

A New Reality: Long-Term Survivorship With a Malignant Brain Tumor

Mary Pat Lovely, PhD, RN, Christina Stewart-Amidei, RN, PhD, APN-CNS, CNRN, CCRN, FAAN, Margaretta Page, RN, MS, Kathleen Mogensen, RN, MSN, APN-C, Jean Arzbaecher, RN, MS, APN-CNS, CNRN, Kathleen Lupica, RN, MSN, CNP, and Mary Ellen Maher, RN, MSN, CNP

An estimated 25,000 new cases of primary malignant brain tumors (PMBTs) are diagnosed each year in the United States (Central Brain Tumor Registry of the United States [CBTRUS], 2012). Contemporary treatment includes surgical debulking where possible, with concomitant radiation and chemotherapy (Mirimanoff et al., 2006). Even with aggressive multimodality treatment, median survival time for people with a PMBT is about 17 months, with a two-year survival rate at 43% (Mirimanoff et al., 2006). Recent advances in the diagnosis and treatment of PMBTs have improved mortality for those affected, and more people with PMBTs are living for longer periods of time (Steinbach et al., 2006). Survivors are challenged by not only treatment-related morbidities but also by consequences of the disease itself (Steinbach et al., 2006). Unlike many other cancers, unique disease-related deficits may occur because of brain involvement, leaving many survivors to suffer from persistent neurologic and cognitive deficits that interfere with their ability to resume previous activities (Steinbach et al., 2006).

Brain tumor survivors report physical problems such as fatigue, weakness, pain, and neurologic deficits. Studies have shown decreased quality of life (QOL) related to the symptom cluster of depression, fatigue, sleep disturbances, and cognitive impairment (Fox, Lyon, & Farace, 2007; Lovely, Miaskowski, & Dodd, 1999). Cognitive sequelae, including poor short-term memory and difficulties with higher executive functions, are of particular concern to survivors with brain tumors (Giovagnoli, Silvani, Colombo, & Boiardi, 2005). Steinbach et al. (2006) surveyed PMBT survivors (N = 10) who were more than five years from diagnosis and found that neuropsychological status was impaired in at least one area in all patients, with attention deficits being the most prominent sequelae after PMBT treatment. Those survivors reported reductions in multiple aspects of QOL using the European Organisation for Research and Treatment

Purpose/Objectives: To explore the survivor experience of adults who have been diagnosed three years or longer with a primary malignant brain tumor (PMBT).

Research Approach: Qualitative using a biographical narrative approach.

Setting: Six sites across the United States.

Participants: Survivors of PMBTs (N = 35) and their family caregivers (N = 35).

Methodologic Approach: Using a semistructured interview guide, survivors and caregivers were interviewed individually about their lives before and since the PMBT diagnosis. Thematic analysis was performed to identify themes.

Findings: Stability in survivor lives disintegrated as a result of the changes experienced related to the tumor and its treatment. Those changes were profound and ultimately contributed to multiple losses in key areas of their lives. Over time, living with the diagnosis and its consequences required survivors and their caregivers to adapt to the new reality of their lives. Through the process of becoming a survivor, individuals were able to take back control of their lives. Adaptation required survivors to use internal and external resources as ways of coping with their new reality.

Conclusions: People with PMBTs require support as they adapt to losses and changes that impact their lives. Assessment of specific changes that impact survivors' lives may be useful in guiding type of support given. Symptom management and mobilization of internal and external resources may lessen the life-changing impact.

Interpretation: Nurses should capture symptom meaning during assessments and expand assessments to include social support systems. Instituting measures that facilitate survivor independence may lessen the impact of disability. The significance of symptom worsening over time requires additional research.

Knowledge Translation: Restoring self-worth and taking control of their lives are critical concerns for survivors of PMBTs.

of Cancer QOL Questionnaire–Core 30 role functioning scale, which assesses ability to work, perform activities of daily living, and participate in leisure activities.

Managing emotional changes that occur presents additional challenges to survivors with PMBT. In a qualitative study, Fox and Lantz (1998) explored the emotional consequences of surviving a malignant brain tumor. They found that those with brain tumors experienced the "stigma of a mind-body illness" (Fox & Lantz, 1998, p. 249) as well as the consequences they associated with loss of self-identity. Survivors of PMBT experienced not only physical changes, such as weakness, but also changes in their thinking and personality that altered their beliefs about their self-value. Loss of the sexual self has been reported in gynecologic cancer survivors (Anderson, 1999); similar effects may be seen with brain tumor survivors. Economic consequences often occur because of job loss and inability to obtain health care and life insurance (Giovagnoli et al., 2005).

