

NOBODY CAN AFFORD A BRAIN TUMOR....

THE FINANCIAL IMPACT
OF BRAIN TUMORS
ON PATIENTS AND FAMILIES:
A SUMMARY OF FINDINGS



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a report from



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ABOUT NBTF

The National Brain Tumor Foundation, founded in 1981, is a nationwide, non-profit organization dedicated to providing information and support for brain tumor patients, family members and healthcare professionals while supporting innovative research into better treatment options and a cure for brain tumors. Our services include a Patient Information Line (1.800.934.CURE), comprehensive website (www.braintumor.org), peer support network, quarterly newsletter and monthly eNews, printed publications, online message boards, caregiver educational workshops, patient financial assistance program, educational conferences and teleconferences, treatment center database, medical information nurse, and support group listings. In 2007, NBTF will award \$1 million in grants for brain tumor research.

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Nobody asks if you can afford a brain tumor, you just go where you are led, then your whole world just implodes on itself, and nothing is ever the same.

—*brain tumor patient*

BACKGROUND

Since 1981, the National Brain Tumor Foundation has been the leading provider of education and support services to brain tumor patients and their families across the United States. Through our contact with tens of thousands of patients and families each year on our Patient Information Line, we have been hearing anecdotally about the real financial crisis that arises when someone is diagnosed with a brain tumor. We have heard stories about patients not being able to return to work, about patients who lost health coverage and had to forego treatment, and about survivors who, despite being disabled, could not qualify for disability insurance.

Research studies in the general oncology population have shown that medical costs related to prescription drugs and insurance coverage may be problematic for all types of cancer patients (Moore, KA 1999, Arozullah, AM 2004). A recent oncology study also indicated that work interruptions and resulting income changes occur across cancer types, but offered no information about brain tumor patients (Kaiser Family Foundation,

2006). Other studies have shown that medical debt, whether from cancer or ongoing chronic illnesses, may have severe negative impacts on individuals' whole lives, not just during the treatment period but well into the future (The Access Project, 2003). People may declare bankruptcy, go deep into credit card debt, or deplete retirement savings in order to pay for needed treatment, and this compromises the long-term financial health of the entire family. Putting these ideas together, we set out to explore how the brain tumor community fared.

Because the brain is the center of thought, personality and an individual's function, tumors and their treatments often have severe impacts which limit working, driving, socializing, and more. We therefore hypothesized that problems seen in the general cancer community would be even greater among the brain tumor community—where patients often cannot return to work as a result of cognitive changes from their tumor or as a result of treatment, and therefore see changes not only in household income but also in the availability and affordability of health insurance coverage. We also know that treatment options for brain tumor patients

A PERSONAL LOOK *at coping financially*

“Only those that have been through it realize what a financial drain an ongoing illness is on a family even with insurance.”

“We had to sell our house to stay afloat.”

“We have used \$50,000 in savings and have credit card debt. We are trying to avoid using accelerated death benefits on his life insurance.”

“This tumor has affected every single aspect of my life. To look at my torn up falling apart furniture and house (which was handed down to me in pristine condition from my dad just before my illness) and know I am not able financially to make the repairs is emasculating. This is not how I pictured my life. It is a source of great depression.”

are limited—currently high-priced “designer” drugs are the standard of treatment and co-pays for these drugs, even for insured individuals, can be over \$1000 each month. What’s more, patients may remain on drugs for six, 12, or 24 months in some cases, extending the treatment costs for several years. Follow-up for brain tumor patients requires MRI scans at regular intervals and they are very expensive. Finally, the disability insurance process is problematic for the brain tumor community; complicated long applications make applying difficult for cognitively impaired patients/survivors, misunderstandings about brain tumors often result in denials on the first application, and those who are accepted must wait two years before receiving Medicare disability, so often face long periods without affordable insurance.

This study was conceived in an attempt to get a more accurate view of these problems in the brain tumor community and to document these issues in a systematic way so that we might better understand the issues patients and families face and develop programs accordingly.

SURVEY

In August 2006, the National Brain Tumor Foundation set out to understand the financial impact of a brain tumor diagnosis on patients/survivors and their loved

ones. Using an online survey administered in SurveyMonkey, NBTF created multiple-choice surveys to which over 500 people responded (277 patients, 224 caregivers). In addition, respondents had the option of entering open-ended comments at the conclusion of the survey. More than 300 people wrote in comments, creating an additional qualitative data set. These comments were analyzed separately using coded thematic analysis. What follows are the key findings of this study.

KEY FINDINGS

The results of the study paint a bleak picture of the financial well-being of brain tumor patients, survivors, and their families. The high cost of treatment, even for insured patients, coupled with difficulty with employability and obtaining disability insurance, leaves patients and families financially strapped, in debt, and even bankrupt. Patients and families pay substantial out-of-pocket costs for medical and non-medical expenses and often go into debt to do so, despite making cutbacks to household expenses. Debt burden extends beyond the treatment period and the consequences of the debt linger for years, sometimes extending beyond the patient’s life.

