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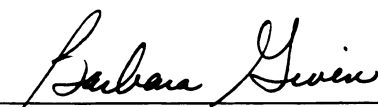
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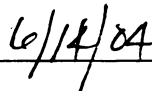
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FAMILY CARE OF PERSONS WITH A BRAIN TUMOR

By

Paula Riess Sherwood

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ABSTRACT: FAMILY CARE OF PERSONS WITH A BRAIN TUMOR

By

Paula Riess Sherwood

Background/Purpose: Research has demonstrated that caregivers of persons with cancer and persons with dementia are at risk for negative consequences from providing care, such as increased mortality, depressive symptoms, and anxiety. However, there have been minimal efforts to describe the impact of providing care for persons with both oncological and neurological sequelae. The purpose of this study was to determine the effects of the care recipient's functional, cognitive, and neuropsychiatric status on the caregiver's level of burden and depressive symptoms for caregivers of persons with a primary malignant brain tumor, and to determine whether caregiver mastery and perceived adequacy of information to care moderated these relationships.

Conceptual Framework: Based on Lazarus and Folkman's Theory of Stress and Coping, the care recipient's functional, cognitive, and neuropsychiatric status dictate care demands identified during the primary appraisal that are met using resources identified during the secondary appraisal (mastery and perceived adequacy of information to care). Caregivers' stress response reflects the imbalance between care demands and caregiver resources, operationalized as caregiver burden and depressive symptoms.

Methods: The cross-sectional, descriptive study consisted of telephone interviews with 95 adult caregivers of adults with a primary malignant brain tumor recruited from two national brain tumor support groups, two urban cancer centers, and a statewide cancer registry. The 45-60 minute interview consisted of sociodemographic questions and the following instruments: Activities of Daily Living/Instrumental Activities of Daily Living

($\alpha = .93$); Cognitive Performance Scale ($\alpha = .71$); Neuropsychiatric Inventory ($\alpha = .78$); Patient Satisfaction Questionnaire ($\alpha = .96$); Caregiver Mastery ($\alpha = .73$); Caregiver Reaction Assessment (subscales: self esteem $\alpha = .79$, abandonment $\alpha = .83$, finances $\alpha = .87$, schedule $\alpha = .75$, health $\alpha = .70$); and CES-D ($\alpha = .89$).

Data Analysis: Using structural equation modeling, relationships were formulated among variables, model fit assessed, and respecification was done to interpret relationships.

Findings: The overall model demonstrated good fit indices (rmsea = .05, $\chi^2 = 11.6$ p = .24, gfi = .93) Care recipients' cognitive status and instrumental activities of daily living status did not significantly affect caregiver burden or depressive symptoms. Higher numbers of neuropsychiatric symptoms predicted higher levels of caregiver depressive symptoms and higher levels of caregiver burden in all burden subscales (self esteem, finances, schedule, abandonment, and health). Higher levels of care recipient dysfunction in activities of daily living led to higher levels of caregiver burden regarding the impact of providing care on the caregiver's schedule and health. When perceived adequacy of information to care and mastery were entered into the model to identify any potential moderating effects, perceived adequacy of information to care did not have a significant moderating or direct effect on caregiver outcomes. Higher levels of caregiver mastery directly predicted less depressive symptoms and burden, and moderated the effects of neuropsychiatric symptoms on caregiver burden and depressive symptoms.

Conclusions: Study findings emphasize the importance of controlling patients' neuropsychiatric symptoms and providing assistance to caregivers on how to cope with and manage neuropsychiatric symptoms in the home. Caregivers also need information on how to manage activities of daily living problems on the part of the care recipient.

Dedication

This dissertation is dedicated to Ryan, and to the caregivers who struggle each day with providing care to a family member with a brain tumor.

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Chapter 1

The incidence of primary malignant brain tumors (PMBTs) is low in comparison with other malignancies. For Michigan for the year 2000, there were only 644 new cases of brain and other central nervous system cancers as compared to 15,052 cases of genitourinary cancers and 9,495 cases of cancer of the gastrointestinal tract and digestive system (Michigan Department of Community Health, 2000). However, despite the fact that cerebral malignancy is not common, family caregivers of persons with a PMBT are at particular risk for negative emotional and physical consequences from providing care because their care recipients often face severe changes in physical and psychological health, such as a high mortality rate and significant declines in physical and cognitive function.

A family caregiver is a friend or family member who provides assistance to someone with an illness (the care recipient). This assistance may include helping with activities of daily living such as bathing, helping the care recipient manage symptoms such as fatigue, dealing with neuropsychiatric symptoms such as agitation or delusions, and accessing the health care system for treatment and disease related information. Researchers have identified negative emotional and physical consequences for caregivers who provide care for someone with cancer (Given, Given, Azzouz, Stommel, & Kozachik, 2000; Kurtz, Kurtz, Given, & Given, 1995; Nijboer et al., 2000; Northouse, Mood, Templin, Mellon, & George, 2000) and those who provide care for someone with a neurological disorder (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Schulz et al., 2001; Vitaliano, Russo, & Niaura, 1995). However, few studies have examined the effects of providing care for someone with both oncological and neurological sequelae,

such as the caregiver of someone with a PMBT. This study was designed to answer the following research questions:

- 1) What are the effects of the care recipient's functional, cognitive, and neuropsychiatric status on the caregiver's level of perceived burden and depressive symptoms for the caregiver of a person with a PMBT?
- 2) Given a care recipient's functional, cognitive, and neuropsychiatric status, what are the moderating effects of the caregiver's level of perceived adequacy of information to care and mastery?

The purpose of Chapter 1 is to provide a brief overview of the concept of family caregiving and to present the issues that a caregiver of a person with a PMBT may face. First, a general review of providing care will be presented, including a discussion of caregiver tasks and the effects of providing care on the caregiver. Next, challenges that are commonly faced by the caregiver of a person with a PMBT will be described. These concepts are further examined in Chapter 2, in which the state of the science of caregiving literature is examined to provide the background for the development of the conceptual framework of the study, which is presented in Chapter 3. The methodology of the study is described in Chapter 4, and the results and implications for practice are presented in Chapter 5.

Providing Care

The financial and systematic reorganization of the nation's health care system has led to increasingly shorter hospitalizations and decreases in the amount of reimbursable home care services. As a result, the delivery of home health care is often the responsibility of lay caregivers who may be ill prepared to both deliver complex care and

cope with the ramifications of providing this care (Sherwood, Given, & Given, 2002). It has been estimated that 12.8 million Americans of all ages need assistance with activities of daily living (National Family Caregivers Association [NFCA], 2000). In addition, family caregivers in the United States have reported spending an average of 18 hours per week providing care, and close to one in five caregivers provide at least 40 hours of care per week, with the amount of time providing care increasing as the care recipient's illness progresses (National Alliance for Caregiving [NAC], 1997; Schulz et al., 2003). In a 1997 survey of over 1,500 caregivers, almost all respondents indicated providing care with independent activities of daily living (IADLs) such as transportation and laundry and just over one-half of the respondents indicated providing assistance with at least one activity of daily living (ADL) such as toileting or bathing (NAC). Caregivers commonly provide assistance with tasks such as getting in and out of beds and chairs, getting dressed, bathing and showering, toileting, feeding, dealing with incontinence, transportation, housework, grocery shopping, preparing meals, managing finances, and administering medication (Alzheimer's Association & NAC [AA-NAC], 1999; NFCA, 2000).

Providing care to a family member requires a significant time and financial commitment. The multiplicity of tasks required to perform activities on behalf of a family member and assume additional roles within the household can limit the caregiver's social and personal time (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). In addition, providing care can also affect the time a caregiver has for occupational activities. In 1999, approximately one half of the caregivers in a national survey of

caregivers of persons with Alzheimer's disease reported either going into work late or taking time off as a result of providing care (AA-NAC, 1999).

Missed time from work and out of pocket expenses can translate into a significant drain on household income, particularly if the missed time is not reimbursed. The financial consequences of providing care have been so striking that federal legislation has been enacted to begin providing financial relief for caregivers (Family Caregiver Alliance, 2004). The Older Americans Act Amendments (Senate Resolution 707, 1999), for example, provided \$155.2 million in funding for home and community based services to ease the burden of providing care for the 2003 fiscal year. Other states offer programs that allow direct reimbursement to family caregivers, tax credits dependent upon the severity and frequency of the care recipient's care demands, or programs that allow family caregivers to seek compensation under tax and labor laws (Polivka, 2001). The constraints placed on caregivers' time and finances in addition to the emotions involved in dealing with a loved one's illness can be a source of stress to the caregiver, and this stress may be manifested as changes in caregivers' emotional and/or physical health.

Consequences of Providing Care

Caregivers have reported positive consequences of providing care (Picot, Youngblut, & Zeller, 1997), such as feeling honored to provide care, a sense of accomplishment, a better relationship with the care recipient (Given & Given, 1996), as well as personal growth and family cohesion (Stetz, McDonald, & Compton, 1996). However, providing care may also be associated with negative consequences, particularly when providing care is perceived as an encumbrance to the caregiver. The negative physical consequences associated with providing care can include increased plasma

norepinephrine levels (Mills et al., 1997), poor antibody response to vaccines (Vedhara et al., 1999), slower wound healing (Kiecolt-Glaser et al., 1995), and exhaustion and decreased appetite (Clipp & Moore, 1995). Caregiving has also been linked to decreased overall physical health for the caregiver (Sparks, Farran, Donner, & Keane-Hagerty, 1998; Winslow, 1997) and an increase in mortality rates (Schulz & Beach, 1999).

Caregivers tend to display more risky health behaviors such as alcohol and tobacco use, are less likely to make and keep routine medical visits, and have poorer perceptions of their health status (Beach, Schulz, Yee, & Jackson, 2000). Burton, Newsom, Schulz, Hirsch, & German (1997) found that when compared to noncaregivers, caregivers with a high level of involvement (defined as caring for a care recipient with at least one impairment in ADLs) reported not having enough time to exercise, not having time to recuperate from illness, and forgetting to take prescriptive medications.

The emotional effects of providing care can also be severe. Caregivers have been shown to be at risk for anxiety (Marsh, Kersel, Havill, Sleight, 1998a; Marsh, Kersel, Havill, Sleight, 1998b), depressive symptoms (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Watanabe, Shiel, Asami, Taki, & Tabuchi, 2000), and overall emotional distress (Sparks et al., 1998; Vedhara et al., 1999). Caregiving has been linked to an increased risk for the development of nervousness and difficulty sleeping (Carter & Chang, 2000; Clipp & Moore, 1995).

As the previously cited research demonstrates, providing care can strain occupational and family roles, as well as limit caregivers' time and financial resources. This strain may be manifested by negative consequences in both the physical and emotional health of the caregiver. In turn, decreases in caregivers' health may affect their

ability to provide quality care and lead to an increase in their demands on the health care system. However, the research findings previously discussed are based on studies of caregivers of persons with cancer or caregivers of persons with a neurological disorder. The caregiver of a person with a PMBT must deal with both oncological and neurological issues.

Caring for a person with a PMBT

Neurological Care Issues

Drastic changes in cognitive and neuropsychiatric status, marked physical limitations, and a short and terminal trajectory of disease often accompany the diagnosis of a PMBT. Care needs for a person with a PMBT may be based on alterations in the care recipient's physical status such as loss of motor and sensory function, altered levels of consciousness, difficulty walking, dysphagia, and headache (Hickey & Armstrong, 1997). These caregivers may also deal with cognitive and neuropsychiatric effects of cerebral malignancy in the care recipient including anxiety, depressive symptoms, irritability, anger, apathy, inefficiency with work, memory deficits, confusion, hallucinations, and mania, among others (Filley & Kleinschmidt-DeMasters, 1995; Irle, Peper, Wowra, & Kunze, 1994). The intensity and frequency of these symptoms may increase as the tumor and treatment progress, leading to further difficulty in physical, occupational, and social functioning (Weitzner, McMillan, & Jacobsen, 1999).

In addition to high levels of morbidity, the caregiver of a person with a brain tumor may also have difficulty in accessing the knowledge that is required in order to provide care. Typically, the care recipient with a PMBT is under the care of a neurologist, neurosurgeon, radiation oncologist, neuro-oncologist, and primary care

physician in addition to possible consults by neuropsychiatrists (Hickey & Armstrong, 1997). Care recipients with other types of cancer may also have more than one health care practitioner. However, in other instances, the oncologist often manages the care situation, and is the person responsible for providing diagnosis and treatment related information. The person with a brain tumor may have multiple practitioners who maintain responsibility for managing different aspects of treatment and symptoms.

For example, a common side effect of a PMBT is cerebral edema, which can lead to changes in the care recipient's physical and psychological status, as well as to changes in the care recipient's level of consciousness. If cerebral edema occurs postoperatively or is due to a recurrence of the tumor, the neurosurgeon is typically the health care practitioner responsible for its management (DeVroom, Smith, Mogensen, & Clancey, in press). If cerebral edema stems from radiation necrosis, the management of the edema may be delegated to the neuro-oncologist. Finally, if the cerebral edema continues past the immediate postoperative period, the neurologist may assume responsibility for management of this complication. Multiple care providers may make it difficult for the dyad to navigate the health care system and to identify the provider responsible for managing different aspects of care (Leavitt, Lamb, & Voss, 1996). Multiple care providers can also increase the possibility of miscommunication and lack of coordination of care, which can affect care recipient outcomes (Anderson & Helms, 1993) and make it difficult for the dyad to access information. Being unable to access useful information can affect not only the quality of care delivered by the caregiver, but the caregiver's feelings of mastery regarding the care situation. Low feelings of mastery (or confidence in the ability to provide care) can increase the risk for negative emotional and physical

consequences to the caregiver from providing care (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Yates, Tennstedt, & Chang, 1999).

Oncological Care Issues

In addition to neurological issues, caregivers of persons with a PMBT must also deal with oncological issues such as a potentially short, terminal illness and treatment related side effects. The mortality associated with a PMBT is so severe that for the most common PMBT, Glioblastoma Multiforme (GBM), only 9 out of every 100,000 persons are alive at 5 years after diagnosis (Surveillance Epidemiology End Results, 1997). Thus, caregivers may not have sufficient time to begin to cope with the grieving and changes in family functioning that accompany this potentially terminal diagnosis.

Other oncological issues for the caregiver include dealing with side effects of cancer related treatment, such as changes in the care recipient's level of consciousness, fatigue, nausea and vomiting, neutropenia, and steroid psychosis (DeVroom et al., in press). Trying to manage problems such as encephalopathy induced side effects (Crossen, Garwood, Glatstein, & Neuwelt, 1994), decreased motor function from radiation and chemotherapy (Scheibel, Meyers, & Levin, 1996), and chemotherapy induced fatigue (Lovely, Miaskowski, & Dodd, 1999) are all challenges to providing care for someone with a PMBT, which may lead to deterioration in the caregiver's emotional or physical health.

Conclusions & Significance

The potentially short, terminal trajectory of disease, the severe morbidity that may be associated with a PMBT, and the difficulty that the caregiver may face in accessing information to provide care can all lead to negative consequences from providing care,

such as caregiver burden and depressive symptoms. Although these factors have been linked to negative consequences from providing care in caregivers of persons with cancer and caregivers of persons with other neurological disorders, the role that these factors play in the negative emotional consequences for the caregiver of a person with a PMBT is unknown. Determining the predictors of negative caregiver consequences for this subset of caregivers is the first step in identifying caregivers who may have difficulty in assuming the role and implementing interventions to improve caregiver health.

The purpose of this research study was to identify the factors that result in negative emotional consequences for caregivers of persons with a PMBT. Specifically, the study examined the effect of the care recipient's functional, cognitive, and neuropsychiatric status on the caregiver's level of burden and depressive symptoms for a caregiver of a person with a PMBT, and analyzed the moderating role of the caregiver's level of perceived adequacy of information to care and mastery. In Chapter 2, the state of the science of caregiving research and the significance of the proposed study are discussed. In Chapter 3, the conceptual model of the study as it was developed from a review of the oncological and neurological caregiving literature is described. The sample, recruitment process, measures, and methods for data collection are presented in Chapter 4, and the findings and implications of the study along with recommendations for clinical practice and suggestions for future research are discussed in Chapter 5.

Chapter 2

The purpose of Chapter 2 is to review the state of the science concerning research in the area of family caregiving in order to lay the foundation for the conceptual model of caring for someone with a PMBT, which is described in Chapter 3. This chapter also includes the significance of the study and the gaps in the neurooncology and caregiving literature that this study will begin to fill.

Family caregiving as used in this study is the provision of unpaid aid or assistance and care by one family member to another family member with an illness. This care goes beyond the usual family activities that are a required part of normal daily life (National Alliance for Caregivers, 2004). The term “family caregiver” can be used interchangeably with “informal caregiver” and “lay caregiver” to denote a person who provides some form of care to a family member with health related needs. Family caregivers may be related to the care recipient by blood (i.e. daughter or parent), by marriage (i.e. spouse), or may be designated as such based on a close relationship with the care recipient (i.e. neighbor, friend, or life partner). For the purpose of this study, caregivers were designated as “family members” if they had an emotional and/or familial relationship with the care recipient (i.e. they were not being reimbursed by a third party to provide care).

Providing care for a family member may result in positive consequences for the caregiver such as a sense of mutuality, a closer relationship with the care recipient, and increased self-esteem (Archbold et al., 1995; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Picot, 1995; Picot et al., 1997). However, providing care can also be associated with negative consequences for the caregiver, particularly when the

caregiver feels unprepared to provide care, has inadequate knowledge to deliver care, or receives little guidance from the formal healthcare system (Bucher et al., 2001; Scherbring, 2002; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Family caregivers often do not know how to assume the role of caregiver, may be unfamiliar with the type of care they must provide or the amount of care needed, and may not know how to utilize available resources to provide care (Given & Given, 1996; Oberst, Thomas, Gass, & Ward, 1989). As a result of these personal and system issues, caregivers often neglect their own healthcare needs in order to assist their family member, causing deterioration in the caregiver's health and well-being (Beach et al., 2000; Given et al., 1993; McCorkle et al., 1993; Northouse, 1988; Oberst et al., 1989; Schulz & Beach, 1999).

Research regarding the needs and roles of family caregivers, and the impact of caregiving on family members, has been ongoing for the past three decades, although little research has been done with caregivers of a person with a PMBT. In this chapter, existing caregiver research is reviewed in order to identify potential negative consequences of providing care to a family member with a PMBT, and to illustrate some of the relationships between care demands and negative consequences for the caregiver that are highlighted in the conceptual model in Chapter 3. A review of the literature is provided first, followed by a general critique of caregiving research to date and the gaps in the research that this study will begin to fill. Because the purpose of the literature review was to provide support for the model, caregiver intervention studies were reviewed but only included if they illustrated key concepts in the model.

Negative Consequences from Providing Care

Emotional Consequences

Recognition of negative emotional consequences in family caregivers began to be explored in the 1980's. Studies have shown that family members often experience distress in response to the care recipient's diagnosis, which is exacerbated by the assumption of new caregiver roles and may continue over time, often well beyond the end of the care recipient's active treatment (Given et al., 1993; Given, Stommel, Collins, King, & Given, 1990; Nijboer et al., 1999; Northouse et al., 2000; Northouse & Peters-Golden, 1993; Raveis, Karus, & Siegel, 1998; Toseland, Blanchard, & McCallion, 1995).

Caring for a family member can be a stressful experience with various negative emotional consequences for caregivers (Weitzner, Meyers, Stuebing, & Saleeba, 1997), including depressive symptoms, anxiety, helplessness, fear, psychosomatic symptoms, burden, restrictions of activities, role strain, and strain in marital relationships (Blank, Clark, Longman, & Atwood, 1989; Douglas & Spellacy, 1996; Gaugler, Davey, Pearlin, & Zarit, 2000; Gitlin et al., 2003; Given et al., 1992; McCurry, Gibbons, Logsdon, & Teri, 2004; Siegel, Raveis, Mor, & Houts, 1991; Stetz, 1989; Weitzner, Moody, & McMilliam, 1997). Caregiver burden and depressive symptoms (typically referred to as 'caregiver depression') are the primary negative consequences for the caregiver that are described in this section, as they have been the most consistently reported emotional consequences in caregiver research.

Caregiver burden can be considered an initial negative emotional consequence of providing care – one in which care demands are outweighed by the availability of caregiver resources to meet those demands, resulting in distress for the caregiver (Given

et al., 1993; Schulz & Williamson, 1991). Caregiver burden is a multi-dimensional concept that grows from the imbalance between the social, psychological and economic consequences that permeate a care situation and caregivers' coping strategies to meet care demands. Caregivers who employ ineffective coping strategies or who are unable to bring appropriate coping strategies to the demands of the care experience develop a sense of burden related to providing care, which if sustained, may lead to depression (Given et al., 1992; Kozachik et al., 2001). It should also be noted that caregiver burden may co-exist with positive rewards from the provision of care. The co-existence of burden and rewards from caregiving should be considered so that they are not conceptualized as polar ends of a continuum.

Researchers who describe burden focus on reaction demands specific to the provision of care. Blanchard, Albrecht, and Ruckdeschel (1997) suggest that 20 – 30% of family caregivers suffer negative emotional consequences related to the care situation. Disruption of daily activities, competing demands, and the distress associated with assisting with physical care demands have all been shown to affect caregiver burden (Acton & Kang, 2001; Cooley & Moriarty, 1997; Kristjanson & Ashcroft, 1994; Laizner, Shegda, Barg, & McCorkle, 1993; Northouse, Dorris, & Charron-Moore, 1995; Pinquart & Sorenson, 2003; Sales, Schulz, & Biegel, 1992; Siegel et al., 1991; Stommel, Given, Given, & Collins, 1995; Weitzner, Meyers, et al., 1997).

Caregiver depression, on the other hand, is typically considered as a secondary or long-term mood disturbance that develops over time as a result of providing care (Fortinsky, Kercher, & Burant, 2002; Harris, Godfrey, Partridge, & Knight, 2001). Caregiver depression may emerge as a negative consequence of sustained burden from

the care situation and may be manifested by feelings of loneliness, isolation, fearfulness, and being easily bothered. In addition, caregiver depression may have a somatic component such as decreased appetite, fatigue, and insomnia. Caregiver depression is differentiated from clinical depression because it is considered to be of a situational nature, related to providing care. Caregiver depression may be regarded as a chronic mood disturbance that is mediated by the amount of burden the caregiver perceives during the care situation (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Sherwood, Given, Given, & von Eye, in press). Thus, the development of caregiver depression may be less dependent upon the caregiver's level of involvement in providing care and more dependent upon whether the caregiver is able to employ adequate coping mechanisms to alleviate burden before it progresses to caregiver depression. Studies have shown that although depression and burden are often highly correlated (Raveis et al., 1998), interventions aimed at alleviating burden and depression have differential effects, suggesting that each variable captures a unique portion of the emotional consequences of providing care (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Toseland et al., 1995).

Providing care can result in the more immediate negative consequence of caregiver burden, as well as the long-term consequence of caregiver depression. In turn, caregivers who are burdened or depressed can negatively affect care recipient outcomes. Researchers report that caregiver and care recipient distress and role adjustment are correlated and have a correspondence over time (Given & Given, 1996; Northouse, Templin, Mood, & Oberst, 1998; Northouse et al., 2000). It appears that by moderating elements of distress and improving the emotional health of caregivers, it may be possible

to lower the distress experienced by the care recipient and improve the care recipient's overall emotional health. This synergistic effect between partners underscores the importance of a family focused approach in the care of patients and their family members (Kurtz, Given, Kurtz, & Given, 1994; Kurtz et al., 1995; Given et al., 1993; Nijboer et al., 1999; Northouse, 1988). Northouse and colleagues (2000) emphasized that patients' and spouses' role adjustments after a diagnosis of cancer are interrelated and that interventions aimed at improving caregiver health should be family-focused to maximize effectiveness. Affecting caregiver outcomes, then, should target interventions aimed at all persons within the care team (including secondary carers), and should focus on both short term caregiver responses, such as burden, as well as long term sequelae from providing care, such as caregiver depression.

Physical Consequences

Negative consequences from providing care may also be manifested as changes in the caregiver's physical health. General declines in physical health and increased mortality rates in caregivers have been reported (Schulz & Beach, 1999; Schulz et al., 2001). Given and Given (1992), Given et al. (1993) and Kurtz et al. (1994) found that family caregivers experience significant negative physical consequences as the care recipient's illness progresses. In particular, decreases in caregiver health have been associated with caregivers who perceive themselves as burdened (Schulz & Beach, 1999). Caregiver burden has been related to caregivers' ratings of their health status as 'poor', increased health risk behaviors (such as smoking), and higher use of prescription drugs (Beach et al., 2000; Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Other researchers have reported that caregivers are at risk for fatigue and sleep disturbances

(Jensen & Given, 1993), altered immune functioning, (Kiecolt-Glaser et al., 1991; Pariante et al., 1997), altered response to influenza shots (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), slower wound healing (Kiecolt-Glaser et al., 1995), higher blood pressure (Franklin, Ames, & King, 1994), and altered lipid profiles (Vitaliano et al., 1995).

Carter (2002) found that caregivers suffered severe fluctuations in sleep patterns over time and that these changes affected depressive symptoms. Burton and colleagues (1997) examined the relationships between provision of care by family members and their health behaviors and health maintenance, and found that caregiving increased the odds of getting inadequate rest, not having time for exercise and forgetting to take prescription drugs when compared to non caregivers.

The previous sections have illustrated potential negative emotional and physical consequences that can result from providing care. Caregivers are at risk for feeling burdened and depressed, as well as being at risk for changes in their immune and cardiovascular systems, and neglecting their own health care needs. Furthermore, caregivers' emotional and physical health are interdependent, as caregivers who perceive themselves as burdened are at increased risk for negative physical consequences to providing care. These well documented negative consequences of providing care underscore the need to identify factors that affect how a caregiver will respond to assuming this new role, so that interventions can be targeted toward caregivers at risk for negative consequences.

Risk Factors for Negative Consequences from Providing Care

Factors that increase the risk for caregivers' negative emotional and physical consequences from providing care include variables from the care situation – the care recipient's functional and mental (cognitive and neuropsychiatric) status and the presence and severity of the care recipient's treatment related symptoms – and caregivers' personal characteristics, such as gender, age, socioeconomic status, caregivers' emotional and physical health, caregiver/care recipient relationship, mastery, and perceived adequacy of information to provide care. Each of these risk factors are discussed.

Variables from the Care Situation

Care recipient functional status

Care recipient and illness related variables such as the cell type of the tumor and treatment options such as surgery and radiation dictate the care recipient's functional status (or how well the care recipient is able to perform ADLs and IADLs), and have been consistently associated with negative consequences from providing care. Severity of functional impairment (e.g. limitations in ADLs and IADLs) has been found to significantly affect caregiver distress, particularly when the care recipient is non-demented (Clipp & George, 1992; Given et al., 1993; Jepson et al., 1999; Nijboer et al., 2000; Oberst et al., 1989; Pinquart & Sorensen, 2003; Breitbart, Gibson, & Tremblay, 2002).

Providing assistance with the care recipient's personal care (Vitaliano, Russo, Young, Teri, & Maiuro, 1991), as well as activities such as errands or transportation (Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999), increase time demands on the caregiver. Increased time demands on the caregiver restrict the caregiver from fulfilling

other roles or activities, particularly if the care recipient's functional impairment requires 24 hour care. The amount of care provided (i.e. the number of tasks with which the caregiver provides assistance), is directly associated with caregiver burden and depressive symptoms (Yates et al., 1999).

Although functional status has been linked to negative consequences from providing care for caregivers of persons with cancer and persons with Alzheimer's disease, the effect of care recipients' functional status on caregivers of persons with a PMBT is unknown. In addition, the effect of care recipients' functional status on caregivers of persons who also have deficits in mental status (such as cognitive or neuropsychiatric problems) is just beginning to be explored. More detail regarding the role that care recipients' functional status plays in negative consequences from providing care in the presence of cognitive and neuropsychiatric problems is further discussed in the following section.

Care recipient cognitive and neuropsychiatric status

One of the most commonly cited indicators of negative consequences from providing care in the non-cancer caregiver population is the care recipient's mental status (defined here as the care recipients' cognitive status and the presence or absence of neuropsychiatric symptoms). The majority of this literature is found with caregivers of persons with Alzheimer's disease or related dementias. Researchers have reported that the presence of neuropsychiatric symptoms in the care recipient such as agitation, dysphoria, irritability, delusions, depression, inappropriateness, violence, and apathy (Calhoun, Beckham, & Bosworth, 2002; Fillit, Guterman, & Brooks, 2000; Groom,

Shaw, O'Connor, Howard, & Pickens, 1998; Kaufer et al., 1998) may be particularly difficult for caregivers to manage.

Caregivers of persons with changes in mental status report that managing the sequelae of impaired cognition and the presence of neuropsychiatric symptoms produces higher caregiver distress than assisting with impaired physical functioning (Pinquart & Sorensen, 2003). Family caregivers may adapt to the demands that impaired physical functioning places upon them, resulting in less burden from providing care, but caring for persons with cognitive deficits produces high and sustained levels of caregiver burden (Carey, Oberst, McCubbin, & Hughes, 1991). This could be due to the fact that caregivers have reported that other family members are more likely to assist with care demands resulting from changes in functional status (Given, Given, Stommel, & Lin, 1994) rather than those resulting from changes in the care recipient's mental status (Breitbart et al., 2002). This could also be due to the fact that providing assistance with functional tasks is associated with a sense of predictability – i.e. caregivers know what care demands will be present and are able to integrate providing care into their schedules. The presence and severity of cognitive and neuropsychiatric problems, on the other hand, are less predictable, and caregivers may be less able to cope with not knowing whether the care recipient will recognize them or be agitated.

The previous sections described variables related to the care situation that can place family members at risk for negative consequences from providing care. The care recipient's functional status and mental status can both affect how the caregiver will respond to providing care. However, it is not simply the presence of care demands that dictates whether the caregiver will have negative consequences from providing care.

Caregiver characteristics (such as the caregiver's gender, age, socioeconomic status, emotional and physical health, relationship to the care recipient, mastery, and perceived adequacy of information to care) can influence whether the caregiver will suffer negative consequences as a result of providing care.

Caregiver Personal Characteristics

Caregiver gender

Gender has been shown to be differentially related to the development of caregiver burden and depressive symptoms, as well as being related to how caregivers respond to interventions aimed at improving caregiver health (Gitlin et al., 2003; Sorenson, Pinquart, & Duberstein, 2002). Overall, caregiving is reported to be more stressful for women (wives and daughters) than for men (husbands and sons) (Baider et al., 1996; Northouse et al., 1995; Northouse et al., 2000; Raveis et al., 1998; Sales et al., 1992; Schulz, Visintainer, & Williamson, 1990; Schulz & Williamson, 1991; Stommel, Given, & Given, 1990). Caregiving may produce less burden and depressive symptoms in men because men who take on the caregiving role do so with little or no normative pressure. Women, however, may feel much greater pressure from family members and health care practitioners to assume this role, and thus react to not only the caregiving requirements, but to the pressures that force them to assume that role.

Caregiver age

Age has also been related to caregiver distress (Given & Given, 1996; Given et al., 2003; Kristjanson, Leis, Koop, Carriere, & Mueller, 1997; Nijboer et al., 2000). Older family caregivers may have other problems related to care tasks, such as their own decreased physical capacity resulting from co-morbid conditions. Social isolation and

decreased or fixed family resources may also pose problems for the older caregiver.

Older caregivers may become enmeshed in the care situation (often because they provide care by themselves) and isolate themselves from friends and family to become completely focused on providing care for their spouse. This strong sense of obligation may increase their levels of distress.

Middle-aged caregivers (often adult children of the care recipient) may also be at risk for negative consequences of providing care (Given et al., 1993; Schumacher, Dodd, & Paul, 1993). Middle-age is a time when individuals seek to reach personal goals and stability in family life, and adult child caregivers may feel caught between their work life, professional careers, family life, and the caregiving demands for their parent. Sense of obligation to parents may seem more pressing and immediate and take precedence over responsibilities to their spouses, children, coworkers, and employers (Barnes, Given, & Given, 1992), causing conflict and resulting in less personal time for the caregiver. This personal conflict and multiple demands on caregivers' time may lead to negative consequences for caregivers (burden, depressive symptoms, and decreased physical health) (Kurtz et al., 1994; Nijboer et al., 2000).

Caregiver socioeconomic status

Low personal and household incomes and limited financial resources can place caregivers at risk for negative consequences from providing care, particularly if there are substantial out-of-pocket costs involved in providing care (Nijboer et al., 1999; Stephens, Townsend, Martire, & Druley, 2001). Given, Given, and Stommel (1994), Hayman et al. (2001), and others report that out-of-pocket costs, loss of income, and family labor costs all contribute to the financial burden of family care (Stommel, Given, & Given, 1993).

Unemployed or low-income caregivers may experience more distress because they may have fewer resources and less capacity to meet care demands. Income and overall financial concerns cause particular distress for caregivers during long treatment periods, (Clipp & George, 1992; Given et al., 2003), as resources become depleted. Davis-Ali, Chesler, and Chesney (1993) concluded that higher-income families might not become as distressed or burdened as those with limited resources, as they have financial resources to purchase care. Individuals with a higher income are able to purchase external support thereby lowering burden, especially if they can forego those tasks considered more onerous. Individuals with a higher socioeconomic status are also more likely to have a higher level of education, which can influence the effectiveness of caregiver interventions to improve caregivers' emotional and physical health (Gitlin et al., 2003).

Caregivers' own emotional and physical health

Several researchers have examined how the caregivers' own physical and emotional health may place them at risk for negative consequences from providing care. Nijboer et al. (1999) studied the depressive symptoms and quality of life of caregivers, and found that caregiver depressive symptoms were associated with caregivers who experienced a loss of physical strength. (Interestingly, caregivers sustained their quality of life perspective through the increased self-esteem they received from providing care). Kozachik et al. (2001) also found that baseline caregiver depressive symptoms predicted caregiver depressive symptoms at 9 and 24 weeks after recruitment into their study. Caregivers with alterations in emotional health (such as anxiety or depression) may perceive providing care as more of a burden (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Schulz & Williamson, 1991; Sherwood et al., in press; Winslow, 1997).

Although caregivers' emotional health impacts their perceived burden and depressive symptoms, little research has been done regarding caregivers' use of antidepressants and anti-anxiety medications.

Concerning physical health, caregivers who have pre-existing comorbid conditions are less likely to be able to meet care demands (Bugge, Alexander, & Hagen, 1999). Raveis et al. (1998) found that care-providing daughters who had an existing health condition themselves reported limitations in their ability to care and reported higher levels of depressive symptoms. Deterioration in caregivers' own emotional and physical health can limit the resources that caregivers are able to employ to meet care recipients' care demands.

Caregiver/care recipient relationship

Family caregiving must be placed within the context of prior family relationships. Quality of prior relationship impacts the care recipient–caregiver relationship when care demands are present, and must be considered in order to understand when risks for negative consequences from providing care may occur (Pinquart & Sorenson, 2003). Both the care recipient and caregiver bring a set of past relationships and role expectations that may enhance or complicate the care process. Family relationships during care may reflect the way families usually function (past relationships), while discordance among family members may be aggravated as a consequence to the challenges of providing care (Nijboer et al., 1999; Northouse, Templin, & Mood, 2001). The quality of the prior relationship may be a form of social support (Nijboer et al., 1999) and influence taking on care responsibilities. Some individuals assume caregiving responsibilities to show that they are committed to supporting the family (Cicirelli, 1992),

and for some this responsibility is positive, but for others this may be negative.

Northouse et al. (1995, 1998, 2000) found that spouses of patients with cancer reported lower family functioning and less social support combined with increases in emotional distress. Fewer spouses' role problems at baseline and higher levels of marital satisfaction were predictors of fewer role problems. Illness uncertainty, care recipient symptom distress, low levels of social support, and feelings of hopelessness accounted for spouse role problems.

Family relationships may also affect providing care as wives, husbands, daughters, and sons appear to approach the practice of caregiving in different ways (Gerstel & Gallagher, 1993; Raveis et al., 1998). Studies have reported that husbands caring for wives focus on caregiving tasks while continuing their own activities and interests, and do not expect that their wives' needs for care will interfere with their usual activities. Wives, however, give priority to their husbands' needs and choices (Miller, 1990), and consider their own needs to be secondary. Wives also focus attention on the interpersonal aspects of caregiving such as how their relationships with their husbands are changing and tend to find such changes in their relationships to be uncomfortable.

Spousal caregivers may be at risk for negative consequences from providing care because they live with care recipients, and typically provide the most extensive and comprehensive care, maintain their role longer, and tolerate greater levels of care recipient disability. Recent work (Given et al., 2003) shows that in the first year following the diagnosis of an advanced stage cancer, spouse caregivers, when compared with non-spouses and more distant relatives, experienced higher levels of burden (Given et al., 2003). Adult children and other non-spousal caregivers, on the other hand, may be

at risk for negative consequences from providing care because they experience more lifestyle adjustment (Siegel et al., 1991). The impact of caregiving and its associated distresses on marital relationships such as divorce or separation have not been well described in the literature.

The previous sections have described sociodemographic characteristics, such as age and gender, which may place the caregiver at risk for negative consequences from providing care. Other potential moderators of negative consequences from providing care include caregiver mastery and perceived adequacy of information to care (PAIC).

Caregiver mastery

Mastery is defined as the amount of control that a person feels over the forces that are impinging upon him or her (Pearlin & Schooler, 1978). Caregiver mastery involves the caregiver's perceptions of being able to meet the challenges of providing care and feeling in control of the care situation. Caregivers with high levels of mastery feel that they are usually certain about what to do in providing care, perceive themselves as able to handle most of the problems they face in the care situation, and believe that they are mastering most of the challenges in caregiving (Pearlin, Mullan, Semple, & Skaff, 1990).

Caregivers with higher levels of mastery regarding the care situation have fewer negative consequences from providing care (Bookwala & Schulz, 1998) because they perceive themselves as able to meet care demands (Gitlin et al., 2001). Caregiver mastery can also decrease negative consequences from providing care by influencing the availability of healthy coping strategies to meet care demands (Szabo & Strang, 1999). For example, higher levels of caregiver mastery have been associated with problem-focused coping strategies (rather than emotion focused coping strategies) (Li, Seltzer, &

Greenberg, 1999), which can reduce negative consequences of providing care (Nijboer et al. 2001; Yates et al., 1999).

Perceived adequacy of information to care

Perceived adequacy of information to care is caregivers' perception of their ability to access information from the health care system that is necessary to provide care, and their perception of the usefulness of that information. At all points in the care recipient's disease trajectory, caregivers need information to deal with the care recipient's care and treatment demands, yet healthcare providers often expect caregivers to be responsible for sorting out relevant information and applying it to the care situation. Northouse and Peters-Golden (1993) and Oberst and Scott (1988) indicated that caregivers need information not only about physical tasks of caregiving activities, but also about how to manage care recipients' emotional needs (such as depression, anxiety, or anger). The results of National Cancer Institute (NCI) focus groups with caregivers and social workers (NCI, 2003) revealed that caregivers need information in five areas: how to prepare for medical visits, how to research disease related information on the internet, how to seek and reconcile different medical opinions, what the care recipient is likely to experience physically and emotionally throughout the disease process, and how the caregiver can best support the care recipient at each stage. Caregivers also expressed the need for information on the emotional experience of caregiving, their own self care, the importance of networking with other caregivers, the importance of seeking support, warning signs of stress and medical risks, general financial and insurance information, and information regarding the value of volunteerism and advocacy (NCI, 2003).

