



National
Brain Tumor
Society

A Needs Assessment of Brain Tumor Patients, Survivors and Loved Ones



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By Jenette Spezeski, MPH, Program Manager
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About the National Brain Tumor Society

National Brain Tumor Society (NBTS) is a leader in the brain tumor community, bringing together the best of research and patient services to be a comprehensive resource for patients, families, caregivers, researchers, and medical professionals.

We invest wisely and strategically across the research spectrum, seeking new therapeutic targets and improving existing treatments, which will ultimately lead to a cure. Our staff and advisory team encourage research that connects directly to patient care and enhances quality of life for all brain tumor patients.

National Brain Tumor Society offers top-notch resources and caring support for everyone affected by brain tumors. We provide education and information to help patients, families, and caregivers make informed decisions and develop strong support systems during every stage of the journey—from diagnosis through treatment to end of care and survivorship.

Note: In 2008, the National Brain Tumor Foundation and Brain Tumor Society joined forces to become the National Brain Tumor Society.

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Note: All quotes included in this publication are taken directly from the survey's findings.

“There is no normal anymore. Life just stopped and went a whole 180 degrees the other way. So what is normal? What is life about now?”

- Brain tumor patient

Background

National Brain Tumor Society, through its Patient Services department, serves as a resource for information, referrals, and support for more than ten thousand families each year. We provide education and resources to help patients, families, and caregivers make informed decisions and develop strong support systems during every stage of the journey—from diagnosis through treatment to survivorship. As part of our commitment to being responsive to the brain tumor community, we set out to investigate the information and support needs of those affected by a brain tumor diagnosis.

Each year over 40,000 people are diagnosed with a primary brain tumor (a tumor originating in the brain) and an additional 150,000 people are estimated to be diagnosed with a metastatic brain tumor (a tumor that spreads to the brain from another location in the body). While numbers give an indication of how widespread the disease is, they do not give a real sense of the impact.

Those familiar with brain tumors and their effects attest that brain tumors are unique among medical conditions (Lipsman, et al. 2007). The brain directs not only a person’s physical, cognitive, and emotional functions, but also their personality, sense of identity and the essence of who they are. Brain tumors, whether malignant (cancerous) or benign (noncancerous), cause harm to the brain and affect patients in many ways.

Physical changes may encompass sensory loss, balance problems, and chronic seizures. In addition, many people with brain tumors experience cognitive changes. Studies have documented cognitive impairment in as many as sixty to ninety percent of patients with different types of brain tumors (Tucha,

et al. 2000, Meyers and Brown 2006). Cognitive deficits that arise include slowed thinking, memory loss, and difficulty multitasking. Psychological consequences entail personality changes, behavior problems, anxiety, and depression (Andrewes, et al. 2003, Pangilinan, et al. 2007). Benign brain tumors can also have devastating effects on patients’ cognitive and physical functioning.

The repercussions of a brain tumor significantly impact quality of life for both patients and loved ones. In recent years, a quality of life model for understanding survivorship has emerged in the cancer/disease community; it encompasses not only physical well-being, but also psychological, social, and spiritual well-being (Ferrell and Hassey Dow 1997). This psychosocial approach to meeting survivors’ needs has gained increasing attention in the medical community (Institute of Medicine 2008).

A literature review by Catt et al. (2008) examined recent studies of the psychosocial and supportive care needs of brain tumor patients with high-grade gliomas. Unmet needs included support for cognitive deficits, mood disturbance, fatigue, and palliative care. Other studies of people affected by brain tumors have identified the need for supportive care for coping with stress, depression, caregiving tasks, and coping with personality/behavior changes (Sherwood, et al. 2004, Janda, et al. 2008).

People in the broader cancer community have accepted that a person is a survivor from the time of diagnosis through the balance of life (National Coalition for Cancer Survivorship 2006). However, patients facing a brain tumor diagnosis (whether malignant or benign), as well as their health care team, may not identify with this definition

of survivorship. There has been a tendency for the focus on the acute control of the tumor to overshadow addressing the many long-term and sub-acute quality of life issues that affect brain tumor survivors.

Through the study described here, the National Brain Tumor Society has attempted to further define and better understand the experience of patients and families affected by a brain tumor diagnosis. This report highlights major themes and findings that emerged from a broader survey we conducted of over 1,400 patients and caregivers. Our research questions included:

- What are the biggest challenges in coping with a brain tumor?
- What information and support needs exist?
- What services are families likely to use?
- How do needs differ between groups (i.e. by age, or diagnosis)?

Ultimately, our goals are, first, to identify areas of unmet need and, second, to work with the brain tumor community to develop resources that better address the needs of patients, survivors and their loved ones.

Key Findings

The results of this survey underscore the multifaceted ways in which a brain tumor diagnosis affects patients and their loved ones. From changes in the patient's day-to-day functioning and abilities to a shift in family dynamics, the psychological well-being of the entire family is in the balance.

Diagnosis and Survivorship Needs: There is still a lack of information and support that adequately prepares patients and their loved ones to anticipate changes related to the tumor and to live with the cognitive, physical and psychosocial repercussions

of a brain tumor. The need for services spans the brain tumor journey, from diagnosis through treatment and beyond. Survivorship, quality of life, and the difficulty of adjusting to life changed by a brain tumor are prominent concerns. Certain subgroups within the brain tumor community, such as young adults, have additional needs that are not being met.

