

Maternal Caregiving Demands for Adolescent and Young Adult Survivors of Pediatric Brain Tumors

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With advances in multimodal therapy, including surgery, chemotherapy, radiation, and supportive care, the five-year survival rate for the 4,300 children who will be diagnosed with a brain tumor in 2015 has improved to 75% (National Cancer Institute, 2013). Therefore, an increasing number of survivors of pediatric brain tumors are living into adolescence and young adulthood while dealing with late effects of treatment, such as cognitive deficits, hearing impairment, visual disturbances, endocrine dysfunction, neurologic deficits, and changes in physical appearance. They may require care long after completing treatment and are less likely than survivors of other childhood cancers to become independent adults (Oeffinger et al., 2006). The demands of caring for these survivors are important to understand because of the implications for their ongoing care, as well as for parental psychosocial and physical health (Klassen et al., 2011). Although the demands of caring for children with chronic conditions (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2003; Sullivan-Bolyai, Knafl, Sadler, & Gilliss, 2004), children receiving cancer treatment (Klassen et al., 2011; Wells et al., 2002), and older adults (Northouse, Katapodi, Song, Zhang, & Mood, 2010) have been identified, they have not been determined for the adolescent and young adult (AYA) population.

Mothers typically are the nonprofessional caregivers providing day-to-day care to children who survived pediatric brain tumors (Deatruck, Mullaney, & Mooney-Doyle, 2009; Forinder & Norberg, 2010). The current study takes the first steps in identifying primary caregiver demands directly related to AYA survivors. It seeks to answer the question, "What are the daily caregiving demands experienced by mothers of AYA survivors of pediatric brain tumors who live with their families?" The long-term goal is to study primary and secondary demands experienced by the family (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994) to promote their well-being (Deatruck et al., 2014).

Purpose/Objectives: To examine the daily maternal caregiving demands for adolescent and young adult survivors of pediatric brain tumors who live with their families.

Design: A secondary analysis was conducted on interview data gathered during a large mixed-methods study that focused on perceived maternal caregiver competency and survivor health-related quality of life.

Setting: Home interviews.

Sample: A purposive sample of 46 maternal caregivers was selected from participants in the larger study.

Methods: Semistructured interviews were conducted with mothers. A directed content analysis was informed by Sullivan-Bolyai's framework describing the components of primary caregiving.

Main Research Variables: Caregiving demands.

Findings: Data regarding four main categories of maternal daily caregiving demands were identified from 25 of the 46 interviews: managing the illness; identifying, accessing, and coordinating resources; assisting with everyday responsibilities; and fostering psychosocial health.

Conclusions: Potential day-to-day management tasks or demands of mothers of adolescent and young adult survivors of pediatric brain tumors were identified.

Implications for Nursing: The major demands of caregiving are similar to those for children with other chronic conditions, with the addition of assisting with everyday responsibilities and fostering psychosocial health.

Key Words: caregiver tasks; pediatric brain tumors; caregiving demands; caregiving burden; parents; qualitative research

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Because frameworks do not exist for caregiving in families of young adults, child and adult caregiving frameworks are summarized according to the framework proposed by Sullivan-Bolyai et al. (2003, 2004). Primary caregiving demands include managing the illness and identifying, accessing, and coordinating resources. Secondary caregiving needs include maintaining the family unit and maintaining self.

To move the science of caregiving forward, the similarities and differences within and across populations need to be identified (Grady & Gullatte, 2014). As shown in Table 1, mothers caring for survivors of pediatric brain tumors may share similarities with caregivers of individuals with other chronic conditions across the lifespan. Contextual differences exist regarding developmental considerations, role obligations and responsibilities (e.g., mother versus partner or spouse), and duration (e.g., lifetime of care for a child). Each illness may carry different demands (e.g., physical versus neurocognitive symptoms) and commitments (e.g., limited time versus lifelong).

Illness management requires knowledge, vigilance, advocacy, and balance (of parental work and the burdens of treatment) (Kelly & Kelly, 2013), which may be fulfilling for the caregiver but may take a toll on them (Xu et al., 2012). In addition, as family members transition to the role of caregiver for adults with brain tumors, social support from family and friends is seen as vital to the emotional health of the caregiver (Hricik et al., 2011).