For brain tumor patients and their families, health insurance is necessary although not sufficient to protect

A PERSONAL LOOK *at health insurance*

“I have insurance through Medically needy Medicaid but it does not cover the first \$942 of my illness, prescriptions, hospital or doctor visits each month. It is like having a renewing deductible each month”

“We had over \$30,000 in COBRA expenses and other medical expenses in just the first year.”

“My biggest challenge is anti-seizure medication cost. I have stagnated my life to be able to afford the \$500 plus (in co-pays) for my meds.”

“My insurance is a major medical policy that only pays if I’m in the hospital. So all my outpatient doctor visits and treatments and oral chemo are not covered. MRIs are also not covered.”

them from the steep financial cost of a brain tumor diagnosis. For most patients in this study, medications were only partially covered by insurance, meaning that patients and/or families had to pay in part for expensive oncology medications, which are often needed for months or years. Medication costs coupled with high out-of-pocket costs, high health insurance premiums and deductibles, and in some cases pre-existing illness exclusion clauses, greatly affect the affordability of care.

WHO RESPONDED

In total, 277 patients and 224 caregivers completed the survey. A table detailing our sample is on page 7. Highlights include:

- 66% of patients and 84% of caregivers responding were female
- 89% of respondents were Caucasian
- 61% of respondents were married or in a domestic partnership, with 20% single, never married.
- 46% of respondents had completed a bachelor's degree or higher
- 83% of respondents owned their own homes.

HEALTH INSURANCE

Ninety-one percent of the patients and caregivers who responded to this study had health insurance coverage and 86% of these individuals had either an HMO, PPO, other private insurance or Medicare. Despite this, both patients and caregivers reported problems with COBRA premiums, problems with premiums in general and difficulty with coverage limits. Even though the majority

of study respondents were out of active treatment, they still had high out-of-pocket costs, with 34% of patients and 54% of caregiver respondents spending over \$250 each month on out-of-pocket medical expenses related to their brain tumor, and 15% of patients and 27.2% of caregivers spending over \$1000 each month out of pocket.

In every category, caregivers reported higher out-of-pocket expenses than patients in the corresponding category. Among both patients and caregivers, prescription drugs were the highest out-of-pocket expense.

EMPLOYMENT AND INCOME CHANGES

Changes were reported in both the patient's and the caregiver's employment. Though 91% of patients were employed before their diagnosis, only 33% were working post-diagnosis. Caregivers continued to work in greater numbers, with only 16% quitting their jobs, but they made other work adjustments. A total of 62% of caregivers reported either taking a leave of absence, using up vacation time, cutting back on hours, taking on additional paid work or some combination thereof. These employment changes for both the patient and caregiver resulted in downward shifts in household income, reported by nearly half (48%) of respondents.

Income distributions, both before and after diagnosis, are included in the table below.

The percentage of people who reported being in the lowest income category increased 300% after diagnosis. Simultaneously, the number of respondents reporting income above \$75,000 per year dropped from 38.3% to 25.3%.

Annual Household Income	Percent of Respondents Before Diagnosis	Percent of Respondents After Diagnosis
0-\$14,999	4.8%	17%
\$15,000-\$24,999	7%	12%
\$25,000-\$34,999	8.8%	12.7%
\$35,000-\$54,999	22.8%	17.2%
\$55,000-\$74,999	18.4%	15.6%
\$75,000-\$100,000	18.4%	12.3%
Over \$100,000	19.9%	13%

A PERSONAL LOOK *at out-of-pocket expenses*

“I am spending several hundred dollars each month in gas getting to and from my loved one’s home (to care for her).”

“Our medical bills are over \$85,000 so far and we’re still not sure how much of that we will have to pay out of pocket.”

DISABILITY COVERAGE

Most respondents (62%) were not receiving disability coverage of any kind, a surprising finding in a survey where over 60% of respondents were 2+ years from diagnosis and in which nearly two-thirds of previously full-time working individuals were unable to return to work after their treatment. Even those receiving disability coverage, however, often experienced drops in their household incomes.

HOW PATIENTS AND FAMILIES MAKE ENDS MEET

Patients and caregivers reported similar information about out-of-pocket costs for brain tumor related medical and non-medical expenses.

The most common out-of-pocket costs for medical expenses in rank order were:

1. medications
2. physician visits
3. hospital bills
4. herbs/supplements/vitamins
5. additional services (i.e. rehabilitation).

The most common out-of-pocket costs for non-medical expenses in rank order were:

1. additional meals out
2. transportation to treatment
3. additional telephone bills
4. hotels
5. consumer goods related to treatment.