Caregiving and Family Needs: Family caregivers are affected on many levels when their loved one has a brain tumor. Caregivers feel unprepared to cope with changes in their loved one and indicate interest in services that provide both practical and emotional support. Our findings also confirmed the substantial impact of diagnosis on families' financial situations.

Needs in the Health Care Setting: Significantly, half of respondents reported they did not utilize psychosocial services, such as social work or counseling, in the months following diagnosis. Findings also highlighted the difficulties of navigating the health care system.

Many of our findings highlight the need to re-examine what it means to live with a brain tumor diagnosis. The concept of brain tumor survivorship is expanding to include not only *quantity* of life but also *quality* of life for people with a brain tumor.

Our findings call attention to possible shortcomings in the range of services that are considered to be the standard of care for brain tumor patients and survivors. There is a need for more routine assessments and services that go beyond standard treatment regimes and holistically address the spectrum of cognitive, physical and psychosocial needs of brain tumor survivors. Special attention to the needs of both patients and their loved ones is crucial to supporting families throughout the brain tumor journey.

Methodology

Survey

From February to April 2008, the legacy organizations of the National Brain Tumor Society launched a national survey to assess the needs of brain tumor patients and their loved ones.

The survey was conducted online using Survey Monkey and widely advertised in the brain tumor community. Over 1,440 surveys were completed, including 709 patient respondents and 702 caregiver respondents. Twenty-nine health professionals also completed the survey; however, this report focuses only on findings from the patient and caregiver respondents.

The survey included both multiple-choice and open-ended questions and provided rich quantitative and qualitative data sets. Quantitative data was analyzed using statistical software. Comments and responses to open-ended questions were analyzed separately using qualitative data analysis techniques, specifically coding for themes. A copy of the complete survey is available at www.brainumor.org.

Who Responded

In total, 709 patients and 702 caregivers (defined as a brain tumor patient's relatives or friends) participated in the survey. A table summarizing respondents' characteristics is available in the appendix.

An overview of respondent characteristics reveals that the respondent sample was primarily female, Caucasian, and had completed at least some college or more. Seventy-one percent of respondents were married or living with a partner, and eighty-seven percent of respondents reported using the internet daily.

The two most common tumor types represented by respondents were glioblastoma (30%) and meningioma (19%). Caregivers were more likely to represent high-grade tumors (68%), while patients were more likely to represent low-grade tumors (48%). About half of respondents reported that treatment had been completed (46%), while one-fifth reported that the patient was still undergoing active treatment (19%). Nine percent reported a recurrence or further treatment, and seventeen percent reported the patient was no longer living.

Diagnosis and Survivorship Needs

When facing a brain tumor diagnosis, patients and their loved ones are propelled into an unknown world characterized by complicated terminology and concepts. After diagnosis, making treatment decisions is a primary concern.

Information Needs related to Diagnosis

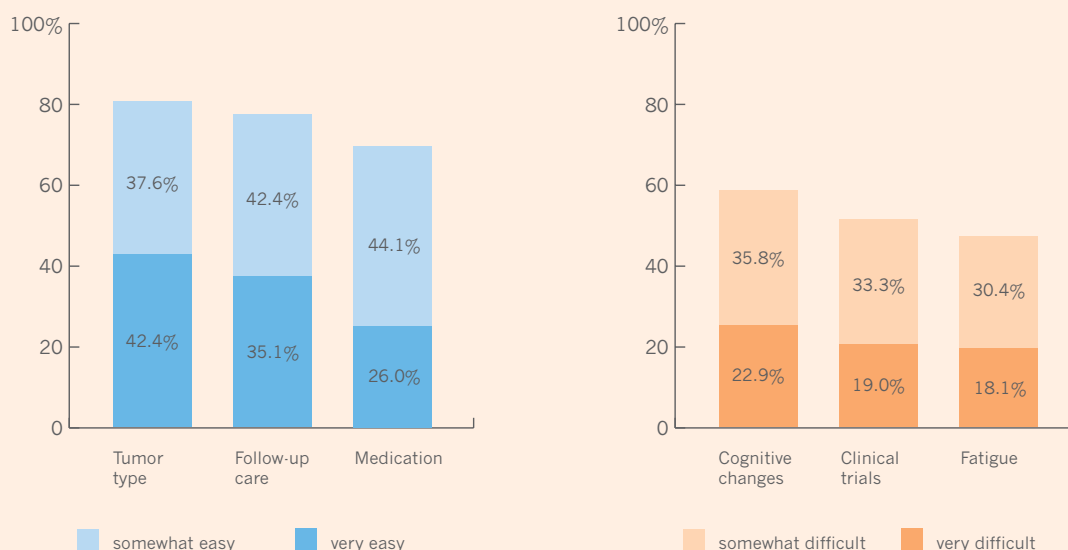
Diagnosis and treatment information are crucial at the beginning of the brain tumor journey. Depending on the severity of the tumor, families must sometimes make rapid decisions with little time to fully investigate treatment options. Many respondents stressed the need to be proactive in seeking information and educating themselves about brain tumors. Sometimes information was readily available; sometimes it was not.