Providing caregivers with information not only helps the caregiver feel in control of the care situation, but also helps the caregiver deal with care related issues in the future. Grimm and colleagues (2000) documented the importance of cancer education to meet caregivers' psychosocial needs for caregivers of persons undergoing bone marrow transplantation. These researchers found significant correlations between caregivers' mood and their satisfaction of informational needs (among others) across various treatment time points over 12 months. Ferrell, Grant, Chan, Ahn, and Ferrell (1995) specifically examined the impact of pain education on family caregivers who were providing care to elderly persons with cancer. While care recipients' pain experience had a significant impact on family members' distress, the pain education program was effective in improving caregiver knowledge and attitudes regarding pain management.

Family members continue to report that a lack of knowledge regarding the disease and treatment status of the care recipient and uncertainties in care expectations leads to negative consequences from providing care (Blanchard, Albrecht, Rucksdeschel, Grant, & Hammick, 1995; Given & Given, 1996; Northouse et al., 2000; Oberst et al., 1989; Oberst & Scott, 1988). Ongoing informational needs include updates on clinical status, prognosis, and treatment expectations, and providing information has been reported in the literature as a useful way of reaching family caregivers (Northouse & Wortman, 1990; Zahlis & Shands, 1991).

Although caregivers indicate a need for information, they also report difficulty in obtaining information from healthcare professionals, particularly physicians and nurses (Dyck & Wright, 1985; Sherwood, Given, Doorenbos, & Given, 2004; Wilson & Morse, 1991; Zahlis & Shands, 1991). Caregivers desire to learn more about the emotional

aspects of illness and recovery (NCI, 2003; Northouse & Peters-Golden, 1993; Oberst & Scott, 1988), in addition to providing information about the physical aspects of the illness of the care recipient.

In summary, studies exploring the impact of providing care on caregivers' emotional and physical health have been done with caregivers of multiple patient populations. Caregiver burden, depressive symptoms, and changes in caregiver health, such as changes in immune function and sleep disturbances, have all been identified as potential consequences of providing care. Factors that affect potential consequences of providing care have also been identified, such as the care recipient's functional and mental (cognitive and neuropsychiatric) status, and the caregiver's gender, age, socioeconomic status, emotional and physical health, relationship to the care recipient, mastery, and PAIC. Despite the breadth of this work, however, the lack of research with caregivers of persons with a PMBT is a consistent theme throughout the review. In the few published studies with neuro-oncology caregivers, sample sizes were small and exploratory, and qualitative analyses were commonly utilized.

Caregivers of Persons with a PMBT

The majority of research in the area of caregivers of persons with a PMBT has focused on the caregiver's reaction to the family member's diagnosis. Salander (1996) and Wideheim, Edvardsson, Pahlson, and Ahlstrom (2002) both describe the crisis that the family undergoes when trying to cope with the care recipient's illness. Anxiety, helplessness, and fear were recurring themes in caregivers who were trying to cope with day to day activities following their family member's diagnosis. Other researchers have examined caregiver perspectives on mechanisms of support. Leavitt, Lamb, and Voss

(1996) and Wyness, Durity, and Durity (2002) found that caregivers of persons with a brain tumor emphasized seeking and exchanging information as extremely important in trying to deal with the care recipient's disease.

These neuro-oncology studies are beginning explorations of caregiver reactions to the care recipient's diagnosis of a PMBT and some of the mechanisms of support that may be helpful in dealing with the patient's illness. However, the research studies were typically designed to capture the caregiver's reaction to the care recipient's illness and disease, rather than evaluating the negative consequences to the caregiver from providing care. In addition to the limitations of current research involving caregivers of persons with a PMBT, there are several other limitations to past caregiver research in general resulting in gaps in the literature. These are described in the following section.

Limitations of Past Caregiver Research and Gaps in the Literature

Limitations of past caregiver research involve those resulting from the design of the study, the patient populations included in study samples, and the types of analyses that have been applied to the data. Some of these gaps were addressed by the research study described here, while others need to be addressed in future studies.

The first limitation of past caregiver research pertains to research design. The majority of caregiver studies to date have used a cross-sectional, descriptive design. Although this design is useful in identifying relationships, it does not allow potential consequences from providing care to be studied over time, nor does it help to establish causality. For example, how consequences from providing care change over the course of the care situation, and change in response to alterations in care demands is not well established. In addition, most caregiving studies recruit caregivers at varying points

within the care situation, rather than employing an inception cohort design and recruiting caregivers at the onset of care demands. This means that in past research, caregivers with relatively little experience in providing care are included in a sample with caregivers who have months of experience. There is little information regarding how care demands affect caregiver outcomes at various points along the life cycle and at various points in the care recipient's trajectory of disease. Although the study described here also used a cross-sectional design (and thus shares this limitation with other caregiving research), the project was constructed to provide the basis for a longitudinal, inception cohort study, which would be able to address some of these issues in a later study.

Second, past caregiver research has also been limited in regard to the potential responses to providing care included as outcome variables and in regard to the participants targeted for measure. The majority of caregiver research has focused on negative aspects of providing care. Little is known about potential positive responses to providing care and how those positive responses may buffer the caregiver's negative consequences from providing care. In addition, research on caregiving has been, for the most part, limited to examining a single caregiver. The impact of providing care on the entire family, particularly on the level and duration of involvement of secondary carers, is not well established. Due to time constraints, these issues were not explored in the current study, although positive aspects of care and the involvement of secondary carers were examined in a concurrent study of caregivers of persons with a PMBT [Sherwood et al., 2004].

The third major limitation of past caregiving research is the inability to distinguish relationships among negative consequences from providing care. Negative

emotional consequences, for example, are typically identified as burden and depressive symptoms. However, the relationship between burden and depressive symptoms, and the way in which burden and depressive symptoms predict each other over time is not well established. In addition, most caregiver research to date has employed analytic techniques such as regression analyses, which is not well suited to determining the individual effects of variables on caregiver responses that are interrelated. This study attempted to address this limitation by using an analytic technique that controls for covariance among predictor and among outcome variables (Structural Equation Modeling [SEM]).

Lack of research to demonstrate how variations in caregiver contact with the formal health care system interact with the amount and types of responsibilities faced by family caregivers is the fourth limitation of past caregiver research. How the interplay between the formal and informal systems of care affects the ongoing needs of caregivers has not been well established. This study began to address this gap in the literature by examining the potential effect of the relationship between the caregiver and health care practitioners on caregiver responses to providing care.

The final limitation of caregiver research to date is the lack of studies investigating the effect of the care recipients' mental status on caregivers of persons with cancer. These studies have been largely missing from the cancer literature, despite the potential for cancer treatment to affect care recipient cognition (such as the effect of chemotherapy on cognition, and the neurological changes that can result from malignancies in the central nervous system; Barton & Loprinzi, 2002; Freeman & Broshek, 2002). The primary aims of this study began to fill this gap in the literature by

identifying the relationship between the care recipients' cognitive and neuropsychiatric status and caregiver responses to providing care.

Conclusion and Significance

In summary, the study described here will begin to fill some of the gaps in caregiving literature to date and advance the science of caregiving research in the following ways. First, study results begin to examine the negative consequences from providing care for an understudied population – caregivers of persons with a PMBT. By studying this group of caregivers, we are also able to begin to address another limitation of past caregiver research – the paucity of studies investigating the effect of the care recipient's mental status on caregiver outcomes for caregivers of persons with cancer.

Second, the analytic technique used in the study (SEM) was designed to allow for covariance among independent and among dependent variables, which has been identified as a limitation in most caregiving studies to date. Third, this study begins to examine caregivers' interactions with the formal health care system through evaluating caregivers' PAIC, and how those interactions may affect consequences from providing care.

Although this study shares some limitations with other caregiving research (i.e. a cross sectional, descriptive design was used, positive aspects of care were not measured, and the impact of providing care on the family was not evaluated), the previous sections illustrate the way in which the study will begin to fill some gaps in the literature and advance the science of caregiving research. Both the gaps in past caregiving research, as well as the results from decades of studies in this area, were used to develop the

conceptual model of providing care for a person with a PMBT, which is described in Chapter 3.

Chapter 3

The conceptual model illustrated in Figure 1 is based on Lazarus and Folkman's Theory of Stress and Coping (Folkman 1997; Lazarus 1996) and supported by caregiver research in the area of cancer and neuroscience, as well as by the investigators' clinical expertise. The model was developed to depict the potential stress response of someone who is providing care for a family member with a PMBT. [Note: The phrase 'stress response' is used in this chapter to denote negative consequences of providing care for the caregiver.] In the model, the caregiver faces a potentially stressful situation brought on by the stimulus event of the care recipient's diagnosis. During the primary appraisal, the caregiver assesses the nature of the care demands that are being placed upon him/her (such as providing assistance based on alterations in the care recipient's functional or cognitive status). During the secondary appraisal, the caregiver examines resources that are available (such as financial resources or PAIC) that may moderate or buffer the effect of the care demands on his/her stress response. The caregiver's stress response is conceptualized as an emotional response (such as caregiver burden) and physical response (such as altered immune functioning).

In the following sections, the stimulus event, primary appraisal, secondary appraisal, and potential consequences from providing care (the caregiver's stress response) for a caregiver of a person with a PMBT are discussed. Finally, an overall model summary is presented and pathways and interrelationships within the model are described.

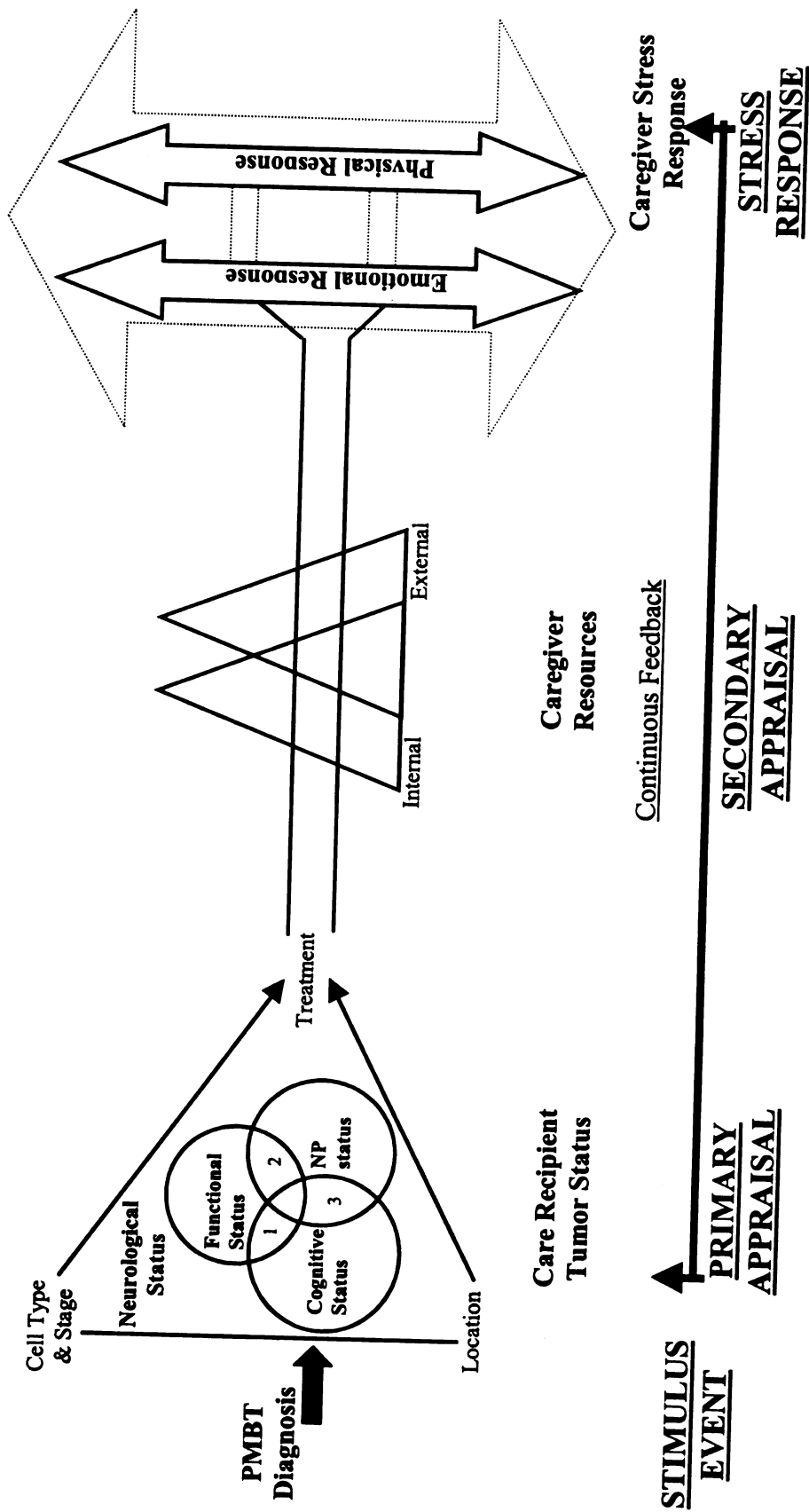


Figure 1. Conceptual model: Caring for a family member with a PMBT

Stimulus Event

For the caregiver of a person with a PMBT, the stimulus event that initiates the caregiver's stress response is the care recipient's diagnosis of a brain tumor. As described in Chapter 1, cerebral malignancy is relatively uncommon compared to other malignancies (Michigan Department of Community Health, 2000). However, the diagnosis of a PMBT often follows a sudden and traumatic event such as a seizure or sudden loss of consciousness (Brinar, Bozicevic, Zurak, Gubarev, & Djakovic, 1991; Greenberg, Chandler, & Sandler, 1999), and the disease trajectory can include severe morbidity and mortality (Greenberg et al.). Investigators have identified the period following diagnosis as a state of acute crisis for the caregiver accompanied by anxiety and fear of losing the care recipient (Wideheim et al., 2002).

Morbidity associated with a PMBT can also be severe and difficult for the caregiver to handle. Intracranial surgery to remove the tumor often causes changes in the care recipient's functional, cognitive, and neuropsychiatric status, which may be permanent or temporary. Due to the location of the tumor and the chemoresistance of the blood brain barrier, treatment options such as chemotherapy and radiation therapy may be of limited use (Newton, Turowski, Stroup, & McCoy, 1999) and have additional neurological side effects, such as further deterioration in cognitive function (Scheibel et al., 1996). The onset and trauma of diagnosis, and the mortality and morbidity associated with the disease trajectory of a person with a PMBT form the stimulus event that triggers the caregiver's stress response. The caregiver's stress response, then, is determined by the number and type of care demands that are identified during the caregiver's primary

appraisal of the care situation, as well as by the resources that are available to meet those demands.

Primary Appraisal

During the primary appraisal, the caregiver assesses the nature of the demands that are being placed upon him/her. As Figure 1 illustrates, the nature of the demands in the care situation of a person with a PMBT stem from the care recipient's functional, cognitive, and neuropsychiatric status, which are dictated by the care recipient's tumor status and overall neurological status.

Tumor Status

The care recipient's tumor status includes cell type and stage, location, and treatment of the tumor. Cell type and stage determine the nature of the disease trajectory (such as the aggressiveness of the tumor in recurring), which in turn, may dictate the nature and number of demands that will be placed on the caregiver. For example, an aggressive tumor such as a Grade III or IV Astrocytoma may require multiple surgical resections, leading to severe cognitive or motor dysfunction. Cell type and stage also dictate the length of survival for the care recipient, which can affect the caregiver's feelings of loss and grief (Lindgren, Connelly, & Gaspar, 1999) and may influence his/her perception of the stressful nature of care demands. For instance, a caregiver of a person who faces the short terminal prognosis associated with a GBM may consider the opportunity to provide care as a privilege if time together is limited. On the other hand, a caregiver may also feel "robbed" of time with the care recipient if the caregiver's time must be directed toward meeting care demands. Overall, caregivers of persons with a

PMBT may become preoccupied with the time until the care recipient's death (Adelbratt & Strang, 2000), which can increase the stress response to providing care.

The location of the tumor also influences the demands of the care situation. Persons with left hemisphere lesions, for example, may need assistance based on verbal deficits, whereas care demands for persons with right hemisphere lesions may be based on the care recipient's poor facial recognition (Scheibel et al., 1996). A tumor in the frontal lobe, on the other hand, may be associated with impaired judgment, decreased reasoning ability, and changes in emotional control, creating the demand for constant supervision of the care recipient. A temporal lobe lesion may result in seizures and memory loss, which may create the need for someone to provide transportation to treatment sessions. There are relatively few areas of the brain in which the tumor may be located without causing noticeable physical, cognitive, or neuropsychiatric side effects, which in turn, help to determine care demands.

The final factor involved in the care recipient's tumor status that affects care demands is treatment of the tumor. "Curative" treatment strategies, including surgical resection, radiation, and chemotherapy, may lead to immunosuppression, decreased cognitive functioning, fatigue, and neuropsychiatric symptoms (Crossen et al., 1994; Scheibel et al., 1996), and can prompt the care recipient to require more assistance. For instance, fatigue from chemotherapy may limit the care recipient's ability to perform ADLs and IADLs, requiring the caregiver to assist with household chores. In addition, the intensity and frequency of treatment related problems may increase as the tumor and its treatment progress, leading to further declines in the care recipient's neurological status (Weitzner et al., 1999), and placing additional demands on the caregiver.

Other treatment efforts focus on symptom management and palliative care (such as controlling cerebral edema and preventing seizures), and also create care demands for the caregiver. Steroids, for example, are commonly used to treat tumor-related edema, postoperative edema, and radiation-induced edema. However, the side effects of steroids can include myopathy, gastrointestinal perforation, opportunistic infections, steroid diabetes, and skin and facial changes (Koehler, 1995), which can increase the demands of the care situation as the caregiver is required to monitor the care recipient and intervene with managing these side effects.

The previous sections have described the effect of the tumor status on the demands of the care situation. Although tumor status may affect care demands directly (such as the effect of cell type and stage on the caregiver's feelings of grief and loss), the most obvious effect of tumor status on care demands is its influence on the care recipient's neurological status. During the primary appraisal, the caregiver must consider how the care recipient's tumor status (including cell type and stage as well as treatment) will affect the care recipient's neurological status.

Neurological Status

Neurological status is defined as the care recipient's functional and cognitive status, and the presence or absence of neuropsychiatric symptoms. Neurological status is a direct result of the cell type, stage, location, and treatment of the tumor, and is intimately involved in creating care demands. Functional status, defined as the care recipient's ability to coordinate muscle movement for the purpose of performing a task, is an important contributing factor to the demands of the care situation. In persons with a brain tumor, alterations in functional status may be linked to paralysis, paresis, gaze

disorders, sensory loss, blindness, decreased level of consciousness, ataxia, difficulty swallowing, headache, and nausea and vomiting (Forsyth & Posner, 1993; Greenberg et al., 1999; Morita, Tsunoda, Inoue, & Chihara, 1999). Decreases in functional status can limit the amount of self-care and treatment related activities the care recipient can perform, including continuing with employment, performing ADLs such as bathing and dressing, and driving to and from treatment sessions. If the care recipient is unable to perform these tasks, a demand is created for the caregiver to either assist the care recipient or assume the task entirely. The functional status of the care recipient, then, helps to define the care demands of the situation, along with the care recipient's cognitive status and the presence or absence of neuropsychiatric symptoms.

Alterations in cognitive status, defined as the processes by which sensory input is elaborated, transformed, reduced, stored, recovered, and used (Neisser, 1967), can also create demands for the caregiver of a person with a PMBT. Cognitive effects of cerebral malignancy may include memory deficits, confusion, and inefficiency with work, among others (Filley & Kleinschmidt-DeMasters, 1995; Irle et al., 1994), and can affect the demands of the care situation. Although the care recipient may have the physical ability to perform ADLs and IADLs, he/she may not have the cognitive ability to coordinate motor movement, or the attention span to perform a task with several steps, such as making meals. The caregiver may be required to give the care recipient multiple directions and reminders to perform routine activities, and may be responsible for providing more direct supervision of the care recipient than a caregiver of someone without cognitive dysfunction. Ory and colleagues (1999) reported that caregivers of persons with cognitive dysfunction provided assistance with a significantly higher

number of ADLs and IADLs than caregivers of persons who were cognitively intact. Alterations in the care recipient's cognitive status can also increase demands on the caregiver by limiting the care recipient's involvement in treatment choices. A care recipient who is unable to process new information often leads to the caregiver being solely responsible for gathering information and making decisions. A care recipient with altered cognitive status may also be less able to make decisions involved in their previous roles in the household, such as making financial and legal decisions, which force the caregiver to acquire multiple new roles (Sherwood et al., 2004).

Both the amount of direction the care recipient requires to perform a task and the amount of responsibility designated to the caregiver to assume new roles and make treatment and care decisions increase time demands on the caregiver (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000; Bell, Araki, & Neumann, 2001; Clipp & Moore, 1995). These time demands may force caregivers to change the type of job they have, the number of hours they work, or to give up work entirely (Ory et al., 1999). The care recipient's cognitive status can also influence the caregiver's primary appraisal of the care demands through its effect on the dyad's relationship. Caregivers may have more negative consequences from providing care to someone with cognitive dysfunction than to someone who is cognitively intact. Shelton (1993) described a negative response from caregivers of persons with cognitive changes as an additional loss felt by caregivers because the care receiver was a different person than he/she was before the caregiving began. Caregivers of persons with a PMBT have reported that upon the death of the care recipient, they felt they had grieved twice – once for the care recipient who was lost to cognitive changes, and again after the care recipient's death (Salander, 1996; Sherwood

et al., 2004). These feelings of grief may exacerbate the threatening nature of the care demands, ultimately affecting the caregiver's stress response (Lindgren et al., 1999).

Whereas cognitive status involves the care recipient's ability to think and remember clearly, neuropsychiatric status is concerned with the presence or absence of tumor-related psychiatric symptoms such as hallucinations, delusions, and disinhibition (Kaufer et al., 2000). As previously mentioned, neuropsychiatric symptoms that have been found in persons with a PMBT include anxiety, depressive symptoms, irritability, anger, apathy, hallucinations, and mania, among others (Filley & Kleinschmidt-DeMasters, 1995; Irle et al., 1994). The severity (Neundorfer, 1991), frequency (Clyburn et al., 2000) and number (Kreutzer, Gervasio, & Camplair, 1994) of the care recipient's neuropsychiatric symptoms can increase the care demands and affect the caregiver's stress response. For example, managing neuropsychiatric symptoms can place time demands on the caregiver (i.e. if the care recipient wanders or displays unsafe behavior, the caregiver may be responsible for either arranging or providing 24-hour supervision). In addition to the effect of neuropsychiatric symptoms on the caregiver's time, neuropsychiatric symptoms can also create care demands by affecting the care recipient's functional status. Gaugler and colleagues (2000) found that increases in problematic behavior were associated with increases in care demands to assist with ADLs.

The ways in which neurological status (functional and cognitive status, and the presence or absence of neuropsychiatric symptoms) and the care recipient's tumor status affect care demands are considered during the caregiver's primary appraisal of the care situation. Factors resulting from the care recipient's tumor and neurological status can have both a direct effect on the demands of the care situation (such as poor functional

status causing the need for assistance ADLs), as well as an indirect effect (such as short term memory loss affecting the care recipient's ability to perform ADLs, thereby decreasing the care recipient's functional status and creating additional care demands). A thorough appraisal of all the demands of the care situation is the first step in determining the caregiver's stress response. Once the primary appraisal is complete, the caregiver's stress response will be dependent upon the resources available to the caregiver to meet care demands, which are considered during the secondary appraisal.

Secondary Appraisal

During the secondary appraisal, the caregiver considers the resources that are available to meet the care demands imposed by the diagnosis and treatment of the care recipient's tumor. Resources can be both external (not endogenous to the caregiver) and internal (emotional and physical traits of the caregiver), and will influence the stress response of the caregiver as he/she attempts to meet care demands (Neundorfer, 1991). The following sections describe potential resources for the caregiver to meet care demands as well as depict the way in which resources have been shown to affect the caregiver's stress response. It should be noted, however, that simply the presence or availability of resources does not necessarily lead to more positive consequences from providing care. In addition to being available, resources must also be applicable to the care demands, considered acceptable to the caregiver, and be used by the caregiver in order to affect the caregiver's stress response (Collins, Stommel, Given, & King, 1991).

External Resources

External resources are factors that are not endogenous to the caregiver (i.e. not a personality trait), and can include educational, personnel, financial, and support

resources. The availability and acceptability of educational resources to help the caregiver meet care demands and decrease their stress response can be conceptualized as the caregiver's perceived adequacy of information to care (PAIC). Educational resources provide information on the care recipient's disease process, treatment options, and symptom management, as well as provide information on assistance that may be available to the caregiver such as information on tax credits for caregivers and insurance coverage for home health care (Pasacrete, Barg, Nuamah, & McCorkle, 2000). Educational resources can also include information targeted at ways to improve the caregiver's emotional health, such as relaxation, which may be particularly helpful for caregivers of persons with alterations in cognitive status (Williamson & Schulz, 1993).

Implementing educational resources to increase caregivers' PAIC has been shown to decrease negative stress responses for caregivers of persons with cancer (Jepson et al., 1999; Kozachik et al., 2001) as well as caregivers of persons with neurodegenerative diseases (Marriott, Donaldson, Tarrier, & Burns, 2000; Teri, Logsdon, Uomoto, & McCurry, 1997), although the long term effects on the caregiver's stress response is not known (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). Caregivers utilize educational resources to meet care demands by learning how to deal with difficult care recipient behaviors (Gitlin et al., 2001; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999), as well as by learning how to provide assistance, how to communicate with the care recipient and health care team, and by learning effective coping strategies (Chang, 1999), which in turn can decrease the caregiver's negative stress response (Matsuda, 1995; Schumacher et al., 1993). Education aimed at caregivers has also been shown to have an effect on caregivers' social health (Rodgers et al., 1999) and quality of life

(Mant, Carter, Wade, & Winner, 1998), which can, in turn, affect the caregiver's stress response.

Caregivers of persons with a PMBT may have a difficult time accessing educational materials and information on disease and treatment related issues (Sherwood et al., 2004). Due to the relative infrequency of brain tumors, information for patients and caregivers is not as readily available as that for other types of cancer. Furthermore, caregivers of persons with a PMBT have reported that when they were able to access information, it did not always meet their needs. Education regarding managing symptoms and providing day to day care, for example, is largely absent (Sherwood et al.). Although national support groups have increased the availability of educational material, caregivers of persons with a PMBT continue to emphasize both their need for information on disease and treatment options as well as the lack of available sources of information (Fox & Lantz, 1998; Leavitt et al., 1996; Wyness, Durity, & Durity, 2002).

The second type of external resources that can affect the caregiver's stress response are personnel resources, which include both professionals (such as home health care agents, chore services, physicians, nurses, social workers, and counselors) and lay persons (including family members, friends, neighbors, and colleagues). Professional and lay personnel can assist the caregiver in meeting care demands, thus affecting the caregiver's stress response, in several ways. First, both professional and lay personnel may assume responsibilities for meeting portions of the care recipient's needs, such as employing a home health care agent to assist the care recipient with dressing changes or utilizing a neighbor to sit with a care recipient while the caregiver runs errands. Second, health care personnel may act as resources to provide education that can be used to meet

care demands, such as health care professionals who provide information and techniques on symptom management (Shikiar et al., 2000). Third, professional and lay personnel may help to coordinate aspects of the care situation (Smeenck et al., 1998), such as a social worker who arranges for respite care or a family member who assumes responsibility for managing family finances. Professional and lay personnel available to assist with care coordination can improve caregiver satisfaction with care, leading to a better stress response to the care situation (Dennis et al., 1997).

Financial resources are also considered during the secondary appraisal, as they can affect the caregiver's ability to meet care demands, and caregivers' stress response (Schulz & Williamson, 1991). Financial resources are determined by comparing the household income (including salaries and benefits) with the cost of daily living expenses, out of pocket medical expenses, transportation costs, costs of home care supplies, sick days and time off not reimbursed for the caregiver, and number of persons dependent on household income. During the secondary appraisal, financial resources are considered to identify means by which the caregiver can meet care demands, such as whether the care recipient's insurance benefits will reimburse home health care agents or whether the caregiver will be able to use state and federal assistance programs to receive reimbursement for providing care (Polivka, 2001). Moore, Zhu, and Clipp (2001) found that caregivers of persons with dementia suffered approximately \$10,709 per care recipient in lost earnings and others have reported that family caregivers provide services for "free" that are estimated to be worth \$257 billion per year (Arno, 2002). If the demands on income that stem from providing care outweigh available financial resources, or if providing care places a significant financial burden on the dyad, the caregiver may

have a negative stress response to the care situation (Beckham, Lytle, & Feldman, 1996; Mullins & Erin, 1998).

Caregivers of persons with a PMBT may be particularly susceptible to the influence of financial resources on their stress response. First, treatment options for persons with a PMBT are limited due to the chemoresistance of the blood brain barrier and the availability of practitioners to treat cerebral malignancy in rural areas (Newton et al., 1999). Caregivers of persons who have exhausted routine treatments often turn to experimental therapy, which can be costly unless it is offered through a clinical trial. Even for those persons who qualify for a clinical trial, costs for transportation and lodging for physician visits may not be reimbursed. Caregivers of persons with a PMBT are also particularly susceptible to financial concerns because they may have fewer financial resources at the onset of the care situation. Recent literature has suggested that persons with a lower socioeconomic status are at a higher risk for developing a PMBT (Sherwood, Stommel, Murman, Given, & Given, in press). Beginning the care situation with already limited financial resources may decrease the caregiver's access to services that would be useful in helping to meet care demands.

The last type of external resources described here are social resources. Social resources can provide emotional support (such as family and friends), spiritual counsel (such as a pastor or spiritual advisor), and psychological therapy (such as a counselor or psychologist), and have been shown to affect caregivers' stress responses (Clyburn et al., 2000; Robinson & Kay, 1994). Caregivers of persons with a PMBT use support resources to vent frustration over care demands, difficult care recipient behaviors, and changes in roles and relationships that occur as a result of providing care (Leavitt et al.,

1996; Sherwood et al., 2004). For example, caregivers of persons with a PMBT have described having to transform their family role from a reciprocal relationship to a custodial or parental relationship (Horowitz et al., 1996). Having personnel available for social support may alleviate some of the stress that can accompany these changes in roles.

Support resources can also be used by the caregiver to express feelings of grief related to the potentially short, terminal trajectory of illness. Some caregivers prefer expressing feelings of grief to others, particularly those caregivers who are reluctant to grieve with the care recipient (despite the fact that the care recipient may have filled this role in the past) because they don't want to 'burden' the care recipient. In addition, caregivers of persons who have neurological sequelae (such as a person with a PMBT) may not be able to rely on the care recipient for emotional support because the care recipient is no longer cognitively intact. Caregivers who are unable to obtain support from the care recipient may need support resources to decrease the negative consequences of providing care.

Unfortunately, although support resources can be used to decrease the stress involved in meeting the demands of the care situation, the care situation may, in turn, dictate the caregiver's access to support resources. The care recipient's behavior may limit the dyad's social interactions (Marsh et al., 1998a; 1998b) thus limiting persons available for emotional support. Clyburn et al. (2000) found that caregivers who provided care for a person with neuropsychiatric and cognitive symptoms received less help from family and friends. The care recipient's worsening cognitive and neuropsychiatric status has also been linked to poorer family functioning (Douglas &

Spellacy, 1996), which can limit the amount of persons available to provide support to the caregiver.

As the previous sections have illustrated, external resources (such as educational, personnel, financial, and support resources) can be used by the caregiver to meet care demands, and in turn, affect the caregiver's stress response. Although external resources are often considered first, caregivers also have access to internal resources that can impact their response to providing care.

Internal Resources

Internal resources are emotional and physical traits of the caregiver and can include mastery, physical health, and emotional health, among others. The availability of positive internal resources can give the caregiver a sense of confidence and strength to meet care demands, which can affect the caregiver's stress response (Strang & Strang, 2001). The first internal resource described here, mastery, is defined as the amount of control that a person feels over the forces that are impinging upon him or her (Pearlin & Schooler, 1978). Caregiver mastery involves caregivers' perceptions of being able to handle most problems in providing care, having influence over what happens in the care situation, and generally feeling in control of both the care situation and their own lives. As described in Chapter 2, caregivers with high levels of mastery feel that they are usually certain about what to do in providing care, perceive themselves as able to handle most of the problems they face in the care situation, and believe that they are mastering most of the challenges in caregiving (Pearlin et al., 1990).

High levels of mastery have been associated with more healthy coping strategies (Li et al., 1999; Szabo & Strang, 1999), which may improve the caregiver's stress

response (Nijboer et al., 2001; Yates et al., 1999). Mastery has also been associated with positive consequences from providing care (Bookwala & Schulz, 1998) because caregivers with high levels of mastery perceive themselves as more able to meet care demands (Gitlin et al., 2001). The control over the care situation associated with caregiver mastery has also been linked to a lower stress response and more positive disease prevention behaviors among caregivers (Burton et al., 1997), and may result in less caregiver bother as a result of the care recipient's neuropsychiatric symptoms (Gitlin et al., 2003).

Caregivers' own physical and emotional health can also affect their stress response. The caregiver's physical health and comorbidities have a direct effect on his/her physical ability to meet care demands (Bugge et al., 1999; Raveis et al., 1998). If the caregiver is unable to lift heavy objects, for example, assisting the care recipient with ADLs such as transferring from a bed to a chair may not be possible. Being unable to meet care demands may force the caregiver to utilize other resources to provide care, such as employing a chore service or asking family members to assist with care. However, employing a chore service places an additional financial demand on the caregiver and some caregivers may be reluctant to ask family members for assistance, if in fact, other family members are available and willing to help. In addition, being physically unable to provide care may cause the caregiver to have feelings of inadequacy or powerlessness. These feelings may lead to lower levels of caregiver mastery, and an increased risk for depressive symptoms in caregivers (Bookwala & Schulz, 1998).

Caregivers' emotional health (including such factors as depressive symptoms, anxiety, and optimism) will affect their ability to cope effectively with the care situation

and meet care demands, and will determine in part their stress response to the care situation (Given et al., 1993). Caregivers who are emotionally distressed may be less able to cope with the care situation, feel more burdened when providing care (Sherwood et al., in press), and may exhibit a more negative stress response to providing care (Dennis et al., 1998). Caregiver emotional health can also affect the caregiver's long-term negative emotional consequences from providing care (Schulz & Williamson, 1991; Winslow, 1997). Kurtz, Kurtz, Given, and Given (1997) found that the caregiver's emotional health during the care situation predicted whether the caregiver's depressive symptomatology would improve or not after the care recipient had died.

The importance of caregiver emotional health is particularly evident in the care situation of someone with a PMBT. Attempting to deal with oncological issues such as a potentially short, terminal trajectory of disease may be particularly difficult for the caregiver with emotional instability. In addition, coping with neurological sequelae such as changes in cognition and neuropsychiatric symptoms, which can be particularly distressful for caregivers (Gonzalez-Salvador et al., 1999, Pinquart & Sorenson, 2003), will be even more difficult to deal with if the caregiver has emotional problems such as underlying depression or anxiety. The caregiver trying to manage the oncological and neurological sequelae of a family member with a PMBT, then, requires both the physical health to perform physical tasks on behalf of the care recipient, as well as the emotional health to contend with the potential decline and loss of the care recipient, and the neurological sequelae that are associated with such a decline.

The previous sections have described both the factors that may influence the demands of the care situation (the care recipient's tumor status and neurological status) as

well as the potential external and internal resources available to the caregiver to meet those demands. The nature of the care demands identified during the primary appraisal, as well as the available resources identified during the secondary appraisal, will determine how stressful the caregiver will perceive the care situation to be. The caregiver's perception of the stressfulness of the care situation is manifested as the caregiver's stress response.

Stress Response

The caregiver's stress response to the care situation can range from low stress to high stress, depending upon the balance between care demands and caregiver resources. This stress response, in turn, can be manifested as an emotional or physical response to the care situation. The caregiver's emotional stress response has been categorized as a global emotional response, such as caregiver burden, strain, or distress, or as a specific emotional response such as depressive symptoms or anxiety.

Emotional Response

The caregiver's global emotional response to providing care has been described as "a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (Given et al. 2001, p. 5). Multiple factors have demonstrated an effect on the caregiver's global emotional response to the care situation. Poor functional status has been linked to negative global emotional responses in both caregivers of persons with cancer (Nijboer et al., 1999) and caregivers of persons with neurological disorders (Prescop, Dodge, Morycz, Schulz, & Ganguli, 1999). In particular, the inability of the care recipient to

perform ADLs (Vitaliano, Russo, Young, Teri, & Maiuro, 1991) and IADLs (Gonzalez-Salvador et al., 1999) has been directly tied to a negative emotional response. Assisting with the care recipient's daily functioning can increase the time demands on the caregiver, which has been associated with limiting caregivers' personal time, thereby causing stress on the caregiver (Marsh et al., 1998a; 1998b). Nagatomo et al. (1999) found that assistance with one of five tasks (bathing, dressing, management of affairs, self-expression, and verbal comprehension) was specifically associated with a global negative emotional stress response. In addition, functional limitations in persons with a brain tumor have been linked to care recipient reports of quality of life (Weitzner et al., 1996), which may indirectly affect the caregiver's emotional reaction to providing care.

Poor cognitive function has also been correlated with a poor global emotional response for the caregiver (Aarsland, Larsen, Karlesen, Lim, & Tandberg, 1999; Matsuda, 1995), particularly when the care recipient is unaware of their deficit in memory, social awareness, or self-care (Seltzer, Vasterling, Yoder, & Thompson, 1997). Browning and Schwirian (1994) reported that poor cognitive function had a significant negative impact on caregiver's emotional health regardless of the care recipient's physical problems. A negative caregiver emotional stress response has also been linked to the presence of neuropsychiatric symptoms (Douglas & Spellacy, 1996; Gaugler et al., 2000), in particular aggression (Nagaratnam, Lewis-Jones, Scott, & Palazzi, 1998), anger, and lack of motivation (Marsh et al., 1998a).

The caregiver's negative emotional response to providing care may also be manifested as a specific mood disturbance such as depressive symptoms and/or anxiety, which may stem from the care recipient's neuropsychiatric symptoms (Schulz &

Williamson 1991), pain (Miaskowski, Kragness, Dibble, & Wallhagen, 1997), overall symptoms (Kurtz et al., 1995), or functional status (Schumacher et al., 1993). The caregiver's level of depressive symptoms and anxiety may in turn predict the caregiver's long-term emotional response to providing care (Winslow, 1997). In addition, the caregiver's global emotional response may affect specific negative emotional consequences from providing care. Caregiver burden, for example, has been shown to be a predictor of depressive symptoms in caregivers (Clyburn et al., 2001; Raveis et al., 1998; Sherwood et al., in press; Song, Biegel, & Milligan, 1997; Whitlatch, Feinberg, & Sebesta, 1997). Furthermore, a negative emotional response for caregivers can also affect caregivers' physical responses.

