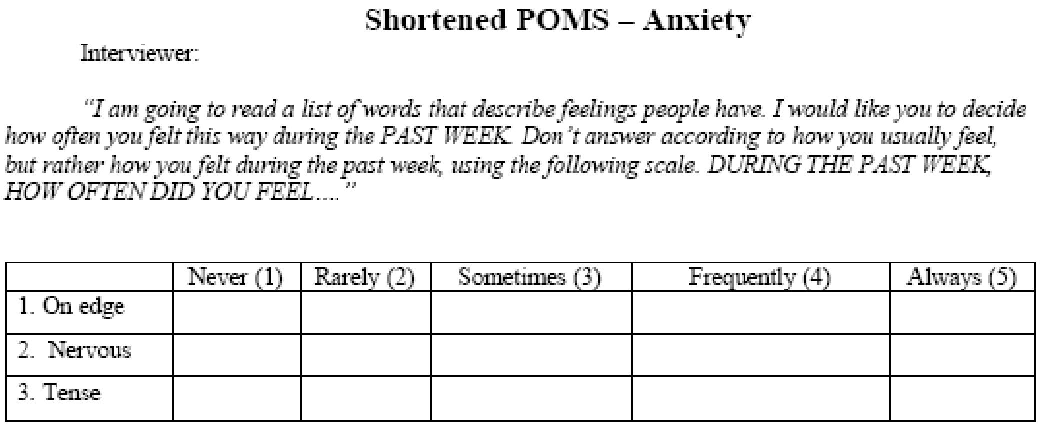
ISEL (Social Support)

Interviewer:

"I am going to read a list of statements each of which may or may not be true about you. For each statement please indicate how true that statement is about you, using the following scale."

	Definitely False (1)	Probably False (2)	Probably True (3)	Definitely True (4)
1. If I wanted to go on a trip for a day (for example, to the country or mountains), I would have a hard time finding someone to go with me.				
2. I feel that there is no one I can share my most private worries and fears with.				
3. If I were sick, I could easily find someone to help me with my daily chores.				
4. There is someone I can turn to for advice about handling problems with my family.				
5. If I decided one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.				
6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.				
7. I don't often get invited to do things with others.				
8. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.)				
9. If I wanted to have lunch with someone, I could easily find someone to join me.				
10. If I was stranded 10 miles from home, there is someone I could call who could come and get me.				

C.6 SHORTENED POMS



Shortened POMS – Anxiety

Interviewer:

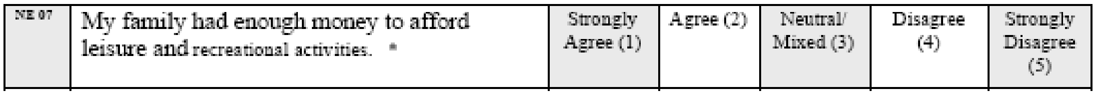
"I am going to read a list of words that describe feelings people have. I would like you to decide how often you felt this way during the PAST WEEK. Don't answer according to how you usually feel, but rather how you felt during the past week, using the following scale. DURING THE PAST WEEK, HOW OFTEN DID YOU FEEL…."

	Never (1)	Rarely (2)	Sometimes (3)	Frequently (4)	Always (5)
1. On edge					
2. Nervous					
3. Tense					

