



# **PEDIATRIC BRAIN TUMOR FOUNDATION** COMMUNITY HEALTH NEEDS ASSESSMENT

February 2018

**USC Price**

Sol Price School of Public Policy  
*Sol Price Center for Social Innovation*



**Pediatric  
Brain Tumor  
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*This report was commissioned by the Pediatric Brain Tumor  
Foundation, with generous support from Coverys*



# EXECUTIVE SUMMARY

The Sol Price Center for Social Innovation at the University of Southern California collaborated with the Pediatric Brain Tumor Foundation (PBTf) to produce a needs assessment of pediatric brain tumor patients and their families. The PBTf works to fight pediatric brain tumors and their effects on diagnosed children and their families. This needs assessment defines the nature and extent of the problems families face, and details existing gaps in services and resources, to guide the allocation of resources to those identified areas.

This needs assessment finds that pediatric brain tumor patients and their families face key challenges in four general areas:

- **Interpersonal and emotional distress:** Interpersonal and emotional distress was a consistent challenge for patients and their families. For example, 25% of respondents reported that the patient had trouble making and keeping friends and 20% reported that the patient feels isolated and alone. Further, 80% of parents and caregivers expressed significant worry about the future, and 45% reported often neglecting their own well-being at considerable personal cost.
- **Logistical complications and financial hardship:** Many respondents noted logistical and financial issues as a primary challenge for patients and families. For example, 40% of parents and caregivers cited logistics and financial hardship as a challenge. These challenges are especially severe for families with multiple children and for parents with less flexible work schedules.
- **Information gathering and processing challenges in medical decision making:** Practitioners and families cited a need for additional care coordination support to help navigate the health care system, assist in the coordination of care, and learn medical information and resource availability to advocate for the patient and their family.
- **Difficulty reintegrating patients into educational and vocational environments:** Patients often experience barriers to reintegrating into academic and professional environments without a needs advocate who understands the legal landscape in greater detail than most parents. This may be due to late and lasting effects from treatment, such as cognitive and emotional changes, difficulty with balance and coordination, vision and hearing impairment, and other effects.

This report suggests a need for strong support services for patients, families, and caregivers across all stages of the brain tumor journey. Extended care coordination and patient advocacy support is critical to helping patients, families, and caregivers overcome fragmented care and navigate complex medical information. Additionally, mental health services are critical to helping patients address fears, anxieties, and depression. Mental health and social support services also help parents and siblings of patients cope with their own fears, anxieties, and grief, as well as the stress of navigating and coordinating care. Investment in these family support services can help ease many of the challenges that pediatric brain tumor patients and their families face.



# INTRODUCTION

Pediatric brain tumors afflict children of all ages. In the United States, more than 28,000 children and teenagers live with the diagnosis of a primary brain tumor (Porter, McCarthy, Freels, Kim, & Davis, 2010). In 2017, an estimated 4,820 new cases of childhood primary malignant and non-malignant brain and other central nervous system tumors were expected to be diagnosed in children ages 0 – 19 in the United States. The five-year relative survival rate for this group is nearly 75 percent (Central Brain Tumor Registry of the United States, 2017). Nevertheless, survivors often suffer from lifelong side effects caused by their illness or by various treatments such as surgery, radiation and chemotherapy. Commonly identified late effects of treatment include a decline in intellectual functioning and processing speed, performance IQ deficits, memory deficits, psychological difficulties, deficits in adaptive functioning (daily life skills), and an overall decrease in health-related quality of life. As one study powerfully concludes, individuals with brain tumors face consequential and wide-ranging effects across their lifespan: “Compared to controls, childhood brain tumor survivors are less likely to marry, complete high school, maintain employment, or receive appropriate health care. Brain tumor survivors face additional problems related to motor, sensory, and behavioral disturbances, often culminating in social isolation and failure to attain independence” (Castellino, Ullrich, Whelen, & Lange, 2014). Furthermore, improvements in survival rates over the past 30 years have been slower in pediatric brain tumors than in other types of childhood cancer, with the result that pediatric brain tumors have now surpassed leukemia as the leading cause of cancer death in children ages 0-19 (Centers for Disease Control and Prevention and National Cancer Institute, 2016).

Given the extreme vulnerability that pediatric brain tumor patients and their families face, it is crucial for support organizations to understand how to better meet the needs of this population. To address this question, the Sol Price Center for Social Innovation at the University of Southern California collaborated with the Pediatric Brain Tumor Foundation to produce a needs assessment of pediatric brain tumor patients and their families. The Pediatric Brain Tumor Foundation (PBTf) works to fight pediatric brain tumors and their effects on diagnosed children and their families. As the PBTf expands family support programming to communities across the country to meet a critical need in support services, a comprehensive needs assessment can help ensure that the PBTf effectively directs resources to alleviate the greatest unmet needs within the pediatric brain tumor population.

The purpose of this needs assessment is to define the nature and extent of the problems families face, and detail existing gaps in services and resources to guide the allocation of resources to those identified areas. To address these questions, the needs assessment draws from primary data collected specifically for this needs assessment, including two surveys of 906 family members and 40 practitioners, 11 interviews, and one focus group. This research design has generated a unique dataset to ensure that the needs assessment is tailored specifically to the research goals of the PBTF, particularly focused on the targeted population. Furthermore, the combined interview, focus group and survey approach was undertaken in order to ensure that the research generates both a rich, qualitative understanding of the drivers underlying patient and family needs, as well as to test the prevalence of patterns across the broader population through large-scale surveys.

The report is organized in the following manner: first, the data and research methods are described. Next, the report presents descriptive data from the surveys, which contextualizes the subsequent analysis, and provides broad information on the characteristics of pediatric brain tumor patients and their families. In the third section, the report reviews key challenges for support. The needs assessment concludes with recommendations based on the research findings and analysis.





## DATA AND METHODS

The report is based on data from two email surveys, 11 interviews with practitioners and one focus group with pediatric brain tumor patients and family members. The first survey targeted adult patients (over 18 and able to respond to surveys) and family members of pediatric brain tumor patients. The survey was sent via email to lists provided by the PBTF, and subsequent emails were added for families who had heard about the survey and expressed a willingness to participate. Participants received an initial inquiry and two follow-up emails, for a total of three opportunities to participate. In total, the family survey targeted 7225 individuals. Out of those, 1198 emails (nearly 17 percent) were not able to be delivered, and therefore the total population of responses was 6027. Of these, 906 individuals responded to the survey, which produced a response rate of over 15 percent. This is a strong sample for an email-based survey, particularly one that asks respondents about sensitive issues. Therefore, these survey data can be understood to sufficiently reflect the target population, such that the findings can be trusted to capture the experiences of pediatric brain tumor patients and their families with characteristics similar to the survey sample (Nulty, 2008; Sheehan, 2001).

A second survey gathered information from medical professionals working to support patients and their families. These emails were also provided by the PBTF, and professionals were also emailed three times to participate in the survey. 472 initial inquiries were sent, and 58 of these emails could not be delivered (over 12 percent). Of these individuals, 40 responded to the survey, for a response rate of over 10 percent. This response rate is similarly consistent with strong email survey samples, particularly for medical professionals, who tend to respond to survey inquiries at lower rates (VanGeest et al., 2007).

These survey data are supplemented with data from eleven (11) telephone interviews with practitioners who work with patients diagnosed with pediatric brain tumors. These interviews were conducted to understand what resource gaps and challenges professionals would reference most frequently in caring for this population. Of these interviews with professionals, four (4) specialized in survivorship and palliative care, which likely influences the distribution of responses toward the challenges faced at those particular stages of care. Finally, one focus group was conducted with patients and family members, which yielded important qualitative data about patient care and gaps in support services.

As with any research strategy, it is important to note the data limitations inherent to the sample of respondents and the research design. Most significant, survey, interview and focus group respondents were identified by the PBTF. It was necessary to employ this sampling strategy because there was no feasible alternative to reach all families affected by pediatric brain tumors and professionals working in this field, or even a large subsample of the population, than to go through organizations working to support them. However, by conducting outreach

through the PBTF, this report draws data from individuals who likely enjoy relatively higher levels of support as compared to the total population of pediatric brain tumor patients and their families, since sampled individuals are already connected to at least one support organization. As a result, this report likely underestimates the disconnectedness that pediatric brain tumor patients and their families experience, since the most isolated populations affected by pediatric brain tumors are likely systematically omitted from the survey, interview and focus group sample. This is a challenge inherent to research designs that seek to target isolated populations (Shaghghi et al., 2011). Therefore, those interpreting the findings presented here should understand that, if anything, these data likely *underestimate* the financial, emotional, logistical and information issues that affected families face.



Furthermore, among survey respondents in the PBTF sample, it is reasonable to assume that individuals were more likely to respond if their relative had survived the brain tumor journey. Anecdotal evidence from email responses to the survey inquiry suggests that those whose relative had passed away (generally speaking, targeting the parent of a child with a pediatric brain tumor) were less likely to respond.<sup>1</sup> This suggests a relative oversampling of the experiences of pediatric brain tumor survivors and their families, as compared to family members of patients who had died from pediatric brain tumors.

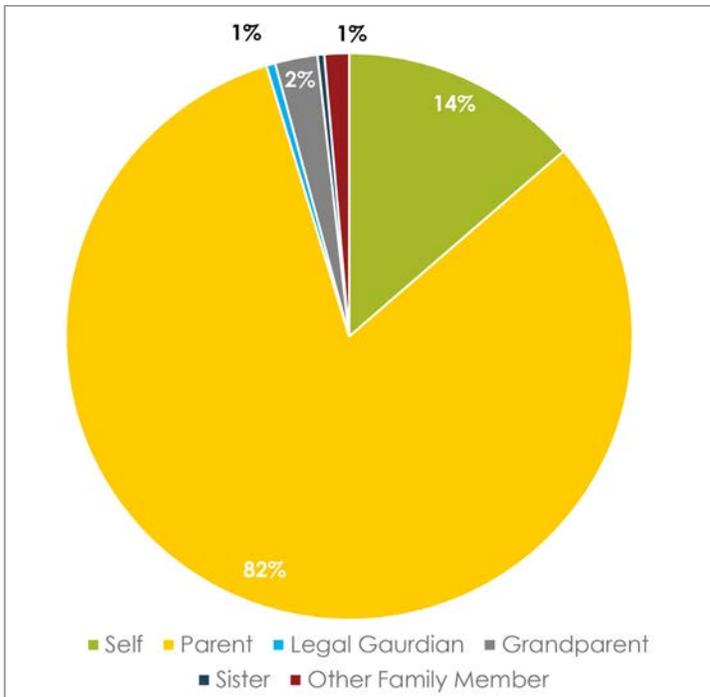
The following section reviews descriptive data from the surveys, including descriptive information on the survey respondents, to provide a deeper understanding of the population of respondents in the survey samples. The section that follows details the findings from the surveys, interviews and focus group organized by the different key challenges that patients and their families experience.

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<sup>1</sup>Survey administrators received multiple emails from individuals whose child had passed away and refused to take part in the survey, but did not receive similar emails from relatives of pediatric brain tumor survivors.

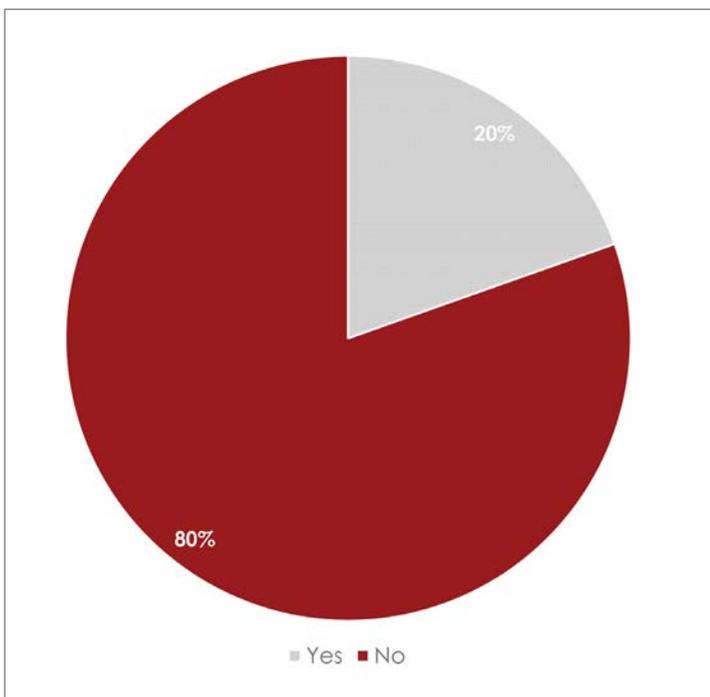
# DESCRIPTIVE EVIDENCE (FAMILY SURVEY)

[FIGURE 1] RELATIONSHIP BETWEEN THE SURVEY RESPONDENT AND PATIENT



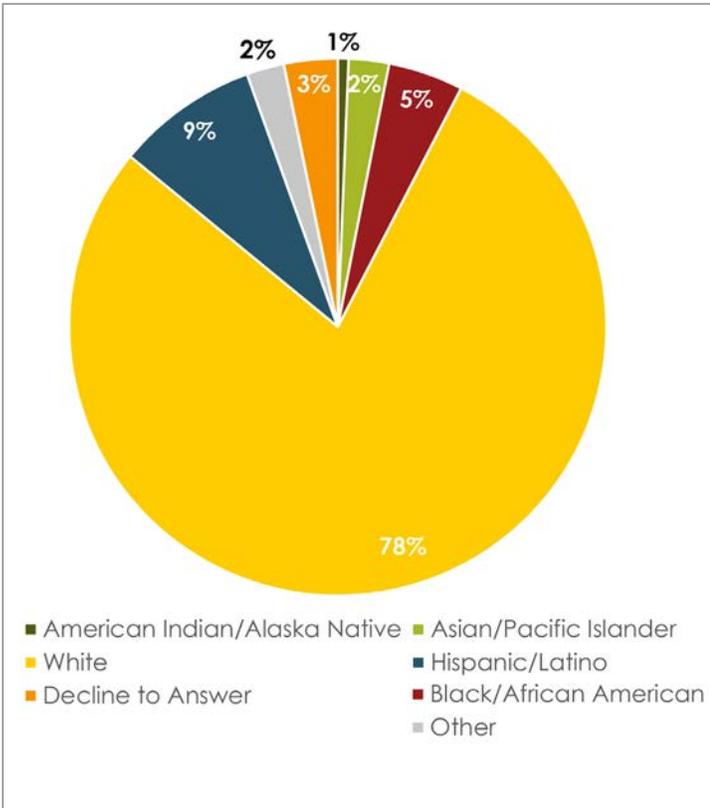
As Figure 1 shows, the family survey draws mostly from the experiences of parents of pediatric brain tumor patients (82 percent). The second largest respondent category is patients (14 percent). The other categories represent less than 2 percent of respondents, but include grandparents, guardians, siblings, and other family members. Therefore, the findings from this report largely reflect parental experiences, followed by the experiences of patients themselves. Interestingly, about one in five respondents work in the medical field (Figure 2). The vast majority of respondents are white and speak English as the primary language in their homes (Figures 3 and 4), and over half of respondents graduated from a 4-year college (Figure 5). Half of respondents live in a household that earned \$80,000 or more per year, but among the other half, there was a fairly even distribution across earnings levels, with almost one in five respondents living in a household earning less than \$40,000 per year (Figure 6). Furthermore, 87 percent of survey respondents are female (Figure 7). This statistic, coupled with the fact that most respondents were parents, indicates that the survey largely reflects a mother's perspective of the challenges and issues related to pediatric brain tumors on patients and families.

[FIGURE 2] DOES SURVEY RESPONDENT WORK IN THE MEDICAL FIELD?

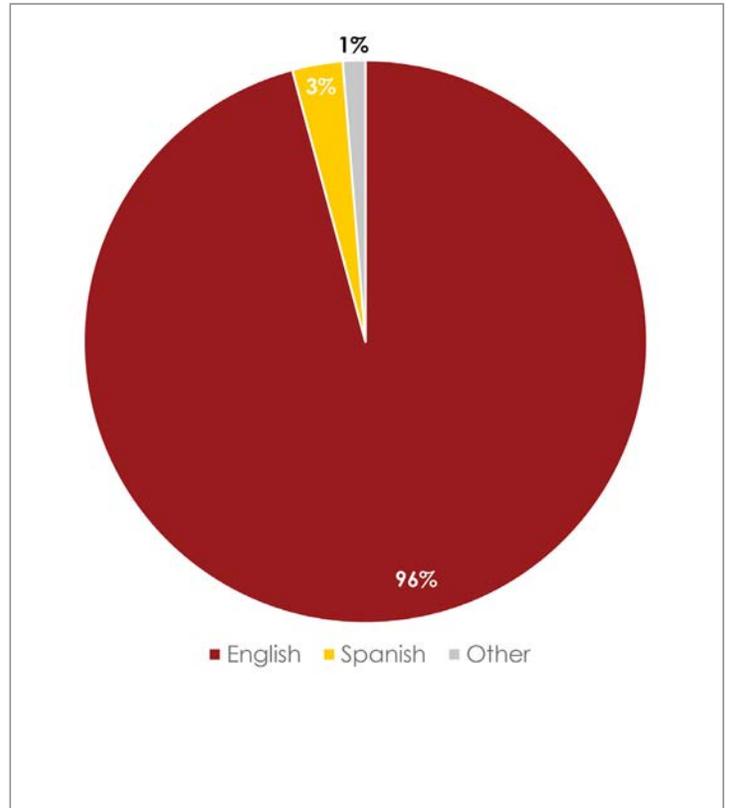


Since brain tumors do not discriminate across socioeconomic characteristics, a representative survey sample would roughly correspond to the characteristics of the population as a whole. Therefore, it is fair to conclude that the survey sample is more white and higher income than the general population of pediatric brain tumor patients and their families, and these individuals are likely better connected than their peers, consistent with the pattern that surveys under-sample the most disconnected populations (Shaghghi et al., 2011). This underscores the note of caution provided in the data and methods section, that these survey data likely underestimate the barriers and disconnectedness facing pediatric brain tumor patients and their families.

