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### Permalink

<https://escholarship.org/uc/item/9zg3f232>

### Journal

Journal of Pediatric Hematology/Oncology Nursing, 34(4)

### ISSN

2752-7530

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### Publication Date

2017-07-01

### DOI

10.1177/1043454216688660

Peer reviewed



# HHS Public Access

Author manuscript

*J Pediatr Oncol Nurs.* Author manuscript; available in PMC 2018 October 23.

Published in final edited form as:

*J Pediatr Oncol Nurs.* 2017 ; 34(4): 239–249. doi:10.1177/1043454216688660.

## “She Was a Little Social Butterfly”: A Qualitative Analysis of Parent Perception of Social Functioning in Adolescent and Young Adult Brain Tumor Survivors

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### Abstract

Psychosocial sequelae of diagnosis and treatment for childhood brain tumor survivors are significant, yet little is known about their impact on adolescent and young adult (AYA) brain tumor survivors. Interviews were conducted with parents of AYA brain tumor survivors with a focus on social functioning. Semistructured interviews were conducted with English- and Spanish-speaking parents of AYA brain tumor survivors 10 years of age who were >2 years postdiagnosis, and analyzed using emergent themes theoretically integrated with a social neuroscience model of social competence. Twenty parents representing 19 survivors with a survivor mean age  $15.7 \pm 3.3$  years and  $10.1 \pm 4.8$  years postdiagnosis were interviewed. Several themes relevant to the social neuroscience social competence model emerged. First, parents’ perceptions of their children’s impaired social functioning corroborated the model, particularly with regard to poor social adjustment, social withdrawal, impaired social information processing, and developmentally inappropriate peer communication. Second, ongoing physical and emotional sequelae of central nervous system insults were seen by parents as adversely affecting social functioning among survivors. Third, a disrupted family environment and ongoing parent psychosocial distress were experienced as salient features of daily life. We document that the aforementioned framework is useful for understanding the social impact of diagnosis and treatment on AYA brain tumor survivorship. Moreover, the framework highlights areas of intervention that may enhance social functioning for AYA brain tumor survivors.

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#### Ethical Approval

This article does not contain any studies with animals performed by any of the authors. All procedures performed in this study involving human participants were in accordance with the ethical standards of the Institutional Review Board of the University of California, Irvine and Children’s Hospital of Orange County and with the 1964 Helsinki declaration and its later amendments.

#### Informed Consent

Informed consent was obtained from all individual participants included in the study.

#### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Keywords

brain tumor; social functioning; social competence; childhood cancer survivorship; adolescent-young-adult

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## Background

At the end of 2013, it was estimated that there were more than 420 000 childhood cancer survivors in the United States. Childhood brain tumor survivors, henceforth referred to as survivors, are the largest group of pediatric solid tumor survivors, representing 15.6% of all childhood cancer survivors (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). They are disproportionately at risk for physical and psychosocial sequelae when compared with survivors of other types of childhood cancers (Meeske, Katz, Palmer, Burwinkle, & Varni, 2004; Pogorzala et al., 2010), and they are more likely to experience poor social functioning, poor adjustment to new social situations, impaired social-information processing, and a lack of friends (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005; Bonner et al., 2008; Carey, Barakat, Foley, Gyato, & Phillips, 2002; D'Agostino & Edelstein, 2013; Howard et al., 2013; Ribí et al., 2005; Robinson et al., 2015; Salley et al., 2014; Upton & Eiser, 2006). As survivors become adolescents and young adults, these deficits have been associated with diminished work satisfaction (D'Agostino & Edelstein, 2013; Pompili et al., 2002), greater depression (Pompili et al., 2002), and below average quality of life (Arsen et al., 2006). Compared with healthy peers, survivors who are now adolescents and young adults (AYAs) demonstrate impaired educational achievement, employment, and mental health (Jones, Greenberg, & Crowley, 2015). Therefore, amelioration of the social deficits faced by survivors continues to represent an urgent and unmet need.

