

# Caring for the brain tumor patient: Family caregiver burden and unmet needs

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The rapid onset and progression of a brain tumor, cognitive and behavioral changes, and uncertainty surrounding prognosis are issues well known to health practitioners in neuro-oncology. We studied the specific challenges that family caregivers face when caring for patients experiencing the significant neurocognitive and neurobehavioral disorders associated with brain tumors. We selected 25 family caregivers of adult brain tumor patients to represent the brain tumor illness trajectory (crisis, chronic, and terminal phases). Interviews documented caregiving tasks and decision-making and information and support needs. Themes were permitted to emerge from the data in qualitative analysis. We found that the family caregivers in this study provided extraordinary uncompensated care involving significant amounts of time and energy for months or years and requiring the performance of tasks that were often physically, emotionally, socially, or financially demanding. They were constantly challenged to solve problems and make decisions as care needs changed, yet they felt untrained and unprepared as they struggled to adjust to new roles and responsibilities. Because the focus was on the patient, their own needs were neglected. Because caregiver information

needs are emergent, they are not always known at the time of a clinic visit. Physicians are frequently unable to address caregiver questions, a situation compounded by time constraints and cultural barriers. We provide specific recommendations for (1) improving the delivery of information; (2) enhancing communication among patients, families, and health care providers; and (3) providing psychosocial support for family caregivers. *Neuro-Oncology* 10, 61–72, 2008 (Posted to *Neuro-Oncology* [serial online], Doc. D06-00061, November 9, 2007. URL <http://neuro-oncology.dukejournals.org>; DOI: 10.1215/15228517-2007-040)

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It is estimated that more than 359,000 persons were living with a diagnosis of primary brain and central nervous system tumor in the United States in 2000.<sup>1</sup> Approximately 20,500 new cases of brain and other nervous system cancers and 12,740 deaths are expected in 2007.<sup>2</sup> Cognitive impairment, seizures, paralysis, and permanent neurological damage are the potential results of either the disease or the treatment, and these have effects on those living with the tumors as well as unpaid (usually family) caregivers.<sup>3</sup> Added to these burdens is the knowledge that, for most brain tumors, the likelihood for long-term survival is poor: the 5-year relative survival rate following diagnosis of a primary malignant brain and central nervous system tumor (based on 1973–2002 data) is 28.1% for males and 30.5% for females.<sup>4</sup> Providing health information is not without challenges: patients and families can require

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accurate, up-to-date information on any of the more than 125 subtypes of brain and central nervous system tumors and their symptoms, aggressiveness, treatment, and potential outcomes.

Some of the challenges faced by family caregivers are documented in the literature. Caregivers report high levels of stress and poor physical and emotional health, as well as career sacrifices, monetary losses, and workplace discrimination.<sup>5</sup> In the setting of a brain tumor, family caregivers face special challenges posed by the neurocognitive and neurobehavioral effects.<sup>6</sup> Brain tumor patients make up a unique diagnostic and treatment group. The diagnosis is catastrophic, often made after a sudden symptom onset such as a seizure or significant change in cognition. Following the sentinel event, ongoing limitations in physical and cognitive function and quality of life are prevalent and bring additional coping challenges for family caregivers.<sup>7-9</sup>

The needs of brain tumor patients differ from those of other cancer patients and often are unmet by existing resources. Fox and Lantz<sup>7</sup> conducted a quality-of-life study using individual and support group interviews. Their findings were organized around the following conceptual themes: (1) the stigma of a mind-body illness, (2) an invasive disease of self, (3) a brain tumor as a family disease, (4) dealing with the medical system, and (5) quality of life. Leavitt et al.<sup>8</sup> analyzed themes from a brain tumor support group's meetings to understand experiences, needs, and supportive mechanisms of these patients. They also reported themes that include changes in family life and managing medical advice. The "long haul" theme captured unexpected problems and complications, quality of life, need for resources, provider burnout, and balancing hope with realistic expectations. Information seeking emerged as a distinct theme. Sherwood et al.<sup>10</sup> built on earlier theories of stress and coping to describe a conceptual model of providing care for someone with a primary malignant brain tumor. Their model suggests an ongoing feedback loop as family caregivers appraise care demands and resources, and they describe factors that affect caregiver stress response.

The research on information needs and chronic illness suggests that almost all cancer patients want to be fully informed about the various aspects of their disease and treatment and, in increasing numbers, are assuming a proactive role in their own care.<sup>11-17</sup> However, a number of large retrospective surveys have found high levels of dissatisfaction among patients and their relatives with the information they receive after a diagnosis of cancer.<sup>18</sup> Because information needs are emergent along with the condition of the patient, patients and caregivers are not likely to know all of their information needs during an office visit.<sup>19</sup> Oncologists may not be ready to support patients with the range of quality health care information that caregivers might need on palliative care, pain management, quality-of-life assistance, family problems, psychosocial issues, home care, managed care, and complementary and alternative medicine.

