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## Identifying Family Members Who Are Likely to Perceive Benefits From Providing Care to a Person With a Primary Malignant Brain Tumor

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### Abstract

**Purpose/Objectives**—To identify changes in positive aspects of care (PAC) from the time of diagnosis to four months following the diagnosis in family caregivers of care recipients with primary malignant brain tumors.

**Design**—Longitudinal.

**Setting**—Dyads were recruited from neurosurgery clinics in Pittsburgh, PA, at the time of care recipients' diagnosis with a primary malignant brain tumor. A second data collection took place four months following the diagnosis.

**Sample**—89 caregiver and care recipient dyads.

**Methods**—Paired t tests were used to examine change in PAC, univariate analyses were used to determine predictors of PAC at four months, Mann-Whitney U tests and t tests were used to examine associations between categorical predictor variables and PAC at four months, and univariate linear regressions were used to examine associations between continuous predictors and PAC at four months.

**Main Research Variables**—The impact of sociodemographic factors, caregiver-perceived social support, mastery, neuroticism, and marital satisfaction on PAC.

**Findings**—Caregivers' PAC scores during the first four months following diagnosis appeared to remain stable over time. Significant differences were found between the care recipient reasoning domain group at diagnosis and PAC score. Care recipients who scored below average were associated with caregivers with higher PAC scores. Caregiver PAC at four months following diagnosis was significantly predicted by care recipient reasoning and caregiver social support.

**Conclusions**—PAC scores appear to remain stable over time, although levels of PAC may be related to care recipients' level of functioning. Future research should focus on the development of interventions for caregivers who report low levels of PAC at the time of diagnosis in an attempt to help these individuals identify PAC in their caregiving situation.

**Implications for Nursing**—Findings have clinical and research implications. Clinicians may be able to better identify caregivers who are at risk for negative outcomes by understanding the risks faced by caregivers of patients with milder symptoms in addition to those caring for more profoundly affected care recipients.

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The body of literature on family caregiving has begun to capture and document many aspects of the overall caregiving experience. The majority of research has focused on negative reactions (e.g., burden, depressive symptoms) that result when family members assume the role of caregiver and are forced to make sacrifices and major life changes to adapt to their new responsibilities. Recent studies suggest that benefits and rewards also can be associated with providing care (e.g., personal growth, discovering a sense of purpose) that coexist with the less-favorable reactions (Boerner, Schulz, & Horowitz, 2004; Kramer, 1997; Tarlow et al., 2004).

Although research has shown that these positive aspects of caring (PAC) can be present within the caregiving experience, studies have yet to identify family caregivers who are and are not likely to perceive benefits and rewards from providing care. To help family caregivers maintain their emotional health and potentially improve the quality of patient care delivered in the home, identifying how caregivers' perception of the benefits and rewards of providing care change over time as a function of patient and caregiver characteristics is vital.

The purpose of the current study was to identify changes in PAC from the time of diagnosis to four months following the diagnosis in family caregivers of care recipients with primary malignant brain tumors. The authors also sought to identify variables that predict PAC four months after the diagnosis. Specifically, the authors sought to determine the impact of sociodemographic factors, caregivers' perceived social support, mastery, neuroticism, and marital satisfaction on PAC.

## Background

The experience of a family caregiver is rarely one that initially presents itself as an opportunity. Under most circumstances, family members must embrace the situation and assume the role of caregiver when a spouse, parent, child, or sibling becomes ill. Caregivers assume a host of new tasks and responsibilities while continuing to fulfill other roles in the family, at work, and in the community. That process generally coincides with the task of coming to terms with a decline in health or a life-threatening diagnosis of a loved one, creating a stressful, unexpected life change (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995).

The role of the family caregiver has been explored in a variety of contexts and with many different populations. Murphy, Christian, Caplin, and Young (2007) and Lach et al. (2009) reported that caregivers of children with disabilities have been found to display negative emotional health resulting from their caregiving experience, including elevated stress levels

and increased worry about the future. In addition, they also were found to have compromised physical health, including chronic fatigue and sleep deprivation, and the presence of asthma, arthritis, back pain, and migraines. Similar results were found in a study of family caregivers of people with dementia, which reported that caregivers indicate high levels of burden and compromised psychological health, as well as feelings of social isolation (Brodaty & Donkin, 2009). A study by Schulz and Beach (1999) found that caregivers of an older adult spouse who were under heightened emotional stress were more likely to die within four years compared to a control group of noncaregivers.