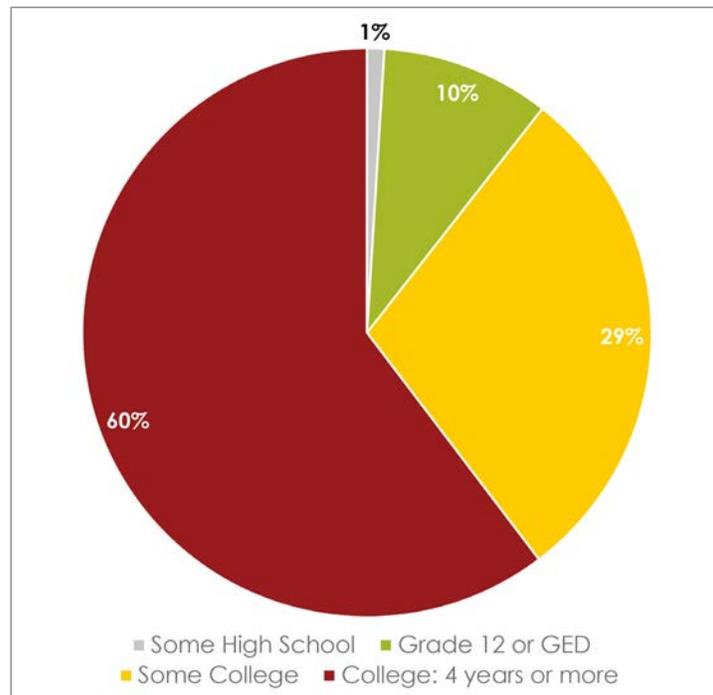
[FIGURE 3] RACE/ETHNICITY OF SURVEY RESPONDENTS



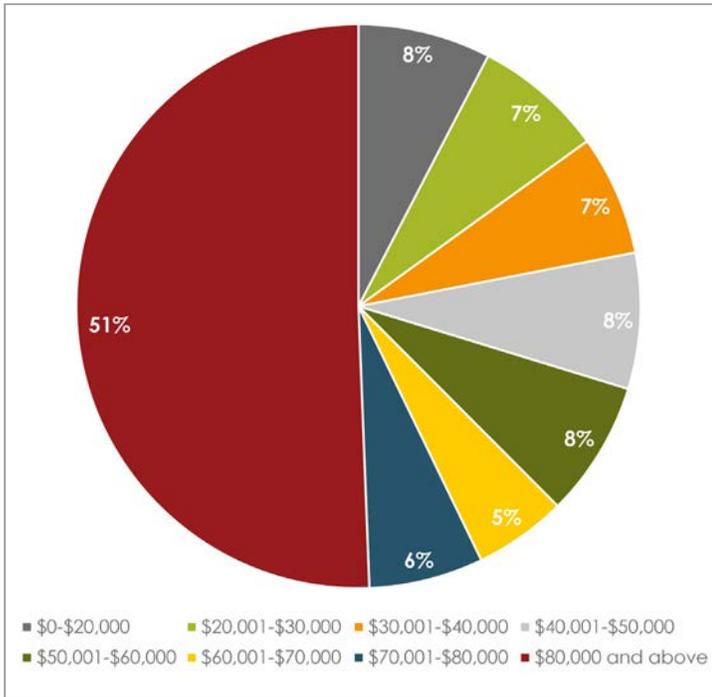
[FIGURE 4] PRIMARY LANGUAGE SPOKEN AT HOME



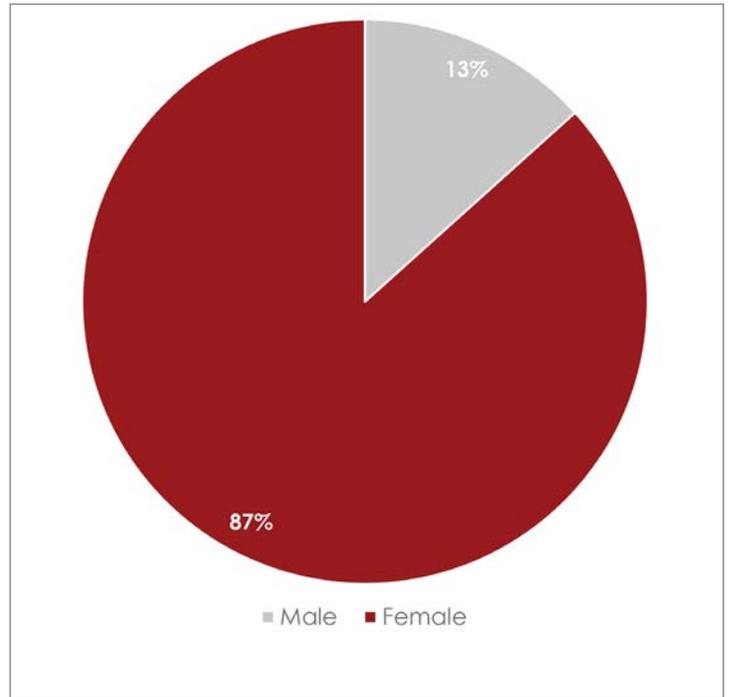
[FIGURE 5] EDUCATIONAL ATTAINMENT OF SURVEY RESPONDENT



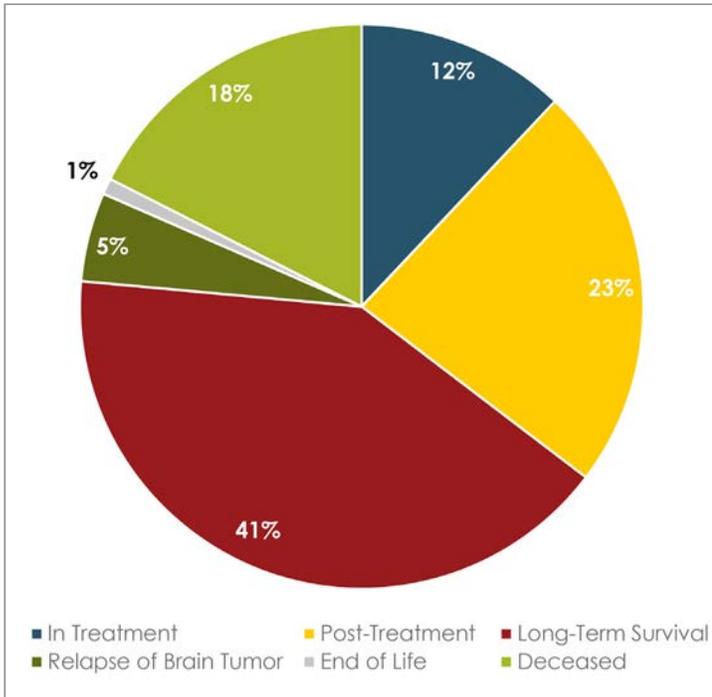
**[FIGURE 6] HOUSEHOLD INCOME OF SURVEY RESPONDENTS**



**[FIGURE 7] GENDER OF SURVEY RESPONDENTS**



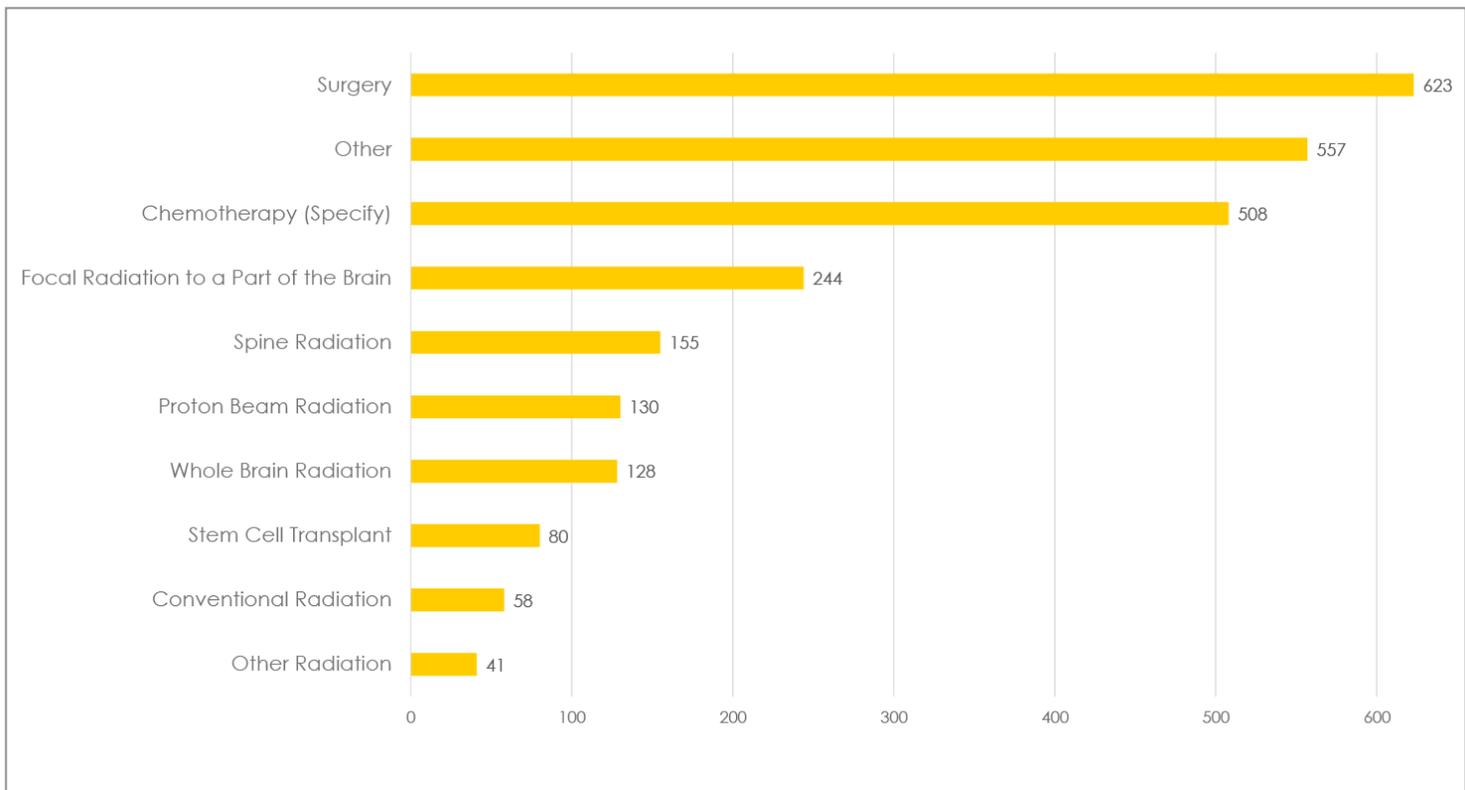
**[FIGURE 8] STAGE IN ILLNESS**



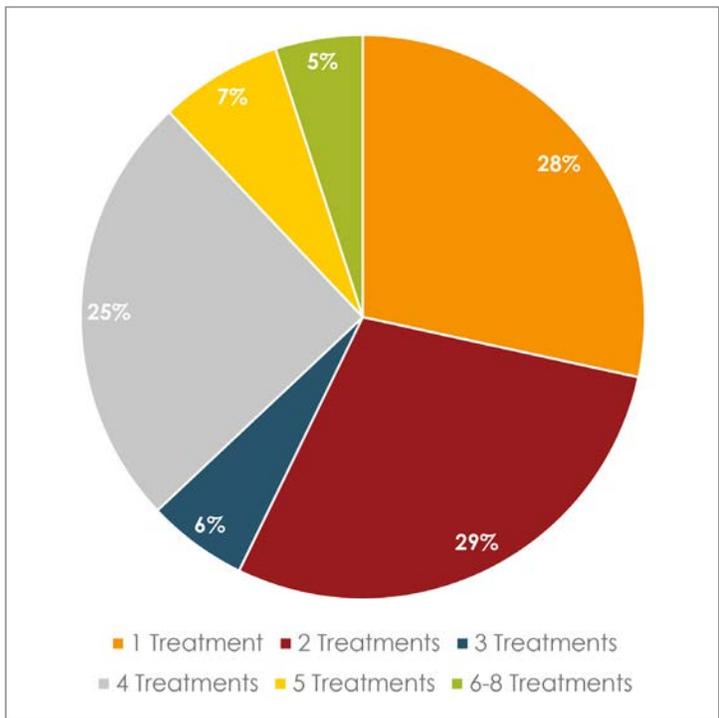
Respondents reported on patients from a range of stages in their illness (Figure 8). The largest group represented long-term survival (41 percent), followed by post-treatment (23 percent). Approximately 18 percent of patients had died from the pediatric brain tumor, and 12 percent were currently in treatment. Additionally, 5 percent had experienced a relapse, and 1 percent were in end-of-life care. Furthermore, patients were fairly evenly distributed both in their current ages and age of diagnosis, and respondents reported that the patient was diagnosed with a wide variety of tumor types (see Appendix 3). This suggests that the findings reflect a wide range of experiences related to the patient’s current age, age at diagnosis, and their tumor type.

Further, patients had received varied treatments (see Figure 9). The vast majority of patients had received surgery (623 of 906 respondents, or almost 69

**[FIGURE 9] TYPES OF TREATMENT RECEIVED TO DATE<sup>2</sup>**



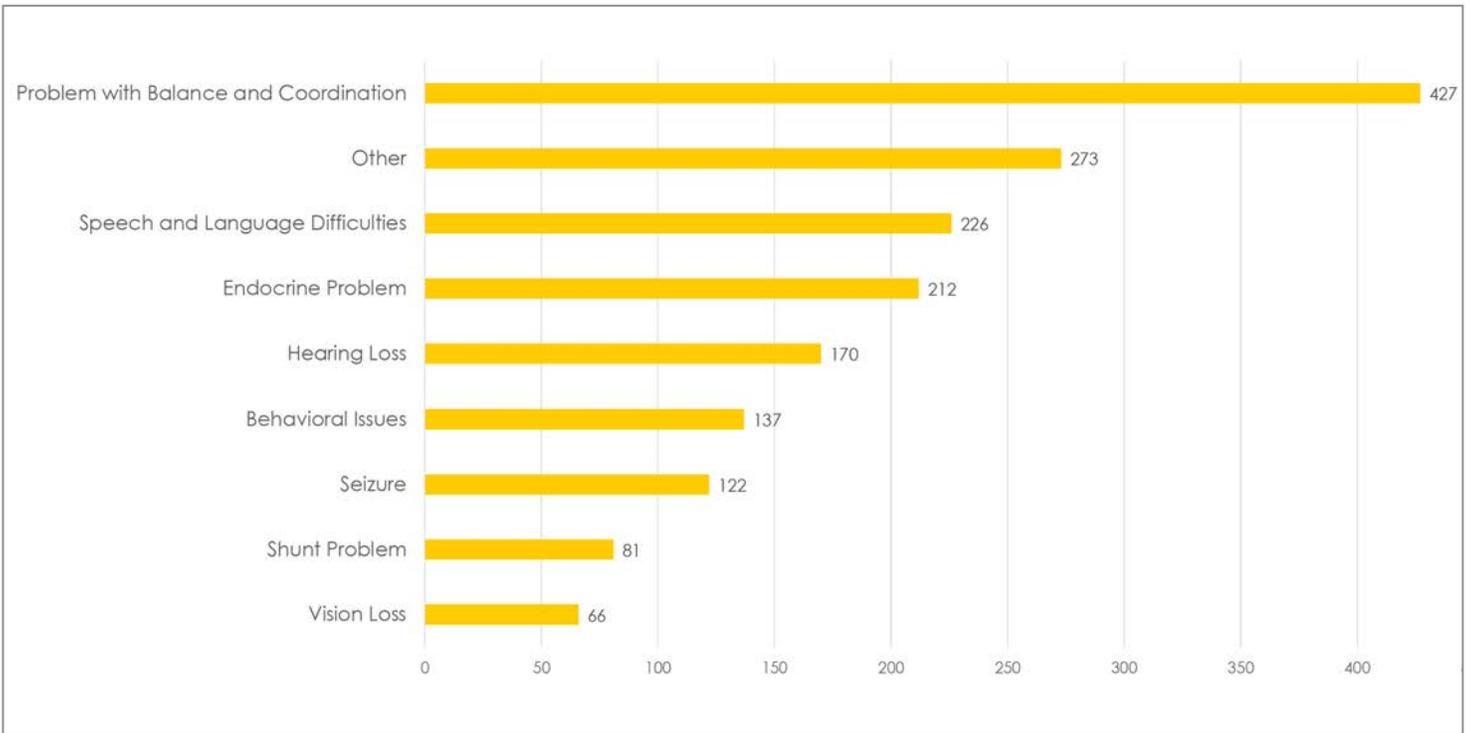
**[FIGURE 10] NUMBER OF DIFFERENT TREATMENTS RECEIVED**



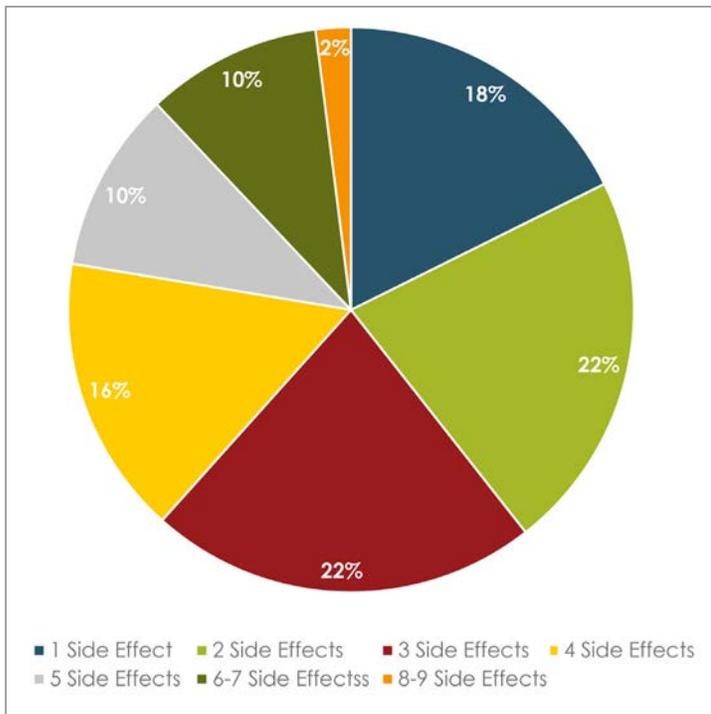
percent). The second highest category was “other” (557 respondents, or 61 percent) and then chemotherapy (508 respondents, or 56 percent). Among types of radiation received, focal radiation to a part of the brain was most common (about 27 percent of all patients), followed by spine radiation (17 percent), then proton beam radiation and whole brain radiation (roughly 14 percent each). As Figure 10 shows, 28 percent of respondents reported receiving one type of treatment, 29 percent reported receiving two types of treatment, 6 percent reported receiving three types of treatment and 37 percent of respondents reported receiving four or more types of treatments. Surgery and chemotherapy were reported as the two most co-occurring treatment types. Surgery and chemotherapy, combined with whole brain radiation and focal radiation to a part of the brain, were the most common combinations for respondents that reported receiving three types of treatment.