While identifying, accessing, and coordinating resources, caregivers can simultaneously experience positive and negative changes. Financial resources are particularly crucial (Cadell, Kennedy, & Hemsworth, 2012), and travel over long distances may be necessary to access needed healthcare resources (Shepherd & Woodgate, 2011).

To maintain the integrity of the family unit, caregivers strive to manage issues resulting directly or indirectly

from the care of seriously ill children, such as finances, work, health of family members, family life, and time (e.g., taking time for family vacations, pressure on marital relationships) (Davis et al., 2010; Fletcher, 2010; Murphy, Christian, Caplin, & Young, 2007; Svavarsdottir, 2005). They also manage anxieties, fears, and grief regarding potential or actual losses that arise within the family unit.

In terms of maintaining self, caregivers can experience health consequences of caregiving that can limit their ability to perform the caregiving role and potentially increase tasks of self-care. Studies have reported poorer general health, with symptoms including fatigue (Brehaut et al., 2004; Chien et al., 2003; Davis et al., 2010; Murphy et al., 2007; Skalla, Smith, Zhongze, & Gates, 2013) and poor quality of sleep (James et al., 2002; Meltzer & Mindell, 2006; Skalla et al., 2013; Yamazaki, Sokejima, Mizoue, Eboshida, & Fukuhara, 2005). Caregivers also can experience emotional, psychological, and psychosocial effects (Aitken et al., 2009; Brehaut et al., 2004; Chien et al., 2003; Hatzmann, Heymans, Ferrer-i-Carbonell, Van Praag, & Grootenhuis, 2008; James et al., 2002; Klassen et al., 2008; Yamazaki et al., 2005), which decreases their perceived ability to provide care (Cooper, Robertson, & Livingston, 2003; Driscoll, Montag-Leifling, Acton, & Modi, 2009; Iwamoto, dos Santos, Skare, & Spelling, 2008; Raina et al., 2005; Reiter-Purtill et al., 2008). In addition, caregivers often cannot be employed, pursue their own careers (Cadell et al., 2012; Fletcher, 2010), or

maintain social relationships (Davis et al., 2010). In terms of risk factors, caregivers perceive increased demands if they have low incomes and education (Klassen et al., 2011) or poor health (Deatrick et al., 2014), or if they are female, are poor, are relatively uneducated, spend more hours with the care recipient, are depressed, are socially isolated, or perceive that they have no choice about the role (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014).

Methods

The qualitative interviews were conducted as part of a large, mixed-methods study, approved by the Children's Hospital of Philadelphia and University of Pennsylvania institutional review boards, that focused on perceived caregiver competency and survivor health-related quality of life (Barakat et al., 2014; Deatrick

Table 1. Components of Primary and Secondary Caregiving for Children and Adults Identified in the Literature

Component	Framework	
	Children	Adults
Primary caregiving		
Managing the illness	Klassen et al., 2011; Stewart et al., 1994; Sullivan-Bolyai et al., 2003, 2004	Northouse et al., 2010; Skalla et al., 2013
Identifying, accessing, and coordinating care	Sullivan-Bolyai et al., 2003, 2004	Northouse et al., 2010
Basic needs	Stewart et al., 1994	Northouse et al., 2010; Skalla et al., 2013
Emotional needs	Klassen et al., 2011	Northouse et al., 2010; Skalla et al., 2013
Secondary caregiving		
Maintaining family life	Stewart et al., 1994; Sullivan-Bolyai et al., 2003, 2004	Skalla et al., 2013
Maintaining self	Stewart et al., 1994; Sullivan-Bolyai et al., 2003, 2004	—

et al., 2014). The study was conducted in two phases (quantitative followed by qualitative), with separate consents obtained for each phase. A subsample of participants from the quantitative phase was included in the qualitative phase. A secondary analysis of the qualitative data is reported in this article.