The meaning of these collective consequences to the individual requires additional study. Healthcare providers need to understand brain tumor survivor perspectives to deliver patient-centered care. Rowland, Aziz, Tesauero, and Feuer (2001) called for surveillance of cancer survivors (all types) to identify physical, cognitive-behavioral, and emotional changes that may require interventions beyond the treatment period. Researchers have studied the experience of living with cancer in other populations, such as those with breast and lung cancer (Carter, 1993; Macleod, 2000; Pelusi, 1997; Prouty, Ward-Smith, & Hutto, 2006) and chronic neurologic illness such as traumatic brain injury (Kao & Stuijbergen, 2004) and multiple sclerosis (Courts, Buchanan, & Werstlein, 2004). However, to date, no study was found that addressed the experience of long-term survivors with PMBT.

The aim of the current study was to understand the experience of surviving the diagnosis of a high-grade PMBT for more than three years. That time frame was chosen because participants would have completed their treatment course and would be well beyond the period of median survival, making them likely to be experiencing persistent disease and treatment-related morbidities. Qualitative data gained from studies of the experience of surviving with a PMBT can be used to inform research of the factors contributing to specific symptoms experienced by long-term survivors of a PMBT. In addition, findings may be used to direct research on areas for assessment as well as appropriate interventions for patients and families dealing with this difficult disease.

Methods

Design

In this qualitative study, the researchers used a biographical narrative approach to elicit from the survivor a story of how life was before the tumor, how the tumor caused a life change, and how life is now (Denzin, 2001). The changes to meaning of life after surviving a PMBT

were sought, as well as strategies, supports, and resources survivors used to manage those changes. Because cognitive deficits may occur in survivors as a result of the tumor or treatment, the family caregiver was interviewed separately about how life had changed for the survivor to augment the survivor's narrative.

Sample Recruitment

Advanced practice neuro-oncology nurses were the investigators in this multisite study. The nurses recruited a purposive sample of survivors and their caregivers from their respective institutions around the United States. Recruiting took place in the clinic, in support groups, or on referral from one of the other investigators. A total of 47 survivors were approached, and the survivors and caregivers gave several reasons for declining participation. In four cases, the survivors' health status had deteriorated rapidly from the time of recruitment to interview. In five cases, the caregiver declined because of work responsibilities. Two survivors and their families chose not to participate in interviews of such a personal nature. One survivor and caregiver could not find a suitable interview location that would work with their time constraints.

To be eligible for inclusion in the sample, survivors had to be aged 18 years or older, diagnosed with a highly malignant brain tumor (e.g., glioblastoma multiforme, anaplastic astrocytoma, anaplastic oligodendroglioma) for at least three years, and have a person they could designate as a caregiver who was willing to be interviewed. Participants had to speak English and be able to articulate events relating to living with a brain tumor, as determined by the recruiter on initial screening. Using the **Neurobehavioral Cognitive Status Exam** (Kiernan, Mueller, Langston, & Van Dyke, 1987), survivors were screened for severe language and cognitive deficits that would prevent articulation of their perspectives.

The institutional review boards (IRBs) from each of the participating institutions (University of Chicago; University of California, San Francisco; University of Central Florida; Roswell Park Cancer Institute; Cleveland Clinic; and Northwestern University) approved the study. University of California, San Francisco was the primary center and housed the data. The investigators used the IRB-approved protocols and consents from their respective institutions when interviewing participants. Saturation was achieved after 35 sets of survivors and their caregivers were interviewed.

Procedure

Once a perspective survivor/caregiver dyad agreed to participate, the investigator explained the study protocol and set up an appointment to meet with the participants. The interviews occurred at a location mutually agreed

on by the participants and investigator. Twenty-six interviews were conducted in the survivors' homes, and six were conducted in private areas located in the clinic building but away from the actual clinic setting. Two interviews were in a business office, and one took place in a wellness center. For purposes of describing the sample, survivors and caregivers filled out a demographic data questionnaire and survivors completed a brief medical history form detailing their tumor treatments.