The presence of depression in family caregivers also has been well documented in the literature. Pirraglia et al. (2005) conducted a study on informal caregivers of HIV-positive individuals and found that half of the caregivers had levels of burden that led them to be depressed. More specifically, caregivers who spent a large majority of the day with the HIV-positive individual and the longer duration of the individual's diagnosis had greater levels of depression. Depression in cancer caregivers also has been associated with level of burden. Caregiver characteristics such as being female, being the spouse of the patient, reporting poor personal health, and having low income contributed to burden level and were related to higher depression rates (Rhee et al., 2008; Rivera, 2009). In addition, Given et al. (2004) found that many caregivers of patients with cancer at the end-of-life reported increasingly high depression levels, in some cases equaling or exceeding the thresholds for clinical depression on the screening tests.

Although a great deal of research has focused on negative caregiver outcomes, a number of positive aspects of the caregiving experience also have been identified. Caregiver burden and satisfaction can coexist even in situations where moderate stress is present in caregivers of family members with dementia (Andr n & Elmst hl, 2005). Cohen, Colantonio, and Vernich (2002) reported that, among caregivers of older adult individuals, 73% could find one PAC in their situation. Common PAC named were companionship, fulfillment or reward, enjoyment, a sense of duty or obligation, and providing a high quality of life for a loved one. In a study of female caregivers of relatives diagnosed with cancer, many viewed the caregiving experience as an opportunity to return or reciprocate by giving back to loved ones who had cared for them in the past, or to fulfill their role with the expectation that they themselves will be cared for in the future (Mehrotra & Sukumar, 2007).

In addition to the identification of PAC, work has been done to link the presence of PAC to caregiver outcomes. Kim, Schulz, and Carver (2007) found that caregivers of cancer survivors who embraced the caregiving situation and accepted new possibilities for emotional and spiritual growth, in addition to appreciating new relationships with others, demonstrated greater adaptation to the overall experience. Studies have suggested that caregivers who report higher levels of benefit while in the care situation are more likely to suffer from higher levels of depression following the death of their loved one. That may be a result of the caregiver losing an important and meaningful role, in addition to their primary loss (Boerner et al., 2004). The duration of the caregiving experience may be an important factor in that relationship. In a study of hospice patients with end-stage lung cancer or dementia and their caregivers, fewer months of caregiving was a significant predictor of higher depression and grief post-loss (Burton et al., 2008). That is consistent with the anticipatory grief hypothesis, which suggests that individuals who have time to prepare themselves for the loss psychologically may be at a lower risk for difficulties after their loved one passes away. If the duration of the caregiving experience is short, caregivers may not have adequate time to accept or prepare for the death of their loved one, whereas those who care for the patient for a longer period of time may feel a sense of relief that their loved one is no longer suffering and that the burden of caring has been alleviated (Burton et al., 2008; Schulz, Newsom, Fleissner, deCamp, & Nieboer, 1997).

Social support also may be an important factor to consider when examining positive aspects of the caregiving experience and caregiver outcomes. In a review of the literature, Schulz et al. (1997) found that support received by family and friends during the caregiving experience was directly related to bereavement outcomes. Caregivers who received high levels of support were less likely to experience negative outcomes, both during the time that they were caregiving and post-loss (Schulz et al., 1997).

Although research has focused on identifying PAC and interpreting caregiver outcomes in relation to the perceived benefits that can result from the caregiving situation, important pieces of information are missing from this foundational knowledge of the caregiving experience. To date, few studies have longitudinally explored PAC. Hilgeman, Allen, DeCoster, and Burgio (2007) sought to explore limitations in current research on PAC by examining the impact of time-varying depression, behavioral bother, and daily care burden on time-varying PAC over 12 months. They concluded that race and decreases in daily care burden were associated with increases in PAC. To better understand that multidimensional interaction, researchers should continue to explore caregiver variables, as well as patient characteristics that may be predictors of PAC at the time of diagnosis or four months following the diagnosis.

