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Mother-caregiver expectations for function among survivors of childhood brain tumors

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Abstract

Purpose—Children diagnosed with brain tumors increasingly survive to adulthood, although they do so with needs often requiring continued parental caregiving. We sought to describe the nature of caregivers' expectations about survivors' function and how expectations connect to ongoing management and decision-making.

Methods—Forty-five qualitative interviews with mother-caregivers were conducted and coded for themes related to expectations for their adolescent/young adult children living post-childhood brain tumors.

Results—Five main themes emerged as integral to mother-caregiver expectations: realizing a difference in the survivor, noticing limitations to independence in the survivor, memories of learning about clinical prognoses as understood from consent meetings and education, managing these realizations, and acknowledging unresolved challenges.

Conclusions—Caregiver expectations are influenced by both initial clinical interactions and contemporary family dynamics and require individual- and family-specific survivorship planning. As caregiver expectations can influence management behaviors that impact outcomes and possibly independence, implications for clinician-caregiver shared decision-making are substantial.

Keywords

Oncology; Qualitative approaches; Communication; Decision-making; Adolescent/young adult survivors

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

Childhood brain tumors are no longer a death sentence as children diagnosed with brain tumors have an overall relative 5-year survival rate of 74.2 % [1]. Compared to their siblings or peers with other oncologic diagnoses, many more live with their parents into young adulthood with the potential to outlive parent-caregivers without having attained independent living [2]. Approximately 82 % of survivors of childhood brain tumors suffer from at least one treatment-related physical, neurocognitive, or psychosocial late medical sequelae affecting functioning and interfering with milestone achievement (higher education, employment, life partnership) and independence [3–7]. These treatment-related sequelae have variable latency [8] and worsen as the child ages into adulthood, often leaving caregivers unprepared to meet everyday needs [3, 9]. We do not understand, either at diagnosis or in survivorship, what caregivers expect about survivors' function and how expectations affect ongoing management and decision-making about survivors' healthcare, education, therapies, and social issues.

Here, we report the results of a qualitative study of mother-caregivers for adolescent/young adult (AYA) children who have survived a childhood brain tumor to describe caregivers' expectations about survivors' function and how expectations relate to ongoing management and decision-making. Mother-caregivers navigate complex relationships among prior-experience and memory, current practices and expectations, and future planning. Findings from this study inform both clinician-caregiver shared decision-making and continued family management and assistance.

Background

Clinicians' prognoses for children diagnosed with cancer, when shared, are variable in content and approach [10] and generally focus on treatment and anticipated function-associated changes of the child [11, 12]. Few empirical findings report on caregiver expectations, however. In this paper, we define caregiver expectations as cognitive and emotional aspects of caring for survivors of childhood brain tumors that influence caregivers' overall future assessment of their children's developmental capabilities. These can include expectations arising from interactions with clinicians as well as those occurring in daily life and community activities. Caregiver expectations are integral to understand as they may powerfully influence future support needed from clinicians, family members, and other service providers in their communities.

We do know that caregivers of children with cancer and chronic conditions often experience uncertainty about the course of their children's health, a source of stress complicating caregiving [13, 14]. Caregivers report grieving for and about a child who is alive, consenting for and observing lifesaving treatments with (un)known sequelae, and parenting a child who has not developed effective coping strategies [15]. Intrafamilial dynamics and circumstances, such as identifying, accessing, and coordinating resources; maintaining both the family and self; educating others; and negotiating caregiver-survivor expectation conflicts [16–18], also influence both caregiving and caregivers' views of the survivors' quality of life [19].

Other research on caregivers focuses on the lenses through which caregivers form management plans. Many caregivers reframe understandings of “typical” with a “normalcy

lens,” adapting family-focused management patterns to incorporate care into ongoing family life—including minimizing differences between child and peers [20, 21]. The contrasting condition-focused management pattern centers family life around care of the child—including maximizing differences between child and peers [21]. Family dynamics also influence expectations for survivor functioning and caregiving [22]. For example, family members criticizing caregivers for arranging socialization opportunities for survivors believe that survivors are not helping themselves and eventually may lead caregivers to discontinue such efforts. Finally, expectations may differ within the caregiver-survivor dyad, with the survivor concentrating on different issues than either clinician or caregiver [18]. Caregivers might perceive their children as having more social and communication problems than others, but the survivors see themselves like peers [23].