The investigator interviewed the survivors and caregivers separately. Choice of interview order was left up to the survivor. Investigators assured participants that all data would remain confidential, would not be shared with the other person in the dyad or their healthcare providers, and that they would not be individually identified.

A semistructured interview guide consisting of open-ended questions (see Figure 1) was used to elicit the stories from the patients and caregivers. Clinical expertise and a literature review informed the interview questions, and questions were structured to gather the meaning of changes in daily life after surviving a malignant tumor, as well as strategies, supports, and resources used to react to those changes. When writing interview questions, the investigators consulted a qualitative nurse research expert for methodology. The open-ended nature of the questions allowed participants the opportunity to share information beyond the question content. Interviews lasted 30–120 minutes each, with most interviews lasting about one hour.

Analysis

The investigators recorded the interviews using a digital audio recorder. Interviews were uploaded and transmitted via password-protected e-mail to the primary site. A professional transcriber converted the interviews verbatim into printed documents and then sent the interviews to the investigators to read for clarification, accuracy, and verification. The investigators then analyzed the interviews for emerging themes using thematic description, which requires examination of the spoken word for emerging themes (Sandelowski & Barroso, 2003). Three investigators read and selected themes independently for each transcription. The investigators then met and discussed the main themes until consensus was reached. Interviews were reread to ensure no new themes emerged.

Maintenance of Rigor

The research team compiled a detailed Interview Guideline Booklet that included a recruitment manual and interview and data-processing guidelines. To minimize the effect of multiple interviewers, each recruiter learned the interview procedure and then demonstrated the interview with the primary investigator serving

1. What was life like for you before you had the brain tumor?
2. Tell me what happened when you were diagnosed with the brain tumor. What was this like?
3. What was life like after the brain tumor? What is your life like now?
4. Anything else you would like to offer about your experiences?

Note. Interviews with caregivers followed the same guide, substituting "the survivor" for "you" in questions 1–3.

Figure 1. Semistructured Interview Guide

as the survivor. Transcribed interviews were read by all investigators, and themes were determined by all investigators collectively in face-to-face review sessions and conference calls with detailed notes maintained of all analyses to maintain rigor of thematic analysis.

Findings

Survivors were predominantly men with a mean age of 51 years (see Table 1). All but one survivor had undergone surgery, radiation therapy, and chemotherapy as part of their treatment. These demographics are characteristic of the population with malignant brain tumors (CBTRUS, 2012). Survival time from diagnosis was a mean of six years (range = 3–15 years), indicating that participants were well beyond the period of active treatment and median survival for their disease. Most survivors manifested cognitive impairment ($n = 25, 71\%$), as indicated by their scores on the Neurobehavioral Cognitive Status Exam (Kiernan et al., 1987). Of those who were cognitively impaired, 11 (46%) had mild impairment, 5 (21%) had moderate impairment, and 9 (38%) had severe impairment in at least one cognitive area, with memory impairments being most common. Caregivers were predominantly women with a mean age of 52 years. All but one caregiver was a spouse or significant other living with the survivor; the remaining caregiver was a parent living with the survivor.

Two key themes emerged in this analysis: "stability disintegrates" and "a new reality." Brain tumor survivors characterized their lives as stable before receiving their diagnosis. The stability in their lives disintegrated as the survivor experienced changes related to the tumor and its treatment. Those changes were profound and ultimately contributed to multiple losses in key areas of their lives. Over time, living with the diagnosis and its physical, cognitive-behavioral, and social consequences required survivors and their caregivers to adapt to the new reality of their lives. Through the process of becoming a survivor, individuals were able to take back control of their lives. Adaptation required survivors to use internal and external resources as ways of coping with their new reality.

Table 1. Demographic Characteristics (N = 70)				
Characteristic	Survivors (n = 35)		Caregivers (n = 35)	
	\bar{X}	Range	\bar{X}	Range
Age (years)	51	30–65	52	43–77
Education (years)	16	12–22	15	12–22
Characteristic	n		n	
Gender				
Male	22		13	
Female	13		22	
Race				
Caucasian	33		31	
Other	2		4	
Tumor type				
Glioblastoma	25		–	
Anaplastic	10		–	

Stability Disintegrates

Survivors and caregivers consistently described stability in their lives prior to the brain tumor diagnosis. Stability was described in terms of being involved with family, being employed, and having social relationships. Once the diagnosis was received, stability disintegrated. As one survivor described it, “My life was my work, my family, and my friends. My life was grounded, and it was great. But the tumor changed all of that. It destroyed all that was real for me.” The disintegration was caused by changes produced by the tumor and its treatment; those changes contributed to multiple losses in the survivors’ lives.

