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# Informal Caregiving in Patients With Brain Tumors

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**A**s early discharge from hospital and the use of outpatient services has increased, informal caregiving for patients with cancer has become more common. A complex relationship called a *caregiving dyad* forms between the caregiver and the care recipient as they work together in the experience of illness (Shyu, 2000). The caregiving dyad is initiated and sustained by the forces of informal caregiving dynamics, which may vary with different illness populations (Williams, 2007) (see Figure 1). Informal caregiving dynamics is defined as the “commitment, expectation management, and role negotiation supported by self-care, new insight, and role support that move a caregiving relationship along an illness trajectory” (Williams, 2008, p. 263).

Caregivers of patients with primary brain tumors face a particular set of challenges as they deal with the functional, cognitive, and neuropsychological changes that accompany this diagnosis and treatment. The changes require family caregivers to provide emotional support and assistance in activities of daily living, health-related tasks, and financial management (Sherwood, Given, Doorenbos, & Given, 2004). The positive effects caregivers experience involve increased sense of self and accomplishment, whereas negative effects include depression, anxiety, and physical illness (Sherwood, Given, Given, & Von Eye, 2005).

Research involving the experience of caregivers of patients with primary brain tumors is limited. As a result, the purpose of this qualitative, exploratory study was to describe the informal caregiving dynamics involved in the care of patients with primary brain tumors.

## Literature Review

Studies of caregiving have examined predictors of the experience, such as caregiver and patient characteristics, illness factors, and the dynamics involved in the process

**Purpose/Objectives:** To explore the experience of informal caregivers of patients with a primary brain tumor by identifying themes of the caregiving experience specific to this population.

**Research Approach:** Qualitative study employing Parse’s descriptive exploratory method.

**Setting:** National Cancer Institute–designated comprehensive cancer center in a major city in the southern United States.

**Participants:** 20 patients with primary brain tumors and their caregivers.

**Methodologic Approach:** Data collection involved a tape-recorded dialogue with caregivers using Story Theory. Patient and caregiver demographic information was collected.

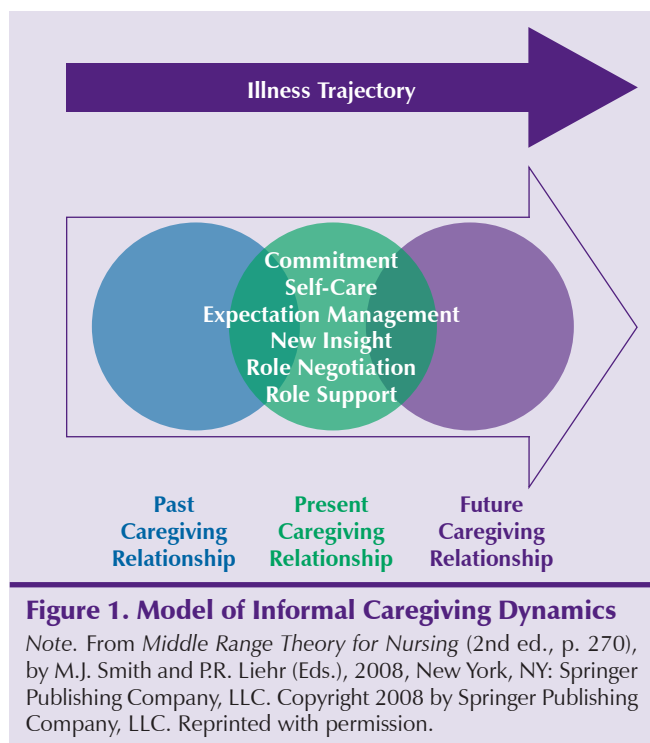
**Main Research Variables:** Concepts of commitment, expectation management, role negotiation, self-care, new insight, and role support.