Underscoring the importance of theory-driven research on social functioning deficits in survivors (Schulte & Barrera, 2010), we and others (Hocking et al., 2015; Schulte 2015) have adopted the use of a social neuroscience model of social competence in the context of childhood brain disorder (Yeates et al., 2007) as depicted in Figure 1. The model defines social competence as a product of (a) cognitive abilities, social skills, and behaviors; (b) the physical sequelae of the original insult; and (c) the child's social environment, composed of parent factors, family factors, and socioeconomic factors. While a growing body of research has begun to illuminate the cognitive and behavioral factors of impaired social competence in survivors, little is known about the model's environmental moderating factors, such as parent and family factors. It is also unclear how AYA survivors and their families experience impaired social outcomes and their insult-related and non-insult-related risk and resilience factors. Given the burden of domain specific aftercare provided to survivors, it is critical to understand the lived experience of these moderating factors of social outcomes in AYA survivors. This study aimed to qualitatively examine the experiential dimensions of social competence and related factors in adolescent and young adult brain tumor survivors and their parents. Thematic analysis is organized around the theoretical factors highlighted in the social competence model proposed by Yeates et al. (2007) and advanced by Schulte and colleagues (2015; Schulte & Barrera, 2010) and Hocking et al. (2015). Our objective is to

provide experiential contour to the variables and relationships currently under examination in social competence intervention design and testing in survivor populations.

## Methods

The study was cross-sectional and recruited parent participants from a single institution (CHOC Children's Hospital) in Orange County, California. In-depth, semistructured interviews were conducted via telephone as part of a mixed-method study of psychosocial outcomes in AYA brain tumor survivors and their parents. The interview guide (see the appendix) was developed by the authors of the study and was guided by a review of pertinent literature. The study protocol was approved by the institutional review board. All parent participants provided written informed consent.

## Participants

English- and/or Spanish-speaking parents were eligible to participate in the study if they were parents of eligible AYA brain tumor survivors. Eligible AYA brain tumor survivors were defined as having an age  $\geq 10$  years and  $>2$  years postdiagnosis and off therapy. All survivors had received previous neuropsychological testing and followup care. We chose to recruit and conduct interviews with parent respondents because parents continue to provide a significant proportion of aftercare including psychosocial care. At their children's regularly scheduled clinic visits, eligible parent participants were invited in-person to participate in the study. In addition to providing informed consent, participants also gave consent to access their child's medical records. Diagnostic and treatment-related information was obtained from the survivors' medical record by the completion of a medical record abstraction using a defined protocol. Of the eligible parents ( $n = 31$ ), a total of 20 completed interviews. Provided in Table 1 is a description of the parent respondents, survivors, and brain tumor survivor-related characteristics. Eighteen interviewees were mothers and 2 were fathers. All survivors had received neurocognitive evaluations and regular follow-up care before the time of the interviews.

## Procedures

A total of 10 interviews were conducted in English by the principal investigator (DB) and 10 interviews were conducted in Spanish by a bilingual research assistant with expertise in cancer survivorship research. During their clinic visit, the parents accompanying the survivor were invited to complete demographic and psychosocial questionnaires and asked to provide dates and times convenient for a phone interview. The semistructured interviews followed an interview guide consisting of open-ended questions (see the appendix). All interviews were audio recorded and verbatim transcripts were completed by Viva and Transcription Professionals. Each participant received a \$25.00 honorarium by mail at the completion of the study procedures.

## Analysis

Transcribed interviews were analyzed by 3 authors (JW, DB, MF) using an inductive grounded theory approach. According to this approach, data coding and theory selection inform each other in a multistage iterative process (Charmaz 2014). An initial round of

coding by all 3 coders was completed on a limited sample and used to inductively generate themes. Memos and summaries were generated and used to achieve consensus on naming and meaning of themes. A second round of coding on the full sample was conducted with the consensus themes. The grounded theory approach allowed for key themes to emerge during the coding, memo-writing, and discussion process. All transcript coding was reviewed by each author. After the second round of coding, extant theoretical frameworks of psychosocial functioning in traumatic brain injury patients were reviewed to organize the themes that emerged in the second round of coding. The social competence model articulated by Yeates et al. captured each emergent theme and provided “analytic power” and “directionality” that characterizes theoretical framing in grounded theory coding and analysis (Charmaz, 2014). Full transcripts were reviewed at this stage to contextualize terms, phrases, and full quotes. The final stage of analysis consisted of arranging all inductive themes of the first 2 stages of analysis and coding into the broader categories of the aforementioned theoretical framework of social competence by Yeates et al. (2007).

## Results

### Social Competence in AYA Brain Tumor Survivors

**Social Adjustment.**—As depicted in Figure 1, social adjustment represents the overall quality of a child’s relationships as perceived by others and the child. Parents reported a low number and quality of peer relationships, at times euphemistically (“He’s a lone wolf”), and at other times bluntly:

Socially, he is completely inept, horrible. This whole summer, he has not seen one friend or wanted to see a friend. . . . Outside of the school setting he has no socializing, he never does anything. . . . He is not social.

