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Exploring Family Management of Childhood Brain Tumor Survivors

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Abstract

Family management of childhood chronic conditions consists of 6 family factors: (1) the family's view of the child's daily life, (2) the impact of the condition on family life, (3) the difficulty of family life, (4) the family's effort managing the child's condition, (5) the family's ability managing the child's condition, and (6) parental mutuality. Recently, the Family Management Measure (FaMM), which measures family management of children with chronic conditions (excluding cancer), was validated. The purpose of this descriptive study was to examine the comparability of these 6 factors in families with childhood brain tumor survivors. First, 14 advanced practice nurses who are experts in neuro-oncology and survivorship rated items on the FaMM as relevant and clear to families of brain tumor survivors. Second, 22 cognitive interviews with parents of brain tumor survivors described family management as comparable with families of children with other chronic illness. In this report, 2 hypothetical, contrasting case studies of family management are used to illustrate family management within the context of brain tumor survivors.

Keywords

childhood brain tumor survivors; adolescent and young adults; family management

Standardized measures of family functioning present a mixed picture of the effects of illness on family life in pediatric oncology populations. This is due to the complexity of the science as well as the need for increased theoretical coherency and methodological sophistication (Klassen et al., 2007). A recent meta-analysis reported that mothers of children with cancer perceived more family conflict than mothers of physically healthy children. Because increased family conflict is predictive of adjustment problems in children with cancer, these findings are of concern for both the families and children. Limited specificity of family measures, however, makes it difficult to ascertain the genesis of family conflicts and how they may relate to the children's cancer. Additionally, authors of the meta-analysis suggested that more precise methods are needed to describe and measure family functioning related to childhood cancer (Pai et al., 2007).

The Family Management Framework was developed on the basis of more than 20 years of conceptual, empirical, and methodological work to describe how the family functions to care for their child's condition (Knafl, Deatrick, & Gallo, 2008). Most recently, 6 family management factors were identified in a quantitative validation study, creating the Family

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Management Measure (FaMM): (1) the child's daily life, (2) the impact of the condition on family life, (3) the difficulty of family life, (4) the effort managing the condition, (5) the ability managing the condition, and (6) parental mutuality (Knafl et al., in press; see Table 1). The instrument has 53 total items for partnered parents and 45 items for nonpartnered parents. Families of children with cancer and developmental disabilities were beyond the scope of the validation study (Knafl et al., in press).

It is likely that family management characteristics are similar for childhood cancer survivors as for children with other chronic illnesses. However, some differences may exist as a result of family members' beliefs about the life-threatening nature of childhood cancer and the difficulty they have putting the illness in the background rather than making it a central focus of family life (Clarke-Steffen, 1997; Gonzales, Steinglass, & Reiss, 1989). Therefore, the applicability of existing factors that constitute family management needs to be compared with those of this population.

Illness situations characterized by intense uncertainty (Santacroce, 2003), conflict, and burden (Knafl & Deatrick, 2002) have been found to be most troublesome in the family life of children who are seriously ill. Families of children with brain tumors may face similar issues that make family management different from or more difficult than family management of other chronic conditions and types of cancer. In fact, recent data published from the Childhood Cancer Survivor Study comparing 10 397 survivors and 3034 siblings found that the 3 groups of survivors most at risk for severe or life-threatening chronic conditions are survivors of bone tumors, central nervous system tumors, and Hodgkin disease (Oeffinger et al., 2006). In addition, recent concern about health disparities experienced by adolescents and young adult survivors of childhood cancer justify focusing on adolescent and young adult survivors of childhood brain tumors (Department of Health and Human Services, National Institutes of Health, National Cancer Institute, & LIVESTRONG Young Adult Alliance, 2006).

Brain tumors are the most common solid tumors of childhood. Five-year survival rates, which have slowly improved to 65%, can be attributed to advances in multimodal therapy, including surgery and radiation, as well as to improvements in supportive care. Treatment can affect cognition in a variety of ways, including changes in overall IQ, slower processing speed, decline in shortterm memory, poor attention span, and impaired organizational skills. Physical sequelae often require care by multiple specialists and may include endocrine dysfunction, neurological deficits, hearing impairment, and changes in physical appearance (Ries et al., 2008).