Sample and Settings

Potential participants were screened and recruited in telephone interviews. Inclusion criteria were maternal caregivers of survivors who were (a) diagnosed with brain tumors, (b) at least five years from diagnosis, (c) at least two years from discontinuation of treatment, (d) aged 14–30 years, (e) living in the same household as the caregiver, and (f) legally related to the caregiver. For inclusion, the maternal caregiver also had to be acknowledged as the primary caregiver by herself and the survivor. Maternal caregivers were excluded if the survivors were (a) married or living in a partnered relationship, (b) diagnosed with genetic basis for brain tumor, (c) diagnosed with mental retardation or developmental delay prior to cancer, or (d) not able to speak English or read independently at about a fifth- to sixth-grade level. A purposeful, maximum variation-based sample of 46 maternal caregivers then was selected to be interviewed based on mothers who expressed varying types of caregiver demands during the telephone interviews and lived within a drivable distance for the interviewer (1 hour and 30 minutes one way from the hospital). Because the interviews focused on caregiver competence and survivor health-related quality of life, interviews were identified by the first two authors that best focused on rich descriptions of primary caregiving demands or tasks.

The semistructured interview guide was constructed by the study team and an expert in family research and then modified after pilot testing with five families. The guide began with broad, less probing questions about the family and illness experience followed by questions about the major conceptual components of the parent study, including caregiver competence and the survivor's health-related quality of life (Deatrick et al., 2014). The interviews were conducted face-to-face in a private setting in the maternal caregivers' home by the second author after maternal caregivers provided written consent. After the interview, the maternal caregivers received \$20 for their participation. Interviews were digitally recorded, shared with a professional transcription service by a secure file-transfer dropbox, transcribed verbatim by the transcription service, and stored on a secure server. In addition to the transcriptions, case summaries and field notes were included in the analyses.

Data Analysis

Descriptive or topical categories in the data were identified by principles of directed content analyses (Hsieh & Shannon, 2005) based on the conceptual framework. The first two authors independently applied the categories to a sample of two interviews and compared their application of the categories to identify lack of clarity and overlap in categories. The investigators created a code book that contained a definition of categories, guidelines for their application, and excerpts of data exemplifying the categories. The first two authors independently coded the data and compared how they applied the categories to the data and resolved any differences during biweekly meetings. ATLAS.ti, version 6.2, accommodated ongoing changes and additions to the coding structure.

The overall study was designed to ensure the trustworthiness or scientific adequacy of the data and the rigor of the mixed-methods analysis. The investigators generated qualitative data that provided a comprehensive answer to study questions. In addition, software specifically designed to support qualitative analysis was used. Checks were built into the design of the analysis to ensure that categories were consistently applied and identified based on a systematic inspection of the data. Strategies to increase transferability included a thick description of the results and final confirmability audit (Guba, 1981) of the data and results by an investigator naive to the original analyses (last author).

Sample Characteristics

The data for this analysis were extracted from the interviews, which consisted of 46 mostly Caucasian and non-Hispanic caregivers aged 41–67 years (see Table 2). Most caregivers were employed full-time, attended at least some college or graduated from college or graduate school, and were married or with a partner. They were caregivers for 7–27 years, with an average of 15 years, and all were biologically related to the survivor. Including the survivor, the number of children living in the home was two ($n = 19$), three ($n = 12$), four ($n = 10$), and five ($n = 5$). Thirty-nine caregivers reported a spouse or partner living in the home, and four reported another adult female living in the home. The mothers reported receiving help from a spouse or partner ($n = 31$), brother ($n = 3$), or aunt ($n = 2$).