Most parents reported the low quality of their child’s social relationships in more measured terms. In these cases parents simply described their child as “not hav[ing] any friends.” “Does he have any friends?” one parent responded to a question. “No, not really.” Some parents spoke about their child’s social isolation not in terms of friends but in terms of leaving the home:

I am concerned because she does not want to leave the home. She is afraid to be on her own and so that would be a concern. She does not feel she can do things on her own.

And another parent said,

[He] is 16 and he does not have any friends, he just feels like he has to be around me or his sister all the time because we are the only ones that know how to take care of him, you know, to watch him, he has like no social life at all.

Several parents of older adolescents and young adults mentioned a lack of romantic relationships and speculated on whether their children would find a romantic partner in the future. Finding a compatible partner was a concern:

I think [a romantic relationship] is possible, I don’t know. It would probably take a special girl that is very patient, very kind and all that stuff. But you know a lot

could change from now to then. So, I am not sure. It is definitely possible, it is just kind of up in the air. I mean at this point, I would be just assuming that he would need a lot of help with things.

Self-esteem was an important perceived factor in parents' assessments of their child's social adjustment. In both males and females, body image was associated with self-esteem. For male AYA survivors, height was a concern. For females, weight was a concern. One parent reported that her adolescent daughter no longer wanted to eat because of her concern with weight. A parent of an older female adolescent reported that her daughter experienced low self-esteem in addition to constant feelings of anxiety and shyness, and these feelings affected her potential for romantic relationships.

*Interviewer:* Do you think she will be in a relationship?

*Parent:* We believe she will. She does not think she is worthy or pretty enough to be in one because she is not the ideal looking person because she has weight on her, she does not feel that anyone is going to want to be around her, it is a self-esteem issue. So, we are significantly working on that one too. She has no desires to date anybody because she wants to do schoolwork, which is fine.

**Social Interaction.**—In Figure 1, styles of social interaction are distinguished by 3 broad categories—aggressive, affiliative, and withdrawn. Parents in our sample reported a predominately withdrawn social interaction style. Thirteen of 20 parents reported clear social withdrawal through statements regarding a lack of friends and social unease. Both male and female AYA survivors were seen to avoid school and other social situations for a variety of reasons. Parents often spoke about their child's withdrawn interaction style in terms of home-based isolation. For example,

I am concerned because she does not want to leave the home. She is afraid to be on her own and so that would be a concern. She does not feel she can do things on her own.

Although many parents described their children as shy and actively avoiding social interaction, not all children were described in this manner. In fact, one child was described as demonstrating aggressive behavior toward peers at school whereas another child was described as “charismatic” and a child “everybody likes.” These were not common experiences, however. Many parents described their children as shy and as actively avoiding social interaction. A common complaint was that the survivor did not want to introduce herself or himself:

She does not want to go introduce herself to people, which I don't really get that except it's something that her and I still struggle with. I asked her why not, I do not know.

This was the case not only with strangers but with known acquaintances. As one parent described,

[K]ids at the school say, hey [name retracted], and he won't even acknowledge that they spoke to him. [I tell him], just say “Hi.” He says, “Well, I don't know who that is.” [I tell him,] “Well, just say hi back. You don't have to say anything other than

that.” So, at least give the people something back or you just look kind of rude and he doesn’t get that.

**Social Information Processing.**—Social information processing (SIP) is represented in Figure 1 as the cognitive ability to regulate one’s social behavior and respond appropriately to social stimuli. Parents’ reports of poor social outcomes were accompanied by reports of cognitive deficits that are directly related to SIP. Of the 20 parents interviewed, 13 reported general learning problems or deficits in memory, attention, or information processing. Many parents directly associated impaired social functioning with their children’s cognitive deficits. They connected attention problems and “slow processing speed” directly to the poor social interactions and social adjustment they perceived. For example:

But in school . . . the processing speed is just with everything, it just covers everything. It’s the worst thing. Because even socially it affects him. He cannot keep up with the conversation with other kids his age and he is a lot more immature the way he interacts. It is more physical with him like poking and being silly, but if they are just having a conversation, he just doesn’t fit in that way. He just can’t keep up at this point with that.