These effects on both mind and body greatly affect the survivor's ability to meet normal milestones such as the development of social skills. In turn, as these survivors attempt to transition to adolescence, young adulthood, and beyond, they may demonstrate strengths as individuals but may not be fully capable of managing the complexity of their chronic physical health care needs and functioning independently in society (Eisner, Vance, Glaser, & Galvin, 2003; Langeveld, Grootenhuis, Voute, de Haan, & van den Bos, 2004; Mitby et al., 2003). For instance, although a survivor may be able to carry out a given set of employment responsibilities, he or she may not be able to do so at a speed that is acceptable to the employer. In the social realm, the survivor may have good intrafamily relationships but may have few friends of his or her own age.

As previously discussed, the treatment necessary for cure of these children can significantly influence their cognitive and social functioning, growth and development, and major organ function. This may create a unique constellation of issues for their families to manage. A gap exists in our understanding of what family management means to parents of adolescent and young adults who survived brain tumors. As a first step to understanding these potential

concerns, this pilot research project sought to describe both nurse expert and parental perceptions regarding family management of adolescents and young adults who survived brain tumors.

For the purposes of this research, and consistent with a family management approach, a household definition of family and a functional definition of parents was adopted. Family was defined as groups of intimates living together in close geographic proximity that functioned together with strong emotional bonds and had a history and a future (Fisher et al., 1998). Parents were defined as persons who viewed themselves as assuming major responsibility for their child's care. Partners referred to any other adult who was legally or emotionally linked to the primary caregiver. This study was limited to the perceptions of 1 parent.

Methods

A descriptive design was used to compare the meaning of family management in families who have children with chronic conditions other than cancer and those whose children survived brain tumors. A 2-step process was used to accomplish this purpose: (1) professional expert survey and (2) cognitive interviews with parents.

Expert Survey

To systematically determine the potential use of the FaMM for children who have cancer, 16 cancer survivorship and neurooncology advanced practice nurses were asked to assess its use with families of brain tumor survivors. These experts were identified from the professional literature, interest groups, and rosters of specialty meetings. An information packet approved by the institutional review board was then sent to each prospective participant. Those who agreed to participate then completed the survey in which they rated the relevancy of each item of the FaMM for this population and the clarity of each item on a 4-point Likert-type scale. Additional feedback was elicited about the wording and tone of the items as well as about additional themes and topics that may be pertinent to brain tumor survivors and their families. Data from the ratings obtained through the item-by-item survey were then used to calculate the scale-level content validity regarding both clarity and relevance (average proportion of items on an instrument whose clarity and relevance were rated 3 or 4 by all raters). The standard criterion for scale-level clarity and relevance is 90% (Polit & Beck, 2006).

Cognitive Interviews

A convenience sample of parents accompanying their children to neurooncology and cancer survivorship clinics were approached by clinic staff about their potential participation. Inclusion criteria included the following:

- resides in the same household as the survivor (who is defined as a person at least 5 years from last evidence of disease, 2 years from discontinuation of treatment, and between the ages of 14 and 30 years) and
- speaks English and reads independently at approximately the 5th or 6th grade level.

Exclusion criteria included parents of survivors who were

- married or living in a partnered relationship or
- diagnosed with neurofibromatosis.

Parents who gave permission to be contacted were then telephoned using an institutional review board approved script to assess their eligibility and, if appropriate, to obtain their verbal consent. Telephone appointments were then made to schedule the data collection interview session.

Cognitive interviews with parents were conducted via the telephone. Interviews were tape recorded and then transcribed. Items of the FaMM were read, and the parents were asked, “What does this mean to you?” This enabled assessment of the parents’ interpretation or understanding using their own situation as a point of reference. Parents’ interpretations were summarized on spreadsheets using content analysis and organized according to the 6 factors describing family management as well as other issues that emerged from the data.

Data were then compared with existing conceptualizations of each factor to determine consistency between them. For example, the investigators looked at whether parental interpretations of items related to *the difficulty of family life* (the extent to which the child’s condition makes family life more demanding) clearly referred to family level issues. In addition, parents were asked the following questions to help judge the applicability of the FaMM to adolescent and young adult brain tumor survivors: Does this apply in your situation? To whom does this refer? From what perspective? Are the wording and tone acceptable?

Sample

The parent sample is described in Table 2. Of 22 parents, the majority of the respondents were female (77.3% or 17/22), white (82%), and employed full-time (63.6 % or 14/22). A spouse resided in the majority of homes and participated in the care of the brain tumor survivor (86.4% or 19/22 and 81.8% or 18/22, respectively mothers and fathers). Of note is that 5 of the 22 mothers reported that they had a serious illness, including diabetes mellitus type I and type II and fibromyalgia.