A growing body of research finds that when patients and families have a better understanding of their diagnosis and treatment, they are more able to cope with their

illness (e.g., adjust to stressful situations and overcome problems),<sup>20</sup> use the health system more effectively, and have less psychological distress.<sup>5,19,21</sup> Improved coping strategies, in turn, generally result in better adjustment to a cancer diagnosis. Research is lacking, however, to explain how best to achieve this understanding for patients and their families.<sup>22</sup> Health education theory suggests that just because information is available does not mean that it is in a format that will be useful. An understanding of how people seek, use, and process information can help health practitioners structure and deliver information more effectively.<sup>23,24</sup> Few studies have examined the evolution of cancer patients' information needs over the course of the illness.<sup>17</sup>

To help inform the education of patients and their family caregivers, we undertook a qualitative study of the roles and needs of the caregivers of brain tumor patients. In this study, we used the chronic illness management model of Corbin and Strauss<sup>25</sup> as a conceptual framework to understand how information needs change. This theory makes a distinction between the "course of illness" (a medical perspective) and illness trajectory (a sociological perspective that reflects the physiological unfolding of a disease). The diagnostic period that accompanies chronic illness is conceptualized as a "diagnostic quest," with phases that include uncovering the source of symptoms, the announcement, and the postdiagnostic or "filling-in" period. Management of chronic illness after diagnosis—the process of "accommodation"—encompasses the day-to-day struggle of patients and families as they try to keep some sense of balance and give meaning to their lives. Central to this theory is the fact that patients and their families, not the medical staff, are the key players in accommodating a chronic illness at home.

Family caregivers were purposively selected to address needs across the trajectory of the disease. These individuals were interviewed on their caregiving and decision-making activities and their needs for information, as well as the methods they used to seek it. Qualitative analysis was used to elucidate the central themes of the unmet needs of caregivers, which can help inform the future task of meeting information needs. Here, we present our findings on these topics, along with our recommendations for (1) improving the delivery of information; (2) enhancing communication among patients, families, and health care providers; and (3) providing psychosocial support for family caregivers.

## Methods

### Study Setting

The Neuro-Oncology Center at the University of Virginia Health System was the primary setting for this study. The Center offers treatment for patients with primary and metastatic central nervous system tumors. Its multidisciplinary physician staff included neuro-oncologists, neurosurgeons, radiation oncologists, neuropsychologists, neuropathologists, nurses, therapists,

social workers, and chaplains. This study was approved by the University of Virginia institutional review board for the protection of human subjects.

### *Selection and Recruitment of Participants*

At least 500 new adult patients present at the Neuro-Oncology Center with a brain tumor diagnosis each year. Data for this study were collected from January 2002 to March 2003. All adult family caregivers (18 or more years of age) accompanying patients with a brain tumor seen at the Neuro-Oncology Center were considered for possible inclusion in this study. We used a purposeful and stratified sampling strategy<sup>26,27</sup> to select cases so that all phases of the illness trajectory were represented, particularly to illustrate the subgroups of the crisis, chronic, and terminal phases of illness, and so that the selected patients were representative of the range of patient demographics of the greater population. No other selection criteria were made, and no a priori hypotheses were formed, to allow themes to emerge in an unbiased manner.

Twenty-five family caregivers were approached either during office visits or over the telephone and invited to participate; all agreed to be interviewed. Eighteen caregivers were spouses (or the significant other) of the brain tumor patient, four were parents, two were children, and one was a sibling. Eighteen caregivers were women and seven were men, and caregiver ages ranged from 37 to 72 years. The index patients of these caregivers ranged in age from the mid-20s to mid-70s; all patients had a diagnosis of a primary brain tumor and were in various stages of treatment and disease progression. In six cases, the patient was deceased at the time of the caregiver interviews.

### *Data Collection*

In-depth interviews were conducted with the caregivers about their caregiving tasks and decision making, information, and support needs across the trajectory of their relative's brain tumor disease. The interviews were semistructured, guided by a questionnaire template developed for this study by the researchers (see Appendix). The template ensured that data collection covered the topics of interest, including participants' information and support needs, information-seeking behaviors, and satisfaction with information received. As each participant described the trajectory of the brain tumor, questions were asked about decision making and coping. Participants preferred to tell their "story" in chronological order. Thus, we obtained both a historical account of their experience and an account of the current issues and concerns experienced at the time of the interview. The interviews were approximately 60–90 min each. Because patients were geographically dispersed, there were occasional access limitations to conducting in-person interviews. For this reason, some of the interviews were conducted by telephone; others were integrated into clinic visits. The interview sessions were audiotaped and transcribed verbatim by a paid transcriptionist. Written notes were taken during the interview and compared

with transcriptions for maximum accuracy. Patient and family caregivers' names and other patient identifiers were changed.

### *Research Design*

The study sought to *describe* and *interpret* by determining essential features and identifying and understanding themes, as described by Tesch.<sup>28</sup> This qualitative method is a powerful and appropriate way to approach this topic. New themes that the researchers had not thought of at the onset of the study were allowed to emerge and were then explored in interviews with subsequent subjects. This design allows categories or dimensions of analysis to emerge from open-ended observations without presupposing what the important dimensions will be by specifying hypotheses. Study subjects were recruited and interviews were conducted until no new themes emerged from at least one subject (analogous to repeated focus groups for new participants). The third author, a neuropsychologist, and the neuro-oncology physicians of this hospital center recommended patients to include, in order to achieve a purposeful sample representing patients and families at different phases in the trajectory of illness (crisis, chronic, terminal). The only criteria used to select patients were time since diagnosis and demographics. The third author also served as a peer debriefer for the interviewer, reviewing the coding (words assigned to capture the meaning of the data and to begin to conceptualize the emerging themes) and examining inclusiveness and conceptual congruity. The research questions included the following: (1) *Caregiving*—What kinds of tasks do family members perform, and how does caregiving affect the family members? (2) *Decisions*—What kinds of decisions do patients and family members need to make during a brain tumor illness? When are these decisions made and by whom? (3) *Information*—What kinds of information are sought by patients and their caregivers? What sources are used? Are the sources sufficient?