In general, brain tumor patients and loved ones seemed able to find information about diagnosis and follow-up care. At least seven out of ten respondents reported having the easiest time (defined as “somewhat to very easy”) finding information about tumor type, necessary follow-up care, and medications.

However, patients and loved ones felt unsupported and found it difficult to find information about addressing other issues following diagnosis. Half of respondents reported having difficulty (defined as “somewhat to very difficult”) finding information about cognitive changes, clinical trials, and fatigue.

The three most common sources of brain tumor information included websites (83%), the health care team (73%) and nonprofit cancer organizations (56%).

FIGURE A: How easy or difficult has it been to find information about these topics?



Understanding and choosing between treatment options also was frequently cited as a challenge for patients and caregivers in their open-ended responses. Patients and their family members felt pressure about evaluating complicated treatment information and making decisions that would influence the course of care and recovery.

Financial Impact on Medical Treatment

Patients' journey through treatment may also be influenced by financial concerns related to insurance coverage and the cost of treatment. Treatment options for brain tumor patients are limited and typically involve "designer" medications for which no generic is available. The cost of treating brain tumors has been ranked among the most expensive of cancers (Yabroff 2008). The financial impact is overwhelming for many people, and sometimes can influence which treatments a patient receives and when, regardless of insurance status.

As our findings demonstrated, financial concerns affected the timing of some patients' treatment or follow-up care. In fact, nearly one-fifth of respon-

"Insurance referrals to neurosurgeons were taking two to four months and we could not afford to pay for them ourselves."

"We have had times when we couldn't afford to drive to the medical center for different check-ups, so we had to put them off until the money was available."

"I'm on a 24 month oral chemo program (second time around). Sometimes I need to make my cycles six weeks rather than four because of expense."

"I aged out of my parents' medical insurance three years after being diagnosed, and now am not able to get good insurance. I have put off routine MRI checks because of money issues."

dents noted that, since diagnosis, there had been a delay in getting care for the patient due to the cost of care. One in ten respondents reported that the patient had chosen one medical treatment over another treatment due to the cost of care.

In their comments, some respondents cited the high cost of care as a deterrent to following treatment or follow-up regimens. Others mentioned care had been affected by the difficulty of working within the "network" requirements of their insurance plan, delays in obtaining approval for referrals, and the burden of travel expenses for treatment.

Continuing Needs throughout Survivorship

As treatment is completed, the primary concerns of patients and their families often shift. Greater attention becomes directed toward survivorship as patients learn to live with the effects of their tumor and its treatment in the weeks, months, and years after diagnosis.

Many respondents described feeling unprepared for the changes they would experience following treatment. Our survey findings underscored the extent to which survivorship and quality of life issues were a major concern and continue to be an unmet need for the brain tumor community. Our analysis identified the following themes:

- **Need for information and services addressing the long-term cognitive and behavioral changes** that occur in brain tumor patients, including memory loss, personality changes, and an inability to return to work.
- **Presence of life-long physical effects of the tumor and its treatment** such as fatigue, headache, hearing and vision deficits, and problems with speech and mobility. Respondents noted that the brain tumor diagnosis often meant a loss of independence for the patient, whether temporary or long-term.

- **Emotional trauma of coping with the life-changing and often life-threatening brain tumor diagnosis.** Respondents struggled with coming to terms with the diagnosis, accepting changes in the patients’ abilities, and learning to live with fear and uncertainty about the future.
- **Feelings of isolation and aloneness.** Many respondents felt that those around them did not understand the full impact of the diagnosis and noticed changes in the way that their families, friends, and acquaintances related to them. Respondents expressed a desire for opportunities to connect with others who had been through a similar situation.

The majority of respondents expressed an interest in participating in services that would provide psychosocial support. *Nearly half of respondents (both patients and caregivers) indicated they would very likely use in-person counseling or an in-person*

brain tumor support group if offered free of charge in their community.

Seven out of ten respondents said they were somewhat or very likely to use these top three informational or networking services: information and referral hotline, brain tumor conference for patients and families, and informal activities to get to know other patients and families.

Examining respondents according to demographic characteristics indicated that there was greater interest in educational and support services among less educated, rural, and young adult subgroups. This pattern may suggest a higher level of unmet need within these special populations. It is likely our analysis minimized the full extent of differences among these subgroups due to our relatively homogeneous sample and the overall need for supportive services in the brain tumor community as a whole.

FIGURE B: How likely would you be to use the following support services if available in your community and free of charge?

	Already Using This Service	Somewhat or Very Likely	Not Very Likely or Would Not Use	Don't Know	TOTAL
In-person support group	129 11.3%	810 71.0%	155 13.6%	47 4.1%	1,141 100.0%
Online support group	181 16.0%	752 66.3%	178 15.7%	23 2.0%	1,134 100.0%
In-person counseling	50 4.5%	819 73.3%	202 18.1%	46 4.1%	1,117 100.0%
Penpal	74 6.6%	707 63.5%	292 26.2%	41 3.7%	1,114 100.0%
Telephone counseling	21 1.9%	645 58.0%	393 35.3%	53 4.8%	1,112 100.0%
Services for children	31 2.9%	560 52.0%	337 31.3%	149 13.8%	1,077 100.0%
Telephone support group	13 1.2%	502 45.4%	546 49.4%	45 4.1%	1,106 100.0%

“People assume because there is no visible scar, that I should be at 110% and can’t understand why I’m not.”