## Methods

### Recruitment and Data Collection

Caregivers and care recipients were recruited through either an urban outpatient neurosurgery or neuro-oncology clinic within one month of diagnosis and completed questionnaires at diagnosis and four months later. Both the caregiver and care recipient had to agree to participate, although caregivers were retained in the study if the care recipient attrited after the baseline interview. Caregivers were considered eligible if they had regular and reliable access to a telephone and were a non-professional (nonpaid) caregiver, at least 21 years of age, able to read and speak English, and not a primary caregiver for anyone else excluding children younger than 21. Care recipients were eligible if they were diagnosed with a primary malignant brain tumor within the past month (verified by surgical pathology) and at least 21 years of age. University of Pittsburgh institutional review board approval of the study was obtained prior to consent. A total of 111 dyads were approached; 89 agreed to participate (76% consent rate) and were included in the analysis. A total of nine caregivers withdrew from the study between baseline and four months because they were overwhelmed or the care recipient died. Four caregivers were lost to follow-up or chose to skip the four-month time point because they were overwhelmed by caregiving duties and life changes related to the care recipient's illness. Five caregivers completed a bereaved interview after the death of the care recipient, which was a modified version of the interview and did not contain all of the original measures. Eleven interviews were missing data and were not included in the final analysis.

### Predictor Variables

**Caregiver measures**—Sociodemographic information was collected, including gender, age, years at current marital status, years of formal education, and relation to the care recipient. Age, years at current marital status, and years of formal education were treated as continuous variables, whereas gender and relation to the care recipient were dichotomized variables (male or female, spouse or other, respectively). In addition, instruments assessing the caregivers' perceived social support, mastery, neuroticism, and marital satisfaction were included.

Social support was measured using the **Interpersonal Support Evaluation List (ISEL)**. Participants rated the availability of three types of special support (appraisal, belonging, and tangible). Individual items were summed to produce a score for each subscale, and subscale scores were summed to produce an overall support score. Higher scores reflected more social support. Validity for the ISEL was established using the Inventory of Socially Supportive Behaviors, number of close friends, and the Partner Adjustment Scale (Cronbach alpha 0.87, 10 items) (Brookings & Bolton, 1988; Cohen, 1991; Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Schonfeld, 1991).

Mastery was measured using the **Mastery Scale** (Pearlin & Schooler, 1978). Participants used a four-point Likert-type scale to indicate the degree to which they felt they had mastered important life outcomes and were in control of the things that happen to them. Items were summed to produce an overall score, with a higher score indicating a greater level of mastery. The Mastery Scale has been shown to be valid in caregivers of people with a primary malignant brain tumor or dementia and people with various types of cancer (Cronbach alpha = 0.68, 7 items) (Leger et al., 1999; Marshall & Lang, 1990).

Neuroticism was measured using the modified **Goldberg Adjective Scale** (Goldberg, 1992). Participants indicated how well adjectives described themselves, using a five-point Likert-type scale. The adjectives characterized five personality types (extraversion, agreeableness, conscientiousness, neuroticism, and openness). Subscale scores for each personality type were generated by summing individual items, with higher scores indicating stronger traits. Goldberg's Adjective Scale has been shown to be a valid measure of personality type when compared to the NEO Personality Inventory and clinician examination (Cronbach alpha = 0.77, 5 items) (Egger, Delsing, & De May, 2003; Saucier, 1994).

Marital satisfaction was measured using the **Marital Adjustment Scale** (Freeston & Pléchaty, 1997; Locke & Wallace, 1959). Participants answered questions about their general happiness, level of agreement with their partner, satisfaction in handling disagreements, and regrets concerning their relationship using a seven-point Likert-type scale. The scale also had several questions that asked about the couple's ability to problem solve and their similarities in social preferences. A total score was generated by summing individual items, with higher scores indicating greater marital satisfaction. Validity for this test originally was demonstrated in clients of the American Institute of Family Relations (Locke & Wallace, 1959) and more recently was supported by Freeston and Pléchaty (1997) (Cronbach alpha = 0.66, 15 items).

**Care recipient measures**—The **Neurobehavioral Cognitive Status Examination** was used to assess patients' neurologic status in multiple cognitive domains, including level of consciousness, attention, language, constructional ability, memory, calculations, and reasoning (Kiernan, Mueller, Langston, & Van Dyke, 1987). Participants answer questions and perform tasks that indicate ability in the different domains. Scores are generated for each domain via an algorithm (0 = average ability, 1 = mild impairment, 2 = moderate impairment, and 3 = severe impairment), and an overall score is calculated by summing the scores for each domain. Higher scores indicate higher levels of neurologic dysfunction.

The care recipients' functional status was determined by using the **Medical Outcomes Study 36-Item Short Form (SF-36<sup>®</sup>) physical function subscale**, which has been validated for use in people with cognitive impairment (Findler, Cantor, Haddad, Gordon, & Ashman, 2001; McHorney, Ware, Lu, & Sherbourne, 1994; McHorney, Ware, & Racezk, 1993). Participants indicate their level of limitation in activities of daily living and instrumental activities of daily living on a three-point scale. An overall score is calculated by

summing individual items, with higher scores indicating more limitations in physical function.