### *Data Analysis*

The grounded theory methodology<sup>29</sup> is an inductive method that allows a conceptual scheme, themes, or a theory to emerge from the data "from the ground up" without a priori conceptual frameworks or hypotheses. The researcher provisionally codes the raw data by "open" coding—that is, assigning words to capture the meaning of the data. The data are then compared, sorted, and clustered to develop substantive conceptual categories and themes.<sup>8</sup>

FolioViews 3.01 qualitative software (Folio Corp., Provo, UT, USA) was used to organize and facilitate analysis of the data collected. This specialized software allows coding upon multiple themes and provides utilities for quickly searching documents and extracting coded segments and reporting themes. Interview data were broken into distinct chunks of information, each of which was coded with a descriptor, such as patient symptoms, depression and anxiety, uncertain future, and caregiving burden. Coding was ongoing and iterative. Data were

**Table 1.** Trajectory of illness coding scheme

Phase	Stage	Description
Crisis	Diagnostic quest	Acute phase
	Comeback	Journey back to a workable life within the boundaries imposed by physical and mental limitations—may be partial or complete, depending on the brain tumor
Chronic	Stable	Symptoms may still be intrusive; regimens still difficult; long-term management and physical wear and tear; a time of adapting (to devices and routines)
	Unstable	Symptoms (new or prior) occur; additional treatment may be required; patient may or may not return to a stable condition
	Deteriorating	Treatment is not effective or not possible as the brain tumor grows; the patient loses functional (physical and/or cognitive) ability
Terminal	Dying	The last weeks of life; hospice home care generally sought; patient and family prepare for death

Adapted from Corbin and Strauss<sup>25</sup> and Rolland.<sup>21</sup>

simultaneously collected and coded to accommodate new data and insight as the study progressed.

Because information needs at the time of diagnosis are very different from information needs during chemotherapy or at the end of life, a second coding dimension indicated the stages or trajectory of the brain tumor. Groups were assigned based on the trajectory phases of crisis, chronic, and terminal. In this way, the data were also coded into the period of time in which the patient experienced the event. These codes were based on the theoretical framework previously described for this study and are listed in Table 1.

Within-case displays (text descriptions) were used to draw and verify descriptive conclusions about the phenomena in a bounded context that makes up a single “case.”<sup>30</sup> Cross-case analysis was used to provide a deep understanding of the information and support needs of brain tumor patients and their families across the illness trajectory. The cross-case analysis involved comparing cases in a number of different ways: across different phases of illness; among caregivers with different relationships to the patient (self, spouse, parent, or child); among different socioeconomic groups; and between active caregivers (patient still alive) and former caregivers of a deceased patient.

Accepted criteria for qualitative naturalistic inquiry were used to ensure the trustworthiness and quality of the data.<sup>30,31</sup> These methods included checking for representativeness of the data, data triangulation (use of multiple methods to collect and record data, including verification of specific clinical variables from the medical record), and thick description (inclusion of field notes to capture the conditions and contexts of the data collected). The patient’s medical chart was used to corroborate data collected where possible (e.g., verify diagnosis, diagnosis date, hospitalizations, treatment types and dates). A possible source of error was the potential for sampling of nonrepresentative informants by relying on (or overweighting the data from) articulate, well-educated participants and underrepresenting those from other populations. To avoid this error, cases were sorted based on demographic information as the data were collected and an additional effort was made to collect data from weakly sampled case types.

## Results

Twenty-five family caregivers participated in interviews about their needs and uses of information in caring for a person with a brain tumor. Table 2 lists the participant cases.

At the time of diagnosis, patient and family caregiver information needs revolved around understanding the specific diagnosis and recommended treatment. This information was usually provided through direct communication with physicians and nurses. All family caregivers in the study obtained additional information from the Internet, either accessing it themselves or (more often) with assistance from a friend or other family member. Although several had known someone with a brain tumor, all of the caregivers felt that they lacked sufficient understanding and reported being overwhelmed and “in shock” at the time of diagnosis. One caregiver said, “I would like to understand the diagnosis. The Web site made me nervous. I know part is fast growing and part less risk, but I don’t know how much is more risk.”

Family caregivers felt inadequately prepared for the daunting tasks that they had to undertake. Because they were present during hospitalizations and clinic visits, the family caregivers in this study had direct contact with the health care team. Yet, these caregivers reported a general lack of coordination between themselves and the formal health care system in terms of the communication and training they needed to take care of their family member. Even so, they expressed high levels of satisfaction with the care provided by physicians and nurses, recognizing that health providers are very busy, and even defending their failure to provide adequate information.

Several important themes were evident across the 25 family caregiver cases (Table 3): (1) family issues, (2) managing challenging behaviors, (3) personal feelings, and (4) navigating through the medical system. Because the issues are interrelated, there is some overlap in this thematic categorization.