The adolescents and young adults are described in Table 3. Most of the sample comprised survivors of primitive neuroectodermal tumor/medulloblastoma or astrocytomas. Most (59% or 13/22) of the survivors underwent surgery, radiation, and chemotherapy. The majority of parents reported that their child had medical effects from their cancer therapy (90.9% or 20/22), including cognitive/academic, physical, and social functioning issues.

Results

Expert Survey

A total of 14 of the 16 nurse experts responded to e-mail and telephone invitations to participate in the study. These professional experts generally endorsed the FaMM. They rated items on the FaMM for this population as relevant (96%) and clear (95%). Five of the items were rated by more than 2 experts as being unclear. During the quantitative validation study of the FaMM with children with other chronic illnesses that ran concurrently with this study, 2 of the items rated as unclear were revised, 1 item was deleted, and 2 items were retained (Knafl et al., in press).

Cognitive Interviews

Parents generally supported the same interpretations of family management as did the parents of children with chronic conditions (see Table 4). Because the specific nature of their caregiving differed, however, parent’s descriptions of family management related to managing their child’s brain tumor. Each of the 6 factors will be presented and then illustrated in 2 case studies.

The *child’s daily life* focuses on the parent’s overall perceptions of the child and his or her everyday life. Parents of children with brain tumors focused their interpretations on how the brain tumor and its treatment affected their children’s abilities and how their abilities may have changed as a result of the tumor and the treatment. Parents described how they had to reacquire themselves with their children and their abilities to perform physically, intellectually,

emotionally, and behaviorally. They also had to reacquaint their children with themselves, their families, and the outside world after treatment.

Parent's *view of the impact of the condition* was embedded in the relative amount of emphasis placed on the implications of the brain tumor for the future of the child and the family. Most parents expressed their concerns about an uncertain future and cancer as a potential life threat.

Family life difficulty is the extent to which the condition makes family life problematic. Much like families of children with other chronic conditions, parents varied in their perceptions regarding their ability to balance developmental or condition-specific concerns with those necessary for a harmonious family life.

Parents expressed ideas about the *condition management effort* or the time and work needed to manage their child's illness. Parents were very clear that their efforts were divided into 2 categories: (1) "then," that is, during diagnosis and treatment and (2) "now," that is, during survivorship. They made it very clear that the effort "then" and "now" was different and could change again in the future.

The parent's perception of their *condition management ability* is another element of family management. They explained manageability in terms of their abilities to handle the needs of the survivor over the long term within a dialectical context of loss and recovery. Thus, while trying to organize and execute their children's care, parents found themselves distracted by simultaneous feelings of grief over their children's losses in functional status and relief about their survival.

Parental mutuality is described as a critical component of family management for partners in terms of their perceptions of support, shared views, and satisfaction with working together to manage the child's condition. For partnered parents, mutuality was interpreted early in the illness through the impact of the brain tumor diagnosis and treatment on the couple and the family, and in survivorship through the impact on their parenting and their ability to balance protectiveness with independence. Each laid the foundation for family life and the couple's relationship.

Case Studies

Tim's Family: More Manageable (Perceives Less Difficulty and Effort)

Tim is a 23-year-old male who was diagnosed with medulloblastoma at 8 years of age. He was treated with all modalities: surgery (near total resection), chemotherapy (cisplatin, CCNU, and vincristine), and radiation (3600 cGy [whole brain and spine] + 5580 cGy boost to the posterior fossa). He had the following complications during treatment: postoperative ventriculitis, postoperative cerebellar artery infarct, and herpes zoster. Posttreatment issues consisted of hypoplasia of craniospinal axis, alopecia, hypothyroidism, growth hormone deficiency, seizures, scoliosis, cataracts, diabetes, learning disabilities, and herpes simplex virus encephalitis. He is currently followed by the cancer survivorship team, endocrinology, neurology, and ophthalmology. Tim will graduate from a community college in May. He has not been employed while attending college.

Tim is 1 of 2 children of Beth (aged 43) and Mike (aged 46). His grandparents are also involved with Tim's daily life. His maternal grandmother died of cancer during the time that Tim became a long-term survivor. Tim's family appears to be a cohesive and supportive one who "rolls with the punches." The overall guiding belief of the family seems to be that it is best to keep working at a problem until it is solved or changes.