<sup>2</sup>Survey respondents were instructed to mark all that applied, and many listed multiple treatments.

[FIGURE 11] SIDE EFFECTS THAT THE PATIENT EXPERIENCED WITHIN A YEAR OF TREATMENT <sup>3</sup>



[FIGURE 12] NUMBER OF SIDE EFFECTS THAT RESPONDENTS REPORTED

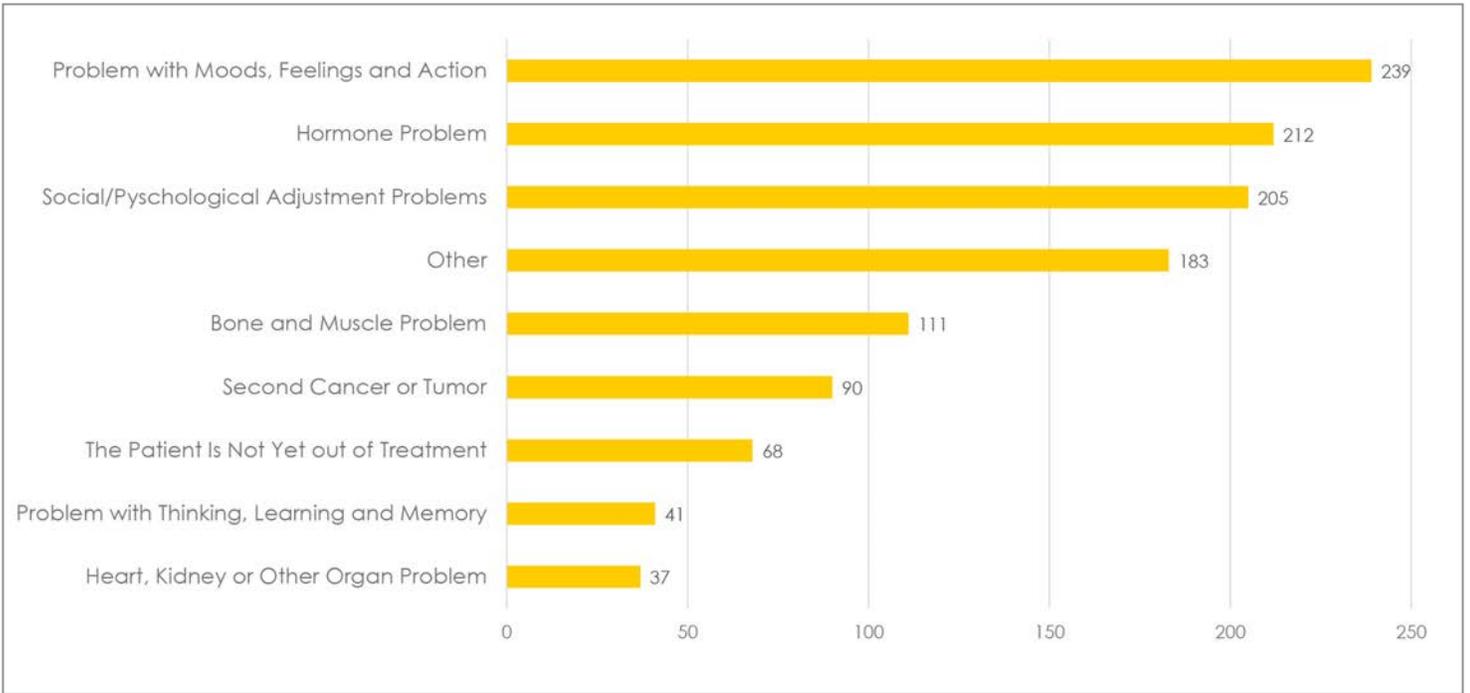


Figures 11 and 13 describe the side effects and late effects, if any, that patients experienced related to treatment for a pediatric brain tumor. Of the 658 people who responded to the question about side effects, 543 reported at least one side effect, or over 82 percent. The most frequent response was problems with balance or coordination (427, or 65 percent of individuals responded to this question), “other” (273, or 41 percent), speech and language difficulties (226, or 34 percent), endocrine problems (212, or 32 percent), hearing loss (170, or 26 percent), behavioral issues (137, or 21 percent), and seizures (122, or 19 percent). The “other” category was generally selected in addition to listed responses. Frequent mentions include memory issues, headaches and migraine, cognitive impairment, vision impairment, learning issues and academic processing, partial or complete paralysis, fatigue and weakness.

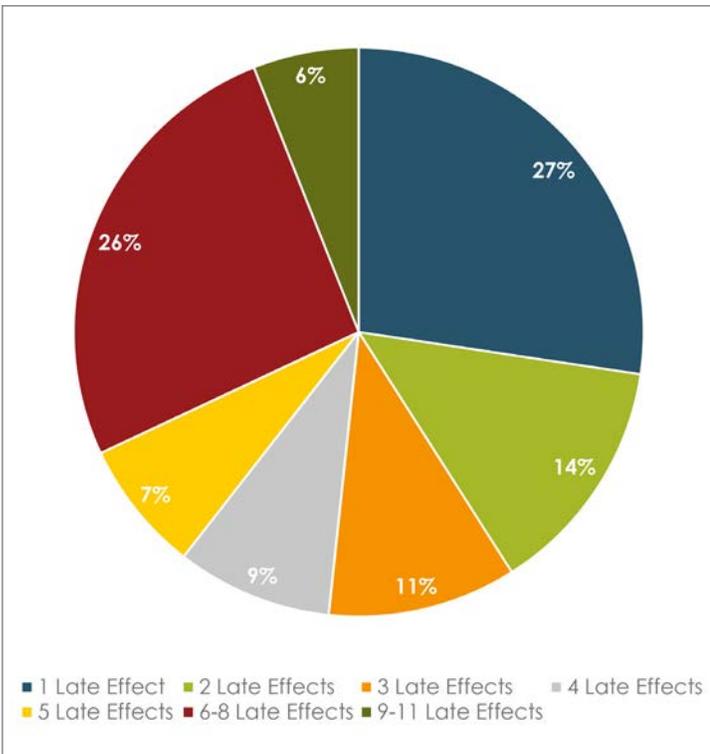
Respondents reported numerous side effects (Figure 12), with a median of three side effects. Eighteen percent of respondents listed one side effect, and 22 percent cited two side effects,

<sup>3</sup>Survey respondents were instructed to mark all that applied, and many selected multiple effects.

**[FIGURE 13] LATE EFFECTS EXPERIENCED MORE THAN ONE YEAR AFTER TREATMENT<sup>4</sup>**



**[FIGURE 14] NUMBER OF LATE EFFECTS REPORTED BY RESPONDENTS**



for a total of 40 percent who reported experiencing one or two side effects. Another 22 percent reported suffering from three side effects and 16 percent reported four side effects, meaning that nearly the same share reported three or four side effects as those who reported one or two. The final 22 percent listed between five and nine or more side effects. All respondents that listed behavioral issues as a major side effect also listed speech and language difficulties. The most frequently occurring combination of side effects was: problems with balance and coordination, endocrine problems, hearing loss, vision loss, shunt problems and speech and language difficulties. Furthermore, most respondents who mentioned seizures also listed most problems from the above combination. Since the vast majority of individuals cope with multiple effects, these data hint at the complex, multifaceted and significant issues that pediatric brain tumor patients and their families cope with on a daily basis.

In terms of late effects (Figures 13 and 14), survey respondents most frequently listed moods, feelings or actions (239), hormone issues (212), sociological/ psychological adjustment

<sup>4</sup>587 people responded to the question about late effects.



(205), and “other” (183).<sup>5</sup> Within the “other” category, frequent responses included eating disorders, low self-esteem, headaches/migraines, and spinal injuries.<sup>6</sup> As Figure 14 shows, 27 percent of respondents reported experiencing one late effect, and 14 percent identified two late effects, for a total of 41 percent of respondents reporting either one or two late effects. In addition, 20 percent of respondents listed three or four late effects, and 39 percent of respondents cited five or more late effects. Therefore, roughly the same share of respondents reported suffering from between one and two late effects as those experiencing five or more. This is a wide distribution, which has revealed some patterns in the co-occurrence of effects that patients experience. In particular, all of the respondents who mentioned problems with thinking, learning and memory also mentioned problems with social and psychological adjustments and problems with moods, feelings and action. Respondents also reported another frequently occurring combination of late effects: heart problems, bone and muscle problems, problems with hormones, and problems with thinking, learning and memory, problems with social and psychological adjustments and problems with moods, feelings and actions.

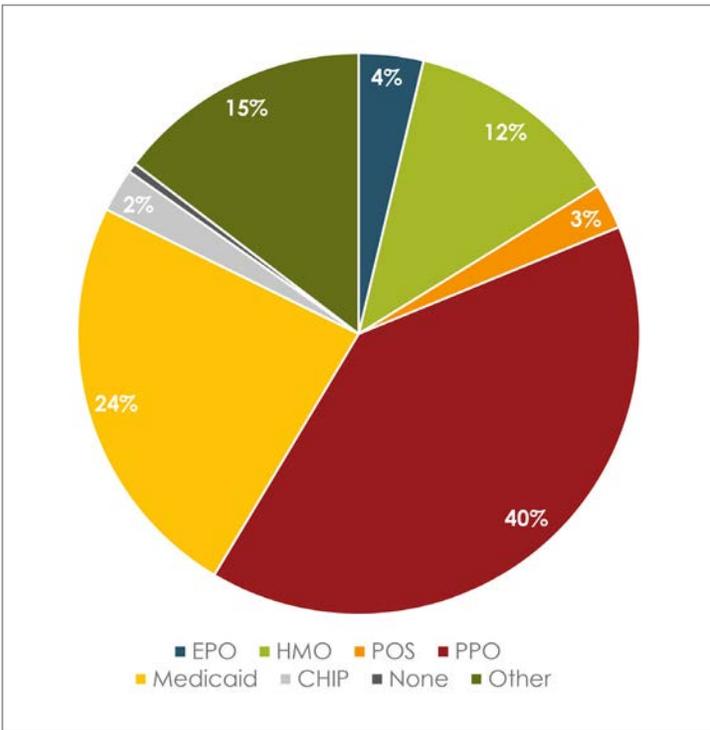
The survey also asked multiple questions about health insurance, including the patient’s type of health insurance (Figure 15), whether this has changed since diagnosis (Figure 16), and if so, what type of health insurance the patient previously held (Figure 17). Respondents cited PPOs as the most common health insurance type for patients (39 percent), followed by EPO (23 percent), “other” (14 percent) and then HMO (12 percent). Two in three patients had not changed health insurance since diagnosis, and only one in three patients had done so (Figure 16). Many of these individuals had likely carried the same insurance type for many years, since almost two thirds of patients that the survey concerned were in the post-treatment or long-term survival stages. For those patients who switched insurances after diagnosis, most had previously had a PPO (36 percent, or roughly the same rate of current PPO patients) or an HMO (20 percent, which is much higher than the rate of current HMO patients).

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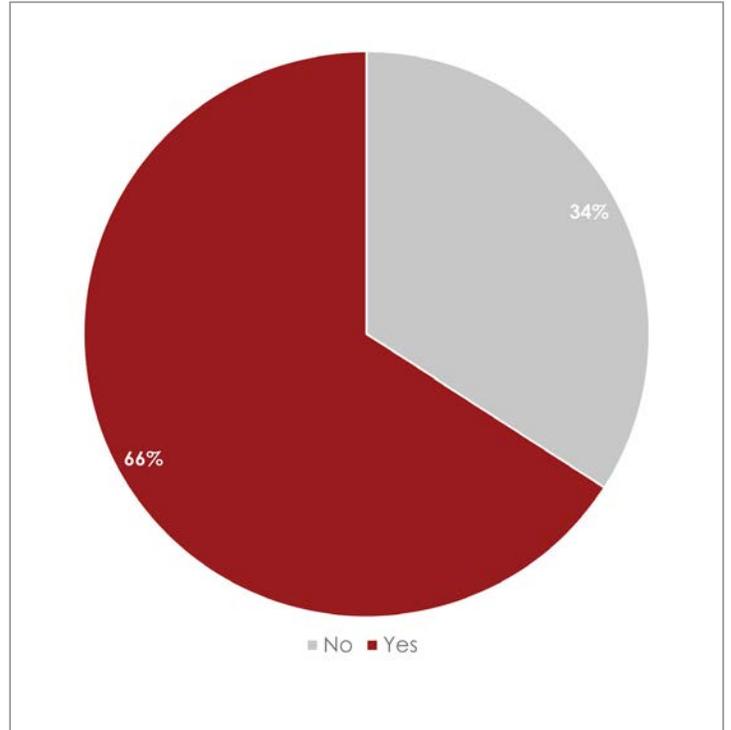
<sup>5</sup> Other, less frequent responses to the “other” category included ADHD or attention issues, depression, anxiety, liver failure, dyslexia, swelling, hair loss and speech issues.

<sup>6</sup> Survey respondents were instructed to mark all that applied, and many selected multiple effects.

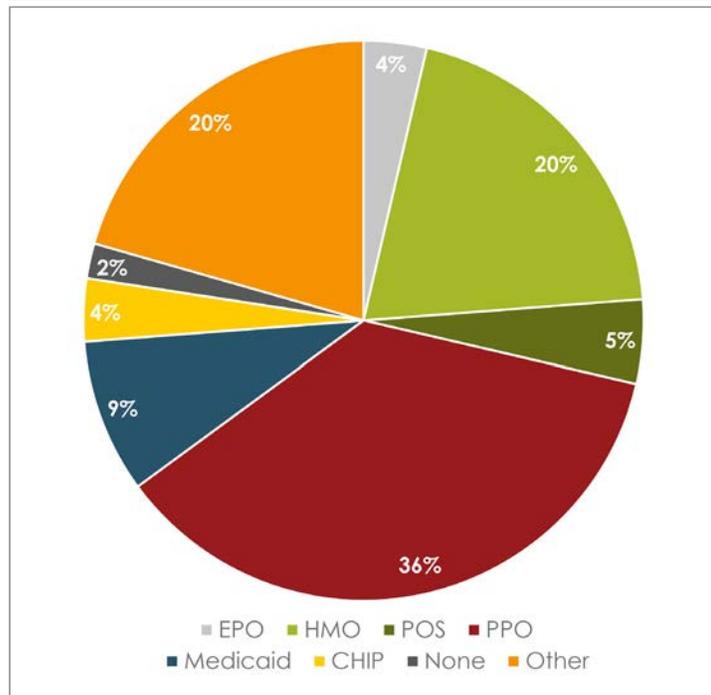
**[FIGURE 15] PATIENT'S CURRENT TYPE OF HEALTH INSURANCE**



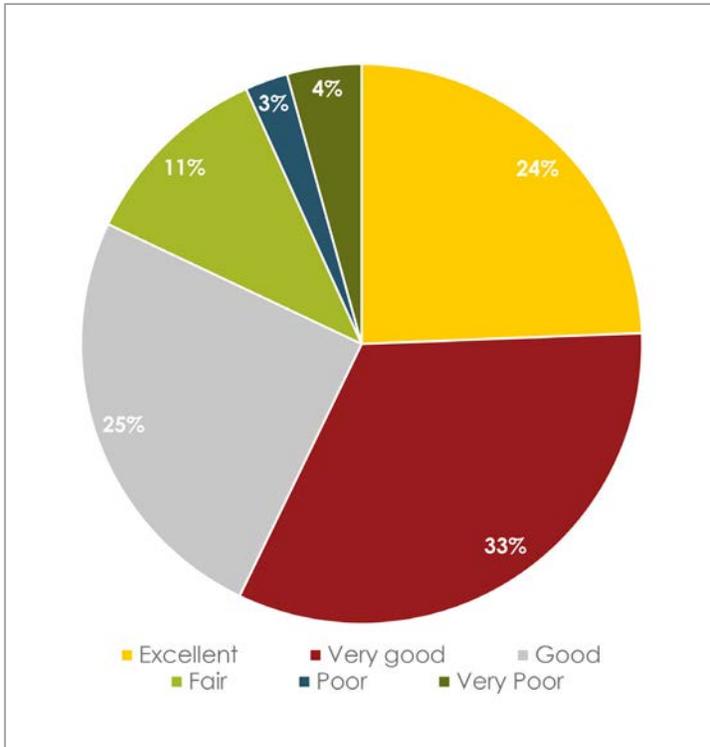
**[FIGURE 16] DID THE PATIENT HAVE THE SAME HEALTH INSURANCE AT DIAGNOSIS?**



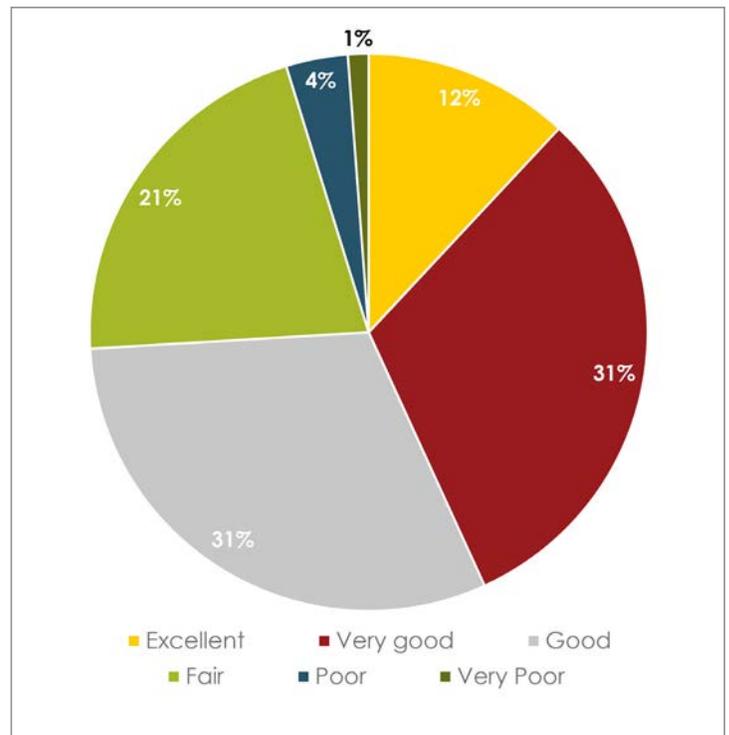
**[FIGURE 17] TYPE OF INSURANCE PREVIOUSLY HELD**



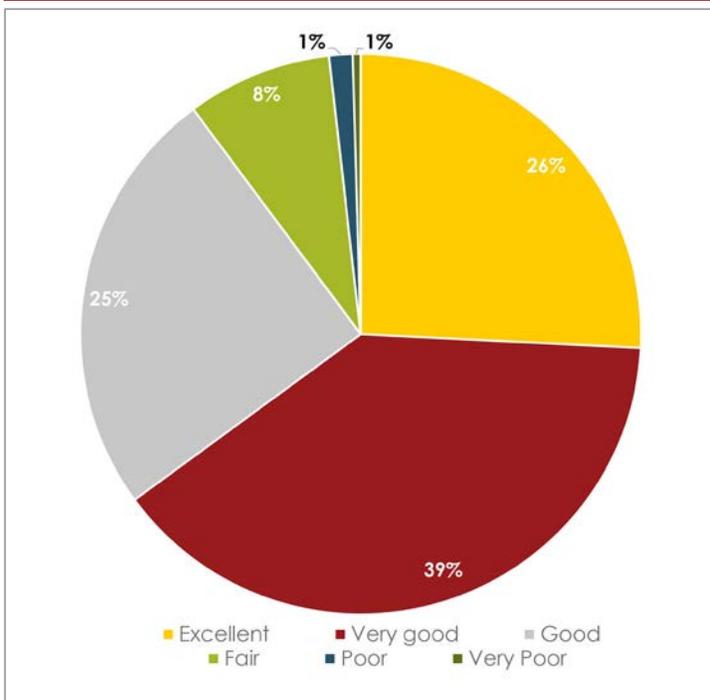
[FIGURE 18] PATIENT'S CURRENT QUALITY OF LIFE



[FIGURE 19] PARENTS' AND CAREGIVERS' CURRENT QUALITY OF LIFE



[FIGURE 20] SIBLINGS' CURRENT QUALITY OF LIFE<sup>7</sup>



Respondents were also asked a series of questions about the patient's current quality of life, the parents' and caregivers' current quality of life, and the sibling(s)' quality of life (Figures 18, 19 and 20). Parents and caregivers reported higher quality of life for the patients than themselves. Over half of patients were reported to have an "excellent" or "very good" quality of life. An additional 36 percent were reported to have a "good" or "fair" quality of life. Only 7 percent were reported to have a "poor" or "very poor" quality of life.