### Family Issues

It was clear that a brain tumor diagnosis, and the disability it brings, affects the whole family. As one caregiver

**Table 2.** Caregiver/participant characteristics

Case	Relationship to the Patient	Caregiver's Age	Patient Status at Time of Interview	Tumor Type	Time since Diagnosis of Patient's Brain Tumor	Phase in the Illness Trajectory
1	Mother	Early 60s	Deceased	Anaplastic oligoastrocytoma	Died 6 years after diagnosis. Caregiver interviewed 13 months later.	Mourning death
2	Wife	Late 50s	Alive	Anaplastic oligoastrocytoma	2 months	Chronic/deteriorating
3	Wife	Early 70s	Deceased	Glioblastoma	Died 2 months after diagnosis. Caregiver interviewed 14 months later.	Mourning death
4	Wife	Mid 50s	Alive	Other high-grade tumor	12 years	Chronic/unstable
5	Wife	Mid 40s	Alive	Glioblastoma	10 months	Chronic/unstable
6	Husband	Mid 60s	Alive	Anaplastic oligodendroglioma	1 year, 3 months	Chronic/stable
7	Wife	Late 50s	Alive	Anaplastic oligodendroglioma	4 years	Chronic/deteriorating
8	Wife	Late 30s	Alive	Glioblastoma	7 years	Chronic/stable
9	Wife	Early 60s	Alive	Glioblastoma	1 year, 5 months	Terminal/dying
10	Husband	Mid 40s	Alive	Anaplastic oligodendroglioma	2 months	Crisis/comeback
11	Husband	Late 50s	Deceased	Glioblastoma	Died 16 months after diagnosis. Caregiver interviewed 10 months later.	Mourning death
12	Mother	Early 50s	Deceased	Anaplastic oligoastrocytoma	Died 4 years after diagnosis. Caregiver interviewed 2 years later.	Mourning death
13	Mother	Mid 50s	Deceased	Anaplastic oligoastrocytoma	Died 5 years after diagnosis. Caregiver interviewed 1 year later.	Mourning death
14	Wife	Late 50s	Alive	Hemangiopericytoma	2 years, 3 months	Chronic/stable
15	Wife	Mid 40s	Alive	Anaplastic oligoastrocytoma	1 year, 3 months	Chronic/stable
16	Mother	Early 60s	Alive	Diffuse astrocytoma	2 years, 4 months	Chronic/stable
17	Wife	Mid 40s	Alive	Oligodendroglioma	1 year, 4 months	Chronic/stable
18	Daughter	Early 50s	Alive	Glioblastoma	New	Crisis/diagnostic quest
19	Husband	Mid 50s	Alive	Central neurocytoma	2 years, 6 months	Chronic/stable
20	Wife	Early 60s	Alive	Glioblastoma	4 months	Crisis/comeback
21	Husband	Mid 50s	Alive	Oligodendroglioma	3 years	Chronic/stable
22	Sister	Late 50s	Alive	Meningioma	3 years	Chronic/stable
23	Daughter	Mid 50s	Alive	Oligoastrocytoma	2 years	Chronic/stable
24	Husband	Early 50s	Alive	Oligodendroglioma	2 months	Crisis/comeback
25	Significant other	Early 40s	Deceased	B-cell lymphoma	Died 1 year after diagnosis. Caregiver interviewed 3 months later.	Mourning death

said, "When one family member is ill, all of the family is ill." Relationships, roles, and responsibilities change with the diagnosis of a brain tumor. The changes may have been subtle at first but generally became more profound as the tumor progressed. Family caregivers talked about the adjustments they made as a result of their loved one's declining abilities. These included changing expectations about what the person could and could not do. It meant compensating for the person's disabilities by assuming a growing number of responsibilities.

The different effects of a brain tumor on the family

caregiver (as well as on the patient and other family members) depended on when the illness struck, relative to the family's development and that of each individual member within it. For example, one caregiver's response to her husband's diagnosis was clearly affected by the deaths that she had already experienced with her mother and grandmother. Another's relationship with her husband seemed increasingly fragile as she balanced the competing needs of her husband's care and the care of her children. A third couple had a more mature relationship that was supported by a strong marital commitment to each other.

**Table 3.** Themes across family caregiver cases

Theme	Family Caregiver Case																								
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
<b>Family issues</b>																									
Relationships and changing roles		Δ			Δ	Δ	■	Δ	Δ	■	■			■	Δ		■	■		Δ			■	Δ	
Helping with activities of daily living/ nursing duties					Δ	Δ			■	■		■	■	Δ	■	Δ	Δ	■	Δ	■	Δ	Δ	Δ	Δ	■
Employment and financial issues		■	Δ		■	Δ	Δ	Δ	Δ		■	Δ	Δ	■	■	Δ		■	Δ		■	Δ	Δ	Δ	
Balancing the needs of other family members	Δ				■			■			Δ		Δ	Δ		■				Δ			Δ		
<b>Managing challenging behaviors</b>																									
Understanding neurocognitive changes	Δ	Δ		Δ	Δ	Δ	Δ		Δ	■		■	■	Δ	Δ	Δ	Δ	Δ		Δ	Δ	■	Δ	Δ	
Dealing with depression and personality changes					■		■		Δ	■	■	Δ	■	■		Δ	Δ	Δ	■						Δ
Dealing with impulsivity or aggressive behavior		■			■													Δ			Δ				
<b>Personal feelings</b>																									
Feeling overwhelmed	Δ	■			■		■	Δ	■		■	Δ	■	Δ	Δ	Δ	Δ	Δ		Δ	Δ	Δ	■	■	
Denial	■	Δ										Δ		Δ			Δ	Δ			Δ				
Resentment, anger, guilt, depression, and anxiety	Δ		■		■		Δ				Δ		Δ	Δ	Δ		Δ	■	Δ				Δ	Δ	
Isolation					■		■		Δ								Δ				Δ				
Sense making	Δ	Δ	Δ						■	Δ	Δ	Δ	■	Δ		Δ				Δ			Δ	Δ	
<b>Navigating through the medical system</b>																									
Improving physician-caregiver communication	■	■	■	■		Δ		Δ		■	Δ	Δ	Δ	■	Δ		Δ	Δ	Δ			Δ	Δ	Δ	
Understanding the medical system	Δ	■	■				Δ	■	■		■	Δ	Δ	■	Δ	■	Δ	Δ	Δ	Δ	Δ	Δ	Δ	■	Δ