And another parent said,

What I notice with him, he gets very distracted. So, for example if a TV is on in the room, he cannot do what he needs to get done, he is like sucked into the TV. So, that would be an example. And then when you are asking questions of him, it takes him just a little longer than it should to get an answer. I wouldn’t say like a long time, but he can’t just answer the question like, “Hey, do you want apple?” And . . . it is like an extra beat before you get an answer from him.

Several other parents reported impaired social functioning and impaired cognitive functioning but did not link the two.

### Insult-Related Risk and Resilience Factors

**Health Problems.**—Insult-related risk and resilience factors are conceived as modifying factors in Figure 1. Parents often directly associated long-term sequelae of the brain tumor and its treatment with their children’s social functioning deficits. Some health problems, such as thyroid dysfunction and adrenal insufficiency, were commonly reported but not perceived as problematic. However, several commonly reported health problems related to disease and treatment, such as impaired balance and mobility, loss of hair, weight, and short stature, were seen to affect social functioning. For many parents, ongoing health problems appeared to be associated with decrements in social adjustment.

You know, she was on her student council at school and she was a little social butterfly and now not so much. She, I don’t know, like she does not want to put herself out there anymore and part of that it is because, you know, when she reentered her school clearly in a wheelchair and barely having hair, you know, very visibly that she was different.

## Non-Insult-Related Risk and Resilience Factors

Non-insult-related risk and resilience factors are the second group of modifying factors represented in Figure 1. This construct is composed broadly of the child's social environment but is particularly salient with regard to the parenting and family environment.

### Changes in Family Relationships.

Parents often reported a strengthening of sibling and child-parent relationships. Some respondents noted a strengthening of spousal relationships, but for several others this relationship was negatively affected. The marital relationship was a primary area that was affected by the cancer experience. For some parents, the diagnosis, treatment, and recovery brought them closer together. For others, it had that effect initially, but eventually the couples split. For still others, the cancer experience was seen as a disruption which their marriages could not withstand. Among the couples that were brought closer, different reasons were given for the strength of their relationships. One parent identified "faith," while another attributed the closeness to positive communication that emerged over the experience. Among the parents who experienced marital distress after the diagnosis and treatment, the practical pressures of managing a family in the midst of intense treatment demands was seen as a source of marital discord. For example,

He is not very involved in everything related to [the child] because he has to work. He has to work, and only when I have been at the hospital, he brings me food, he stays for a while, and then he has to go to sleep, and return to work. So, he is not very. . . . Same thing with his appointments. I am the one who comes and goes and everything. So, he is not very. . . . But sometimes I . . . I would like more help or something, right? But no.

Even in cases of divorce or marital distress, parents often reported a strengthening of relationships in the primary family between siblings and between children and parents. In one family experience of marital distress, the parent interviewed described a very different situation in the primary family as a whole:

Thanks to that illness we as a family learned to support each other. That is more important than anything else. And yes, it's hard to take care of a child who has cancer but at the same time it's a learning experience and it's something we should thank God for. . . . It taught us survival, to love as a family. We all know how to make a difference by staying together. That even though we were alone, isolated from our families, from our siblings, all that, we were together as parents and children.

Several parents reported feelings of concern for the siblings of the survivor. Concern over siblings feeling "alone" or as if they "got the short end of the stick" were common. Less common, but still present, were parent reports of emotional and behavioral problems among siblings. In a family with a severely affected survivor who requires daily assistance, the parent described the development of problematic behaviors in the sibling:

My other child felt alone because we were always at the hospital, and we were almost always with my oldest son, my sick son. . . . So, my other son always said



that he wanted to get sick because he wanted his dad and his mom to be with him. . . . Even now we have problems with him because he says we didn't devote as much time to him as we devoted to [name redacted]. And since he started school, he was always a boy who had behavior problems, [he felt] nobody loved him. He is sixteen and he still feels that way. And [name redacted] feels extremely sad because he feels responsible for his brother growing up alone.

**Change in Family Priorities.**—Parents reported positive changes in their families' priorities. Parents used terms such as *grateful*, *blessed*, *fortunate*, and *rewarding* when describing the effects of cancer treatment and survivorship. The experience was seen to positively intensify the parent–child relationship, slow down otherwise hectic lives, and shift life priorities toward building and maintaining family relationships.

**Relationships With Other Families.**—Similarly, the experience of cancer treatment was seen to provide a unique opportunity for building unusually meaningful relationships with other cancer families. As a parent explained,

One family in particular happened to have the same diagnosis . . . and they were diagnosed, gosh, like 6 weeks apart. So we had the opportunity to come and learn with them. . . . The mom and I talked frequently and just kind of expressed our feelings . . . to share that with [someone] who gets it.