Life changes after diagnosis: Survivors experienced life-altering changes. The changes were sudden, unexpected, and uncontrollable. The brain tumor diagnosis was the source of change. As one survivor noted, “It has really changed the way I live from day to day.” Survivors were able to clearly demarcate life before and after the diagnosis. Life direction changed, with participants having to acknowledge prior life expectations would go unfulfilled. Changes were persistent, and participants struggled to adjust to these changes to achieve a new balance in their lives.

Survivors attributed the life-altering changes to the physical and cognitive-behavioral symptoms they experienced. Symptoms were not only a result of the tumor, but also from treatment effects, and the two were indistinguishable to the participants. Symptoms also continued to progress for years after diagnosis, even in the absence of tumor recurrence. Psychological problems experienced included depression, trouble with thinking, trouble completing activities, and challenges in working with or remembering numbers. Those cognitive losses were significant and frustrating to survivors. Difficulty processing

and being easily distracted made it very hard to stay on task. Poor short-term memory for most survivors led to a requirement of daily reminders to accomplish activities. Survivors and caregivers described the predicament of the survivors having cognitive losses that other people can’t see, yet being expected to perform as they had prior to the brain tumor. One survivor described that by stating, “I have a lot of invisible deficits that people don’t see unless they know me. People do not understand that I am the same person but different, and that makes me sad.”

Many survivors experienced loss of energy resulting in fatigue and lack of motivation. They were exhausted from trying to compensate for the cognitive changes that had occurred, and found this limiting and disabling. One participant explained it by saying, “I have to think, think, think, all day long, even about the simplest things, and this just wears me down.”

Physical symptoms were noted by all survivors and included problems such as headaches, weakness, lack of coordination, language difficulties (e.g., reading, writing, speaking), and vision problems. Seizures were a major concern for some as they were unpredictable, uncontrollable, and potentially injurious. Seizures occurred at diagnosis for some, and many years after diagnosis for others, with frequency and intensity varying by individual. Medications taken for seizures or to treat brain edema often compounded symptoms by causing fatigue or trouble thinking. Many participants expressed concerns about falling, which could not only result in injury but also social embarrassment. Some of the symptoms experienced waxed and waned, whereas others were persistent. Recurrence or exacerbation of symptoms represented a unique concern to survivors because they were fearful that symptoms represented tumor progression. For longer-term survivors, symptoms worsened as they aged in spite of stable disease on follow-up scans. Those symptoms served as a constant reminder of their disease and threatened life stability.

Survivors adopted avoidance behaviors as a means of camouflaging symptoms; for example, they avoided social interactions where symptoms would be more evident. Caregivers also supported those avoidance behaviors, usually as a protective measure. One caregiver described the need to limit activities for the survivor to those where only minimal walking was required. Falls and other safety concerns were issues, and caregivers described the need to be vigilant for unsafe situations for the survivor. Survivors found themselves relinquishing pleasurable activities because of symptoms. One survivor who could no longer take part in his passion for gardening described that as being worse than tumor diagnosis or treatment.

Other behavior changes were noted by both survivors and caregivers. Survivors reported behavior changes from frustration, depression, and anger. However,

survivors were less concerned with behavior changes than with physical or cognitive-behavioral symptoms. Interestingly, caregivers appeared to be more aware of behavior changes than survivors themselves, reporting personality changes such as moodiness, impulsiveness, intolerance, and withdrawal. A common concern of caregivers was the feeling of suddenly being presented with a different person.

Loss: Changes survivors experienced culminated in a multitude of losses for the survivor, permeating every aspect of life. Loss was experienced from the beginning of the diagnosis and continued throughout the course of the disease. Loss evolved and came in phases, often exacerbated by worsening symptoms.