Tim's mother and father have a complementary relationship in that they manage differently but have similar views about the illness. For instance, during Tim's illness, his mother was extremely anxious and attentive to details, and his father managed more long-term goals and would step in when his wife's distress escalated.

Tim is seen by his mother as more fragile than his sibling, but when pressed, she is able to redirect her concerns to long-term goals for Tim. For instance, she recently was able to agree with her husband that Tim could return to college after a 3-week episode of herpes simplex virus encephalitis and coma. For his part, Tim lets his mother hover and do things for him and only complains about being "overprotected" when he is talking privately with his nurse practitioner.

Allison's Family: Less Manageable (Perceives More Difficulty and Effort)

Allison is a 22-year-old female who was diagnosed with a thalamic hypothalamic anaplastic astrocytoma at 14 years of age. She was treated with all 3 modalities: surgery (near total resection and ventriculostomy), chemotherapy (procarbazine, CCNU, and vincristine), and radiation (4140 cGy focal and total of 5940 cGy with cone downs), so she received more focal treatment than Tim. She had the following complications during treatment: postoperative diabetes insipidus and adrenal insufficiency, transient language and memory loss, and chemotherapy reduction because of depressed counts (6 cycles rather than 8). She is currently followed by endocrinology, nutrition, psychology, and the cancer survivorship program for panhypopituitarism, obesity, diabetes, asthma, sensorineural hearing loss, migraines, learning disabilities, and alopecia/hypoplasia of craniospinal axis. Allison graduated from a community college. She has worked part-time at a grocery store for 6 years, but the store will not grant her full-time employment.

Allison is 1 of 2 children born to Antonia (aged 40) and Chris (aged 42). Her brother is a 19-year-old college sophomore who lives outside the home. One nephew survived leukemia; a distant cousin died of a brain tumor. There is a large extended family, but they are not involved with Allison on a day-to-day basis. Antonia and Chris struggle with their finances and live paycheck to paycheck.

Although very competent and appearing in control, Allison's mom perceives that she carries a great burden. She oversees the medication management and appointment attendance and advocates for services from agencies such as the Office for Vocational Rehabilitation. Although both parents have a similar goal of helping Allison learn to function independently, they have discrepant views about how to accomplish the goal. Allison's mother sees her daughter as more fragile than does her husband. Allison's father thinks that his wife "coddles" Allison too much and criticizes her because of it.

Allison's mother feels that the safety net is not there and that "if I don't do it, who will?" She sees the experience as a "lifetime deal," struggles with being able to "really do this," and continuously wonders when things will get easier, as she doesn't "see light at the end of the tunnel." Allison's mother has the sense that her husband and his extended family don't "get" the seriousness of Allison's situation and that her concerns are not taken seriously.

Application of Family Management Framework to Case Studies (See Table 5)

Tim's family illustrates one that is thriving and sees his condition as more manageable, less difficult, and requiring less effort than Allison's family. His parents' view of his daily life (*child's daily life*) is central to their management of his condition in that they see that he has a relatively normal life despite his condition. That is, they believe that his everyday life is similar to that of other children his age. His mother said, "You know, his normalcy is his normalcy. I

don't see any differences with regard to his illness that would be of any consequence when compared to other kids his age." In terms of his enjoyment of life, his father said,

There are things he can't do that other kids his age, but he has acclimated so that he can do those activities in some way. For example, he loves hockey, but can't play, so he used to be the manager of the team and helps out in other ways and is a huge fan.

How the parents view his condition (*view of condition impact*) is obviously central to understanding their management of his condition as well, in that they no longer focus on the condition as the center of family life. His mother said, "We don't focus on the condition. It used to be the first thing we'd think about. That is not how life works. Life is hard for all the kids at one point. It's always something."

Tim's parents found that their ability to manage (*condition management ability*) has increased. Tim's father stated, "... not that we understand brain tumors any more [than doctors or nurses], but we understand him and what he's been through." He stated that they second guess themselves now that Tim is becoming a young adult,

It's getting harder as he's become more of an adult, you know, but we've always had specific ideas about the ways things should be done and agreed as a family up to this point about everything. I'm not saying we disagree and it is getting a little harder.