In contrast, parental or caregiver respondents reported that their own quality of life was much worse. Only 43 percent reported an "excellent" or "very good" quality of life. Over half (52 percent) reported a "good" or "fair" quality of life. Only 5 percent reported a "poor" or "very poor" quality of life. Respondents reported similar qualities of life for patients and parents/ caregivers on the low end of the quality of life spectrum. However, the median responses for patients rested at the high end of the quality of life spectrum, while it fell in the

<sup>7</sup>Since so few survey respondents were siblings, this question largely reflects parents reporting on the perceived quality of life of the patient's sibling(s).

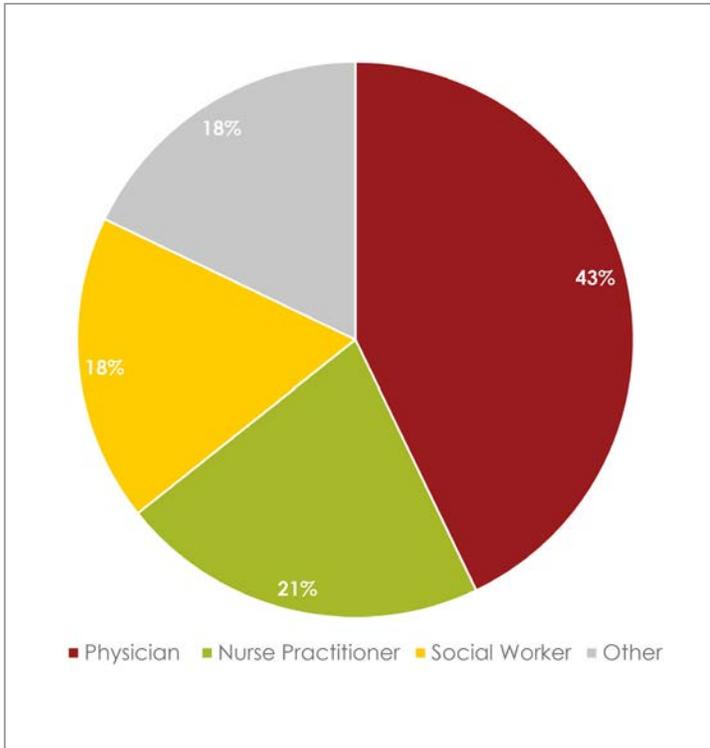
middle for parents/ caregivers. Responses to the quality of life question were highest for siblings, with nearly two in three respondents citing an “excellent” or “very good” quality of life.” However, as the section on familial issues illustrates, parents frequently listed issues with siblings as a challenge, which suggests that siblings struggle with issues related to a family pediatric brain tumor diagnosis in consequential ways, even though siblings do enjoy a high quality of life overall. In summary, this question illustrates the pervasive emotional toll of a pediatric brain tumor beyond the patient and across the entire family, with a particular burden resting on parents and caregivers.

The next section presents similar descriptive data from the survey of medical professionals. The subsequent section summarizes the findings from the survey and interview data, organized by the key challenges that patients and family members face.



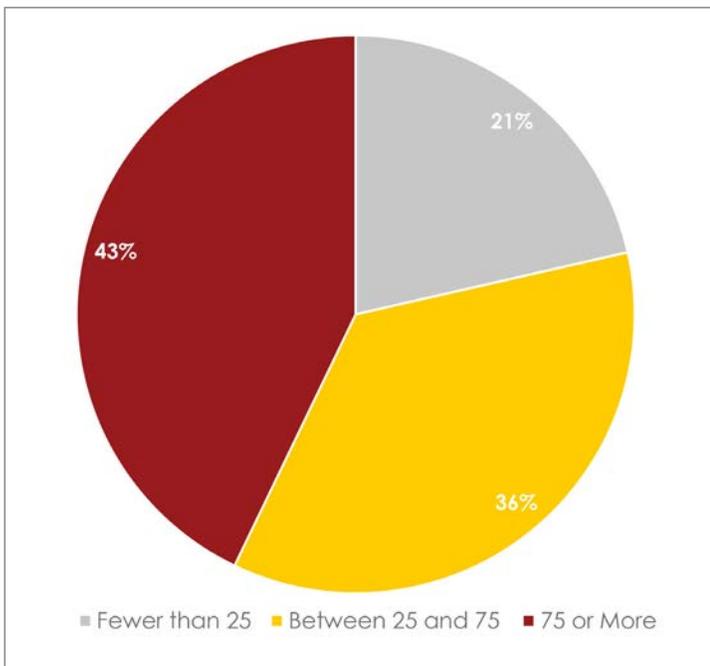
# RESPONDENTS OF PROFESSIONALS SURVEY

[FIGURE 21] SURVEY RESPONDENTS BY JOB TYPE

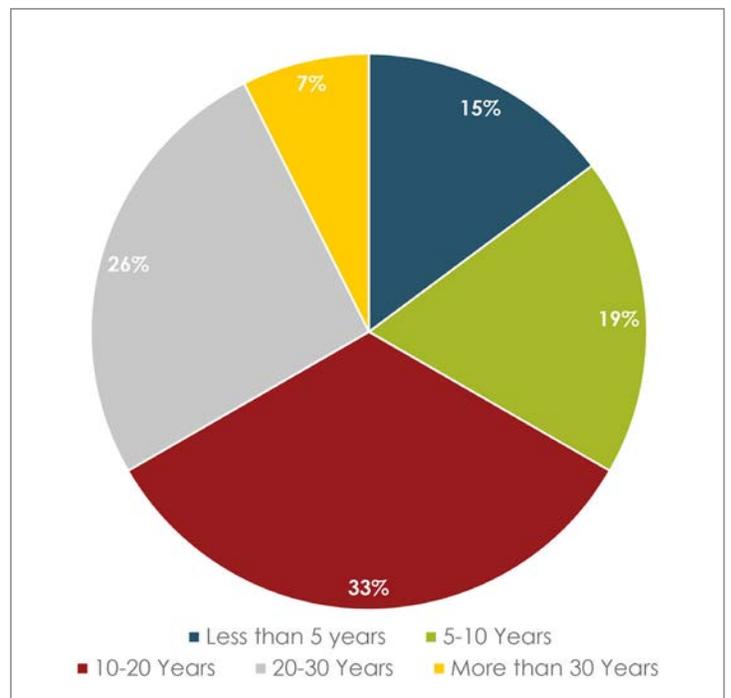


As Figure 21 shows, the professionals survey mostly draws from physicians (43 percent). The next largest respondent group is nurse practitioners (21 percent), followed by social workers and “other,” both at 18 percent. The “other” category includes researchers, special educators, consultants, and special program coordinators. Most of the medical professionals (43 percent) receive 75 or more patients annually, 36 percent of them receive between 25 to 75 patients and 21 percent of them receive less than 25 patients (Figure 22). This 21 percent figure is well distributed across all medical professional groups including physicians, nurse practitioners and social workers. Only 15 percent of the professionals have been working in this field for less than 5 years. Around 19 percent have been in the field for around 10 years, 33 percent have been in the same field for 10 to 20 years, 26 percent have been working in the same field from 20 to 30 years and over 7 percent have been engaged for over 40 years (Figure 23). Therefore, professionals survey respondents represent a diverse cross-section of different practitioners working in the medical field related to pediatric brain tumors.

[FIGURE 22] NUMBER OF NEWLY-DIAGNOSED PEDIATRIC BRAIN TUMOR PATIENTS ANNUALLY TREATED BY RESPONDENT’S INSTITUTION



[FIGURE 23] NUMBER OF YEARS WORKING IN THE MEDICAL FIELD





## KEY CHALLENGES

Across all stages, the key challenges identified by families and practitioners fall into four different categories: (1) interpersonal and emotional support, (2) logistical and financial support, (3) information and medical education gathering, and (4) educational and vocational anxieties.<sup>8</sup> The interpersonal and emotional challenges, referenced frequently by practitioners and families alike, span resource gaps for patient, parent/caregiver, and sibling populations, identifying distinct mental health and counseling resource gaps for each group. The second two categories, of logistical and financial support and information and medical education gathering, primarily focus on parents and caregivers as the target population. These categories, which address logistical challenges, financial challenges, and barriers to information gathering, primarily affect parents and caregivers, many of which arise because medical decisions are made in collaboration with a care team often professionally fragmented in disciplinary silos. Finally, educational and vocational resource gaps primarily concern patients, who experience barriers to reintegrating into academic and professional environments without a needs advocate who understands the legal landscape in greater detail than most parents.

A majority of professionals mentioned late effects, long-term effects, cognitive effects and social issues as the greatest challenge. Interestingly, all physicians and nurse professionals mentioned effects related to treatments like cognitive impairment and side effects of chemotherapy, while the social workers emphasized social isolation and stress as the biggest challenge. These differences could result from their professional backgrounds, which shape their interpretations of patient and family need. The nurses and the physicians repeatedly mentioned difficulty with learning and working, living independently, and adapting to the effects of treatments as pressing issues, while social workers identified reintegration into social setups and losing the normalcy of life as key patient challenges. The responses of social workers resembled the responses from the family survey. Both groups emphasized interpersonal and emotional support-related challenges, while the majority of practitioners stressed challenges related to treatment, information medical costs and medical insurance.

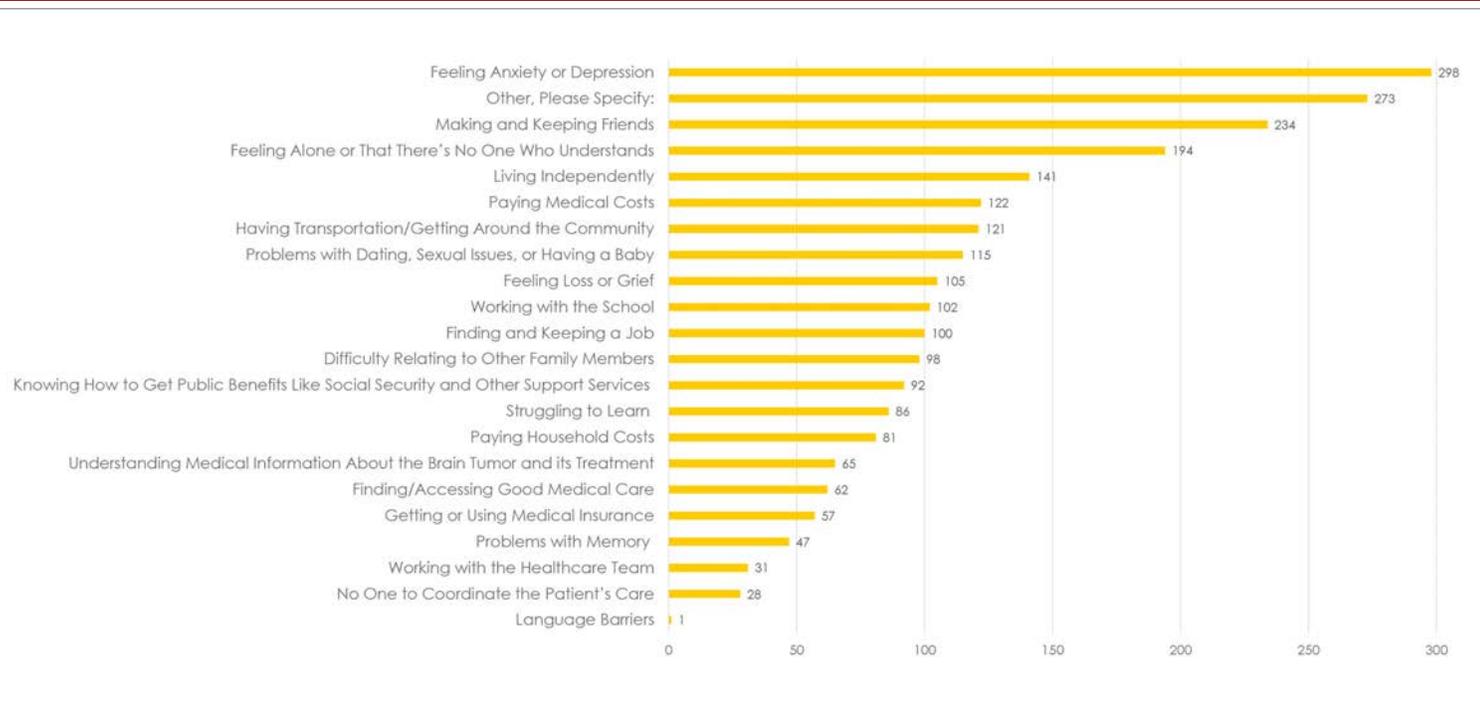
### **INTERPERSONAL AND EMOTIONAL SUPPORT: PATIENTS**

Results from the family survey and the interviews and surveys with professionals roughly correspond to reveal that interpersonal and emotional support issues present some of the deepest and most pervasive challenges for patients and families. Interpersonal and emotional support spans topics of

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<sup>8</sup> Interviewees were not explicitly asked about the stage that presents the biggest challenge, but were asked directly about challenges at diagnosis. Therefore, there was a strong emphasis on the diagnosis stage, and less information emerged about other stages.

[FIGURE 25] TYPES OF CHALLENGES PATIENTS FACE<sup>9</sup>



**One survivor said, “I’ve never actually had a close friend before.”**

current emotional distress, familial needs, and the necessity for connection and normalcy. Figure 25 displays responses to the question of what challenges patients face as a result of his or her brain tumor diagnosis. Family survey respondents cited patient anxiety and depression in nearly one in three cases, with isolation lagging not far behind. Specifically, one in four respondents reported that the patient had trouble making and keeping friends, and one in five reported that the patient feels alone or that there is “no one who understands” their situation. About 13 percent cited issues with dating, and 10 percent further reported feeling loss or grief, and a similar rate had difficulty relating to other family members.

Forty-six percent of respondents (273 out of 591) cited “other” challenges apart from the ones mentioned above (Figure 25). One-third of these “other” responses referenced emotional challenges like social isolation, emotional issues arising from insufficient community support, constant fear and worry about the future, feeling of distrust, low self-esteem, consciousness of body image and being bullied. Lack of confidence due to physical appearance (including weight issues, physical development and facial features) was predominantly reported for female patients. 2 respondents reported feeling suicidal. Another one-third of “other” responses related to additional medical challenges including anxiety, depression, ADL, ADHD, constant constipation and eating disorders, fine motor issues, fatigue, dysphagia, and aphasia, vision deficit, hearing loss and chronic pain. Remaining responses mentioned a variety of challenges such as decreased learning ability, loss of mobility, lack of employment opportunities, financial challenges and long-term care.

<sup>9</sup>Survey respondents were instructed to mark all that applied, and many listed multiple challenges.

