



Published in final edited form as:

J Neurooncol. 2009 July ; 93(3): 333–342. doi:10.1007/s11060-008-9778-z.

Perceptions of economic hardship and emotional health in a pilot sample of family caregivers

Sarah E. Bradley,

Graduate School of Public Health, University of Pittsburgh, Pittsburgh, USA

Paula R. Sherwood,

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA, prs11@pitt.edu

Department of Neurosurgery, School of Medicine, University of Pittsburgh, Pittsburgh, USA

Jean Kuo,

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Candace M. Kammerer,

Graduate School of Public Health, University of Pittsburgh, Pittsburgh, USA

Elizabeth A. Gettig,

Graduate School of Public Health, University of Pittsburgh, Pittsburgh, USA

Dianxu Ren,

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Wesley M. Rohrer,

Graduate School of Public Health, University of Pittsburgh, Pittsburgh, USA

School of Health & Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, USA

Heidi S. Donovan,

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Allison Hricik,

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Alyssa Newberry, and

School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Barbara Given

College of Nursing, Michigan State University, East Lansing, USA

Abstract

Although several studies have quantified costs of cancer care; none to date have examined how cancer costs impact family caregivers' emotional health. This study was designed to evaluate how perceptions of economic hardship influence burden, depressive symptoms, and anxiety in family

caregivers of persons with a primary malignant brain tumor. Caregiver (CG)/patient dyads ($n = 33$) were recruited at the time of diagnosis; data were collected at diagnosis and 4 months, and linear regression determined the impact of economic hardship on caregivers' emotional health. Economic hardship did not predict CG burden-schedule at diagnosis or 4 months. Economic hardship predicted burden-abandonment at diagnosis ($P < 0.01$), but not 4 months. There was a trend for economic hardship to predict CG depressive symptoms at 4 months ($P = 0.09$), but not at diagnosis. Economic hardship predicted CG anxiety at 4 months ($P = 0.06$), but not diagnosis. Results suggest caregivers' economic hardship is an important and dynamic aspect of the emotional health of neuro-oncology family caregivers.

Keywords

Brain tumor; Caregiver; Emotional health; Economic hardship; Cancer cost

Introduction

Research has shown that persons undergoing treatment for cancer face many expenses, such as co-payments and deductibles for prescription medications and hospital stays, and loss of income. In addition, due to care demands, many family caregivers are forced to leave or reduce paid employment, leading to a loss of earnings in addition to those lost by the patient. It is clear that cancer is a costly disease, both for persons diagnosed and their family caregivers. Yet, while studies have reported work on quantifying the costs of cancer care, little research has explored how these costs impact family caregivers, who have been consistently shown to be at risk for negative outcomes.

Over the past several decades much research has documented the toll that providing care has on the emotional health of the caregiver, placing caregivers at risk for depression, anxiety, and feelings of burden [1–3]. However, to date, no research has examined whether the perception of economic hardship contributes to these outcomes. There is also a paucity of research describing how the perception of economic hardship changes over time, as the patient's disease and treatment progress. Finally, almost no research to date has focused on the financial impact of cancer care on caregivers of persons with a primary malignant brain tumor (PMBT), a population that faces challenges due to both patients' neurological dysfunction and treatment side-effects. The purpose of this study was to evaluate how perceptions of economic hardship influence burden, anxiety, and depressive symptoms in caregivers of persons with a primary malignant brain tumor.

Background

Advances in diagnosis and treatment have extended patients' survival making some cancers, even in advanced stages, a chronic, rather than immediately life threatening, illness. While improved treatment has enabled Americans to live with cancer longer, it has also caused the national cost of the disease to balloon to over \$206 billion in 2006 [4]. Of this, only \$78 billion, or roughly one-third of the total cost, is spent on direct medical costs; the other two-thirds are incurred as indirect costs due to factors such as lost productivity at work [4]. Direct costs are expenses related to cancer treatment, and include bills and copayments for clinic visits or hospital stays. These costs may be fully or partially covered by third party payers. Indirect costs, on the other hand, are often due to opportunities lost because of cancer treatment, such as loss of income, used savings that were earmarked for another purpose, canceled vacations, transportation and child care [5]. These indirect expenses are absorbed by patients and their families, can be significant, and have real impact on not only the person with cancer, but their family members as well.

With few exceptions, much of the research on the impact of cancer costs has focused on persons affected with more common types of cancer, such as breast, prostate, colon, and lung. For example, Bradley et al. explored the amount of time that employed breast and prostate cancer patients spent away from work, and found that women treated for breast cancer missed an average of 44.5 days from work, while men with prostate cancer missed an average of 27 days [6]. In addition, the greatest increase in missed days occurred 6 months following the patient's diagnosis, while by 12 and 18 months many patients had returned to work [7]. Similar to other studies in this area, Bradley et al.'s work focused primarily on the person with cancer, rather than the impact of those costs on family members.

