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Adolescent and young adult survivors of childhood brain tumors: Life after treatment in their own words

Wendy L. Hobbie, MSN, CRNP, FAAN^{1,3}, Sue Ogle, MSN, CRNP¹, Maureen Reilly, BSN, RN¹, Lamia Barakat, PhD^{1,2}, Matthew S. Lucas, PhD⁴, Jill P. Ginsberg, MD^{1,2}, Michael J. Fisher, MD^{1,2}, Ellen M. Volpe, PhD⁵, and Janet A. Deatrck, PhD, FAAN³

¹The Children's Hospital of Philadelphia

²Perelman School of Medicine of the University of Pennsylvania

³University of Pennsylvania School of Nursing

⁴Temple University School of Medicine

⁵University of Buffalo

Abstract

Background—To date there are few studies that examine the perspectives of older survivors of childhood brain tumors who are living with their families in terms of their sense of self and their role in their families.

Objective—To describe how adolescent and young adult survivors (AYA) of childhood brain tumors describe their HRQOL, that is their physical, emotional, and social functioning.

Methods—This qualitative descriptive study included a purposive sample of 41 AYA survivors of a childhood brain tumor who live with their families. Home interviews were conducted using a semi-structured interview guide. Directed content analytic techniques were used to analyze data using HRQOL as a framework.

Results—This group of brain tumor survivors described their everyday lives in terms of their physical health, neurocognitive functioning, emotional health, social functioning, and self-care abilities. Overall, survivors struggle for normalcy in the face of changed functioning due to their cancer and the (late) effects of their treatment.

Conclusions—Neurocognitive issues seemed most compelling in the narratives. The importance of families went beyond the resources, structure, and support for functioning. Their families provided the recognition that they were important beings and their existence mattered to someone.

Implications for Practice—The value and complexity of care coordination was highlighted by the multifaceted needs of the survivors. Advocacy for appropriate and timely educational, vocational, and social support is critical as part of comprehensive cancer survivorship care.

Although five-year survival rates for children diagnosed with brain tumors have improved to 75%, survivors report late effects that can be acute or long-term, episodic or progressive. These late effects are persistent, adverse changes that are related to the treatment process, disease process, or a combination of the two and lead to diminished health related quality of life (HRQOL)^{1,2,3} with caregiver proxy ratings of HRQOL even poorer than those of the brain tumor survivors.⁴⁻⁷ The three highest risk groups for long-term late effects (over 28 years) of childhood cancer are survivors of brain tumors, bone tumors, and Hodgkin's disease. Risk is highest for brain tumor survivors who were young when diagnosed, were treated with cranial radiation, and/or had tumor locations of greater risk.⁸⁻¹⁰

HRQOL is the subjective evaluation of the survivor's physical, emotional, and social functioning and incorporates perceptions about their sense of self and any insights that they may have about their families, peers, and their future potential.¹¹ As survivors of childhood brain tumors become adolescents, and young adults, they develop their sense of self through their relationships with their peers and families. In addition, they develop goals, explore intimate relationships, and formulate future education/training and work roles. Concurrent with the experience of emerging and/or progressive late effects of treatment, adolescent and young adult (AYA) survivors of childhood brain tumors are also processing how their physical, emotional, and social abilities may have changed as a result of their cancer treatment. A positive sense of self comes from acceptance of current competencies while setting goals and striving to achieve realistic developmental milestones. Within their families they would individuate and separate to their potential. HRQOL (physical, emotional, and social) serves as the conceptual framework for this study. We specifically asked, how do AYA survivors of childhood brain tumors describe their HRQOL (physical, emotional, and social functioning)?

Conceptual Framework

The survivors' physical quality of life can be influenced by late effects such as endocrine dysfunction, neurological deficits, and changes in physical appearance and often requires the care of multiple subspecialists and complex treatment and medication regimes.^{12,13} Resulting symptoms can affect their physical HRQOL through fatigue, aches and pains, difficulties with coordination and ambulation, alterations in sight and hearing, and weight gain. In our own research as well as in the literature, parents are most concerned about physical HRQOL and rate the brain tumor survivors' physical HRQOL worse than the ratings by the survivors themselves. The survivors of childhood brain tumors become more concerned about their physical HRQOL as they move into adolescence and young adulthood.^{14, 15} Our own research identified the importance of late effects for explaining their reports of HRQOL.⁵

In terms of emotional HRQOL, 25-93% of investigators found an increased risk of emotional problems, which are associated with neurocognitive late effects of childhood brain tumors and treatment (declines in global intellectual functioning or deficits in specific neurocognitive functions including attention, memory, processing speed, and executive functions).¹⁶⁻¹⁷⁻²¹ In fact, in our past research and that of others, brain tumor survivors rate their emotional HRQOL worse than their parents do and worse than their physical

HRQOL.^{22, 23} As these survivors transition to adolescence, young adulthood, and beyond, emotional functioning can significantly limit school, vocational, and social functioning and self-care ability. Thus, survivors of childhood brain tumors may not be able to live on their own and manage the complexity of their chronic physical healthcare needs due in part to emotional late effects.^{24, 25}