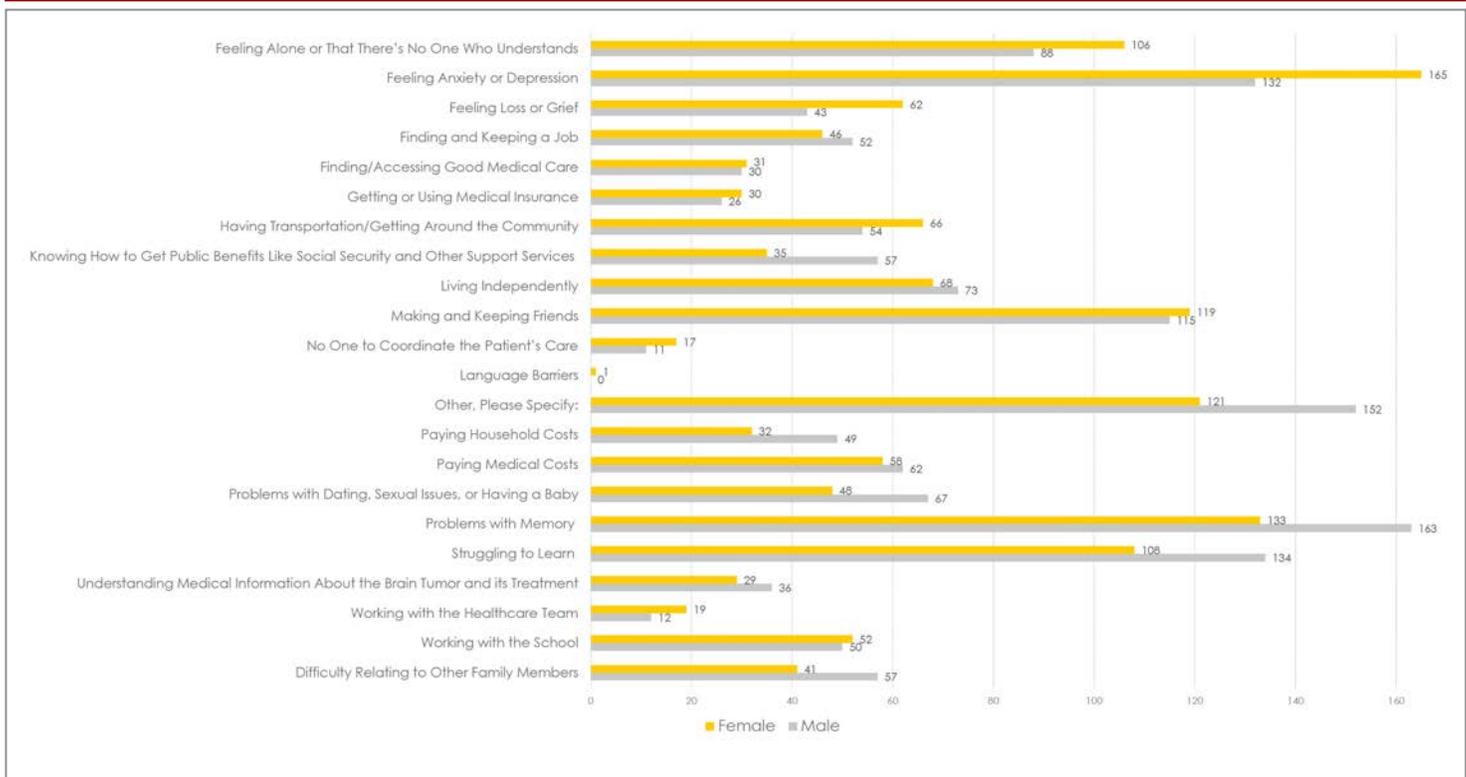
Individuals described the deep impacts of isolation and emotional issues on patients and family members alike. A caregiver described one patient’s struggle, stating that,

*“Due to the location of the tumor, she has extreme mood swings and violent outbursts lasting over an hour without a trigger or cause, which don’t subside with behavioral modifications or interventions. These are so severe that we had to sign a contract at the oncologist’s office stating if she injured a staff member she would no longer be able to receive care there. Her behavioral issues are so extreme they prevent her from any social, educational, or future occupational healthy interactions.”*

A different parent described how her daughter’s emotional challenges “impact the quality of her relationships. She looks like any other child, so no one would know what she has experienced. This experience changed her personality from a child who was light hearted, funny, and easily laughed, to serious and very guarded with others.” As one parent described, his son “gets very lonely and feels isolated”—a situation that many patients and affected family members face. Another parent echoed a similar sentiment for patients: “There is no one his age that can relate to what he’s been through.” One patient summarized it simply by stating, “I cannot relate to anyone, as I see the world in a completely different way.” For patients and family members alike, their unique experiences produce considerable isolation, making it difficult for them to relate to others.

Patient challenges varied across gender. Females patients reportedly face greater rates of emotional and interpersonal challenges, including making friends, feeling anxiety or depression, feeling alone, or feeling grief, while males reported a higher number of educational and vocational anxieties, including struggling

**[FIGURE 24] TYPES OF CHALLENGES PATIENTS FACE BY GENDER**



to learn and problems with memory (see Figure 24). Furthermore, female patients reportedly face

**As one patient said, “I’m not the normal 19-year-old. I have never had a boyfriend and don’t care about all the things kids at school talk about!”**

issues related to appearance and low confidence, a theme that did not arise concerning male patients. One parent described her daughter’s struggle, saying that, “People point or mistake her as a boy even when she’s in all pink. People have pointed at her so much that she hides in public.” Another said her daughter coped with, “just generally being different, not looking like the other girls her age, and not developing physically like her friends. In a society where looks are revered, this is a struggle.” However, some of the differences across gender could reflect societal gender norming behaviors. By one parent’s account, her son denied admitting he had unsettled emotions as a young adult due to his disability. Rather, he believed “he was a teenage boy that was supposed to be STRONG and able, and someone who does not need a crutch.”



Significant differences exist across the challenges that patients face based on the patient’s age at diagnosis (see Appendix 2). Patients diagnosed under age 1 are relatively younger (68% of them are born in/after 2000). Most of these patients mentioned educational anxieties, and few cited problems with mental and physical development. Patients diagnosed between ages 1 and 2 faced similar challenges, but also included more instances of social isolation, including “feeling alone or that there’s no one that understands.” Differences existed between those patients diagnosed under age 2 and those diagnosed at age three or above. Patients diagnosed between ages 3 and 5, and patients diagnosed between aged 5 and 9, reported challenges in all categories, with emotional and isolation challenges listed most frequently. Uniquely, patients diagnosed between ages 10 and 13, also cited “problems with dating, sexual issues and having a baby,” which was not listed among the other diagnosis age groups. Moreover, among patients diagnosed at an older age, a greater proportion of patients reported “problems with memory” as their greatest challenge. In general, patients diagnosed above age 5 were the only ones that reported concern about “losing normalcy,” physical appearance and low confidence. Patients diagnosed between ages 14 and 17 predominantly mentioned educational and vocational anxieties and social isolation as their greatest challenges, while patients diagnosed between 18 and 19 emphasized financial and logistic issues like “not being able to move around in the community” and “living independently.” It is important to note that patients in all categories mentioned all types of challenges and the differences mentioned above do not indicate that they do not face other challenges.



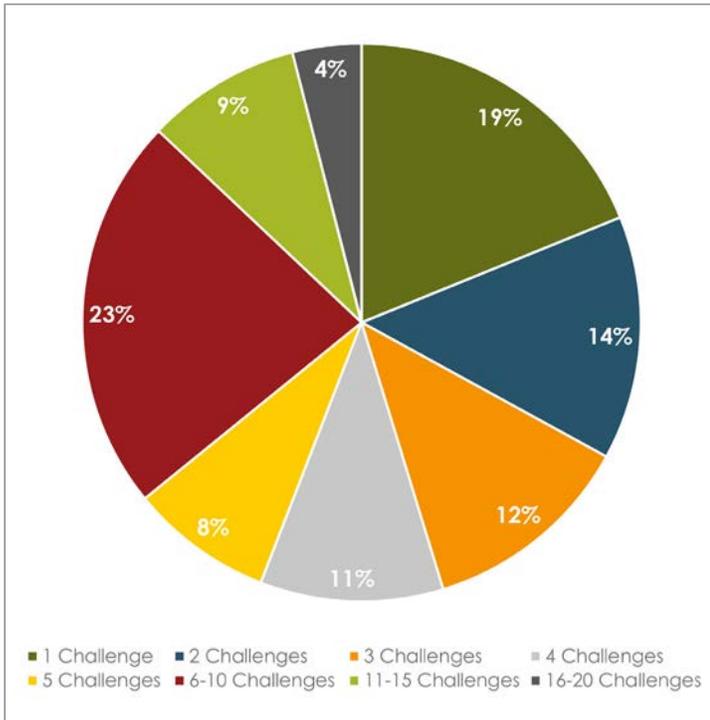
The type of challenges faced by patients varied by the stage of treatment, except for anxiety and depression, which presented a constant challenge throughout all treatment stages. Patients or parents and caregivers of patients in the “in treatment” stage disproportionately cited financial difficulties, challenges navigating medical procedures, behavioral issues and functionality issues. 30% of these respondents mentioned functionality issues, 16% reported behavioral and 11% reported financial challenges as their greatest challenge. Patients or parents and caregivers of patients in the “post-treatment” stage predominantly reported issues with “memory, learning and thinking,” “fear of reoccurrence,” and physical health challenges like hearing loss, vision loss, issues with mobility and walking. A large proportion also mentioned anxiety or depression. Social isolation was not frequently mentioned among the “in treatment” and “post treatment” groups, which suggests that social isolation issues for patients arise after these stages, or that other, more pressing issues trump social isolation during the treatment phase.

However, even parents with surviving children expressed coping with loss as they adjust to a new normal.

**“Seeing a child one day playing on the monkey bars then confined to a wheelchair was the hardest.”**

Patients or parents and caregivers of patients in the “long-term survival” stage reported issues with living independently, finding and keeping a job, social isolation, anxiety or depression and financial difficulties as their greatest challenge. Around 45% of respondents in this stage reported social issues, 27% of respondents reported anxiety or depression, 11% reported living independently and 7% reported financial difficulties as the greatest challenge. Patients experiencing a relapse reported a mix of all challenges. Their parents, however, listed “worrying about the future” as their greatest challenge. For respondents related to an “end of life” patient, the patient’s greatest challenge was “giving up on life” and anxiety or depression. Parents or caregivers of deceased patients overwhelming reported emotional distress (including feeling of loss, grief, feeling alone, feeling guilty) and anxiety or depression as their greatest challenges. Over half (51%) of these parents reported coping with loss and grief, 26% reported anxiety or depression and 17% reported dealing with constant guilt as their greatest challenge. As one parent described, “seeing an empty seat at the dinner table” provided a constant reminder of their loss. Others mentioned struggling to get through every day, a crisis of faith, struggling to stay hopeful, having issues with their spouses or partners, and difficulty relating to others. Another parent described the pervasive, enduring nature of their loss: “Our daughter has been deceased for a while now... We are now doing so much better, but it’s taken every bit of 9 years to get to where we are now, and that only began when we got involved with our church 4 years ago.”

**[FIGURE 26] NUMBER OF CHALLENGES PATIENTS FACE**



The challenges patients faced varied by the type of treatment they received. To analyze this, patients were divided into two types: those who received at least one treatment that involved radiation (such as focal radiation and whole brain radiation), and those who received no treatments that involved radiation. Since many patients received a combination of treatment (see Figure 10), most patients had received at least one form of radiation. 449 respondents reported on patients who received at least one form of radiation, and 335 respondents reported on patients who did not receive any radiation. Across patients who received radiation and those who did not, the most commonly cited problems were issues with anxiety or depression, memory problems, and problems with learning. However, patients who received radiation reportedly suffered from more late effects and a broader range of late effects than those who did not. For those patients who did not receive radiation, they reportedly experience a narrower range of effects, largely focused around emotional issues.

As Figure 26 shows, patients experience an overwhelming number of challenges related to pediatric brain tumors.

Nineteen percent of respondents reported that patients face

one challenge, 14 percent mentioned two challenges, and 31 percent reported three to five challenges. An additional 36 percent cited more than five challenges, out of which 9 percent experienced more than 10 challenges and 4 percent faced more than 15 challenges. All respondents who reported that the patient struggles to make and keep friends also listed “difficulty relating to other family members,” “anxiety or depression,” a “feeling of loss or grief,” “struggling to learn” and “problems with dating, sexual issues or having a baby.”

Patterns emerged in the co-occurrence of certain issues, particularly those issues that related to isolation. All respondents who listed difficulty “living independently” also mentioned problems with “having transportation/getting around the community,” “struggling to learn,” “understanding medical information”, “feeling alone or that there is no one who understands,” and “problems with dating, sexual issues or having a baby.” Respondents who reported challenges with “finding and/or accessing good medical care” also mentioned “problems working with the health team,” “paying medical costs,” “paying household costs,” “getting or using medical insurance,” “knowing how to get public benefits like Social Security and other support services,” and “having transportation/getting around the community.” Respondents also listed another combination frequently: “finding and keeping a job,” “paying medical and household costs,” “struggling to learn,” “having transportation and/or getting around the community,” “feeling alone or that there is no one who understands,” “working with the school” and “living independently.”

When asked in interviews about social challenges for patients, practitioners cited establishing and maintaining connections, navigating social isolation, and creating a sense of normalcy as the biggest challenges. As children and adolescents, patients need regular socialization, but spend much of their time in

**A parent from the family survey echoed similar concerns with insufficient programming and local support, stating that, “I did not find a local support group for kids with brain tumors and he didn’t seem to fit in with the kids with leukemia and lymphoma. [It was] hard to find mental health professionals who specialize in this type of care, versus ADD, ADHD, drug dependency, etc. [It was] hard to find someone to talk about chronic illness and how to get through life, especially during teen years.”**

isolated medical settings rather than socializing in school. For this reason, adolescent and younger adult patients often struggle with building relationships, dating, and finding others in which they can confide. Practitioners decisively agreed that one of the best resources available to patients are age-appropriate social support groups where they have the opportunity to connect with other patients who can relate to their experience. The patient support groups referenced were predominately provided in-person, but online access was also cited as a potential way to maintain those relationships over time and across geography. According to practitioners, the key ingredient of an effective support group is whether it is tailored to participants, as challenges differ across ages and developmental levels.



Practitioners specifically cited a need for more teen and young adult specific groups. As the teenage years tend to be an especially vulnerable time, teenage patients may need even more psychosocial support and socialization, such as support groups and individual psychotherapy. For the teen and young adult population, making and keeping friends was cited as a common challenge, and in particular, anxiety surrounding disclosure of their diagnosis was mentioned as a wedge preventing patients from feeling truly connected in their relationships. According to one practitioner, “disclosure is a big deal for adolescents—especially to a potential mate.”

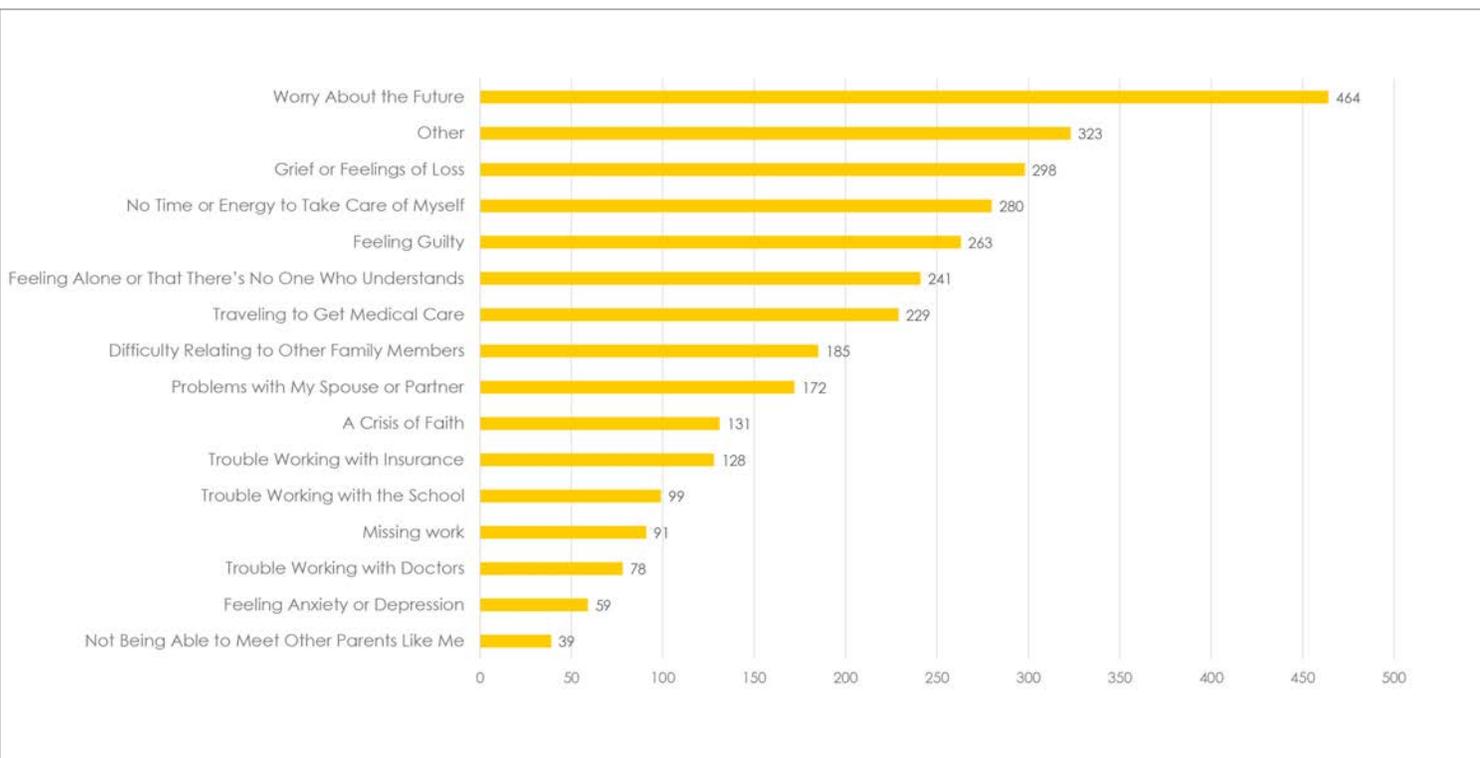
Practitioners struggle to create a sense of normalcy as patients cope with pediatric brain tumor diagnoses and treatments. Physicians expressed that patients often struggle with the side effects of treatment, indicating that social support may be even more important during this time. One Southern California-based oncologist explained how it is difficult for patients to deal with

**As one practitioner explained, “I’m careful, I don’t use jokes all the time, but I like to throw it in there. I feel like it lightens it. I feel like it brings people back to reality and to normalcy.”**

personality changes and “not being the person they once were.” To help patients cope, practitioners suggested more lighthearted and fun activities for patients to help them feel normal.<sup>10</sup> In particular, some social workers suggested using humor to at least temporarily lift some of the stress and weight of their treatment so that conversations are not always clinical. Practitioners intentionally used activities to lighten the mood and create a sense of independence to help support the emotional state of patients and families alike.

Several social workers identified a labor gap in social work, child life services, psychiatry, and psychological services available at the hospitals where they work, and argued that addressing this labor gap could help bridge support. Furthermore, practitioners agreed that increasing access and regularity of camps and events could help develop connectedness, by linking patients and families with shared experiences and relatability, which minimizes their fear of disclosure to those who may not understand their circumstances. In the absence of connection to other patients, practitioners worry about social isolation among their patients, especially those less likely to participate in support groups. As one practitioner described, “They have nowhere to make friends. They’re considered quite different, and just are kind of socially isolated.” Practitioners attributed isolation to the difficulty of keeping up with peers, both physically and cognitively, as well as missing key social milestones like prom or graduation, and dealing with bullies.