In the past, research has shown that the families and caregivers of other types of ill patients experience financial strain, or discouragement that their financial situation will improve. A study by Wimo et al. in 1993 showed that family caregivers of dementia patients experienced financial burden [8]. A large study of male dementia patients and their female caregivers illustrated that the largest component of cost to the caregiver is lost earnings [9]. The average lost earnings was calculated to be \$10,709 per year. These dementia caregivers also spent a significant amount of valuable time with their respective patients, and used their own resources to pay for care-related goods and services. Moore et al. estimated this cost to be approximately \$360 per month [9]. The findings of the study suggested that as the disease progressed, caregivers were spending more time providing care, and therefore informal costs increased with disease progression [9]. It remains to be seen whether these financial pressures alter caregivers' emotional health.

In previously healthy persons, financial concerns have been shown to have an impact on health. In a prospective study of 1,759 men, Kubzansky et al. showed that men who reported high levels of worry about social conditions or financial concerns had an increased risk for myocardial infarction and angina [10]. A Swedish study from 1995 of over 2,400 adolescents showed that participants who frequently or constantly worried about their families' finances were more likely to report being in poor health [11]. To date, no additional research has explored this finding in other populations.

Persons diagnosed with a PMBT are faced with a unique and challenging set of circumstances that affects not only them but those close to them as well. Neurologic dysfunction in the patient forces caregivers of persons with a PMBT to face stressors similar to those of caregivers of persons with dementia, a subset of caregivers who have been shown to suffer from negative psycho-behavioral responses such as depressive symptoms, anxiety, and difficulty sleeping [1–3]. Besides neurologic dysfunction, caregivers of persons with a PMBT must also grapple with oncologic issues, such as the diagnosis of a potentially terminal illness and the side effects of cancer treatment. Therefore, these caregivers are also at risk for negative outcomes similar to those of caregivers for persons with other types of cancer. Persons caring for a loved one with cancer have been shown to be at risk for negative emotional responses such as depressive symptoms, anxiety, and burden [2,12,13]. It is not known if worries about money, which may be exacerbated by disease-related costs, influence the emotional health of caregivers.

Prior work has suggested that the costs related to cancer treatment do have a negative effect on patients with primary malignant brain tumors (PMBT) and their families [14]. A descriptive, qualitative study examined responses from 20 participants who had been diagnosed with a PMBT who were queried regarding the financial impact of their care. The analysis suggested that patients with a PMBT felt that their treatment- and cancer-related costs caused repercussions for their family and friends [14]. For example, participants described feeling frustrated because they were not able to continue to provide well for their families and voiced anxiety and distress over financial concerns. Although the study was limited by self-selection,

this beginning work suggests that worries over cancer costs affect not only the patient but also the patient's family.

It appears that costs related to cancer diagnosis and treatment can have a significant effect on not only the patients, but also their caregivers. While past studies suggest that financial worry may have an effect on physical health, no research to date has explored how the perception of economic hardship caused by cancer diagnosis and treatment affects the emotional health of caregivers. The purpose of this study was to explore the extent to which perceived economic hardship influences caregiver burden, depressive symptoms, and anxiety controlling for caregiver age, gender, income, relationship to the patient, neuroticism, caregiver social support, and the patient's neuropsychological status.

Methods

Recruitment

As part of a prospective, descriptive, longitudinal study (NCI R01CA118711; Sherwood, PI), a pilot sample of caregiver/patient dyads ($N = 33$) were recruited through neuro-oncology and neurosurgery clinics at an urban tertiary medical center. Caregivers were denoted by the patient as the person who would be providing the majority of support (including emotional, financial, and physical support) to the patient. It was not a requirement of the study that caregivers be legally related to or live with the patient. Caregivers were considered eligible if they were not paid for their care (non-professional), 21 years of age or over, able to read and speak English, were not a primary caregiver for anyone else other than children under 21, and had reliable telephone access. Patients were eligible if they were over 21 years of age and newly (within 1 month) diagnosed with a PMBT verified via pathology report. Potential subjects were identified through referral from clinic staff. Details of participation were explained to each dyad; it was explained that both caregiver and patient had to agree to participate in order for the other to be eligible and that data collection would be performed twice, once at baseline and once in 4 months. Human subject approval was obtained from the author's institution prior to participant recruitment.

Data collection

Data were collected separately from each member of the dyad. Patient data were collected via medical record review and in person interview; caregiver data were collected during a telephone interview within 72 h of the patient's interview. All caregiver measures were administered by a trained member of the research team who recorded responses to instrument items in order to ensure completeness of data.