The inverse of these experiences was the common expression by parents that families who have not had a child diagnosed and treated for cancer could not understand their lives. One of the most salient points of disconnection reported by parents was with regard to survivorship. “I do not think that most people realize,” a parent related, “that this does not end.” There was a commonly expressed feeling that once a child finished treatment, other families perceived the crisis to be over. For these parents, however, the challenges of brain tumor survivorship “just keep going.”

**Parent Worries, Uncertainty, and Continued Distress.**—The continued demands of caregiving well into adolescence and young adulthood weighed heavily on many parents. Parents reported uncertainty about the future and chronic stress regarding the survivor's current and future health. Some parents focused on the continued regular medical appointments and therapies as a source of stress, while others focused on the uncertainties of their child's future health. Adult independence and cancer recurrence were the most commonly reported sources of health-related uncertainty. Cancer recurrence, in particular, elicited a substantial amount of reflection.

I am going to tell you right now just because you are done with therapy does not mean you are done, you know. I have seen so many kids that, you know, I knew a kid, for example, that 3½ years after therapy his cancer came back and a year later he was gone. So you know not that, I mean, it could come back after 8 years and your kid could be gone again.

The chronic worry and uncertainty that parents expressed were ultimately experienced as a deep sense of fatigue. The words “exhausting,” “draining,” “tired,” “desperate,” and “overwhelmed” characterized the responses of parents when asked about their own

wellbeing. Parents often identified the continuous nature of the survivor's health-related needs as the source of this fatigue. These expressions, however, were often coupled with a sense of gratitude for their children being alive and a deep pride in their children's resilience. As difficult and exhausting as continuous care was, seeing even minor progress was a source of joy.

Yeah, just to see him walk now, you know he is walking a little bit more. Before he could not even brush his teeth on his own. . . . So, just to see him doing all of this, you know. . . . It is rewarding to me just to see him alive and try to do things for himself and if he cannot do it then he will ask me. But just to see him like that is rewarding for me.

**Support Needs.**—Parents were asked open-ended questions about desired support services for AYA brain tumor survivors and their families. The most commonly mentioned support services were parent support groups, parent survivorship education classes, and an age-matched, ability-matched social support group for AYA brain tumor survivors. In the latter, parents expressed a desire for opportunities for their child to simply “hang out” with similar others. Other services mentioned were parental health and self-care classes and tangible support such as financial assistance.

## Discussion

The qualitative data presented in this study provide insight into the experiential dimensions of impaired social outcomes in AYA survivors. By organizing parent-reported qualitative data along categories of Yeates et al.'s (2007) model of social competence, we demonstrated how the specific mechanisms and relationships that contribute to impaired social competence are perceived by the families that experience this psychosocial sequela. Our results also support the use of this model of social competence for understanding the perceptions of parents of AYA survivors. For each major component of the model, parents commonly reported experiences that corroborated the model's specified relationships.

1. Impairment in the 3 internal components of social competence—SIP, social interaction, and social adjustment—was evident in parents' descriptions of their children's poor social functioning. Delayed SIP was commonly related by parents to their child's withdrawn social interaction style, which was, in turn, connected to an overall parental evaluation of poor social adjustment. Parent descriptions of these 3 internal components emerged over the course of longer descriptions of their children's social challenges. That their descriptions could be organized into these components quite cleanly suggests that the survivors' social impairment follow similar patterns and have similar determinants.
2. The insult-related risk and resilience factors were identified in a corresponding quantitative analysis (Buchbinder et al., 2015). The present qualitative analysis shows that parents directly associated many cancer- and treatment-related physical sequelae to social functioning.
3. Although parents did not as clearly relate noninsult-related risk and resilience factors of the model to survivors' social outcomes, their reporting of changes in

family functioning and parent psychosocial experience supports the model's posited relationship. Specifically, the model posits family functioning and parenting style (among other environmental factors) as moderating factors on social competence. While parents did not express perceptions of this relationship, their reports of disrupted family functioning and high levels of parental stress and fatigue suggest that the model's posited relationship is plausible.

The broader picture that emerges of impaired social outcomes in AYA survivors in our sample is one that supports the model of Yeates et al. (2007). However, the rich description provided by parents also contributes to the model by adding experiential depth to its abstract constructs. This experiential depth has several implications for future research and, more importantly, future intervention design and evaluation.