The survivors who were studied in phase two were aged 15–36 years ($\bar{X} = 23$ years, $SD = 4.86$). Twenty-eight were male, and 38 were Caucasian. Nine did not go to school or work, five volunteered only, and 27 had moderate restriction to daily activities. Tumors most often were located in the posterior fossa ($n = 23$). The

Table 2. Sample Characteristics (N = 46)

Characteristic	\bar{X}	SD	Median	Range
Caregiver age (years)	52	4.86	52	41–67
Characteristic	n			
Caregiver race				
Caucasian	41			
African American	4			
Asian or Pacific Islander	1			
Caregiver ethnicity				
Non-Hispanic	45			
Hispanic	1			
Caregiver employment				
Full-time	25			
Part-time	9			
Not employed	12			
Caregiver education				
High school, vocational school, or less	15			
Some college	10			
College	12			
Graduate school	7			
Other	2			
Family income (\$)				
Less than 20,000	1			
20,000–29,000	–			
30,000–39,000	4			
40,000–49,000	1			
50,000–59,000	2			
60,000–74,000	4			
75,000–99,000	7			
100,000–149,000	9			
More than 150,000	12			
Not reported	6			
Caregiver marital status				
Married or with partner	39			
Single, divorced, or widowed	7			

most common histologies were low-grade glioma (n = 20) and medulloblastoma (n = 15). No significant difference ($p > 0.05$) was found between this sample and the sample of caregivers and survivors in the larger study (Hobbie et al., in press).

Results

Four categories of primary caregiving demands were described: managing the illness; identifying, accessing, and coordinating resources; assisting with everyday responsibilities; and fostering psychosocial health. Although the first two categories were consistent with the framework developed by Sullivan-Bolyai et al. (2003, 2004), the last two were new components.

Managing the Illness

Maternal caregivers described having to manage medications, diet, and equipment for the survivor. In particular, endocrine dysfunction secondary to the tumor or its treatment created caregiving demands,

including those related to obesity, diabetes, or intolerance to certain foods. Mothers reported having to prepare special meals for their children and assist them in establishing exercise regimens. According to one mother, “With the diabetes and everything, we’re always saying you have to walk or do something every other day, at least.” They also described condition- and equipment-related caregiving tasks. One mother said,

Because he has an ileostomy, this morning, my husband got up at quarter to six and heard [name] cursin’ and carrying on in his room. . . . Because it got so full from overnight, I guess the pressure of it, like, undid the Velcro, and his bag just emptied right on his carpet in his bedroom. And so, my husband yells up to me and says, “You gotta get up. [Name] needs help.”

In addition, mothers often reported having to manage the survivors’ medications for them. According to one mother, “I wouldn’t trust him to take medication. . . . I wouldn’t just, like, give him a bottle of pills. . . . He gets confused very easily.”

Mothers also illustrated how they went about managing the illness. They reported having to ask medical questions on behalf of the survivors, document and keep records, make medical decisions for their children, and monitor and interpret signs and symptoms of possible health problems. One mother said, “She is not aggressive, like, she’s not very even observant . . . which is why she needs somebody watching, asking questions.”

Identifying, Accessing, and Coordinating Resources

This category was broken down into three different types of resources—health, personal, and community—that the mothers identify, access, and coordinate. The first type of resource, health-related, is closely related to the first category, managing the illness, in which mothers coordinate healthcare resources for their children. They reported making appointments, going to appointments with the survivor, negotiating and advocating with healthcare professionals, and seeking appropriate healthcare providers. According to one mother,

Her endocrine life that was pretty much driving a lot of her day-to-day care. So once that happened, then we were forced to get in line with a new endocrinology contact. We can’t do anything to help other than to get her into the right hands so that the people who can help her could help her.

Mothers assisted the survivors with many personal resources that young adults normally would coordinate for themselves (e.g., living arrangements, employment opportunities, insurance issues). One mother said,

He was trying to hold down [a] job, and he went through several places of employment, and they found reasons why they couldn't keep him. . . . He was just really not quite capable. . . . We even tried to sort of have an at-home business for him with the machining that he has learned in high school, and it just wasn't going well.

Maternal caregivers described the community resources they access and coordinate as well. One mother said, "She had emailed us some stuff about what [another hospital] does. . . . They have, like, cancer survivors that meet. . . . I think it was called 'navigating the new normal.'"