Measures

Independent variables and covariates—Perceived economic hardship was measured using Barrera et al.'s Economic Hardship questionnaire ($\alpha = 0.95-0.92$) [15]. Participants rated their perception of economic hardship in several areas, including how much financial strain they felt, their ability to make ends meet, having enough money for necessities, and whether they had to make any lifestyle adjustments due to financial need. Individual items were summed to produce an overall score, with higher scores indicating greater perception of economic hardship.

Several covariates were included in the analyses based on their documented association with emotional health [1,16–28]. Caregiver age was treated as a continuous variable; gender and relationship to the patient (spouse versus other) were dichotomized. Caregiver neuroticism was measured using the Goldberg Adjective Scale ($\alpha = 0.75$) [29]. Scores were generated by summing individual items; higher scores indicated stronger trait. Social support was measured

using the Interpersonal Support Evaluation List (ISEL) ($\alpha = 0.85\text{--}0.87$) [30]. Subjects rated the availability of three types of social support (appraisal, belonging, and tangible). Individual items were summed to produce an overall score, higher scores indicating more social support. The patients' neuropsychological status was measured by the Neurobehavioral Cognitive Status Examination (NCSE) ($\alpha = 0.43\text{--}0.76$) [31]. Subjects answered questions and performed tasks that indicated disability in the following domains: level of consciousness, attention, language, constructional ability, memory, calculations, and reasoning. Scores were calculated by summing the scores for each domain.

Dependent variables—Caregiver burden is a multidimensional concept and was therefore measured via two subscales of the Caregiver Reaction Assessment (CRA), which asks caregivers to indicate the degree to which providing care causes feelings of burden ($\alpha = 0.72\text{--}0.87$) [32,33]. The schedule subscale consists of five items that assess the impact of providing care on the caregiver's usual activities, including whether providing care has forced them to eliminate activities and interfered with relaxation. The abandonment subscale measured the ability of the family to support the caregiver and work together in the care situation (including the caregiver's perception of being 'abandoned'). Subscale scores resulted from summing individual items, and greater caregiver burden was indicated by higher scores.

Caregivers' depressive symptoms were measured using the modified Center for Epidemiologic Studies-Depression (CES-D) scale ($\alpha = 0.87$) [34–36]. Subjects indicated how often they experienced various symptoms. Individual items were summed to produce an overall score, higher scores indicating higher levels of depressive symptoms. Anxiety was measured using the anxiety subscale of the Profile of Mood States (POMS) scale ($\alpha = 0.94\text{--}0.91$) [28,37]. Individual items were summed to produce a total score, higher scores indicating higher levels of anxiety.

Statistical analysis

Separate backwards stepwise regression analyses were performed for each dependent variable in which the least significant of the independent variables was removed one at a time. Because it was the primary variable of interest, economic hardship was also forced in each model. Independent variables were removed until all variables in the model had a *P* value of 0.10 or lower (with the exception of economic hardship), and the overall model was significant ($P < 0.05$).

Results

Sample

A total of 33 caregiver/patient dyads were recruited for the project. As illustrated in Table 1, the majority of caregivers were Caucasian ($n = 32$, 97%), women ($n = 26$, 79%), and were spouses of the patient ($n = 21$, 64%). The mean age of the sample was 52.15 years (range: 21–81), and the caregivers had a mean number of 2.5 children (range: 0–12). At the time of the first interview, approximately one-half of the caregivers were employed ($n = 15$, 47%). Of those who were employed, 53% ($n = 8$) worked in a professional or technical occupation. The caregivers had an average length of formal education of 14.74 years ($SD = 3.32$), indicating that many had at least some post-secondary education. The caregivers reported an annual household income of less than \$50,000 in 42% ($n = 13$) of the cases. Study participants were classified as high, medium, or low income based on relationship to poverty thresholds determined by the U.S. Census Bureau [38]; 15% ($n = 5$) were low-income, 33% ($n = 11$) were moderate-income, and 45% ($n = 15$) were high-income. A majority (85%, $n = 28$) of the caregivers held private health insurance, while two caregivers reported they did not have health insurance.

The majority of the patients were men ($n = 23$, 70%) with a mean age of 52.51 years (range: 22–85). Most of the patients' tumors were classified as either astrocytoma grade I–III ($n = 7$, 21%) or astrocytoma grade IV (glioblastoma multiforme) ($n = 20$, 61%). Many of the patients ($n = 15$, 45%) underwent at least one craniotomy. Of those patients known to have received chemotherapy, Temodar was the most common drug received ($n = 22$, 67%). Seventy percent ($n = 23$) of the patients were known to have had radiation as part of their treatment regimen.