**Findings:** Caregivers of patients with primary brain tumors used the energy sources identified by the Model of Informal Caregiving Dynamics. Commitment is sustained through enduring patient cognitive and behavioral decline. Expectations are based on a realistic understanding of the disease trajectory and known mortality, and allow caregivers to hope for the ability to manage declining patients. Caregivers express difficulty in gauging the behavior of cognitively impaired patients. Healthcare providers support caregivers by supplying information and listening to caregivers’ stories. In contrast to a similar study involving caregivers of bone marrow transplantation recipients, these caregivers reported negative perceptions.

**Conclusions:** Commitment, expectation management, role negotiation, self-care, new insight, and role support motivate informal caregivers of patients with primary brain tumors in a unique way.

**Interpretation:** Healthcare providers can support the caregiving experience by validating efforts, providing information, and listening to frustrations. Additional research should explore interventions aimed at assisting caregivers.

of caregiving. Predictors for poor caregiving outcomes include female gender, wife and daughter caregivers, and being of Caucasian non-Hispanic ethnicity (Baumgarten et al., 1992; Collins & Jones, 1997; Connell, Janevic, &



Gallant, 2001; Given et al., 2004; Lawton, Rajagopal, Brody, & Kleban, 1992; Lee, Colditz, Berkman, & Kawachi, 2003; Picot, Debanne, Namazi, & Wykel, 1997; Pinquart & Sorensen, 2005; Sherwood et al., 2005).

Caregiving is an ever-changing process, and successful caregiving dyads are able to prioritize, negotiate roles, and prepare for changes. Shyu (2000) described the process of developing the caregiving role as *role tuning*, which involves engaging, negotiating, and settling. Caregivers often understand their experience by finding meaning, which they base on values (Ayres, 2000a, 2000b; Farran, Keane-Hagarty, Salloway, Kupferer, & Wilken, 1991). Within the process of caregiving, the type and amount of support (informal and formal) influence the experience of the caregiver (Albinsson & Strang, 2003; Holtslander, Duggleby, Williams, & Wright, 2005; Upton & Reed, 2006; Wuest, Ericson, Stern, & Irwin, 2001; Zarit, Reever, & Bach-Peterson, 1980). Williams (2005) studied the dynamics of caregiving among informal caregivers of blood and marrow transplantation recipients, identifying six energy sources for caregivers: commitment, role negotiation, expectation management, caring for self, gaining insight, and connecting with others.

Although some generalizations can be made for caregivers of all disease processes, the literature suggests that the dynamics of caregiving may differ by diagnosis. Clipp and George (1993) presented evidence that the experience of caring for a spouse with dementia results in greater deterioration of caregiver well-being than the experience of caring for a spouse with cancer. Flaskerund, Carter, and Lee (2000) found significant increases in symptoms of anxiety, anger, and sleep disturbances

in caregivers of patients with cancer when compared to caregivers of patients with AIDS and dementia. Haley, LaMonde, Han, Narramore, and Schonwetter (2001) found that spousal caregivers of hospice patients with lung cancer had a similar experience with physical and mental health outcomes when compared to spousal caregivers of hospice patients with dementia. However, differences in the findings of those studies may be explained by the patient's stage of disease when the caregiver's experiences were described. Clipp and George (1993) studied caregivers of patients with cancer in earlier stages of disease, where the caregiving needs and symptom levels may have differed greatly from those of patients with neurologic disease. Haley et al. (2001) sampled caregivers of patients who were in hospice care regardless of diagnosis and, as a result, were more likely to require similar levels of care. Therefore, differences in the experience of caregiving across diagnoses may be explained by factors specific to the stage of the illness itself, such as symptoms, prognosis, treatment effects, and the type of care required.

Research is limited concerning the experience of caregivers of patients with primary brain tumors, a population that combines the experiences of caregivers of patients with cancer and those of patients with neurologic disease. Caregivers of patients with cancer report difficulty when patient needs require emotional support or behavioral management, and they are affected acutely by the symptoms with which the patient presents (Andrews, 2001; Bakas, Lewis, & Parsons, 2001; Biegel, Sales, & Schultz, 1991; Carey, Oberst, McCubbin, & Hughes, 1991; Given et al., 2004; Haley et al., 2001). Caregivers of patients with neurologic disease must handle extensive physical and cognitive impairment, often reporting difficulty in dealing with neuropsychiatric and behavioral symptoms (Chenoweth & Spencer, 1986; Clipp & George, 1993; De la Cuesta, 2005; Haley et al., 2001; Pinquart & Sorensen, 2003; Sherwood et al., 2005).