“The biggest challenge has been getting others to realize that although my tumor is benign and doesn’t affect the *quantity* of life, it definitely has affected the *quality* of life.”

“FATIGUE, FATIGUE, FATIGUE, EVEN 6 YEARS POST SURGERY, FATIGUE, I AM EVEN JUST TIRED TYPING THE WORDS.....”

“The emotional trauma is enormous. The doctors acted like everything was fine once the tumor was removed. They should have discussed with me and treated me for the consequences of the ‘insult’ to the brain, as well

as what to expect to experience while the brain was healing.”

“I am unable to lead the professional life I had prior to the tumor. Unable to complete tasks or remember to do so. No longer capable at an executive level. Patience is worn very thin. I am missing a bone flap, and this has resulted in a complete loss of self confidence.”

“I wish I could find more information age-group specific. I was diagnosed at 25 and live four hours from my treatment facility. The only support groups I have found within an hour’s drive are mainly cancer in general and people much older than me. I am now 32 and still find it hard to locate people who can relate to cancer at my age.”

FIGURE C: How likely would you be to use the following services if available in your community free of charge?

	Already Using This Service	Somewhat or Very Likely	Not Very Likely or Would Not Use	Don't Know	TOTAL
Conference for patients and families	110 9.5%	894 77.2%	112 9.7%	42 3.6%	1,158 100.0%
Information hotline	50 4.3%	928 80.4%	123 10.7%	53 4.6%	1,154 100.0%
Listserv or message board	141 12.2%	803 69.7%	160 13.9%	48 4.2%	1,152 100.0%
Informal events	83 7.2%	858 74.4%	157 13.6%	56 4.9%	1,154 100.1%
Neuropsychological testing/ Cognitive rehabilitation	91 8.0%	828 72.5%	135 11.8%	88 7.7%	1,142 100.0%
Family caregiver training*	43 3.8%	805 70.9%	196 17.3%	92 8.1%	1,136 100.1%
Patient navigator	15 1.3%	790 70.1%	162 14.4%	160 14.2%	1,127 100.0%

*Note: When caregivers were analyzed separately, 84% of caregivers said they would somewhat or very likely use family caregiver trainings, the top choice of services among caregivers only.

Caregiving and Family Needs

Loved ones who accompany the patient throughout the brain tumor journey are affected on many levels. Caregivers are called upon to restructure their lives in order to best support their loved one. Along with these new roles, many family members experience changes in the way their family operates and relates.

Providing Care

Many respondents identified the tasks and trials of caregiving as one of the biggest challenges they had faced. Caregivers identified a need for practical guidance, particularly in terms of symptom management and coping with physical, cognitive and personality changes. Others mentioned a need for more information about palliative care and what to expect throughout the treatment journey.

Caregivers struggled with juggling the multiple demands of providing care to their loved one at home along with fulfilling other responsibilities, such as earning a paycheck, parenting, and staying on top of medical paperwork. The need for financial assistance was frequently mentioned.

Many caregivers also struggled with watching their loved one transform into a different person because of the effects of the tumor and treatment. Caregivers emphasized the need for information about ways to support the patient while addressing changes that had occurred in their loved one. Personality and behavioral changes were particularly distressful, and caregivers expressed being unsure of how to interact with the patient.

“My biggest challenge was having to continue to be a mom to our two young daughters, care for a disabled and ill husband, and continue to work at a part-time level. Supervising home medical personnel, completing numerous forms, relating to my husband’s illness and care plus trying to take care of myself (which I did not do very well) was difficult and exhausting for me. I suffered from anxiety attacks and mild depression.”

“With my mother’s diagnosis, there were many extreme changes, but the complete change in personality and short term memory loss were the most difficult. Having to look at your parent and get to know a complete stranger was emotionally exhausting.”

“The most difficult thing I faced was having a strong, energetic, loving and supportive best friend (husband) one day and a very disabled and sick, weak, frail and exhausted husband the next day... There are no words to describe what you experience.”

“It was a roller coaster ride. He did so well after the first surgery ... then it came back with a vengeance. It was heartbreaking and so very, very frightening for both of us. My challenge has been to go on without him.”

One in three caregivers responded that they felt “not prepared” to cope with:

- Personality changes in the patient (33%)
- Cognitive changes in the patient (33%)
- Physical changes in the patient (32%), such as seizures, fatigue or driving limitations

In addition, many caregivers identified the emotional hardship of being a caregiver, experiencing feelings of isolation, fear, loss, resentment, acceptance and grief. Trying to stay positive even in the face of a serious prognosis was a challenge for many caregivers, and those who had lost a loved one described a need for support for bereavement. Some particular subgroups of caregivers (such as young adults or same-sex couples) encountered additional challenges and feelings of isolation.

Changes Experienced by the Family

As many caregivers told us, when someone is diagnosed with a brain tumor, his or her loved ones also share the burden of coping with the tumor and its effects. Along with assuming the tasks of caring for their loved one at home, many families experience a change in the dynamics of their family and feel unprepared to cope.