Caregiver burden

Burden due to schedule—Analyses are summarized in Table 2. At baseline (Model A), caregiver burden related to the caregivers' schedule was not predicted by caregivers' perception of economic hardship ($P = 0.27$). However, burden due to schedule was predicted by caregiver neuroticism ($P = 0.04$), caregiver sex ($P = 0.05$), and caregiver age ($P = 0.04$). There was also a trend for social support to predict burden ($P = 0.06$). Caregivers with higher levels of neuroticism and those who were women, older, and reported less social support reported that providing care negatively impacted their schedule. Four months after the diagnosis, perceived economic hardship continued to be nonsignificant as a predictor of caregiver burden related to schedule, although social support did have a significant relationship ($P = 0.01$) (Model B). Caregivers who had lower levels of social support reported higher levels of caregiver burden due to their schedule. There was also a trend for caregivers had higher levels of neuroticism ($P = 0.08$) to report higher levels of burden related to schedule.

Burden due to feelings of abandonment—Caregiver burden due to feelings of abandonment at baseline was significantly predicted by perceived economic hardship ($P < 0.01$), and the patient's total neuropsychological functioning ($P = 0.01$) (Model C). Caregivers who perceived a high level of economic hardship and those who were caring for persons with high levels of neuropsychological function reported higher levels of burden related to feeling abandoned by family and friends. At 4 months following diagnosis, caregiver burden related to feelings of abandonment was not predicted by perception of economic hardship. It was, however, related to the patient's neuropsychological function ($P < 0.01$) and caregiver sex ($P = 0.02$) (Model D). Caregivers of persons who had higher levels of neuropsychological function and female caregivers were more likely to report higher levels of burden due to abandonment.

Depressive symptoms—At the time of diagnosis, depressive symptoms were not predicted by the perception of economic hardship, but were predicted by neuroticism ($P < 0.01$) (Model E). Caregivers with higher levels of neuroticism reported higher levels of depressive symptoms. There was also a trend of caregivers who were caring for patients with greater neuropsychological functioning to report more depressive symptoms ($P = 0.06$). Four months after the patient's diagnosis, perception of economic hardship was the only predictor of caregiver depressive symptoms ($P = 0.09$) that approached significance. As caregivers had greater perception of economic hardship, they also tended to report more depressive symptoms (Model F).

Anxiety—The final analysis of caregiver emotional health at the time of diagnosis was performed to identify predictors of caregiver anxiety. Perception of economic hardship did not predict anxiety ($P = 0.24$), although caregiver neuroticism was a significant predictor ($P < 0.01$) (Model G). Caregivers with greater levels of neuroticism reported higher levels of anxiety. At 4 months following diagnosis, there was a trend for caregiver anxiety to be predicted by caregivers' perception of economic hardship ($P = 0.06$) (Model H). Caregivers who reported higher levels of perceived economic hardship tended to report higher levels of anxiety.

Discussion

Cancer is a costly disease, both for those diagnosed and their family members. Research has shown that undergoing treatment for cancer results in many expenses over and above the direct costs of care, the impact of which is often felt by family members who serve as family caregivers. While studies have reported work on quantifying the costs of cancer care, and a separate body of literature has shown that financial concerns affect emotional health in healthy adults, little research has explored how the costs of cancer impact caregivers' burden, depressive symptoms, and anxiety. The purpose of this study was to explore the extent to which perceived economic hardship contributes to caregiver burden, depressive symptoms, and anxiety.

Burden due to schedule

Perception of economic hardship did not predict burden due to schedule at either the time of diagnosis or 4 months into the disease trajectory. Caregiver burden due to schedule at baseline was predicted by neuroticism, age, sex, and social support. Persons who were more neurotic reported higher levels of burden, data which supports work in caregivers of persons with Alzheimer's disease and persons with cancer [15,29]. In this sample, caregiver age also predicted burden due to schedule in a manner such that older caregivers were more likely to report feeling burdened. In general, studies have suggested that younger caregivers were more likely to feel burdened [1,39,40]. However, the majority of the caregivers (64%) were spouses, a group who has been shown to also be at risk for feelings of burden [1], which may be complicating results. This interaction should be explored in a larger sample. Lastly, at the time of diagnosis, social support predicted burden due to schedule in such a way that caregivers with less social support reported more feelings of burden. This finding holds with previous research with caregivers of terminally ill cancer patients that suggest that low social support is associated with higher levels of burden [20]. Nabors et al. [41] found that in their study population of caregivers of patients with traumatic brain injuries, caregivers with less social support and more unmet family needs tended to report higher levels of burden. In fact, at 4 months after diagnosis, social support was the only significant predictor of caregiver burden due to schedule.

Burden due to feelings of abandonment

At the time of diagnosis, caregivers were more likely to feel abandoned in the care situation when they perceived a higher level of economic hardship, an association which disappeared 4 months following diagnosis. It may be hypothesized that at the time of diagnosis the caregiver may worry about many things, but one stressor may be the looming bills and financial pressures. These worries may cause the caregiver to feel alone and without support, particularly if the patient, who used to help shoulder financial responsibility, is no longer able to do so. At 4 months into the care situation, however, the caregiver is likely to have received help from others in caring for the patient, so that he or she may go to work and fulfill other responsibilities. It may also be hypothesized that some of these caregivers are finding that their ill loved ones are able to return to work and are therefore sharing in the financial load.