A qualitative study involving bereaved caregivers of patients with primary brain tumors revealed six themes involved in the caregiving experience: the work of caring, informal support, formal support, information, dealing with symptoms, and end of life (Sherwood, Given, Doorenbos, et al., 2004). Results point to major themes of the caregiving experience, although the study was limited as it only provided the perspective of bereaved caregivers reflecting on the experience. A description of the experience of current informal caregivers specific to the population of patients with primary brain tumors is needed to provide an evidence base for interventions.

## Methods

### Research Design

This qualitative, descriptive study was modeled after the work of Williams (2005) with a population

of caregivers of blood and marrow transplantation recipients. As in the original study, the current research used Story Theory (Smith & Liehr, 2003) for data collection, as well as a descriptive exploratory data analysis method (Parse, Coyne, & Smith, 1985). Qualitative research allows for the development of knowledge about human experiences from descriptions given by people (Parse, 2001). Story Theory (Liehr & Smith, 2000) defined the human story as a “health story in the broadest sense; a recounting of one’s current life situation to clarify present meaning in the context of the past, with an eye toward the future all in the present moment” (p. 14). Liehr and Smith (2000) proposed the story path as a structural method for obtaining data, where the researcher invites the caregiver to talk about the experience by focusing first on the present moment, then on the past and the importance of past experiences at the present time, and finishing the story with a focus on the future expectations for the health challenge. Although qualitative research often requires that the results are driven entirely by the data, this type of research also can be informed by theory, allowing the data to be explored with structure, while remaining open to unanticipated findings (Parse, 2001).

The Model of Informal Caregiving Dynamics was used to explore and inform the analysis of the data (Williams, 2005). In the model, *commitment* is defined as “enduring caregiver responsibility that inspires life changes to make the patient priority . . . whether or not they are experiencing a self-affirming loving connection with the patient” (Williams, 2007, p. 381). *Expectation management* involves envisioning the future and looking to return to normal or a new normal. *Role negotiation* is appropriate pushing by the caregiver toward patient recovery and independence while getting a handle on the care that is required. *Self-care* involves the action of caregivers in taking care of themselves during the experience. *New insight* is characterized by “changing awareness through experiencing personal growth, believing that a higher power controls the situation, and recognizing positive treatment outcomes” (Williams, 2008, p. 266). Finally, *role support* is caregivers finding strength through knowing others care, receiving competent care and helpful information, and finding support for other responsibilities.

## Sample

The sample included 20 primary informal caregivers of patients with primary brain tumors being evaluated or treated at a National Cancer Institute–designated comprehensive cancer center in the southern United States. Purposive sampling of the patients and their informal caregivers broadened the scope of data collection and provided a wide exploration of the experience of caring for patients with brain tumors. Patients were eligible to participate if they were aged 18 years or older, English speaking, and diagnosed with a grade II–IV primary

brain glioma. Caregivers were eligible to participate if they were aged 18 years or older, English speaking, and identified by patients as primary caregivers.

## Procedure

The institutional review board of the comprehensive cancer center and the University of Texas Health Science Center at Houston’s committee for the protection of human subjects approved the study. The researcher first contacted patients and then approached their caregivers to obtain their consents for participation in a dialogue about their caregiving story. If a caregiver agreed, a single tape-recorded interview was conducted. Open-ended questions and the methods of story path were used to guide the dialogue. Dialogues were conducted in private rooms in inpatient and outpatient areas of the cancer center by the researcher. After the dialogue was finished, the caregiver completed a sociodemographic questionnaire. The researcher then collected sociodemographic, disease, and treatment information from the patients’ health records.