**[FIGURE 27] TYPES OF CHALLENGES PARENTS & CAREGIVERS FACE<sup>11</sup>**



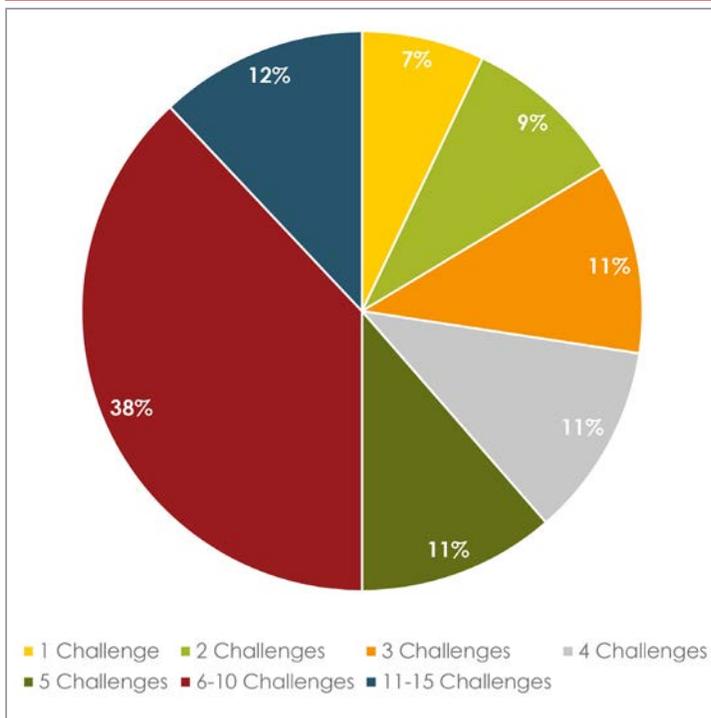
<sup>10</sup> Practitioners recommend introducing fun activities on a more regular basis, but did not identify specific situations in which levity is best.

<sup>11</sup> Survey respondents were instructed to mark all that applied, and many listed multiple challenges.

## **INTERPERSONAL AND EMOTIONAL SUPPORT: PARENTS/CAREGIVERS AND SIBLINGS**

Beyond patients, interpersonal and emotional issues represented the dominant category of challenges for families, as well. Figure 27 displays responses to the question of what challenges the respondent (mostly parents or caregivers) faces as a result of the patient’s brain tumor and treatment. 579 people responded to this question. The most frequent responses concerned emotional or interpersonal support issues, including “worrying about the future” (464, or 80 percent of people who responded to this question), “other” (323, or 55 percent), “grief or feelings of loss” (298, or 51 percent), “no time or energy to take care of myself” (280), “feeling guilty” (263, 45 percent), and “feeling alone or that there’s no one who understands” (241, 41 percent). The “other” category included mentions of financial burdens, work-related issues, physical and mental exhaustion, mental stress, issues comprehending medical information, PTSD, having less time with their children and suicidal feelings. Furthermore, 172 respondents (30 percent) cited “problems with my spouse or partner” as a key issue subsequent to diagnosis, 185 (32 percent) had difficulty relating to other family members, and 131 (23 percent) had a crisis of faith. These similar responses across the surveys and interviews underscore the isolation and emotional challenges that patients and families face, which represents a major change after diagnosis, and a key issue as they navigate their lives after a brain tumor diagnosis.

**[FIGURE 28] NUMBER OF CHALLENGES THAT PARENTS AND CAREGIVERS FACE**



In the family survey, respondents (again, overwhelmingly parents and caregivers) were asked to list the single greatest issue they face as a result of the patient’s brain tumor. 494 people responded to this question. Social and mental stress, mental health and financial challenges arose as the most common themes. Respondents listed worrying about the future 154 times as the greatest challenge, followed by anxiety and depression mentioned 75 times (15 percent of people who responded to that question). Many parents mentioned that they did not look to treat their anxiety and depression due to lack of time, money and resources. Many also stated they felt guilty thinking about their problems, as the patient’s suffering far exceeded their own. Respondents listed feelings of loss, grief and trauma as their single greatest issue 57 times (12 percent), followed by guilt (27 percent) and lack of time and energy to care for themselves (14 percent). Financial challenges (45 percent) and marital and relationship stress (35 percent)

also represented prominent themes throughout the section. Elaborating on their financial challenges, parents cited insurance and medical costs as the drivers of their financial stress. Some also reported that high transportation costs exacerbated their financial burden. Finally, parents mentioned work-related issues as key stressors (20 percent), but it was always mentioned as a secondary issue to the emotional challenges related to pediatric brain tumor diagnoses.

**“Those constant reminders for parents about how to take care of themselves are really important”**

In interviews, practitioners similarly emphasized that parents face enormous emotional and interpersonal challenges, including navigating marital stress, supporting other children, setting aside time for self-care, and managing their relationship with the hospital. Practitioners attributed

many sources of marital stress<sup>12</sup> to poor coping and communication skills that put strain on marital relationships, particularly where there is financial hardship and multiple children for whom to care. Practitioners also suggested that parents need additional support with both childcare for additional siblings and parenting and communication strategies to deal with the secondary trauma that siblings experience. Practitioners stressed that parents and caregivers need to practice self-care, but parents and caregivers frequently neglect to sufficiently take care of themselves because they are overwhelmed caring for the patient, maintaining their marital relationship, and trying to support siblings. Practitioners argued that parents need to take even the simplest of steps to support themselves, including getting additional sleep, taking a coffee break, or exercising. However, practitioners noted that parents saw these activities as “leisure” rather than necessity, and therefore eliminated them first during times of high stress.

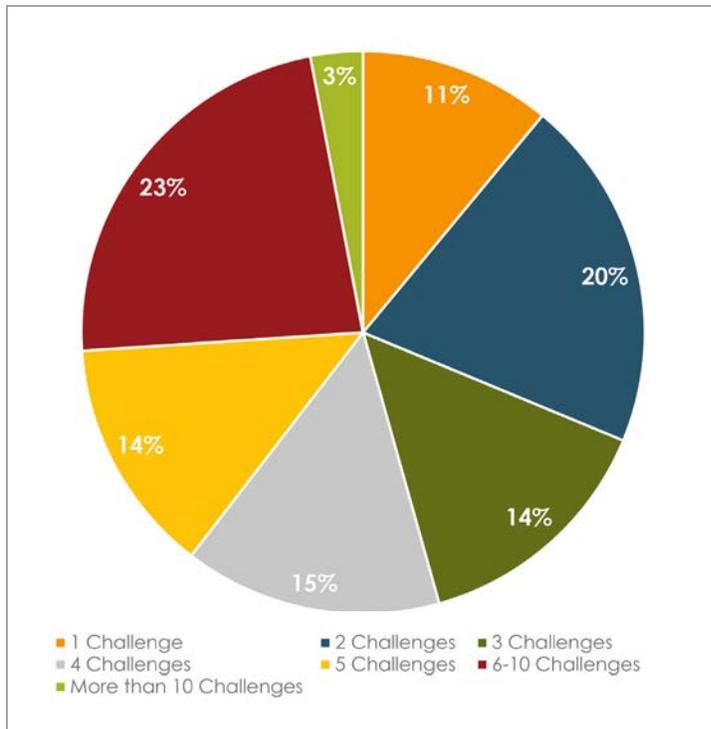


Similar to the patients, most parents and caregivers experience an overwhelming amount of challenges. Sixteen percent of respondents reported facing one or two challenges, and approximately one in three respondents reported experiencing three to five challenges. Half of respondents experienced more than five challenges, with 12 percent listing more than 10 challenges. All respondents who reported experiencing a “crisis of faith” also noted “feeling grief or loss,” “difficulty relating to other family members,” “feeling guilty,” “worry about the future,” “not being able to meet other parents like me,” “feeling anxiety or depression,” and “trouble with doctors and trouble working with schools.” Each respondent who reported “feeling anxiety or depression” also mentioned “feeling alone or that there is no one who understands,” “worrying about the future,” “not being able to meet other parents like me,” and “trouble working with insurance, schools and doctors.” Another reoccurring combination was “missing work,” “travelling to get Medicare,” “feeling anxiety or depression,” “no time and energy for myself,” and “feeling alone or that there’s no one who understands.”

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<sup>12</sup> Domestic violence was identified as a key concern during the high stress diagnosis and treatment period by two social work practitioners, but anecdotal evidence was not provided.

**[FIGURE 29] NUMBER OF CHALLENGES SIBLINGS FACE**



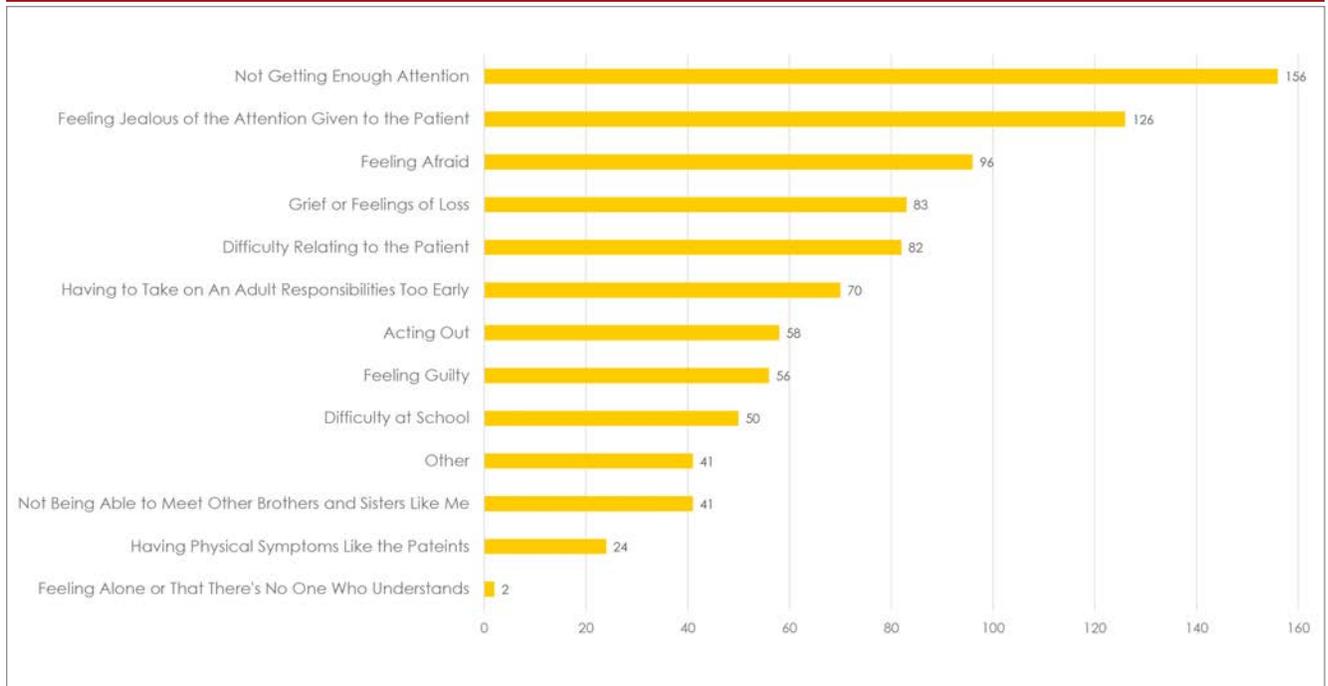
Over two-thirds of respondents reported that siblings face three or more challenges (Figure 29). Eleven percent of respondents reported that siblings face one challenge. Further, 20 percent of respondents reported that siblings face two challenges, 43 percent reported that siblings face three to five challenges and 26 percent reported that siblings experience more than five challenges. Out of those 26 percent, 3 percent reported that siblings face more than ten challenges. The most reoccurring combination was “feeling jealous of the attention given to the patient,” “not getting enough attention,” “difficulty relating to the patient,” “acting out,” “feeling guilty,” “not being able to meet other brothers and sisters like me,” and “feeling alone or that there’s no one who understands.” Another reoccurring combination was “grief or feelings of loss,” “feeling afraid,” “having to take on adult responsibilities too early,” “feeling alone or that there’s no one who understands,” and

“not being able to meet other brothers and sisters like me.” These findings suggest that siblings would greatly benefit from additional opportunities to be surrounded by siblings in similar circumstances.

Figure 30 displays responses to the question of what challenges the patient’s sibling(s) face(s) as a result of the patient’s brain tumor and treatment. 436 people responded to this question. Emotional and interpersonal issues dominated these responses. In particular, respondents reported that siblings felt “insufficient attention” from parents or caregivers (156 mentions, or 36 percent of people who responded to this question), “feeling jealous of attention given to the patient” (126, 29 percent), “feeling afraid” (96, or 22 percent), “feeling grief or loss” (83, or 19 percent), “difficulty relating to the patient” (82, or 19 percent), “having to take on adult responsibilities too early” (70, or 16 percent), “acting out” (58), “feeling guilty” (56, 13 percent), and “difficulty in school” (50, or 11 percent).

Family survey respondents were asked to list the single greatest challenge that siblings faced. Out of all the challenges, respondents cited lack of attention as the greatest challenge (50 mentions). Respondents also frequently reported the fear of losing the patient and worry (45), feeling of loss and grief (32) and difficulty relating to the patients (25). Respondents cited feelings of jealousy (23), taking on adult responsibilities (20) and acting out (19) at relatively similar rates. Many respondents mentioned lack of identity and feelings of abandonment as a pressing issue, as well as anger and resentment in siblings. A few respondents also mentioned that siblings have grown distant from the patient and feel embarrassed in social situations around them. Most respondents discussed that the presence of jealousy, anger, resentment and embarrassment resulted in siblings feeling guilty about their feelings, out of love and admiration for the patient.

[FIGURE 30] CHALLENGES FACED BY PATIENT'S SIBLING(S)<sup>13</sup>



Practitioners cited sibling support as a key gap in services, and a significant issue. As the family survey illustrates, siblings often feel neglected by their parents, have few opportunities to be around siblings coping with similar issues, and/or fear that their diagnosed sibling will pass away. Practitioners argued that siblings need additional support in the form of age-appropriate support groups, as siblings often struggle to understand the lack of attention they receive and face new challenges in school. Often siblings are unable to continue engaging in extracurricular activities they once enjoyed due to coordination or financial constraints, and need new outlets to help them cope and achieve a sense of normalcy.

The findings for issues that siblings face corresponds across surveys and interviews. All respondents mentioned the greatest challenge for siblings was insufficient attention and dealing with the changing dynamics in the family. Half of respondents to the professionals survey mentioned that siblings often struggle to relate to the patient. One in four professionals mentioned that the greatest challenge for siblings related to fear and worry—of either losing the patient and their own safety. Another one in four professionals cited the greatest challenge for siblings as not being able to meet other siblings like them.

In interviews, practitioners cited insufficient adequate mental health resources as the primary deficit for patients and families, and found it most challenging for patients and families to manage emotions at diagnosis, and again during relapse or when late effects from treatment set in. Practitioners saw counseling and therapy as an area where more resources should be provided to help patients and family members develop coping skills and self-care techniques, to manage especially difficult moments such as relapse and bereavement. Practitioners expressed particular concern at the gap in mental health services offered through insurance once the treatments have concluded but when families continue to endure

<sup>13</sup> Survey respondents were instructed to mark all that applied, and many respondents selected multiple challenges.



significant emotional distress. Furthermore, practitioners noted that many patients and families were reluctant to participate despite their need for such services.

At the point of diagnosis, practitioners expressed that patients and families experience fear as their dominant emotion and that it is the most challenging to manage; parents often ask, “what’s going to happen to my child when something happens to me?” Their fears primarily relate to an unknown future where relapse, dependency, trust in others, and death emerged as dominant undertones. Beyond fear, practitioners found that patients and families alike experience anxiety, depression, and guilt, particularly early in the diagnosis and treatment stage. One oncologist described how patients often ask, “is it something we didn’t do, or did do” as they try to understand how this has happened to their child, and express considerable guilt. A pediatric neuro-oncologist mentioned that psychological issues related to depression or anxiety typically develop after age seven as a result of going through the treatment process, underscoring how critically patients need psychological services at the hospital. Thirty-seven percent of respondents from the professionals survey reported that the greatest challenges families face are long-term caregiving, their child’s increased dependency, and worries about their child’s care in their absence.

Treatment can produce additional emotional distress, when symptoms escalate, and side effects and diminished faculties develop. As treatment concludes, challenges emerge for patients struggling to integrate their identity as a survivor, manage a sense of survivor’s guilt, and cope with post-traumatic stress. Subsequent treatment after relapse may require adding new treatments, enrolling children in clinical trials, or an increased amount of social support, and the uncertainty often provokes deep anxiety. As one social worker described post-treatment families, “what they really want to do is walk away from the diagnosis and pretend it’s all over,” but the onset of late effects and potential for relapse make that outcome unlikely. Another physician described the particular difficulty of patient relapse, since there are fewer resources from which families can draw:

*“And that’s a very, very hard time, and often needs another whole swing of emotional support—at a time when most of the emotional support that has been provided during the acute phase and the initial diagnosis phase of the illness is now gone.”*

**“Medical people don’t look at parents as partners. Parents are looked upon as being flawed, or damaged because of the overwhelming emotional consequence of the diagnosis that has been made on their child.”**

In interviews, practitioners described secondary trauma experienced by both parents and siblings as a common problem where resources are needed to help parents process their own trauma and parent siblings effectively. Additional mental health resources were recommended to help parents identify maladaptive coping strategies in themselves and their children so they can be substituted for more adaptive emotional processing. One social worker in a survivorship program discussed how parents feel the need to be strong for themselves and their children, which also may signal the need for coping and support mechanisms. However, practitioners described multiple barriers to addressing mental health and emotional support needs across the family unit. Hospital staff and practitioners perceived a gap in financial and mental health resources, particularly for family members beyond the patient, which has forced external foundations and organizations to step in to support parents, siblings and other family members in need. In particular, families who have completed treatment have started organizations to support others, and seem particularly attuned to the mental health resources and financial resources that fall outside of the scope of what the hospital or insurance can provide.

Furthermore, several social work practitioners voiced concerns that hospital staff do not listen to what families need, and just go through the motions focusing only on the services that are billable. Medical professionals may similarly only focus on patient care and medical needs, and remain insensitive to the burden parents face logistically, financially, and emotionally when caring for siblings.

### **LOGISTICS & FINANCIAL**

Similar to the interviews with professionals, challenges related to logistical and financial support also emerged as a key theme for family survey respondents, second only to emotional and interpersonal issues. The most highly cited challenge for respondents (Figure 27), after emotional or interpersonal challenges, was traveling to get medical care (mentioned 229 times). Other issues, cited with roughly half the frequency of the transportation issues, included “trouble working with insurance” (128 times), “trouble working with the school” (99 times) and missing work (91 times). Few cited issues meeting parents in similar circumstances, and only 78 expressed trouble working with doctors. Respondents reported that patients struggle with these key logistical and financial issues (Figure 25), which create major challenges for family members, as well: struggling to live independently (16 percent), transportation (13 percent), accessing public benefits (10 percent), and paying for medical or household costs (9 percent and 13 percent respectively).