KEY:

■ Very strong theme (mentioned three or more times by the caregiver, or topic dominates interview).

Δ Moderately strong theme (mentioned at least twice by the caregiver).

Financial problems were reported by all of the families, including issues around employment, difficulties in understanding insurance and other benefits, and insufficient income to meet all of the family’s needs with the added burden of the cost of caring for a patient with a brain tumor. For some, the patient’s job was either lost or threatened because of the brain tumor. One couple’s finances dwindled to the point that they relied on charity, mostly from two church parishes, to pay the heat bills and their small monthly mortgage. One caregiver reported that she never even had time to investigate disability benefits. In cases where the patient had managed the household finances in the past, the financial effect caused by the patient’s brain tumor was often not noticed right away. One caregiver discovered several months of unpaid bills in her husband’s dresser drawer after he was hospitalized. Another patient shredded all of the couple’s important papers, including stock certificates and insurance policies, demonstrating the impulsive behavior of a patient with a frontal lobe lesion.

Five of the family caregivers were wives tending their afflicted husbands while also caring for children living at home. The time demands were physically and emotionally exhausting, and they reporting feeling that they were neglecting their children. Decisions about how much information to share with children (and when) were difficult to make, given the uncertainty surround-

ing the brain tumor diagnosis. Often caregivers reported finding themselves “sandwiched in” between taking care of an aging parent and taking care of the brain tumor patient who was either the spouse or child.

All of the patients involved in this study had been hospitalized at least once because of their brain tumor. Several had experienced multiple hospitalizations. In all cases, after those hospitalizations, the family caregivers took on added responsibilities for assisting with activities of daily living, such as bathing and feeding, and instrumental activities of daily living, such as shopping, managing the household finances, and taking care of the children. Family caregivers also performed nursing duties, such as changing dressings and administering medications, without training—tasks that are often carried out by trained health professionals. There was also the added work of comforting—preventing isolation, providing emotional support, and managing the limitations of activity. These new tasks often crossed the barriers of privacy. For example, even the wife who has been married many years is not likely to have dealt with assisting her husband with private toileting activities. The family caregivers interviewed generally carried out these additional responsibilities alone. Community resources were not used or even sought, although the need for help and respite care was quite obvious in several cases.

### *Managing Challenging Behaviors*

Neurocognitive changes were often challenging for the family member to assess, with reported symptoms including memory loss, impaired reasoning and processing, attention deficits, language difficulties, psychomotor deficits, and problems with working memory, such as the ability to sequence or perform multiple tasks at one time. Caregivers who did not understand neurocognitive changes found them more challenging. The caregiver who does not understand may say, "He's just not paying attention to me," without realizing that her husband is no longer able to pay attention because of the neurocognitive effect of the brain tumor. Family caregivers often had to deal with the patient's depression and other negative emotions, a task reported as more challenging than the physical care. Behavior and personality changes were also reported, including aggressive and impulsive behaviors. Caregivers who understood that the person could not control or change behaviors were more resilient and found ways to cope (e.g., writing things down for the patient with memory loss or communicating information in smaller chunks). Most caregivers in this study learned as events unfolded, by seeking information from the physician or other health care providers. Several families reported benefit from having a neuropsychologist involved in the patient's care. Other caregivers who had not seen a neuropsychologist remained uncertain about the neurocognitive and emotional changes that were taking place.

### *Personal Feelings*

All of the family caregivers interviewed described feeling overwhelmed. Some described the tiring physical, day-to-day work of caregiving. When asked what sorts of things they do for their family members, many were quick to respond, "Everything!" Others spoke of being overwhelmed in emotional terms.

Denial of a brain tumor diagnosis was common. Denial often persisted through the chronic phase when the patient was deteriorating. In several cases, only after the caregiver could no longer manage the patient alone and accepted hospice services did the denial of a terminal brain tumor diagnosis lift. One caregiver reported that her denial remained until after her son's death; sadly, she reported feeling significant guilt that she could have done more to help. Our results show the negative effect on caregivers who did not overcome denial. Anger was also a common response to the diagnosis. This anger was sometimes directed toward the patient. One caregiver's husband was still able to work in spite of memory problems, but she was doing more errands for him as she began her new role as caregiver and found she resented it. The anger may also be directed at the health care system, as in one case in which a caregiver wrote a letter to the president of the university where her husband had obtained health care with complaints about her husband's care, essentially because she was very angry that he had died: "These are supposed to be our golden years together." Also, because caregivers typ-

ically assume the burden of their roles without help, they often feel isolated. Several mentioned the isolation and social stigma associated with a cancer diagnosis. One caregiver noticed that, "Most people who know what's going on don't quite know what to say to me, and will walk away to avoid saying something wrong."