Education is a resource that mothers explored in the interviews as a personal and community resource. Mothers described having to negotiate with schools for certain resources and advocate for their children, as well as having to assist survivors in identifying and accessing appropriate resources at college. According to one mother,

So, the college process search for her was really, really unusual compared to what most people do because we were paying very, very close attention to not just the size of the campus but their medical supports and their supports for any other kind of accommodations that she might need. Where is the closest hospital? Where are the pharmacies?

Assisting With Everyday Responsibilities

Mothers of AYA survivors of pediatric brain tumors described having to assist their children with everyday tasks, including cleaning their rooms, doing their laundry, cooking meals, making sure they eat, giving directions, driving them, keeping track of their belongings, managing finances, organizing daily life, giving reminders, shopping for them, and promoting hygiene. One mother said,

He was in the wedding, and they knew his limitations. . . . Like, he can't wear dress shoes. He needs high-top sneakers. He's wearing sandals now because he's in the house and, again, he put them on the wrong feet. That's one of the little things that he doesn't get.

The amount of assistance survivors needed depended heavily on the extent of cognitive or physical limitations from the disease or associated treatment. For example, although several mothers described having to assist their children with meal preparation and cooking, only one mother verbalized having a hard time getting the survivor to physically eat. She said, "[My daughter] can get him to eat when no one else can. I don't know how or why." Some of these limitations may be permanent, and survivors may continue to need assistance with everyday responsibilities well into adulthood.

Fostering Psychosocial Health

The interviews identified the psychosocial needs of AYA survivors of pediatric brain tumor and the mothers' intricate involvement with and management of these needs and how they fostered communication skills. According to one mother,

I tried to help him out and [told him to] say, "I really don't like you talking to me like that." Don't allow people to treat you whatever way they want. And I think it's his insecurity and his stature maybe.

One mother also described providing companionship.

We have a television upstairs, and occasionally he doesn't want to watch what I want to watch, but he'd rather be with me than have me go upstairs to watch my show. He likes to have the companionship, some company.

Many of the mothers expressed that they spend time worrying about their children having difficulty meeting friends and significant others. They have to encourage and assist the survivors in pursuing friendships and romantic relationships. According to one mother,

Sometimes he puts his guard up, and that maybe drives people away . . . you know, a protection thing. And of course I'd love for him to meet a girl, that he could just have a girlfriend like everybody else. Normalcy . . . if I could just get him meeting people more, that would open that door so much more.

They also promote independence. One mother said, "But the hardest thing for me is—I'm so used to doing for him—backing off. And I'm a little better. I think I've come a long way, but I know I have a long way to go."

Another role is decision maker. According to one mother, "Generally, I would say pretty much all the executive functioning skills. She needs help with making decisions. She needs help understanding that things aren't obvious."

They aid with transitions as well. One mother said, "It's a lot of transitions, and even with me telling her ahead of time exactly what to expect and talking her through the whole thing before it's happening and as it's happening, it's overwhelming."

In addition to encouraging relationships, mothers encourage activities. According to one mother, "We volunteered for the Livestrong® event that just happened, so if I can kind of do things like that to not only engage myself in community kind of activities, but also help her."

Lastly, the researchers identified how mothers provide anticipatory guidance. One mother said, "Because he isn't a real drinker, but because he's shy, I didn't want him to like it relieving his inhibitions. But I said, 'You know the endocrinologist said not more than three beers.'"

Discussion

The mothers of AYA survivors of pediatric brain tumors shared many of the same day-to-day management tasks identified by Sullivan-Bolyai et al. (2003, 2004), with the addition of assisting with everyday responsibilities and fostering psychosocial health. Primary and secondary components of caregiving were synthesized into a proposed caregiving framework that potentially can be applied across the lifespan. Such lifespan frameworks are important to identify caregiving demands across populations that may or may not be typical for specific populations. In fact, a 24-year-old survivor of childhood cancer has similar cumulative incidence of severe health conditions as a 50-year-old sibling (Armstrong et al., 2014).

Sullivan-Bolyai et al.'s (2003, 2004) categories of secondary caregiving needs—maintaining the family and maintaining self—were not the focus of the current study. Mothers in the current study revealed that because of the many caregiving demands, they had less time and energy to dedicate to maintaining self and family. Similar to the chronic illness literature, the mothers in the current study described feeling fatigued and having a difficult time making decisions for themselves and their other children, maintaining their own social relationships, and pursuing their own careers (Brehaut et al., 2004; Meltzer & Mindell, 2006).