Caregivers also reported higher levels of feeling abandoned when they were caring for patients with higher levels of neuropsychological function. This finding differs from the studies that report an association between increased caregiver burden in the presence of increased neurological dysfunction [1,16,42,43]. It may be the case that at the outset of the care situation, caregivers of higher functioning persons do not receive as much help from friends and family members. Because the patient seems to be doing well, friends and family may not think it necessary to offer support and assistance to the caregiver.

Four months after the patient's diagnosis, caregiver burden due to feelings of abandonment was predicted by patient neuropsychological functioning such that caregivers caring for patients with worse functioning were more likely to report feeling burdened. This is the expected relationship as reported by previous studies [1,16,42,43], but differs from that seen in this study at the time of diagnosis. The relationship between patient neuropsychological function and caregiver emotional health may be a changing one. Lastly, 4 months after the patient's diagnosis caregiver burden due to feelings of abandonment was predicted by caregiver sex, such that female caregivers were more likely to report feeling burdened.

Depressive symptoms

At the time of diagnosis, caregiver reports of depressive symptoms were not predicted by perception of economic hardship. However, 4 months into the care situation it was the only predictor of these symptoms to approach significance. This study found that, 4 months into the disease trajectory, caregivers who reported greater perception of economic hardship tended to report having more depressive symptoms. This study, therefore, provides evidence that the perception of economic hardship may influence caregiver depressive symptoms, and that this relationship develops over the disease course. Perhaps, as time passes, financial pressures feel more and more like insurmountable obstacles to these caregivers.

At the time of diagnosis caregiver depressive symptoms were predicted by personality type such that caregivers with higher levels of neuroticism were more likely to report depressive symptoms. This is a finding that is supported in studies of caregivers of persons with Alzheimer's disease and persons with cancer [15,29,33]. In keeping with some of the findings reported earlier, the patient's neuropsychological functioning predicted depressive symptoms such that patients with better functioning tended to have caregivers who reported more depressive symptoms. Several past studies have found the opposite effect, that caregivers were more likely to report depressive symptoms, and feel burdened and anxious when caring for poorly functioning patients [1,16,42,43]. It is possible that the discrepancies found in this study in terms of the relationship between the neurological functioning of the patient and caregiver burden and depressive symptoms may be partly a function of the timing of the interviews. It may be that caregivers of highly functioning patients feel greater dread about the inevitable decline of their loved one, which may in turn affect their levels of burden and depressive symptoms. The variance in results suggests that analyses should be further explored in a larger sample, and at several time points over a longer treatment trajectory.

Anxiety

At the time of diagnosis, perception of economic hardship did not predict caregiver anxiety. However, four months into the care situation, perceived economic hardship was the only predictor of anxiety that neared significance. At 4 months, caregivers who perceived more economic hardship tended to report more anxiety. This suggests that the relationship between perceived economic hardship and anxiety may be a changing one.

Summary

These results suggest that perceived economic hardship may play an important role in caregivers' emotional health. However, it appears that the nature of this relationship changes over time, even though the actual perception of economic hardship may not (*t*-tests comparing caregiver reports of economic hardship between baseline and four months did not reveal a significant mean difference, data not shown). At the outset, these PMBT caregivers felt more burdened due feelings of abandonment when they had a greater perception of economic hardship, but this relationship did not hold up throughout the disease trajectory. In contrast, as time progressed, caregivers who reported more perceived economic hardship tended to report

greater depressive symptoms and anxiety. These data suggest that economic hardship plays a volatile, yet significant role in caregivers' emotional health. Suggestions for future research are detailed in Table 3.

Limitations

This study is limited by its relatively small sample size of 33 participants. The majority of participants in the sample were Caucasian and had private health insurance. Although this is representative of the way in which the disease occurs, it precludes generalization to other ethnic groups where other avenues of financial and family support may vary. In addition, participants were recruited solely from medical clinics serving the Western region of one state. It is likely that economic concerns vary across geographical settings. Care recipients were also diagnosed with both low-grade and high-grade tumors. Although all care recipients had tumors that were classified as malignant, it is likely that economic concerns differ when the trajectory of disease is different (e.g., the difference in survival between someone with a grade IV astrocytoma and someone with an oligodendroglioma). A larger sample size would be able to help discern these effects. The ages of children in the home may also have impacted financial burden, which should be considered in a future study. Another limitation of this work concerns the dependent variable of interest. Although the purpose of this study was to determine predictors of *perceived economic hardship*, it is likely that income level plays a large role in perceptions of economic hardship. Initial analyses found a significant correlation between income level and perceived economic hardship. However, sample size precluded examinations of the interactions between income level and perceived economic hardship in the regression analyses. Sample size also precluded the use of more sophisticated types of analyses, which could, among other things, account for correlations among variables. In the future, a larger sample size may be better able to distinguish differing ways in which socioeconomic status affects perceived economic hardship, particularly when longitudinal data are analyzed using repeated measures or mixed model approaches. Finally, although persons with differing annual household incomes were represented in the sample, approximately 1/2 of the caregivers reported incomes above \$50,000, which may limit generalization. Alternately, slightly <1/2 of the caregivers reported incomes below \$50,000, which may suggest that financial distress is likely to have been present for a period of time prior to diagnosis. Including a variable to indicate length of time in current financial category would help to clarify whether this is a potential confounding variable.