Three out of ten caregivers said they felt “not prepared” to cope with changes in family roles. Some caregivers described becoming the breadwinner after being a stay-at-home parent; other role changes included children assuming household tasks well beyond their years. Furthermore, respondents described stress in family relations; several respondents reported marriages that had fallen apart or unhealthy coping strategies, such as alcohol abuse.

When asked which services would be helpful to them, caregivers mentioned a range of psychosocial services, like counseling, burnout prevention services, and services to help children. Caregivers were significantly more likely to say they would use

“How do other families cope with personality changes, financial struggles, etc? ... How do I tell our children so that they will understand that Daddy still loves them but is not acting like himself any more?... What information I have found seems geared towards the elderly not young families.”

“In the very beginning, the dynamic in our family got very weird. My dad took to drinking. My mom took to having multiple online relationships. My sister was in college and turned to drugs and alcohol. It was really a rough time.”

“Our relationship took a major shift of dependence on me rather than a shared approach to marriage.”

“All my children have been in counseling at one time or another to deal with the stress of coping with their father’s illness. Because he hasn’t worked for the past 10 years they have had to make financial sacrifices. Because of his inappropriate behavior they stopped bringing friends home and are sometimes embarrassed to go out in public with their father. They miss terribly the man and father he was... hard to deal with the person who has taken his place. Every aspect of our lives is impacted by the accommodations we make for his illness. His illness has been the priority for so long.”

“We don’t seem to laugh as much, be as spontaneous as we used to be. The boys don’t get to spend one-on-one time with Dad...My husband and I don’t go out anymore on “dates”. We can’t be as adventurous as we used to be (e.g. backpacking) because of the concern of having access to medical center in case of a seizure or hemorrhage, etc.”

in-person counseling services and online support groups as compared to patient respondents.¹

Financial Impact on Household

In addition to changes within the family structure, many households undergo a shift in their financial situation. A loss of income combines with increasing expenses to create a substantial financial burden for patients and their families.

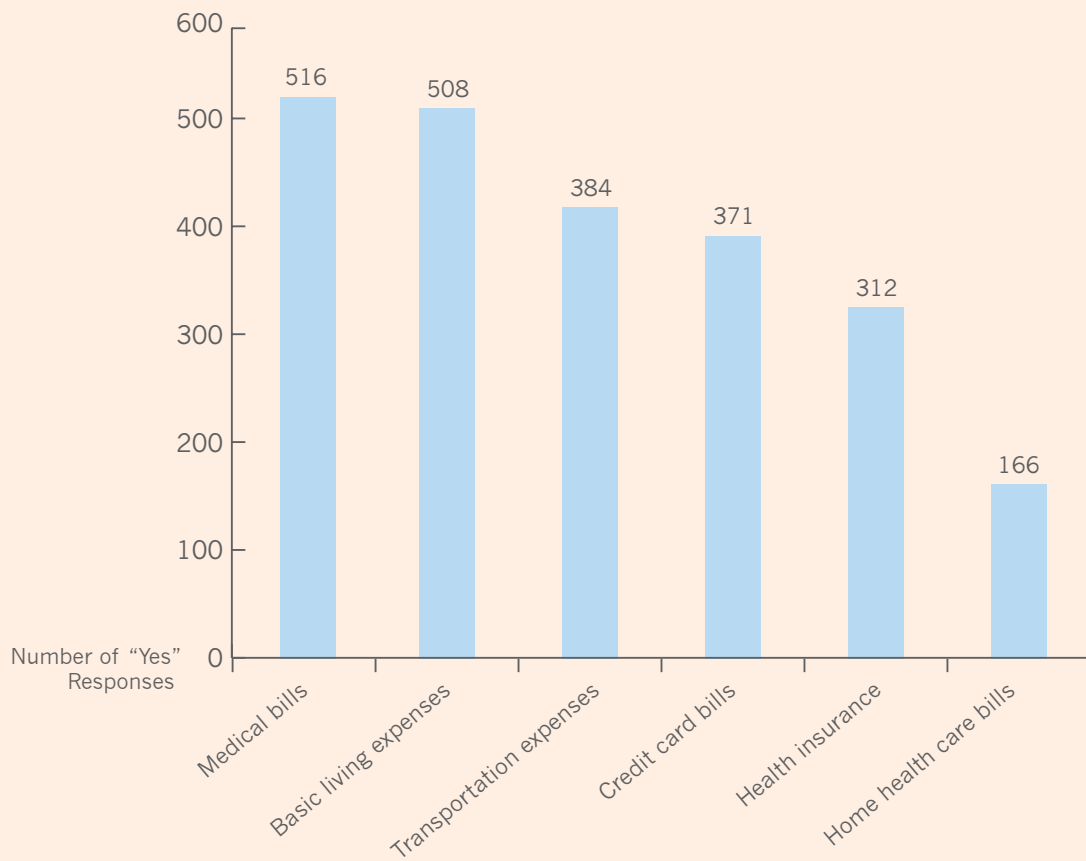
For the majority of respondents, the brain tumor diagnosis affected their financial situation in at least

one way, if not several ways. Many respondents described the financial challenges they experienced, which ranged from adjusting their lifestyles to filing for bankruptcy. Medical expenses were frequently cited as a concern, and the loss of income stood out as particularly challenging for respondents.