All four categories are represented equally across the 25 interviews. Under each category, however, specific tasks were evident and had varying frequencies. Although the mothers in the interviews all indicated several different tasks they faced while caring for the survivors, the intensity varied. Some described only a few items with which they assisted their children, but others detailed lengthy lists of tasks. In addition, some described less intense types of activities (e.g., cooking, driving), but others recounted the details of more involved tasks (e.g., dressing, physically feeding the survivor), which may be related to the extent of cognitive impairment in the AYA survivor. Managing medications, monitoring the survivor and interpreting symptoms, going to healthcare appointments, negotiating with healthcare providers, negotiating with the school, assisting with employment and insurance resources, encouraging relationships, promoting independence, and driving are the tasks the caregivers reported most often.

Although the current study did not include analyses of risk to the caregiver regarding caregiving demands, several factors may protect them in that they are predominantly educated, employed, and have relatively high incomes (Klassen et al., 2011). However, because of the subjective nature of primary caregiving demands, as well as the obligations and responsibilities of family

Knowledge Translation

Assessment and teaching for caregivers of adolescent and young adult (AYA) survivors of pediatric brain tumors can focus on primary caregiving demands.

Nurses can provide leadership for multidisciplinary approaches to best assess, prepare, and support maternal caregivers and AYA survivors of pediatric brain tumors.

Caregiving described in this article and in the literature shares similar characteristics: primary (focused on the care recipient) and secondary (focused on the caregiver and family) demands.

caregiving, financial resources may ameliorate but not eliminate certain areas of perceived demand (Adelman et al., 2014). In addition, a majority of the mothers noted that they had others who could help them, which would be crucial because 35 of the caregivers were employed. The fact that they are female, spend many hours a day with their children, and have been in their roles much longer than most caregivers for adults increases their risk for psychosocial sequelae (Adelman et al., 2014).

The sample of the current study is limited in that the researchers identified all AYA survivors of pediatric brain tumors in the tumor registry who responded to a mail contact and met study criteria. The cohort was predominantly Caucasian and non-Hispanic and had good financial resources. Additional studies are needed to clarify the caregiving demands and measure them accurately. The current study can be replicated to further test the framework with other caregivers, the consequences (e.g., parenting stress), and relative risk posed by factors associated with the demands.

Implications for Nursing

Nurses can provide leadership to the interdisciplinary team regarding the importance of assessing and educating caregivers about the demands that they face with AYA survivors of childhood brain tumors. Because the results show that the mothers spend a lot of time monitoring the survivor, interpreting signs and symptoms, and making medical decisions for the survivor, nurses may need to educate caregivers on problem-solving and critical-thinking skills that pertain to managing the illness. According to Sullivan-Bolyai et al. (2003),

If one considers the time and experience it takes for novice nurses to learn and feel confident with this type of critical thinking, the expectation of parents to function similarly in a relatively short period of time and during a period of immense emotional stress underscores the magnitude of the challenge. (p. 458)

The importance of advocating for case management resources for this population was demonstrated by the amount of time that mothers spent navigating employment, insurance, and education resources for the survivors. Therefore, caregivers need to be linked to existing services that help with these processes. A comprehensive understanding of the survivors' functional and self-care abilities, as well as caregiving resources, is needed when planning with the caregiver how best to assist the survivor with everyday responsibilities. The healthcare team needs to involve the family in problem solving the multifaceted demands of caregiving. Because caregivers report the need to promote independence in their AYA children, programs need to be created to assist survivors in accomplishing this goal. Multidisciplinary clinics for treating and transitioning complex survivors, including eligible survivors of brain tumors, are one example of how institutions can garner resources and train staff to provide a win-win arrangement for the survivor, maternal caregiver, family, and healthcare system (Carlson, Hobbie, Brogna, & Ginsberg, 2008).

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