References

1. Pinquart M, Sorensen S. Differences between caregivers and non-caregivers in psychological health and physical function: a meta-analysis. *Psychol Aging* 2003;18(2):250–267.10.1037/0882-7974.18.2.250 [PubMed: 12825775]
2. Sherwood P, Given B, Donovan H, Given C, et al. Guiding research in family care: a new approach to oncology caregiving. *Psychooncology* 2008;17:986–996. [PubMed: 18203244]
3. Vitaliano P, Scanlan J, Zhang J. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129(6):946–972.10.1037/0033-2909.129.6.946 [PubMed: 14599289]
4. American Cancer Society. *Cancer facts & figures 2007*. American Cancer Society; Atlanta: 2007.
5. Moore KA. Breast cancer patients' out-of-pocket expenses. *Cancer Nurs* 1999;22(5):389–396.10.1097/00002820-19991000 0-00007 [PubMed: 10526432]
6. Bradley CJ, Oberst K, Schenk M. Absenteeism from work: the experience of employed breast and prostate cancer patients in the months following diagnosis. *Psychooncology* 2006;15:739–747.10.1002/pon.1016 [PubMed: 16374893]
7. Bradley CJ, Neumark D, Luo Z, Schenk M. Employment and cancer: findings from a longitudinal study of breast and prostate cancer survivors. *Cancer Invest* 2007;25:47–54.10.1080/07357900601130664 [PubMed: 17364557]

8. Wimo A, Mattsson B, Adolfsson R, et al. Dementia day care and its effects on symptoms and institutionalization—a controlled Swedish study. *Scand J Prim Health Care* 1993;11:117–123.10.3109/02813439308994913 [PubMed: 8356361]
9. Moore MJ, Zhu CW, Clipp EC. Informal costs of dementia care: estimates from the national longitudinal caregiver study. *J Gerontol* 2001;56B(4):S219–S228.
10. Kubzansky LD, Kawachi I, Spiro A, et al. Is worrying bad for your heart? A prospective study of worry and coronary heart disease in the normative aging study. *Circulation* 1997;95:818–824. [PubMed: 9054737]
11. Hagquist CEI. Economic stress and perceived health among adolescents in Sweden. *J Adolesc Health* 1998;22(3):250–257.10.1016/S1054-139X(97)00168-7 [PubMed: 9502015]
12. Given B, Wyatt G, Given C, et al. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum* 2004;31(6):1105–1117.10.1188/04.ONF.1105-1117 [PubMed: 15547633]
13. Kozachik SL, Given C, Given B, et al. Improving depressive symptoms among caregivers of patients with cancer: results of a randomized clinical trial. *Oncol Nurs Forum* 2001;28(7):1149–1157. [PubMed: 11517848]
14. Bradley S, Sherwood PR, Donovan HS, et al. I could lose everything: understanding the cost of a brain tumor. *J Neurooncol* 2007;85:329–338. [PubMed: 17581698]
15. Barrera M, Caples H, Tein J. The psychological sense of economic hardship: measurement models, validity and cross ethnic equivalence for urban families. *Am J Community Psychol* 2001;29:493–517.10.1023/A:1010328115110 [PubMed: 11469118]
16. Nijboer C, Tempelaar R, Triemstra M, et al. The role of social and psychologic resources in caregiving of cancer patients. *Cancer* 2001;91(5):1029–1039.10.1002/1097-0142(20010301)91:5<1029::AID-CNCR1094>3.0.CO;2-1 [PubMed: 11251956]
17. Gaugler J, Davey A, Pearlin LI, Zarit SH. Modeling caregiver adaptation over time: the longitudinal impact of behavior problems. *Psychol Aging* 2000;15(3):437–450.10.1037/0882-7974.15.3.437 [PubMed: 11014707]
18. Bookwala J, Schulz R. The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. *J Gerontol Ser B* 1998;53(3):155–164.
19. Jang Y, Clay OJ, Roth DL, et al. Neuroticism and longitudinal change in caregiver depression: impact of a spouse-caregiver intervention program. *Gerontologist* 2004;44(3):311–317. [PubMed: 15197285]
20. Goldstein NE, Concato J, Fried TR, et al. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care* 2004;20(1):38–43. [PubMed: 15132075]
21. Goode KT, Haley WE, Roth DL, Ford GR. Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychol* 1998;17(2):190–198.10.1037/0278-6133.17.2.190 [PubMed: 9548710]
22. Fillit HM, Gutterman EM, Brooks RL. Impact of donepezil on caregiving burden for patients with Alzheimer's disease. *Am J Manag Care* 2000;6(22):S1149–S1155. [PubMed: 11142179]
23. Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. *J Neuropsychiatry Clin Neurosci* 2000;12(2):233–239.10.1176/appi.neuropsych.12.2.233 [PubMed: 11001602]
24. Sherwood PR (PI) (2003) Family care of persons with a brain tumor (grant # F31 NR8069), Funded by the National Institute for Nursing Research, 8/02–8/04
25. Sherwood PR, Given B, Doorenbos AZ, Given CW. Forgotten voices: lessons from bereaved caregivers of persons with a brain tumor. *Int J Palliat Nurs* 2004;10(2):67–75. [PubMed: 15039610]
26. Sherwood PR, Given B, Given CW, et al. Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health* 2006;29(2):105–120.10.1002/nur.20116 [PubMed: 16532486]
27. Schulz R, Belle SH, Czaja SJ, et al. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004;292(8):961–967.10.1001/jama.292.8.961 [PubMed: 15328328]
28. McNair DM, Lorr M. An analysis of mood in neurotics. *J Abnorm Soc Psychol* 1964;69:620–627.10.1037/h0040902