Caregivers discussed a "sense making" that happens as the family attempts to come to terms with the brain tumor diagnosis and asks, "Why me?" All of the caregivers interviewed had reasons to despair, yet among their stories of struggle and suffering were stories of hope. There is also a type of sense making involving the *process* of the brain tumor illness. This sense making provides some sense of control when bad things are happening. For example, several caregivers kept detailed diaries, noting physical and emotional events as their family member's health declined. For some, information that added to their understanding of the brain tumor helped them to make some sense of the illness.

### *Navigating through the Medical System*

For most of the caregivers, the day that their family member was diagnosed with a brain tumor was a vivid memory down to the smallest detail. Communication with the physicians was a key theme. Although the time spent with the physician was often limited and information needs unmet, the physician was the most trusted source of information in all cases. Most participants relied on their physicians to make treatment choices; in several cases, however, caregivers were not certain that the treatments offered were the most promising available for their family member's particular diagnosis, but they did not know where else to go. As one caregiver said, "I don't know how long his battle will last or what the outcome will be. I do know that if I don't come out of this with some certainty that we did everything to fight it that we possibly could, I won't be able to live with myself." Caregivers were afraid of offending the physician by asking too many questions: "He cautioned me to stop playing doctor."

Although our interviews focused on the caregiving activities that took place in the home, caregivers insisted on recounting their hospital experiences. Transitions or transfers from one care setting or physician to another were times of heightened stress for the family caregiver, but respondent comments suggested that the health system tended to ignore the needs of family caregivers. Although caregivers would mention an individual (e.g., a particular nurse or physician) who was especially supportive and responsive, at the institutional level there was a perceived lack of formal structures to support family caregivers. Often the information they received on the medical aspects of care came from someone they knew or consulted informally. The medical system and related issues of health care costs and disability insurance were confusing, and the system was thought to be impersonal and even hostile. Although caregivers reported a lack of needed information from the formal health system, they also recognized that the health providers are busy and were quick to forgive the lack of information.

### *Discussion and Practice Implications*

The family caregivers in this study provided extraordinary uncompensated care involving significant amounts of time and energy for months or years and requiring the performance of tasks that were often physically, emotionally, socially, and/or financially demanding. The information needs of these family caregivers changed across the trajectory of the brain tumor. In all cases, the diagnosis of a brain tumor was an unexpected, emotionally devastating event. Initially, the families sought to learn more about the brain tumor and what it meant. In some cases, they needed information to make treatment decisions quickly for a complex condition that they knew very little, if anything, about. They needed to understand the options, including experimental treatments, side effects, and risks as they searched for the best chance for a cure. Recommendations for meeting these information and support needs pertain to (1) the delivery of information; (2) communication among patients, families, and health care providers; and (3) psychosocial support for family caregivers. These components of an effective plan are discussed in this section.

#### *Specific Information Needs of Caregivers*

Information seeking was highest immediately following diagnosis. Family caregivers generally used all available sources; in addition to physicians and other health care providers, they often sought information from family, friends, and the Internet. Yet, finding useful information specific to their relative's brain tumor and the prognosis and treatment was difficult for even the most educated family caregivers in our study. This is not surprising, given that there is a great deal of variability surrounding the sequelae of the subtypes of brain tumor, with symptoms and aggressiveness varying widely. Prognosis in terms of survival and quality of life also varies, and while some statistics exist for various types and treatments, the expected outcome for an individual will be largely unknown. As a family's focus shifts from understanding the patient's diagnosis and treatment to overall home-based care management, their information needs change. Yet, our results suggested that family caregivers do not return to the information seeking mode that they were in during the time of diagnosis.

Because information needs are emergent, they are not always known at the time of a clinic visit. And, while the physician is often the most trusted source of information, because of time constraints and cultural barriers, caregiver questions and concerns often go unanswered. More often, caregivers learn by trial and error and through informal channels, such as a neighbor or friend. Caregivers reported that they wanted physicians to tell them what to expect ahead of time, before a crisis. They wanted to be prepared to manage neurocognitive changes that are likely to happen. They wanted to know how to address the patient's depression and personality changes, how to deal with aggressive or extreme behavior, and when to seek professional help.

Thus, an effective practice strategy should include

providing clear communication of information about the individual patient's diagnosis and treatment. Patients with poor health literacy are more likely to benefit from an emphasis on the information they need to act on, with detailed facts available as a secondary resource. Since emotion during crisis can prevent maximal learning by patients and their caregivers, the same information should be presented numerous times and in numerous formats (e.g., spoken, written, on the Web), and staff should be trained in communicating overwhelming news to patients.

Information and support are especially important for the transition from hospital to home-based care, because education at the time of hospital discharge is usually very limited. Family caregivers need to be prepared for the specific tasks that they will likely perform for the patient. Most of the family caregivers took on nursing care tasks that they had little, if any, training to perform. In-home visits by home-health staff specially trained to assist families of patients with nervous system cancers, early after discharge and at other pivotal transition points, would improve the benefit of this information and promote better patient care. If home visits are not practical for logistical and other reasons, an alternative might be planned (e.g., educational sessions that coincide with routine clinic appointments). All families expressed a desire to know what to expect in the future.