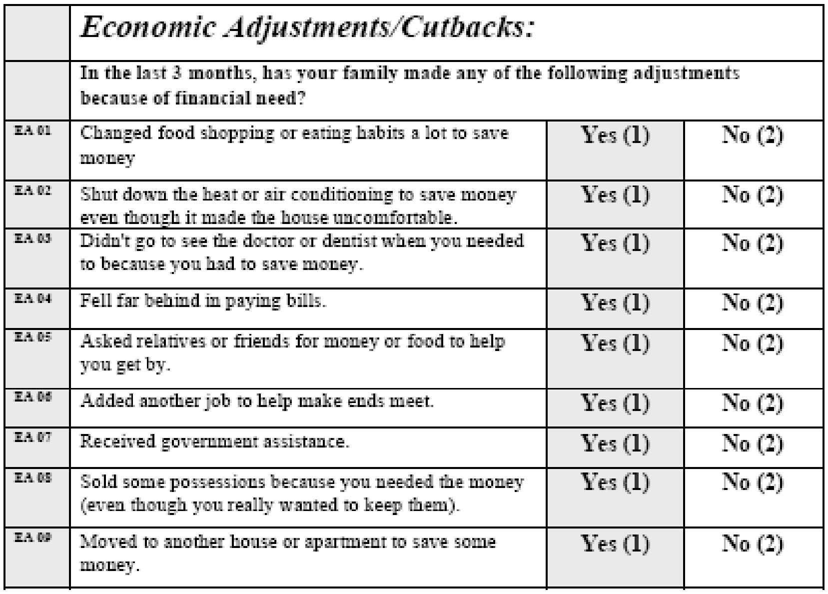
C.7 PERCEIVED ECONOMIC HARDSHIP

Perceived Economic Hardship

	Financial Strain:					
FS 01	In the next three months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food?	almost never (1)	once in a while (2)	Sometimes (3)	a lot of the time (frequently) (4)	almost always (5)
FS 02	In the next three months, how often do you expect that you will have to do without the basic things that your family needs?	almost never (1)	once in a while (2)	Sometimes (3)	a lot of the time (frequently) (4)	almost always (5)
	Inability to Make Ends Meet:					
MEM 01	Think back over the past 3 months and tell us how much difficulty you had with paying your bills. Would you say you had	a great deal of difficulty (1)	quite a bit of difficulty (2)	some difficulty (3)	a little difficulty (4)	no difficulty at all (5)
MEM 02	Think again over the past 3 months. Generally, at the end of each month did you end up with	more than enough money left (1)	some money left (2)	just enough money left (3)	somewhat short of money (4)	very short of money (5)
	Not Enough Money for Necessities:					
	Please think about how you felt about your family's economic situation over the past 3 months. Indicate how much you would agree or disagree with each statement.					
NE 01	My family had enough money to afford the kind of home we should have.	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)
NE 02	We had enough money to afford the kind of clothing we should have.	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)
NE 03	We had enough money to afford the kind of furniture or household appliances we should have.	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)
NE 04	We had enough money to afford the kind of car we need.	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)
NE 05	We had enough money to afford the kind of food we should have. *	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)
NE 06	We had enough money to afford the kind of medical care we should have. *	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)



NE 07	My family had enough money to afford leisure and recreational activities. *	Strongly Agree (1)	Agree (2)	Neutral/ Mixed (3)	Disagree (4)	Strongly Disagree (5)



	Economic Adjustments/Cutbacks:		
	In the last 3 months, has your family made any of the following adjustments because of financial need?		
EA 01	Changed food shopping or eating habits a lot to save money	Yes (1)	No (2)
EA 02	Shut down the heat or air conditioning to save money even though it made the house uncomfortable.	Yes (1)	No (2)
EA 03	Didn't go to see the doctor or dentist when you needed to because you had to save money.	Yes (1)	No (2)
EA 04	Fell far behind in paying bills.	Yes (1)	No (2)
EA 05	Asked relatives or friends for money or food to help you get by.	Yes (1)	No (2)
EA 06	Added another job to help make ends meet.	Yes (1)	No (2)
EA 07	Received government assistance.	Yes (1)	No (2)
EA 08	Sold some possessions because you needed the money (even though you really wanted to keep them).	Yes (1)	No (2)
EA 09	Moved to another house or apartment to save some money.	Yes (1)	No (2)

C.8 CAREGIVER REACTION ASSESSMENT

Caregiver Reaction Assessment (Burden)

Interviewer:

"I will now read a number of statements about your feelings about caregiving over the past month. Please answer according to the following 5 point scale where 1 equals strongly disagree, 2 equals disagree, 3 equals neither agree nor disagree, 4 equals agree, and 5 equals strongly agree."

	Strongly disagree (1)	Disagree (2)	Neither disagree nor agree (3)	Agree (4)	Strongly agree (5)
1. I feel privileged to care for (patient's name).					
2. Others have dumped caring for (patient's name) onto me.					
3. My financial resources are adequate to pay for things that are required for caregiving.					
4. My activities are centered around care for (patient's name).					
5. It is very difficult to get help from my family in taking care of (patient's name).					
6. I resent having to take care of (patient's name).					
7. I have to stop in the middle of work to help (patient's name).					
8. I really want to care for (patient's name).					
9. I visit family and friends less since I've been caring for (patient's name).					
10. I will never be able to do enough caregiving to repay (patient's name).					
11. My family works together at caring for (patient's name).					
12. I have eliminated things from my schedule since caring for (patient's name).					
13. Since caring for (patient's name), I feel my family has abandoned me.					
14. Caring for (patient's name) makes me feel good.					
15. The constant interruptions make it difficult to find time for relaxation.					

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