In terms of their effort to manage (*condition management effort*), although the family acknowledged the changing nature of the demands, they also felt that the condition now does not take a great deal of time to manage the way it did when he was first diagnosed. In terms of crises situations, Tim's mother said, "The encephalitis last year ... it was horrible ... it was a reminder that it [brain tumor] could come back." On the other hand, developmental issues also increase their effort, as Tim's mother explained,

It's constantly changing, depending where you are in life and I take it like, Ok, we're good now and then he turned 16 and wanted to drive ... you're flying down the roller coaster again ... and then you're ok for a while because you get past that and then ... and then he's 18 and wants to go away to college ... and then issues of the short-term memory and issues with academics ... there's the condition with a million, bazillion things.

Tim's condition does not get into the way of family relationships (*family's daily life*). Tim's mother reflected on the dynamic nature of these processes,

[S]o, I guess we are (closer) because, you know, he's part of our family and everybody loves him and we all want to share in whatever he needs. But there are times when it does cause issues ... I'm not trying to paint a Little House on the Prairie ... but it did bond us. Sometimes we even get into fights over it ... but, basically, it's a good thing.

Finally, in terms of *parental mutuality* it is not simply the idea of agreeing on aspects of the care or on the division of labor. Tim's mother related,

I think we're pretty much in sync as to what the condition is. I think with me, however, because I've been involved a lot more with the hospitalizations and things, I may have a little bit more of an understanding of it, but that would be the only difference. He [the dad] sees things in black and white, but he would be the first to go to bat for him.

Rather than thriving like Tim's family, Allison's family appears to endure through the hardships of her condition. As with Tim's family, the parental view of her daily life (*child's daily life*) was central to their management of her condition. They see that Allison has a fundamentally different life than others her age because of her condition. "I mean, I hate to answer for her, but I think so. She's 21 years old and doesn't go out with friends and doesn't have a boyfriend. It's not what 21 year olds usually do."

They viewed her condition (*view of condition impact*) as one of the most important things in their family. Her mother said,

I'd like to say that her condition is not the most important thing in our family, but there's not a day that goes by that I don't think about it. Either I am thinking about the late effects or the chance of it coming back. It's like waiting for the other shoe to fall. It's always on the back burner.

Allison's mother feels able to manage her condition (*condition management ability*) on a day-to-day basis but is frustrated with her attempts to help Allison become more independent. "We have ideas that we would like her to be more in charge of the condition, but realistically, I don't think it will happen. It will always fall back to me."

Regarding the effort needed to manage the condition (*condition management effort*) however, Allison's mother emphasized issues of burden and unpredictability, "Things take a great deal of time because of her disabilities. I always focus on it being her disability; the results from her treatment are going to affect her future ... I am always on edge."

Moving beyond Allison and on to the *family's daily life*, the condition did get into the way of family relationships,

It can be a strain and kind of push you ... you gotta take care of your other kids, too. He kind of feels a little neglected. I get very preoccupied with worrying about Allison. I know her best and I have been taking care of her for so long. She's my baby. How can I be sure she is safe or making the best decisions? I have to stay on top of her for her meds and appointments. It is scary.

Finally, in terms of *parental mutuality*, Allison's parents could not agree on aspects of her care and criticized each other about their care of Allison. Her mother reflected,

Is it emotional closeness or because we felt under assault by everybody, did we build walls and then were inside there? Do you know what I'm saying? It's not necessarily because we want to be inside there together ... and the other kids feel kind of neglected.

Basically, Allison's mother and father did not agree on the seriousness of her condition and her potential to live independently, which led to serious disagreements between them.

Discussion

These parents generally supported the same interpretations of family management as did parents of children with chronic conditions. The nature of their caregiving work differed, however, in the examples and descriptions used to communicate their ideas. In particular, their interpretations are imbued with descriptions of loss and fears about the future.

Practice Implications

Family management is an organized and structured framework to assess family functioning that appears relevant to the care of adolescent and young adult survivors of childhood brain tumors. Assessing strengths and potential weaknesses across each factor constituting family management as well as family management as a whole provides a systematic glimpse into what management of a brain tumor survivor is like outside the four walls of the hospital.

In daily practice, tools are not available to simultaneously assess how the family is functioning and how they manage the child's cancer; therefore, clinicians find it challenging to tailor interventions to particular family needs. For instance, one family and its members may see their situation as more manageable, less difficult, and requiring less effort. This family may

require professional vigilance so that they can gently provide anticipatory guidance about future situations, such as when the survivor who was able to finish school cannot find a job once school is no longer an option. Another family and its members may see their situation as less manageable, more difficult, and requiring more effort. This family may require focus on common goals and family roles.