First, research on parents of survivors has generally focused on psychosocial outcomes in parents. Little attention has been paid to the effect of parenting styles on psychosocial and especially social outcomes in survivors. Our findings of strong and widespread expressions of gratitude, family intimacy, and an intense focus on the health needs and uncertainty of the survivorship experience could be areas for future investigation that may help us understand parenting factors and social isolation. Parental concern may lead to a limiting of social opportunities, especially during the survivorship period. Additionally, future research should focus on the relation between parent self-care, health, and distress as moderating factors for survivors' social outcomes. Because family and parent functioning are key moderators of social competence, our findings of fatigue and distress in parents suggest that research on parent psychosocial wellness should inform social competence intervention designs.

Second, our findings that many parents connected their child's cognitive impairments with his or her social competence corroborate the importance Yeates et al.'s (2007) model places on SIP. Our findings also support the association between cognition and social outcomes in recent studies (Moyer et al., 2012; Poggi et al., 2005). However, to our knowledge, no social competence interventions have included a cognitive rehabilitation component. SIP was of particular concern to parents who reported poor social outcomes for their child. Because of the very specific nature of the cognitive demands of SIP, future research should focus on factors that improve SIP in particular.

Finally, of the support needs expressed by parents, social support for survivors was commonly mentioned. The expression by parents of a need for a time and space for their survivors to "hang out" should be taken seriously. An intervention designed to allow age-matched, ability-matched AYA survivors to spend semistructured time together in a safe environment may, through repeated exposures over time, have positive effects on the components of SIP, especially social problem solving and socialaffective functioning. The obvious difficulty is recruiting enough AYA survivors in a given geographic region with similar ages and abilities. These challenges suggest that the study of social media interventions for this population may be of value.

## Study Limitations

This study has several limitations. It is a small, crosssectional study and thus did not follow participants over time. The heterogeneity of our sample of survivors also limits our ability to draw specific conclusions relating to individual subgroups of survivors such as those with specific diagnoses, treatment exposures, or sociodemographics. More importantly, the overrepresentation of mothers in this sample may have biased the results. Discrepancies between mothers and fathers in assessing child behavior is well documented and can be influenced by parent psychological states, state of parent relationship, and child gender (Luoma, Koivisto, & Tamminen, 2004; Seiffge-Krenke & Kollmar, 1998; Treutler & Epkins, 2003). It is possible that we would find more heterogeneous assessments of AYA social competence if fathers were more evenly represented in our sample. Nevertheless, the ability to explore a broad spectrum of survivor's experiences ensures a rich background for developing hypotheses. Of particular note, the racial and ethnic heterogeneity of our sample, which is reflective of the sociodemographics of the surrounding community in Orange County, California, provides a unique opportunity to characterize a diverse range of experiences of families affected by the survivor's experience. The themes that emerged from this study and associated analyses (Buchbinder et al., 2015) provide an important starting point for the validation of a conceptual framework which has been proposed in the context of survivorship research and clinical care as it relates to social competence. Moreover, these emergent themes provide insight into many of the moderating factors that impact the social competence of survivors.

## Conclusion

Many AYA brain tumor survivors remain at high-risk for the development of adverse social functioning long-term, yet it remains understudied. The recent shift in research from establishing the prevalence of social functioning deficits in survivors to modeling determinants of social outcomes and designing interventions represents a new phase in understanding this particular dimension of childhood cancer survivorship. We add to this growing body of knowledge by providing an in-depth understanding of the experiences of parents of AYA survivors in the context of a social neuroscience model of social competence in childhood brain disorder. Findings underscore the need for novel psychosocial interventions that mitigate risk factors and enhance resilience with respect to central nervous system insults, the family environment, and characteristics of the individual survivor.

## Acknowledgments

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

## Appendix

### Interview Guide

**Caregiver Interview Guide. Introduction:** My colleagues and I are doing a study to learn more about how having a child with a brain tumor might affect the parent who cares for the

child. Understanding the parent's perception of the care your child that has a brain tumor has been given and the care your child will need long-term is important when thinking about ways to support children who have had brain tumors and their parent caregiver. This information will help us design better ways to support children who have brain tumors and their parents. I would like to ask you some questions about your experience as a parent caregiver for your child who had a brain tumor.

#### Current care giving experiences

1. Tell me about yourself and your family AFTER the diagnosis and treatment of the brain tumor.

*Prompts:* Who is living in the house with the child; how many brothers and sisters (include half sibs and step sibs) are there; are there other sibs who did not live within the home. Maybe they are grown and living on their own? Are there other family members that live in the house? Are there other paid employees or other non-paid caregivers that live in the house?