### Outcome Variables

The primary outcome variable was PAC. Positive responses to providing care were measured through the use of the **Positive Aspects of Caregiving scale** (Boerner et al., 2004), an 11-item measure in which the caregiver was asked to rate the degree to which he or she agreed with statements relating to their feelings about their caregiving experience. The scale is a valid and reliable measure (Cronbach alpha = 0.908) (Tarlow et al., 2004).

### Statistical Analyses

Paired t tests were used to examine change in PAC from diagnosis to four months following diagnosis. Univariate analyses of baseline and four-month measures were conducted to identify significant predictors of PAC at four months. Neuropsychological scores from the **Neurocognitive Status Exam** were dichotomized into average and below-average performance using a clinical cutoff (Kiernan et al., 1987). Independent t tests and Mann-Whitney U tests (when appropriate) were used to examine associations between categorical predictor variables and PAC at the four-month point. Univariate linear regressions were used to examine associations between continuous predictors and PAC at the four-month point, as well. A multivariable model was built using a backward selection procedure, including all predictors significant at  $p < 0.1$  in univariate analyses.

### Results

The majority of participants were Caucasian women in their early 50s with an average of 14.31 years of formal education. The majority of caregivers were married, and many were the spouse or significant other of the care recipient (see Table 1). A paired samples t test comparing the mean PAC score from diagnosis ( $\bar{X} = 44$ ,  $SD = 8.04$ ) to four months following diagnosis ( $\bar{X} = 42.8$ ,  $SD = 7.37$ ) found no significant difference ( $p = 0.13$ ). Therefore, univariate analyses were conducted to identify potential caregiver and care recipient predictors of PAC at four months.

A Mann-Whitney U test revealed a significant difference between the care recipient reasoning domain group at diagnosis and PAC score. Care recipients who scored below average were associated with caregivers with higher PAC scores ( $\bar{X} = 51.3$ ,  $SD = 5.1$ ) compared to those who scored average or greater ( $\bar{X} = 41.7$ ,  $SD = 7.3$ ;  $p < 0.01$ ). Univariate regressions revealed a border-line significance association between the caregivers' perceived social support ( $p = 0.06$ ) and caregivers' marital satisfaction ( $p = 0.06$ ) at four months following diagnosis with PAC score.

The final multiple linear regression model ( $R^2 = 0.17$ ) revealed that caregivers' PAC at four months following diagnosis were significantly predicted by baseline care recipient reasoning and caregiver social support reported at four months (see Table 2). For each one-point increase in social support, caregivers significantly increased 0.4 points in positive aspects of care ( $p = 0.05$ ). Caregivers significantly rated 8.74 points higher in positive aspects of care if their care recipients performed below average on the reasoning test compared to care recipients in the average group ( $p = 0.01$ ).

### Discussion

Based on the results of the analysis, PAC scores during the first four months following diagnosis appear to remain stable over time in caregivers of patients with primary malignant

brain tumors. Those findings are consistent with the work of Hilgeman et al. (2007), who found that PAC were not variable over time in caregivers of patients with Alzheimer disease. The authors suggested that outlook on life and self-affirmation may be stable traits (Hilgeman et al., 2007). Caregivers who can identify positive aspects of their experience when caring for a loved one also may have a more positive outlook or perception of their own lives.

Significant differences were observed in the care recipient reasoning domain scores and caregiver PAC scores at the time of diagnosis. Care recipients' lower reasoning scores were associated with higher caregiver PAC scores compared to those who scored in the average or above-average range. That may suggest that providing care to an individual with cognitive deficits provides more tangible things to do when providing care compared to caregivers of those with full cognitive abilities. Neurobehavioral Cognitive Status Examination scores generally are correlated with care recipient outcomes. Higher scores indicate typical or better levels of functioning, whereas lower scores indicate cognitive deficits or progression of the disease (Kiernan et al., 1987). That strengthens the theory proposed by Andrén and Elmståhl (2005), who found that caregivers express a high level of satisfaction in their caregiving role despite the level of burden placed on them as a result of being a caregiver. Stress and satisfaction can be present in the same situation (Andrén & Elmståhl, 2005). Those results do not support the findings of Kim et al. (2007), who suggested that caregivers reported greater life satisfaction when they were faced with lower levels of stress from the caregiving situation and when cancer survivors had better mental and physical functioning. That difference could be attributed to the timing of data collection. In Kim et al.'s (2007) study, participants were caregivers who were nominated by cancer survivors, and they were well-versed in their caregiving role. The participants included in the current study were interviewed close to the time of diagnosis. Those caregivers may have still been adjusting to their role as a family caregiver, or they may have been in the honeymoon phase of the caregiving situation, where relationships within the family or between the caregiver and care recipient improved, and priorities and values were shifted to accommodate the diagnosis and subsequent life changes. Similarly, caregivers may be more hopeful during the first four months because the tumor has not recurred, and a full recovery may seem likely (Hricik et al., 2011).