## Data Analysis

Caregiver sociodemographic characteristics and patient sociodemographic and health parameters were analyzed with descriptive statistics. Transcripts of the dialogues were verified against the audio tapes by the researcher. The dynamics of caregiving and energy sources used by caregivers were described with descriptive exploratory analysis (Parse et al., 1985). The dialogues were coded into statements, and the energy sources from the Model of

**Table 1. Sociodemographic, Disease, and Treatment Characteristics of Patients With Brain Tumors**

Characteristic	n
<b>Gender</b>	
Male	12
Female	8
<b>Ethnicity</b>	
African American	2
Caucasian	16
Hispanic	2
<b>Marital status</b>	
Married	15
Not married	5
<b>Place of permanent residence</b>	
Local metropolitan area	5
Outside local metropolitan area	15
<b>Grade of tumor</b>	
II–III	5
IV	15
<b>Time since diagnosis (years)</b>	
Less than 1	7
1–5	9
More than 5	4

N = 20



Informal Caregiving Dynamics were used to understand and inform the unique experience of these caregivers. For bias control and to ensure accuracy in analysis, two other researchers with experience in qualitative studies and oncology nursing were consulted in the analysis process.

## Results

Sociodemographic, disease, and treatment data for the patients (see Table 1) and sociodemographic data for the caregivers (see Table 2) were analyzed descriptively. The mean age of the patients was 48.7 years (SD = 12.5, range 22–76). For caregivers, the mean age was 51 years (SD = 10.7, range 28–74) and the mean years of education was 14.9 (SD = 2.4, range 10–20). Themes related to commitment, expectation management, role negotiation, self-care, new insight, and role support were identified in this caregiver population. Those six main energy sources were further subdivided into themes according to the Model of Informal Caregiving Dynamics (Williams, 2005) (see Table 3).

## Discussion

Caregivers of patients with brain tumors used the six energy sources found in the Model of Informal Caregiving Dynamics, but their use of those sources differed

from caregivers of blood and marrow transplantation recipients (Williams, 2005). Although caregivers in the current study did express feelings of commitment as outlined in the model, they often reported a willingness and responsibility to endure frustrating personality changes and cognitive decline. The unpredictable and problematic behaviors that accompany cognitive and psychological decline are predictive of a negative caregiving experience (Pinquart & Sorensen, 2003; Sherwood et al., 2005). In the care of patients with cancer, caregiving tasks involving emotional support or behavioral management are reported as the most time consuming and difficult (Bakas et al., 2001; Carey et al., 1991). In the care of patients with dementia, Chenoweth and Spencer (1986) reported that the major problem faced by caregivers is the need for constant supervision. Caregivers in the current study described a dramatic change in the personality and cognitive functioning of the patients, often resulting in conflict with the patient, making it difficult to feel appreciated. Those caregivers found a self-affirming, loving connection by recognizing their own ability to manage behavioral problems, similar to findings of LoboPrabhu, Molinari, Arlinghaus, Barr, and Lomax (2005).

Caregivers managed their own expectations through recognizing the natural disease trajectory of primary brain tumors. In this population of caregivers, envisioning tomorrow actually is envisioning the eventual decline of the patient and hoping that it will be manageable. The sudden onset, quick progression, and morbidity and mortality associated with the diagnosis of primary brain tumors may contribute to this view of the future, particularly when compared to the hope expressed by caregivers of patients undergoing bone marrow transplantation, which often is seen as curative therapy (Sherwood, Given, Given, et al., 2004; Williams, 2005). Wuest, Ericson, and Stern (1994) described the concepts of holding on and letting go in the process of “becoming strangers.” Holding on involves caregivers implementing strategies to maintain a normal life and sustain the relationship, whereas letting go has been described as a dynamic process that includes the begrudging acceptance of the inevitable and then adapting to ensure the caregiver’s ability to manage the declining patient (LoboPrabhu et al., 2005; Wuest et al., 1994). The experience of becoming strangers and “letting go” is similar to the expectations of caregivers in the current study, where envisioning the future provided caregivers an opportunity to prepare for the patient’s loss of cognitive and functional abilities and eventual death. Sherwood, Given, Doorenbos, et al. (2004) described preparation for the future in this same caregiver population as an important time for caregivers to ready themselves for the care that will be necessary as the patient continues to decline and reaches the end of life.