Loss of roles and relationships were mentioned by all participants. Roles often were reversed with or assumed by the caregiver, and participants were not entrusted with many responsibilities they had previously performed. Relationship changes were perhaps the most profound. Loss of true intimacy (more than sexual intimacy alone) was frequently described in the context of the marital relationship and contributed to additional relationship changes such as distancing or even divorce. Loss of parenting responsibilities also was discussed; participants talked about being overruled or left out of involvement in childrearing decisions. In some situations, children became premature caregivers for the survivors, watching over the parent instead of the parent watching over the child. Social relationships also were lost. Many survivors described their social circles as becoming smaller, with true friends comprising the circle and mere acquaintances separated out. The remaining friends were vital to their survival. Survivors also gained new friends, but those relationships often were based on the commonality or tolerance of their diagnosis.

Participants also consistently experienced loss of employment status. Noise intolerance, easy distractibility, and fatigue contributed to loss of employment status in addition to physical deficits. One survivor described the noise intolerance as, "all the stuff in the office, all the just general noise, the phones ringing, the fax machine going, the computers being on and the typing, and just the noise was just overwhelming." Employment losses included job modification, unemployment, or disability. Many times, the participants sought a lower-level job because they found themselves unable to perform at the same level as prior to their diagnosis. Others sought to work in a less stressful environment as a means of psychologically coping with the magnitude of their disease. Some were advised by healthcare providers to quit working because of their diagnosis, even though they may have been able to work at some level.

Loss of employment contributed to a change in identity as a consequence. Survivors struggled with

not only finding a new identity but also with how to fill their time in a meaningful way. The employment loss also contributed to financial strain in their primary relationship. Survivors felt guilty about not contributing financially to their relationships, as spouses often needed to assume employment in their stead. One survivor stated, "I used to be the breadwinner, and now I don't make enough money to buy a loaf of bread. My wife has to do that." Lifestyle was reduced as a consequence of income loss, as well.

Another common loss among the survivors was independence. One survivor said, "I miss being able to go off and do things by myself." Loss of a driver's license was significant. Cognitive changes, seizures, or visual impairment were common reasons for inability to drive. Getting lost was a frequent problem for a person who previously had excellent direction sense. Caregivers incurred significant burden because of this loss of independence. They had to take on many of the physical and mental tasks survivors had performed.

Loss of spontaneity permeated the survivor experience. Whether it was the survivor or the caregiver, most activities were carefully planned out based on medication regimen, scheduling of tests, or degree of difficulty in performing tasks required. What should have been pleasurable activities, such as vacations or family outings, required the most intense planning. In seeming contrast, other life plans (e.g., retirement planning, relocation, job change) were abandoned because of the diagnosis, and uncertainty precluded any long-term planning for the survivor.

Loss of hope was common at diagnosis, persisting to some degree for most survivors, particularly at times when follow-up scans were necessary or when symptoms recurred or worsened. Survivors collectively described being deeply affected by the message of the diagnosis. Messages such as "making the most of what time you have left" and "get your affairs in order" were perceived as being given a dismal prognosis without any hope for survival. Participants dealt with time frames for expected survival, measured in months to, perhaps, two years. However, survivors in this study lived beyond those time frames or, as one survivor described it, "I'm living beyond my expiration date." Loss of hope created challenges as participants quit their jobs or spent money to "make the most" of their remaining time. The "death sentence" participants were given caused them to face their own mortality and, consequently, to make changes in their lives.

Perhaps the most difficult loss for survivors to articulate was loss of sense of self. "I became the person with the brain tumor and was no longer me," was how one survivor explained the loss. That loss resulted in decreased self-esteem and confidence. Several survivors described themselves as feeling incompetent. Some felt

they had achieved a certain life status or a job, whether it was work, family, or church, or as one survivor described it, she “had arrived” at her stage in life. Inability to manage activities as previously executed led to a decrease in status at home, work, and in social circles for all survivors.

A New Reality

Over time, survivors adapted to changes and subsequent losses in their lives. The adaptations allowed survivors to develop a “new reality” in their lives, and caregivers were integral in directing that new reality for the survivor. The process of becoming a survivor characterized the new reality. Although tenuous and sometimes overwhelming, the new reality also was characterized by the survivors taking back control of their lives. Survivors used internal and external resources in coping with this new reality.

Becoming a survivor: Participants described the process of becoming a survivor as acknowledging that they are alive and finding value in surviving, even if their lives are different from before or different from what was anticipated. The process occurred over time, often after treatments were completed. Identifying reasons to live became a key component of the process, and this was accomplished by examining their past lives, putting their current situations into perspective, and re-establishing future goals. Tenacity and an enduring will to live were additional key components in becoming a survivor.