PAC at four months following the diagnosis were predicted by care recipient reasoning scores and caregiver-perceived social support. For each point of increase in social support, caregivers' PAC scores increased. In addition, a trend was identified between caregivers' marital satisfaction and PAC four months following the diagnosis. Ergh, Rapport, Coleman, and Hanks (2002) reached similar conclusions based on the results of a study of caregivers of people with traumatic brain injury and caregiver distress. Those findings suggested that social support perceived by the caregiver was highly influential on the caregiver's well-being, and a lack of social support was related to higher levels of psychological distress (Ergh et al., 2002). Social support systems may buffer the negative effects of providing care by providing the caregiver with the help and emotional support necessary to cope with the major life change and adjustments that accompany transitioning into the caregiver role.

## Limitations

Limitations to the current study include a small, homogeneous sample size comprised of participants who were recruited from the same geographical area. The majority of participants were middle to upper class and Caucasian. Caregivers of other socioeconomic statuses might report very different PAC than the participants included in this analysis, and different factors could impact PAC between the time of diagnosis and four months following diagnosis based on the specific needs of other caregivers.

## Implications for Nursing Practice and Research

The significance of these findings has clinical and research implications. When targeting caregivers who may be at risk for developing negative outcomes, clinicians should focus not only on the caregivers of patients who present with the most serious cognitive and physical deficits for intervention, but should be prepared to intervene with caregivers of those with milder symptoms who may be at risk for negative outcomes. Clinicians can encourage caregivers to identify sources of social support from friends, family members, or the community.

From a research perspective, future work should focus on the development of interventions for caregivers who report low levels of PAC at the time of diagnosis in an attempt to help these individuals identify positive aspects of their caregiving situation. By doing that early on, caregivers could develop the skills necessary to increase their levels of PAC, which could potentially remain stable for the duration of their caregiving experience. Additional research also should focus on exploring PAC in more depth to validate the current study's findings, which suggest that PAC are stable traits throughout the later stages of the caregiving experience. If PAC are stable over time, research should focus on whether PAC simply have the ability to capture a person's outlook, or if they truly reflect how a caregiver responds to the caregiving situation.

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Table 1

## Sample Characteristics

Characteristic	$\bar{X}$	SD	Range
Education (years)	14.31	2.48	5–23
Age (years)	51.3	11.93	21–77
Characteristic	n	%	
<b>Gender</b>			
Male	66	74	
Female	23	26	
<b>Relationship to care recipient</b>			
Spouse or significant other	66	74	
Parent	9	10	
Daughter or son	5	6	
Friend or companion	4	5	
Sibling	1	1	
Niece or nephew	1	1	
Other	1	1	
Missing	2	2	
<b>Current marital status</b>			
Married	79	89	
Living with significant other	4	5	
Divorced	4	5	
Separated	1	1	
Widowed	1	1	
<b>Race</b>			
White	86	97	
Asian	2	2	
American Indian	1	1	
<b>Tumor type</b>			
Glioblastoma	45	51	
Oligodendroglioma	14	16	
Astrocytoma III	5	6	
Astrocytoma II	3	3	
Astrocytoma I	2	2	
Other <sup>a</sup>	10	11	
Missing	10	11	

N = 89

<sup>a</sup>Other tumors included hemangioblastoma, subependymoma, infiltrating astrocytoma, large B-cell lymphoma, malignant glioma, infiltrating glioma, and granular cell astrocytoma IV.

Note. Because of rounding, percentages may not total 100.

**Table 2**

Multiple Linear Regression Analysis of Significant Factors Associated With Positive Aspects of Care at Four Months

Factor	$\beta$	SE	t	p
Care recipient reasoning score at baseline (below average versus average)	8.74	3.3	2.65	0.01
Caregiver social support at four months	0.4	0.2	2.04	0.047

N = 60

SE—standard error

Note.  $F(2,57) = 5.69$ ,  $p = 0.006$ ,  $R^2 = 0.17$