Six out of ten of respondents reported that the diagnosis affected their ability to pay medical bills (62%) and basic living expenses (61%), such as housing, utilities, and food. Nearly half of respondents indicated that their ability to pay transportation expenses and credit card expenses were also affected. While about 10% of respondents reported that the diagnosis had little financial impact (often

¹Likelihood (“somewhat or very likely”) to use support services if offered free of charge in your community: In-person counseling: (82%, 71%) (p=.000); Online support group: (73%, 63%) (p=.000).

FIGURE D: Has your ability to pay for any of these expenses been affected?*



*Note: Check all that apply, n=836.

attributed to good health insurance), the mere ability to pay for health insurance was affected for one-third of respondents (37%).

In addition, transportation was sometimes a practical barrier to utilizing services. Respondents reported that lack of adequate transportation was a barrier to some or a large extent to getting to medical appointments (30%) and to using support services, such as support groups and counseling (22%). Several respondents described having difficulties with transportation because of driving restrictions and the need to rely on others (whether friends or an imperfect public transportation system) to get around.

“This diagnosis hits you emotionally, physically, & FINANCIALLY!!! Even with insurance, you end up with big copays, and in a lot of cases, it is the bread winner who is off work. Then the spouse may have to take time off work to be a caregiver. Home health care is expensive.”

“The medical cost has been enormous. Our son is 31 but has not been able to work. My husband and I carry this load. My husband and I are not working and our savings is drying up. We also pay copays, prescriptions, travel, lodging and meals for the doctor appointments and treatments. Then, we have to help our son with living expenses. We need help. And we don't want our son to worry because it can't be good for his recovery.”

“We had to adjust our lifestyle to accommodate the daily difficulties faced. The hardest part for our family has been financially, as we can't find anyone to help with the mounting medical expenses we are facing.”

Needs in the Health Care Setting

Over the course of their journey, brain tumor patients and their loved ones spend considerable time in the health care setting. The team of specialists that oversees care plays a crucial role in disseminating information and in supporting patients and families throughout the brain tumor journey. Sometimes interacting with the health care system can be challenging at best.

Navigating the Health Care System

Many respondents reported that managing paperwork, record-keeping and working with insurance companies were major challenges. Some cited the difficulty of waiting for referrals and getting reimbursement or approval for a particular service. Others encountered difficulty in navigating state and federal benefit programs, a confusing and time-consuming process. Seven out of ten respondents said they would be very or somewhat likely to use a patient navigator service, if available for free.

Some respondents felt local doctors did not have specialized experience treating brain tumors and therefore traveled to another city for treatment. Upon returning home, they reported having trouble finding a local provider and felt overlooked in the transition of their care.

Beyond the maze of paperwork and insurance red tape, patients and their loved ones must manage their interactions with the medical professionals who make up the treatment team.

Interaction with Health Care Team

During the first six months following diagnosis, respondents indicated that they saw members of

“The administrative, communications and coordination tasks associated with this diagnosis are enormous. They require a skill set that many people don’t have in the first place, and is certainly impeded by stress.”

“When there is no brain tumor center near your home, how do you get the doctors to talk to each other? There is no team; we felt lost even when we asked all the questions. Nothing was tied together.”

“My parents live in a rural area without many services. They do not have support groups. It has been an incessant battle to get information, and we have learned that we need to do our own research and be armed with as much information as possible because the doctors and nurses do not have experience in dealing with brain tumor patients.”

“The most difficult time for me was when I first learned I had a brain tumor and had to wait one month before I could see a neurologist. I was terrified and had no one to answer my questions.”

“Qualifying for MediCal was very stressful because no one ever explained the rules. I was disqualified for having too much money in the bank (more than \$2100 when my bills were adding up to \$3000). I really could have used some knowledge on how to navigate the system.”

their health care team that were involved with their physical medical care much more frequently than members involved with psychosocial and rehabilitative care.

The top four specialties that respondents reported seeing “often” during the first six months after diagnosis were the oncology doctor (60%), neurosurgeon (43%), nurse (43%) and neurologist (41%).

The health care team was respondents’ top choice for receiving information; eight out of ten respondents indicated a preference for receiving information directly from the treatment team. Nonetheless, our respondents described a range of frustrations about interactions with their health care teams, including:

- Receiving insufficient attention from the doctor.
- Having unaddressed concerns about side effects and emotional repercussions. As one person told us, “Basically the surgeon took out the tumor – that’s it. He sent me on my way. Never told me what to expect post-op. I had to find out everything on my own.”
- Getting connected with appropriate specialists. Several people mentioned a need for referrals to professionals who specialize in working with brain tumor patients, whether physical therapists or mental health specialists.

Respondents less frequently saw those specialists whose roles have a greater emphasis on psychosocial care. More than *half of respondents reported never seeing a social worker, and two-thirds never saw a counselor or therapist*. Three out of every four patients with low grade tumors reported they never saw a social worker.

In addition, *nearly half of respondents never saw a rehabilitation specialist, and three-fourths never saw a neuropsychologist*. Again, there was a notable difference related to tumor types. Significantly fewer patients with low-grade tumors (64%) reported seeing a rehabilitation specialist than patients with

high grade tumors (75%) ($p=.006$), despite the fact that people with low grade tumors are likely to live longer and benefit more from such services. Fifty-four percent of respondents indicated they would very likely use neuropsychological testing if available free of charge in their community.