**Table 2. Sociodemographic Characteristics of Informal Caregivers**

Characteristic	n
<b>Gender</b>	
Male	6
Female	14
<b>Ethnicity</b>	
African American	2
Caucasian	16
Hispanic	2
<b>Marital status</b>	
Married	17
Not married	3
<b>Place of permanent residence</b>	
Local metropolitan area	5
Outside local metropolitan area	15
<b>Relationship to patient</b>	
Spouse	14
Parent	1
Child	1
Other	4
<b>Normally reside with patient</b>	
Yes	16
No	4
<b>Employment status</b>	
Full-time	8
Part-time	3
Not employed	9

N = 20

**Table 3. Main Energy Sources for Informal Caregivers**

Theme <sup>a</sup>	Definition <sup>a</sup>	Example <sup>b</sup>
<b>Commitment</b>		
Enduring responsibility	Caregiver feelings of responsibility for the welfare of the patient that extend over time, despite difficulties or challenges that may arise	A 68-year-old husband of a patient expressed his desire to meet the challenges ahead: "It is a role that I relish because I wouldn't want anybody else to be that caregiver. . . . Whenever that tumor was diagnosed, I knew . . . [we] were going to have to face this together."
Making the patient priority	Placement of patient needs before all others; often requires significant life changes made for patient's welfare	A 53-year-old mother described a difficult decision made in the best interest of her son; although she wanted to spend every moment with her son, she chose to continue working to support the family.
Self-affirming, loving connection	Caregiver feelings of connectedness with the patient, where meeting patient needs is emotionally satisfying for the caregiver	The 62-year-old wife of a patient described the importance of her role as a caregiver: "In some ways it is better because you are closer now than you were, and I feel sorry for him mostly because he had a wonderful brain, and a wonderful memory, and to see someone lose that, but he seems happy [and] that is the main thing. . . . He is so grateful to me for helping him."
Supportive presence	Remaining at the patient's side with comfort, encouragement, and a positive attitude when the caregiver can do nothing else for the patient	A 50-year-old husband caring for his wife described his support for her: "You have got to be very supportive because their mind changes after a brain tumor. . . . Sometimes she would say . . . she is sorry she is such a hard patient to work with. I guess . . . you have to remember that love is the thing that brought us together and our love and our faith in God is what is keeping us going."
<b>Expectation Management</b>		
Envisioning tomorrow	Struggling with an unknown future involving hope, fear, or both to help caregivers find purpose and prepare for disappointments	A 40-year-old wife caring for her husband described both a hopeful and fearful outlook on the future: "What I hope to happen and what is going to happen are two different things. I hope they can contain the growth . . . and he could just live another two to three years . . . but it looks like it is going to be six months. It is a monster tumor and it grew through radiation and [chemotherapy], so it is going to be much more difficult now that he understands that he is dying, because he had a lot of hope."
Gauging behavior	Explaining, predicting, or reacting to the patient's actions or statements based on previous knowledge and experience	A 50-year-old husband caring for his wife described anticipating his wife's needs: "I have been doing it [caring] with her so long now that I kind of know what needs to be done before she asks [and] I . . . anticipate what she will be wanting or needing."
Getting back to normal	Anticipating the return of an ordinary life that was lost in the demands of illness and treatment	A 52-year-old husband caring for his wife described a hope for a return to normal life: "I would like to have a sense of normalcy. . . . I know that it might be kind of a false sense of normalcy, but a feeling that . . . at least things are good for now."
Reconciling treatment twists and turns	Comparing actual to anticipated patient outcomes to accept the reality of the outcomes	A 28-year-old woman caring for her sister told of accepting the reality of the outcomes of treatment: "I am not all that medically inclined, but [I] try to work with her and help her understand that if this procedure don't work, there is going to be another one . . . and that one might be a little bit better than the first one or it might be a little worse than the first."
Taking one day at a time	Focusing in the present as a means of dealing with an ambiguous future that cannot be envisioned	A 38-year-old wife caring for her husband described dealing with illness by living one day at a time: "His favorite saying all along . . . is, 'None of us know what our date is on our contract.' . . . It is obvious that we are just supposed to live it one day at a time."
<b>Role Negotiation</b>		
Appropriate pushing	Caregiver taking responsibility to ensure that the rules for recovery set by healthcare providers are followed	A 74-year-old wife described taking responsibility and enlisting the support of her son to convince her husband to take his medications, despite his disinclination to do so.
Attending to patient voice	Describes caregivers listening and considering patient perspectives before deciding on a course of action	A 50-year-old husband described listening to his wife's perspective: "If I had tried to pressure her into signing up for disability, that would have been a bad deal. So I didn't pressure her . . . and she made up her mind that she was going to [apply]."