Patients and families reported making cutbacks to make ends meet. The most reported cutbacks were on:

1. taking vacations
2. recreational activities

3. buying new clothes
4. putting money into retirement savings
5. dining out

Families were least likely to make cuts in the following areas:

1. buying medication
2. paying the rent/mortgage
3. paying utility bill
4. getting medical treatment
5. buying groceries

Even these household cutbacks were not enough to absorb additional costs associated with brain tumors or the income changes as a result of work stoppage and disability. The two most common reported actions people took to pay for medical and non-medical expenses were to incur credit card debt (47%) and/or to borrow money from family and friends (42%). Other actions included declaring bankruptcy (7.2%), taking on second or third mortgages (15%), and cashing in retirement plans or life insurance policies (8.4%).

In addition, there was a significant relationship between length of time since diagnosis and both incurring credit card debt and cutting back on retirement savings. The longer it has been, the more likely it is that people have done both, indicating that while families may have some small cushion to help them in hard times, few are prepared for the extended high costs of brain tumor treatments and the more permanent shifts in household income over the long term.

LONG-TERM EFFECTS

It is not just during the acute treatment phase that the financial well-being of patients and families is compromised. The effect of these actions people took to “make

ends meet” lasted well beyond the treatment period. Sacrifices made during treatment as described in the open-ended comments included selling homes, selling cars, taking on credit card debt, cashing in on retirement savings, depleting emergency savings, declaring bankruptcy, and in a few extreme cases, becoming homeless. All of these were difficult to recoup from once families adjusted to post-treatment life, especially given the realization that the patient/survivor might never be able to return to work. Others reported worrying how they would live for the next 15 years given that they had depleted all their retirement savings to pay for treatment and stay afloat.

FINANCIAL BURDEN

Respondents were asked at the end of the survey for responses to several statements about financial burden. A total of 59% of patients and 65% of caregivers agreed

that brain tumor-related expenses were a major problem and four out of five respondents felt their financial situation had changed for the worse since their loved one was diagnosed.

In addition, many respondents described feeling forgotten. People expressed frustration at having worked their whole lives and paid into a system that did not help them when they needed it.

“I am 47 years old, no job, and no retirement left,” said one respondent. “I have no idea what I am going to do. I can’t believe I live in a society that would not help me...Worked and paid taxes all my life, and could get nothing in return when I really needed help.”

This study describes a clear picture of downward mobility—full-time, home-owning, largely middle-class and above families experienced a moderate downward shift in household income due to a medical crisis and this shift is experienced in lifestyle cutbacks whether major (loss of home) or more minor (stopping vacations and dining out).

A PERSONAL LOOK *at financial burdens and long-term debt*

“My tumor caused me to lose our home and declare bankruptcy. Disability kicked in when everything we had accumulated was gone. Thank god for family...we would never have survived.”

“We are having a tremendously difficult time financially, even seven months after my wife’s death.”

“She can’t work and we struggled to get disability...we both lost our jobs and we were on food stamps. We lost our savings and when we declared bankruptcy we lost our primary home...”

“It is a travesty that middle class Americans have to go through most of their savings/life insurance before they can qualify for additional help with medical expenses. My children’s college savings are being depleted, as is my husband’s early dispersal of life insurance.”

“My husband thought I would be okay after he passed because of the life insurance. But his employer cancelled the policy because he was out of work for a year. Now I have just enough to make it to next year to sell our house.”

A PERSONAL LOOK *at disability coverage*

“She eventually got \$300 a month for SSD after 18 months. We appealed her initial denial but she was not ‘sick enough’ according to the state doctor. This was an insult. The SSD payment only covered about one-sixth of our COBRA payment.”

“We were turned down for every government program we applied for. There is a gaping hole for support for the middle class homeowner. We lost the kids’ school funds, our stocks, our retirement, everything.”

IMPLICATIONS

Brain tumors are a major medical crisis for the patient and his or her family. What this study shows, however, is that they represent a major financial crisis as well.

- 1. A brain tumor diagnosis is not just a medical crisis; it is a financial crisis.** While a brain tumor diagnosis is viewed as a medical crisis it is generally not seen as a financial one. However, medical debt and its impact extends well beyond the treatment period and continues to weigh down families, in many cases even after the patient has died. Having insurance does not protect patients and families from experiencing debt. When diagnosed with a brain tumor, patients and families receive a medical and psychosocial assessment but few receive a financial assessment. We need more programs and services designed to help families plan for their future so they are better prepared for the financial impact of a brain tumor diagnosis.
- 2. There are enormous gaps in coverage for middle class families.** Working middle-class families with health insurance are falling through the cracks because there is little or no support to help people at this income level. They are “too resourced” for major benefit programs and/or considered “not disabled enough” for programs into which they have paid throughout their working lives. More attention needs to be paid to meeting the needs of people “in the middle” of the income curve to ensure that they

do not shift down to the lower end of the income curve as we saw in this study.