Therefore, several factors influence caregivers’ expectations for their AYA children with chronic conditions, including clinical uncertainty and intrafamilial factors. What the literature does not reveal is whether or how expectations might influence the *performance* of caregiving, including decisions made for the family and the AYA child, which have strong potential to influence future health and health-related quality of life outcomes for the AYA child, caregiver, and family. Here, we report the results of a qualitative study of mother-caregivers for AYA children who have survived a childhood brain tumor but continue to reside with the caregiver to describe caregivers’ expectations about survivors’ function and how these expectations connect with ongoing management and decision-making. Our intention is that these findings may provide non-parent caregivers with better understandings of caregivers’ expectations about their children, how these expectations may be identified and addressed, and implications for shared decision-making.

Methods

These findings are a secondary analysis from data collected during the qualitative phase of a two-phase mixed-methods study of perceived caregiver competence, psychosocial functioning of survivor and caregiver, and household functioning among AYA survivors of childhood brain tumors and their mother-caregivers. The quantitative phase is described elsewhere [24]. The qualitative descriptive methods included in-depth, semi-structured, face-to-face interviews in the family’s home with mother-caregivers. This study received institutional review board approvals from the University of Pennsylvania and The Children’s Hospital of Philadelphia. Informed consent (and assent for survivors under 18 years) was obtained from all individual participants included in the study.

Participants

The quantitative phase recruited from facility databases and outpatient clinics mother-caregivers who had AYA survivor children aged 14–40 living at least 5 years post-diagnosis and 2 years post-treatment cessation, residing in the same household as survivors and having major responsibility for the survivors’ care. Ineligibility criteria included the following: mothers younger than 21 years; survivors married or living in a partnered relationship; survivors diagnosed with a genetically based cause of brain tumor (such as neurofibromatosis), intellectual impairment, or developmental delay prior to brain tumor

diagnosis; or caregiver or survivor did not speak English. Of 1140 mother-caregivers contacted, 384 (34 %) responded. Of those, 260 were eligible (68 %) and 186 (48 %) completed the quantitative data collection. Participants were purposively selected for maximum variation [25] from a latent class regression analysis based upon scores from the quantitative phase. Selection criteria were based upon perceptions of the mother-caregivers' management ability, caregiving demand, and ratings of survivor's quality of life (physical subscale). Forty-five participants were successfully recruited to the qualitative phase. Demographic information for these 45 mother-caregivers and their AYA child survivors is detailed in Table 1 and is similar to the quantitative sample [24].

Data collection and analysis

Janet A. Deatruck (PI of original study) performed in-depth, semi-structured, face-to-face interviews with mother-caregivers in the families' homes. The focus of the primary study included caregiving competence and demand for the AYA child survivor. Interviews were recorded, professionally transcribed, de-identified, and checked for transcription errors before being loaded into ATLAS.ti (version 7) data software package. As existing theory and literature are limited to describe expectations, conventional content analysis [26] was used by Em Rabelais to code whole interviews, followed by a second close reading and coding by Janet A. Deatruck. Code and category names were inductively derived from the data. The team met weekly to resolve coding differences and refine code lists and categories, which were revised during data analysis to reflect the data and evolving analytic insights [27]. Final codes were analyzed across interviews to identify themes about expectations and compared to the audit trail to observe evolution of analytic insights. As this is a secondary analysis, we were unable to conduct follow-up with participants to confirm our interpretations of their statements about expectations.

Results

Five themes emerged from coding and provide insight into mother-caregivers' expectations for current and future function of their AYA survivor children: realizing a difference in the survivor, noticing a lack of independence in the survivor, memories of learning about clinical prognoses from informed consent meetings and clinician-led education, management of these realizations, and acknowledging unresolved challenges. Three brief cases, of mother-caregiver and AYA child survivor dyad, are first presented to serve as exemplars of the themes and offer a holistic presentation of the caregivers' areas of concern. Themes are then presented chronologically following the mothers' experiences (Table 2). All 45 mother-caregivers discuss each theme, though to varying degrees.

Cases

Teresa (all names are pseudonyms) is married and works fulltime as a social worker. She is the mother of 24-year-old Tiffany, survivor of a hypothalamic high-grade glioma diagnosed at age 14 years and treated with surgery, chemotherapy, and radiation. At the time of the interview, Tiffany had ongoing complex endocrine management and difficulty with obesity but worked full-time as an administrative assistant at a laboratory testing facility. She had just purchased her first car and had a younger brother attending university.