Physical Response

The caregiver's stress response may be manifested as a physical response and can include changes in health such as poor antibody response to vaccines (Vedhara et al., 1999) and increased days of respiratory tract infections (Kiecolt-Glaser et al., 1991). In general, caregivers with a negative stress response exhibit decreased overall physical health (Sparks et al., 1998; Weitzner et al., 1999; Winslow, 1997), exhaustion (Clipp & Moore 1995), and an increased risk for mortality (Schulz, O'Brien, Bookwala, & Fleissner, 1995). Specifically, the presence of neuropsychiatric symptoms in the care recipient may lead to negative changes in immune function for the caregiver (Kiecolt-Glaser et al., 1995). In addition, caregivers who do not have adequate respite time in comparison to care demands may display higher basal plasma acetylcholine than caregivers who incorporate respite time into their schedules (Irwin et al., 1997).

As illustrated in the previous sections, caregivers may have both an emotional stress response (such as burden or depressive symptoms) and a physical stress response (such as negative changes in immune functioning) to providing care. These physical and emotional consequences can stem from both the demands of care that are identified during the primary appraisal, as well as from the availability of resources to meet those demands, which are identified during the caregiver's secondary appraisal.

Model Summary

When Lazarus and Folkman's Theory of Stress and Coping (Folkman, 1997; Lazarus, 1996) is applied to the caregiver of a person with a PMBT, the conceptual model presented in Figure 1 is described. After the stimulus event of the care recipient's diagnosis of a PMBT, the caregiver undergoes a primary appraisal to determine the nature of the care demands that must be met. These care demands stem from both the care recipient's tumor status and neurological status. The tumor status consists of the cell type and stage, location of the tumor, and treatment regimen. The arrows from cell type and stage to treatment, and from location to treatment depict the influence of the tumor's properties on the care recipient's treatment options. For example, a tumor located in the brain stem may be unable to be surgically resected, whereas surgical intervention may be recommended for a tumor in the frontal lobe.

Neurological status is also considered during the primary appraisal and consists of the care recipient's functional and cognitive status, as well as the presence or absence of neuropsychiatric symptoms. The location of neurological status within the care recipient's overall tumor status illustrates the concept that the cell type and stage, location, and treatment of the brain tumor will characterize the care recipient's

neurological status (in other words, the care recipient may have functional loss from the location of the tumor, from fatigue secondary to radiation therapy, or from a particularly aggressive tumor that requires multiple surgical resections). Intersecting circles are used to depict the previously described interrelationships among these concepts (i.e. the way in which cognitive status may affect functional status). In particular, the numbered areas of the circles represent the effect of differing subsets of demands. For example, a care recipient who fell within the area designated by the number '3' would suffer from both changes in cognitive status as well as the presence of neuropsychiatric symptoms. A care recipient who fell within the area designated by the number '4' would have changes in functional status, cognitive status, and the presence of neuropsychiatric symptoms. These areas have been distinguished because it is hypothesized that different combinations of disabilities will have varying effects on care demands, and will require the identification of different resources to meet care demands during the secondary appraisal. Together, the care recipient's tumor and neurological status define the care situation and care demands that are considered during the primary appraisal.

The caregiver's secondary appraisal is illustrated in the next portion of the conceptual model, during which the caregiver evaluates the availability of resources to meet care demands, such as personnel resources (visiting nurses) as well as internal resources (i.e. a sense of mastery regarding the care situation. As the previous sections described, resources can be external and internal, and will affect the caregiver's stress response to the care situation. External and internal resources may be interrelated, such as the effect of educational resources on the caregiver's mastery. This relationship is illustrated in the model by the overlap in the triangles that represent resources. In

addition, the caregiver's resources must be applicable to the care demands. The availability and acceptability of these resources will determine the caregiver's stress response, which may be manifested as an emotional and/or physical response.

The caregiver's emotional and physical stress response to providing care is illustrated as an interrelated continuum from excellent to poor, in which emotional and physical health are somewhat dependent upon each other. Factors in the primary and secondary appraisal dictate differing levels of stress dependent upon combinations of factors. For example, someone who has to deal with severe cognitive dysfunction but who has good personnel resources to help provide care and good support resources to use in venting frustrations may have a more positive stress response than someone who has to deal with slight cognitive dysfunction, but has no help.

Finally, the double-headed arrow from the caregiver's stress response back to the primary appraisal illustrates the continuous feedback process whereby the caregiver's stress is dynamic in relation to changes in the care demands and available resources. Because care demands are dependent upon multiple factors, a change in any factor within the primary or secondary appraisal may alter the caregiver's stress response. For example, after the initial surgical resection, the care recipient may not require assistance with ADLs. However, assistance with ADLs may become necessary after chemotherapy, subsequent resections, or tumor recurrence. Care demands may also decrease along the disease trajectory. For example, the care recipient may require supervision during the immediate postoperative period due to cognitive impairment from cerebral edema. However, as cerebral edema resolves, the care recipient's cognition may improve, and supervision may no longer be necessary. The availability of resources may also change

during the disease trajectory, causing a change in the caregiver's stress response. For example, if care demands increase, the caregiver may be forced to modify employment in order to have more time to provide care, which may limit the financial resources available to meet care demands. The continuous feedback process illustrates the dynamic nature of the care situation, in which constant reappraisal of the primary and secondary factors of the care situation dictate a varying stress response.

In summary, the model depicts the stress response for a caregiver of a person with a PMBT. First, a primary appraisal is performed, during which care demands are identified. Internal and external resources available to meet those demands are evaluated during the secondary appraisal and will determine the caregiver's stress response to the care situation. Although many studies have examined the relationships proposed by this model in caregivers of persons with cancer and caregivers of persons with a neurodegenerative disorder, and no studies were found that examined how the model applies to caregivers of persons with a PMBT.

Conclusion

The next step in developing a conceptual model such as the one described in this chapter is model testing. Model testing involves evaluating the strength and direction of specific relationships within the model. The current study was designed to test several of these relationships in a sample of caregivers of persons with a PMBT. The effect of three of the factors involved in the primary appraisal (the care recipient's functional, cognitive, and neuropsychiatric status) on two aspects of the caregiver's emotional stress response – caregiver burden and depressive symptoms – were evaluated in this study. In addition, the way in which two resources identified during the secondary appraisal (caregiver

mastery and perceived adequacy of information to care) moderate the effects of care demands on caregiver burden and depressive symptoms was also examined.

Chapter 4

In Chapter 4, the methodology of the study is presented. First, the design of the study is described. Then, operational definitions as well as the measurement of key variables are presented. The subsequent sections describe the target sample, power of the study, and recruitment sites and procedures, including recruiter training. Key issues in data collection are presented in the following sections, including interviewer training, data management, and the methods that were employed to protect the rights of human subjects.

Design

A cross-sectional descriptive design was used to answer the following research questions:

- 1) What are the effects of the care recipient's functional, cognitive, and neuropsychiatric status on the caregiver's level of perceived burden and depressive symptoms for the caregiver of a person with a primary malignant brain tumor (PMBT)?
- 2) Given a care recipient's functional, cognitive, and neuropsychiatric status, what are the moderating effects of the caregiver's level of perceived adequacy of information to care and mastery on their level of perceived burden and depressive symptoms for the caregiver of a person with a PMBT?

Operational Definitions

Operational definitions of the study's key variables are included here, including the independent variables (care recipient functional, cognitive, and neuropsychiatric

status), moderating variables (caregiver perceived adequacy of information to care and mastery), and dependent variables (caregiver burden and depressive symptoms).

- **Family caregiver:** A person with a significant, “family-type” bond who regularly performs tasks on behalf of another that the care recipient is no longer able to perform due to illness.
- **Care recipient functional status:** The independence level of the care recipient in performing activities of daily living (bathing, dressing, toileting, transferring, ambulating within the house, and eating) and instrumental activities of daily living (transportation, laundry, shopping, housework, and preparing meals) (Katz & Akpom, 1976).
- **Care recipient cognitive status:** The ability of the care recipient to remember long- and short- term events and to make consistent and reasonable daily decisions (Morris et al., 1994).
- **Care recipient neuropsychiatric status:** The presence or absence of delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor, nighttime disturbances, and appetite/eating disturbances (Kaufer et al., 2000).
- **Perceived adequacy of information to care:** Caregivers’ perception of their ability to access information from the health care system that is necessary to provide care and their perception of the usefulness of that information.
- **Mastery:** Caregiver’s perception of how certain they are about what to do in providing care, how they perceive themselves as able to handle most of the

problems they face in the care situation, and how well they believe that they are mastering most of the challenges in caregiving (Pearlin et al., 1990; Pearlin & Schooler, 1978).

- Caregiver burden: Caregivers' perception of the impact of providing care on their self-esteem, finances, schedule, health, and feelings of abandonment (Given et al., 1992).
- Caregiver depressive symptoms: Caregivers' report of depressed and positive affects, somatic and retarded activity, and interpersonal skills (Radloff, 1977).

Measures

The measurement model of the study is presented in Figure 2. All of the instruments of the study were administered to the caregiver only. Due to the incidence of cognitive impairment in individuals with brain tumors, the caregiver reported care recipient characteristics by proxy. The entire interview instrument is presented in Appendix A.

Independent Variables

The independent variables in the study included the care recipient's functional status, cognitive status, and neuropsychiatric status as reported by the caregiver. The caregiver's perception of the care recipient's *functional status* was evaluated by the Involvement with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scale (Katz & Akpom, 1976). This 11-item instrument summarizes caregiver reports of care recipient dependencies in two areas – activities of daily living and instrumental activities of daily living.

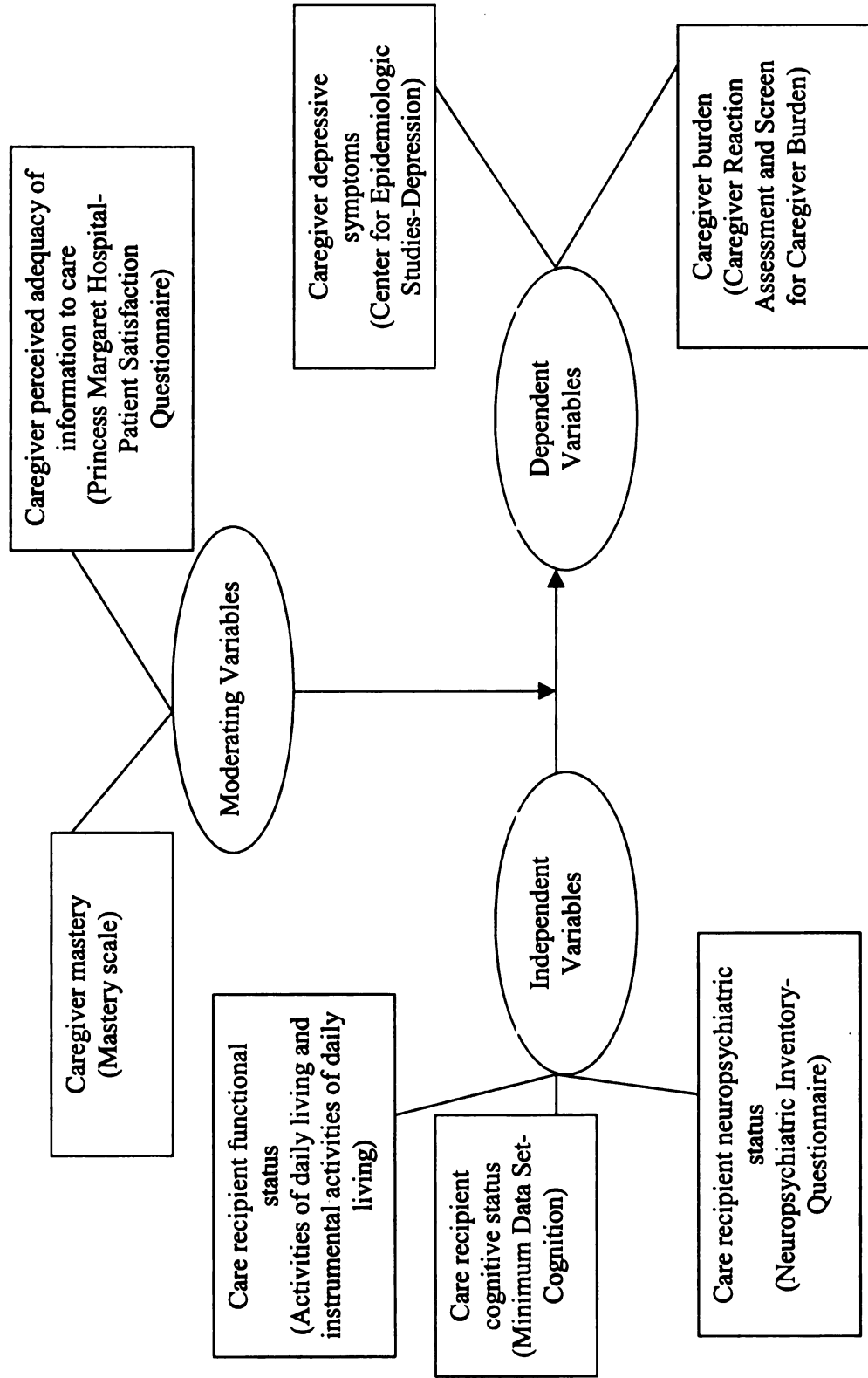


Figure 2. Measurement model for the study: Direct effect of care recipients' functional, cognitive, and neuropsychiatric status on caregiver burden and depressive symptoms and moderating effect of caregiver mastery and PAIC.

Activities of daily living are personal care activities (National Center for Health Statistics [NCHS], 2003a) and include bathing, dressing, toileting, transferring, ambulating within the house, and eating. *Instrumental activities of daily living* are activities related to independent living (NHCS, 2003b) and include transportation, laundry, shopping, housework, and preparing meals.

Caregivers identified, during the past two weeks, the level of assistance the care recipient required with six ADLs and five IADLs (0 = the care recipient was independent, 1 = care recipient required supervision, 2 = care recipient required some physical help, 3 = care recipient required total physical help). A total score for ADL and for IADL for each participant was generated by summing the level of assistance required for each activity over the total number of activities (possible range for ADL 0 to 18; possible range for IADL 0 to 15). Higher scores indicated higher levels of caregiver assistance. This instrument yielded a Cronbach's alpha of .93, which is higher than other reports in the literature (Katz and Akpom (1976) reported a Cronbach's alpha of .79).

The Minimum Data Set – Cognitive Performance Scale (MDS) (Morris et al., 1994) was used to evaluate the care recipient's *cognitive status*. The MDS contains 10 items and asks the respondent questions regarding the care recipient's ability to remember things after 5 minutes, things from the past, the season, where he/she lives, names and faces of friends and family, that he/she was at home, and asks the respondent to rate the care recipient's independence in making decisions regarding tasks of daily life (such as bathing and shopping). The MDS also contains questions which ask the caregiver to describe during the previous 7 days, whether the care recipient had times when he/she was

easily distracted, times when the caregiver could not understand the care recipient's speech, and times when the care recipient's thinking changed during the day. Responses were scored as either yes or no or on a Likert-type scale depending upon the item, and were summed to produce a total score. Possible scores ranged from 0 to 13, higher scores indicating worse cognitive status. Reliability for the MDS was $\alpha = .71$, which is lower than others' reports (Morris and colleagues reported Cronbach's alphas between .83 and .88). Lower reliability for the scale in this population than has been reported in the literature may be due to the fact that the amount of cognitive dysfunction in care recipients was minimal compared to other studies (this is further discussed in Chapter 5).

The care recipient's *neuropsychiatric status* was assessed by the Neuropsychiatric Inventory-Questionnaire (NPI-Q) (Kaufer et al., 2000). The NPI-Q is a 12-item instrument in which the caregiver is asked to indicate the presence of care recipient behaviors from 12 neuropsychiatric domains: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor, nighttime disturbances, and appetite/eating disturbances. Presence of a particular behavior was rated either 0 (not present) or 1 (present). Scoring for the NPI-Q consisted of summing individual items across all 12 symptoms to generate a total score that ranged from 0 (no abnormal behaviors were present) to 12 (all 12 abnormal behaviors were present). The NPI-Q yielded a Cronbach's alpha of .78, which is similar to the authors' report of a Cronbach's alpha between .71 and .97 (Kaufer et al.).

Moderating Variables

The moderating variables of the study were perceived adequacy of information to care and mastery. Perceived adequacy of information to care (PAIC) was addressed by the Princess Margaret Hospital Satisfaction with Doctor Questionnaire (PMH) (Loblaw et al., 1999). The PMH consists of 29 items that assess satisfaction with provider care in four domains – information exchange, interpersonal skills, empathy, and quality of time. Although reports of the use of the PMH have been centered on patient responses, in this study, the PMH was reworded to capture the perspective of the caregiver. Information exchange measures the caregiver's perception of the ability of the health care practitioner to understand and meet the educational needs of the dyad. Items on the interpersonal skills subscale assess the comfort level of the caregiver with the health care practitioner. The empathy subscale measures the caregiver's perception of the health care practitioner's attention to the dyad's emotional needs. Finally, the quality of time subscale includes items that measure the caregiver's perception of the adequacy of the length of time the health care practitioner spent with the dyad as well as the ability of the caregiver to express his/her concerns during their time together. Participants identified the health care practitioner that was consulted most often for questions regarding the care recipient's functional, cognitive, and neuropsychiatric status. The respondent's agreement with statements on the PMS are scored on a Likert-type scale from 1-5 (1 = strongly agree, 2 = agree, 3 = no opinion, 4 = disagree, 5 = strongly disagree) and averaged to produce a mean score for the entire instrument (after negative items were reverse scored). Possible mean scores range from 0 to 5, with higher scores indicating

higher levels of perceived adequacy of information to care. The scale demonstrated an overall Cronbach's alpha of .96 (similar to Loblaw et al.'s reports of an alpha of .97).

Mastery was assessed by Pearlin and Schooler's (1978) work with mastery and coping modified to the caregiving situation (Given, Given, & Champion, 1999; Mullan, 1992). This is a 7-item scale that asks caregivers to indicate their perception of how certain they are about what to do in providing care, how they perceive themselves as able to handle most of the problems they face in the care situation, and how well they believe that they are mastering most of the challenges in caregiving on a 5-point Likert-type scale (1 = strongly agree, 2 = agree, 3 = no opinion, 4 = disagree, 5 = strongly disagree). Scoring for the mastery scale involved reverse coding for negative items and summing item scores to generate a total score between 7 and 35, higher scores indicating higher levels of mastery. Cronbach's alpha for this scale was .73, slightly lower than other reports of reliability (Mullan reported a Cronbach's alpha between .75 and .79).

Dependent Variables

Caregiver burden and depressive symptoms were the dependent variables of the study. Caregiver burden was assessed via the Caregiver Reaction Assessment (CRA) scale (Given et al., 1992; Stommel, Wang, Given, & Given, 1992) and the Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991). Because caregiver burden had not been studied in the brain tumor population, two caregiver burden instruments were selected because each had demonstrated reliability and validity in either caregivers of persons with cancer or caregivers of persons with a neurodegenerative disease. The analysis that was performed to determine the most appropriate measure for caregiver burden in this study is described in Chapter 5.

The CRA is a 24-item instrument that asks caregivers to indicate their level of agreement with statements regarding burden on a 5-point Likert-type scale (1 = strongly agree, 2 = agree, 3 = neither agree nor disagree, 4 = disagree, 5 = strongly disagree) (Given et al., 1992). Because caregiver burden is a multidimensional concept, the CRA was developed to measure five different aspects of burden, rather than a total burden score – the impact of providing care on the caregiver’s self-esteem, schedule, finances, feelings of abandonment, and health (Given et al.; Stommel et al., 1992). The seven item self-esteem subscale ($\alpha = .79$) assessed whether providing care was enjoyable and rewarding or caused resentment. The five items on the abandonment subscale ($\alpha = .83$) 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’). The finance subscale of the CRA ($\alpha = .87$) contains three items that measured caregivers’ perception of the adequacy, difficulty, and strain of their financial situation. The five items on the schedule subscale ($\alpha = .75$) assessed the impact of providing care on the caregiver’s usual activities, including whether providing care had forced them to eliminate activities and interfered with relaxation. Lastly, the four item health subscale ($\alpha = .70$) measured the caregiver’s energy and physical capability to provide care. Reliability coefficients in this study were slightly lower than other reports (Given et al. reported Cronbach’s alphas above .80 for all subscales). Future studies should continue to monitor reliability in a larger sample. Scoring for the CRA involved reverse coding for negative items and summing item scores to generate a subscale score (range based on number of items in subscale).

The Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker, & Maiuro, 1991) is a 25-item scale that assessed both the presence of care demands as well as the caregiver's perception of distress associated with these demands on a Likert-type scale. Questions on the SCB assess the caregiver's perception of the distress caused by the abnormal behaviors, disruptions in family and social life, and presence of caregiver affective responses. Each item was scored on a 5 point Likert-type scale from 0 (did not occur) to 4 (occurred and caused the caregiver severe distress). Possible scores ranged from 0 (no occurrences or none of the occurrences caused distress) to 100 (all 25 experiences were present and caused severe distress). Cronbach's alpha for the SCB was .86 (similar to Vitaliano et al.'s reports of a Cronbach's alpha between .84 and .89).

Caregivers were screened for depressive symptoms using the Center for Epidemiologic Studies Scale (CESD) (Radloff, 1977). The CES-D is a 20-item scale that assessed the respondent's current level of depressive symptoms on a 4-point Likert-type scale (0 = rarely/none of the time, 1 = some of the time, 2 = most of the time, 3 = almost all the time). Scoring the CES-D consisted of reverse coding negative items and summing individual items to generate a score between 0 and 60, with higher numbers indicating the presence of more depressive symptoms. The CES-D had a Cronbach's alpha of .89, which is slightly higher than other reports in the literature of Cronbach's alpha of .85 when the CES-D was used with caregivers of persons with cancer (Given et al., 2003; Kozachik et al., 2001).

Potential Confounding Variables

Due to the scarcity of research with caregivers of persons with a PMBT, it was uncertain which factors might confound the effects of the care recipient's functional,

neuropsychiatric, and cognitive status on the caregiver's level of perceived burden and depressive symptoms. Caregiver variables that have played a confounding role in caregiver research with other care recipient populations include caregiver age (Schumacher et al., 1993) and gender (Nijboer et al., 2000), as well as the caregiver's relationship to the care recipient (Clipp & Moore, 1995). It was hypothesized that these factors may also affect the caregiver of a person with a PMBT. To identify any potential confounding effects, two additional questionnaires were added to the study instrument.

The Caregiver Sociodemographic Questionnaire provided information on the caregiver's age, sex, marital status, educational level, occupation, and race. In addition, this questionnaire contained items that asked general questions regarding the impact of providing care on the caregiver's residence (i.e. "Have you changed your home in any way to accommodate (care recipient's name)'s needs?"), employment (i.e. "In the past month, has (care recipient name)'s cancer or cancer treatment, including visits to doctors or having to stay in a hospital caused you to take paid time off work, take unpaid time off work," etc.), and finances (i.e. "Since (care recipient name) was diagnosed with cancer, in the past 3 months, have you, (care recipient name), or other family members spent money out of pocket on (care recipient name)'s hospital bills or hospital-related doctor bills, office visits, medications or other health related charges that were not covered by his/her insurance?").

The second additional questionnaire was the Patient Sociodemographic Information and Diagnosis and Treatment Summary (PSI-DTS). The PSI-DTS collected limited sociodemographic information (i.e. gender and age) as well as information regarding the care recipient's diagnosis and subsequent treatment (i.e. type and location of the tumor,

surgeries and other treatment regimens). The PSI-DTS also contained items that assessed the effect of the brain tumor diagnosis and treatment on the care recipient's occupational and insurance status (i.e. "Did (care recipient name) change his/her work status because of his/her brain tumor" and "Has this change impacted his/her insurance/benefits package").

The number of all items on the instruments measuring primary and secondary variables was 109. Average time for completing the interview was 72 minutes. Caregivers who became fatigued during the interview, or did not have enough time to complete the entire interview during one phone call were given the option of completing a shorter interview in which only the instruments most vital to the primary study aims were delivered or completing the remainder of the interview within 7 days. None of the caregivers requested the option of completing the shortened interview, although two caregivers completed the interview at two different points in time (both within 2 days of the first interview).

Sample

The target sample consisted of adult family caregivers (over 21 years of age) of adults (over 21 years of age) with a primary malignant brain tumor. The concept of adequate sample size for power using the statistical analysis proposed in this study (structural equation modeling [SEM]) is controversial. Some authors have indicated that a minimum of 100 to 150 subjects provides adequate power to identify significant relationships in SEM, while others have recommended a sample of 400 participants (Boomsma, 1983). The concept of adequate sample size may also be based on the number of variables in the study. Bentler and Chou (1987), for example, suggest five

subjects per variable for normal and elliptical distributions with latent variables that have multiple indicators. For the purposes of this study, recruitment of 10 subjects per primary variable was considered adequate (Schumacker & Lomax, 1996). As there were three independent variables, two moderating variables, and two dependent variables, 70 participants were considered adequate to achieve acceptable power for the study. Because of the overall advantages of increasing sample size on the generalizability of results, the sample was not limited once 70 caregivers had completed participation, but continued for 13 months.

Inclusion/Exclusion Criteria

Family caregivers of persons with a primary malignant brain tumor were recruited for the study. Caregivers had to be able to hear, read and speak the English language, and have regular and reliable access to a telephone. Although it was hypothesized that the majority of caregivers would be spouses (Given et al., 1999), it was not a requirement of the study that the caregiver be legally related to the care recipient or that the caregiver live in the same household as the care recipient.

Caregivers who were health care practitioners and who were being financially reimbursed for providing care from a third party were excluded from the sample. In addition, persons under the age of 21 were not allowed to participate in the study. Although children may be caregivers of persons with a brain tumor in rare instances, it was doubtful that the sample would contain enough caregivers in this age group to identify significant relationships. In addition, the majority of instruments utilized in this study had not been tested with persons under the age of 21, and may not have been appropriate for use. Finally, because caring for a child with a brain tumor presents

unique factors and characteristics that may not be comparable to caring for an adult, caregivers of persons with a brain tumor who were under the age of 21 were also excluded from participating in the study.

Gender and minority inclusion

Because the majority of PMBTs occur in males (Central Brain Tumor Registry, 2000; Michigan Department of Community Health, 2000) and the majority of caregivers in general are spouses or adult daughters (Given et al, 1993), it was anticipated that the majority of study participants would be female. Women of childbearing age were not excluded from the study. All of the recruitment sites utilized a convenience sample. The two large support groups recruited a convenience sample at the national level, the state cancer registry recruited a convenience sample at the statewide level, and two metropolitan brain tumor treatment centers recruited a convenience sample at the local level (Recruitment processes are described later in this chapter).

The majority of brain tumors occur in Caucasians. From 1990 to 1997, the national incidence of brain and central nervous system tumors was an average of 6.4 persons/100,000 person-years in Caucasians compared to 3.8 persons/100,000 person-years in African Americans and 2.2 persons/100,000 person-years in American Indians (SEER Cancer Statistics Review, 2001). This trend is mirrored at the state level, as well (Michigan Department of Community Health, 2000). Based on these findings, it was expected that the majority of care recipients in the sample would be Caucasian.

Recruitment efforts related to minority recruitment focused on taking measures to ensure that the study was sensitive to ethnic or racial diversity. The graphics on the study brochure (see Appendix B) were ethnically and racially diverse and were not limited to

persons of any particular ethnic or racial group. Nurses with experience in conducting research with, and delivering health care to, different ethnically and racially diverse populations were available for consultation if potential participants described the language of the brochures, instrument, and consent forms as lacking cultural appropriateness and/or sensitivity.

Recruitment Sites and Procedures

Participants were recruited from five sites. Recruitment at each site is described in the following sections.

Databases and clinical sites for recruitment

The first two organizations, the National Brain Tumor Foundation (NBTF) and American Brain Tumor Association (ABTA), are national support organizations composed of persons with a brain tumor, caregivers, and health care professionals. The NBTF and ABTA published an advertisement in both their written and electronic newsletters. The advertisement (see Appendix C) described the purpose of the study as well as inclusion criteria and provided a toll free phone number and email address to be used by persons who were interested in contacting the investigator to discuss the study. Once the caregiver had initiated contact with the investigator, the investigator determined eligibility and mailed consent forms to eligible caregivers. A follow up letter was sent by the investigator if consent forms are not received within two weeks of the time they were mailed.

From the next database, the Michigan State Cancer Registry (MSCR), registry persons with primary malignant brain tumors over the two-year period prior to the inception of data collection were cross checked with the State of Michigan Death

Registry for determination of patient status. If the person had not died, the MSCR mailed a letter to the registering facility requesting that updated information including the name and address of both the patient and the treating health care practitioner be sent to the MSCR. Once this information was received by the MSCR, a letter was sent to the patient's health care practitioner explaining the study and asking that the MSCR be notified in writing within 3 weeks of any updates in patient status or circumstances that would render the caregiver ineligible for the study. If no information was received from the patient's health care practitioner within 3 weeks, the patient was sent a letter explaining the study and a copy of the consent forms and the patient was asked to give the material to his/her family caregiver. The dyad was provided with a toll free telephone number and email address to contact the principal investigator if they had any questions or concerns regarding the study. Once the caregiver had signed the consent forms, they were mailed to the MSCR, who in turn mailed them to the principal investigator.

At Karmanos Cancer Institute, participants were identified from a larger study of persons with a brain tumor. The principal investigator of the larger study mailed a letter to everyone who had been recruited for the original study, explaining the caregiver study and asking patients to refer material to their family caregivers. Family caregivers were given a toll-free phone number and email address to use if they were interested in participating. Caregivers who were interested in participating contacted the primary investigator of this study, who was responsible for determining eligibility and obtaining consent.

From the last recruitment site, the Hermelin Brain Tumor Center (HBTC), a recruiter was identified for the study. This recruiter was a registered nurse with

experience in neurooncology. The recruiter identified potential participants through the neurosurgery, neurology, and neuro-oncology clinics by reviewing inclusion/exclusion criteria for participants and clinic appointment rosters with the clinic nurses each week. The HBTC recruiter completed a screening/enrollment form (see Appendix D) for each dyad, including limited eligibility and demographic information, which was sent to the investigator with the consent forms when a caregiver was enrolled. Once potential participants were identified, the recruiter approached patients with a primary malignant brain tumor who had a designated caregiver and described the study to the dyad. If the caregiver and patient agreed to participate in the study, they were asked to sign the consent forms. The recruiter mailed the signed consent forms to the investigator.

Attrition

Caregivers were free to withdraw from the study at any time. A caregiver was considered as having attrited from the study if he/she completed the consent form and then refused to complete the interview, or did not complete the instruments that comprise the primary variables of the study. Number and characteristics of participants who withdrew from the study are discussed in Chapter 5.

Data Collection

Participants were recruited for the study from 10-24-02 to 11-29-03. After a dyad was recruited for the study and had signed consent forms, the caregiver was assigned an ID number. A master list linking participant names and ID numbers was kept on a password-protected computer. Consent forms and all correspondence with the dyad did not list an ID number and were kept in a locked cabinet.

Once the investigator received a signed consent from the caregiver, the caregiver was called and arrangements were made for a time to conduct a telephone interview. Only the caregiver was interviewed. Data were recorded on paper interviews with the ID number of the participant as the only identifying piece of information. Paper interviews were kept in a locked cabinet separate from the cabinet containing the consent forms. Only the investigator had access to the locked cabinets and to the password-protected disc that contained the master list linking participant names and ID numbers.

Recruiter Training

A recruiter was employed at the Hermelin Brain Tumor Center to enroll participants in the study. Prior to the beginning of recruitment, this individual underwent training sessions that included discussion on the overall objectives and schema of the study, inclusion and exclusion criteria, policies and procedures for identifying and recruiting participants, completing the screening/enrollment form, and principles of confidentiality. A portion of this training included orienting the recruiter to the recruiter manual (see Appendix E). The manual was used as a reference for the recruiter and contained information on the research team, overall study goals and objectives, eligibility criteria and screening procedures, and instructions on how to approach the caregiver and care recipient, including a recruitment script. The manual also included sample letters for following up with participants.

Recruiter Quality Assurance

The investigator reviewed each screening/enrollment form submitted by the recruiter at HBTC for missing data and to verify eligibility prior to assigning the caregiver an interview. For those participants recruited from the Michigan State Cancer

Registry, the National Brain Tumor Foundation, the American Brain Tumor Association, and Karmanos Cancer Institute, the investigator was responsible for verifying eligibility prior to the participant's consent and interview.

Interviewer Training

A graduate student in the field of health care was hired to conduct interviews for the study (the principal investigator also conducted several of the interviews). Prior to interviewing participants, the interviewer completed a training session that included discussion on the overall objectives and schema of the study, general interviewing techniques, study policies and procedures (see Appendix F), methods of quality assurance, and principles of confidentiality. A portion of the time during this training was spent reviewing the interviewer manual (see Appendix G).

The interviewer manual was used as a reference for the interviewer and contained information on the research team, overall study goals and objectives, study protocol (such as scheduling and conducting the interview and sending thank you letters), interview techniques such as probing and clarification, procedures for maintaining participant confidentiality, and a description of the consent form (see Appendix H). The manual also provided information on techniques for handling special situations such as caregivers who did not remember giving consent, caregivers who became emotionally distraught during the interview, and protocols for incomplete interviews. At the end of the training session, the interviewer conducted two mock interviews that were evaluated by the primary investigator and the dissertation advisor.

Interviewer Quality Assurance

The interviewer audiotaped every 10th interview with the caregiver's audible permission. The interviewer completed a self-evaluation form and gave the tape and the self-evaluation form to the investigator for review. The investigator critically evaluated the quality of the interview including the pace of the interview, the interviewer's probing and clarification techniques, and the interviewer's attention to any distress the caregiver may exhibit. Feedback was provided to the interviewer, and the dissertation advisor was available for counsel if problems arose.

Data Management and Quality Assurance

Data Management

Caregiver responses were recorded on paper during the telephone interview. Once the interview was completed, the interviewer gave the paper copy to the principal investigator, along with a status sheet (indicating the length of the interview, number of attempts to call the participant, etc.). The principal investigator entered data from the paper copy of the interview into an SPSS computer program on a password-protected computer. Once the data analysis portion of the project began, the data in SPSS was transferred to a LISREL program. All data will be kept on a password-protected disc at Michigan State University for five years from the completion of the study.

Data Quality Assurance

Data collected during the interviews and entered into the computer was reviewed by the investigator every two weeks to identify missing data and for protocol adherence of the interviewer. Strategies for dealing with missing data are discussed in Chapter 5.

Protection of Human Subjects

Data sources

Information concerning the caregiver and care recipient was collected during a telephone interview with the caregiver. All information obtained from the caregiver was identified by participant number only and no individual information was shared with any recruitment database or provider. No names appear on any written material other than consent forms and correspondence, which are kept in a locked cabinet. All interview data are devoid of individual names and are kept in a separate locked cabinet. A master list linking names with participant numbers is kept on a password-protected computer. Once interviews were completed, the responses were entered into a database on a password-protected computer that is separate from the computer that contains the master list linking names with participants. All data will be published in aggregate form, without agency or individual names or identification. All information generated from the study, including consent forms, screening/enrollment forms, interviews, and electronic data will be stored in a locked cabinet at Michigan State University for a period of five years following the completion of the study.

Institutional review board

Approval of the research study from the Institutional Review Board (IRB) or designated reviewing committee of each proposed database as well as approval from the IRB of the investigator's institution was obtained prior to the recruitment of any participants. The recruiter, interviewer, and investigator also adhered to all mechanisms for the protection of human subjects that are in place at each site and maintained the

human subjects certification provided by the University Committee on Research Involving Human Subjects.

Potential risks

Because the proposed research was descriptive in nature and did not involve an intervention or investigational drug, caregivers were not placed at physical risk by their participation in the study, other than the time and effort involved in answering questions by telephone. The caregiver may have felt apprehensive or uneasy about sharing personal information. Caregivers were encouraged to discuss any of these feelings that arose during the interview. If the interview became distressing to the caregiver, they were given the alternative of completing a shortened interview (in which only questions regarding the primary variables are included) or concluding the interview immediately and either withdrawing from the study or finishing the interview within 7 days. All participants had the option of withdrawing from the study at any time without fear of recrimination and were given a toll free number to contact the investigator's dissertation advisor if they had questions or concerns about the project. No caregivers reported any adverse effects from completing the interview.

Participant benefits

Although there were no direct benefits to the caregivers in the present sample, future caregivers may benefit from HCPs' knowledge of what factors increase their burden and how this can affect their health and well being.

Chapter 5

This cross-sectional, descriptive study was designed to determine the effect of the care recipient's functional, cognitive, and neuropsychiatric status, and the caregiver's perceived adequacy of information to care and mastery on caregiver burden and depressive symptoms for caregivers of persons with a primary malignant brain tumor. Participants were recruited from five sites, two national brain tumor support groups, a statewide cancer registry, and two metropolitan brain tumor treatment centers.

Sample

A total of 104 participants signed consent forms to participate, and 95 participants completed interviews. Of the nine caregivers who agreed to participate but did not complete an interview, one caregiver reported that the care recipient died before the interview could take place, three caregivers reported that care recipients were too ill to take time to complete the interview, and five caregivers were unable to be contacted to set up an interview.

The majority of participants (91%, $n = 86$) were recruited from the two national support groups and from one metropolitan brain tumor treatment center (see Table 1). In Table 2, the sociodemographic characteristics of the caregivers are presented. The majority of caregivers were female (74%, $n = 70$) and Caucasian (94%, $n = 89$). Concerning the relationship of the caregiver to the care recipient, most caregivers were spouses (74%, $n = 70$) or parents (12%, $n = 11$) of the care recipient. Age of the caregivers ranged from 25 to 76 years with a mean age of 51 ($SD = 12$). The majority of caregivers had provided care for less than three years (77%, $n = 73$), although time providing care ranged from one to 216 months ($M = 31$, $SD = 36$, median = 18).

Caregivers in the sample were well educated; 85% (n = 81) reported having taken at least some college courses.

Table 1

Number and Percentage of Participants by Recruitment Site

<u>Site</u>	<u>n</u>	<u>%</u>
National Brain Tumor Foundation/American Brain Tumor Association	46	48.4
Hermelin Brain Tumor Center, Henry Ford Hospital	40	42.1
Michigan State Cancer Registry	8	8.4
Karmanos Cancer Institute	1	1.1

Table 2

Descriptive Statistics of Sociodemographic Characteristics of Caregivers

<u>Characteristic</u>	<u>n</u>	<u>%</u>
Caregiver Gender		
Female	70	73.7
Male	25	26.3
Relationship to the Care Recipient		
Spouse	70	73.7
Parent	11	11.6
Other	14	14.8
Caregiver Ethnicity		
Caucasian	89	93.7
African American	4	4.2
Other	2	2.1
Caregiver Education		
Completed high school	14	14.7
Some college	20	21.1
Completed college	32	33.7
Completed graduate degree	29	30.5
	<u>Range</u>	<u>Mean (SD)</u>
Caregiver age	25-76 years	51.4 (11.7)
Length of time providing care	1-216 months	30.8 (36.0)

Sociodemographic characteristics of the care recipients are presented in Table 3.

The majority of care recipients were male (58%, n = 55). The most common tumor types for care recipients were Glioblastoma Multiforme (GBM) (44%, n = 42), Astrocytoma

grades I-III (23%, $n = 22$), and Oligodendroglioma (17%, $n = 16$). Age of the care recipients ranged from 21 to 78 years ($M = 48$, $SD = 14$), and number of months since care recipients' diagnoses ranged from 2 to 216 ($M = 33$, $SD = 37$), although 75% ($n = 68$) of the care recipients were within three years of diagnosis (median = 19 months) when the caregiver was interviewed.