29. Goldberg L. The development of markers for the big five factor structure. *Psychol Assess* 1992;4:26–42.10.1037/1040-3590.4.1.26
30. Cohen, S.; Mermelstein, R.; Kamarck, T.; Hoberman, H. Measuring the functional components of social support. In: Sarason, IG.; Sarason, BR., editors. *Social support: theory, research and applications*. Martinus Nijhoff: The Hague; 1985. p. 73-94.
31. Kiernan RJ, Mueller J, Langston JW, Van Dyke C. The neurobehavioral cognitive status examination: a brief but quantitative approach to cognitive assessment. *Ann Intern Med* 1987;107(4):481–485. [PubMed: 3631786]
32. Given CW, Given B, Stommel M, et al. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992;15(4):271–283.10.1002/nur.4770150406 [PubMed: 1386680]
33. Nijboer C, Triemstra M, Tempelaar R, et al. Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Soc Sci Med* 1999;48:1259–1269.10.1016/S0277-9536(98)00426-2 [PubMed: 10220024]
34. Radloff L. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;1:385–401.10.1177/014662167700100306
35. Radloff LS. The use of the center for epidemiologic studies depression scale in adolescents and young adults. *J Youth Adolesc* 1991;20(2):149–166.10.1007/BF01537606
36. Hann D, Winter K, Jacobsen P. Measurement of depressive symptoms in cancer patients: evaluation of the center for epidemiological studies depression scale (CES-D). *J Psychosom Res* 1999;46:437–443.10.1016/S0022-3999(99)00004-5 [PubMed: 10404478]
37. Usala P, Hertzog C. Measurement of affective states in adults: evaluation of an adjective rating scale instrument. *Res Aging* 1989;11(4):403–426.10.1177/0164027589114001 [PubMed: 2623354]
38. Poverty Thresholds. US Census Bureau. 2006. <http://www.census.gov/hhes/www/poverty/poverty.html> Cited 11 June 2008
39. Blood GW, Simpson KC, Dineen M, et al. Spouses of laryngeal cancer: caregiver strain and burden. *J Commun Disord* 1994;27:19–35.10.1016/0021-9924(94)90008-6 [PubMed: 8006204]
40. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260–266. [PubMed: 3721233]
41. Nabors J, Seacat J, Rosenthal M. Predictors of caregiver burden following traumatic brain injury. *Brain Inj* 2002;16(12):1039–1050.10.1080/02699050210155285 [PubMed: 12487718]
42. Chumbler N, Grimm JW, Cody M, Beck C. Gender, kinship, and caregiver burden: the case of community-dwelling memory impaired seniors. *Int J Geriatr Psychiatry* 2003;18:722–732.10.1002/gps.912 [PubMed: 12891641]
43. Bookwala J, Schulz R. A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: the caregiver health effects study. *Psychol Aging* 2000;15(4):607–616.10.1037/0882-7974.15.4.607 [PubMed: 11144320]