Irene is married and works full-time. She is the mother of 21-year-old Isabella, survivor of a posterior fossa low-grade glioma diagnosed at age 4 years and treated with surgery and chemotherapy. A recurrence at age 12 years was treated with chemotherapy. Isabella has significant learning impairment with neurological changes. Her younger brother was attending university.

Christine is divorced and not employed, though has a medical education. She is the mother of 18-year-old Chloe, survivor of a primitive neuroectodermal tumor (medulloblastoma) diagnosed at age 3 years and 9 months that was treated with surgery, chemotherapy, and radiation. Chloe experiences hearing loss, hypothyroidism, and psychological (primarily anxiety) problems, requires growth hormone injections, has severe learning impairments, scoliosis, leg-length discrepancy, alopecia, and vision loss, and participates in special educational services in high school. She has a younger, 13-year-old sister to whom she compares herself.

Themes

Realizing a difference—The acknowledgement that their child was different came upon noticing that the survivor was not able to meet expectations set for other children. Our interviews show this realization occurring both before and after diagnosis, but generally within a few years after treatment completed. As Christine, for example, remembers the following:

By the middle of fifth grade, it was obvious, she was never, ever going to be able to do even the remedial work for learning differences [children]. It was beyond that. That was probably the first time that it hit home.

Realizing a difference has implications for more than just the child, as shown by Irene's reflection:

Knowing that I had a normal daughter, I lost so much and I had no idea what was gonna happen next. You're going to sometimes be on edge. You're going to not always give the right answer or act the right way.

Lack of independence—Distinct from realizing a difference, mothers noted a lack of independence or potential independence in the survivors. Teresa's fears about Tiffany's future illustrate this concern:

I don't know. What happens if you can't control the diabetes, you know? What happens if she can't work? What happens if—Do I stay home? Do I, you know? I don't even know if there are resources available for that.

Teresa and other mothers fear that their potentially forever-dependent children might outlive them, a prospect that they know is becoming realistic because of advances in cancer and follow-up care.

Clinical prognoses—Mothers recalled clinical prognostic information discussed during meetings for treatment or clinical trial consent and later education. The extent of information remembered from informed consent processes during times of life threat, and its accuracy,

is unknown, but subjective memory may be as or more relevant to understanding caregiver expectations. Irene remembered that “They told us she would never walk. She would spend all her life in a special education classroom. That’s what they had told us. They had very little expectations for Isabella, very little expectations.” Parents generally have few options but to agree to treatments with toxicities in order to try to save their children’s lives. They do, though, have a choice in clinicians; Christine recalled: “I think when you are diagnosed, the way somebody prepares you is real important and, again like I said to you, [one clinician] was so awful. We left him ‘cause he just, like, he literally just shouted out numbers.” The mothers’ understandings of clinical prognoses are powerful, and they come to these understandings generally with hindsight.

Managing realizations—Mothers discussed how they put together clinician-provided expectations along with other sources of knowledge and beliefs in managing both the condition and family. These other sources stem from experiences of reacting to their own expectations and the child’s changing conditions. Hence, mothers approached management in different ways, based upon their own understandings and expectations along with the individual cluster of late effects manifesting in and around the survivor. Teresa does not know what the future holds, “so I kind of just take it one day at a time. I guess that’s demanding because you can’t ever, you never assume anything.”

Unresolved challenges—Finally, all mothers discussed challenges to their expectations and sometimes attempted to suspend making and holding expectations. This may be because the mothers were, as Christine noted, “used to doing A and B and getting very easily to C. And here there is no C.” Many mothers perceive that their children have differences from children with other, non-cancer survivorship-related chronic conditions. They refer to the combination of their children overcoming/surviving cancer while acquiring one or more treatment-related chronic conditions that worsen over time and are sometimes coupled with a fear that the cancer will recur, once again threatening the children’s lives. The presence of challenges still requiring future solutions, including what happens when the caregiver can no longer provide care, epitomizes the struggle that many of the mothers face. While they may hope that unresolved challenges of having a child who has survived a brain tumor decrease over time, often they describe these challenges as increasing.

Discussion

Survivors of childhood brain tumors are living longer [1] with treatment-related sequelae (including neurocognitive effects) that may worsen with age [3, 7] and the potential to outlive their parent-caregivers [2]. This is the first study describing expectations of caregivers for such AYA survivors. From diagnosis, caregiver expectations are continuously adapted due to their, and their family members’, peers’, and clinicians’, interactions and experiences with the survivor. Their expectations are influenced by more than their children’s clinical functional prognoses and are more broadly woven into views of their children and their functioning and their own caregiving roles.