Table 3

Sociodemographic Characteristics of Care Recipients

<u>Characteristic</u>	<u>n</u>	<u>%</u>
Care recipient gender		
Female	40	42.1
Male	55	57.9
Care recipient tumor type		
Glioblastoma Multiforme	42	44.2
Astrocytoma, grades I-III	22	23.2
Oligodendroglioma	16	16.8
Other	15	15.8
	<u>Range</u>	<u>Mean (SD)</u>
Care recipient age	21-78 years	48.2 (14.1)
Months since care recipient's diagnosis	2-216 months	33.1 (36.9)

Measures

Descriptions of the measures used in the study, as well as how scale scores were generated, were provided in Chapter 4. Discussion of scale scores obtained from the sample is provided here. The number of missing data in the sample was minimal (less than two missing data points per instrument with the exception of one instrument; see Table 4 for missing values by measure). Linear trend at point was used to replace missing data. Linear trend at point replaces missing values with the linear trend for that point. The existing series is regressed on an index variable scaled one to n , and missing values are replaced with their predicted values (Little & Rubin, 2002; SPSS, 1999).

Table 4

Range and Mean Scale Scores and Frequency of Missing Data by Variable and Measure

Measure	Variable of interest	Possible Range	Mean score (SD)	# missing values
ADL	Care recipient functional status	0 to 18	2.8 (4.3)	0
IADL	Care recipient functional status	0 to 15	4.5 (4.1)	0
MDS-CPS	Care recipient cognitive status	0 to 13	3.2 (2.7)	2
NPI-Q	Care recipient neuropsychiatric status	0 to 12	4.5 (2.8)	2
PMH	Caregiver perceived adequacy of information to care	0 to 5	4.2 (0.6)	20
Mastery	Caregiver mastery	7 to 35	26.3 (4.2)	1
*Self esteem	Caregiver burden	7 to 35	13.0 (4.1)	1
*Abandonment	Caregiver burden	5 to 25	10.5 (4.4)	0
*Finances	Caregiver burden	3 to 15	7.3 (3.3)	0
*Schedule	Caregiver burden	5 to 25	17.5 (4.3)	1
*Health	Caregiver burden	4 to 20	9.9 (3.2)	1
SCB	Caregiver burden	0 to 100	18.6 (14.2)	0
CES-D	Caregiver level of depressive symptoms	0 to 60	14.9 (8.9)	2

* These are all subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

Note. ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; MDS-CPS = Minimum Data Set-Cognitive Performance Scale; NPI-Q = neuropsychiatric inventory; PMH = Princess Margaret Hospital scale (measuring perceived adequacy of information to care); SCB = Screen for Caregiver Burden; CES-D = Center for Epidemiologic Studies-Depression

The possible range, mean score, and standard deviation for each of the measures are presented in Table 4. Care recipients' functional status (ADLs and IADLs), cognitive status, and neuropsychiatric status were the independent variables in the measurement model (see Figure 2). Approximately 1/3 of the caregivers assisted with ADLs and ½ of the caregivers assisted with IADLs. The most common activities of daily living with which caregivers provided assistance were dressing (35%, $n = 34$), walking inside the house (28%, $n = 27$), and bathing (27%, $n = 26$). The most common IADLs with which

caregivers provided assistance were transportation (52%, n = 49), laundry (44%, n = 42), and housework (44%, n = 42) (see Appendix I, Table A). [Note: Assistance with ADLs and IADLs was defined as assistance that was provided as a result of changes in care recipients' abilities due to the brain tumor. For example, for a caregiver who was providing assistance with laundry, but had always done the laundry prior to the care recipient's diagnosis, providing assistance with laundry would have yielded a score of '0' in the IADL instrument.]

Although scores on the overall cognitive status instrument were relatively low (indicating that cognitive problems were not common in the sample), over 1/3 of the caregivers reported that care recipients had some problems with short term memory (64%, n = 61) and had some difficulty making decisions concerning activities of daily life, such as bathing and dressing (45%, n = 43) (see Appendix I, Table B). Few care recipients, however, had problems remembering things such as friends and family, where they lived, and the season. With regard to neuropsychiatric status, 88% of the caregivers stated that at least one neuropsychiatric symptom was present in the care recipient. The most commonly cited neuropsychiatric symptoms in care recipients were dysphoria/depression (59%, n = 56), irritability/lability (55%, n = 52), nighttime disturbances (awakening the caregiver during the night, rising too early in the morning, or taking excessive naps during the day) (54%, n = 51), and apathy/indifference (40%, n = 38) (see Appendix I, Table C).

Mastery and perceived adequacy of information to care (PAIC) were the moderating variables of the study. Overall, levels of caregiver mastery were high (M = 26, SD = 4.2), and caregivers indicated that they felt comfortable and confident in their

dealings with health care practitioners (PAIC) ($M = 4.2$, $SD = 0.6$). Caregiver burden and levels of depressive symptoms were the outcome variables of the study. Caregivers' levels of depressive symptoms were high ($M = 15$, $SD = 9$) (Andresen, Malmgren, Carter, & Patrick, 1994; Zuckerman, Bauchner, Parker, & Cabral, 1990) (see Limitations section for further discussion of overall CES-D scores).

Two measures of burden were included in the original proposal – the Caregiver Reaction Assessment (CRA) (Given et al., 1992) and the Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991). When the two measures were compared, the CRA contained more variability, measured more dimensions of caregiver burden, and had lower correlations with depressive symptoms than the Screen for Caregiver Burden (see Table 6 in the following section). For these reasons, the CRA was chosen as the outcome measure for caregiver burden. Future studies may use Screen for Caregiver Burden to quickly identify caregivers at risk for negative responses, after which the impact of providing care on multiple dimensions could be measured using the CRA. Based on factor analysis that demonstrates the validity of the different subscales as separate measures of burden, all burden subscales of the CRA were included in the final analysis (Given et al., 1992; Stommel et al., 1992; Nijboer et al., 1999). Levels of caregiver burden in the sample varied according to subscale. Caregivers reported moderate levels of burden relating to the impact of providing care on their health, finances, and perception of being abandoned, and reported higher levels of burden related to the impact of providing care on their schedule and self esteem (see Table 4 for mean scores relative to subscale ranges).

Correlational Analyses

Correlations between variables were examined prior to the final analysis (see Tables 5 and 6) to identify potential covariance and to help determine the most appropriate method for analysis. Reviewing the correlations in Table 5 among the independent and moderating variables, there is a significant moderate correlation (defined as $r \geq .40$) between cognition (MDS) and neuropsychiatric status (NPI) ($r = .50$), IADL and cognitive status ($r = .40$), ADL and cognitive status ($r = .47$), and between IADL and ADL ($r = .70$). Correlations between cognitive and neuropsychiatric status were expected, because as neurological status declines, it is likely to simultaneously affect both cognition and the presence of neuropsychiatric symptoms. The correlation between IADL status and cognitive status and between ADL status and cognitive status mirror reports in the literature suggesting that as care recipients' cognitive status declines, they are less able to perform the steps involved in ADLs and IADLs (Gaugler et al., 2000; Ory et al., 1999). These results illustrate the need for including measures of both functional and neurological status when evaluating negative consequences of providing care for the caregiver of a person with a PMBT.

Table 5

Correlations among Independent and Moderating Variables

	PMH	NPI-Q	MDS	ADL	IADL	Mastery
PMH	1.00					
NPI-Q	.14	1.00				
MDS	.04	.50**	1.00			
ADL	-.06	.26*	.47**	1.00		
IADL	.01	.36**	.40**	.70**	1.00	
Mastery	.37**	-.27*	-.14	.04	.10	1.00

* Correlation is significant at the .05 level

** Correlation is significant at the .01 level

Note. ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; MDS-CPS = Minimum Data Set-Cognitive Performance Scale; NPI-Q = neuropsychiatric inventory; PMH = Princess Margaret Hospital scale (measuring perceived adequacy of information to care); SCB = Screen for Caregiver Burden; CES-D = Center for Epidemiologic Studies-Depression

When correlations among the dependent variables are examined in Table 6, a significant moderate correlation is seen between level of depressive symptoms and all measures of burden with the exception of the impact of providing care on the caregiver's self esteem and finances (correlations between depressive symptoms and the following measures were: impact of providing care on abandonment, $r = .41$; health, $r = .54$; and impact on schedule, $r = .40$). The correlation between level of depressive symptoms and subscales of caregiver burden emphasizes a debate in the literature concerning whether caregiver burden and depressive symptoms are separate constructs, or merely measures of the same construct (Gitlin et al., 2003; Schultz et al., 1995; Stommel et al., 1990). Despite relatively high correlations between burden and depressive symptoms, recent studies have suggested that burden and depression are separate constructs, although they are both rooted in the emotional consequences of providing care (Given, Wyatt, et al., in press; Sherwood et al., in press). The variance remaining after the correlation between burden and depressive symptoms is squared further supports the distinction between the two concepts.

Based on the moderate correlations found among the independent and moderating variables and among the dependent variables, an analytic technique that controls for covariance when determining the effects of independent and moderating on dependent variables was necessary. Structural Equation Modeling (SEM) is a useful technique for analyzing relationships among variables that may be interrelated (or 'covary'), which was

the case with caregiver burden and depressive symptoms and with the care recipient's functional, cognitive, and neuropsychiatric status, and caregiver mastery and PAIC.

Table 6

Correlations among Dependent Variables, N=95

	SCB	CES-D	*Self esteem	*Abando nment	*Finan ces	*Sched ule	*Health
SCB	1.00	--	--	--	--	--	--
CES-D	.55**	1.00	--	--	--	--	--
*Self esteem	.47**	.38**	1.00	--	--	--	--
*Abandonment	.28**	.41**	.46**	1.00	--	--	--
*Finances	.48**	.36**	.33**	.50**	1.00	--	--
*Schedule	.39**	.40**	.11	.36**	.37**	1.00	--
*Health	.54**	.54**	.38**	.33**	.32**	.49**	1.00

* These are all subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

** Correlation is significant at the .01 level

Note. SCB = Screen for Caregiver Burden; CES-D = Center for Epidemiologic Studies-Depression

The last step in examining the data prior to the final analysis was to examine the effect of potential confounding variables. Variables that have been shown to affect negative consequences of providing care in addition to the independent variables of the study include caregiver age, gender, relationship to the care recipient, length of time providing care, and care recipient tumor type (Sorensen, Pinquart, & Duberstein, 2002; Kozachik et al., 2001). Because the sample size was not large enough to accommodate the inclusion of these variables in the SEM model, regression equations were run to determine whether any of the variables previously listed affected any of the outcome variables (see Appendix I, Table E). The majority of covariates did not significantly affect any of the outcome variables (depressive symptoms or the five subscales of caregiver burden), with the following two exceptions. First, a significant association was found between relationship to the care recipient and depressive symptoms (non-spouses had a mean depressive symptom score of 18.4, $SD = 2.0$ versus a mean depressive symptom score for spouses of 13.7, $SD = 8.1$). Second, caregiver age was a significant predictor of the impact of providing care on caregivers' finances (older caregivers were more likely to report that providing care was a burden on finances). Because none of the covariates consistently affected outcome variables (with these two exceptions), they were not included in the SEM models in consideration of sample size issues.

Results

The models examining the relationship between care recipients' functional, cognitive, and neuropsychiatric status, caregiver mastery and PAIC, and caregivers' burden and level of depressive symptoms were evaluated using SEM, Lisrel 8.52 (Jöreskog & Sörbom, 2002). First a primary model evaluating the effects of care

recipients' functional, cognitive, and neuropsychiatric status on caregivers' burden and level of depressive symptoms was constructed. Once goodness of fit indices were considered adequate by established standards (MacCallum, Browne, & Sgawara, 1996; Nunnally & Burnstein, 1994), caregiver mastery and PAIC were entered into the model (a secondary model) to determine their moderating effects.

Research question #1: What are the effects of the care recipient's functional, cognitive, and neuropsychiatric status on the caregiver's level of burden and depressive symptoms for caregivers of a person with a primary malignant brain tumor (PMBT)?

The hypothesized SEM model was fit using an unweighted least squares method of approximation. The model fit the data well, resulting in a goodness-of-fit chi square of 0.4, $p = .9$ ($df = 4$, $N = 95$). The model yielded a root mean square error of approximation of .00, which indicates a close fit (MacCallum et al., 1996). The model depicted a goodness of fit index of .92, which also indicates a good fit (Nunnally & Burnstein, 1994).

Total direct effects of the model are presented in Table 7. As the coefficients in Table 7 illustrate, the care recipient's cognitive status and IADL status did not significantly affect caregiver burden or depressive symptoms, and thus were deleted from the model. The parsimonious model of the final data (with nonsignificant variables deleted) is presented in Figure 3. The care recipient's neuropsychiatric status, however, consistently affected both caregiver levels of depressive symptoms (standardized path coefficient .48) and every subscale of caregiver burden (self esteem, .29; abandonment, .28; finances, .47; schedule, .35; and health, .42). The direction of the signs of the path

coefficients indicates that as the number of care recipient's neuropsychiatric symptoms increased, caregiver depressive symptoms and caregiver burden also increased.

The care recipient's ADL status significantly affected the schedule subscale (.33) and health subscale (0.26) of caregiver burden. The direction of the sign indicates that as the care recipient required more assistance with ADLs, caregivers felt more burdened regarding the impact of providing care on their daily schedule and health.

Table 7

Direct Effects of Independent Variables on Outcome Variables–Standardized Coefficients

	CES-D	**Self esteem	**Abandonment	**Finances	**Schedule	**Health
NPI-Q	.48*	.29*	.28*	.47*	.35*	.42*
MDS	.09	.09	.06	.13	.03	.17
ADL	-.03	-.06	-.41	-.07	.33*	.26*
IADL	.09	-.13	-.60	-.02	-.17	-.17

* Coefficient significant at the $t > 2.00$ level

** All subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

Note. ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; MDS = Minimum Data Set-Cognitive Performance Scale; NPI-Q = neuropsychiatric inventory; CES-D = Center for Epidemiologic Studies-Depression

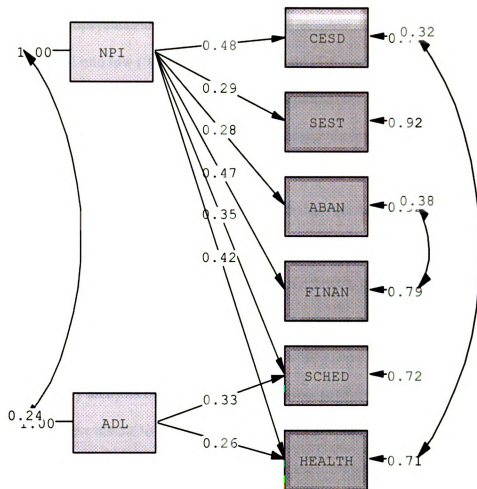


Figure 3. Parsimonious primary structural model: Effect of functional (ADL) and neuropsychiatric (NPI) status on caregiver depressive symptoms (CESD) and caregiver burden (sest = self esteem; aban = abandonment; finan = finances; sched = schedule; and health). Only significant paths are shown ($t < 2.00$). Full model with non-significant paths in Appendix J.

Note. Hidden error variances: CES-D = 0.77; Aban = 0.92; Sched = 0.72.

To further evaluate how caregiver burden and depressive symptoms differ in the presence of neuropsychiatric symptoms in the care recipient, the scores for the NPI-Q were categorized into low (0-3 symptoms), moderate (4-6 symptoms), and high (7 or more symptoms) numbers of neuropsychiatric symptoms (see Table 8). Data from Table 8 indicate that mean scores for all subscales of depressive symptoms and burden increase with increased levels of neuropsychiatric symptoms, with larger increases occurring when the number of neuropsychiatric symptoms change from moderate to high than from low to moderate. The largest difference in means is in the scores for depressive symptoms – caregivers of persons with 1-3 neuropsychiatric symptoms (n = 35) had a mean depressive symptom score of 10.0 (SD = 7.3) versus a mean depressive symptom score of 21.5 (SD = 9.0) for caregivers of persons with ≥ 7 neuropsychiatric symptoms (n = 23). A one-way analysis of variance (ANOVA) was performed and found the differences in these means to be significant ($F = 12.0$, $p = .00$, $df = 2$).

Table 8

Mean (SD) Burden and Depressive Symptom Scores by Number of Neuropsychiatric Symptoms in the Care Recipient

Mean Outcome Score	0-3 Neuropsychiatric Symptoms (n = 35)	4-6 Neuropsychiatric Symptoms (n = 37)	≥ 7 Neuropsychiatric Symptoms (n = 23)
*Self esteem	12.3 (2.6)	12.5 (4.8)	15.2 (4.9)
*Abandonment	9.5 (4.1)	10.6 (4.4)	12.2 (5.2)
*Finances	6.0 (2.4)	7.4 (3.2)	9.3 (3.9)
*Schedule	15.2 (4.6)	17.8 (3.5)	19.7 (4.0)
*Health	8.6 (3.0)	9.9 (2.8)	12.3 (3.3)
*CES-D	10.0 (7.3)	15.8 (8.5)	21.5 (9.0)

*Subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

Note. In all outcome scores, higher values represent worse levels of burden or depressive symptoms; CES-D = Center for Epidemiologic Studies-Depression; Values are presented as mean scale scores (SD)

Research question #2: Given the care recipient's functional, cognitive, and neuropsychiatric status, what are the moderating effects of the caregiver's level of perceived adequacy of information to care and mastery on the caregiver's burden and depressive symptoms for the caregiver of a person with a PMBT?

Once the original model was specified and adequate fit indices were obtained, caregiver mastery and PAIC were added to form the secondary model, which was used to first determine whether mastery and PAIC had any direct effects on burden and depressive symptoms. The secondary hypothesized model was also fit using an unweighted least squares method of approximation. The parsimonious model fit the data well, resulting in a goodness-of-fit chi square of 1.34, $p = .97$ ($df = 6$, $N = 95$). The model yielded a root mean square error of approximation of .00, which indicates a close fit (MacCallum et al., 1996). The model depicted a goodness of fit index of .95, and a normative fit index of .91, which also indicate a good fit (Nunnally & Burnstein, 1994).

Similar to the original model, the care recipient's cognitive status and IADL status did not have any significant effects on caregiver depressive symptoms or burden. In addition, the care recipient's PAIC did not significantly affect caregiver depressive symptoms or burden. In the interest of parsimony, cognitive status, IADL status, and PAIC were then deleted from the model (see Figure 4). The care recipient's neuropsychiatric status continued to affect both depressive symptoms (standardized path coefficient .40) and all subscales of caregiver burden (self esteem, .21; abandonment, .24, finances, .38; schedule, .28; health, .37); increasing numbers of neuropsychiatric symptoms on the part of the care recipient led to increased depressive symptoms and burden (see Table 9).

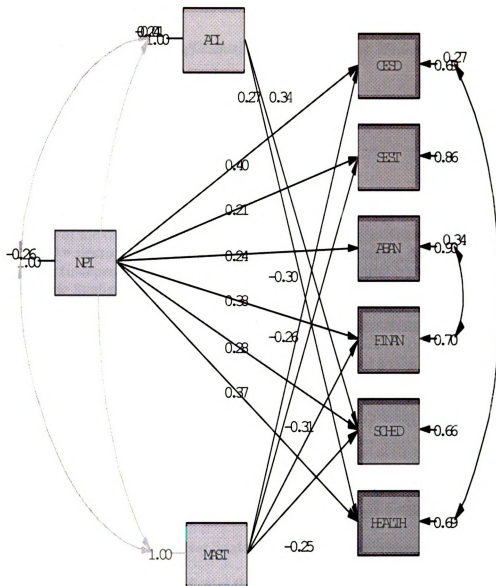


Figure 4. Parsimonious secondary structural model: Effect of functional (ADL), neuropsychiatric (NPI) status and mastery (mast) on caregiver depressive symptoms (CESD) and caregiver burden (sest = self esteem; aban = abandonment; finan = finances; sched = schedule; and health). Only significant paths are shown ($t > 2.00$), full model with nonsignificant paths in Appendix J.

Note. Hidden error variances: CES-D = 0.69; Aban = 0.90; Sched = 0.66.

Table 9

Direct Effects (Standardized Coefficients) of Independent and Moderating Variables on Outcome Variables

	CES-D	**Self esteem	**Abandonment	**Finances	**Schedule	**Health
NPI-Q	.40*	.21*	.24*	.38*	.28*	.37*
ADL	-.02	-.05	-.10	-.01	.34*	.27*
Mastery	-.30*	-.26*	-.14	-.31*	-.25*	-.15

* Coefficient significant at the $t > 2.00$ level

** Subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

Note. NPI-Q = neuropsychiatric inventory (independent variable); ADL = Activities of Daily Living (independent variable); Mastery (moderating variable); CES-D = Center for Epidemiologic Studies-Depression

In the secondary model, the care recipient's ADL status continued to affect the impact of providing care on the caregiver's schedule (.34) and health (.27). These data indicate that as the care recipient requires more assistance with ADLs, there is more impact of providing care on caregiver's schedule and health.

When the direct effects of caregiver mastery on the outcome variables are examined, caregiver mastery had a significant effect on caregiver depressive symptoms (-.30) and three subscales of caregiver burden (self esteem, -.26; finances, -.31; schedule, -.25). The direction of the sign indicates that as caregivers' level of mastery increases, caregiver depressive symptoms and some portions of caregiver burden decrease.

The next step in the analysis was to determine the moderating effects of mastery on caregiver burden and depressive symptoms. [Note: A mediating model was also run to determine whether caregiver mastery could be a mediating, rather than moderating variable (Baron & Kenny, 1986). The data did not support the role of mastery as a mediating variable.] Because the sample was not large enough to detect a moderating effect in SEM, regression analyses were performed to examine how neuropsychiatric

symptoms affect caregiver burden and depressive symptoms by differing levels of mastery (the moderating effect of mastery). The sample was divided into two groups – those with low levels of mastery (mastery score ≤ 26 , $n=41$) and those with high levels of mastery (mastery score ≥ 27 , $n=54$). Separate regression models were run with neuropsychiatric symptoms as the predictor variable and measures of depressive symptoms and burden as the outcome variables (see Appendix I, Table D).

Regardless of level of mastery, neuropsychiatric symptoms significantly affected caregiver depressive symptoms (low mastery: $\beta = 1.18$, $t = 2.9$, $p = .01$; high mastery: $\beta = 1.9$, $t = 4.9$, $p = .00$) and burden related to the impact of providing care on finances (low mastery: $\beta = 0.6$, $t = 4.1$, $p = .00$; high mastery: $\beta = 0.5$, $t = 2.7$, $p = .01$), and the impact of providing care on caregivers' health (low mastery: $\beta = 0.5$, $t = 3.6$, $p = .001$; high mastery: $\beta = 0.4$, $t = 2.6$, $p = .01$). However, when the effect of neuropsychiatric symptoms on burden related to self esteem, feelings of abandonment, and schedule were examined in relation to varying levels of mastery, the following results were obtained. Neuropsychiatric symptoms significantly affected self esteem only for those persons with low mastery (low mastery: $\beta = 0.7$, $t = 3.2$, $p = .01$; high mastery: $p = .95$). Similarly, neuropsychiatric symptoms significantly affected feelings of abandonment only for those persons with low mastery (low mastery: $\beta = 0.5$, $t = 2.9$, $p = .01$; high mastery: $p = .40$). This phenomena was also found in the effect of neuropsychiatric symptoms on caregivers' schedule (low mastery: $\beta = 0.6$, $t = 3.3$, $p = .002$; high mastery: $p = .09$).

Discussion

Despite research documenting the negative effects on the caregiver of providing care for someone with cancer and providing care for someone with a neurodegenerative

disorder, there has been little research done to investigate the effects of providing care for someone with both oncological and neurological sequelae. This cross-sectional study was designed to determine the effects of the care recipient's functional, cognitive, and neuropsychiatric status on caregiver levels of depressive symptoms and burden, and to determine the potential moderating effects of caregiver mastery and perceived adequacy of information to care.

The primary model of the study examined the effects of the care recipient's functional, cognitive, and neuropsychiatric status on the emotional response of the caregiver (burden and depressive symptoms). Similar to other reports in the literature (Calhoun et al., 2002; Fillit, Guterman, & Brooks, 2000; Groom et al., 1998; Kaufer et al., 1998), care recipients' neuropsychiatric status consistently affected caregivers' depressive symptoms. As the number of neuropsychiatric symptoms in the care recipient increased, particularly from moderate to high numbers of neuropsychiatric symptoms, caregivers had higher levels of depressive symptoms. The care recipient's neuropsychiatric symptoms also had a strong effect on the impact of providing care on the caregiver's finances, feelings of abandonment, health, self esteem, and schedule, which are all dimensions of caregiver burden. In fact, the care recipient's neuropsychiatric symptoms were the most consistent and strongest predictor of caregiver responses in the model.

Other authors have reported that specific symptoms on the part of the care recipient, such as agitation, dysphoria, irritability, delusions, depression, inappropriateness, violence, and apathy can lead to negative consequences from providing care (Calhoun et al.; Fillit et al.; Groom et al.; Kaufer et al.). Data from this

study reinforce these findings, as care recipient dysphoria/depression and apathy/indifference were two of the most common neuropsychiatric symptoms reported by caregivers, and neuropsychiatric symptoms consistently affected caregiver burden and levels of depressive symptoms. Health care practitioners interested in decreasing the negative consequences of providing care should target interventions at both helping caregivers cope with neuropsychiatric sequelae and trying to decrease the severity of neuropsychiatric symptoms in the care recipient (such as the use of anti-psychotics), as both strategies have been shown to be effective with caregivers of persons with Alzheimer's disease (Feldman et al., 2003; Sorensen et al., 2002).

Unlike other reports in the literature (Carey et al., 1991; Given et al., 1993; Jepson et al., 1999; Nijboer et al., 2000), the care recipient's cognitive status and IADL status did not affect caregiver burden and depressive symptoms, although assisting with ADLs led to more burden related to caregivers' schedules and health. The lack of an effect of care recipients' cognitive status on caregivers' depressive symptoms and burden could have been due to the low number of care recipients who had alterations in cognitive status (as previously described), or due to differing ways in which cognitive status was operationalized.

Concerning the absence of a relationship between assisting the care recipient with IADLs and caregiver burden and depressive symptoms, it is plausible that caregivers who are faced with managing multiple neuropsychiatric problems, such as agitation, depression, and hallucinations, do not perceive assisting with IADLs such as transportation and shopping as particularly burdensome. Recent literature has begun to explain this phenomenon. Pinquart and Sorenson (2003) performed a meta-analysis of

caregiver studies and found that assisting the care recipient with functional problems was typically burdensome only to those caregivers who were not also faced with dealing with neurological problems on the part of the care recipient. It may be the case that when caregivers are faced with managing both neuropsychiatric and functional problems, managing neuropsychiatric problems are so devastating that it actually becomes a relief to the caregiver to assist with IADLs. The lack of a negative effect of IADLs on the outcome variables could also be due to the fact that when IADL problems are present, other family members are more likely to provide assistance with care (Given, Given, Stommel, & Lin, 1994), than when neurological problems are present (Breitbart et al., 2002). Increased involvement on the part of secondary caregivers may be able to decrease the burden involved in providing care. The goal for health care practitioners, then, may be to increase the involvement of secondary carers to assist with care, particularly when neuropsychiatric symptoms are present. Sherwood, Given, Doorenbos, and Given (2004) reported friends and family of persons with a PMBT may not want to be involved in the care situation when the care recipient has neuropsychiatric symptoms, which would emphasize that caregiver interventions should include strategies to increase the involvement of secondary carers.

The secondary analysis was designed to determine the potential moderating effects of caregiver mastery and perceived adequacy of information to care (PAIC). PAIC did not significantly affect caregiver depressive symptoms or caregiver burden, nor did it moderate any of the direct effects of the care recipient's functional, cognitive, and neuropsychiatric status on caregiver burden and depressive symptoms. The lack of a sustained effect of PAIC on the outcome variables may be due to the lack of variability in

the instrument chosen to measure PAIC. The majority of caregivers reported that they felt comfortable discussing the care recipient's status with health care practitioners and felt well understood by practitioners, which was also reported by Wideheim and colleagues (2002).

However, another study of caregivers of persons with a PMBT reported less favorable attitudes regarding the information that caregivers receive to provide care (Sherwood et al., 2004). In the study by Sherwood and colleagues, caregivers reported that accessing information from health care practitioners (HCPs) was time consuming and frustrating, and that HCPs were unable to provide assistance in how to manage the care recipient's neuropsychiatric symptoms at home. Despite opposing attitudes regarding information to care, receiving useful information is a common theme throughout neuro-oncology caregiving literature (Leavitt et al., 1996; Sherwood et al.; Wideheim et al., 2002; Wyness, Durity, & Durity, 2002), and should be further developed. For example, HCP empathy is quite different from the reliability and usefulness of information given to the caregiver to help provide care. It is possible that the instrument used in the study measured perceptions of the availability and accessibility of the HCP, rather than the availability and accessibility of information from the HCP to assist in providing care. Future studies should be done to assess the caregiver's perception of the availability, accessibility, and appropriateness of the information they receive to provide care at various points in time during the care trajectory.

In the secondary model, the care recipient's neuropsychiatric status continued to consistently affect caregiver depressive symptoms and burden. Regression analyses were performed to determine whether the effect of neuropsychiatric status on burden and

depressive symptoms varied according to the caregiver's level of mastery. Mastery did not affect the relationship between neuropsychiatric symptoms and caregiver depressive symptoms, burden related to the impact of providing care on caregivers' finances, and burden related to the impact of providing care on caregivers' health. However, when burden related to the impact of providing care on caregivers' self esteem, feelings of abandonment, and schedule were examined, there was a significant effect of neuropsychiatric status on the outcome variable only for those persons with low levels of mastery. It may be that depressive symptoms, caregiver health, and caregiver finances are more stable variables over time, whereas self esteem, abandonment, and schedule are all portions of burden that are more easily affected by changes in the care recipient's status. These results suggest that caregiver mastery moderates the effect of the care recipient's neuropsychiatric status on caregiver burden related to self esteem, abandonment, and schedule, which has been reported in other literature (Gitlin et al., 2003). Noting the potential for HCPs to affect mastery through educational and cognitive behavioral interventions (Gitlin et al.), HCPs may be able to decrease these three areas of caregiver burden by increasing levels of caregiver mastery through education and counseling regarding how to manage neuropsychiatric symptoms in the home (see Suggestions for Future Research).

In the second model, caregiver mastery also had a significant direct effect on caregiver depressive symptoms and three of the five subscales of caregiver burden (the impact of providing care on caregiver's self esteem, finances, and schedule). Data suggest that as caregivers feel more comfortable and confident in their role, they are less likely to feel depressed. In addition, caregivers with higher levels of mastery are less

likely to feel that providing care is a burden on their finances and schedule, and are more likely to report higher self esteem. These associations indicate that how masterful the caregiver feels in his/her role, the less likely providing care will lead to a negative emotional response as a result of the care situation. Data support other research that emphasizes the association between higher levels of mastery and more positive consequences from providing care (Bookwala & Schulz, 1998; Li et al., 1999; Szabo & Strang, 1999), and emphasize that health care practitioners should assess levels of mastery and focus interventions on improving caregivers' feelings of confidence in their role.

Finally, findings from the study were examined in light of the conceptual model proposed for the study (see Figure 1). The variables identified during the primary appraisal were tumor status (i.e. cell type and location of the tumor) and neurological status (functional, cognitive, and neuropsychiatric status). Data from the study did not support a direct link from tumor status to negative consequences from providing care (i.e. there was no direct effect of cell type on caregiver burden or depressive symptoms). However, tumor status dictates neurological status (the sequelae from an aggressive tumor and subsequent treatment will lead to worsening functional and neuropsychiatric status, [Hickey & Armstrong, 1997]), which in turn affects negative consequences from providing care, thus supporting inclusion of these variables in the model.

Regarding the effect of neurological status (functional, cognitive, and neuropsychiatric status) on negative consequences from providing care, one measure of functional status (ADL) led to higher burden, while IADL did not affect burden or depressive symptoms. Care recipients' neuropsychiatric symptoms caused more burden

and depressive symptoms, and cognitive status had no effect on burden or depressive symptoms. While it is possible to argue that cognitive status should be deleted from the model, it is more likely that the lack of a significant relationship between cognitive status and negative consequences from providing care was due to the lack of cognitive problems in the care recipients in the sample. The inclusion of functional and neuropsychiatric status in the model was supported, and further studies should examine functional status as a potential moderating variable in buffering the effects of the care recipient's neuropsychiatric status on caregiver burden and depressive symptoms.

The numbers within the functional, cognitive, and neuropsychiatric circles suggested that different combinations of disabilities will have varying effects on care demands (for example, a care recipient could have problems with both functional and neuropsychiatric problems, which would cause a different level of caregiver burden than a caregiver of a person with only functional problems). Although the number of participants in the study did not allow for significance testing of this hypothesis, a preliminary examination of outcome scores based on varying levels of assistance was done. The care recipient's functional status (assistance with both ADLs and IADLs) was categorized into three levels – low, moderate, and high – indicating the level of assistance the caregiver provided with functional tasks. The care recipient's neuropsychiatric symptoms were also categorized into three levels to indicate whether the caregiver had to manage low, moderate, or high numbers of neuropsychiatric symptoms. (There was not enough variability in scores from the cognitive status instrument to include cognitive status in this analysis).

As the mean outcome scores in Table 10 indicate, caregivers' depressive symptoms increased along with increases in the care recipient's neuropsychiatric symptoms, but remained relatively stable in the presence of worsening functional status, which was suggested by Browning and Schwirian (1994). This trend was mirrored in mean scores for the self esteem, finances, and health subscales of caregiver burden. Only in the case of the schedule and abandonment subscales, did burden increase with worsening functional status where neuropsychiatric symptoms remained relatively constant. These findings support the data that showed that assistance with functional tasks had a significant effect on burden related to the caregiver's schedule, and emphasize the need to replicate the study on a larger level where the effect of care recipient scores in varying categories on negative consequences from providing care can be further evaluated.

Table 10

*Mean Caregiver Depressive Symptom and Burden Scores by Differing Levels of Functional and Neuropsychiatric Status in the Care**Recipient, N=95*

Category (N)	CES-D	*Self- esteem	*Abandonment	*Finances	*Schedule	*Health
Low function and moderate NP (19)	10.3 (8.4)	12.4 (2.5)	8.8 (2.9)	5.8 (1.7)	13.9 (3.7)	8.8 (2.2)
Low function and high NP (13)	16.2 (8.9)	11.9 (4.4)	10.3 (4.0)	8.5 (2.9)	17.2 (3.5)	9.5 (2.5)
Moderate function and moderate NP (11)	16.5 (9.7)	12.7 ((5.2)	12.0 (5.5)	5.8 (2.7)	16.8 (3.4)	9.4 (2.3)
Moderate function and high NP (11)	20.5 (10.2)	16.0 (3.0)	11.4 (4.3)	8.5 (3.9)	18.9 (4.9)	12.3 (3.3)
High function and low NP (6)	9.5 (5.4)	12.3 (2.2)	10.2 (5.0)	5.8 (1.7)	20.2 (4.3)	9.7 (3.1)
High function and moderate NP (9)	14.3 (7.0)	13.1 (5.4)	9.1 (2.9)	8.0 (3.8)	19.9 (3.2)	11.1 (3.7)
High function and high NP (8)	23.0 (8.1)	15.0 (6.7)	13.8 (6.5)	9.9 (3.9)	20.6 (2.6)	13.0 (3.0)

* Subscales of the Caregiver Reaction Assessment (measures of caregiver burden)

Note. Categories indicate care recipient status (i.e. low function and low NP indicate that the care recipient required little assistance with activities of daily living and instrumental activities of daily living and also had few numbers of neuropsychiatric symptoms); values are presented as mean scores (SD) for each instrument; NP = neuropsychiatric symptoms; CES-D = Center for Epidemiologic Studies-Depression; Categories that contained five or fewer respondents were not included in the table.

The resources considered during the secondary appraisal included variables that could potentially moderate the effect of the care recipient's tumor and neurological status on the caregiver's stress response (such as mastery, PAIC, optimism, and caregiver health). Two of these variables were tested within the model – mastery and PAIC. Although mastery was identified as a significant moderator of neuropsychiatric symptoms on three subscales of caregiver burden, PAIC did not affect burden or depressive symptoms. Studies to evaluate other potential moderators, such as optimism and caregiver health, should be done in addition to further investigating the role of PAIC in improving negative consequences from providing care. The inclusion of mastery as a potential internal resource in the model was supported.

The two stress responses chosen for examination in the study were caregiver burden and depressive symptoms (two potential emotional consequences from providing care). Both burden and depressive symptoms showed variance in the sample and appear to be good indicators of caregivers' emotional responses. Other potential emotional responses, such as anxiety, should be evaluated in future studies, along with potential physical responses, such as changes in immune functioning and blood pressure.

Overall, data from the study did not suggest any deletions from the model, with the potential exception of PAIC. However, the lack of a significant effect of PAIC may have been due to measurement issues (the instrument may have been a more accurate measure of provider empathy, rather than PAIC). Study findings, along with findings from other research (Archbold et al., 1995; Picot et al., 1995, 1997; Sherwood et al., 2004), suggest that one of the biggest limitations to the model is the lack of identification of positive consequences from providing care. The potential for benefits as a positive

outcome from assuming the role of caregiver should be considered, in addition to examining the ways in which positive consequences of providing care may buffer the caregiver's negative stress response.

The next steps in testing the conceptual model are described here (recommendations for practice and research based on the study findings are included in a later section of this chapter). Once the questions below have been answered, interventions to improve the emotional and physical health of caregivers can begin to be evaluated. The next step in model testing is to implement a longitudinal study using a larger, more ethnically diverse sample. Future studies will need to draw from multiple recruitment sites, particularly those sites whose patients represent larger proportions of caregivers of varying ethnic backgrounds. Future grant proposals will need to include requests for finances to support recruitment at multiple sites. Concerning increasing numbers of minority participants, recruitment via support group failed to produce large numbers of non-Caucasian participants, thus, employing recruiters at each site should be encouraged. More in-depth consultation with investigators who have experience in recruiting minority participants will be done, as the strategies employed in this study (i.e. targeting geographical areas with larger proportions of minority caregivers, assuring study materials were ethnically diverse) were not adequate to recruit large numbers of minority participants. The next study will be designed to support the data here, to implement a pilot intervention trial, and to answer the following questions (variables to be introduced in future studies have been underlined):

1. What are the effects of the care recipient's tumor and neurological status on the caregiver's physical stress response? (For example, what is the effect of the care

- recipient's neuropsychiatric status on the caregiver's immune functioning or blood pressure?)
2. What are the moderating effects of positive aspects of providing care (such as mutuality), optimism, caregiver emotional and physical health, and caregiver education on the caregiver's emotional and physical stress response? (For example, how do underlying caregiver depressive symptoms affect depressive symptoms or burden that result from providing care?)
 3. How does PAIC, rather than provider empathy, affect caregivers' emotional and physical response to providing care?
 4. In a longitudinal design with an inception cohort of caregivers, how do care demands, moderating resources, and stress responses vary over time given changes in the care recipient's disease status? (For example, is caregiver burden higher at the beginning of the care situation, or does it increase as the length of time providing care increases? Furthermore, does caregiver burden vary as a function of the care recipient's disease trajectory?)
 5. How should an intervention directed toward caregivers of persons with a PMBT be structured? (For example, are caregivers able to participate in a one-on-one session with an intervener or are group sessions more appropriate? How would a telephone intervention be received? How long should intervention sessions last – do caregivers have less than 30 minutes to 'attend' to an intervention, are interventions spaced over one month long enough to reduce the negative effects of providing care?) These questions can be answered during a pilot study supported by a National Institutes of Health K award.