*(Continued on next page)*<sup>a</sup> Based on information from Williams, 2005, 2007.<sup>b</sup> Caregiver quotes were transcribed from the current study's sample.

**Table 3. Main Energy Sources for Informal Caregivers (Continued)**

Theme <sup>a</sup>	Definition <sup>a</sup>	Example <sup>b</sup>
<b>Role Negotiation (Continued)</b>		
Getting a handle on it	Coming to grips with the reality of the demands of illness and identifying strategies to meet caregiving demands	A 53-year-old wife caring for her husband described getting a handle on the new diagnosis and new responsibilities: "This has been [our] first experience with cancer . . . so dropping into brain cancer has been sort of jumping into the deep end of the pool. What has been difficult for me has been the amount of additional work that fell in my lap: taking care of financial things, taking care of insurance, taking care of the worries of all of that."
Sharing responsibilities	Determining caregiving needs and dividing responsibilities between people such as the caregiver, patient, healthcare provider, and family and friends	A 32-year-old daughter caring for her father discussed sharing caregiving responsibilities: "This is just way over my mother's head. I have a pill organizer and I fill it up. . . . She doesn't even know what those pills are."
Vigilant bridging	Caregiver communication with healthcare personnel to support the best interest of the patient	A 50-year-old husband caring for his wife described how he connected her with the healthcare system by insisting that the physician order magnetic resonance imaging following a seizure episode.
<b>Self-Care</b>		
Cultivating healthy habits	The caregiver maintaining or improving their own health to meet the caregiving demands	A 53-year-old mother caring for her son described taking care of her own health: "I am taking some vitamins and eating very well so I can be strong."
Getting away from it	Finding space to temporarily experience ordinary life away from the demands of caregiving	A 53-year-old wife caring for her husband described getting away from her caregiving responsibilities on occasion: "I really tried to keep my life going. . . . Every now and then I do get to a concert or I go to see friends, and I know that part is real important for me."
Letting it out	Expressing the feelings and frustrations associated with caregiving	A 28-year-old woman caring for her sister described expressing her frustrations: "She needs help, and I often tell [my family], 'She is going to have these mood swings, that is what drugs do to you . . . you have to be patient. You might have to walk out of the room, grit your teeth, go outside and scream and holler, but come back.' That is what I do sometimes."
Supportive physical environment	Creating accommodations, food, and other amenities that are comfortable and convenient for caregiving	A 32-year-old daughter caring for her father told of creating a physical environment amenable to being able to stay with her father at all times by keeping an inflatable mat in her car.
<b>New Insight</b>		
Experiencing personal growth	Gaining new perspectives, knowledge, and skills in the caregiving experience	A 53-year-old husband caring for his wife exhibited new perspective: "The good thing about it is I think we have learned to appreciate each day."
Leaning on the Lord	Finding comfort and strength in the belief that a higher power has control of the situation	A 48-year-old husband caring for his wife described leaning on the Lord: "We both prayed and said, 'God, you are going to have to help us with this one, this is bigger than us,' and when we turned it over, it is not a burden."
Recognizing positive outcomes	Being uplifted by events that signify to the caregiver an improvement in the patient's health	A 53-year-old husband described how surgery led to a perceived improvement in his wife's health, giving her immediate relief and uplifting him.
<b>Role Support</b>		
Encountering competent, compassionate care	Finding healthcare personnel who meet the needs of both the patient and caregiver	A 53-year-old wife caring for her husband described finding strength in competent medical care: "One of the things that . . . made it easier for me to handle was coming here and [letting go] of worries about the medical treatment. . . . That is a huge thing [to] have that confidence."
Finding support for other responsibilities	Caregivers accessing assistance from other people to handle responsibilities not related to caregiving	A 32-year-old daughter caring for her father told of having her mother watch her children one day a week so she could share the day with her father.