Taking back control: Survivors initially found that their uncertain future made it difficult to look ahead. Survivors began to take back control of their lives where they could by setting new priorities, slowing down, changing their expectations, taking one day at a time, and making the most of every day. Healthy lifestyle changes were a key component in taking back control. To make changes in their lifestyles, survivors chose to eat healthier, developed exercise routines, avoided stress, and sought out counseling or support groups. By controlling what they could in their lives, a sense of normalcy was restored.

Life experience offered little guidance in dealing with a brain tumor for these individuals. Participants took back control and tried to make sense of their new reality through information gathering. Having information and knowledge about treatment options, consequences, and disease course allowed survivors to feel in control. All sought information outside the world of the healthcare providers to verify or expound on information provided. The Internet was mentioned as a frequent source for information, but participants reported frustration in trying to understand information they found. Other sources for information included support groups and patient education organizations such as the American Brain Tumor Association.

Neurologic deficits such as weakness, emotional problems such as anger or despair, or cognitive problems contributed to an inability to take back control for some. The control was relinquished to the caregiver, and survivors came to accept that. However, survivors felt guilt about burdening their caregivers. The caregivers realized the need for survivors to be in control, and often created protective scenarios for the survivor to augment control. For example, one caregiver carefully scheduled outings during less busy times of the day and week.

Coping: Coping with the new reality required participants to mobilize internal and external resources. Creating and maintaining a positive attitude was an elemental internal resource. Participants were hopeful for the future, appreciative of life and family, and grateful for the opportunity to become a survivor. Faith was a closely related internal resource. Participants found a more spiritual perspective in their lives when they became a survivor, feeling closer to God and being at peace with their situation. The spiritual perspective allowed them greater control over their lives. Sensing that their providers also held that perspective enhanced their ability to cope. Finding humor in their situations also eased their worries.

External resources were critical to becoming a survivor. Family, friends, and even pets were cited as significant external supports. Finding external support often was challenging. Old friends often were lost, and new friends were difficult to make. New friendships were made on the basis of their diagnosis, often through support groups or church activities. One survivor described support group involvement by stating, “I can help others who have been there or who are there. I feel like we’re in a club, so to speak, the ‘Survivor’s Club.’ I can speak to them on a different level than I could Joe on the street because I know what it’s like to be in my position.” Survivors often found it difficult to reach out to or accept help from others, but doing so brought control to their lives and the opportunity to give something back to others, restoring meaning and value to their lives. Finding activities to keep themselves engaged and active also was important to survivors.

Although becoming a survivor usually incorporated positive coping skills, some survivors reported using negative coping skills. Avoiding or limiting social situations was a common approach adopted, but served the purpose of allowing control. As one participant described it, “My world became a much smaller place, but it was one I could manage.”

Discussion and Implications for Nursing Practice

Survivorship has been described as “the process of living through the cancer experience” (Farmer & Smith,

2002, p. 779). Survivors in the current study were very articulate in addressing the challenges they faced during this process, in spite of their cognitive impairments. Symptoms included physical and cognitive complaints, were highly individual, and varied over time. Use of a symptom inventory, such as the MD Anderson Symptom Inventory (Armstrong et al., 2006) may be useful in quantifying the symptom experience but may not capture all symptoms, nor does it capture the meaning of the symptoms for the individual. Clinicians should be mindful of the need to capture symptom meaning during symptom assessments. Additional research focusing on the impact of symptoms would enhance understanding of the symptom experience and could lead to development of more optimum symptom management.

Depression was noted by many of the survivors, highlighting the need for healthcare practitioners to screen for depression at each encounter. The impact of depression on the process of becoming a survivor requires additional research. Injuries from seizures and falls represented distinct concerns to survivors with malignant brain tumors, indicating that education geared toward injury prevention may be useful in this population. Symptoms worsened over time, even in the absence of disease, representing a unique concern of participants. Whether that worsening is a consequence of treatment is not known and requires additional study.

Inability to maintain previous level of employment was a common thread among survivors, and this contributed to financial stressors. Schmidinger et al. (2003) found that 44%–60% of people surviving with glioblastoma for longer than 18 months were able to go back to work, but often only on a part-time basis or in a different capacity. Survivors may benefit from vocational counseling as part of a comprehensive treatment program. In addition, healthcare providers may be instrumental in providing documentation of support for disability claims. With loss of independence being a frequently reported concern, efforts should be made to facilitate independence. For example, mobility or memory aids may be an integral factor in promoting independence.