Limitations

Although the study begins to fill some of the gaps in caregiving research (examining an understudied population, utilizing an analytic technique that controls for covariance, and beginning to examine caregiver interactions with the formal health care system), it also shares limitations with other caregiver studies, many of which were outlined in the limitations section of Chapter 2. First, similar to the majority of caregiver studies, the research utilized a cross-sectional design. This design was chosen because it is not vulnerable to attrition and is a good method of beginning to study a population where previous research is sparse. However, a cross-sectional design has the limited ability to report relationships rather than determining causation. Once predictors of burden and depressive symptoms in caregivers of persons with a brain tumor have been established, longitudinal studies should be done to examine how these factors vary given changes in the care situation.

The second limitation of the study is in the area of generalizability. The incidence of brain tumors is relatively low in comparison to other malignancies (Michigan Department of Community Health, 2000), and the majority of brain tumors occur in Caucasians (National Cancer Institute, 2003). Due to these constraints, the number of minorities in this sample was low, limiting generalizability to minority populations. Other studies have reported that minorities may present with later stage cancers and may have difficulty accessing health care (Benjamin, Reddy, & Brawley, 2003; Gadgeel & Kalemkerian, 2003), which may impact caregiver burden and depressive symptoms. Although these issues have not been identified in the area of neuro-oncology (Barnholtz-Sloan, Sloan, & Schwartz, 2003), race related health care disparities may lead to higher

levels of negative consequences from providing care for minority caregivers. Studying the effects of care recipient dysfunction on negative consequences from providing care, and the role of mastery in moderating these effects, should be replicated in studies with higher proportions of minority participants to identify any confounding variables that affect outcomes as a result of race related health disparities.

Recruitment procedures may also have limited generalizability. Approximately $\frac{1}{2}$ of the sample was recruited through a national support group. Members of a support group may have higher levels of depressive symptoms, which lead them to seek emotional support. To test this theory, t-tests were performed to detect significant differences in mean levels of burden and depressive symptoms by site of recruitment for the two sites with the highest recruitment (the national support groups versus the metropolitan brain tumor treatment center [HBTC]). Patients in the national support group had significantly ($t = 1.98$, $df = 83$) higher levels of burden related to self esteem ($M = 13.7$, $SD = 4.0$ for national support group versus $M = 12.0$, $SD = 4.2$, for HBTC; $p = .05$), feelings of abandonment ($t = 2.81$, $df = 84$) ($M = 11.5$, $SD = 5.1$, for national support group versus $M = 8.9$, $SD = 2.9$ for HBTC; $p = .01$), and impact of providing care on caregivers' health ($t = 2.54$, $df = 83$) ($M = 10.6$, $SD = 3.2$, for national support group versus $M = 8.8$, $SD = 3.0$ for HBTC; $p = .01$). Patients recruited from the national support groups also had significantly ($t = 2.10$, $df = 82$, $p = .04$) higher levels of depressive symptoms ($M = 16.4$, $SD = 7.9$) than patients recruited from HBTC ($M = 12.6$, $SD = 9.0$).

The third limitation is related to the way in which care recipients' functional and neurological status was measured. In order to obtain an adequate sample to perform the

analyses, caregivers were recruited from across the nation, which prohibited face to face interviews. Therefore, all measures of care recipient status were done by proxy. It is possible that caregivers who were more burdened or depressed were biased in their reports of care recipients' health; caregivers who are distressed may not be as accurate when reporting care recipients' symptoms as those who are not distressed (Porter et al., 2003). Future research should include objective measures of care recipient status.

Finally, because previous studies with this caregiving population are largely absent, variables that may affect the emotional response of caregivers of persons with a brain tumor were included based on caregiver research in other areas and clinical judgment. Additional variables that may impact burden and depressive symptoms of caregivers of persons with a brain tumor may not have been included as potential predictor variables.

Implications for Clinical Practice

Data from the study provide several implications for clinical practice and research, which are highlighted in the following section.

- Caregiver burden and depressive symptoms were related to high numbers of neuropsychiatric symptoms in the care recipient. Interventions aimed at improving caregivers' emotional health should focus on assisting the caregiver to manage and cope with care recipients' neuropsychiatric symptoms. Caregivers should be taught how to recognize and monitor neuropsychiatric symptoms, be aware of potential causes for changes in behavior, and integrate strategies for decreasing the severity and impact of neuropsychiatric symptoms on the caregiver and other household members (such as organizing secondary carers to watch the

patient and provide respite for the caregiver). Next, pharmacologic strategies for the care recipient such as antipsychotics may be beneficial in reducing the severity of the care recipient's neuropsychiatric symptoms, so that the caregiver is better able to manage the problems in the home. A dual approach – pharmacologic therapy to affect the severity of symptoms and education and counseling to assist the caregiver in managing problems in the home – may help to decrease caregiver burden and depressive symptoms. Education and counseling on possible triggers for care recipient behaviors, environmental modification, breaking down tasks for care recipients, and stress relaxation techniques to help caregivers cope with negative emotions that may result from care recipient dysfunction can be particularly effective for caregivers of persons with neuropsychiatric symptoms (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Mahoney, Tarlow, & Jones, 2003).

- Two indicators of caregiver burden (impact on schedule and health) were related to providing assistance with ADLs. Interventions to affect caregiver burden and depressive symptoms should include strategies for assisting caregivers to integrate care activities into their schedule, encourage healthy behaviors such as exercise and respite, and should also include strategies to employ secondary carers. Future research should be done to determine how the numbers of caregivers assisting with care relate to burden secondary to functional limitations.
- Caregiver mastery was directly related to decreased burden and depressive symptoms, and also moderated the effect of care recipients' neuropsychiatric symptoms on three subscales of caregiver burden (self esteem, schedule, and

abandonment). Increasing caregiver knowledge can lead to higher levels of caregiver mastery (Mahoney et al., 2003), and caregivers have reported needing information and assistance in dealing with neuropsychiatric symptoms (Sherwood et al., 2004). Interventions to improve caregiver emotional health for caregivers of persons with a PMBT should be aimed at improving levels of mastery through education and support, and subsequently monitoring caregiver depressive symptoms and burden. Improving mastery may be accomplished by providing caregivers with education on neuropsychiatric sequelae, teaching caregivers better ways to cope with problems (such as realizing the aberrant behavior is a result of the tumor, rather than the care recipient), and providing stress reducing techniques such as relaxation and guided imagery.

- The caregivers in our sample had a high level of depressive symptoms. Practitioners interested in improving caregiver health should monitor caregivers of persons with a PMBT for depressive symptoms, and intervene with cognitive behavioral support (such as counseling and support groups) and pharmacologic measures (such as antidepressants) as needed. In particular, caregivers who were recruited from support groups had higher levels of depressive symptoms than those recruited from other sites. Clinicians who are working with caregivers in support groups should be aware that these caregivers may be at high risk for depressive symptoms.
- At the institutional level, information on the relationship between neuropsychiatric status and caregiver burden and depressive symptoms and the potential moderating effect of caregiver mastery should be integrated into

education for physicians and nurses. Preparing health care practitioners to recognize and manage correlates of distress for caregivers can help to improve caregivers' emotional health.

- At the social level, programs to provide financial and educational support for caregivers are often based on care recipients' abilities (Polivka, 2001).

Information from this and future studies should be shared with policy makers to identify specific correlates of distress for caregivers of PMBTs, to make sure that their voices are represented in national policy reform.

In summary, results from the study stress the importance of educating practitioners regarding the variables that produce negative emotional responses in caregivers of persons with a PMBT. Practitioners should then provide assistance to caregivers in managing neuropsychiatric symptoms, helping caregivers integrate care activities into their schedules, and stressing healthy behaviors, with an ultimate goal of improving caregivers' sense of mastery, and decreasing caregiver burden and depressive symptoms.

Implications for Future Research

The study has implications for both descriptive and intervention research in the area of caregiving.

Descriptive Research

- More research is needed to explore the effects of care demands from the primary appraisal (such as cognitive status) on the caregiver's stress response and the potential moderating relationship of other resources, such as optimism and social

support. Specific research questions to address further exploration of the conceptual model were listed at the end of the discussion section.

- Although caregiver mastery and PAIC were included as potential moderators of burden and depressive symptoms, the conceptual model of the study did not allow for the possibility of positive rewards from providing care. Other studies with caregivers of persons with a brain tumor have reported that providing care was considered a privilege and honor (Sherwood et al., 2004), although these caregivers reported positive aspects of care after the care recipient died. Future studies should be designed to identify potential positive aspects of providing care and examine the way in which they may moderate negative consequences.
- The most commonly studied emotional consequences from providing care, caregiver burden and level of depressive symptoms, were included in the model. However, there are multiple other potential consequences of providing care. Physiologic consequences on the caregiver of providing care (such as the physiological stress response, antibody response to vaccines, and hypertension) have been examined in other caregiving populations (Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003), and should be studied in caregivers of persons with a brain tumor. In addition, the health care practices of caregivers should be examined. For example, do caregivers of persons with a PMBT have fewer annual physicals, health screenings such as mammograms and pap smears, and more risk-taking behaviors such as smoking and alcohol use?
- Due to the effect of care recipients' neuropsychiatric symptoms on caregiver burden and depressive symptoms, and the potential for changes in neurological

status following chemotherapy for tumors outside the central nervous system (Barton & Loprinzi, 2002; Freeman & Broshek, 2002), the study should be replicated with caregivers of persons with metastatic lesions in the brain and caregivers of persons with cognitive dysfunction from chemotherapy to investigate the relationship of neurological dysfunction and caregiver burden and depressive symptoms for caregivers of persons with tumors outside the central nervous system.

- The role of mastery in decreasing the effect of neuropsychiatric symptoms on caregiver burden may have implications in other types of caregiving research. Studies should be replicated in the oncology population to determine whether mastery decreases the negative effects of other types of care recipient symptoms (such as pain and fatigue) on caregiver burden.
- The majority of the sample presented here were middle aged, female Caucasian spouses of persons with a brain tumor. Other research has identified differences in negative consequences from providing care based on ethnicity and gender (Kurtz, Kurtz, Stommel, Given, & Given, 2002; Northouse et al., 2000). The study should be replicated in minority populations (i.e. African American caregivers, male caregivers) and in older and younger caregivers to detect differences in the ways in which these groups approach providing care.
- Although general information on the care recipient's tumor type, treatment, and the location of the tumor was collected, future research should include more detailed data regarding treatment options (type of drug, amount of radiation,

medications used for symptom palliation) to identify the effect of specific treatment and disease related characteristics on caregiver responses.

Intervention Research

- Research studies on interventions to manage neuropsychiatric problems in the neuro-oncology population are largely absent. Research has been done, however, in the area of interventions with caregivers of persons with Alzheimer's disease, who may have some of the same neuropsychiatric problems. Interventions that have been shown to be effective include those offering education, cognitive behavioral strategies, counseling, and pharmacologic strategies (Gitlin et al., 2003; Kozachik et al., 2001; Pinquart & Sorenson, 2003). A next step in the area of neuro-oncology caregiving research is to identify caregivers who are at risk for negative consequences from providing care and develop interventions that incorporate some of these strategies. Once the intervention has been developed, it should be tested among various groups of caregivers (spouses versus other types of caregiver/care recipient relationships, Caucasian versus African American caregivers, older versus younger caregivers).
- Interventions to affect caregivers' stress responses may differ in their effectiveness based on the outcome variable that is studied. For example, interventions to impact burden may not impact depressive symptoms, and vice versa. Interventions should be evaluated based on several caregiver outcome variables, such as burden, depressive symptoms, anxiety, quality of life reports, immune functioning, blood pressure, and other measures. Once the effectiveness

of interventions in these domains is established, programs can be implemented to individualize interventions to meet specific caregivers' needs.

- The most appropriate target of interventions to decrease caregiver burden and depressive symptoms is not well established. Research in the area of caregiving has suggested that interventions may be more effective when aimed at the dyad (Brodaty, Green, & Kroschera, 2003) or family (Northouse et al., 2002), rather than just at the caregiver alone. Given the younger age of caregivers of persons with a brain tumor compared to caregivers of persons with dementia, including other members of the family in the intervention should be considered.
- Researchers in the area of caregivers of persons with cancer and with Alzheimer's disease have reported that the effectiveness of interventions can be largely dependent on caregiver characteristics, such as caregiver age, gender, initial caregiver burden and depressive symptoms (Sorensen et al., 2002; Given et al., in press). Gitlin and colleagues (2003) suggested that interventions should be tailored to fit the individual needs of the caregiver and care recipient.

Intervention studies to improve caregiver health in the neuro-oncology population, then, must be planned with a large enough sample size to identify differential effects based on caregiver and care recipient characteristics. As it is unlikely that a large sample would be found in one institution, future intervention studies will need to target a large sample size using multiple large recruitment sites.

Conclusion

This cross sectional, descriptive study was a beginning step in the area of neuro-oncology caregiving research to identify variables that predict negative consequences from providing care for caregivers of persons with a PMBT. Similar to reports in caregiving literature, the care recipient's neuropsychiatric status consistently predicted caregiver burden and depressive symptoms. Interestingly, the study also showed the moderating effect of mastery on three areas of caregiver burden (the effect of providing care on caregivers' self esteem, feelings of abandonment, and schedule). Although decreasing the number and severity of the care recipient's neuropsychiatric symptoms may be difficult depending upon the extent of disease, the role of mastery in the study demonstrates that health care practitioners have the opportunity to affect negative consequences from providing care by increasing caregivers' confidence in managing care recipients' behaviors. Further studies of the predictors of both negative and positive consequences from providing care in the neuro-oncology population are needed to continue exploring the experience of becoming a caregiver of a person with a PMBT. Intervention studies are also needed to begin to implement strategies to improve caregivers' health.

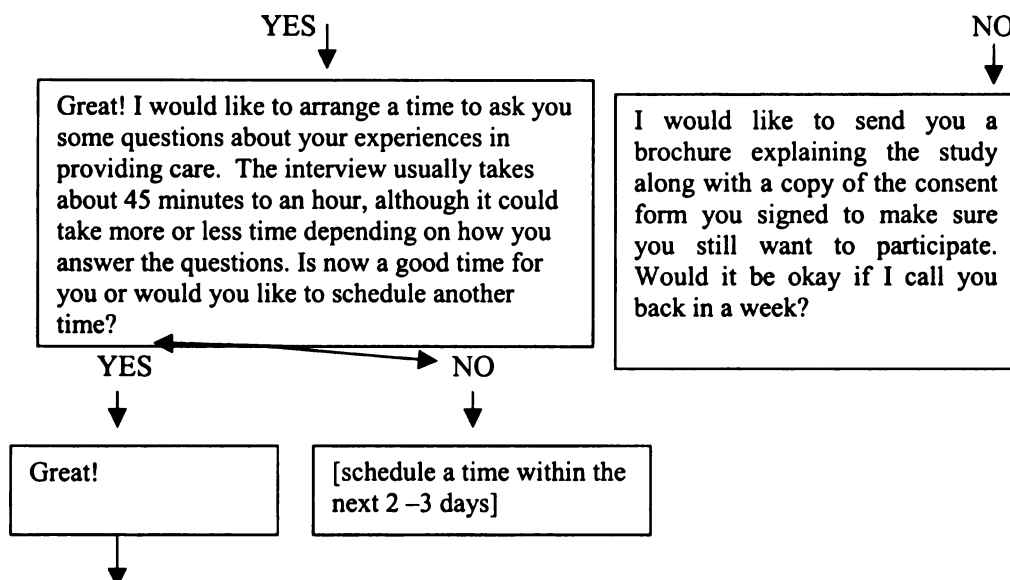
Appendices

Appendix	Title
A	Instrument
B	Recruitment brochure
C	Study advertisement
D	Screening/enrollment form
E	Recruiter manual
F	Policy and procedure manual
G	Interviewer manual
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FAMILY CARE OF PERSONS WITH A BRAIN TUMOR

Interview Introduction

Hello, is _____ at home? This is [your name here] calling from the Family Care of Persons with a Brain Tumor Project at Michigan State University. You may recall that you reviewed some material about a study designed to find out more about caregivers of persons with brain tumors and agreed to participate in an interview. Do you remember agreeing to participate in this study?



Since most people have never participated in an interview like this, let me spend a minute explaining how it works. I'm going to ask you a series of questions, exactly as they are written and in the order they are written so that I ask every person I talk with the same questions.

I'll first read a question, then provide you with some answer options. For example, I might ask you to tell me how you would describe your health, then provide you with the following options: excellent, very good, good, fair or poor. You would tell me in your opinion which option best describes your health. If something is unclear, please let me know. There are no right or wrong answers – we are looking for your opinion on each question.

Some of the questions are similar, but each one is important. If a question makes you too uncomfortable, you do not have to answer it. However, you should know that any information you provide will be strictly confidential. In addition, if a question makes you uncomfortable, you may terminate the interview at any time. If you choose to terminate the interview, I will ask you if I can contact you at a later time to finish the interview. You may either agree to be contacted later, or withdraw from the study at that time.

Caregiver ID# _____ Date of interview __/__/__ Time started _____

CAREGIVER SOCIODEMOGRAPHIC INFORMATION

INTERVIEWER: Complete entire interview noting response to each question. Prior to interview, note patient name and use where indicated. **“First we will start with some basic questions about you and your family. Some of the questions will be about you and some about your loved one with a brain tumor.”**

1. Sex of caregiver: _____ Male (1) _____ Female (2)
(Interviewer – confirm sex of caregiver)

2. What is your birth date? _____ / _____ / _____
month day year

3. What is your current marital status?

_____ Never married (1)
_____ Married (2)
_____ Divorced/Separated (3)
_____ Widowed (4)
_____ NA/Refused (99)

4. What is your highest level of education completed?

_____ No formal education (1)
_____ Less than high school (2)
_____ Completed high school (3)
_____ Some college or technical training (4)
_____ Completed college (5)
_____ Completed graduate/professional degree (post baccalaureate degree) (6)
_____ Refused (99)

5. What is your race or ethnic background?

_____ Caucasian/White (1)
_____ African American/Black (2)
_____ Mexican American/Hispanic/Chicano (3)
_____ Native American/Alaskan (4)
_____ Oriental/Asian/Pacific Islander (5)
_____ Other (6) (Specify: _____)
_____ Refused (99)

6. What is your relationship to (patient name)?

_____ Spouse (1)
_____ Parent (2)
_____ Daughter/Son (3)
_____ Daughter-in-law/Son-in-law (4)
_____ Sister/Brother (5)
_____ Sister-in-law/Brother-in-law (6)
_____ Granddaughter/Grandson (7)
_____ Niece/Nephew (8)
_____ Aunt/Uncle (9)

- ____ Other relative (10) (Please specify _____)
____ Friend or companion with whom he/she lives (11)
____ Other non-relative (12) (Please specify _____)
____ NA/Refused (99)
7. How long have you known (patient name)?
____ years
8. Do you and (patient name) live in the same residence?
____ Yes (1) (go to 8a)
____ No (2) (go to 9)
____ NA/Refused (99) (go to 9)
- 8a. Did you move in together so that you could assist him/her with his/her cancer care?
____ Yes (1)
____ No (2)
____ Were living together prior to the diagnosis of cancer (3)
____ NA/Refused (99)
9. Including yourself, how many people live in your house? _____
9a. How many under the age of 18? _____
9b. How many 18 years or older? _____
10. Have you changed your home in any way to accommodate (patient's name)'s needs (i.e. putting in a wheelchair ramp, security system, raised toilet seat)?
____ Yes (1) (go to 10a)
____ No (2) (go to 11)
____ NA/Refused (99) (go to 11)
- 10a. If so, how? _____
11. Since (patient name) was diagnosed with cancer, in the past 3 months, have you, (patient name), or other family members spent money out of pocket on (patient name)'s hospital bills or hospital-related doctor bills, office visits, medications or other health related charges that were not covered by his/her insurance?
____ yes (1) (go to 11a)
____ no (2) (go to 12)
____ don't know yet (haven't received any bills) (3) (go to 12)
____ refused (99) (go to 12)
- 11a. If so, how much was spent in the past 3 months? _____
- 11b. What was the money spent on? (check all that apply)
____ Hospital bills
____ Physician bills
____ Prescription or over the counter medication
____ Special food or food supplements

- ☐ Supplies (incontinence pads, dressing supplies, bedpans, etc.)
 - ☐ Equipment (wheelchair, hospital bed, oxygen, etc.)
 - ☐ Skilled care
 - ☐ Chore services
 - ☐ Therapists (physical, occupational, speech)
 - ☐ Mental health counselors
 - ☐ Transportation services
 - ☐ Utilities
 - ☐ Other (specify) _____
12. How long have you been providing care for (patient name)?
 _____ years, _____ months
13. Does anyone assist you in providing care for (patient name)?
- ☐ Yes (1) (go to 13a)
 - ☐ No (2) (go to 14)
 - ☐ NA/Refused (99) (go to 14)
- 13a. If so, who (check all that apply)?
- ☐ Patient's Spouse (1)
 - ☐ Patient's Parent (2)
 - ☐ Patient's Daughter/Son (3)
 - ☐ Patient's Daughter-in-law/Son-in-law (4)
 - ☐ Patient's Sister/Brother (5)
 - ☐ Patient's Sister-in-law/Brother-in-law (6)
 - ☐ Patient's Granddaughter/Grandson (7)
 - ☐ Patient's Niece/Nephew (8)
 - ☐ Patient's Aunt/Uncle (9)
 - ☐ Patient's Other relative (10) (Please specify _____)
 - ☐ Patient's Friend or companion with whom he/she lives (11)
 - ☐ Patient's Other non-relative (12) (Please specify _____)
 - ☐ Other (13) (Please specify _____)
 - ☐ NA/Refused (99)
- 13b. On average, how many hours per week do others provide assistance?
 _____ hours

INTERVIEWER: "The next several questions have to do with how caregiving has affected your work."

14. What is your current employment/work situation?
- ☐ employed full time (35hrs/wk or more) (1), (go to 14a)
 - ☐ employed part time (less than 35hrs/wk) (2), (go to 14a)
 - ☐ not employed (5) (go to 15)
 - ☐ other (6) (specify) _____ (go to 14a)
 - ☐ NA/refused (99) (go to patient sociodemographic questionnaire)

14a. Does your employer have:

_____ More than 50 employees (1)

_____ Less than 50 employees (2)

_____ Self employed (3)

_____ Other (4) (specify): _____

_____ Refused (99)

14b. In the past month, has (patient name)'s cancer or cancer treatment, including visits to doctors or having to stay in a hospital caused you to: (check all that apply)

_____ Take paid time off work? (1) How many hrs/day _____ How many days _____

_____ Take unpaid time off work? (2) How many hrs/day _____ How many days _____

_____ None of the above (3)

_____ Other (4) (specify) _____

_____ NA/refused (99)

15. Have you changed employment because of caregiving demands?

_____ yes (1) (go to 15a)

_____ no (2) (go to patient sociodemographic questionnaire)

_____ refused (99) (go to patient sociodemographic questionnaire)

15a. How have you changed employment?

_____ I changed jobs to gain flexibility (1)

_____ I changed jobs to be able to work less (2)

_____ I changed jobs to be able to work more (3)

_____ I changed jobs to improve my benefits (4)

_____ Other (5) (specify) _____

_____ NA/refused (99)

15b. Did the change have any affect on **your** insurance coverage?

_____ yes (1)

_____ no (2)

_____ refused (99)

15c. Did the change have any affect on **your** retirement benefits?

_____ yes (1)

_____ no (2)

_____ refused (99)

Patient Sociodemographic Information
And Diagnosis and Treatment Summary

INTERVIEWER: "The next set of questions is about your family member with a brain tumor."

1. How would you like me to refer to (patient's name)? _____
[INTERVIEWER: Use this name throughout the rest of the interview]

2. Sex of patient: _____ Male (1) _____ Female (2)

3. What is his/her birth date? _____ / _____ / _____
month day year

4. What is his/her current marital status?

- _____ Never married (1)
- _____ Married (2)
- _____ Divorced/Separated (3)
- _____ Widowed (4)
- _____ NA/Refused (99)

5. When was (patient's name) first diagnosed with a brain tumor?

_____ / _____
month year

6. What type of brain tumor does (patient's name) have?

- GBM (1) _____
- Astrocytoma (2) _____ Grade _____
- Ependymoma (3) _____
- Oligodendroglioma(4) _____
- Medulloblastoma (5) _____
- Don't know (6) _____
- Other (7) (specify) _____
- Refused (99) _____

7.

8. Where is the tumor located?

- Frontal lobe (1) _____
- Temporal lobe (2) _____
- Parietal lobe (3) _____
- Occipital lobe (4) _____
- Brain stem (5) _____
- Don't know (6) _____
- Other (7) (specify): _____
- Refused (99) _____

9. How many surgeries has (patient name) had to treat his/her tumor?

Number _____

Don't know/Refused (99) _____

10. What other therapy has (patient name) received to treat his/her tumor (check all that apply)?

Chemotherapy _____

Radiation _____

Seed implants _____

Clinical trial _____

(please specify – chemo, radiation, etc.)

Stereotactic surgery _____

Other _____

(please specify) _____

11. Can (patient name) be left alone?

_____ Yes, but only for short periods of time (1) (go to 10a)

_____ Yes, without time constraints (2) (go to 10a)

_____ No, not at all (3) (go to 11)

_____ NA/Refused (99) (go to 11)

10a. If (patient name) cannot be left alone, why?

_____ Safety concerns (1)

_____ Requires constant care (2)

_____ Other (3) (specify):

_____ Refused (99)

12. What medications is (patient name) currently taking for treatment and management of his/her brain tumor (check all that apply)?

_____ Steroids

_____ Anticonvulsants

_____ Antacid/H-2 Blocker

_____ Antidepressant

_____ Anti-anxiety

_____ Other (specify:)

INTERVIEWER: "The next several questions have to do with (patient name)'s job and insurance coverage."

13. Is (patient name) working?

- ☐ employed full time (35hrs/wk or more) (1)
- ☐ employed part time (less than 35hrs/wk) (2)
- ☐ homemaker (3)
- ☐ not employed b/c of his/her brain tumor (4)
- ☐ not employed for other reasons (5)
- ☐ other (6) (specify) _____
- ☐ NA/refused (99)

14. Did (patient name) change his/her work status because of his/her brain tumor?

- ☐ yes, he/she retired (1) (go to 13a)
- ☐ yes, he/she quit work (2) (go to 13a)
- ☐ yes, he/she took an a paid leave of absence (3) (go to 13a)
- ☐ yes, he/she took an unpaid leave of absence (4) (go to 13a)
- ☐ no (5) (go to 14)
- ☐ NA/refused (99) (go to 14)

13a. Has this change impacted his/her insurance/benefits package?

- ☐ yes, benefits were increased (1)
- ☐ yes, benefits were decreased (2)
- ☐ yes, benefits were lost (3)
- ☐ no (4)
- ☐ NA/refused (99)

13b. Has this change impacted his/her retirement benefits?

- ☐ yes, benefits were increased (1)
- ☐ yes, benefits were decreased (2)
- ☐ yes, benefits were lost (3)
- ☐ no (4)
- ☐ NA/refused (99)

15. Does (patient name) currently have health insurance?

- ☐ yes (1) (go to 14a)
- ☐ no (2) (go to 15)
- ☐ NA/refused (99) (go to 15)

14a. Who is the primary carrier of (patient name)'s health insurance coverage?

- ☐ Caregiver (1)
- ☐ Patient (2)
- ☐ Other (3) (specify) _____
- ☐ NA/refused (99)

16. Since (patient name) became ill, have any of his/her health and medical insurance plans refused to pay for a health care expenditure incurred by him/her?

_____ yes (1) (specify) _____

_____ no (2)

_____ refused (99)

17. During the past year, have any of the following health care practitioners provided care for (patient name)'s brain tumor or its complications? (check all that apply)

_____ Neurosurgeon

_____ Neurologist

_____ Primary Care Physician

_____ Radiation Oncologist

_____ Neuro-oncologist

_____ Neuropsychiatrist

_____ Psychiatrist/Psychologist

_____ Social worker

_____ Visiting nurse

_____ Physical/occupational therapist

_____ Speech therapist

_____ Other (specify): _____

18. Which health care provider do you contact most often for information on (patient name)'s brain tumor and its treatment?

(INTERVIEWER: indicate specialty of provider, if no provider was contacted for information, go to the NPI-Q, otherwise, proceed to the PMH/PSQ-MD on the following page)

PMH/PSQ-MD

INTERVIEWER: "The next set of questions ask you to think about the health care provider that you go to most often for information on (patient name)'s diagnosis and treatment. Please tell me if you completely disagree, disagree, neither disagree nor agree, agree, or completely agree with each statement."

INTERVIEWER: If the health care provider most often contacted for information is not a physician, please read the statements accordingly.

1. I will follow the doctor's advice because I think he/she is absolutely right.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
2. I felt really understood by the doctor.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
3. After our last visit with the doctor, I feel much better about my concerns.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
4. I understand (patient name)'s illness much better after seeing this doctor.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
5. This doctor was interested in us as people and not just (patient name)'s illness.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
6. I feel I understand pretty well the doctor's plan for helping (patient name).

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
7. After talking with the doctor, I have a good idea of what changes to expect in (patient name)'s health over the next few weeks and months.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
8. The doctor told me to call back if I had any questions or problems.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		
9. I felt the doctor was being honest with me.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

10. The doctor explained the reason why the treatment was recommended for (patient name).
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
11. The doctor did not take our problems very seriously.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
12. The doctor did not give us all the information I thought we should have been given.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
13. I didn't have a chance to say everything I wanted to or ask all my questions.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
14. The doctor was not friendly to us.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
15. I would not recommend this doctor to a friend.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
16. The doctor seemed to brush off our questions.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
17. The doctor should have told me more about how to care for (patient name)'s condition.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
18. It seemed to me that the doctor wasn't really interested in (patient name)'s physical well being.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |
19. The doctor considered our individual needs when treating (patient name)'s condition.
- | | | | |
|----------------|-------|-------------------|-------|
| Strongly agree | _____ | Disagree | _____ |
| Agree | _____ | Strongly disagree | _____ |
| No opinion | _____ | | |

20. There were some things about our visits with the doctor that could have been better.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

21. It seemed to me that the doctor wasn't really interested in (patient name)'s emotional well-being.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

22. The doctor usually seemed rushed.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

23. The doctor should have shown more interest.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

24. There were aspects of our visits with the doctor that I was not very satisfied with.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

25. The doctor went straight to (patient name)'s medical problems without first greeting us.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

26. The doctor used words I did not understand.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

27. There wasn't enough time to tell the doctor everything I wanted.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

28. I feel the doctor did not spend enough time with us.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

29. I felt the doctor diagnosed (patient name)'s condition without enough information.

Strongly agree	_____	Disagree	_____
Agree	_____	Strongly disagree	_____
No opinion	_____		

NPI-Q

INTERVIEWER: "The next set of questions have to do with (patient name)'s behavior over the past month."

1. In the past month, has (patient name) had any false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?
_____ Yes (1) – go to #1a
_____ No (2) – go to #2
_____ Don't know/Refused (99) – go to #2
 - 1a. On a scale of 1 to 3, please rate how severe this problem was
_____ 1 – Mild (noticeable, but not a significant change) (1)
_____ 2 – Moderate (significant, but not a dramatic change) (2)
_____ 3 – Severe (very marked or prominent, a dramatic change) (3)
 - 1b. On a scale of 1 to 5, please rate the distress you experienced due to this problem
_____ 0 – Not distressing at all
_____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
_____ 2 – Mild (not very distressing, generally easy to cope with) (2)
_____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
_____ 4 – Severe (very distressing, difficult to cope with) (4)
_____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)
2. In the past month, has (patient name) had any hallucinations such as false visions or voices, or does he/she seem to hear or see things that are not present?
_____ Yes (1) – go to #2a
_____ No (2) – go to #3
_____ Don't know/Refused (99) – go to #3
 - 2a. On a scale of 1 to 3, please rate how severe this problem was
_____ 1 – Mild (noticeable, but not a significant change) (1)
_____ 2 – Moderate (significant, but not a dramatic change) (2)
_____ 3 – Severe (very marked or prominent, a dramatic change) (3)
 - 2b. On a scale of 1 to 5, please rate the distress you experienced
_____ 0 – Not distressing at all
_____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
_____ 2 – Mild (not very distressing, generally easy to cope with) (2)
_____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
_____ 4 – Severe (very distressing, difficult to cope with) (4)
_____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

In the past month, has (patient name) been resistive to help from others at times, or hard to handle?

- _____ Yes (1) – go to #3a
- _____ No (2) – go to #4
- _____ Don't know/Refused (99) – go to #4

3a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

3b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

3. In the past month, has (patient name) seemed sad or say that he/she is depressed?

- _____ Yes (1) – go to #4a
- _____ No (2) – go to #5
- _____ Don't know/Refused (99) – go to #5

4a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

4b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

4. In the past month, does (patient name) become upset when he/she is separated from you, have signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

- _____ Yes (1) – go to #5a

- _____ No (2) – go to #6
_____ Don't know/Refused (99) – go to #6

5a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
_____ 2 – Moderate (significant, but not a dramatic change) (2)
_____ 3 – Severe (very marked or prominent, a dramatic change) (3)

5b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
_____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
_____ 2 – Mild (not very distressing, generally easy to cope with) (2)
_____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
_____ 4 – Severe (very distressing, difficult to cope with) (4)
_____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

5. In the past month, does (patient name) appear to feel too good or act excessively happy?

- _____ Yes (1) – go to #6a
_____ No (2) – go to #7
_____ Don't know/Refused (99) – go to #7

6a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
_____ 2 – Moderate (significant, but not a dramatic change) (2)
_____ 3 – Severe (very marked or prominent, a dramatic change) (3)

6b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
_____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
_____ 2 – Mild (not very distressing, generally easy to cope with) (2)
_____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
_____ 4 – Severe (very distressing, difficult to cope with) (4)
_____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

6. In the past month, does (patient name) seem less interested in his/her usual activities or in the activities and plans of others?

- _____ Yes (1) – go to #7a
_____ No (2) – go to #8
_____ Don't know/Refused (99) – go to #8

7a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

7b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

7. In the past month, does (patient name) seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

- _____ Yes (1) – go to #8a
- _____ No (2) – go to #9
- _____ Don't know/Refused (99) – go to #9

8a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

8b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

8. In the past month, has (patient name) been impatient and cranky, or had difficulty coping with delays or difficulty waiting for planned activities?

- _____ Yes (1) – go to #9a
- _____ No (2) – go to #10
- _____ Don't know/Refused (99) – go to #10

9a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

9b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- ☐ 0 – Not distressing at all
- ☐ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- ☐ 2 – Mild (not very distressing, generally easy to cope with) (2)
- ☐ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- ☐ 4 – Severe (very distressing, difficult to cope with) (4)
- ☐ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

9. In the past month, has (patient name) engaged in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

- ☐ Yes (1) – go to #10a
- ☐ No (2) – go to #11
- ☐ Don't know/Refused (99) – go to #11

10a. On a scale of 1 to 3, please rate how severe this problem was

- ☐ 1 – Mild (noticeable, but not a significant change) (1)
- ☐ 2 – Moderate (significant, but not a dramatic change) (2)
- ☐ 3 – Severe (very marked or prominent, a dramatic change) (3)

10b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- ☐ 0 – Not distressing at all
- ☐ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- ☐ 2 – Mild (not very distressing, generally easy to cope with) (2)
- ☐ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- ☐ 4 – Severe (very distressing, difficult to cope with) (4)
- ☐ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

10. In the past month, does (patient name) awaken you during the night, rise too early in the morning, or take excessive naps during the day?

- ☐ Yes (1) – go to #11a
- ☐ No (2) – go to #12
- ☐ Don't know/Refused (99) – go to #12

11a. On a scale of 1 to 3, please rate how severe this problem was

- ☐ 1 – Mild (noticeable, but not a significant change) (1)
- ☐ 2 – Moderate (significant, but not a dramatic change) (2)
- ☐ 3 – Severe (very marked or prominent, a dramatic change) (3)

11b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

11. In the past month, has (patient name) lost or gained weight, or had a change in the type of food he/she likes?

- _____ Yes (1) – go to #12a
- _____ No (2) – go to next page
- _____ Don't know/Refused (99) – go to next page

12a. On a scale of 1 to 3, please rate how severe this problem was

- _____ 1 – Mild (noticeable, but not a significant change) (1)
- _____ 2 – Moderate (significant, but not a dramatic change) (2)
- _____ 3 – Severe (very marked or prominent, a dramatic change) (3)

12b. On a scale of 1 to 5, please rate the distress you experienced due to this problem

- _____ 0 – Not distressing at all
- _____ 1 – Minimal (slightly distressing, not a problem to cope with) (1)
- _____ 2 – Mild (not very distressing, generally easy to cope with) (2)
- _____ 3 – Moderate (fairly distressing, not always easy to cope with) (3)
- _____ 4 – Severe (very distressing, difficult to cope with) (4)
- _____ 5 – Extreme or very severe (extremely distressing, unable to cope with) (5)

MDS-CPS

INTERVIEWER: "Now I am going to ask you some questions about your family member's ability to think and remember clearly."

1. Is (patient name) conscious (awake)?
☐ No (go to next page) (1)
☐ Yes (go to 2) (0)
2. During the past week, how would you describe (patient name)'s ability to remember things after 5 minutes (short term memory)?
☐ No problem with memory (0)
☐ He/she has problems remembering things that happened recently (1)
3. During the past week, how would you describe (patient name)'s ability to remember things from the past?
☐ No problem with memory (0)
☐ He/she has problems remembering things from the past (1)
4. During the past week, which of the following did (patient name) usually remember? (check all that apply)
☐ The current season
☐ Where he/she lived
☐ Names and faces of friends and family members
☐ That he/she is at home
☐ None of the above
5. How would you rate (patient name)'s ability to make decisions regarding tasks of daily life (such as dressing or shopping)?
☐ Not difficult (his/her decisions are consistent and reasonable) (0)
☐ Somewhat difficult (he/she has difficulty making some decisions in new situations only) (1)
☐ Moderately difficult (he/she makes poor decisions, I have to give cues and supervise him/her) (2)
☐ Extremely difficult (he/she never or rarely makes decisions) (3)
6. During the past seven days, did (patient name) have any of the following? (check all that apply)
☐ (Patient name) was less alert or easily distracted
☐ (Patient name) didn't know where he/she was at times
☐ (Patient name) had times when I couldn't understand his/her speech
☐ (Patient name) had times when he/she was restless (such as pacing) or lethargic
☐ (Patient name)'s ability to remember and think clearly changed during the day
☐ None of the above

7. During the past **3 months**, has (patient name)'s ability to think and remember, perform skills, and abilities changed?

_____ He/she hasn't changed in the past 3 months

_____ He/she has gotten better over the past 3 months

_____ He/she has gotten worse over the past 3 months

Involvement with Activities of Daily Living and Instrumental Activities of Daily Living

INTERVIEWER: "Now I'm going to ask you about (patient's name)'s need for assistance with personal care."