#### *Communication with Caregivers*

This study illuminated the inadequacy of the information obtained during clinic visits to meet caregiver needs and the inadequacy of the health care system to fill this void. Strategies are also needed to improve communication among the patient and the rest of the family, friends, the health care team, insurance companies, and many others. Family caregivers may benefit by an educational plan that includes helping them to develop the skills they need to better communicate with the health care providers, including communicating their own problems and concerns. For example, families need skills to empower them to initiate (often uncomfortable) conversations about concerns of undertreatment and overtreatment. Patient decision aids used in shared decision making about discontinuance of treatment may offer a way to help patients and families arrive at informed value-based choices, although the evidence is unclear about their use in stopping treatment.<sup>32</sup> Families need to communicate and coordinate care with their local primary care physicians and others involved in their care locally, and they need to know how to address unsatisfying relationships with providers. In the hospital setting, family caregivers in our study were not always certain who was "in charge" or whom to contact. The wife of one patient study participant felt "pushed aside" when the physician did not seem to believe her story and relied solely on her husband's incomplete version of events. A social worker dedicated to the neuro-oncology team might help to bridge the gaps between health care providers and insurance companies and patient and family by identifying and arranging appropriate services. Begin-



ning at the time of diagnosis and throughout the course of the brain tumor, resources should be directed toward family-centered care.

### *Emotional Needs of Caregivers*

From the results of this study, it is apparent that caregivers were constantly challenged to solve problems and make decisions as care needs changed. They often took on new tasks that they were not trained to do. It is not surprising that their own needs—physical and emotional—were unnoticed as they juggled time, jobs, money, energy, and roles. In the cases where treatment was not successful, they had to cope with the difficult issues of death and bereavement. They reported feeling overwhelmed and isolated. They struggled with a sense of denial and feelings of resentment, anger, and depression as they attempted to make sense of the disease and what it meant for their loved one and family. Parents in the role of primary caregiver had the same information and support needs as spouses.

Ideally, all families facing illness and disability should have a psychosocial component in their care that includes the family at appropriate times in the illness trajectory. Optimally, this would include a family consultation in the crisis phase, near the time of diagnosis. Rolland's family-systems-illness model, for example, invites the family into this kind of collaborative process at an early stage to promote open communication among health care professionals, the patient, and the family, providing preventative and therapeutic benefits to the family as the central psychosocial unit of care.<sup>21</sup>

In the trajectory of illness, the *chronic phase* is a time of adapting to new roles, responsibilities, and routines as families adjust. Psychosocial support is important for learning to deal with the stress of a chronic illness, as families face the realization that their lives are forever changed by the uncertainty that surrounds a brain tumor diagnosis. Even when the patient is stable, the caregiver will likely feel the wear and tear of dealing with a chronic illness, and caregivers need and want to be prepared for the next phase of disease progression. Taking better care of the caregivers can improve not only their own quality of life but also that of the patient. Indeed, this has been shown in a randomized, controlled trial of psychoeducational, cognitive-behavioral therapy with caregivers of brain tumor patients.<sup>33,34</sup> Effective delivery channels might include telephone support groups, Web-based delivery, and educational sessions that are made available during scheduled clinic visits for the patients. Optimal care and support incorporate an understanding of the psychosocial demands of a brain tumor illness over time.

The *terminal phase* was described by the six family caregivers whose family members had died prior to the interviews. Balancing hope and realistic expectations was a consistent theme. (This topic was also noted by Leavitt and colleagues<sup>8</sup> in their study of brain tumor patients.) All caregivers regretted not being better prepared to manage symptoms as the patient declined and not knowing what to expect. They regretted not accept-

ing hospice care sooner. Two other patients in our study were terminally ill but not receiving hospice care. Their family caregivers did not want to talk about their prognosis. They reported being overwhelmed and dealing with unexpected and difficult symptoms. One of these patients was diagnosed just 2 months before the interview (although it is likely that he had a tumor for 5–7 years and was misdiagnosed).

As the patient becomes progressively disabled, relief from the demands of caregiving tends to be minimal. There is increasing stress caused by the continual addition of new tasks and the continual adaptation to new roles over time. Yet, the psychosocial burden of caregiving at the end of life is vastly underappreciated—overshadowed by the fear of the patient's increased disability and physical death. Implications for practice include improving attention to the caregiver's own health,<sup>35</sup> addressing unspoken fears, and supporting caregivers through end-of-life passages, including clear decision making and preparation for death.

There is a process of coming to terms with the illness itself—of restructuring life around the limitations that it imposes and the possibility of death. In cases of a glioblastoma, where the tumor was diagnosed late or progressed rapidly, the patients moved through the illness phases very quickly—in one case, from crisis to terminal phase, skipping the stable or chronic phase. The psychosocial support needs of family caregivers of glioblastoma patients are likely to be greater, because there is little time to adjust or adapt to the disease. In cases of longer-term survivors in whom the brain tumor is stable for some time, the illness is still intrusive, affecting virtually all aspects of life. Although families tend to work out routines for dealing with the illness, it frames all that they do. Family caregivers want to know the degree of recovery to expect. (Will he be the person that he was before?) For most of the family caregivers in our study, regardless of the specific diagnosis, their personal struggles remained hidden from the outside and even from other family members.