Research Implications

The research reported in this article provided both professional and parental input into the design and implementation of present research regarding family caregiving (NIH/NINR R01 NR009651-01A1). From this study, the interdisciplinary team learned about the importance of carefully framing our empirical model, research questions, and measures to include ideas expressed by these participants. For instance, in the current study, a measure of life threat (Assessment of Life Threat and Treatment Intensity Questionnaire) is included to accurately measure the presence and intensity of said perceptions that were important in defining the *view of the condition*. Finally, directions to the FaMM were modified (ie, acknowledge the importance of their effort during diagnosis and treatment, but stress the importance of reporting their present effort for this instrument) based on the interviews and information obtained.

Long-term goals of this research are to develop interventions to decrease perceived demands and increase the perceived competence of caregivers. Family management is an important key to those processes and eventually to the health and well-being of long-term survivors of brain tumor survivors and their families.

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Table 1

Family Management Measure (FaMM)

Scale	No. of Items	Content (Parents' Perceptions of ...)
Child's daily	5	Child and his or her everyday life (higher values indicate a more normal life, despite the condition)
View of condition impact	10	Seriousness of condition and its implications for child's and family's future (higher values indicate a more serious condition)
Family life difficulty	14	Extent to which condition makes family life more demanding (higher values indicate a more difficult life)
Condition management effort	4	The time and work needed to manage the illness (higher values indicate more work)
Condition management ability	12	Competence to take care of the child's condition (higher values indicate greater capability)
Parental mutuality (completed by partnered parents only)	8	Support, shared views, and satisfaction with how a couple works together to manage the condition (higher values indicate greater satisfaction)

Table 2

Parent Sample for Cognitive Interviews (N = 22)

Respondents	Demographics
Mothers: 77% (17/22)	Married: 86% (19/22)
Fathers: 23% (5/22)	Biological parent of survivor: 100% (22/22)
	Age 31-50 years: 55% (12/22)
	White: 82% (18/22); African American: 14% (3/22); Asian: 5% (1/22)
	Employed full-time: 64% (14/22)
	College educated: 45% (10/22)
	Parents with serious illness
	Mothers: 23% (5/22)
	Fathers: 0% (0/22)

Table 3**Survivors Sample for Cognitive Interviews (N = 22)**

Male: 73% (16/22)
Female: 27% (6/22)
Mean age: 19.3 years
Highest level of education
Grade school: 23% (5/22)
High school: 9% (2/22)
Post-high school: 64% (14/22)
Parental rating of survivor overall health status
Good or excellent: 91% (20/22)
Presence of additional chronic illness: 91% (20/22)
Cognitive/academic functioning: 54.5%
Physical functioning: 45%
Social impact
No impact: 23%
Low impact: 18.2%
Moderate impact: 22.7%
High impact: 36.4%

Table 4

Family Management of Childhood Brain Tumor Survivors

Family Management Scales	Manifestations in Families of Brain Tumor Survivors
Child's daily life: child and his or her everyday life (higher values indicate a more normal life despite the condition)	Child's abilities before and after treatment
View of condition impact: seriousness of condition and its implications for child's and family's future (higher values indicate a more serious condition)	Implications of brain tumor for future of child and family
Family life difficulty: extent to which condition makes family life more demanding (higher values indicate a more difficult life)	Ability of family to balance their focus on ongoing family life with the needs of the survivor
Condition management effort: the time and work needed to manage the illness (higher values indicate more work)	Amount of time and work needed to manage now, during survivorship
Condition management ability: competence to take care of the child's condition (higher values indicate greater capability)	Overall ability to handle needs of the survivor over the long term within a context of loss and recovery
Parental mutuality (completed by partnered parents only): support, shared views, and satisfaction with how a couple works together to manage condition (higher values indicate greater satisfaction)	Relationships, shared views, mutual support; flexibility

Table 5

Two Cases Illustrating Family Management of Brain Tumor Survivors

Perception of Parents ...	Tim	Allison
Survivor's daily life	More "normal"	Less "normal"
View of condition impact	Less "serious"	More "serious"
Family life	Not particularly "difficult"; doesn't interfere	More "difficult"; interferes
Condition management effort	Less "effort" now (low effort)	More "effort"
Condition management ability	High "ability"	Moderate "ability"
Parental mutuality	High satisfaction (high "mutuality")	Low satisfaction (low "mutuality")