A. As a direct results of (patient's name)'s brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with

Note: If person with cancer has never done an activity because of role relationships in family, then score as "independent."

1. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with eating?

Interviewer: This category includes all types of food and liquid taken by mouth. This includes all types of presentation used: tray, finger foods, regardless of whether utensils are needed. This does not include selection or preparation of food.

- _____ Yes (1) (go to 1a)
_____ No, is independent (2) (go to 2)
_____ NA/Refused (99) (go to 2)

1a. Currently, with regard to eating, would you say that (patient's name): (Check one.)

- _____ Needs supervision only (1) (Go to 1b)
_____ Needs some physical help (2) (Go to 1b)
_____ Needs total physical help (3) (Go to 1b)
_____ Receives nutrients intravenously (4) (Go to 2)
_____ NA/Refused (9) (Go to 1) (Go to 2)

1b. If someone helps (patient's name) with eating, who helps: (Check all that apply.)

- _____ You (primary caregiver) (1)
_____ Others Involved (2)
_____ You and others (3)

2. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with bathing?

Interviewer: Does not include washing or drying hair, dressing or undressing

- _____ Yes (1) (go to 2a)
_____ No, is independent (2) (go to 3)
_____ NA/Refused (99) (go to 3)

2a. Currently, with regard to bathing, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 2b)
- ☐ Needs some physical help (2) (Go to 2b)
- ☐ Needs total physical help (3) (Go to 2b)
- ☐ Does not bathe (4) (Go to 3)
- ☐ NA/Refused (9) (Go to 3)

2b. If someone helps (patient's name) with bathing, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

3. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with dressing?

- ☐ Yes (1) (go to 3a)
- ☐ No, is independent (2) (go to 4)
- ☐ NA/Refused (99) (go to 4)

3a. Currently, with regard to dressing, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 3b)
- ☐ Needs some physical help (2) (Go to 3b)
- ☐ Needs total physical help (3) (Go to 3b)
- ☐ Is never dressed (4) (Go to 4)
- ☐ NA/Refused (9) (Go to 4)

3b. If someone helps (patient's name) with dressing, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

4. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with toileting?

Interviewer: This category includes getting to and from toilet (or use of toileting equipment such as bedpan), removal and adjustment of clothing, positioning on toilet, cleaning of body parts, and replacement of clothing.

- ☐ Yes (1) (go to 4a)
- ☐ No, is independent (2) (go to 5)
- ☐ NA/Refused (99) (go to 5)

one

ap

4a. Currently, with regard to toileting, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 4b)
- ☐ Needs some physical help (2) (Go to 4b)
- ☐ Needs total physical help (3) (Go to 4b)
- ☐ NA/Refused (99) (Go to 5)

4b. If someone helps (patient's name) with toileting, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

5. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with walking inside the house?

Interviewer: This category includes all upright movement on foot inside the house. MUST MOVE AT LEAST FIVE FEET. May use cane, walker, crutches, or handrail.

- ☐ Yes (1) (go to 5a)
- ☐ No, is independent (2) (go to 6)
- ☐ NA/Refused (99) (go to 6)

5a. Currently, with regard to walking inside the house, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 5b)
- ☐ Needs some physical help (2) (Go to 5b)
- ☐ Needs total physical help (3) (Go to 5b)
- ☐ Is unable to walk at all (4) (Go to 6)
- ☐ NA/Refused (9) (Go to 6)

5b. If someone helps (patient's name) with walking inside the house, who helps:
(Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

6. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with getting in and out of bed?

- ☐ Yes (1) (go to 6a)
- ☐ No, is independent (2) (go to 7)
- ☐ NA/Refused (99) (go to 7)

6a. Currently, with regard to getting in and out of bed, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 6b)
- ☐ Needs some physical help (2) (Go to 6b)
- ☐ Needs total physical help (3) (Go to 6b)
- ☐ Is completely bed-ridden (4) (Go to 7)
- ☐ NA/Refused (9) (Go to 7)

6b. If someone helps (patient's name) with getting in and out of bed, who helps:
(Check all that apply.)

- ☐ You (primary caregiver (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

7. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with transportation?

- ☐ Yes (1) (go to 7a)
- ☐ No, is independent (2) (go to 8)
- ☐ NA/Refused (99) (go to 8)

7a. Currently, with regard to getting places outside of walking distance, i.e., going to the doctor's, or grocery shopping away from (patient's name)'s neighborhood:

(Check one.)

- ☐ Needs supervision only (1) (Go to 7b)
- ☐ Needs some physical help (2) (Go to 7b)
- ☐ Needs total physical help (3) (Go to 7b)
- ☐ Is entirely unable to walk (4) (Go to 8)
- ☐ NA/Refused (9) (Go to 8)

7b.If someone helps (patient's name) with transportation, who helps: (Check all that apply.)

- ☐ You (primary caregiver (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

8. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with laundry?

- ☐ Yes (1) (go to 8a)
- ☐ No, is independent (2) (go to 9)
- ☐ NA/Refused (99) (go to 9)

8a.Currently, with regard to laundry, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 8b)
- ☐ Needs some physical help (2) (Go to 8b)
- ☐ Needs total physical help (3) (Go to 8b)

- ☐ Has never done laundry (4) (Go to 9)
☐ NA/Refused (9) (Go to 9)

8b.If someone helps (patient's name) with laundry, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
☐ Others Involved (2)
☐ You and others (3)

9. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with shopping?

Interviewer: This category includes all types of purchases.

- ☐ Yes (1) (go to 9a)
☐ No, is independent (2) (go to 10)
☐ NA/Refused (99) (go to 10)

9a.Currently, with regard to shopping, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 9b)
☐ Needs some physical help (2) (Go to 9b)
☐ Needs total physical help (3) (Go to 9b)
☐ Has never done the shopping (4) (Go to 9b)
☐ NA/Refused (9) (Go to 10)

9b.If someone helps (patient's name) with shopping, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
☐ Others Involved (2)
☐ You and others (3)

10. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with housework?

Interviewer: This category includes picking up, dusting, light cleaning, vacuuming, or doing dishes.

- ☐ Yes (1) (go to 10a)
☐ No, is independent (2) (go to 11)
☐ NA/Refused (99) (go to 11)

10a.Currently, with regard to housework, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 10b)

- ☐ Needs some physical help (2) (Go to 10b)
- ☐ Needs total physical help (3) (Go to 10b)
- ☐ Has never done the housework (4) (Go to 11)
- ☐ NA/Refused (9) (Go to 11)

10b. If someone helps (patient's name) with housework, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

11. As a direct result of (patient name's) brain tumor or its treatment (and not as a result of any long standing health problem) does (patient's name) need any assistance with cooking and preparing meals?

- ☐ Yes (1) (go to 12a)
- ☐ No, is independent (2) (go to 13)
- ☐ NA/Refused (99) (go to 13)

11a. Currently, with regard to cooking and preparing meals, would you say that (patient's name): (Check one.)

- ☐ Needs supervision only (1) (Go to 11b)
- ☐ Needs some physical help (2) (Go to 11b)
- ☐ Needs total physical help (3) (Go to 11b)
- ☐ Has never done the cooking (4) (Go to 12)
- ☐ NA/Refused (9) (Go to 12)

11b. If someone helps (patient's name) with cooking and preparing meals, who helps: (Check all that apply.)

- ☐ You (primary caregiver) (1)
- ☐ Others Involved (2)
- ☐ You and others (3)

INTERVIEWER: REVIEW THE AREAS ON PAGE 10 THAT THE PATIENT NEEDS ASSISTANCE WITH.

12. You mentioned that you help patient with (Please include all procedures to which the caregiver made a positive reply). Considering all of these activities where assistance was provided, either directly or indirectly, could you estimate . . .

12a. In the past two weeks, how many hours did you spend assisting (patient's name) altogether? _____ hours _____ minutes (if less than an hour)

12b. In the past two weeks, how many hours did other friends and family members spend assisting (patient's name) altogether?
_____ hours _____ minutes (if less than an hour)

12c. In the past two weeks, how many hours did paid professionals spend assisting (patient's name) altogether? _____ hours _____ minutes (if less than an hour)

Caregiver Experiences

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.”

1. I feel privileged to care for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

2. Others have dumped caring for (patient’s name) onto me.

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

3. **My financial resources are adequate to pay for things that are required for caregiving.

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

4. My activities are centered around care for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

5. Since caring for (patient’s name), it seems like I’m tired all of the time.

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

6. It is very difficult to get help from my family in taking care of (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

7. **I resent having to take care of (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

8. I have to stop in the middle of work to help (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

9. I really want to care for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

10. My health has gotten worse since I’ve been caring for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

11. I visit family and friends less since I’ve been caring for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

12. I will never be able to do enough caregiving to repay (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

13. **My family works together at caring for (patient’s name).

1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

14. I have eliminated things from my schedule since caring for (patient's name).
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
15. I have enough physical strength to care for (patient's name).
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
16. Since caring for (patient's name), I feel my family has abandoned me.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
17. Caring for (patient's name) makes me feel good.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
18. The constant interruptions make it difficult to find time for relaxation.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
19. **I am healthy enough to care for (patient's name).
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
20. Caring for (patient's name) is important to me.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
21. Caring for (patient's name) has put a financial strain on the family.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
22. My family left me alone to care for (patient's name).
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
23. I enjoy caring for (patient's name).
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree
24. It's difficult to pay for (patient's name)'s health needs and services.
1) Strongly disagree 2) Disagree 3) Neither disagree nor agree 4) Agree 5) Strongly agree

Screen for Caregiver Burden

INTERVIEWER: “For each of the following statements, please tell me how much distress the experience or event has caused you. If you have not had the experience, just tell me it did not occur.”

<u>Experience or Event</u>	Did not occur	Occurred, but caused no distress	Mild Distress	Moderate distress	Severe distress
1. (Patient name) continues to drive when he/she shouldn't.					
2. I have little control over (patient name)'s illness.					
3. I have little control over (patient name)'s behavior.					
4. (Patient name) is constantly asking the same questions over and over.					
5. I have to do too many jobs/chores (feeding, shopping) that (patient name) used to do.					
6. I am upset that I can not communicate with (patient name).					
7. I am totally responsible for keeping the household in order.					
8. (Patient name) doesn't cooperate with the rest of our family.					
9. I have had to seek public assistance to pay for (patient name)'s medical bills.					
10. Seeking public assistance is demeaning and degrading.					
11. (Patient name) doesn't recognize me all the time.					
12. (Patient name) has struck me on various occasions.					
13. (Patient name) has gotten lost in the store.					
14. (Patient name) has been wetting the bed.					
15. (Patient name) throws fits and has threatened me.					
16. I have to constantly clean up after (patient name) eats.					
17. I have to cover up for (patient name)'s mistakes.					
18. I am fearful when (patient name) gets angry.					

19. It is exhausting having to groom and dress (patient name) every day.					
20. I try so hard to help (patient name), but he/she is ungrateful.					
21. It is frustrating to find things that (patient name) hides.					
22. I worry that (patient name) will leave the house and get lost.					
23. (Patient name) has assaulted others in addition to me.					
24. I feel so alone – as if I have the world on my shoulders.					
25. I am embarrassed to take (patient name) out for fear he/she will do something bad.					

CES-D

INTERVIEWER: "These questions are about how you feel and how things have been with you within the past month. Please note the answer that comes closest to the way you have been feeling during the past month. The answer choices are 'almost all of the time,' 'most of the time,' 'some of the time,' and 'rarely or none of the time.'"

	3	2	1	0
Almost all of the time	Most of the time	Some of the time	Rarely/None of the time	of the time
During the <u>past month</u> , how much of the time:				
1. Were you bothered by things that usually _____ don't bother you?		_____	_____	_____
2. Have you not felt like eating; had a poor _____ appetite?		_____	_____	_____
3. Have you felt that you could not shake off _____ the blues, even with the help of family or friends?		_____	_____	_____
4. Have you felt that you were just as good as _____ other people?		_____	_____	_____
5. Have you had trouble keeping your mind _____ on what you were doing?		_____	_____	_____
6. Have you felt depressed? _____		_____	_____	_____
7. Have you felt that everything you did was _____ an effort?		_____	_____	_____
8. Have you felt hopeful about the future? _____		_____	_____	_____
9. Have you thought your life has been a _____ failure?		_____	_____	_____
10. Have you felt fearful? _____		_____	_____	_____
11. Has your sleep been restless? _____		_____	_____	_____

- | | | | |
|---|-------|-------|-------|
| 12. Were you happy? | _____ | _____ | _____ |
| _____ | | | |
| 13. Have you talked less than usual? | _____ | _____ | _____ |
| _____ | | | |
| 14. Have you felt lonely? | _____ | _____ | _____ |
| _____ | | | |
| 15. Were people unfriendly? | _____ | _____ | _____ |
| _____ | | | |
| 16. Have you enjoyed life? | _____ | _____ | _____ |
| _____ | | | |
| 17. Have you had crying spells? | _____ | _____ | _____ |
| _____ | | | |
| 18. Have you felt sad? | _____ | _____ | _____ |
| _____ | | | |
| 19. Have you felt that people disliked you? | _____ | _____ | _____ |
| _____ | | | |
| 20. Could you not get “going”? | _____ | _____ | _____ |
| _____ | | | |

Mastery Scale

Please answer the questions below by placing a check mark next to your response:

1. You are usually certain about what to do in caring for (patient's name).
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
2. No matter what you do as a caregiver it never seems to be enough.
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
3. In general, you are able to handle most problems in the care of (patient's name).
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
4. You are not doing as well as you would like as a caregiver.
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
5. You feel that you have a great deal of influence over the things that happen in caregiving.
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
6. You have lost some control of your life since (patient's name)'s illness.
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____
7. You believe you are mastering most of the challenges in caregiving.
Strongly agree _____ Disagree _____
Agree _____ Strongly disagree _____
No opinion _____

Interview Closing Statement

Is there anything else that you would like to share about your experience in providing care for (patient name)?

Great! Thanks for your participation. If you have any questions, please feel free to call Paula Riess, Principal Investigator toll-free at (866) 855-0941 or Dr. Barbara Given (toll free in Michigan) at (888) 353-0306. Again, thank you for your time, we really appreciate it.

Time interview completed: _____

Date interview completed: _____

Interviewer initials: _____

Appendix B

In order to understand the needs and feelings of people who care for persons with a brain tumor, we are conducting a one time, 45 minute telephone interview with caregivers of persons with a brain tumor. All information is confidential and there is no financial cost to you.

Who are we?

Paula Riess, RN, MSN, CNRN, Doctoral student in Nursing at Michigan State University, *in collaboration with*
Michigan State University, College of Nursing
Michigan Department of Community Health
National Brain Tumor Foundation
Hermelin Brain Tumor Center, Henry Ford Health System

We will be asking about:

- What kinds of care activities you do
- What problems are most common and may be hard to handle
- What changes you have made in your life since you became a caregiver

You are invited to participate if you:

- Provide day to day care for someone with a brain tumor
- Are over 21 years old, and
- Have regular access to a telephone

Please call our project toll-free at 1-866-855-0941 or email us at paula.riess@ht.msu.edu.
The information you provide will help us meet the needs of future caregivers.

Support for the study provided by a Neuroscience Nursing Research Grant from the Oncology Nursing Society Foundation and the American Brain Tumor Association, National Institute for Nursing Research/National Institutes of Health, American Cancer Society, Sigma Theta Tau – Alpha Psi chapter, Michigan State University College of Nursing. In collaboration with the Behavioral Cooperative Oncology Group-Mary Margaret Walther Cancer Program of the Walther Cancer Institute.

Appendix C

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Appendix D

“Family Care of Persons with a Brain Tumor”

Conducted in affiliation with the Mary Margaret Walther Program/Walther Cancer Institute,
National Institute for Nursing Research/National Institutes of Health, Sigma Theta Tau – Alpha
Psi Chapter, Michigan State University College of Nursing, American Cancer Society, Oncology
Nursing Society Foundation, and the American Brain Tumor Association
Screening Enrollment Information

Recruitment Site: *(Please specify)*

Pt. Date of Birth: ____ / ____ / ____ (21 yrs. or older) **Pt. Gender:** M F

Pt. Race: *(circle one)* African American Caucasian Asian American Hispanic Native
American

Type of brain tumor (indicate grade if astro): *(write in)*

Location of tumor (lobe): *(write in)* _____ Side (left
vs. right) _____

Date of First Dx: *(write in)* ____ / ____ / ____

Previous Dx for Current Cancer Site?: Yes No **If Yes, Date of Previous Dx:**
____ / ____ / ____

Has the patient undergone surgical resection? Yes No

If Yes, dates of surgical resection: ____ / ____ / ____ ____ / ____ / ____
____ / ____ / ____

Has the patient undergone stereotactic biopsy? Yes No **If Yes, date of biopsy:**
____ / ____ / ____

If Yes, dates of surgical resection: ____ / ____ / ____ ____ / ____ / ____
____ / ____ / ____

Has patient received chemotherapy? Yes No **If Yes, dates of chemo:**
____ / ____ / ____ ____ / ____ / ____

Has patient received radiation therapy? Yes No **If Yes, dates of RT:** ____ / ____ / ____
____ / ____ / ____

Has patient receiving seed implants? Yes No **If Yes, dates of chemo:**
____ / ____ / ____ ____ / ____ / ____

Is patient on a clinical trial? Yes No **If Yes, please specify:**

Patient willing to consent? Yes No **Date consent signed:** ____/____/____

Reason refused: Too busy Not interested Too ill

Overwhelmed

Already participating in a study Other (*write in*)

Caregiver Date of Birth: ____ / ____ / ____ (21 yrs. or older) **Caregiver Gender:**

M F

Caregiver Race: (*circle one*) African American Caucasian Asian American Hispanic
Native American

Caregiver willing to consent?: Yes No **Date consent signed:** ____/____/____

Caregiver reason refused: Too busy Not interested Overwhelmed

Too ill

Other: (specify)

If Patient or Caregiver refuse to consent, STOP here

Recruiter Signature: _____

Date:

____/____/____

Notes:

*Caregiver is defined as an adult (over 21 years of age) who is identified by both the patient and themselves as someone willing to assist the patient, either voluntarily or upon request of the patient for a range of care tasks, i.e., catheter care, dressings, and feedings.

*Patients on other clinical trials, including those on investigational drugs **are** eligible.

*Patients with “benign” tumors (i.e. benign meningiomas) or metastatic tumors are **NOT** eligible.

Appendix E

Recruiter Manual

Family Care of Persons with a Brain Tumor

Conducted in affiliation with the Walther Cancer Institute, Indianapolis, Indiana, National Institute for Nursing Research/National Institutes of Health, the American Cancer Society, Sigma Theta Tau – Alpha Psi Chapter, Michigan State University College of Nursing, the Oncology Nursing Society Foundation, and the American Brain Tumor Association

Recruiter Manual

Principal Investigators:

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A collaborative effort involving Michigan State University College of Nursing, Michigan Department of Community Health, Henry Ford Hospital Hermelin Brain Tumor Center, and the National Brain Tumor Foundation.

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Family Care of Persons with a Brain Tumor

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National Brain Tumor Foundation

Name	Email
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Project Information: Introduction, Hypotheses, Outcomes

The goals of this cross-sectional descriptive study are to determine 1) the effect of the patient's functional, cognitive, and neuropsychiatric status on the burden and depression of a caregiver of a person with a primary malignant brain tumor, and 2) the moderating effect of perceived adequacy of information to care and mastery on the burden and depression of a caregiver of a person with a primary malignant brain tumor.

Primary Hypothesis

Is there an association between the patient's functional status, cognitive status, and neuropsychiatric status and:

1. Level of perceived burden reported by the caregiver
2. Level of perceived depression reported by the caregiver

Secondary Hypothesis

Does the caregiver's level of perceived adequacy of information to care and the caregiver's level of mastery moderate the relationship between the patient's functional status, cognitive status, and neuropsychiatric status and:

1. Level of perceived burden reported by the caregiver
2. Level of perceived depression reported by the caregiver

Executive Summary

The following is an executive summary for the project titled “Family Care for Brain Tumor Patients” conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, American Brain Tumor Association, Barbara A. Given, RN, PhD, FAAN, Principal Investigator; and Paula R. Sherwood, RN, MSN, CNRN Co-Principal Investigator. This research project is a collaborative effort involving Michigan State University College of Nursing, the Michigan Department of Community Health, the National Brain Tumor Association, the American Brain Tumor Association, and the Henry Ford Hospital Hermelin Brain Tumor Center.

BACKGROUND

Changes in health care reimbursement often make family members responsible for providing care, even though they may be ill prepared to deliver this care. Researchers have documented the effects of providing care for a person with a terminal illness such as cancer and for a person with cognitive and behavioral decline such as the dementia patient. However, there have been minimal efforts to describe the impact of providing care for persons who suffer from both a terminal trajectory of illness and a deterioration in cognitive status.

To better understand the issues faced by caregivers of persons with a primary malignant brain tumor, we will be conducting a descriptive study involving a 45-60 minute telephone interview with caregivers. Caregivers will be asked questions regarding the patient’s disease and treatment, the patient’s functional, cognitive, and neuropsychiatric status, and the caregiver’s level of perceived adequacy of information to care, mastery, burden, and depression.

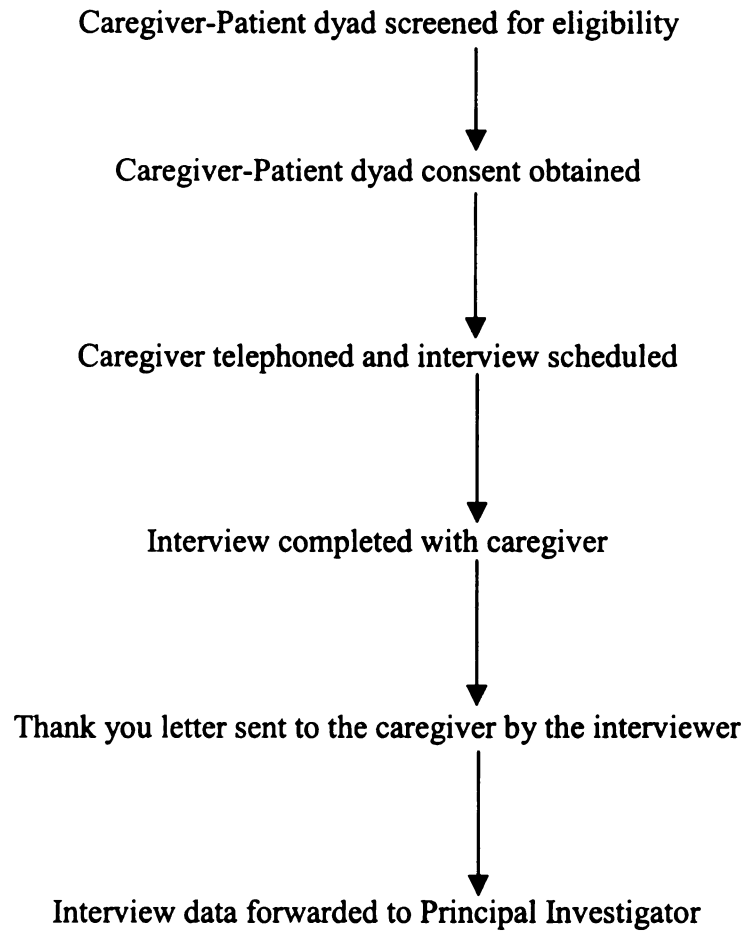
The goal of the project is to determine the effect of the patient’s functional, cognitive, and neuropsychiatric status on the caregiver’s level of burden and depression and to determine if the caregiver’s level of perceived adequacy of information to care and mastery moderates this effect. Persons who undergo specialized training in conducting interviews with caregivers of cancer patients will be interviewing caregivers regarding their feelings and concerns about delivering care to someone with a primary malignant brain tumor.

This descriptive study will involve family caregivers over the age of 21 who are providing care for a person over the age of 21 with a primary malignant brain tumor. Because information will be gathered regarding the patient’s medical condition, both the patient and caregiver must consent to participate in the study. However, only the caregiver will be interviewed. If the patient is unable to give consent, the legally authorized representative will be approached for consent. In addition, it is not a requirement for the study that the caregiver be legally related to the care recipient, or that they reside in the same domicile. Family caregivers will be designated as those who provide daily or weekly assistance to the care recipient without financial reimbursement

from a third party. Eligibility criteria also dictate that the caregiver be able to read and speak the English language and have regular and reliable access to a telephone.

Caregivers who consent to participate will be contacted to set up a 45-60 minute interview. If the caregiver chooses not to complete the interview after having given consent, they will be dropped from the study. In addition, if the caregiver becomes distressed during the interview, they will be given the option of completing a shorter interview, completing the remainder of the interview within 4 days, or attriting from the study.

Study Protocol



Recruiter Job Description

Your Role on the Project

As a recruiter you will represent the project, Michigan State University, Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, and the American Brain Tumor Association. It is important that you conduct yourself in a professional, courteous manner.

Diagnosis and treatment of a brain tumor can be very stressful. Caregivers and patients may be experiencing many emotional ups and downs. You must be sensitive to their emotional turmoil regardless of their response to you. Remember that participation is voluntary and it is possible that your contact could play a pivotal role in a person's decision to participate in the study.

You will be responsible for identifying eligible participants each week. You will be responsible for contacting the patient and their family caregiver to explain the project, answer questions, and leave the appropriate project materials. You will be responsible for follow-up telephone calls, and if necessary, to obtain consent if they decide to participate. You must be sure they understand expectations of the study.

SPECIFIC EXPECTATIONS

1. You must familiarize yourself with the project objectives, purpose and goals so that you can clearly articulate this information to staff, physicians, patients and their family members. It is imperative that patients and their family members understand what they have agreed to, regarding participation.
2. You must develop relationships to work with nursing and administrative staff in order to identify eligible patients. There are few opportunities to approach the patient in person. Good working relationships with scheduling staff will be imperative.
3. Follow recruitment and enrollment protocols. Any deviations from protocol must be discussed with the Principal Investigator at MSU.
4. Develop a process to track dyads during the enrollment period.
5. You must complete an enrollment form for each eligible dyad and follow-up with patients and their family caregivers until each enrollment is brought to closure, i.e., agreed to participate, declined to participate. If dyad agrees to participate, **ENROLLMENT IS NOT COMPLETED UNTIL BOTH CONSENT FORMS HAVE BEEN RECEIVED.** All patient and family caregiver information must be stored in a confidential, secure location at all times.
6. You will keep the Principal Investigator informed of your activities and progress each week by email by 5pm on Friday. You must notify the Principal Investigator immediately when problems are encountered.
8. You must follow the project procedures as outlined in the recruiter manual.

Violation of these procedures is grounds for dismissal.

Agreement and Understanding of the Job Duties to be Performed by the Recruiter:

I agree to meet the standards of the protocol by:

- 1. Accurately describing the study to patients and their family members, answering their questions and ensuring they understand what will be expected of them if they choose to participate.**
- 2. Following the protocol for identification and recruitment of dyads.**
- 3. Accurately completing “screening/enrollment forms” and faxing/mailing to the PI on a timely basis.**
- 4. Keeping the Principal Investigator informed of my progress and any difficulties via a weekly e-mail report by Friday at 5:00pm.**

I understand that if I fail to meet these standards, including failure to follow the protocol, termination from this position may occur.

Date:

(Recruiter Signature)

Eligibility Criteria

Caregivers are eligible for this study if they:

- 1) Are 21 years of age or older
- 2) Are providing care for someone who is 21 years of age or older
- 3) Have a family member with a primary malignant brain tumor who agrees to participate in the study
- 4) Regularly perform tasks on behalf of someone with a primary malignant brain tumor
- 5) Are not receiving financial reimbursement from a third party for providing care
- 6) Have regular and reliable access to a telephone
- 7) Are able to answer questions – are alert and cognitively intact
- 8) Speak and understand the English language

These criteria are to be determined, if at all possible, prior to approaching the patient and/or family member for recruitment.

**** It is not a requirement of the study that the caregiver be legally related to the patient or that the caregiver reside with the patient.**

Screening – Where/How to Identify Eligible Patients

Henry Ford Hospital Hermelin Brain Tumor Center

The recruiter will identify potential participants through the neurosurgery, neurology, and neuro-oncology clinics by reviewing inclusion/exclusion criteria for participants and clinic appointment rosters with the clinic nurses each week. Once potential participants have been identified, the recruiter will verify eligibility by reviewing the patient's medical record. Once the recruiter has determined eligibility, he/she will approach patients with a primary malignant brain tumor who have a designated caregiver, provide the dyad with a study brochure and describe the study to the dyad. If the caregiver and patient agree to participate in the study, they will be asked to sign the consent forms. If the caregiver and patient wish not to participate in the study, the recruiter will thank them for their time.

If the caregiver and patient wish to further consider participation in the study, the recruiter will provide them with telephone numbers for the recruiter and Principal Investigator, in the event that they have questions or concerns. The recruiter will call the dyad in one week following contact in the brain tumor center and ask if they have considered participation. If the dyad indicates a desire to participate, the consent forms will be mailed to the dyad, along with a self-addressed stamped envelope. Follow up phone calls will be made if signed consent forms are not received within 2 weeks. If the dyad does not wish to participate, the recruiter will thank the dyad for their time and end the call. If the dyad would like more time to consider participation in the study, the recruiter and dyad will determine a time to re-contact the dyad. In the event that the recruiter is unable to reach the dyad by phone, the recruiter will attempt to make contact a total of 3 times. If there is still no response, the recruiter will send the dyad a letter thanking them for considering the study and asking them to contact the recruiter if they wish to participate. The recruiter will mail signed consent forms to the investigator within one week of obtaining the consent.

Approaching the Patient

The Screening/Enrollment Form should be completed while determining eligibility of the caregiver and patient via review of patient's record.

All patient information is confidential. Refer to "Policies & Procedures: Confidentiality of Project Participants."

When approaching dyads, be positive, friendly, sincere, honest and observant. Discussions should be held when people are attentive; not when they are easily distracted or tired. If you question the patient or caregiver's orientation, do not obtain consent until you have confirmed their competence and ability to report information accurately.

In the first meeting, introduce yourself. Ask if you could have a few minutes to discuss the project with them. If this time does not appear to be the best, then leave our brochure with them and tell them you will contact them later to go over any questions they may have.

When you describe the project to the patient and family member, be short and concise and tell them you want to give them an opportunity to participate. Be sure to share the following information:

- The goal of this research is to identify some of the challenges that are faced by caregivers of persons with a primary malignant brain tumor, and how those challenges affect the caregiver:
- This information will be used to improve and implement continuing care for caregivers of persons with brain tumors, although it may not benefit them directly at this time.
- The data from the study will help medical providers develop better cancer care plans for patients and families.
- This project involves 1 telephone interview, which will last about 45-60 minutes. The caregiver may be contacted at an additional time if any information they provided needs to be clarified.
- Participating in this project is voluntary and will not affect their doctor's treatment plan or any care they are now receiving. All information received is confidential.
- Ask if there are any questions.
- Then ask if they would be interested in helping us by consenting to be part of the project. If patients or family members say they might not be able to answer questions assure them this is not a test of right or wrong but how they feel.

POSSIBLE RESPONSES

Personal Contact

EITHER THE CAREGIVER OR THE PATIENT STATES NO -- Thank them for their time. Both the caregiver and patient must agree to participate in order for the caregiver to be interviewed. Include number of people who refuse and their reason in your weekly report.

DYAD IS UNDECIDED OR HESITANT -- Ask whether they have any questions. Make certain they have a copy of the brochure. Point to the toll-free number and tell them to call should they have any questions. Tell them you would like to call them at home in a few days to see if they would like to participate. Ask if it would be okay to do so.

DYAD STATES YES -- Thank them. Have them read over the consent form as you explain it and answer any questions they may have. Have them sign the consent form. Update the Screening/Enrollment Form.

Phone Contact

If you have spoken with the patient and given them the recruitment folder but did not get consent; contact will need to be made by phone and mail. When calling, introduce yourself. Ask them if they have ten minutes to talk to you about this project.

IF BUSY -- Arrange for a date and time to call them back.

If YES -- Give a brief overview of the project. Offer answers to questions. Ask if they have read the material you provided and remind them that there is no cost to them. We want to learn about how the challenges of providing care for a person with a brain tumor affect his/her caregiver. Ask if they would be interested in helping the project by participating.

- a. Caregiver and Patient Agree to Participate -- Ask whether they still have the consent forms and could sign them and send them back. If the dyad has misplaced the consent form, state that you are sending another copy of the consent forms and a self-addressed, postage paid envelope, ask them to sign and send back as quickly as possible. Obtain information to contact the family member.
- b. Caregiver and Patient are Undecided -- State that you would like to call again in a few days to answer any questions and get their answer. Thank them for their time.
- c. Caregiver and/or Patient Refuses -- Say thank you and tell them if they change their mind they may call the toll free number. Include in your weekly report how many people refuse and their reason.

Obtaining Medical Information

Upon receipt of the signed consent form from the patient, the “medical record information” section of the Screening/Enrollment Form should be completed. This information should be obtained from the patient’s medical chart.

The Screening/Enrollment Form should be submitted to the Paula Sherwood along with signed consent forms for the patient and family member as soon as the consent forms are received. It is possible that you may have all portions of the Screening/Enrollment Form completed except the medical information you need to obtain from the patient’s medical chart. If this occurs, please make a copy for yourself and submit the original Screening/Enrollment Form along with the signed consents to Paula Sherwood so the dyad can be contacted for interviews. When medical information is complete, submit a copy of the Screening/Enrollment Form that is clearly marked “copy” with the patient’s medical information to Paula Sherwood.

Approaching the Family Member

Family member is Present when Patient Approached -- Consent should be obtained at the same time patient's consent is obtained, follow the same procedures as for the patient.

Family member is not Present -- You should ask the patient for the name of their family member. If the patient does not live with their family member, ask for the address and phone number in addition to the name along with a good time to contact their family member.

The "Family member Information" questions on the Screening/Enrollment Form should be completed at this time.

Please contact the family member within two days of obtaining the information from the patient. When you contact the family member, introduce yourself. Inform them that the patient has agreed to participate in the project. Ask if you could have a few minutes to discuss this project with them.

Again, when you describe the project to the family member be brief and concise and tell them you want to give them an opportunity to participate:

- The goal of this research is to identify some of the challenges that are faced by caregivers of persons with a primary malignant brain tumor, and how those challenges affect the caregiver:
- This information will be used to improve and implement continuing care for caregivers of persons with brain tumors, although it may not benefit them directly at this time.
- The data from the study will help medical providers develop better cancer care plans for patients and families.
- This project involves 1 telephone interview, which will last about 45-60 minutes. The caregiver may be contacted at an additional time if any information they provided needs to be clarified.
- Participating in this project is voluntary and will not affect their doctor's treatment plan or any care they are now receiving. All information received is confidential.
- Ask if there are any questions.
- Then ask if they would be interested in helping us by consenting to be part of the project. If patients or family members say they might not be able to answer questions assure them this is not a test of right or wrong but how they feel.
- The patient's participation in this study is only to give consent so that the caregiver can answer questions regarding the patient's diagnosis and treatment. The patient will not be contacted or participate in any portion of the interview.

POSSIBLE RESPONSES:

IF BUSY – Arrange for a date and time to call them back.

IF YES – State that the patient has agreed to participate in this project. Ask if they are aware of the project. If no, explain the project as you did to the patient. Ask if they would like to participate.

- a. Caregiver agrees to participate – If they received a copy of the consent form from the patient, ask whether they have the consent form and could sign it and send it back. If they have not received a copy of the consent form, offer to mail them one that they need to sign and send back as quickly as possible.**
- b. Caregiver is undecided – Ask whether they have any questions. Tell them you would like to call them at home in a few days to see if they would like to participate. Ask if it would be okay to do so.**
- c. Caregiver refuses – Thank them for their time. If the patient has already consented, indicate to the patient that he/she will not be able to participate.**

Appendix F

Policy and Procedure Manual

Family Care of Persons with a Brain Tumor

Conducted in affiliation with the Walther Cancer Institute, Indianapolis, Indiana, National Institute for Nursing Research/National Institutes of Health, the American Cancer Society, Sigma Theta Tau – Alpha Psi Chapter, Michigan State University College of Nursing, the Oncology Nursing Society Foundation, and the American Brain Tumor Association

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A collaborative effort involving Michigan State University College of Nursing, Michigan Department of Community Health, Henry Ford Hospital Hermelin Brain Tumor Center, and the National Brain Tumor Foundation.

Section I: General Policies and Procedures

SUBJECT:

Confidentiality of Project Participants

POLICY:

All participants will be afforded maximum confidentiality regarding their participation in the project. The health or emotional status of the caregiver is not to be disclosed to anyone by any project staff member.

PROCEDURE:

1. Completed screening enrollment forms and signed consents will be faxed to Paula Sherwood **fax: (517) 353-8612**. All faxes are to have a cover sheet that contains a confidentiality statement.
2. Any and all email exchanges about any project participant **must not** include the participant's name. Participant's are to be identified only by their case ID number (e.g. HB001).
3. When telephoning participants at home or work, do not assume that the caregiver has shared with any person that he/she is providing care for someone with a brain tumor. Identify yourself by name, and state "I am calling on behalf of the Family Care Project from Michigan State University. May I speak with _____".
4. If the project participant is not at home (or work), leave the following message, either with a person, or on an answering machine/voice mail: "This is _____ calling on behalf of the Family Care Project from Michigan State University. I am trying to reach (state participant's name) and may be reached at _____ (leave your work telephone number and days and times in which you are available to receive their return call).
5. Do not telephone participants at their work site unless they have explicitly identified this as an option for contacting them.
6. Project staff members are **not** to enter into any discussions regarding any participant outside of the project area.
7. Project staff members are **not** to enter into any discussions regarding any participants with anyone except for Paula Sherwood or Barbara Given.
8. Verbalization of the caregiver's information will be shared only with those participating in their care and with the consent of the caregiver.

Patient and caregiver information that includes identifiers will be shared only with those individuals who are directly involved in the project (PIs, Co-I, Interviewer), or when the patient/caregiver has given express written permission for such disclosure.

SUBJECT:

Suicidal and Emotionally Distressed Participants

POLICY:

To provide suicidal and emotionally distressed participants with emergency contact telephone numbers to Community Mental Health or other crisis centers.

PROCEDURE:

1. **In the event that a participant reports to a project employee thoughts of suicide, or is emotionally distraught (uncontrollable sobbing), the project employee is to provide to the participant the telephone number to his/her local Community Mental Health Center, crisis hotline or the caregiver's physician's office. Help them find the phone number and encourage them to call as soon as possible.**
2. **The project employee must notify Paula Sherwood via email that day (if participant reports mental distress during routine business hours) or on the next business day, of the name of the participant and case ID number.**
3. **Paula Sherwood is to ensure that participants are followed up and that some arrangements for assistance have been made.**
4. **Paula Sherwood is to inform Barbara Given at MSU of the situation and the resolution of the situation so records regarding how the situation was handled can be documented for permanent records.**
5. **The interviewer must document in the permanent record the information that was given, and the date and time the information was received. Notes require explicit detail on your conversation and action taken. This is for your legal protection. All advice or suspicious situations should be followed up and documented.**

Section II: Recruitment Policies and Procedures

SUBJECT:**Consent Forms****POLICY:**

A consent form for each patient **AND** caregiver must be kept on file at the respective treatment site and at Michigan State University (MSU).