Table 1

Sample characteristics

Variable	N	%
<i>Caregiver characteristics</i>		
Sex (female)	26	79
Race/ethnicity		
Caucasian	32	97
Asian	1	3
Marital status (married)	27	82
Relationship to patient (spouse)	21	64
Employment status (employed)	15	47
Career type (if employed) (N = 15)		
Professional, technical	8	53
Manager, administrator, or proprietor	3	20
Clerical and related	2	13
Other	2	13
Annual household income		
Less than \$20,000	4	12
\$20,000–\$50,000	9	27
Greater than \$50,000	18	55
Unknown	2	6
Socioeconomic status		
Low-income	5	15
Moderate-income	11	33
High-income	15	45
Unknown	2	6
Insurance type		
Private insurance	28	85
Medicare	1	3
Other	1	3
None	2	6
	Mean (SD)	
Age in years	52.15 (13.81)	
Number of children	2.5 (2.22)	
Years of formal education	14.74 (3.31)	
Variable	N	%
<i>Patient characteristics</i>		
Sex (male)	23	70
Patient's diagnosis		
Glioblastoma multiforme	20	61
Astrocytoma, Grades I–III	7	21
Oligodendroglioma	2	6

Variable	N	%
Hemangioblastoma	1	3
Subependymoma	1	3
Central neurocytoma	2	6
Type of Surgical Procedure		
Craniotomy	15	45
Biopsy only	11	33
Other	7	21
Type of chemotherapy		
Temodar	22	67
No chemotherapy	4	12
Unknown	7	21
Received radiation	23	70
	Mean (SD)	
Age in years	52.51 (18.02)	

Table 2
Regression models

Variable	Beta	SE	<i>t</i> -value	<i>P</i> -value
Model A: Predictors of caregiver burden due to schedule at diagnosis; $R^2 = 0.39$, $P < 0.01$				
Perceived economic hardship	0.08	0.08	1.13	0.27
Neuroticism	-0.69	0.31	-2.21	0.04
Caregiver sex	4.40	2.12	2.08	0.05
Caregiver age	0.12	0.06	2.14	0.04
Social support	-0.36	0.18	-2.03	0.06
Model B: Predictors of caregiver burden due to schedule at 4 months; $R^2 = 0.42$, $P = 0.02$				
Perceived economic hardship	0.04	0.11	0.35	0.74
Social support	-0.72	0.25	-2.86	0.01
Neuroticism	-0.72	0.38	-1.93	0.08
Model C: Predictors of caregiver burden—abandonment at diagnosis; $R^2 = 0.67$, $P < 0.01$				
Perceived economic hardship	0.24	0.10	2.86	0.01
Patient neuropsychological status	0.29	0.04	5.68	0.01
Model D: Predictors of caregiver burden—abandonment at 4 months; $R^2 = 0.70$, $P < 0.01$				
Perceived economic hardship	0.07	0.06	1.21	0.26
Patient neuropsychological status	-0.38	0.08	-4.63	< 0.01
Caregiver sex	5.45	1.83	2.99	0.02
Model E: Predictors of caregiver depression at diagnosis; $R^2 = 0.47$, $P < 0.01$				
Perceived economic hardship	0.07	0.10	0.68	0.50
Caregiver neuroticism	-1.31	0.37	-3.54	< 0.01
Patient neuropsychological status	0.39	0.19	2.02	0.06
Model F: Predictors of caregiver depression at 4 months; $R^2 = 0.13$, $P = 0.09$				
Perceived economic hardship	0.28	0.16	1.81	0.09
Model G: Predictors of caregiver anxiety at baseline; $R^2 = 0.56$, $P < 0.01$				
Perceived economic hardship	0.05	0.40	1.22	0.24
Caregiver neuroticism	-0.63	0.15	-4.15	< 0.01
Model H: Predictors of caregiver anxiety at 4 months; $R^2 = 0.17$, $P = 0.06$				
Perceived economic hardship	0.13	0.06	2.07	0.06

Table 3
Suggestions for future research

Descriptive studies

- How do direct disease-related costs impact perception of economic hardship?
- How does perceived economic hardship influence patient adherence to treatment regimens?
- Does perception of economic hardship differ in persons with other types of cancer?
- Does length of time of perceived economic hardship influence impact on emotional health?
- Does number and age of children influence the perception of economic hardship? Does this affect caregiver emotional health?
- How does perceived economic hardship influence patient outcomes (e.g., symptom severity, quality of life)?
- How does caregiver perception of economic hardship change after the care situation is over?

Interventional studies

- Financial planning assistance at the time of patient's diagnosis.
 - How could this assistance affect perceptions of economic hardship throughout the disease trajectory?
 - How could this assistance improve caregivers' emotional health?
 - Is it financially and clinically feasible to offer financial planning assistance?
 - Would psychosocial counseling with family caregivers reduce the impact of economic hardship on emotional health?
 - What would the impact of a public education intervention regarding health insurance options have on the perceived economic hardship of caregivers of persons with chronic diseases?
-