*(Continued on next page)*<sup>a</sup> Based on information from Williams, 2005, 2007.<sup>b</sup> Caregiver quotes were transcribed from the current study's sample.

**Table 3. Main Energy Sources for Informal Caregivers (Continued)**

Theme <sup>a</sup>	Definition <sup>a</sup>	Example <sup>b</sup>
<b>Role Support (Continued)</b>		
Knowing others care	Feeling emotional support from people outside the caregiving dyad, which gives the caregiver a sense of personal value and worth	A 48-year-old husband caring for his wife said, "We have a strong family support, we have a strong church support, and it is all part of the equation."
Meeting financial obligations	Finding ways to pay for added expenses of health care while compensating for lost income.	A 50-year-old husband caring for his wife described their decision to apply for disability.
Receiving helpful information	Acquiring the knowledge needed to perform as a caregiver	A 32-year-old woman described the process of gaining information: "Today I brought my tape recorder and I asked the doctor some questions."

<sup>a</sup> Based on information from Williams, 2005, 2007.

<sup>b</sup> Caregiver quotes were transcribed from the current study's sample.

Gauging behavior and role negotiation were difficult for the current study's caregivers because of the cognitive and behavioral decline exhibited by the patients. Caregivers described having to relearn the patient's personality after diagnosis and as the tumor progressed. Sherwood, Given, Doorenbos, et al. (2004) reported that loss of personhood and memory presented a challenge for caregivers of patients with primary brain tumors, who sometimes referred to care recipients as someone other than the person they knew before. In addition, caregivers in the current study and those in Sherwood, Given, Doorenbos, et al. (2004) reported concerns about safety issues, such as forgetting to turn off the stove, violent behaviors, and confusion. LoboPrabhu et al. (2005) described a process of separation-individuation that begins when caregivers must make decisions for patients with dementia, who may be unable to understand the situation. Caregivers in the current study reported a feeling of accomplishment in being able to gauge behavior, but they often described the difficulty of role negotiation, not knowing where to draw the line between patient independence and complete dependence on the caregiver. Schumacher (1996) described three patterns of caregiving dyads types: the self-care pattern, the caregiving pattern, and the collaborative pattern. Schumacher (1996) emphasized the phenomenon of shifting patterns of self-care and caregiving, describing the dynamic and fluctuating nature of informal caregiving. Caregivers in the current study reported constant reevaluating of caregiving responsibilities.

Several studies have pointed to the importance of providing support to caregivers that allows them to feel a sense of security in the healthcare team (Holt-slander et al., 2005; Janda, Eakin, Bailey, Walker, & Troy, 2006; LoboPrabhu et al., 2005; Sherwood, Given, Doorenbos, et al., 2004; Sherwood, Given, Given, et al., 2004; Wuest et al., 2001). Albinsson and Strang (2003) emphasized the importance of tailoring healthcare pro-

vider support to caregivers. Families of patients with dementia need more support in the areas of respite care and overcoming guilt felt by the family, whereas families of patients with cancer need healthcare providers to be available as the disease changes rapidly. Those support needs are congruent with the individual disease process and perceived effect of the illness on the family. Caregivers in the current study were able to derive strength from their healthcare provider once they were in the position to receive competent care and helpful information from a provider who specialized in this diagnosis.