PROCEDURE:

1. The recruiter will obtain patient and caregiver consent.
2. The recruiter will fax both signed consents and the screening enrollment form to Paula Sherwood at MSU, **fax: (517) 353-8612**. The recruiter will notify Paula Sherwood via electronic mail (paula.riess@ht.msu.edu) that the screening enrollment and consent forms have been faxed.
3. Paula Sherwood will review the screening enrollment form to ensure that the caregiver is eligible to participate, and review the consents to ensure that they have been completed correctly.
4. At the completion of the project, all original signed consent forms stored at the affiliate sites will be forwarded to MSU for storage.

SUBJECT:**Caregiver Eligibility to Participate in Research Protocol****POLICY:**

Caregivers who are: 1) at least 21 years of age; 2) providing care for someone with a primary malignant brain tumor who is also at least 21 years of age, 3) able to read and speak the English language, and 4) have regular and reliable access to a telephone are eligible to participate in this project. Because information regarding the patient's disease and treatment will be collected, both the caregiver and patient must agree to participate in the study. HOWEVER, only the caregiver will be interviewed. If the patient is cognitively impaired and unable to give consent, the patient's legally authorized representative will be contacted in regards to the patient's consent.

PROCEDURE:

- 1. Recruiters will pre-screen patients with a brain tumor who present to treatment clinics for therapy to determine eligibility to participate.**
2. Recruiters will determine caregivers' ability to speak and understand the English language and hear conversational speech.
 - a. Caregivers who do not speak/understand the English language, or who have hearing deficits that will preclude them from participating in the telephone interviews are ineligible for the project.
 - b. Caregivers who do not have a phone will be ineligible to participate.
3. The recruiter will discuss with caregivers, who are eligible to participate in the project and what their level of participation will be:
 - A. Caregivers will be asked to complete a one-time 45-60 minute telephone interview.

If the caregiver or patient decides to cease participation, both patient and caregiver will be dropped from the project.

Section III: Interviewing Policies and Procedures

SUBJECT:

Attrition: Caregiver Refusal to Continue with Interview

POLICY:

Subjects can choose to withdraw or refuse continued participation two ways: 1) they can telephone the MSU Research office toll free, or b) they can withdraw or refuse to complete when the interviewer calls to complete the interview.

Both the patient and caregiver must give consent for the study, however, only the caregiver will be interviewed. If the patient decides to attrit from the project, then both the patient and caregiver will be discharged from the project.

PROCEDURE:

If you answer the toll free line and a subject is calling to quit participation, please do the following:

1. Ask their name and spell it out, first and last, ask for their phone number.
2. Ask if they know whom they've been talking with (the interviewer) or who signed the letter if they got one. (If they do not know their interviewer, take down their information and give the message to Paula Sherwood.)
3. Tell them that the interviewer (use their name) will call them back, end conversation.
4. Leave the message for the interviewer in their mailbox AND also telephone the interviewer at home to leave the message or leave them an email with the message. This message is of utmost importance. The message should say: "Urgent, Case # wants to quit, please call subject. They called at (time and date)". **Do not include the subjects name if leaving a telephone message or email – only the ID#.**
5. Inform the Principal Investigator by leaving a note in her mailbox or sending an e-mail.

The interviewer should then take the following steps:

6. Telephone the subject and explain to them how sorry you are that they cannot further participate.
7. Find out the reason for their decline in participation (i.e., too sick, family situations, moving, angry, does not feel it is relevant to personal situation). If they are too ill or too busy, ask the caregiver to consider other options, including a shortened version of the interview. If they still refuse, express our appreciation for sharing experiences thus far and complete and turn in a Change of Status form to the Project Secretary.

8. Explain to them that you hope it was nothing regarding the interview itself. If it was the interview then apologize and ask them if you could take a couple minutes of their time and write down what they felt was uncomfortable or did not apply to them.
 - a. Ask them if they would like to speak to the Paula Sherwood or Barbara Given about any concerns they may have. If so, please get this information to Paula and Barbara immediately. If they do not wish any further contact, furnish them again with our toll free number in case they have any concerns at a future date.
 - b. Withdrawals after initial participation should receive the appropriate **“Quit Participation” Letters.**

The interviewer should follow steps 7 – 8 above if a subject informs them that they no longer want to participate at the time they telephone to schedule, begin or complete an interview, or if they send a letter saying they want to quit.

SUBJECT:**Interrupted/Incomplete Telephone Interviews****POLICY:**

If unusual telephone interviewing circumstances, such as interruptions in the subject's environment or if the subject becomes too fatigued to continue are encountered, the interview can be split into two or more sessions. The interviewer must schedule another phone appointment before ending the conversation and hanging up the phone.

PROCEDURE:

1. The following contingency plan is to be used for unusual telephone interviewing circumstances, such as if interruptions in the subject's environment or if the subject becomes too fatigued to continue. **Schedule another phone appointment before you end the conversation and hang up the phone.**

Unavoidable Interruptions During the Interview:

- a. If the subject is willing, call back as soon as possible (you should have this scheduled already; time limit: 7 days), and restart from the previous 2-3 questions and then move on.

- b. Explanation for going over old information:

"I know you have already given me some of this information, but in order to be sure our data is accurate, I will have to repeat some of the questions."

- c. Make appropriate notes of the situation in your Field Notes.

Incomplete Interview Because of Refusal (or Inability) to Answer Some of the Questions:

- a. Record pertinent information on the Field Notes. (i.e., subject does not meet the criteria for inclusion).
- b. If subject refuses to answer some items, complete remainder of questions and note on Field Notes.

If the participant completes the interview by telephone, the following letter should be sent.

CAREGIVER THANK YOU LETTER

Today's Date

Participant's name

Address

City, State ZIP

Dear _____,

Thank you for your time and interest in participating in the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University. We respect and value the information you recently shared with us in the telephone interview. Your responses are important in helping us understand the experiences caregivers of persons with a brain tumor.

Please know your answers will be kept confidential and will not be linked to you as an individual. If you have questions or comments concerning this project and your role as a participant, we encourage you to call a member of the project staff at (517) 353-0306, or toll free, 1-888-353-0306 between 9:00 a.m. and 5:00 p.m., Monday through Friday. You may leave a message at any time.

We appreciate your willingness to participate in this project. Thank you again for your time!

Sincerely,

(Interviewer Name)

Research Assistant

SUBJECT:

Participant Reluctance to Complete an Interview

POLICY:

Participants who express reluctance to complete a scheduled interview will have concerns addressed by Paula Sherwood and alternatives offered to them in response to their needs.

PROCEDURE:

1. Interviewer phones participant to schedule the interview.
2. **Participant indicates that he/she is unable or unwilling to complete interview (too ill, too busy, not interested at this time). The interviewer will offer the caregiver the option of completing a shortened interview on the phone or completing the remainder of the interview within 7 days.**
3. If the participant sounds weak, appears to be having difficulty breathing (loud, labored breathing), or sounds upset/frustrated, the interviewer is to immediately ask the participant how they are feeling and if they would like to stop or complete a shortened interview.
4. Remind the subject that **ALL** information is confidential and will never be linked with them or their families.
5. **If participant continues to express reluctance to continue, interviewer takes notes on what participant says, and forwards these notes to Paula Sherwood via email or via telephone along with all pertinent information (case ID number, contents of interaction between the participant and the interviewer) regarding the special circumstance.**

- 6. All notes regarding reluctant or too ill participants will be reviewed by Paula Sherwood, who will follow-up with the specific interviewer to clarify what occurred (e.g. whether the participant seemed angry versus overwhelmed) during the telephone conversation.**
- 7. Paula Sherwood will contact the participant to encourage continued participation in the project.**
- 8. Paula Sherwood will notify the MSU interviewer of the results of that conversation.**
- 9. The MSU interviewer will implement the established plan.**
- 10. If the participant decides to drop from the project, the interviewer will complete the change of status form and mail appropriate quit letter to the caregiver.**

SUBJECT:

Placing Calls to Schedule/Conduct an Interview

POLICY:

No more than one message should be left for subject in a single day. Messages should not be left for subject two days in a row. No more than two messages should be left (over at least three days) before checking on subject's health.

PROCEDURE:

1. The interviewer will check page two of the Screening Enrollment Form to see if the caregiver noted a specific time they wish to be called. Details reflecting best time to call will also be noted on the Field Notes form. Interviewers must respect subject's requests and place calls only during specified times.
2. If direct contact is not established upon an interviewer's first attempt to reach the caregiver, a message should be left, if possible. The interviewer should attempt contact again the following day but should not leave a message two days in a row if the caregiver is still not available. The interviewer should attempt to reach the caregiver again on the third day and leave another message if contact is not successfully made. The interviewer should then notify Paula Sherwood so that one of these individuals can contact the site to inquire on the patient's health.
3. If a participant has privacy manager and the call is not picked up, please send the "Privacy Manager – We're Trying to Reach You" letter. Continue trying one time per day for one week and alert Paula Sherwood if you are still unable to reach.
4. Messages left for the caregiver should always include the toll free number as the return call telephone number (888) 353-0306. Messages from patients/caregivers will be left on the interviewer's home answering machine as well as the interviewer's e-mail. The interviewer's message to the patient should indicate what times they will be available to complete the interview, that they work part-time, and that the patient/caregiver should call our office and leave a message for them if they are not available.

If a participant has privacy manager and the call is not picked up, the following letter should be sent.

PRIVACY MANAGER – WE'RE TRYING TO REACH YOU

Today's Date

Name

Address

City, State, Zip

Dear _____,

We want to thank you for your time and interest in participating in the research project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University.

We have been trying to reach you to schedule a time to complete your telephone interview, but we receive a message that your telephone has a privacy caller ID feature. We hope that you will continue to participate in this project. If you would like to continue in the project, please call us at (517) 353-0306 or use our toll free number, 1-888-353-0306. You can reach a staff member between 9 a.m. and 5 p.m., Monday through Friday, or you may leave a message at any time directing us how to contact you.

We look forward to hearing from you. We appreciate your interest in this research project. It is through information from participants such as yourself, that we are able to strategize problem management for future caregivers.

Sincerely,

Paula Sherwood, RN, MSN, CNRN
Principal Investigator

SUBJECT:

Subjects Who Don't Remember Agreeing to Participate

POLICY:

Although this does not usually occur, a situation may arise when a subject (often angry) does not recall providing consent for us to contact them.

PROCEDURE:

1. In such situations, tell them that we have a consent form on file and can send them a copy if they desire. Explain to the subject that providing care for someone with a brain tumor affects caregivers in many ways. We would like them to share their experiences with us. This will help others who face similar problems. Their role in this project will consist of participating in a one-time 45-60 minute telephone interview.
2. Remind the subject that **ALL** information is confidential and will never be linked with them or their families.
3. If subject is still reluctant, indicate that you will send them a brochure explaining the Family Care for Brain Tumor Patients. Send a "Participant doesn't remember letter" with a brochure and a copy of their consent form.
4. Tell him/her you will be calling in about a week to see if they are still interested in participating in the project. Inform Paula Sherwood of situations like this.

Appendix G

Interviewer Manual

Family care of persons with a brain tumor

Conducted in affiliation with the Walther Cancer Institute, Indianapolis, Indiana, National Institute for Nursing Research/National Institutes of Health, the American Cancer Society, Sigma Theta Tau – Alpha Psi Chapter, Michigan State University College of Nursing, the Oncology Nursing Society Foundation, and the American Brain Tumor Association

Interviewer Manual

Principal Investigators:

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A collaborative effort involving Michigan State University College of Nursing, Michigan Department of Community Health, Henry Ford Hospital Hermelin Brain Tumor Center, and the National Brain Tumor Foundation.

Research Team

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Executive Summary

The following is an executive summary for the project titled “Family Care for Brain Tumor Patients” conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, American Brain Tumor Association, Barbara A. Given, RN, PhD, FAAN, Principal Investigator; and Paula R. Sherwood, RN, MSN, CNRN Co-Principal Investigator. This research project is a collaborative effort involving Michigan State University College of Nursing, the Michigan Department of Community Health, the National Brain Tumor Association, the American Brain Tumor Association, and the Henry Ford Hospital Hermelin Brain Tumor Center.

BACKGROUND

Changes in health care reimbursement often make family members responsible for providing care, even though they may be ill prepared to deliver this care. Researchers have documented the effects of providing care for a person with a terminal illness such as cancer and for a person with cognitive and behavioral decline such as the dementia patient. However, there have been minimal efforts to describe the impact of providing care for persons who suffer from both a terminal trajectory of illness and a deterioration in cognitive status.

To better understand the issues faced by caregivers of persons with a primary malignant brain tumor, we will be conducting a descriptive study involving a 45-60 minute telephone interview with caregivers. Caregivers will be asked questions regarding the patient’s disease and treatment, the patient’s functional, cognitive, and neuropsychiatric status, and the caregiver’s level of perceived adequacy of information to care, mastery, burden, and depression.

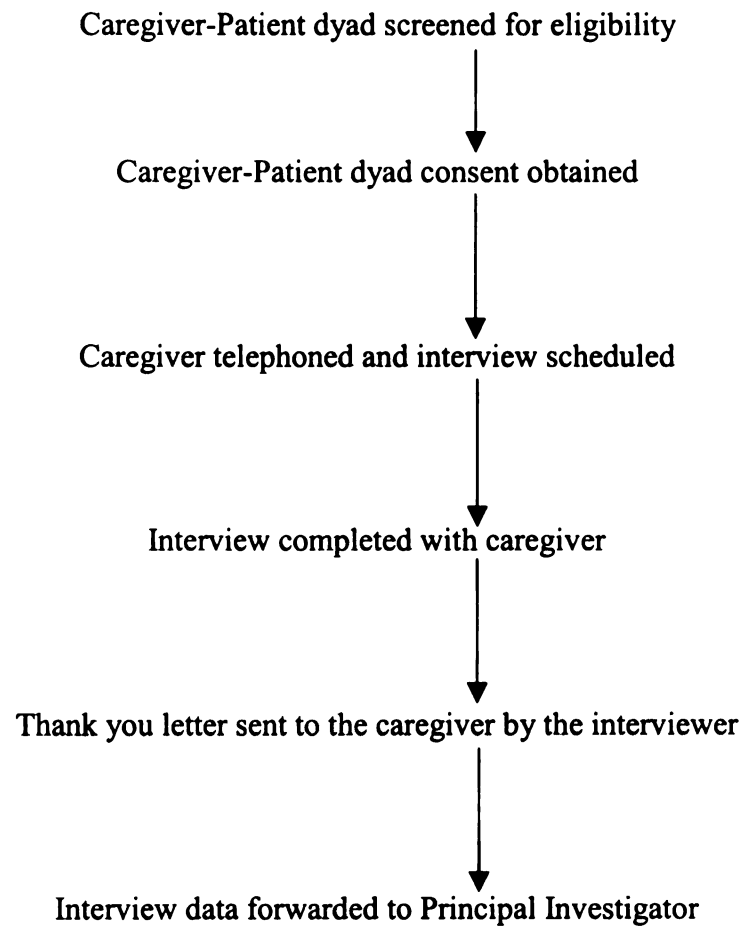
The goal of the project is to determine the effect of the patient’s functional, cognitive, and neuropsychiatric status on the caregiver’s level of burden and depression and to determine if the caregiver’s level of perceived adequacy of information to care and mastery moderates this effect. Persons with specialized training in conducting interviews with caregivers of cancer patients will be interviewing caregivers regarding their feelings and concerns about delivering care to someone with a primary malignant brain tumor.

This descriptive study will involve family caregivers over the age of 21 who are providing care for a person with a primary malignant brain tumor. It is not a requirement for the study that the caregiver be legally related to the care recipient, or that they reside in the same domicile. Family caregivers will be designated as those who provide daily or weekly assistance to the care recipient without financial reimbursement from a third party. Eligibility criteria also dictate that the caregiver be able to read and speak the English language and have regular and reliable access to a telephone.

Caregivers who consent to participate will be contacted to set up a 45-60 minute interview. If the caregiver chooses not to complete the interview after having given

consent, they will be dropped from the study. In addition, if the caregiver becomes distressed during the interview, they will be given the option of completing a shorter interview, completing the remainder of the interview within 7 days, or attriting from the study

Study Protocol



Interviewer Job Description

The interviewer will work closely with the Principal Investigators in tracking caregivers through the study and identifying time frames within which each caregiver should be contacted for data collection.

Responsibilities include:

1. Read over the Interviewer Manual and a paper copy of the interview before attending first training session.
2. Attend all interviewer training sessions and be prepared to ask and answer questions. Your familiarity with the questions will be a major factor in how you interact with the person you interview. Be sure to study all questions until you know what they mean and are familiar with them.
3. An explanation of the question may be necessary at times and you should be ready with an explanation. **If you have questions about how to explain any of the questions, get answers from Paula Sherwood prior to doing an interview.**
4. Participate in taped mock interviews as part of training, review own tape and complete a self-evaluation. Meet with Paula Sherwood to review performance. If your performance is unsatisfactory, Paula Sherwood will discuss problem areas and suggestions for improvement with you. You will be required to complete another mock interview until deemed satisfactory.
5. When assigned your first authentic cases, you will be required to tape the first three interviews (be sure to get permission of participant whom you are interviewing **BEFORE** you begin taping the interview) complete a self-evaluation and submit it to Paula Sherwood. The tapes will be reviewed by Paula Sherwood. If the performances are deemed satisfactory, you will be required to tape every 10th interview thereafter. If the performance is deemed unsatisfactory, Paula Sherwood will meet with you to discuss problem areas and suggestions for improvement. You will be asked to review the techniques for interviewing and will be required to tape each of the interviews you perform until one is deemed satisfactory.
6. An Interviewer self-evaluation must be completed and submitted along with each taped interview (i.e. mock, first authentic, monthly) to Paula Sherwood.
7. Contact participants to schedule interview within one week of being assigned to you.
8. If unable to contact a participant, you are required to try contacting the participant for four consecutive days (including morning, noon, night, and Saturdays). Difficulty contacting a participant should be reported to Paula Sherwood. If you are unable to

contact because of disconnected phone or other problem, follow protocol in manual and discuss with Paula Sherwood.

9. Document all attempts to contact participant on the field note and file photocopies of any written correspondence in subject's interview file. Interviewer must write case ID # on the upper right corner of all correspondence. e.g.: "HB001".
10. Once the interviews are completed, the date that the interview was completed, as well as other dates relevant to the interview (i.e. thank-you sent) or special/unique situations encountered during the interview, are to be recorded on the field notes. It is expected that each interviewer will maintain accurate field notes to help keep our records up-to-date and accurate. Completed field notes or change of status forms should be submitted to Paula Sherwood. A copy of the letters sent should be filed directly in the subject's interview file.
11. The interviewer should communicate weekly activities to Paula Sherwood reporting the information outlined on the **Interviewer's Weekly Report** form.
 - a. Number of cases assigned that week, referred to by case ID number.
 - b. Number of interviews completed that week.
 - c. Number of late interviews outstanding that week.
 - d. Difficulties encountered reaching participants to either schedule interviews, or complete previously scheduled interviews, and problem solving strategies employed.
 - e. Unique occurrences during the telephone interview process. For example, difficult interviews, such as the participant was angry or reluctant to respond to questions, or other cues that may lead you to believe that the participant might drop out of the study.
12. Interviews sometimes bring a lot of suppressed feelings to the surface for caregivers and may require quite a bit of active listening on the interviewer's part. During interviewer training we will try to cover some situations that you may run into as an interviewer and how to best handle these situations. We will also have available a list of crisis intervention numbers that the caregiver may utilize.
13. The interviewer is responsible for reporting any problems they have with equipment, the interview itself, etc. It is also expected that the interviewer will seek assistance from Paula Sherwood if they are unclear of any study protocols relevant to their job as an interviewer.

Other Responsibilities:

1. Submit time sheets to Paula Sherwood every other Thursday by 12:00 p.m. If you should put in fewer hours than submitted, you must deduct this time from the total hours submitted the following week. You are on

an honor system and it is expected that you will act in a professional, ethical manner. Failure to do so may result in termination of employment.

2. Requests for time off need to be submitted in writing **1-2 weeks prior to the requested dates off**. (Requests for 1-2 days off may be made 1 week in advance. Time off for longer vacations must be requested 2 weeks in advance). Please notify Paula Sherwood in writing.
3. If you have difficulty with equipment notify the study office staff as soon as possible. Also, if you have any suggestions for improvement to the procedures or interview please discuss with Paula Sherwood.
4. **If you are ill or unable to make it for a scheduled interview, try to find another interviewer to take your place.** If unable to find a replacement, the interview will need to be rescheduled. You must notify Paula Sherwood when this occurs.
5. If you are ill and unable to work during your on-campus office hours, you must email or telephone Paula Sherwood **BEFORE** your scheduled work time and report your absence. If no one is available to take your telephone call, the answering machine will take your message.
6. Interviewers may need to conduct early morning, evening or Saturday interviews per a patient/caregiver request. Interviewers must keep the office staff aware of the hours they plan on working in the office and the hours they will spend at home making calls to conduct interviews outside your office hours. Whenever possible, please try to schedule interviews during your office hours. Please be very considerate and try to schedule these interviews at the participant's convenience.
7. Be sure to market the value of the project with those you interview to help reinforce to them the importance of their participation. You are the ambassador for the project. This will require reading the executive summary as well as the entire Interviewer Manual. If you have any questions about the goals of this project, please ask Paula Sherwood. All interviews must be conducted during the appropriate time frames, i.e. 7-10 days after you receive the assignment.

Qualifications of the Interviewer include:

1. Excellent communication skills and phone manners.
2. Sensitivity to caregivers of patients diagnosed with a brain tumor.
3. Some higher education, preferably a college degree.
4. Availability for occasional interviews during times other than regular working hours.
5. Excellent record keeping skills.

6. Ability to coordinate clearly and timely with Paula Sherwood.
7. Ability to be sensitive to caregiver's moods and feelings and ability to maintain sensitive yet professional interviewing tone

I understand that if I fail to meet these standards, including failure to follow the protocol, termination from this position may occur.

Interviewer Signature

Date

Interviewing Protocol

A. Interviewer Job Expectations

1. General Information

The interviewers (data collectors) are responsible for contacting the caregiver, for scheduling interviews in accordance with the protocol timeline and for conducting the interviews. Interviewers will participate in an intensive training session to prepare them for interviewing caregivers. Interviewers will protect the confidentiality of subjects' information. The interviewers will consult regularly with and report to Paula Sherwood to review concerns and activities.

2. Specific Duties of Data Collection

a. Procedures for Public Relations

- ❖ Be sure to market the value of the project and the importance of participating. You are the ambassador for the project. This will require reading and understanding the executive summary as well as the entire Interviewer Manual. If you have any questions about the goals of this project, please ask Paula Sherwood.
- ❖ Be sure to study all questions until you know what they mean and are familiar with them.
- ❖ You should be adaptable and gracious to all caregivers, despite their responses.
- ❖ Use an informal, natural manner of speaking aimed at putting the individual at ease and making it easy to give you their responses.
- ❖ The objective of the project is to get the honest, uninfluenced opinion of each individual. You are the medium through which the opinion is conveyed and your bias should not affect the interview results.

b. Training Responsibilities Include:

- ❖ Attend all training sessions, initial and ongoing
- ❖ Participate in role playing sessions
- ❖ Participate in own quality assurance
 - Participate in reliability checks
 - Complete taped interviews as requested
 - Review your taped interviews and complete a self-evaluation form

c. Schedule and Conduct Interviews

- ❖ Telephone the caregivers selected for participation and follow protocol for scheduling interviews
- ❖ Administer instruments according to protocol and timeline
- ❖ Review each interview, make notes, ensure that data and all records are completed as required
- ❖ Complete appropriate information on field notes and in a timely manner
- ❖ Send appropriate letter to participant; ensure dates and records are complete. **Double check spelling of surname.**
- ❖ Return completed interview instruments when requested

d. Assuring Quality Data

- ❖ **Participate in interviewer meetings if scheduled.**
- ❖ Complete the taping of interviews as requested
- ❖ Participate in quality assurance activities (e.g., critique **your taped** interview, complete all paperwork, organize case files)
- ❖ Quality assurance, accurate record keeping, and regular weekly follow-up notes are a regular and essential component of the interviewer position

e. Accountability

- ❖ Compliance with these guidelines is absolutely necessary; you are held accountable for implementing grant policies and procedures
- ❖ You are to participate in your own quality assurance as well as system wide quality assurance; you will be asked to check files and forms to ensure accuracy
- ❖ Violation of grant policies and procedures will be corrected on your own time without pay. **Severe violations will be reviewed for possible termination.** Records are to be accurate; errors are to be reported as soon as they are discovered

f. Report and Discuss Concerns with Paula Sherwood regarding Interview

Protocol or Problems

- ❖ Weekly updates to Paula Sherwood are due at the end of each work week regarding how your activities are progressing

- ❖ Difficulties with subjects, potential loss of subjects or difficulty in doing work according to the schedule should be reflected in your weekly report. You should indicate what you have done to resolve problems (if any) encountered during the week. Communication on specific interviews may include problems, but does not take the place of your weekly report.

g. **Interviewers should NEVER enter into a discussion regarding subjects outside of the project area or with other individuals.** If there is a need to discuss a particular case, the interviewer should contact Paula Sherwood.

REMEMBER: IT IS IMPERATIVE THAT SUBJECT CONFIDENTIALITY AND INFORMED CONSENT ARE ALWAYS PROTECTED.

h. **Other Duties as Required and Assigned**

- ❖ File records, maintain accurate files on participants
- ❖ Complete reports as requested
- ❖ Report any problems with subjects as they occur
- ❖ Report any office type problem as it occurs

B. Procedure for Maintaining Confidentiality

1. Only case ID numbers and interviewer ID numbers are allowed on case file folders as well as the questionnaires.
2. Maintain confidentiality when working with forms, questionnaires, letters, etc.; keep in folder, do not leave unattended at any time.
3. **QUESTIONNAIRES IN PROCESS OR COMPLETED SCREENING/ENROLLMENT FORMS, CONSENT FORMS, OR OTHER CASE INFORMATION ARE NEVER TO BE LEFT OUT ON DESKS.**
4. Do not assume that the caregiver has told family members about the patient's brain tumor diagnosis. Do not identify yourself as being part of a cancer project to anyone other than the caregiver or patient unless special circumstances exist which must be discussed with Paula Sherwood. **The patient's family should not learn about the cancer diagnosis from us.** Special situations should be documented in the caregiver's file. If the caregiver is not available when you call, try to find out a good time to call back. You can always introduce yourself as being part of the study from Michigan State University.
5. Any and all email exchanges about any study participant **must not** include the participant's name. Participants are to be identified only by their case ID number (e.g., HB001).
6. If the study participant is not at home (or work), do not identify the participant as a caregiver of a cancer patient. You may leave the following message: "This is _____ calling on behalf of Michigan State University. I am trying to reach (state participant's name) and may be reached at _____ (leave appropriate number, toll free number, and days and times in which you are available to receive their return call).
7. Do not telephone participants at their work site unless they have explicitly identified this as an option for contacting them.
8. Do not mention the word cancer on any messages left on voice mail.
9. Project staff members are not to enter into any discussion regarding any participant outside of the project area.
10. Project staff members are not to enter into any discussions regarding any participants with anyone except for Paula Sherwood.

C. General Instructions for Conducting an Interview

Your goal is to obtain accurate and complete information by using the questionnaire. It has been devised so that it will provide standardized data that can be analyzed and compared with other data. Therefore, we request that you administer the instruments and **ask all respondents the same questions in the same manner. The analyst must be sure that differences in the data reflect differences in respondents and not differences in the individual interviewers.**

As an interviewer, you are a valuable and crucial link in the long and complex chain of social research. You are the eyes and ears of the project staff, recording all that is seen and heard. The most brilliant questionnaire design and the most sophisticated analysis of data cannot rescue a study if the interviewing is erratic and inaccurate. Therefore, the guidelines and instructions have been written to help you perform your task capably and responsibly.

Do not ever use the term Malignant with these patients or caregivers – it is too distressing to many of them and we are not sure what their physician may have told them.

The Interviewer's Code*

As an interviewer you must be:

1. Completely honest in your work.
2. Reliable and conscientious.
3. Utterly objective in your manner of asking questions.
4. Faithful and neutral in recording answers.
5. Willing to write answers fully and legibly. Add comments as needed to explain answers.
6. Interested in people -- understanding and empathy are necessary skills for successfully interviewing and retaining participants for the project.
7. Able to inspire people's confidence and put them at ease.
8. Sensitive to the pace set by the patient.

Be sure to:

1. Study all questions until you know what they mean and are familiar enough with them so you can really ask the questions. An explanation of the question may be necessary at times. Be careful not to change the meaning of the questions.

2. Interview yourself by answering each question thoughtfully. Then role play with someone else.
3. Re-read your instructions between interviews; you may pick up points you missed before or correct errors you have begun to make.

*Abstracted from Survey Research, Backstrom and Hursh, Northwestern University Press, 1963.

Your attitude and demeanor should be:

1. NEUTRAL

As an interviewer (data collector), you merely soak up information like a sponge without giving any of it back. Your job is to record information, regardless of whether you think it good, bad, indifferent, boring, or exciting.

- a. Do not indicate surprise, pleasure, or disapproval at any answer.
- b. Do not attempt to influence responses in any way. The truth is all that really counts -- what the person really thinks or feels about the subject, NOT YOUR OPINION!
- c. Thus:
 - ❖ Never suggest an answer. Be careful not to give your opinions. This is a project of the caregiver's feelings, not yours. Opinions, feelings, and so forth, can be recorded in your Field Notes.
 - ❖ For the same reason -- so the response will not be influenced in any way -- you must ask the questions exactly as they are worded and in the same order every time. Changing the order of questions and/or sections will result in unreliable data and confusion at the time of coding. Each interview must be done the same way, to ensure uniform and reliable results.

2. IMPARTIAL

- a. Whatever you may think of an individual or his/her opinion, it is important to keep it to yourself. Each person you speak with is equally important.
- b. You should be adaptable to anyone and gracious to all. Each person you approach poses different problems requiring different techniques. The important thing is to inspire the confidence of every person regardless of age, income, lifestyle, etc., as to the importance of the project. You can do this any number of ways:

the tone of your voice, the way you ask the questions, reminding the person and thanking them for furnishing us with their personal experiences with cancer, and so forth.

- c. There may be times when you are particularly bothered or emotionally moved by a certain case. There may be someone that you feel especially close to and "connect" with just through the phone interviews. Please feel free to speak with Paula Sherwood regarding your feelings. Remember, you are dealing with real people, not just case numbers and you may have feelings that arise that you were not even aware existed.

3. CASUAL

- a. You are not a spy out on a secret mission. If you pursue your assignment too earnestly or too grimly, the subject is forced to be defensive and won't tell you what he/she honestly thinks. You are not to subject the individual to the third degree.
- b. Assume that the subject wants to express his/her opinions. You merely are giving them the chance to express him/herself on matters that are important to him/her.

4. CONVERSATIONAL

- a. Use an informal manner of speaking, natural to you, and aimed at putting the subject at ease. The subjects will be able to sense your style. As you continue to interview, you will know which style comes naturally to you. Remember, these people have a story to tell. If you are cold and uninterested, chances are they will pick that up. If the subjects feel that their interview is the most important one, you will be successful.
- b. **Know the questions well so that you never sound as though you're reading them for the first time.**
- c. Although you are conversational, never lose control of the interview. Be ready to handle interruptions or objections. Always maintain a kind, caring attitude with the subjects. They may choose to vent anger, frustrations, or other feelings. Remember to respond with appropriate feedback responses such as, "Uh-huh, I see, thank you for sharing those feelings with me." Become familiar with the feedback responses in this section.

5. FRIENDLY

- a. A major objective is to put the subject at ease. If the subject is not relaxed, you cannot make him/her talk. Your attitude must be empathetic and understanding, not judgmental. The subject must be made to realize that what he/she thinks really is what counts.
- b. If the subject objects to a question, you are allowed to side with him/her only to the extent that you say, "Sometimes researchers ask questions that may seem a little bit different to you. Answer it if you can, if not we can just go on." **OR** "What is it that bothers you about this question?" If a concern regarding a particular question(s) keeps coming up, please note this in your Field Notes and report this to the Principal Investigator. Always put them at ease. It is their right to refuse to answer any question.

REMEMBER: The objective of the project is to get the honest, uninfluenced opinion of each subject interviewed. You are merely the medium through which the opinion is conveyed. Nothing of you should be in the interview results.

D. Interview Guidelines

(Adapted from General Interviewing Techniques, Institute for Social Research, University of Michigan.)

1. Effective interviewers read questions **exactly as they are worded** in the questionnaire.
 - ❖ Read questions with no additions, deletions, or substitutions.
 - ❖ Do not make up your own questions.
2. **Make a choice from parentheses** based on what you have learned about the subject on prior questions (e.g., relationship of caregiver to care recipient, gender of care recipient).
 - ❖ Phrases in parentheses are optional (e.g., does ____ need help with...).
 - ❖ You can include the phrase, eliminate the phrase or use it intermittently.
 - ❖ If you decide to use the phrase, read the entire phrase.
3. **Read the entire question** before accepting the answer.
 - ❖ If the subject interrupts, continue reading the entire question.
4. Read the questions **in the sequence** in which they are listed.
 - ❖ Don't skip questions because the answer was given earlier or because you "know the answer."
 - ❖ Repeat introduction if needed.
5. **Avoid direct reference to past responses.**

- ❖ Don't assume the "answer" you got in passing is the correct answer to a specific question at another point in the interview.
- ❖ In situations in which the subject has already provided information that answers a subsequent question, preface the questions with neutral phrases such as:

"I know you just mentioned this but I need to ask each question as it appears on the questionnaire," or "You have already touched on this but let me ask you..." or "You've told me something about this and this question asks..."

- ❖ Keep references to past answers to a minimum; use options as stated above in 5b only if you feel the subject is getting the impression you're not listening to them.

6. Emphasize underlined words to enhance meaning.

7. Read about two words per second.

- ❖ Alter your normal rate of conversation to promote the subject's understanding.
- ❖ Keep pace with the subject. Some subjects may be hard of hearing, slow to answer questions, or in a hurry to finish the questions. As an interviewer you must use your judgment in a variety of situations regarding the pace of the interview and collecting the data.

8. Record subject reactions and qualifications to answers in the notes field at the end of the interview or in the questionnaire margins of the paper copy, and in Field Notes.

- ❖ **If the participant cannot make a choice or prefers to skip the question, indicate this clearly next to the question.**

9. Repeat the question, if, in your judgment, the subject has misunderstood the question, or not provided an answer to the question you are asking, repeat it exactly as written.

E. Appropriate Feedback

Feedback consists of statements or actions which indicate to the subject that he/she is doing a good job. If feedback is used properly, it encourages the subject to continue to answer questions accurately.

1. An effective interviewer only gives feedback for an acceptable performance.

2. Feedback is given for good performance, NOT "good" content.
3. Although frequently used in everyday speech, "OK" and "all right" are NOT acceptable feedback phrases in interviewing.
4. A brief pause followed by a feedback phrase makes the feedback more powerful.
5. Telephone interviewers should give feedback for acceptable subject performance 30-40% of the time.

Giving Feedback

DO USE Comments on performance.

"This is helpful information."

"It's important to find out what people think about this."

"Thanks, it's important to get your opinion on that."

"Uh-huh."

"Thank you."

"I see."

DO NOT USE Comments on content.

"What a good idea."

"That's very interesting."

"I agree with you there."

"Good."

"Fine"

"Okay"

6. Feedback phrases also include those comments that report on the activities of the interviewer (e.g., "I'm writing this down," "I'm turning the page now," "I'm reviewing what we've just discussed to make sure we've completed all the questions", "I'm scrolling down to the next set of

questions; the computer can be a little slow sometimes"). This is very important for the subject, sometimes people can become uncomfortable with pauses. They may imagine you are documenting information they may not truly have supplied.

F. Techniques for Clarification

You can clarify a question for a subject who requests clarification in the following ways:

1. Accurate repetition of the entire question or a part of the question.
2. Use of clarifications or definitions that have been provided to you.
3. Use of the phrase "Whatever _____ means to you." Or "Whatever you think of as..."

G. Techniques for Probing

If the subjects are having difficulty answering a question, then you must probe for a response at least once. The following techniques may be helpful:

1. Pausing.
 2. Repetition of question exactly as it is written.
 - a. If subject indicates that only one part of the question is misunderstood, read only that part.
 - b. If the subject says, "I don't know" and still can't understand the question as often as it is repeated, the following techniques are useful:
 - If subject has narrowed the choices but can't choose between them: "Which would be closer to the way you feel?"
 - "Of course there are no right or wrong answers, we're interested in your opinion."
- "Well, in general...", "generally speaking...", or "overall..."

THE MOST EFFECTIVE PROBES ARE PAUSES AND QUESTION REPETITIONS.

H. Handling Questions About the Study

When answering questions about the study, refer to the recruitment brochure. If referring to recruitment brochure is insufficient, tell participant you will get back to him/her. Record his/her questions or concern, discuss with Paula Sherwood who will further direct you.

I. Interviewing Procedures for This Project

Interviewers may need to conduct evening interviews per a subject request. Interviewers must keep the Paula Sherwood aware of the hours they plan on working in the office and the hours they will spend at home making evening calls. Whenever possible, please try to schedule interviews during your office hours. Please be very considerate and try to schedule these interviews at the subject's convenience. The screening/enrollment as well as the Field Notes form will include information regarding days/times subjects wish to be called.

NO CAREGIVER FORMS OR FOLDERS ARE ALLOWED OUT OF THE OFFICE EXCEPT FOR THE PURPOSE OF CONDUCTING INTERVIEWS.

A project telephone credit card is to be used only in conjunction with interview calls. Any abuse of this system will result in termination from the project. It is also a matter that will be turned over to Campus Police for investigation and possible prosecution. For your own protection, remember to use the telephone credit card only for interviews and to keep this number confidential.

When you are interviewing participants, reassure them that there are no right or wrong answers and that we are not testing them. We are interested in their thoughts and opinions.

Because we have caregiver interviews it is *IMPERATIVE* that we provide some background information to the caregiver. This information will assist the caregiver in understanding why we are asking questions about the patient's care.

Some family members may not think of themselves as caregivers. If they are uncomfortable with this term, then explain that if some care was needed, they would be involved and thus we are interested in their perspectives as family members where someone has a brain tumor.

Inform the caregiver that you will be asking them some questions about the patient **BUT** you would like to know what the perception of the situation is from their view. They should feel free to express how they see the situation whether it is the same as the patient or different. Remind them that this is not a test but their view. This will no doubt make them feel more comfortable with the interview as well as have a better understanding of what we are trying to accomplish during each interview.

The more information we are able to provide the participants, the less likely they are to feel we are trying to “trick” them. Explain that some questions sound the same or have similar components but the questions are different. (Give the caregiver an example).

Always remember, no matter what interview you are doing, if the subject becomes upset, angry, agitated, or feels as though we are becoming too personal, it is acceptable to say: “I can understand that this topic makes you uncomfortable, why don't we just go on to the next set of questions.” There is never a reason to **make** a subject answer a question that they do not feel comfortable answering. In the long run the subject will no doubt become angry and withdraw from the study. Move on but record reasons for skipping a section.

1. Consent and Initial Contact

BEFORE ANY INTERVIEW CAN BE COMPLETED, A SIGNED CONSENT FORM FOR THE CAREGIVER MUST BE IN THE FILE.

Note: the recruiter should have obtained consent from the caregiver! Interviewers **must** check to be certain that a consent form has been signed and is in the case file! Do not conduct an interview or contact a caregiver unless a signed consent has been obtained!