2. Providing care for a child that is a brain tumor survivor can be challenging. Could you tell me about some of the challenges you have encountered providing care and support for your \_\_\_\_\_ as a result of his/her condition?

*Prompts:* What has been the physical effect of providing care and support for your \_\_\_\_\_ as a result of his/her condition? How does providing care and support for your \_\_\_\_\_ as a result of his/her condition make you feel emotionally? How do you manage your/your families own needs/activities (eg, school, work, family, money) while providing care and support for your \_\_\_\_\_ as a result of his/her condition?

3. Providing care for a child that is a brain tumor survivor can be rewarding. Could you tell me about some of the positive things you have encountered providing care and support for your \_\_\_\_\_ as a result of his/her condition?

*Prompts:* In what ways do you feel gratified by the experience of providing care for your child that has been diagnosed and treated for a brain tumor? As a result of the challenges of the brain tumor experience, some parent caregivers develop knowledge and expertise that helps them meet challenges as they arise, in what ways do you feel a sense of knowledge and expertise? Can you describe the most recent situation where this knowledge or expertise has helped you, your family, or your child?

#### Survivor physical and psychosocial health

4. Some people with brain tumors can have problems after being treated for their brain tumor and others may not have many problems after being treated. Could you tell me about how the brain tumor and its treatment have affected your \_\_\_\_\_ ?

*Prompts:* What kind of things is your \_\_\_\_\_ good at? What kinds of things are hard for your \_\_\_\_\_ ? From your perspective, how has your \_\_\_\_\_ condition affected how he/she functions on a daily basis going (eg, going to work, school, etc)? What changes in attention, memory, language, learning, reasoning, problem solving, and decision making have you

noted in your child as a result of his/her brain tumor and its treatment? What changes in behavior have you noted in your child as a result of his/her brain tumor and its treatment? What other health concerns have arisen (eg, sensory problems, heart problems, lungs problems, intestinal problems, bone/muscle problems)?

Future caregiving experiences

5. Looking ahead, how might you describe your \_\_\_\_\_ life in the future (eg, 10 years from now)?

*Prompts:* Will he/she be: living alone, working, in a relationship, having a family, happy, well? How will the changes in cognition (eg, attention, memory, language, learning, reasoning, problem solving, decision making) or behavior that we discussed earlier impact your \_\_\_\_\_ life in the future? How will the health concerns (eg, sensory problems, heart problems, lungs problems, intestinal problems, bone muscle problems) that we discussed earlier impact your \_\_\_\_\_ life in the future?

6. What are some ways to help and support a parent caregiver that is facing the task of providing longterm care to an aging brain tumor survivor?

*Prompts:* What are some ways to address the concerns or fears you mentioned previously when thinking about providing long-term care and support for your \_\_\_\_\_? What are some ways to alleviate the worries (eg, who will provide care, where the care will be provided, financial concerns) for your \_\_\_\_\_? Do you think there are ways to help parent caregivers minimize this stress? Do you think there are particular resources that should be provided to parent caregivers to minimize the impact of this stress? When should these resources be provided? To whom should these resources be provided?

7. Is there anything else you'd like to tell me so that I could better understand what it is like to have the responsibility of providing long-term care for a brain tumor survivor?

## Biography

**Justin Wilford**, PhD, is a doctoral candidate in the Program in Public Health at the University of California, Irvine. His research focuses on social support and social influence in childhood cancer survivorship.

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**Kathryn Osann, PhD**, is an adjunct professor in the University of California, Irvine School of Medicine. Her research interests are in cancer survivorship, biostatistics, and epidemiological methods.

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**Lilibeth Torno, MD**, is a pediatric oncologist, Assistant Division Chief of Oncology, Clinical Director of Cancer Outpatient Services, and Clinical Director of the After Cancer Treatment Survivorship (ACTS) Program at the Hyundai Cancer Institute at CHOC Children's Hospital.

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**Susan K. Parsons, MD**, is Professor of Medicine and Pediatrics at Tufts University School of Medicine and Founding Director of the Reid R. Sacco Adolescent and Young Adult Program for Cancer and Hereditary Blood Disorders at Tufts Medical Center. Her research program is dedicated to advancing the development and application of health-related quality of life assessment of children with serious illness and their parent caregivers.