The low utilization of rehabilitative and social work services presents an opportunity to address a broader spectrum of medical and psychosocial needs. As people with brain tumors live longer, and as the survivorship movement spreads, greater attention to these services that help patients adapt to life as survivors is crucial to improving the notion of quality brain tumor care.

“We had major problems with the first doctor... She treated only my husband’s tumor and ignored all the secondary symptoms being caused by the tumor and meds. We felt she looked at him like a rat in a lab experiment.”

“My local doctors have been phenomenal. Dealing with the larger research facilities has been a problem. Locally, I’m treated as a person. At the large institutions, I feel like a brain tumor... Our biggest challenge has been finding specialized treatment in a setting that makes you feel like you matter.”

“Because my insurance declined to pay for neuropsychological evaluation and none of the approved doctors in my plan are trained in this field, rehab services where we might have found some support for how to cope, were not an option. They will not meet with us until the neuropsych eval is complete.”

“Why isn’t neuro-cognitive testing done automatically? I’ve been unknowingly living with cognitive deficits and have been very depressed and full of anxiety, put on drugs and what I really needed was help with cognitive issues!!”

Implications

The repercussions of a brain tumor diagnosis extend into virtually every aspect of life for both the patient and his loved ones. Families face a host of challenges as they come to terms with the “new normal” of life after a brain tumor.

The findings from these patients, survivors, and caregivers reflect opportunities for continued progress in services for the brain tumor community. Both challenges and opportunities exist for improving programs for patients and families, and for expanding the standard of care to include a broader range of services that address the range of quality of life needs.

Challenges for the brain tumor community

- **The brain tumor community is heterogeneous in many ways.** Brain tumors affect individuals of all ages, ethnicities and health histories. There are more than 120 types of brain tumors, so the community encompasses a number of sub-diagnoses and prognoses. Effects of these tumors and their treatments on the brain have a wide range of implications and effects. For all of these reasons, a one-size-fits all approach is difficult to apply to this patient population (and therefore to their caregivers); many issues are individual and require an individualized approach to addressing them.
- **Special populations with unique needs require increased outreach and tailored programming.** Certain subgroups within the brain tumor community, such as young adults, non-native English speakers, and those with benign tumors, caring for a loved one

in a nontraditional relationship, or living in a rural area, encounter unique challenges not sufficiently addressed by mainstream services.

- **Brain tumor survivorship has expanded the nature and variety of interventions required.** Historically, medical care and supportive services for brain tumor patients have focused on treatment in the acute period after diagnosis. Now, thanks to advances in clinical trials and new treatment possibilities, people with brain tumors are living longer than ever before. Many survivors must now cope with the life-altering effects of the tumor and treatment. Just as the population of brain tumor patients is diverse, the needs of brain tumor survivors encompass a wide range of issues; to really meet these needs, services must be flexible and adaptable.

Opportunities for improving services and support for brain tumor patients, survivors, and loved ones

- **Anticipatory guidance** to help both patients and loved ones understand the implications of a brain tumor is crucial to helping them navigate not only short-term effects of treatment but also the long-term after-effects of survivorship. Cognitive, personality, and physical changes are a tremendous challenge for both patients and their loved ones. It is crucial to map these changes early in the process and check in at subsequent visits to ensure families are prepared for where they are and what may come.

- **Guidance specific to caregivers** will help friends and family members provide better care to their loved ones. Caregivers need better preparation about what to expect and tangible support for attending to patients' needs as well as their own. Specific information and resources for dealing with the cognitive and personality changes, which increase caregiver burden, are necessary and differentiate brain tumor caregiving from caregiving for patients with other cancers.
- **Practical assistance** is needed to help families cope with the impact of a brain tumor. Substantial medical costs are often accompanied by a loss in income, resulting in a dire need for financial assistance. Physical deficits, transportation needs, and loss of independence contribute to the practical challenges that families face. In addition, navigating the health care system represents a substantial burden for patients and their families.
- **Psychosocial support** is essential to providing holistic care that meets the spectrum of challenges that families experience. Better assessment tools and increased screening for depression and anxiety, as well as greater attention to patients' and their caregivers' psychological well-being, are crucial. Opportunities for families to connect with others in a similar situation can help patients and their loved ones to cope.
- **Interventions that empower survivors** to adapt to changes and regain abilities to the greatest extent possible are needed. Survivors and caregivers need information about practical and realistic activities, as well as utilization of rehabilitative services to maximize functioning. Finding ways to make these services more affordable is essential.
- **Greater utilization of the entire health care team** can help families take advantage of

additional services, such as rehabilitation, social work, and counseling. Physicians may have inadequate training in quality of life issues for brain tumor patients and may need to be educated about the importance of referring patients to rehabilitative and psychosocial services. Increased collaboration between all the members of the health care team may help patients better navigate the different specialties that are available. However, it is also important to note that a large majority of brain tumor patients are not treated at large brain tumor centers and may not have access to a broad multidisciplinary treatment team. Solutions that can link patients at smaller centers with experienced rehabilitative and psychosocial specialists are important to advancing patients' quality care in a variety of settings.