As posited in the literature, our study supports that caregiver uncertainty and intrafamilial processes do contribute to caregiver expectations. Pre-tumor expectations were a basis for

post-tumor uncertainty and worry about the potential that the survivor is too different in important ways and that s/he may not become independent of her, potentially reinforcing a condition-focused approach [21]. Caregiver worries wavered when confronted by encouraging interactions with the survivor (e.g., if the survivor graduated, s/he can most likely get a job). Perceived differences from initial expectations often ultimately required caregivers to alter family management (e.g., finally agreeing to speak with social work about the survivor applying for disability). While we do not understand how parents/caregivers make these changes, over time, they begin to revise expectations [28], making adjustments to tasks of parenting/caregiving. Clinicians can address uncertainty by providing coping skills to manage stressful situations [29] and offering extensive information about potential impairments and available resources [30]. Normalizing available resources and services, such as providing individualized educational plans or life-planning services and offering support until 21 years, can create bridges with pre-tumor expectations and address underlying concerns about caregiving when the caregiver can no longer provide care.

Caregivers described intrafamilial processes reflecting communication with clinicians about the survivors' specific tumor and treatment sequelae. When caregivers notice that survivors are not meeting developmental milestones appropriate for peers, they rely, in part, on clinical guidance to manage and react to the differences. Clinician responses, however, are complicated by several difficulties. First, obsolete treatment protocols may be used as the basis for epidemiologic surveillance, and during a time of life threat to the child, how might a parent, even one knowledgeable of epidemiology, understand long-term health outcomes? Second, neuroscience's immature understanding of intercortical function and brain development through childhood and the AYA period [31] impedes clinician ability to offer precise prognoses. Third, while epidemiology addresses some family concerns, the child's individual survivorship course generally cannot be predicted. Despite clinical prognoses, Isabella did walk and did not spend "her life in a special education classroom." Regular discussions about expectations between clinicians and families would therefore benefit from making explicit the components of expectations for caregivers/families that have downstream influence on management and health outcomes. This approach is not different from methods used by clinicians to understand what is at stake for a patient/family when challenged by ethnocultural differences [32]. The cultures of cancer medicine and survivorship differ from those of everyday family life, and what matters most to the family during experiences of illness and recovery may be identified by asking pertinent questions such as the following: "What matters most to you?" ; "What do you fear most?" ; "What course do you expect it to take?" ; and "How serious is it?" [32].

Beyond issues of uncertainty and family processes, more emphasis regarding expectations for the survivor needs to be placed on bridging the worldviews of the caregiver and clinician to assist parents with caregiving. Family worldviews may not enable translation of clinical perspectives into ongoing family management. Bridging worldviews requires more than just information transfer; it must reflect how families integrate knowledge and skills into family life. The mothers in our study were often able to reiterate clinical prognoses for their children; the most successful translated these functional expectations into how tumor and treatment ultimately changed their expectations for their children and caregiving/parenting.

Our contemporary focus on patient/family-centered care and shared decision-making calls on pediatric and other clinicians to understand caregivers' preexisting expectations from diagnosis and the influence of clinician-caregiver communication on expectations [33]. Assessing the family context, perceptions across family members, and how family members make sense of the loss allows for identification across both function-focused expectations and uncertainty about the future and ambiguity around loss of anticipated "normal" function [34]. Caregivers, families, and children should have a say in negotiating the terms of their healthcare, and clinicians must delicately balance paternalism and best interest with communicating evidence-based guidance [35] that is appropriately situated for families.

Limitations

While the literature suggests that mothers are overwhelmingly primary or sole caregivers, our exclusive focus on mothers leaves out voices of others partaking in caregiving roles, such as fathers. Many survivors in this study were in school full-time, and future studies might benefit from including only survivors who have left protective school environments. Future research is also needed to compare stakeholders' expectations between AYAs with (non-cancer survivorship) special healthcare needs and AYA survivors of any childhood cancer. We do not know if there are important expectations that cross these differing categories. Further, several interview questions required participants to recall details from their past during a time of family crisis; while such memory is subject to changes over time [36], subjective memory appears to have more relevance to caregiver expectations. Finally, treatment for childhood brain tumors is constantly improving, and children treated today and in the future will not receive the same treatment (with the same level of toxicities) as did current survivors.