**Lari Wenzel, PhD**, is Professor of Medicine and Public Health, and Associate Dean of Faculty Development at the University of California, Irvine School of Medicine. She also serves as the Associate Director of Population Science and Cancer Control for the Chao Family Comprehensive Cancer Center. Her research focuses on the biobehavioral aspects of quality of life in cancer survivorship.

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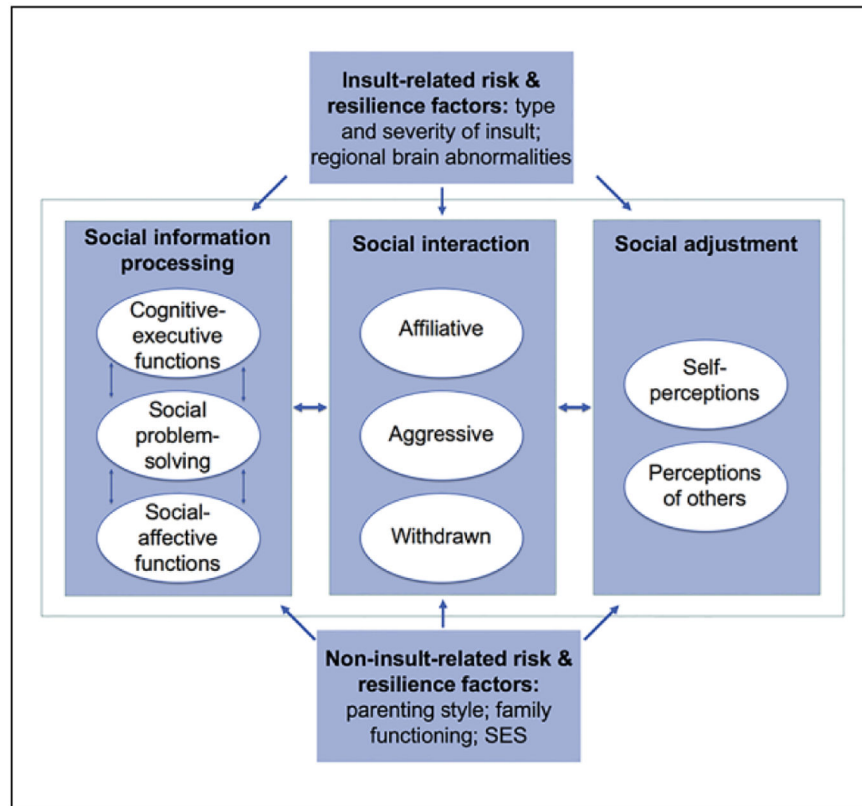
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**Figure 1.** Theoretical model of social competence. Adapted from Yeates et al. (2007).

**Table 1.**

Characteristics of AYA Brain Tumor Survivors and Their Parents.

Variable	Frequency	Total	Percent
<i>AYA brain tumor survivor characteristics</i>			
Mean age	15.7 years (SD 3.0)		
Female	9	19	47%
Health status: Excellent to good	15	19	79%
Health problems: Moderate to severe			
Hearing	3	19	16%
Vision	7	19	37%
Speech/language	7	19	37%
Fatigue	5	19	26%
Pain	3	19	16%
Neuropathy	3	19	16%
Endocrinopathies	7	19	37%
Weight	7	19	37%
<i>Parent characteristics</i>			
Mean age	44.0 years (SD 7.0)		
Female	18	20	90%
Hispanic or Latino	10	20	50%
Full-/part-time employment	4	20	20%
Married or living with partner	15	20	75%
High School/GED/college/grad school	19	20	95%
Annual household income <\$40 000/year	9	18	50%
Diagnosis/treatment characteristics			
Diagnosis			
Astrocytoma/glioma	2	19	11%
Medulloblastoma	8	19	42%
Ependymoma	3	19	16%
Germ cell tumor	1	19	5%
Other	5	19	26%
Primary CNS tumor site			
Cerebral hemisphere	3	19	16%
Cerebellar hemisphere/vermis	9	19	53%
Optic chiasm/hypothalamus/suprasellar area	7	19	37%
Mean age at diagnosis	4.5 years (SD 3.8)		

Variable	Frequency	Total	Percent
Time elapsed since diagnosis	11.8 years (sD 4.4)		
Chemotherapy	16	19	84%
Radiation	14	19	74%
Surgery	18	19	95%
Recurrence	5	19	26%

Abbreviations: AYA, adolescent and young adult; CNS, central nervous system.

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