**“We had to leave our home state to find [care]. There was not a pediatric neurosurgeon in Oklahoma at the time that would attempt to operate on her tumor. If we had not been financially able to travel and prepared to pay out of pocket for her treatment, I believe that she would not be living today.”**

However, financial issues pose a much greater challenge for low-income families. 35% of parents or caregivers who earned less than \$20,000 cited financial difficulties as the greatest challenge they faced. 18% of the parents or caregivers that earned between \$20,000-\$30,000 also mentioned financial issues as their greatest challenge. The proportion of respondents reporting financial difficulty as their greatest challenge decreases considerably with higher income groups. Only 8% for families earning between \$50,000-\$60,000 and 0.03% for families earning above \$80,000 cite financial challenges as their greatest issue. Since families earning above \$80,000 annually comprise 51% of the total respondents (Figure 6), this skewed sample influences the reported data. However, it is worth noting that even among the poorest households, their greatest cited concern was not financial, but rather focused more on other issues impacting their children and family unit.

**“We, as his parents, paid all of his doctor bills, but dealing with insurance was mind numbing and absolutely ridiculous! I spent countless hours on the phone with insurance companies... all this while my son was feeling good! This time was taken from us. We will never have that time together again.”**

In addition to emotional and social resource needs, practitioners felt that logistical challenges and financial hardship ranked among the most significant stressors for patients and their families. Practitioners’ primary logistical and financial concern was maintaining continuity of care across a fragmented care team, followed by supporting families through changes in employment and financial hardship, accessing resources across geographic disparities, managing increased travel and transportation costs, and navigating the complicated insurance and hospital finance systems. The professional survey revealed similar patterns. For example, 28 percent of respondents reported financial hardships and barriers as the greatest challenge that families face. Further, 14 percent reported navigating medical procedures and information as the key challenge for families. One practitioner described how the complex medical system impacts families: “Low income families in Florida face a confusing Medicaid system that often changes or only provides partial coverage at a hospital; this adds additional barriers to an already difficult situation. Locally, we do not have access to appropriate long-term housing for patients who need to relocate to the local area; currently, furnished lodging at an apartment costs \$1700/month.” Professionals in the survey mentioned geographic disparities, which influence resource access and can exacerbate social isolation: “In rural areas, patients are spread out and do not have easily accessible opportunities to meet others with brain tumors.”

Additional analysis on logistics and financial challenges is presented across two areas: fragmentation and continuity, and employment and hardship for parents.

### **FRAGMENTATION & CONTINUITY**

Fragmentation and continuity represented the most frequently discussed dimension of logistical and financial challenges in the practitioner interviews. Maintaining continuity of care across a fragmented care team that can span well beyond childhood into adulthood is challenging in itself, but medical professionals must also cope with understaffed hospital teams, the lack of a central care coordinator, the lack of one central source of information, and the coordination costs of managing a multidisciplinary team

with different working protocols. Practitioners assert that working in disciplinary silos creates logistical challenges not just for patients, but for the practitioners as well. One nurse practitioner said, “I wish that there were a kind of ‘whole expert’ to think about what’s available,” a sentiment which underscored the difficulty for any one medical professional to address the broader systemic challenges within which medical care occurs. A clinical social worker echoed the concern over disciplinary silos, saying that “treatment teams don’t always talk to each other, so the patient has to do a lot more care coordination” when all providers are not on the same page. Most practitioners cited social workers as an important resource that is currently being stretched too thin, despite the valuable services they provide to families. Often social workers fill the gap as care coordinators, working as liaisons between the different members of the treatment team to ensure clear communication.

In addition to connecting members of the care team, practitioners identified the lack of a single, central source of information as a key deficit for families.

This is necessary to ensure that families are not responsible for remembering each detail communicated by different team members. With fragmented communication and information, self-advocacy becomes challenging for patients and families who might not even know what resources are available to them. Physicians and allied health professionals emphasized that parents often face emotional barriers that may include a sense of powerlessness, hopelessness, immobilizing fear, immobilizing anxiety, anger, blaming, guilt, loss of control, and traumatic stress, which make it difficult for them to effectively advocate on behalf of their children. Practitioners suggested that the scope of resources can be overwhelming to navigate, and getting what the patient and family need requires families to know what resources are available and how to access them. In other words, “Most of these kids can’t get [the resources they need] on their own. They need help accessing these kind of resources.” Practitioners overwhelmingly argued that a family advocate could play that crucial bridging support role. As one practitioner said,

**“[A family advocate is needed] to be the representative of their family, and to be able to act as the parents who know their child, and their family’s needs better than anybody else can.”**

*“Sometimes the amount of resources you get is dependent on how big of an advocate the parent can be—and sometimes if you just don’t know what the options are, or what you should be getting, it is really hard to argue what you need. So sometimes having someone who can be the go-between makes it a lot easier too.”*

Practitioners described the challenging new circumstances that parents and families face after a pediatric brain tumor diagnosis. Parents must deal with what may be a completely new experience in navigating the healthcare system, dealing with insurance providers, understanding how to care for their children at home, medication management, and asking the proper questions to their providers in order to be given the right information. There is a general lack of care continuity after leaving the facility, and parents leave with lingering questions about their plan or are not sufficiently supported beyond issues that directly relate to acute treatment. The coordination and advocacy is particularly needed during moments of transition between providers, when falling out of care can be problematic. In particular, key moments of transition include movement from pediatric to adult care, which creates a window when patients fall through the



cracks; survivorship, when the frequency of hospital contact is greatly reduced but late effects are likely to emerge and present new challenges; and bereavement, after the loss of a loved one, which introduces enduring emotional issues, but not necessarily with a corresponding increase in emotional support.

Practitioners described that complaints about lag time between examinations and results, slow or no hospital follow up, and difficulty scheduling and securing medication refills, sour the relationship between the patient and the hospital, leaving the family to feel “held hostage” by the hospital to get the information they need. Some medical professionals rigidly adhere to hospital protocol and fail to view patients as people experiencing distress, which, many argued, meant that they did not respond adequately to patients and their families. As one individual described,

*“There are doctors who will say ‘well, we just can’t always be, you know, running off to get parents MRI results every time they have a scan. You know, we don’t have time to do that. We don’t have complete information,’ so on and so forth. It’s all excuses that don’t relate to the very real needs families have to get answers in real time.”*

A different professional argued that humanity should guide practice, but this occurs too infrequently.

*“There are too many times in my practice where I would have a parent waiting for me saying, please, can you email us scanned results even if it’s 11 o’clock at night, and finally to get that report back, and having to email them and to know that for the next two nights they can rest easy, rather than wait for a clinic appointment. I mean that, to me, is just basic humanity.”*

In essence, medical professionals exert considerable control over reducing or exacerbating the fragmentation and continuity of care challenges that families face and which influence their quality of life and outcomes. Disparate treatment creates varying experiences across the spectrum of families grappling with a pediatric brain tumor diagnosis.

### **NEW FRAGMENTATION AND CONTINUITY CHALLENGES EMERGE POST-TREATMENT**

Practitioners noted that, for survivors, new challenges emerge as they age into adulthood. The transition from pediatric to adult care forces many patients to change insurances and doctors with different specialties. The clinical differences between a pediatric versus adult brain tumor mean that late effects will

manifest differently based on when the tumor developed, and adult brain tumor specialists may not have the pediatric expertise to treat the evolution of the patient's condition effectively. Regardless, after 21, survivors are referred to adult cancer centers or locations to receive primary care, which represents a disruptive transition for many individuals. As one practitioner stated, "Sometimes what insurance companies will do is they'll refer children to adult oncologists for late effects, [even though] adult oncologists don't know necessarily the first thing about late effects of childhood treatment." Therefore, survivors and their families continue to need services tailored specifically to pediatric brain tumor patients even as they age into adulthood—but frequently these resources disappear as the patient ages out. Insufficient resources and information makes pediatric brain tumor patients and their families additionally vulnerable. Social workers described many young adult survivors as extremely isolated, living with their parents because they cannot find adequate employment, coping with barriers to social services access, and their parents cannot help sufficiently because they do not have better information about resource availability.



Furthermore, many cope with permanent side and late effects (as presented in Figures 11 and 13), which further prevent patients from social integration and independent living. Practitioners asserted that the overall care plan neglected a critical need among surviving patients and their families for additional preparation to cope with the challenges associated with transitioning from pediatric to adult care. Social workers, in particular, noted that these patients and their families, who in some cases have been cancer-free for over two years, have insufficient resources to deal with late effects as young adults, such as neurocognitive disabilities, completion of education, social skills, and job/vocational training. One practitioner described the challenge for patients as they age into adult services, stating that, "one of the biggest gaps, I think, is in helping adolescents and young adults transition from pediatric to adult-based care. We do quite a bit of education to prepare families to leave pediatric care, and help them understand how adult medicine is different than pediatric medicine."

Survivorship also poses unique transition challenges, especially in the absence of severe symptoms. Practitioners suggested that the desire for normalcy can lead some patients and families to neglect follow up appointments in the survivorship period stemming from a strong desire to move on from the trauma of treatment. Patients falling through the cracks during survivorship is especially problematic when late effects of radiation treatment kick in, catching families off guard. According to one practitioner, after successful treatment, "[what families] really want to do is walk away from the

diagnosis and pretend it's all over—even though at that point they're still having MRIs every month, and they have very frequent visits back to the hospital.” For some, the desire to regain normalcy, and likely other barriers to resource access, drives them to prematurely end medical services: “they come for one or two years, and then they just stop coming even though we're recommending that they see us every year.”

**In the words of one medical professional, “I think sometimes there's a reluctance to come back to the place where the child was treated and died, or to [be a] burden... most families are very respectful of, and appreciative of, the treatment teams, but yet they just don't want to be like a burden to people.”**

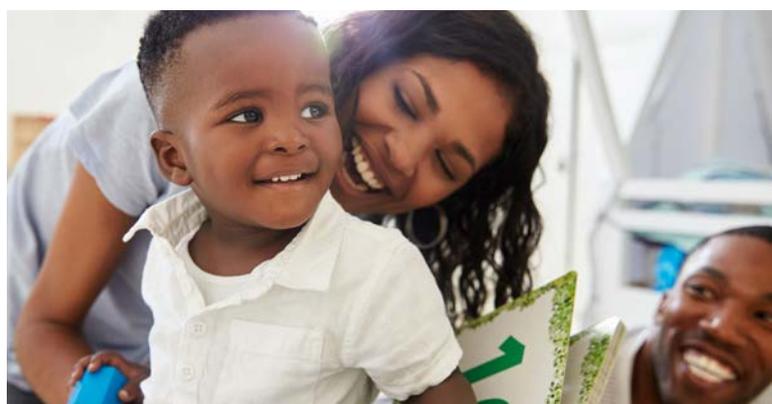
Prematurely ending medical treatment constitutes a particular concern regarding mental health support. Particularly after the death of a child, practitioners expressed significant concern over a steep drop-off in family participation in mental health services, even though they still needed support. Due to a combination

of negative emotional associations with the hospital where their child was lost, and a desire to move past the tragedy, many families become unresponsive to outreach efforts from the hospital team and discontinued leveraging the family support resources available to them—if family members even accessed mental health support in the first place.

### **EMPLOYMENT & HARDSHIP FOR PARENTS**

In addition to challenges coordinating care across the patient lifecycle in a fragmented treatment environment, parents struggle to deal with the financial hardship from growing medical expenses and insufficient resources. This is frequently exacerbated by reduced work hours or lost jobs, which further reduces family income. Low-income and single-parent households additionally struggle to afford added medical and transportation costs. Often parents have to either reduce hours at work or leave their job to transport their child to and from appointments, and for those who do not have paid medical leave provided by their employers it can be particularly challenging. As one practitioner described, low-income families face additional burden to cope with a pediatric brain tumor diagnosis, since they have fewer resources from which to draw. As one professional described, “We have some families [whose] income earners have seasonable jobs, jobs where they work more one month and then [less] the next month, so they're constantly having to report their income, and they have to worry about whether or not they're going to qualify.” For families whose income earners lack benefits, this translates into additional hardship. “Not all folks have jobs that have paid leave, and some folks are not getting paid at all.” For these individuals, taking time off work translates into lower earnings—a heartbreaking tradeoff that can exacerbate vulnerability, rippling across families and into the future.

Beyond medical expenses, moving costs for those who need to relocate closer to the hospital, travel costs to and from appointments, setting up legal conservatorship, arranging funeral costs, ongoing survivorship treatments, and non-treatment related expenses such as rent are often excluded from insurance coverage and difficult to fund from outside foundations. As one medical professional described, “Things like I can't make my next rent... is not a specific medical need. It's harder to get funded.” Another described one particular situation where a patient is “probably close to 25 now, and her parents still haven't got conservatorship because they say they can't afford the three or four thousand dollars it's going to cost.” The costs associated with a pediatric brain tumor diagnosis add up, reach far beyond direct medical costs, and are difficult to fund—particularly for low-income families.

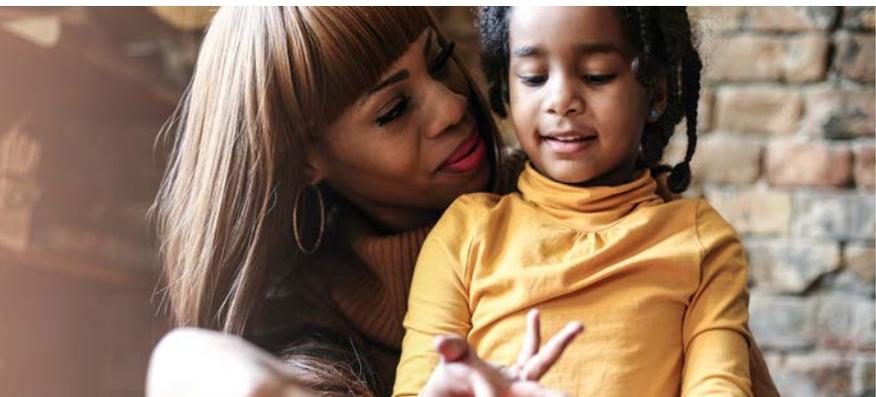


Care varies from state to state and region to region. Challenges are particularly acute for those living in small rural communities that do not have the same resource quality as larger urban areas, and resource access varies on a state-by-state basis. One neuro-oncologist mentioned that tumors are “more likely to be misdiagnosed” at smaller hospitals whose physicians have less exposure to and are less experienced with pediatric brain tumors or with pediatric neuro-oncology. California is a state that provides a variety of social services to assist individuals with cognitive impairments through regional centers and services provided by the Employment Development Department. However, someone who resides in a state that does not provide these types of comprehensive services will face greater barriers to accessing necessary resources, exposing the gaps in survivorship resources depending on where families reside. As a result, children may not receive the most appropriate treatment or information on the latest clinical trials. Additionally, patients may not have access to a social worker at hospitals that do not provide the funding for psychosocial support services and reintegration services, such as a school psychologist or school liaison. Practitioners suggested that a sizeable demand exists for better resources locally and in-home to help families manage the transportation costs for in-hospital treatment. Gas, lodging, meals, parking, traffic, and time are common challenges for commuting families, and the hours away from home increase child care expenses for siblings or necessitate pulling them out of school early if childcare is unaffordable.

Practitioners believe that efforts to narrow the financial gap for families are often inhibited by the complicated, incomplete, and expensive nature of insurance, and the financial nuances of the hospital billing systems. Understanding the scope of insurance coverage often overwhelms families when they find out that certain necessary treatments or equipment fall outside of what is covered. Social workers frequently intervene to connect families to foundations who can offer financial assistance filling in the gap between what insurance covers and what the patient needs, but it is difficult for patients to identify which foundations to go to for what. Practitioners overwhelmingly argued that social workers play a critical role, but cutbacks to hospital budgets have left social work departments understaffed and spread too thin across too many patients, inhibiting their ability to advocate effectively for each family.

Much of the infrastructure necessary to get a family the care they need is not necessarily billable service, and hospitals often only provide those services for which they can be reimbursed through insurance. This becomes especially problematic during survivorship, when the patients are no longer in an acute treatment window, but their well-being still hinges on comprehensive care from

social workers, occupational therapists, and education advocates among other resources. As one practitioner explained, “Money still rules the world, so if you come to a major medical center that has child life services but child life services are not billable and don’t drive revenue, then those services tend to be phased out, or are not funded appropriately.”



### **INFORMATION / MEDICAL EDUCATION**

In response to the most prominent side-effects that patients face (Figure 11), family members listed educational and vocational issues more frequently than issues related to medical information, though medical professionals emphasized the latter. Key issues related to medical information were difficulty understanding medical information about the brain (10 percent), and getting or using medical insurance (6 percent). According to practitioners, access to and comprehension of information presents a key challenge for families. Patients and families need wide, understandable information to make informed decisions and access the resources they need. This is a challenging endeavor because patients and parents are overwhelmed, communication mechanisms are poor, and information is provided in an overly comprehensive but insufficiently tailored way. Social workers, in particular, worry that the volume of information coming at parents during periods of high emotion is too much to process, making it hard to know what questions to ask when the doctors are in front of them. Practitioners suggested that information needs to be delivered more sensitively and incrementally, which would allow parents adequate time to form questions and process information. Moreover, they need opportunities to access doctors beyond the appointment window, to get their questions answered in a timely manner.

A major source of the overwhelming feelings is believed to stem from concerns about how to readjust expectations for their child, recalibrating to a “new normal” and anticipating the onset of late effects so they are not caught off guard. A palliative care nurse in Los Angeles described how, for younger patients, before understanding that their tumor is fatal, they often must “deal with the grief of losing function” which is especially hard because they do not fully understand what is going on. A major tension highlighted by social workers was the need to balance empowering parents with complete information so they can make informed decisions about their care without overwhelming them, noting that often doctors provide incomplete information that lacks true clinical honesty because they don’t believe the parent can “handle it.”