The caregivers of patients with primary brain tumors used the energy sources identified in the Model of Informal Caregiving Dynamics in a unique way. Occasionally, caregivers described their experiences and sources for motivation with a negative connotation. This may be attributed to the morbidity and mortality associated with the diagnosis of primary brain tumor, as discussed previously. The caregivers likely found meaning in their role through acknowledging the negative aspects of their experience. As described by Ayres (2000b), this realistic view of the circumstances may allow caregivers of patients with neurologic and cognitive decline to be more flexible in response to new situations or illness-related decline.

### Limitations

Although measures were taken to prevent researcher influence in the analysis, the biases of the researcher may have influenced study results. Additionally, the relatively high mean years of education may have contributed to a bias in the results. The study was conducted at a single comprehensive, research-driven cancer center, where patients receiving care may have expectations of exposure to clinical trials and newer treatments. Other cancer centers may manage care for patients with brain tumors and assist informal caregivers differently.



## Implications for Nursing

Healthcare providers can assist caregivers of patients with primary brain tumors by understanding the energy sources the caregivers use to sustain their role. Clinicians should recognize the commitment caregivers make to endure responsibility, particularly regarding the impact of cognitive and functional decline. Wuest et al. (2001) discussed connected (helpful) support from healthcare professionals when professionals praise or validate caregiver efforts. LoboPrabhu et al. (2005) reported that clinician attention to caregivers' frustrations and constant validation of their importance help support the caregivers' commitment. Caregivers of patients with primary brain tumors reported gaining strength when healthcare providers acknowledged their role and allowed them to participate with the healthcare team.

Healthcare providers can further improve the caregiving experience by supporting the patients' and the caregivers' expectations, providing truthful, evidence-based information, and acting as a buffer to facilitate understanding through treatment twists and turns. Farran et al. (1991) identified the concept of powerlessness in caring for patients with dementia. Clinicians can provide education and support to decrease the feelings of powerlessness in caregivers, thus helping to manage expectations and build strength for current and future caregiving responsibilities.

Most caregivers in the current study expressed gratitude for the opportunity to share their story with an attentive listener, appreciating that others felt their role was important and valid. Albinsson and Strang (2003) compared the supportive needs of families of patients with dementia and patients with cancer, revealing that both groups need support in the form of listening. Healthcare providers can validate the role of caregivers

by asking about their experiences and acknowledging their contribution to the patient's well-being.

Additional studies evaluating the experience of informal caregivers of patients with primary brain tumors are needed. A longitudinal study of those caregivers would be useful to determine how their experience changes over time. Interventions based on the Model of Informal Caregiving Dynamics should be studied in this population of caregivers.

## Conclusion

The Model of Informal Caregiving Dynamics was used to describe the experience of informal caregivers of patients with primary brain tumors through storytelling. The dialogues provided a new understanding of the elements in the model. In this population, caregivers endure the cognitive and behavioral changes accompanying this diagnosis, envision the eventual decline of the patient, gauge behavior through neuropsychiatric symptoms, and gain strength through competent health care. Healthcare providers can support caregivers by acknowledging their efforts, providing truthful information to support realistic expectations, and listening to their stories to validate the caregiving role. Future research is needed to determine the dynamics of a long-term caregiving relationship in this population and study interventions created to support those caregivers.

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## For Further Exploration

### Use This Article in Your Next Journal Club Meeting



Journal club programs can help to increase your ability to evaluate the literature and translate those research findings to clinical practice, education, administration, and research. Use the following questions to start the discussion at your next journal club meeting. At the end of the meeting, take time to recap the discussion and make plans to follow through with suggested strategies.

1. What effects do you think cognitive impairment that occurs with a brain tumor has on the family or friend caregiver?
2. How can the nurse help the caregiver cope with changes the caregiver might find disturbing or uncomfortable?
3. What is Story Theory, and how does this theory help nurse researchers understand the patient and/or caregiver experience?
4. Select one of the themes identified in the Results section of this article (commitment, expectation management, role negotiation, self-care, new insight, or role support) and discuss how the nurse can support the caregiver. Feel free to use a deidentified patient example to illustrate the nursing interventions you might use.

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