If a copy of the written consent is not in the file, you **MUST** not contact the caregiver! Immediately, contact Paula Sherwood so that this may be rectified!

If written consent has been obtained and a copy is in the file:

- a. Contact the caregiver to arrange a convenient time for scheduling the telephone interview must be made within **7 days** of receiving the case.

2. *Contacting Caregiver for Interviews*

Contacting caregivers is sometimes difficult. Telephone the participant during the day/time requested. You will not have to do the interview at that time if it is not convenient. This is a process of negotiation as to a mutually acceptable time between you (the interviewer) and the participant.

If you call the participant at the pre-arranged time and they are not home, wait **15 to 20 minutes** and try again to reach them. Please remember to note all attempts on the Field Notes form.

If unable to reach:

- a. When leaving messages on a subject's answering machine, an interviewer should leave a message for the subject the first time they call. The interviewer should call the following day but NOT leave a message. The third day the interviewer calls and receives an answering machine, the interviewer should leave a message AND notify Paula Sherwood so that someone can contact the site to inquire on the subject's health.
- b. Messages should always include the toll free number for patients to return the call (888) 353-0306. Messages from subjects will be left on the interviewer's home answering machine as well as their e-mail. Interviewer messages to the subject should indicate what times interviewer would be available to complete the interview, that interviewers work part-time, and that subject should call our office and leave a message if interviewer is not available.

3. Completing the Interview

- a. The paper copy of the telephone interview should have all the appropriate information completed, the participant's answers and comments legibly written, and the **interviewer's ID number, case number, and date of completion** written in the upper right corner by the interviewer.
- b. The date on the telephone interview is the date it was completed.

4. *Completing the Field Notes.*

- a. Record notes on field notes, at the same time as the interview! Do not complete at a later date or time! Completely accurate information on field notes is a must! Record: completed date and any special comments.
- b. Send thank you letters and turn field notes in as soon after completing an interview as possible and be accurate with the dates on each.
- c. Note any unusual circumstances/events that occurred during the interviews, these situations on the field notes.
- d. Make sure the notes include the subject ID, your interviewer code, and the date.

Problems requiring immediate attention should be discussed with Paula Sherwood immediately, even if it means calling Paula at home. Problems not requiring immediate attention should be discussed with Paula Sherwood as soon as possible, without calling her at home.

5. *Sending Thank You Letters.*

Upon completion of the telephone interview, a thank you letter should be sent to each participant. Please refer to the Policies & Procedures: Mailing of Thank-you Letters Following an Interview.

8. Correcting Errors on the Instrument or Forms

It is the interviewer's responsibility to date and initial all corrections (e.g. ~~crossed-out information~~) made on ANY subject documents (interviews or Field Notes). This will assure staff that the person who wrote the information corrected this and not a third party, and any confusion will be avoided. It is also imperative that if you decide to write over, above, or around written comments or answers, **PLEASE** be sure it is legible. Your comments are very important, but only if they are readable and understandable.

As changes in procedures or forms occur, a copy of revised Interviewer Manual pages will be distributed and are to be replaced in your Interviewer Manual. Failure to replace materials or the disregarding of new information will be viewed as non-cooperation and dereliction of duties. In this situation, Paula Sherwood will meet with the interviewer and discuss action to be taken. Ignorance of job responsibilities and policy changes is unacceptable.

It is important for the interviewer to remember and keep up to date with all policy and procedure changes.

If you have questions and Paula Sherwood is not available, please leave a memo in their mailboxes or make contact via E-mail. Please be clear and concise.

Remember your interviewer training! The appropriate responses and feedback, tone of voice, and thank-you's are essential in this type of research project.

Thank you in advance for your work on this project! We appreciate you keeping track of your cases, conducting interviews in a timely manner, and turning in the correct forms and completed questionnaires as indicated.

J. Procedures for Subject Withdrawal or Refusal

1. Definition of Quit

- a. **Withdrawal:** a subject who begins but never completes an interview and then decides to **quit**.
- b. **Refusal:** a subject who signs a consent form but **NEVER** starts an interview.

Remember that all information is confidential and that subjects can withdraw at any time. PARTICIPATION IS VOLUNTARY! Hopefully, the interview can be arranged so that it is convenient and interviewers are responsive and empathetic to needs.

If it is necessary to skip questions to keep the caregiver in the study, then please carefully document which questions were skipped and why in the Notes sections of the Interviewing Software and on the Field Notes. Do not skip questions to get through the questionnaire unless you document why you are skipping them. This will help minimize refusals and withdrawals.

2. Procedure for Withdrawal or Refusal

- a. Subjects can choose to withdraw or refuse continued participation two ways: 1) they can telephone the MSU Research office toll free, or b) they can withdraw or refuse to complete when the interviewer calls to complete the interview.
- b. Please refer to the Policies and Procedures: “Attrition: Caregiver Refusal to Continue with Interview” for specific procedures.

K. Special Situations

1. *Subjects Who Don't Remember Agreeing to Participate*

(See Policies & Procedures: “Subjects who don’t remember agreeing to participate”.)

2. *Distressed Subjects/Referral to Community Agencies*

(See Policies & Procedures: “Suicidal and Emotionally Distressed Participants”.)

3. *Subjects Who are Reluctant to Complete an Interview*

(See Policies & Procedures: “Participant Reluctance to Complete an Interview”.)

- a. Caregivers may be distressed and overwhelmed. As an interviewer, you are intruding on them at the least opportune moment. However, you must market the importance of this study to them and retain them in the study. Appreciate their stresses, illnesses, and inability to complete an interview - we have prepared options when these difficulties occur. However, always remember it is your job to try to help them complete the interview.

Selling the interview:

- This research is important to help health care providers understand the difficulties caregivers of persons with brain tumors experience at home. Health care providers will be able to provide strategies to meet their needs once we have a better understanding of the problems.
- Many persons find this a comfortable way to think and talk about their problems.
- All comments are completely confidential.
- The help this provides is an important source of gratification to many people.

- b. In order to accommodate each caregiver's situation, we have built in the following options for completing an interview:

- Regular telephone interview
- Short telephone interview

4. *Protocol for Interrupted/Incomplete Phone Calls*

(See Policies and Procedures: "Interrupted/Incomplete Telephone Interviews".)

5. *Caregiver has Privacy Manager*

In the event you call to schedule an interview and the participant has privacy manager, please refer to Policies and Procedures: "Placing Calls to Schedule/Conduct an Interview."

Interviewer Training

1. Each interviewer is responsible for reading the interviewer manual as well as the interviews **BEFORE** the day of their interviewer training. It will be expected that all new interviewers will come to their training session with questions regarding the study and the interviews.
2. Interviewer training will consist of going over the interviewer manual, answering as well as asking questions, explaining different aspects of the study, and promoting appropriate, effective, efficient, and professional research skills.
3. The new interviewer will be "walked through" the entire process. Details as how the interviewer receives weekly assignments, where files are located, where to pick up interviews, what telephones are to be used, how to complete the paperwork, as well as special situations and how to handle them will be covered at orientation. Orientation to the offices as well as how to keep the Principal Investigator(s) informed of work status will be discussed.
4. The next step in training will be to go over the interviews. The new interviewer's goal will be to understand the processes of completing an interview based on the procedures and protocols of this grant.
5. As part of the initial interviewer training each interviewer will participate in one or more mock interviews with a designated project employee until a satisfactory

evaluation is reached. This mock interview will be taped. The interviewer will conduct the interview as they would with a participant. This means the interview will be conducted from separate rooms using the telephone, unless otherwise specified. The interviewer is responsible for any equipment that they check out. If you discover a problem with a phone, tape player, or computer you are to immediately inform Paula Sherwood.

6. Once the mock interview is completed, Paula Sherwood will listen to that tape and provide verbal and written feedback. Upon a satisfactory evaluation, the interviewer will be given a "real" case.
7. The interviewer will tape their first three "real" interviews. Remember you **MUST** get verbal permission from the participant **BEFORE** you start taping. You may want to tell them you are a new interviewer and the tape is only to assess your ability as an interviewer and once the tape is heard by your supervisor, it will be destroyed. The interview will remain confidential.

Please begin taped interview by again asking if you may tape the interview "The tape is running now and I need to ask you again, may I tape this interview for quality assurance purposes?"

8. **How to tape** an interview. Please check out a tape recorder. Make sure you have a cassette tape. It is suggested that the interviewer practice taping and get a feel for how things work before they are to start the real interview. The procedure for taping an interview should be followed.

Quality Assurance for Interviewers

Quality Assurance will be performed on a monthly basis including but not limited to: (1) accuracy of the interviewer's case files, (2) making sure interviews were done on time, and (3) that appropriate letters were sent. As part of the Quality Assurance process you may be asked to assist Paula Sherwood in understanding a particular case or situation. You are also responsible to point out discrepancies in any dates, missed interviews, or any questionnaire concerns as you find them.

Procedure for Taping an Interview

Each interviewer will be responsible for completing a tape on this study for the first three interviews and then once a month and listening to their own tape and completing the Self-Evaluation Form. Give both the tape and the written feedback to Paula Sherwood. Attention to protocol is essential.

Before taping this interview the interviewer must get verbal permission from the subject to tape the interview. Obtain verbal consent to tape the interview both before and after beginning to tape. The subjects are to be told that the information they provide will be kept confidential and only authorized research staff will be listening to the tape. The tape will be disposed of after they are reviewed.

Once the tape is submitted it will be reviewed and evaluated using the Evaluation Form in the back of this section. Comments will be made and returned to the interviewer. Paula Sherwood may conduct an inspection of the data at any time; therefore case files and interviews must be accessible at all times.

Interviewer Self-Evaluation Form

Grant: Family care of persons with a brain tumor

Interviewer Name: _____

Number: _____

Date: _____

Circle the following answers:

(1) Did the tape work? Yes or No

(2) Did you remember to ask permission to tape? Yes or No

(3) Describe your pace and understanding level. Was it appropriate for the age and speech pattern of the participant? Yes or No Explain:

(4) Were you able to articulate in a manner that the participant could hear and understand you? Yes or No Explain:

(5) How many incorrect probes did you make? _____ Give 3 examples:

(6) Did you use any inappropriate forms of feedback during responses (e.g., laughter, cueing the respondent, leading the respondent, did you use repetitive responses, "okay")?

(7) Describe the clarification techniques that you used throughout the interview.

(8) Describe any problems that you had with this interview (i.e. was the participant hard of hearing, low education level, agitated, or sick)?

(9) Were you attentive to the comfort level of the participant during the interview?
Yes or No

(10) Was the participant distressed by any questions? Yes or No. If yes, which instrument and which questions?

(11) Were you sensitive to the participant's distress? Yes or No. Please provide an example. If you could have been more sensitive, indicate how you could have handled differently should a participant become similarly distressed in future.

Evaluation Completed by _____
Date _____

Investigator Evaluation Form

Grant: Family care of persons with a brain tumor

Interviewer Name: _____

Number: _____

Date: _____

Circle the following answers:

(1) Did the tape work? Yes or No

(2) Did interviewer remember to ask permission to tape? Yes or No

(3) Evaluating pace. Was it appropriate for the participant? Yes or No Why?

(4) Evaluating articulation. Was it appropriate? Yes or No Why?

(5) Number of incorrect probes? _____

Examples: _____

(6) Number of inappropriate feedback responses? _____

Examples: _____

(7) Description of clarification technique.

Appropriate? Yes or No

(8) Description of problems during the interview.

Examples:

(9) Was interviewer attentive to the comfort level of the participant during the interview?

Yes or No

(10) Was the participant distressed by any questions? Yes or No. If yes, which instrument and which questions?

(11) Was the interviewer sensitive to the participant's distress? Yes or No.

(12) Overall evaluation: Satisfactory Unsatisfactory Incomplete

Evaluation completed by: _____ Date: _____

Forms

Each interviewer must become familiar with all **forms** used with participant communication, especially the field notes.

A. **Field Notes with Participants**

The field notes should be utilized each time a contact and/or attempted contact is made.

You will need to keep track of your telephone contacts. Each time you try to make contact write it on the sheet. You will need to provide us with the date the interview was completed and when the thank you letter was sent. Also, for special situations we need to know when special letters have been sent out (e.g. letters for **Doesn't Remember, Schedule Time, or Phone Disconnected**). Please provide the date the letter was sent. **IT IS IMPERATIVE THAT COMMENTS ARE RECORDED.**

Every call will warrant field notes. Some caregivers are more willing to share their frustrations and feelings about their life experiences and these are the ones that should be written up in detail.

Remember you need to note if the caregiver is reluctant to participate or if you have any clue that they feel bothered by the interview or if the participant is difficult for **you** to interview (please speak to Paula Sherwood in this situation).

Examples of typical Field Notes:

- a. Caregiver too busy to talk today.
- b. Participant very pleasant: "Hope it all helps someone someday." Said that all of the help (speaking of resources, help in their situation) helps us."
- c. Participant is quite pleasant to talk with, and cooperative once you get past trying to get him to admit to any problems at all!
- d. Participant does not remember the study, was quite adamant about this.
- e. Participant is hard of hearing.

Please print small and **legibly** so the data entry can be completed accurately.

In order for information to be entered in a timely fashion, it is imperative that you take the following steps:

- a. At the end of each week, a copy of all pending field notes must be submitted so the computer can be updated.
- b. If you are not sure if a comment is **relevant** it **PROBABLY** is so **WRITE IT DOWN!!** No comment is silly or trivial. A small comment may make a huge difference in the later interview by preparing the interviewer for any circumstance.
- c. If you have any questions or concerns about a case bring it to the attention of Paula Sherwood. **Do not assume that Paula already knows about your concerns.**

B. Change of Status

If either the patient or caregiver withdraw, refuse, or pass away, the caregiver is no longer eligible for the project and a change of status form must be completed.

Field Notes

Family care of persons with a brain tumor

Date Assigned / / **Subject ID#:**

Due Date: / /

Name: _____ **Phone:** _____
Interviewer ID #: _____

Address: _____ **Best Time to Call:** _____

Notes:

CALL SHEET

Call Attempt	1	2	3	4	5	6	7	8
Date								
Time of day								
Code								

CODES:

$C = \text{Complete}$

NA = No Answer

**PD=Phone disconnected-
letter sent**

R = Refused

**AM, LM = Ans Machine,
Left Msg**

DR=Doesn't Remember-letter sent

D = Deceased

AM, NML = Ans
Machine, No Msg.

ST=Unable to Reach-
letter sent

SC=Scheduled Interview

BZ = Busy

O = Other

CB = Call Back

Date Interview Completed ____/____/____ **Paper** ____ **Date T/Y**

Letter Sent ____/____/____

Type of Interview Completed: Regular Short

Special Situations: (circle one)

Doesn't remember Date letter sent ____/____/____

Unable to reach Date letter sent ____/____/____

Phone Disconnected Date letter sent ____/____/____

SAB Date sent ____/____/____ Due Date

____/____/____

Deceased (See Change of Status)

Withdrew/Refused (See Change of Status)

Address/Telephone Number Different Than Indicated Above: YES NO

(If yes) New Address:

Comments:

Referral made? YES NO

a.) To what agency, hospital, nurse or physician?

b.) Date of Referral ____/____/____

c.) For what

reason? _____

Change of Status

Family care of persons with a brain tumor

INTERVIEWER # _____ **CASE ID #** _____ **DATE OF**
WITHDRAWAL ____/____/____

CHECK REASON FOR WITHDRAWAL

____ Patient deceased DATE DECEASED ____/____/____

____ Caregiver no longer involved with patient

____ Caregiver overwhelmed

____ Other (Specify: _____)

INTERVIEWER: Please note any particular issues, circumstances, or concerns reported by the participant which you feel are relevant to this change of status. (If they just don't want to participate, try to solicit the reason and provide some detail).

Notes: _____

All attrition needs to be reported in the weekly e-mail reports to Paula Sherwood.

Interviewer Weekly Report

Weekly report must be sent to Paula Sherwood. These reports may be sent via email but must be sent by Friday of each week. The following information should be included.

- a. Number of cases assigned that week, referred to by case ID number.
- b. Number of interviews completed that week.
- c. Number of late interviews outstanding that week.
- d. Difficulties encountered reaching participants to either schedule interviews, or complete previously scheduled interviews, and problem solving strategies employed.
- e. Unique occurrences during the telephone interview process. For example, difficult interviews, such as the participant was angry or reluctant to respond to questions, or other cues that may lead you to believe that the participant might drop out of the study.

Guidelines for Letters

Each interviewer must become familiar with all letters used with subject communication.

Unless otherwise stated, all letters should be marked as First Class.

Family care of persons with a brain tumor study letterhead should be used for all letters. The original is mailed to the participant and a signed copy is placed in the subject's file. At the top right hand corner of the copied letter, write caregiver ID#. Please check your letter carefully before sending to print. Note that Michigan should be spelled out in a letter and abbreviated "MI" on an envelope.

1. Anytime Caregiver Doesn't Remember Letter should be used to remind caregivers that they consented to be a part of the study.
2. Anytime Schedule Time Letter should be sent if you are experiencing difficulty contacting a participant.
3. Anytime Phone Disconnected Letter should be sent if the participant's phone has been disconnected.
4. Anytime Privacy Manger – We're Trying to Reach You Letter should be used to facilitate scheduling the interview when it is not possible to leave a message.
5. Anytime Quit Participation Letter should be sent if the caregiver has expressed a desire to quit his/her participation in the interview. This letter must be sent in conjunction with a Dropped from study letter (Letters are not sent to participants who refuse upon initial contact.)
6. After interview Thank you Letter should be sent after completion of the interview.

Caregiver Doesn't Remember Letter

Today's Date

Participant Name

Address

City, State ZIP

Dear _____,

I am enclosing a copy of the brochure explaining the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University. Previously, {recruiter's name} spoke with you about this study.

I have also enclosed a copy of the consent form that you signed on _____ and a brochure describing the study. I will call you in a few days to answer any questions you may have and schedule a convenient time for the interview or you may call me at 517-353-0306 or toll free at 1-888-353-0306 after you've reviewed the information, between the hours of 9am – 5pm. You may leave a message at any time.

I look forward to talking with you in a few days.

Sincerely,

(Your Name)

Research Assistant

Enclosure

Schedule Time Letter

If you are experiencing difficulty contacting a participant, the following letter is to be used.

Today's Date

Participant Name

Address

City, State Zip

Dear _____,

We have been trying to contact you for several days to schedule a convenient time to complete a telephone interview for the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University.

If you have any questions about the project or would like to schedule your telephone interview with a member of our staff, please call (517) 353-0306 or toll free at 1-888-353-0306, Monday-Friday, 9:00 a.m. - 5:00 p.m. You may also leave a message at any time.

Thank you for your interest in participating in this study. We are interested in knowing more about how things are going for you. Your participation will help us better understand the effect of symptoms and cancer care on patients and their caregivers.

Sincerely,

(Interviewer Name)

Research Assistant

Phone Disconnected Letter

If the participant's phone has been disconnected use the following letter.

Today's Date

Participant Name

Address

City, State Zip

Dear _____,

Thank you for your interest in the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University.

We have been trying to reach you to schedule a time to complete a telephone interview but receive a message that your phone has been disconnected or is not in service. We hope that you will continue to participate in this project. If you would like to continue in the project, please call us at (517) 353-0306 or use our toll free number 1-888-353-0306 and give us your new phone number. You can reach a staff member between 9am and 5pm, Monday – Friday. You may leave a message at any time.

We look forward to hearing from you. We appreciate your interest in this project. It is through information that our participants supply that we can improve strategies for problem management provided to caregivers of persons with a brain tumor.

Sincerely,

(Interviewer Name)

Research Assistant

Enclosure

Privacy Manager – We're Trying to Reach You Letter

Send letter to all participants who have Privacy Manager and do not pick up the call to schedule an interview.

Today's Date

Name

Address

City, State, Zip

Dear _____,

We want to thank you for your time and interest in participating in the research project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University.

We have been trying to reach you to schedule a time to complete your telephone interview, but we receive a message that your telephone has a privacy caller ID feature. We hope that you will continue to participate in this project. If you would like to continue in the project, please call us at (517) 353-0306 or use our toll free number, 1-888-353-0306. You can reach a staff member between 9 a.m. and 5 p.m., Monday through Friday, or you may leave a message at any time directing us how to contact you.

We look forward to hearing from you. We appreciate your interest in this research project. It is through information from participants such as yourself, that we are able to strategize problem management for caregivers of persons with a brain tumor.

Sincerely,

**Paula Sherwood, RN, MSN, CNRN
Co-Principal Investigator**

Quit Participation Letter

If the caregiver has expressed their desire to quit their participation in the study the following letter should be sent to them and signed by Paula Sherwood.

Today's Date

Participant's Name

Address

City, State Zip

Dear _____,

Thank you for your time in participating in the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University.

We understand that you wish to decline continued participation in the study. We respect your decision not to continue and understand that this may not be the right time for you to participate. Your loved one's medical care will not be affected by this decision to withdraw from this study. If you have care problems, please contact your treatment center.

Thank you for your consideration and willingness to participate to date. If for any reason you decide that you would like to speak with a member of our staff, please feel free to call us at (517) 353-0306 or toll free at 1-888-353-0306 between 9am and 5pm, Monday – Friday. You may leave a message at any time.

Sincerely,

Paula Sherwood, RN, MSN, CNRN
Co-Principal Investigator

Caregiver Thank You Letter

Today's Date

name
address
city and state

Dear (name),

Thank you for your time and interest in participating in the project entitled, Family Care of Persons with a Brain Tumor, conducted in affiliation with the Walther Cancer Institute, American Cancer Society, Oncology Nursing Society Foundation, the American Brain Tumor Association and Michigan State University. We respect and value the information you recently shared with us in the telephone interview. Your responses are important in helping us understand the experiences caregivers of persons with a brain tumor have.

If you have questions or comments concerning this project and your role as a participant, we encourage you to call a member of the project staff at (517) 353-0306, or toll free, 1-888-353-0306 between 9:00 a.m. and 5:00 p.m., Monday through Friday. You may leave a message at any time.

We appreciate your willingness to participate in this project. Thank you again for your time!

Sincerely,

(Interviewer Name)
Research Assistant

Appendix A: Components of Interview and Shortened Interview

Concept	Regular Interview	Shortened Interview
Caregiver Socio-demographics	Written questions	Written questions
Patient Socio-demographics	Written questions	Written questions
Perceived adequacy of information to care	PMH/PSQ-MD	Not included
Patient's neuropsychiatric status	NPI-Q	NPI-Q
Patient's cognitive status	MDS-CPS	MDS-CPS
Patient's functional status	ADL/IADL	ADL/IADL
Caregiver burden	CRA	CRA
Caregiver burden	Screen for Cgvr Burden	Screen for Cgvr Burden
Depression	CES-D	CES-D
Mastery	Mastery	Not included

Instruments listed below:

1. Caregiver Sociodemographics
2. Patient Sociodemographics
3. Princess Margaret Hospital Patient Satisfaction Questionnaire with Physician (PMH/PSQ-MD)
4. Neuropsychiatric Inventory-Questionnaire (NPI-Q)
5. Minimum Data Set – Cognitive Performance Scale (MDS-CPS)
6. Activities of Daily Living and Independent Activities of Daily Living (ADL/IADL)
8. Caregiving Reaction Assessment (CRA)
9. Screen for Caregiver Burden
10. Center for Epidemiologic Studies-Depression
11. Mastery Scale

Appendix H

Michigan State University Family Care of Persons with a Brain Tumor Caregiver **CONSENT FOR RESEARCH**

Purpose and Benefits

You are being asked to participate in a research project to find out what factors are involved in caring someone with a brain tumor. We believe that the knowledge from this study will be helpful to health care professionals who care for families of people with brain tumors.

This study is being conducted by Dr. Barbara Given, who is a professor in the College of Nursing at Michigan State University and Paula Riess who is a doctoral candidate in the College of Nursing at Michigan State University. This study will involve 120 caregivers 21 years of age or older who are providing care for someone with a brain tumor.

Description of Procedures

Because we are asking questions about both you and your family member, we will need both of you to give consent. However, only you will be interviewed. If you both agree to participate in the study, you will sign the consent form and mail it back to investigator in the pre-addressed, stamped envelope provided. Once the investigator receives your consent in the mail, she will contact you at home by telephone two times - once to set up an interview and once to complete the interview. A trained interviewer will call you to ask questions about how you may be assisting your family member with managing symptoms, activities of daily living, and medical procedures at home, as well as questions about how you are feeling about your role as a caregiver and how you are feeling emotionally. **It will take about 45-60 minutes to complete the interview.** You may be contacted one additional time by phone by the investigator to confirm or review any responses that may be unclear. As a participant, you will be enrolled in the study until the study is completed.

Risks and Discomforts

It is not expected that you will be placed at any physical, financial or legal risk as a result of participation in this study, other than the time and effort that you put into answering our questions. Regardless of whether or not you choose to participate in this study, your family member will continue to receive medical care under the direction of their physicians and nurses.

You may feel uneasy about sharing personal information. However, all information collected for this study through the telephone interview will be kept in a confidential file at Michigan State University. Only Paula Riess, co-investigator, will have access to records that could directly or indirectly identify you. Results from the study will be presented as a group summary with no indication of the individual involved, the data will

never be identified directly with you. Your privacy will be protected to the maximum extent allowable by law.

Rights and Responsibilities

Your participation in this study is entirely voluntary. Neither you nor your insurer will incur any extra costs as a result of participation in this study. You are free to withdraw from the study at any time. If you choose not to take part in this study, or if you withdraw after you have started, you will not be penalized in any way, nor will the quality of care you receive be affected. You are encouraged to ask questions about this research and your rights as a research subject at this time or anytime in the future. If you need further information about this research study, you may call Dr. Barbara Given, the Principal Investigator at Michigan State University at (517) 353-3843 or toll free in Michigan at (888) 353-0306 or Paula Riess, the Co-Principal Investigator at Michigan State University at (517) 353-8687 or toll free at (866) 855-0941.

In the unlikely event of any injury from the research, Michigan State University offers no reimbursement, compensation or free medical treatment. Your hospital and/or medical care will continue under the direction of your physicians. Should you have any questions about your rights as a research subject or should you sustain any injury related to the research, you may contact Dr. Ashir Kumar, Chair, Michigan State University Committee on Research Involving Human Subjects at (517) 355-2180.

Subject's Authorization

I have had the "Family Care of Brain Tumor Patients" study explained to me. I have had the opportunity to ask questions, and I was given enough time to consider my participation. I have received a copy of this consent form and I agree to participate in this study.

Caregiver's Signature _____ **Date** _____

Witness' Signature _____ **Date** _____

PLEASE PRINT:

Caregiver Name _____

Address _____

Phone Number _____

Michigan State University

Family Care of Persons with a Brain Tumor
PATIENT CONSENT FOR RESEARCH

Purpose and Benefits

You are being asked to participate in a research project to find out what factors are involved in caring for someone with a brain tumor. We believe that the knowledge from this study will be helpful to health care professionals who care for families of people with brain tumors.

This study is being conducted by Dr. Barbara Given, who is a professor in the College of Nursing at Michigan State University and Paula Riess who is a doctoral candidate in the College of Nursing at Michigan State University. This study will involve 100 caregivers 21 years of age or older who are providing care for someone with a brain tumor.

Description of Procedures

Because we are asking questions about both you and your caregiver, we will need both of you to give consent. However, only your caregiver will be interviewed. If you both agree to participate in the study, you will sign the consent form and mail it back to investigator in the pre-addressed, stamped envelope provided. Your caregiver will be contacted by phone twice - once to set up an interview and once to complete the interview. A trained interviewer will call your caregiver to ask questions about how they may be assisting you with managing symptoms, activities of daily living, and medical procedures at home, as well as questions about how they are feeling about their role as a caregiver and how they are feeling emotionally. Your caregiver may be contacted one additional time by phone by the investigator to confirm or review any responses that may be unclear. **You will not** be contacted at any time throughout the study. However, your permission is necessary to collect some of the information we will be asking such as your cancer type, treatment, and symptoms. As a participant, you will be enrolled in the study until the end of the study.

With your consent, a member of the research staff will either review part of your current medical record or talk to your caregiver to obtain information about your medical diagnoses/problems, and the treatment(s) you are receiving for cancer or other health problems.

Risks and Discomforts

It is not expected that you will be placed at any physical, financial or legal risk as a result of participation in this study. Regardless of whether or not you choose to participate in this study, you will continue to receive medical care under the direction of your physicians and nurses.

All information collected for this study through the telephone interview and the medical audit will be kept in a confidential file at Michigan State University. Only Paula Riess, co-investigator, will have access to records that could directly or indirectly identify you. Results from the study will be presented as a group summary with no indication of the individual involved, the data will never be identified directly with you. Your privacy will be protected to the maximum extent allowable by law.

Rights and Responsibilities

Your participation in this study is entirely voluntary. Neither you nor your insurer will incur any costs as a result of participation in this study. You are free to withdraw from the study at any time. If you choose not to take part in this study, or if you withdraw after you have started, you will not be penalized in any way, nor will the quality of care you receive be affected. You are encouraged to ask questions about this research and your rights as a research subject at this time or anytime in the future. If you need further information about this research study, you may call Dr. Barbara Given, the Principal Investigator at Michigan State University at (517) 353-3843 or toll free in Michigan at (888) 353-0306 or Paula Riess, the Co-Principal Investigator at Michigan State University at (517) 353-8687 or toll free at (866) 855-0941.

In the unlikely event of any injury from the research, Michigan State University offers no reimbursement, compensation or free medical treatment. Your hospital and/or medical care will continue under the direction of your physicians. Should you have any questions about your rights as a research subject or should you sustain any injury related to the research, you may contact Dr. Ashir Kumar, Chair, Michigan State University Committee on Research Involving Human Subjects at (517) 355-2180.

Subject's Authorization

I have had the "Family Care of Brain Tumor Patients" study explained to me. I have had the opportunity to ask questions, and I was given enough time to consider my participation. I have received a copy of this consent form and I agree to allow my caregiver to release medical information regarding my condition.

Patient's Signature _____ **Date** _____

Legal Representative if unable to sign:

Name _____

Signature _____ **Date** _____

Witness' Signature _____ **Date** _____

PLEASE PRINT:

Patient Name _____

Address _____

Phone Number _____

Caregiver Name _____

Caregiver Phone _____

Appendix I
Additional Analyses

Table A

Number and Percentage of Respondents who Provided Assistance with ADLs and IADLs (n=95)

Activity	Number provided assistance	% provided assistance
Eating	18	18.9%
Bathing	26	27.4%
Dressing	34	35.8%
Toileting	17	17.9%
Walking inside the house	27	28.4%
Getting out of bed	21	22.1%
Transportation	49	51.6%
Laundry	42	44.2%
Shopping	39	41.1%
Housework	42	44.2%
Meal preparation	41	43.2%

Table B

Number and Percentage of Respondents whose Care Recipients had Cognitive Problems

Problem	N	Number of Respondents indicating problem was present	% Respondents indicating problem was present
Short term memory loss	95	61	64.2%
Long term memory loss	95	32	33.7%
Inability to remember current season	95	10	10.5%
Inability to remember where s/he lived	95	9	9.5%
Inability to remember friends and family	95	17	17.9%
Inability to remember s/he was at home	95	10	10.5%
Times when s/he was less alert	94	29	30.5%
Inability to remember where s/he was	95	10	10.5%
Times when his/her thinking changed during the day	94	40	42.1%

Table C

Number and Percentage of Respondents whose Care Recipients had Neuropsychiatric Problems (N=95)

Problem	Number of Respondents indicating problem was present	% Respondents indicating problem was present
Delusions	22	23.7%
Hallucinations	12	12.8%
Agitation/aggression	35	36.8%
Dysphoria/depression	56	60.2%
Anxiety	33	35.9%
Euphoria/elation	14	14.7%
Apathy/indifference	38	40.0%
Disinhibition	27	28.4%
Irritability/lability	52	54.7%
Aberrant motor	20	21.1%
Nighttime disturbances	51	54.8%
Appetite/eating disturbances	60	65.2%

Table D

Regression Models Determining the Effect of NPI on Caregiver Outcomes for Persons with Varying Levels of Mastery

Effect of NPI on caregiver depression for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance
Constant	12.6	2.3	5.6	.000
NPI	1.18	.4	2.9	.006
Effect of NPI on caregiver depression for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	4.2	1.8	2.3	.03
NPI	1.9	.4	4.9	.000
Effect of NPI on self esteem subscale of CRA for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance
Constant	10.9	1.2	9.1	.000
NPI	0.7	0.2	3.2	.003
Effect of NPI on self esteem subscale of CRA for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	12.3	0.9	13.4	.000
NPI	0.0	0.2	0.1	.954
Effect of NPI on abandonment subscale of CRA for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance
Constant	9.4	.9	9.4	.000
NPI	0.5	0.2	2.9	.006
Effect of NPI on abandonment subscale of CRA for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	8.6	1.4	6.3	.000
NPI	0.3	0.3	0.9	0.4
Effect of NPI on finances subscale of CRA for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance
Constant	5.2	0.8	6.9	.000
NPI	0.6	0.1	4.1	.000
Effect of NPI on finances subscale of CRA for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	4.6	1.9	5.3	.000
NPI	0.5	0.2	2.7	.009
Effect of NPI on schedule subscale of CRA for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance
Constant	14.6	1.0	14.3	.000
NPI	0.6	0.2	3.3	.002
Effect of NPI on schedule subscale of CRA for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	14.1	0.9	14.2	.000
NPI	0.4	0.2	1.7	.090
Effect of NPI on health subscale of CRA for persons with low mastery (n=41)				
	Beta	Standard Error	t-test	Significance

Constant	7.7	0.8	9.5	.000
NPI	0.5	0.1	3.6	.001
Effect of NPI on health subscale of CRA for persons with high mastery (n=54)				
	Beta	Standard Error	t-test	Significance
Constant	6.9	1.7	10.1	.000
NPI	0.4	0.1	2.6	.014

Note. CRA=Caregiver Reaction Assessment (measure of caregiver burden);
NPI=neuropsychiatric inventory (measure of the sum of the care recipient's
neuropsychiatric symptoms).

Table E

Regression Models Determining the Effect of Covariates on Caregiver Outcomes (N=95)

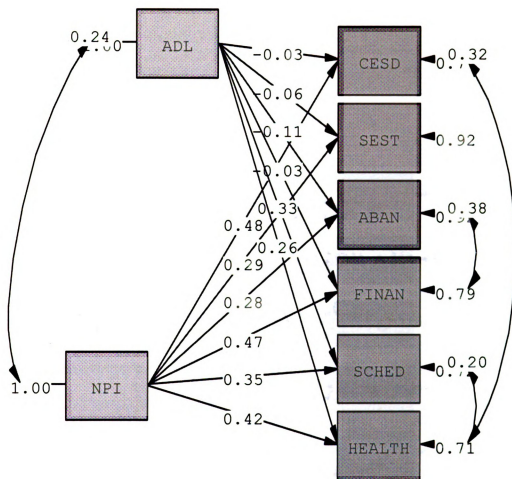
Effect of covariates on caregiver depression				
	Beta	Standard Error	t-test	Significance
Constant	29.7	6.7	4.4	.000
Sex	-1.6	1.8	-0.9	.370
Age	-0.1	0.1	-0.9	.384
Relationship to care recipient	4.9	1.8	2.8	.006
Length of time providing care	-.01	0.02	-0.3	.749
Type of tumor	-1.8	1.6	-1.1	.281
Effect of covariates on self esteem subscale of caregiver burden				
	Beta	Standard Error	t-test	Significance
Constant	17.1	3.7	4.7	.000
Sex	0.3	0.9	0.3	.778
Age	0.02	0.04	0.5	.618
Relationship to care recipient	-0.3	0.9	-0.4	.725
Length of time providing care	-0.01	0.01	-0.6	.548
Type of tumor	0.6	0.9	0.7	.483
Effect of covariates on abandonment subscale of caregiver burden				
	Beta	Standard Error	t-test	Significance
Constant	9.1	3.9	2.3	.022
Sex	0.8	1.1	0.7	.472
Age	0.1	0.04	1.9	.059
Relationship to care recipient	-0.1	1.0	-0.07	.943
Length of time providing care	-0.02	0.01	-1.3	.208
Type of tumor	0.4	0.9	0.4	.659
Effect of covariates on finances subscale of caregiver burden				
	Beta	Standard Error	t-test	Significance
Constant	9.03	2.4	3.7	.000
Sex	1.4	0.7	2.1	.059
Age	0.05	0.02	2.2	.030
Relationship to care recipient	-1.3	0.6	-2.0	.057
Length of time providing care	-.02	0.01	-1.9	.054
Type of tumor	0.5	0.6	0.9	.388
Effect of covariates on schedule subscale of caregiver burden				
	Beta	Standard Error	t-test	Significance
Constant	18.8	3.2	5.8	.000
Sex	-0.7	0.9	-0.7	.459
Age	0.03	0.03	0.8	.419
Relationship to care recipient	-0.4	0.9	-0.4	.669
Length of time providing care	-0.01	0.01	-1.1	.264
Type of tumor	1.5	0.8	1.9	.056
Effect of covariates on health subscale of caregiver burden				
	Beta	Standard Error	t-test	Significance

Constant	9.9	2.5	3.9	.000
Sex	-0.4	0.7	-0.6	.576
Age	-.01	0.03	-0.4	.704
Relationship to care recipient	0.2	0.7	0.2	.819
Length of time providing care	-0.01	0.01	-1.04	.300
Type of tumor	1.1	0.6	1.9	.066

Note. Predictor variables (neuropsychiatric status and activities of daily living scores are not presented here). Relationship to the care recipient was coded as 0=spouse, 1=all other; Type of tumor was coded as 0=GBM, 1=all other.

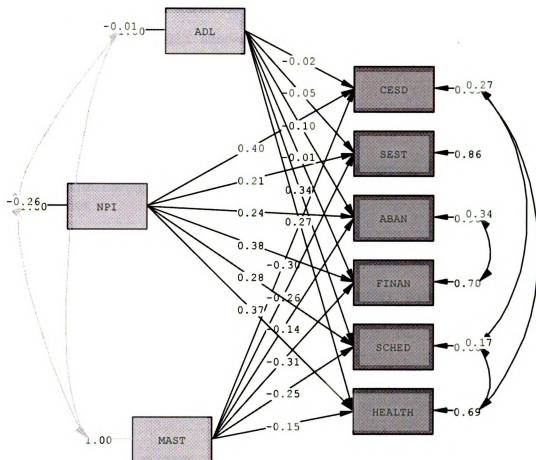
Appendix J

Full Models with Nonsignificant and Significant Paths



Full model of Figure 3. Parsimonious primary structural model: Effect of functional (ADL) and neuropsychiatric (NPI) status on caregiver depressive symptoms (CESD) and caregiver burden (sest = self esteem; aban = abandonment; finan = finances; sched = schedule; and health). * Path significant at the $p < .05$ level.

Note. Hidden error variances: CES-D = 0.77; Aban = 0.92; Sched = 0.72.



Full model of Figure 4. Parsimonious secondary structural model: Effect of functional (ADL), neuropsychiatric (NPI) status and mastery (mast) on caregiver depressive symptoms (CESD) and caregiver burden (sest = self esteem; aban = abandonment; finan = finances; sched = schedule; and health). *Path significant at the $t > 2.00$ level.

Note. Hidden error variances: CES-D = 0.69; Aban = 0.90; Sched = 0.66.

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