Conclusion

Expectations influence condition management, decision-making about the children's conditions, and psychosocial outcomes for the child, mother, and family. As seen by Davis [37] more than 50 years ago in his classic study of families of children with polio, many mothers experienced their children based on how typical the child appeared, and others felt detached or preoccupied with their children's differences and conditions. Also consistent in these past 50 years, as new technology and therapeutics allow children a greater chance at survival for previously life-limiting conditions, understanding parent/caregiver expectations will continue to be challenging for both those with children surviving cancer and with other chronic conditions.

We do not know how the caregivers' expectations about survivors' function relate to ongoing management and decision-making in the up to 90 % of children with once-fatal conditions, both cancer and non-cancer related [38, 39]. This is certainly an area in which future study is needed, perhaps beginning with a qualitative synthesis or meta-analysis.

Clinicians, with a more exclusively clinical focus, may not understand other sources of uncertainty and thus how best to help parents negotiate their roles over time [40–42], especially as treatment-related sequelae emerge and contribute to worsening health status. Nuanced communication is needed, from diagnosis and treatment descriptions, consent,

and including family-specific approaches to survivorship planning, to meet the needs and goals of both clinical team and family. Recognition and identification of expectations have the potential to change interactions among clinicians and family members at multiple points during care. Clinicians can help anchor family management by recognizing caregiver expectations, helping facilitate communication about realistic expectations based upon scientific evidence and family goals, and assisting mothers in (re)negotiating the goals of their caregiving.

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Table 1Caregiver and survivor characteristics (*N*=45)

Characteristic	<i>M</i> (<i>SD</i>) or frequency	Range or percent
Caregivers		
Age	52 (6.45)	41–67
Partnered	38	84.4
Employed full-time	25	55.6
Education		
High school graduate	15	33.3
Some college	10	22.2
College graduate or higher	20	44.4
Survivors		
Age (years)	23 (4.99)	15–36
Time since diagnosis (years)	15 (5.57)	7–27
Sex (M)	28	62.2
Education/work		
Not in school or working	13	28.9
In school	14	31.1
Working	18	40.0
Tumor type		
Low-grade glioma	19	42.2
Primitive neuroectodermal tumor	16	35.6
High-grade glioma	3	6.7
Craniopharyngioma	3	6.7
Germ cell	2	4.4
Choroid plexus	2	4.4
Tumor location		
Posterior fossa	23	51.1
Cortex	8	17.8
Sellar	5	11.1
Pineal	4	8.9
Ventricle	2	4.4
Other	3	6.6

Table 2

Pattern of expectations from caregivers of survivors of childhood brain tumors

Expectation themes	Brief description	Example
Realizing a difference	Noticing differences in the survivor after the brain tumor diagnosis and treatment	"I think if you give birth to a child with deformities, you know what you've got. It's heartbreaking. Don't get me wrong, but I think when you have a totally, normal healthy and then all of a sudden, this. It's [...] a curve ball that nobody can ever expect and no matter how you tell a parent what it is, what can be done about it, the devastation and shock of the moment takes over, and you can't sit and wait on it either." (Christine)
Lack of independence	Noticing lack of potential independence in survivor	"When she turned eighteen and she graduated, being a transition person and this is what I tell parents [to] do, I was like at this age she should be living on her own and be independent. And Isabella would not do very well if she was in an apartment by herself." (Irene)
Clinical prognoses	Recalling prognostic information from clinicians	"Certainly, if somebody said to me, here are your options, you only do chemo and it's thirty percent survival, but you won't have an invalid so to speak, or you do radiation and chemo and you might have an eighty-five percent survival but her quality of life is such that, you may not be able to enjoy the load, I would have done chemo alone." (Christine)
Managing realizations	Reacting to recalled prognostic information combined with caregiver's knowledge/beliefs	"But there weren't any guys there [at the support group]. Like how do you meet guys? You know, that's—I have no idea. She doesn't go to bars. I wouldn't encourage that, anyway. The only thing I kept saying is we should join a church. One of these days we're gonna have to join a church." (Teresa)
Unresolved challenges	Challenges to expectations and ability to manage the survivor, family, and self	"I think parents with normal children probably look at me like, 'Get over it already,' but they don't realize 'cause I don't sit there and bitch and moan about all of the added responsibilities and worries and concerns and how many times you'll you know, you want her to gain more and more independence but you kind of have to keep the eyes in the back of your head because of prudence and safety and the rest of it. They don't get all of that. If you talk to parents who have truly physically disabled involved children with cerebral palsy, they get it. They get it completely." (Christine)