### *Limitations of the Study*

The participants in this study were all family caregivers of patients seen at a single academic medical center. Thus, the experiences they described with the health care system may not be generalizable to other settings. Second, the study sample did not include any indigent or impoverished families or any extremely wealthy families. It did include one participant of low socioeconomic status and another whose native language was not English, but it did not include members of any racial or ethnic minority groups, reflective of the overall population of patients seen at this center. Third, the study did not capture the experiences of family caregivers in “real time” either at the very beginning (crisis of hearing the diagnosis) or at the very end (death) of the illness trajectory. Thus, the information obtained about caregiver needs at these phases was recounted in hindsight and may have introduced recall bias.

### *Recommendations for Future Research*

Additional qualitative studies are needed to provide information about the depth and diversity of family members' experiences and to include their interactions with the health care professionals who care for brain tumor patients, to better understand and meet the needs of these important contributors to the health care process. Future studies that include people of low literacy and low socioeconomic status, as well as people from different cultures, would allow comparisons across different caregiving settings. Research is also needed to measure discrepancies between patient and family expectations and their actual experiences to determine the education and support needed to obtain optimal health and quality-of-life outcomes. This study focused on the health information needs of family caregivers. Future studies that further explore specific needs identified might include the diversity of how families cope. Much can be learned by the successes and strategies that caregivers have developed.

### **Conclusions**

To meet the changing needs of patients and families, an effective information and support plan for family caregivers should follow the illness trajectory of the brain tumor from diagnosis to end of life. In this way, the educational strategy—both the content and the delivery channel—will match where the family is in the illness trajectory, from the initial crisis of onset and diagnosis through treatment, recovery, relapse, and end of life. It is important to take into account the emotional state of the family, which tends to change over the course of an illness.

In summary, the rapid onset and progression of a brain tumor, cognitive and behavioral changes, and uncertainty surrounding prognosis are issues well known to health practitioners in neurooncology. Family caregivers are the frontline providers of most of the day-to-day care of brain tumor patients, yet they are usually untrained and unprepared as they struggle to adjust to new roles and responsibilities. Because the focus is on the patient, the emotional aspects of caregiving often go unnoticed and unsupported.

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## **Appendix. Family Caregiver Interview Questionnaire Guide**

### *Prior Events (before Coming to the UVA Neuro-Oncology Center)*

First, I'd like to ask about the events that led to you and [patient's name] coming to the UVA Neuro-Oncology Center.

How did you find out that [patient] had a brain tumor? What were the first symptoms?

Thinking back to the day when you first learned that [patient] had a brain tumor, what did you know about brain tumors? Have you known anyone else who had a brain tumor? What kind of tumor? What happened?

*Guide respondent through any procedures, scans, biopsy/resection, radiation, or other treatment that happened prior to coming to UVA. Ask about sources of information and understanding.*

### *First UVA Neuro-Oncology Center Visit and Information Sources*

Try to think back to your first visit. Can you remember that visit?

Do you remember what you were told in the clinic? By whom?

*Did the patient and family caregiver feel that they understood the diagnosis at the time (tumor location, size, characteristics, prognosis)? Did they understand the treatment that was going to happen?*

Were you given any materials to take home during the first clinic visit, like a pamphlet or a video?

After you got home, how did you feel about the information that you were given? What sorts of things were confusing or unclear at that time?

How did you learn more about brain tumors? *Ask about actual resources accessed, such as books, the Web, family physician, and friends.*

### *Computer Usage and Brain Tumor Information*

Have you used the Internet (or Web) to find information about brain tumors?

Do you have a computer at home? *If no, ask if they have access to a computer.*

*If the caregiver uses a computer, then ask:*

- What sorts of things do you use your computer for? Was it helpful for accessing brain tumor information?
- Did you use a discussion group? *Get Web addresses if Web is used.*
- How do you connect to the Internet (modem, DSL . . .)? What is a typical connection speed?

- Do you get on the computer from home and/or work? *Probe for a sense of level of computer skills and comfort.*
- Do you use a handheld computer, also called PDA, like a Palm Pilot?

*If the caregiver does not use a computer, ask about feelings about how helpful it might have been.*

### Follow-up Neuro-Oncology Clinic Visits

From our records, it looks like you were first seen in our Neuro-Oncology Clinic in [month, year]. Is this correct?

What usually happened during these clinic visits? *Probe to understand typical visit, whether patient and caregiver felt confused by the process, whether additional information was ever given and in what form.*

Did you understand the test results (MRI, CT, angiograph, other)? Did you understand how to schedule appointments, whether to bring MRI films, how to know what you were supposed to do?

### Decision Making

What kinds of decisions or choices did you and [patient] have to make about treatment?

My next question is about clinic follow-up time. Follow-up time is something that patients may have some choice about. Some people feel less anxious if they come in more often. Others prefer less frequent visits. Do you recall making a decision about how often you wanted to come here? What would you have liked to have been the amount of time between appointments?

*Ask about desire for rehabilitation services (physical, cognitive, emotional problems), symptom management, psychosocial, hospice care, other end-of-life services, bereavement counseling.*

### Family Roles and Relationships, Challenges

What have been the most challenging or difficult aspects of [patient's] brain tumor for you and your family?

*Ask follow-up questions to address unexpected or difficult behaviors, aspects of care, family roles, and relationships. Ask about help and support services as appropriate (formal and informal), for both patient and family caregiver. Ask what kind of support would be helpful now and, in hindsight, what support would have helped.*

What advice would you give another person whose family member is faced with the same diagnosis as [patient]?

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