- 3. A brain tumor, even more than other cancers, often brings about a significant reduction in income and productivity.** Though nearly every respondent in this survey was working prior to diagnosis, only a third of respondents were able to return to work. There is currently no support to help brain tumor patients and survivors find ways to be productive members of society or help them get back to whatever level of work they can do.
- 4. Disabled brain tumor patients are not able to receive immediate insurance coverage through Medicare but must wait two years, leaving many without affordable health coverage.** This report clearly documents that the two-year wait for Medicare insurance coverage represents a major hardship for disabled brain tumor patients. This gap leaves many people struggling to find, qualify for, and pay for insurance coverage during the critical treatment and follow-up period. A bill was introduced over two years ago in Congress to fast-track patients with the most aggressive brain tumors but has yet to be passed. During those two years, 80,000 more brain tumor patients have been diagnosed. This will continue to be an issue until a coherent, comprehensive national health policy is developed that ensures these patients access to affordable health coverage at the onset of disability.

MORE INFORMATION *For a copy of the full report, visit www.braintumor.org.*

DEMOGRAPHICS OF RESPONDENTS

Category	Patients	Caregivers
Gender	66% Female 34% Male	84% Female 16% Male
Marital Status	20.3% Single/never married 58.2% Married 16% Divorced 2.2% Widowed 3.3% Domestic partnership	5.2% Single, never married 80.8% Married 5.2% Divorced 5.6% Widowed 3.3% Domestic partnership
Age	Mean age 44 years Range 18-82 years	Mean age 45.4 years Range 21-75 years
Education Level	2.2% Did not finish high school 25.6% H.S. Diploma 25.6% 2 year college degree 25.3% 4 year college degree 21.3% Graduate degree	1.9% Did not finish high school 22.2% H.S. Diploma 23.6% 2 year college degree 27.8% 4 year college degree 24.5% Graduate degree
Home Ownership	66.2% Own their home 24.1% Rent their home 9.7% Other	83.3% Own their home 13.9% Rent their home 2.8% Other
Ethnicity	88.9% Caucasian 3.3% Black/African American 2.6% Latino/Hispanic 1.8 % Asian 3.3% Other	96.2% Caucasian 0.5% Black/African American 0.5% Latino/Hispanic 1.4 % Asian 1.4% Other

A PERSONAL LOOK *at employment*

“Since my husband was dismissed from his job, we have lost a car and were forced to go to churches to ask for food just so my two daughters could eat.”

“All of our savings have been exhausted as my husband was not able to go back to his job field after treatment.”

“I need to work to get benefits but my husband needs care 100% of the time. This is very difficult.”

“I was the breadwinner in the family but had to stop working to be with our son for radiation, chemotherapy, physical therapy, occupational therapy... Our household income has been cut by at least two-thirds.”

“After the diagnosis, I as the caregiver was forced from my job. I took a lower-paying job closer to home to have some income.”

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LIMITATIONS OF THE STUDY

This study has the following limitations:

This was not a random sample. This study was conducted as an online survey with a self-selected sample of participants and is constrained by limitations typically associated with this type of sampling. We would expect that those most negatively affected financially would have the highest interest in responding. Similarly we would expect those who have no financial repercussions at all to be less likely to complete the survey.

Response rates cannot be calculated. Since study participation was open to those viewing the NBTF website during a five-week period and participants were also recruited during this period using email newsletter, printed newsletter, and word of mouth, it is not possible to calculate a response rate given this method of distribution.

Online surveys are skewed to more educated and highly resourced individuals. In addition, the online nature of this survey likely skewed our sample—participants had to read English, have some connection to an advocacy group, and have access to the internet and a computer. As expected, given these parameters, we drew a disproportionately highly educated, middle-class or higher,

predominantly Caucasian, suburban sample. This study offers an in-depth look at the financial impact of brain tumors on a well-insured, well-educated, middle-class population. It does not offer much information about those most vulnerable members of society, for whom the results would likely be much worse.

Our sample was skewed toward long-term survivors. We also drew a skewed sample of brain tumor patients and caregivers, with much greater representation from long-term survivors (defined as 2+ years post-diagnosis) and from “benign” tumor survivors than we would expect statistically. This is understandable given that people in acute stages of treatment or at end of life would be less likely to complete this survey.

While these limitations may inhibit our ability to draw complex conclusions about specific sub-groups of brain tumor patients, we are able to gain insight more broadly into the issues examined in this study for brain tumor patients as a whole and have laid ground for future research into more specific research questions. What’s more, the responses documented here very clearly echo what we have been hearing anecdotally from patients and families for years.



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