Addressing the tension between too much and too little information is magnified online, where the volume of information from a range of credible and non-credible sources can become unmanageable. Beyond its overwhelming characteristics, online information dissemination is critiqued by practitioners as being impersonal, stripping the care team of their ability to gauge distress via nonverbal cues. On the other hand, online resources can make information more accessible (particularly in a range of languages) and can assist underserved communities who struggle to come in-person to the hospital.<sup>14</sup> Practitioners cited camps as the best mechanism for information dissemination, since medical expertise is combined with social support over the course of several uninterrupted days, which allows adequate time for information to be processed so families can truly get the information they feel they need. With all information, tailoring is a huge concern; practitioners expressed concern that different audiences have different informational needs, and resources should be presented in context and delivered at the appropriate time. As one East Coast-based resource specialist mentioned, families differ by what they are eligible for, and so they spend a significant amount of time filling out required paperwork for these families. As this resource specialist stated, “eligibility typically revolves around five factors, those being income, residency status, age, diagnosis, and location.” In response, “it’s important to help families understand how each child needs to be evaluated in services for their unique needs, and not just kind of throwing, you know, a big gigantic resource at somebody who just needs a little bit of help.”

### **EDUCATION / VOCATION**

Beyond hospitals, patients have unique educational and vocational needs that must be addressed to help them reach their potential and find a sense of purpose moving forward. Among the educational and vocational issues that families listed in the survey (Figure 25), the following emerged as the most prominent: working with schools (11 percent), finding or keeping a job (11 percent), struggling to learn (9 percent), and problems with memory (5 percent). Within school settings, practitioners believe families need support advocating for their needs and navigating the reintegration phase that includes disclosure of the diagnosis and treatment effects to peers and school administrators. Within schools, families need help identifying appropriate supports for their child, and teachers are often under-resourced in their efforts to support children with cognitive deficits. One parent described the complexity of her daughter’s school-related challenges:

*“There are two [challenges] that are equal and generally relate to one another; school and anxiety. The university she is attending does not want to provide the accommodations deemed necessary for her to succeed. We have filed a formal complaint with the EOD at the school but the process is long and the outcome has yet to really take effect. Persons with disabilities face so many challenges! People who want to succeed should be given the opportunity under the conditions that help them to.”*

One Southern California-based nurse practitioner argued that a school liaison associated with the hospital can help ease the patient’s transition back into school. These types of services allow for parents to understand how to address their child’s disabilities as they navigate the educational system, including how to participate in developing an appropriate individualized education plan (IEP) for each stage of the child’s subsequent schooling.

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<sup>14</sup> Despite wide Internet availability, low-income populations still face barriers to accessing quality health information online (Cheong, 2007).

**A parent described their son's employment challenges, stating that, "He graduated from college with a bachelor's degree, but hiring managers seem to be turned off by his slow speech."**

Social workers cited understanding the laws and government resources available to patients as a key element of a school liaison's job. Many of the physicians also suggested that

the hospital could do more to provide tutoring services and college counseling so that students do not fall behind while they are receiving treatment. Once patients are able to reenter the school system, the disclosure of the diagnosis and cognitive deficits that result from treatment is a source of anxiety for families. Some described the experience as "coming out" as a survivor, and emphasized that the conversation is not a one-time event, but instead an element of every relationship that the child has to navigate. Repeated disclosures can have the effect of re-traumatizing the patient and the parents as they relive the story, and practitioners believe additional counseling resources would be beneficial to help families process their emotions and role-play the disclosure, increasing their comfort with these difficult conversations.

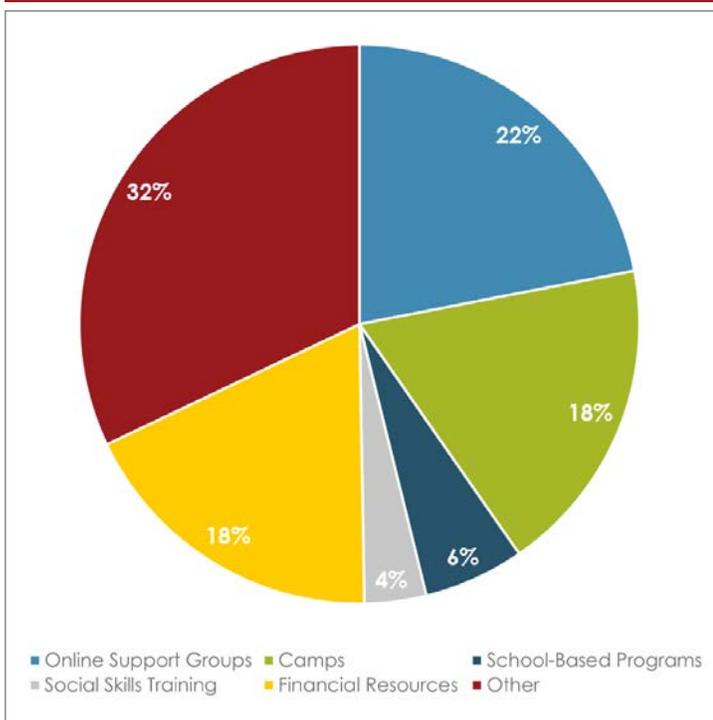
In addition to classroom and academic challenges, many patients go on to experience vocational challenges in both managing expectations and accessing training and placement resources. Practitioners expressed concern that, when adapting to a work environment, it is challenging for patients, parents, and employers to set appropriate expectations about performance. A significant challenge is that cognitive effects from treatment worsen over time, making it more difficult to maintain productivity in the workplace, as one Southern California-based nurse explained. The physical and cognitive deficits of survivors range widely, and it can be challenging to align expectations so that work is appropriately stimulating and meaningful while achievable. Counselors were referenced as key resources for navigating vocational expectations, helping patients adjust their expectations without shame and communicate those expectations appropriately to current and future employers.

**Resources like career counseling, job training, job placement, and occupational therapy were celebrated by social workers as incredibly helpful, and most practitioners agreed patients would benefit from greater access to those resources.**



## SUPPORT SERVICES

**[FIGURE 31] PROGRAMS OR RESOURCES MOST HELPFUL IN MEETING PARENT AND/OR CAREGIVER NEEDS**



The family survey also asked respondents about the support services from which they draw.<sup>15</sup> Family members mentioned “Other” services most helpful, followed by “Online Support Groups”, “Camps” and “Financial Resources”. Parents and caregivers repeatedly mentioned the lack of support groups near them and the help of online support groups to meet families like them. As one respondent mentioned, “brain tumor and epilepsy support groups on social media help me understand that other parents deal with the same feelings and emotions.” Another said, “it’s sometimes easier to open up to people that are not around me every day, and different Facebook groups have helped with that.” When asked to list which online support groups they access, respondents listed groups on Facebook, PBTF, BTF, CBTF, Momcology and Yahoo groups. This was followed by DIPG groups and Ependyparent group.

Furthermore, 163 individuals listed “other” support services (Figure 31). Among these responses, people frequently discussed support from family and friends (40), counseling and therapy (31), church and faith-based groups (15), foundations like PBTF, MAW, CURE and others (13), followed by social workers (9) and service centers (4). Parents and caregivers mentioned that they felt socially isolated because their friends and family

members struggled to relate to their experiences. As one mentioned, “Some of our close friends have distanced themselves from my husband and I, which is heartbreaking!” To cope, parents or caregivers described having stopped expressing themselves in social situations and seeking therapy for additional support. Parents and caregivers frequently mentioned that they needed more opportunities to meet families like them, and that when they had such opportunities to meet other families in similar circumstances, they felt more supported. One parent described, “By chance, I have met a couple of families that have a child dealing with the same tumor. Those are such important connections! I wish the hospital could provide each other’s name, if they sign a waiver that they didn’t mind connecting with other families. That would be awesome.”

<sup>15</sup> It is important to note that, as explained in the data and methods section, survey respondents were identified through PBTF. Therefore, this support services section reflects the connections of individuals already connected to PBTF.



Beyond meeting other families coping with a pediatric brain tumor diagnosis, parents and caregivers also mentioned that they needed different types of support groups, including specific groups for parents, siblings, and patients in different stages. Similarly, when discussing the greatest unresolved challenges they face, parents and caregivers cited anxiety, depression, social isolation, lack of support and guidance, a need to meet other families facing similar problems, loss of normalcy in life, guilt, fear, worry about the future, marital stress and financial resources and support as challenges that have not been resolved.

In terms of financial resources and programs, respondents to the family survey mentioned insurance coverage, PBTF funds, the Butterfly Fund, California Children Services, charity organizations and personal donations as most helpful. According to one, “when we were homeless, jobless and in treatment, we found quite a few financial resources to help us through it.” Despite some financial resources, most respondents cited the need for additional financial support. Many attributed financial difficulties related to the cost of the patient’s brain tumor to factors including high medical, traveling and accommodation costs. Most respondents admitted that financial constraints produced enormous stress, and needed additional financial support.

Across the survey and interviews, practitioners noted that external foundations and organizations play a crucial role in bridging gaps faced by families afflicted by pediatric brain tumors.<sup>16</sup> Beyond mental health and financial support, external foundations are brought in to help families better communicate and navigate internal discussions within the family unit through interpersonal skill building and family therapy, and help to provide legal support as families struggle to navigate their rights. In addition to mental health resources, practitioners cited the PBTF’s Veteran Parent Program as a key resource, helping families address current challenges and set expectations about the challenges to come. In particular, the Veteran Parent Program proved helpful in assisting parents as they navigate their relationship with the hospital, which is often paternal rather than collaborative.

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<sup>16</sup> In the survey, practitioners most frequently mentioned the Pediatric Brain Tumor Foundation, the Brain Tumor Foundation, Gilda’s Club, Imerman’s Angels, B+, Bryan’s Dream Foundation, Michael Matters Foundation and Hawaii Children’s Cancer Foundation. One mentioned a hospital-to-school checklist developed by Sharon Grandinette, published in 2014. Others mentioned local support from a few school based programs, wellness centers and camps, which were not specifically cited. Camps like Camp Mak-a-Dream, Okizu, Jack’s Camp, Camp Anuenue, Camp Ikaika and We Can Family Camps were also mentioned.

**“This is a new world for parents. They do not know or understand education law, the child’s rights, or the school’s responsibilities. School personnel have no support (financial or time off ) to learn how to help these children succeed.”**

Respondents were also asked whether they think support services are adequate. 80% of respondents to this question argued that services are *not* adequate to meet need. A caregiver stated, “I don’t feel like I

have found a good support group—online or otherwise; it would be great if he could connect with another child who did understand what he’s gone through.” Some mentioned that the mental health support did not reach enough people, while others cited insufficient financial support, and others pointed to support deficits for families and siblings. While noting the struggle for families to pursue financial aid, a respondent mentioned that although some services exist,

*“Ideally a family wouldn’t have to submit 10 different applications over time when assistance is needed. However, each grant has its own requirements, guidelines, applications, etc. This can be overwhelming for a family in need but given staffing levels, social workers are unable to complete these applications on their behalf. Information like income, rental amount, costs of transportation is information that would have to come from the family directly.”*

Other respondents highlighted the difficulty of getting to programs in large metropolitan areas like Phoenix, even though these programs exist. Together, responses to this question pointed to two separate issues: first, insufficient resources and services overall; and two, geographic, time, and other constraints that prevent patients and families from accessing those resources that do exist.

When asked about additional services to help patients, the most common response was more support groups, counseling, career guidance and job training for patients, financial support (especially for transportation and accommodation while travelling for treatment), rigorous training for school and hospital staff to cater to patients with neurological deficits, and training and counseling for parents. Other suggestions for services included more activities for parents and siblings like camps and trips, more specific support groups, helplines for parents, and community services to take care of patients during daytime (in their homes) so the parents didn’t have to miss work.





## CONCLUSIONS BASED ON GAP ANALYSIS

Based on the data collected for this needs assessment, pediatric brain tumor patients and their families face challenges across four dimensions: (1) interpersonal and emotional distress, (2) logistical complications and financial hardship, (3) information gathering and processing challenges in medical decision making, and (4) difficulty reintegrating patients into educational and vocational environments. Both families and practitioners argue for additional support across each of these dimensions.

Interpersonal and emotional challenges represented a key theme listed by both practitioners and families. Patients and families need help coping with the changes that diagnosis, treatment and post-treatment bring, as well as for the emotional distress experienced by the entire family. Understandably, the patient is generally the key focus of attention for parents and practitioners, but this report suggests that the entire family needs additional support, and particularly parents, who suppress their own need at great personal cost. As diagnosis and treatment creates a whole new set of challenges and involves a significant learning curve, coping takes a huge emotional toll. Even in cases where treatment is successful, families must learn to live with a new normal, including continuing the full scope of needs described in this assessment and late effects, which often are insufficiently resourced. And when the patient does not survive treatment, emotional needs persist.

Multiple important gaps in support and services exist for patients and their families, which contributes to their ongoing need. Insufficient mental health services exist throughout treatment, but also post-treatment, including for surviving family members in instances where the patient passes away, but also when the patient survives. When coping with challenges in treatment and afterwards, patients and their families are extremely isolated, and need additional opportunities for interacting with families facing similar circumstances. Without such interactions, patients, parents and siblings feel alone, and have difficulty relating to others who have not experienced similar life events. Logistical and financial issues are also a key source of stress and vulnerability, and respondents cited a need for more assistance in overcoming information barriers, accessing resources, and navigating the complex world of healthcare systems. Particularly for families with multiple children and for parents with less flexible work schedules, logistical and financial burdens can produce other sources of stress and vulnerability, and represent a barrier to accessing services and support. Furthermore, gaps in services persist beyond treatment. When survivors experience late-effects, key resource and informational gaps exist in schools and in relation to employment, which makes it even more difficult for patients and their families to help survivors adjust to life after treatment and far beyond.

These pervasive, continuing challenges suggest a need for support services, including mental health support, care coordination and patient advocacy. The key function of a care coordinator should be to align communication among the fragmented care team, and help to triage the flow of information to patients and families so they are provided a tailored set of options and pointed in the direction of resources most relevant to their circumstances. Beyond the coordination role, an advocacy component is key in navigating insurance, educational, and vocational environments so patients and parents understand their rights and have access to appropriate resources. Families repeatedly discussed the need for additional resources to help them overcome fragmented care, access information and to bridge support across all the treatment stages.



Mental health services for patients and family members presents a key, significant gap in support. Mental health services must extend far beyond treatment, to match need. Interpersonal and emotional challenges manifest differently for patients, parents, and siblings who face unique social, logistical, financial, educational, and vocational challenges at different stages. For patients, mental health counseling is a particularly important resource for addressing fears and anxieties, developing and maintaining social relationships, navigating reentry into educational and vocational environments, and developing coping skills and a sense of self-efficacy. Practitioners assert that parents would benefit from mental health resources to address their fears and anxieties, including to cope with the added stressors of navigating a fragmented care team, adjusting to changes in employment, managing the costs of travel and treatment, and processing the flood of medical information presented to them as options. Practitioners caution that the needs of siblings often go neglected with patients and parents hyper-focused on treatment and survival. In addition to improved mental health resources to address the challenges above, providing additional care coordination resources would help to address the logistical and informational challenges in the hospital, and link patients and their families to appropriately tailored resources for their home, school, and professional life. Moreover, mental health services could better facilitate the need for parents and caregivers to practice self-care and support throughout the diagnosis and treatment stages.

Lastly, both patients and their families need significant support coping with late effects, long-term effects, and cognitive and social effects as survivors age into adulthood. Specifically, support is needed to help patients complete their education, find adequate employment, live independently, and integrate into social settings. Across the entire family unit, patients, siblings and parents need more social support, particularly to have opportunities to interact with families in similar circumstances.

While this needs assessment has highlighted a broad set of needs that families, patients, and long-time survivors face, the Pediatric Brain Tumor Foundation may want to focus additional efforts in reaching out to subsamples of families affected by pediatric brain tumors to hone particular programming to meet those needs. As noted earlier, the samples of families responding to the focus group and survey invitations include fewer families that may have English as a second language and fewer bereaved families than exist in the general population of families affected by brain tumors. Research suggests that these families are likely to face even more severe challenges than those already noted in this needs assessment. The needs assessment suggests clear actionable areas for investment in family support that can happen even while additional research may occur to identify special needs of these under-sampled populations.

**[APPENDIX 1] YEAR THE PATIENT WAS DIAGNOSED**

Age of the patient at Diagnosis	Percentage
Less than Age 1	4.5
Age 1	5.8
Age 2	8.2
Age 3	7.3
Age 4	7.4
Age 5	5.8
Age 6	5.4
Age 7	5.4
Age 8	3.6
Age 9	4.5
Age 10	5.4
Age 11	5.9
Age 12	4.6
Age 13	2.8
Age 14	4.2
Age 15	2.4
Age 16	2.7
Age 17	2.4
Age 18	0.7
Age 19	1.1
Age 20	0.3
More than Age 20	0.4

**[APPENDIX 2] CURRENT AGE OF THE PATIENT**

Patient's Current Age	Percentage
Age 1	0.1
Age 2	1.2
Age 3	1.3
Age 4	1.2
Age 5	3.6
Age 6	3.0
Age 7	3.3
Age 8	1.4
Age 9	2.2
Age 10	2.9
Age 11	2.9
Age 12	3.3
Age 13	4.5
Age 14	4.5
Age 15	2.6
Age 16	3.6
Age 17	3.9
Age 18	3.3
Age 19	4.2
Age 20	3.9
Age 20-25	16.4
Age 26- 30	11.8
Age 31-40	2.4

[APPENDIX 3] TYPE OF TUMOR THE PATIENT WAS DIAGNOSED WITH

Type of Brain Tumor Patient was Diagnosed With	Frequency
Astrocytoma Optic Glioma	3
Anaplastic Astrocytoma	7
Anaplastic Ependymoma	9
Anaplastic Medulloblastoma	5
Angiocentric Glioma	2
Astroblastoma	5
Astrocytoma	41
ATRT	12
Benign	5
Bi-Lateral Optic Glioma	4
Brain Stem Ganglioglioma	4
Brain Stem Glioma	6
Cerebellar Astrocytoma	4
Choroid Plexus Carcinoma	7
Choroid Plexus Papilloma	3
Craniopharyngioma	34
Diffuse Astrocytoma	5
Diffuse Fibrillary Astrocytoma	3
Diffuse Intrinsic Pontine Glioma	34
Disembryoplastic Neuroepithelial Tumor	10
Ependymoma	36
Fibrillary Astrocytoma	4
Ganglioglioma	29
Germ Cell	4
Germinoma	14
Glioblastoma	7
Glioblastoma Multiforme	5
Glioma	17
Gliomatosis Cerebri	3
Hypothalamic	6
Juvenile Pilocytic Astrocytoma	38
Medulloblastoma	131
Mixed Germ Cell	3
Neuroblastoma	4
Oligoastrocytoma	3
Oligodendroglioma	6
Optic Glioma	10
Optic Pathway Glioma	10
Pilocytic Astrocytoma	36
Pilomyxoid Astrocytoma	6
Pineal Germinoma	9
Pineoblastoma	5
Primitive Neuro Ectodermal	18
SPNET	6



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