Significant changes in relationships were noted by survivors; social relationships often were lost and survivors found it difficult to develop new relationships. Although survivors found comfort and stability in relationships with their significant other (most often a spouse) after their diagnosis, this often was accompanied by loss of true intimacy. Overall, these findings suggest the need for healthcare providers to extend assessment beyond the physical and cognitive symptoms, as well as the need to include social support systems in patient assessments, which patients identified as lacking in their plan of care. Hricik et al. (2011)

noted that physical health is affected by social support, and survivors may benefit from assistance in finding support systems. Brain tumor support groups offer opportunities for survivors to develop new relationships and represent a potentially important form of social support for survivors and their caregivers. The Internet and social media also were mentioned by survivors as forms of social support used; additional research comparing forms of social support would be beneficial to the PMBT population. Although intimacy issues have been explored in other cancer populations, they have not been explored in patients with a malignant brain tumor. Neurologic and cognitive deficits create unique intimacy concerns and require more delineation. Specific assistance in re-establishing intimacy may be provided through referrals to practitioners with expertise in sexuality and sexual dysfunction.

Behavior changes were noted more commonly by caregivers, and caregivers qualitatively reported themselves as more distressed than survivors by these changes. Behavior changes affect many aspects of the survivors' lives, including relationships, ability to work, and safety. Quantitative evaluation of behavior changes and associated distress is indicated to provide more insight into whether behavioral modification programs might be of benefit in this population. In addition, caregiver involvement in support groups may provide insight in approaches to dealing with these changes.

Given the loss of sense of self that many survivors experienced, restoring self-worth and taking control of their lives were critical concerns for survivors. Survivors need to be encouraged to identify and mobilize personal resources. Faith and spirituality were common resources used. To support survivors in this endeavor, providers need to view the healthcare relationship as a partnership rather than a paternalistic relationship. Survivors also may be encouraged to seek out providers in their faith communities, such as parish nurses, where available. That will allow the survivor to take control within their faith-based communities.

Limitations

Four of the seven investigators had long-term clinical relationships with the study participants, which may have biased interviewers or limited the responses participants offered. The inclusion of participants without long-term relationships with investigators was thought to mitigate that influence. An additional limitation was the exclusion of people without caregivers; several survivors wanted the opportunity to tell their stories but could not participate without a caregiver, and many caregivers were too busy with family and work obligations to participate. Those with severe deficits who may not have been able to articulate their concerns also were excluded, and their lived experiences may have

been different. Individuals who were not successful at becoming a survivor or taking back control of their lives may have been excluded because they may have not been accessible to the investigators.

Conclusion

People who survive longer than three years with a primary malignant brain tumor experience profound change and loss in their lives that create a new reality for them. Adjusting to that new reality occurs through the process of becoming a survivor, as individuals struggle to cope and take back control of their lives. By developing an understanding of this experience from the survivor's perspective, the nurse can assess changes that occur and facilitate the process of becoming a survivor.

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Mary Pat Lovely, PhD, RN, is an adjunct faculty member in the College of Nursing at the University of California, San Francisco; Christina Stewart-Amidei, RN, PhD, APN-CNS, CNRN, CCRN, FAAN, is an advanced practice research nurse in the Department of Neuro-Oncology at the University of Chicago in Illinois; Margaretta Page, RN, MS, is a clinical specialist in neuro-oncology at the University of California, San Francisco; Kathleen Mogensen, RN, MSN, APN-C, is a neuro-oncology clinical nurse specialist at Roswell Park Cancer Institute in Buffalo, NY; Jean Arzbaecher, RN, MS, APN-CNS, CNRN, is a clinical specialist in neuro-oncology at the University of Chicago; Kathleen Lupica, RN, MSN, CNP, is a neurology nurse practitioner at the Cleveland Clinic in Ohio; and Mary Ellen Maher, RN, MSN, CNP, is a neurosurgery nurse practitioner at Northwestern University in Chicago. No financial relationships to disclose. Stewart-Amidei can be reached at camidei1@bsd.uchicago.edu, with copy to editor at ONFEditor@ons.org. (Submitted December 2011. Accepted for publication September 10, 2012.)

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