- **More research** is needed to better understand the barriers that contribute to the underutilization of rehabilitative and psychosocial services. Our study did not explore respondents' reasons for not using services; however, it is likely that a number of factors including insurance coverage, cost, availability, lack of awareness, fragmentation of services, individual preferences and logistical considerations (such as childcare or driving restrictions) contribute to low utilization of these services. Developing strategies that reduce barriers to care will contribute to better quality of life for patients and their families.

Appendix A

Respondent Characteristics

	Aggregate (%)	Patients only (%)	Caregivers only (%)
Gender			
Female	79.9	75.6	84.7
Male	20.1	24.4	15.3
Age			
Under 18	0.4	0.3	0.4
18-24	2.4	2.2	2.7
25-34	11.6	10.2	13.3
35-44	23.5	24.6	22.3
45-54	33.8	34.0	33.5
55-64	22.3	22.9	21.6
65 and Above	6.0	5.8	6.3
Community Type			
Rural	22.0	22.6	21.4
Suburban	58.5	58.2	58.9
Urban	19.4	19.2	19.7
Ethnicity			
African American, Black	1.9	2.5	1.3
Alaskan Native, Native American	1.0	1.3	0.6
Asian	2.6	2.8	2.3
Caucasian	88.9	88.9	88.9
Hispanic, Latino, Spanish	4.3	3.1	5.6
Pacific Islander	0.5	0.3	0.8
Other	0.8	1.0	0.6

Respondent Characteristics (cont.)

	Aggregate (%)	Patients only (%)	Caregivers only (%)
Education			
Less than high school	0.9	0.5	1.3
High school diploma or GED	9.5	10.6	8.3
Vocational, trade, or technical school	6.1	6.0	6.2
Some college	22.2	23.5	20.8
2 or 4- year college	34.8	33.4	36.3
Graduate or professional degree	26.5	26.0	27.0
Marital Status			
Single, never married	10.9	13.1	8.3
Living with a partner	4.1	4.8	3.4
Married	66.5	63.9	69.3
Separated	2.0	2.4	1.5
Divorced	10.0	13.3	6.3
Widowed	6.6	2.6	11.2
Internet Use			
One or more times a day	87.8	84.8	91.1
A few times a week	10.0	12.6	7.0
A few times a month	1.4	1.5	1.3
Almost never	0.7	1.0	0.4
I don't use the Internet	0.1	0.0	0.2

Tumor type chart

Tumor Type	n	%
Anaplastic Astrocytoma	94	6.9%
Glioblastoma Multiforme	405	29.9%
Oligodendroglioma	126	9.3%
Oligoastrocytoma / Mixed Glioma	59	4.4%
Malignant meningioma	4	0.3%
Astrocytoma, grade 1 or 2	109	8.0%
Acoustic Neuroma or Schwannoma	28	2.1%
Meningioma*	261	19.2%
Pituitary tumor (Pituitary Adenoma)	47	3.5%
Metastatic	12	0.1%
Medulloblastoma	15	1.1%
Brain stem glioma	11	0.8%
Ependymoma	23	1.7%
Other	96	7.1%
Don't know	66	4.9%
TOTAL N	1356	

*Unspecified benign or malignant.

For ease of analysis when testing for statistical significance, tumors coded as “high grade” included anaplastic astrocytoma, glioblastoma, oligodendroglioma, oligoastrocytoma/mixed glioma, and malignant meningioma. Tumors grouped as “low grade” included astrocytoma grade 1 or 2, pituitary tumor/pituitary adenoma, acoustic neuroma/scwannoma, meningioma. Metastatic tumors were coded as “metastatic”. The remaining types were coded as “other”.

Appendix B

Study Limitations

The study has limitations common to many online surveys. First, response rates could not be calculated since the number of patients and caregivers who were eligible to participate in the study is unknown. Also, because the survey was publicly available, it is possible that some people who were not eligible could have completed the survey.

Second, this was not a random sample. The demographic characteristics of the study reveal that the study population consisted of computer literate patients and caregivers most of whom spend time on the internet on a daily basis. Because patients and caregivers had to take the survey on either the NBTF or BTS web site, they may be unlike other brain tumor patients and caregivers since they are in some way affiliated with a brain tumor organization. The study population was also well educated, largely Caucasian, and female and is not representative of the brain tumor patient and

caregiver population in the United States, limiting the generalizability of the findings. Brain tumors affect people of all ages, ethnicities and walks of life. It is worth noting that even with our well-educated, and presumably high-resourced sample, our respondents indicated considerable unmet need. It is likely that many of the needs that were identified are heightened among brain tumor patients and families who have fewer resources at their disposal.

Fourth, as is common with online surveys, there were some data quality issues. For instance, the data reflected certain terms were interpreted differently (e.g. “newly diagnosed”). In addition, in some cases, both the patient and their caregiver completed a survey which likely biased the results to a small degree and may have led to some results being overstated. It was not possible to identify cases in which this occurred since there were many shared IP addresses in the dataset and IP addresses are not unique identifiers.

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National
Brain Tumor
Society

Patient Services 800 934 2873

Toll-free 800 770 8287

www.brainumor.org