In terms of social HRQOL, the late effects experienced by AYA childhood brain tumor survivors may interfere with social processing, developing social skills, and achieving typical developmental milestones regarding developing and sustaining relationships with peers resulting in poorer overall HRQOL.^{23, 26} AYA childhood brain tumor survivors can, therefore, experience profound social disconnections and suffer in social interactions with their peers.²⁷ AYA childhood brain tumor survivors also demonstrate more difficulty with social functioning as they age and most are more likely to become socially isolated.²

Gaps exist in evidence regarding the perspectives of AYA childhood brain tumor survivors regarding their HRQOL, including concern that the current science may not capture the intersection of the survivor's ongoing development with their experience of functional loss. In addition, to date there are few studies that examine the perspectives of AYA survivors of childhood brain tumor in terms of their sense of self and their role in their families, especially for those young adult survivors who are not progressing developmentally (e.g. continue to live with parents; exhibit problems with physical, neurodevelopmental, and mental health).²⁵ In order to capture this intersection, Haase and colleagues²⁸ urged researchers to shift away from sole reliance on function-based studies that focus on biomedical morbidity and mortality outcomes to meaning-based studies using qualitative methods. In addition, most studies use HRQOL data by parent proxy. Finally, individuals being queried about their HRQOL often shift their responses to such questions after a life-changing event. That is, survivors may artificially adjust (usually positively) their quantitative ratings after a new baseline is established during diagnosis and treatment.^{16, 29} No systematic studies were located regarding response shift for this group of AYA survivors who are at increased risk for neurocognitive changes^{4, 12, 24, 30} thus increasing the difficulty of interpreting quantitative studies of their HRQOL.

Methods and Design

This cross sectional, single occasion, qualitative study was the second phase of a larger mixed methods (Phase 1=QUAN; Phase 2=Qual) study.^{5, 31} Both phases of the study were approved by the appropriate IRBs. Phase 1 quantitatively tested hypothesized models of caregivers' perceived competence and survivors' HRQOL. Data collection in Phase 1 was conducted by telephone with 186 caregivers (mothers) and 135 survivors that were deemed capable to participate by their mothers. Phase 2 qualitatively examined the perceptions of maternal caregivers about their caregiving and of survivors about their HRQOL in order to better understand the factors identified and tested in Phase 1.³²

In order to be included in the study, survivors were between the ages of 14-40 years old, at least 5 years from last evidence of disease, off treatment for at least 2 years, and living at least part time in the same household as their mothers who were considered the primary

caregivers by the survivors and the mothers. As recommended by the AYA Progress Report Group defining AYA and the AYA research agenda, AYA was defined as 14-40 years.³³ This decision was confirmed in our own research in which survivors' age and time since diagnosis were not significantly correlated with any caregiver (caregiving demands) or survivor (e.g. HRQOL) outcomes most likely because many of these survivors are developmentally delayed.⁵ The living arrangements of the survivors while not singularly unusual, when combined with other risk factors, may be developmentally important to their HRQOL. Exclusion criteria included survivors who lived in partnered relationships, had a genetic basis for their brain tumor, did not speak English, did not consider their mothers as caregivers, or who had mental retardation or developmental delay prior to the brain tumor diagnosis.

Sampling/Procedure

A purposive, maximum variation-based sample was drawn from the 135 AYA survivors participating in Phase 1 and who gave permission (along with their caregiver as appropriate) during Phase 1 to be contacted for Phase 2. (All but one had given permission to be recontacted). The actual sample was then purposively selected based on quantitative Phase 1 reports in order to identify a maximum variation of survivorship quality of life and maternal caregiving demands from 118 (87%) survivors who lived inside a 1½ hour driving range of the hospital.^{5,32} Fifty-two survivors were successfully contacted and consented or assented while 3 of them were deemed ineligible because of changes in living arrangements. In addition, when re-contacted to schedule the home visit, 1 survivor refused and 7 interviews could not be scheduled. Interviews were successfully completed with 41 survivors.

A semi-structured interview guide was constructed that was consistent with but not constrained by the HRQOL conceptual framework and the relevant literature. The interview structure was funnel-shaped, starting with a broad set of opening questions that were meant to encourage a conversation with the interviewer followed by more specific questions pertaining to the various facets of HRQOL. Additional probes were used based on actual responses in order to facilitate communication. See Table 1 for sample questions from the interview guide.

Treatment intensity ratings and medical late effects ratings were completed on each survivor using the *Intensity of Treatment Rating*. Data were collected from medical charts and each survivor was rated by a pediatric oncology nurse practitioner (WLH) and a pediatric oncologist and neuro-oncologist (JG or MF) specializing in survivorship and blinded to the participant's identity (interrater reliability Kappa = 0.97). This scale provides an objective rating of the child's treatment intensity based on number and combination of therapies received³⁴ and was adapted for a pediatric brain tumor population. An objective ratings of the late effects of cancer treatment were collected with a similar protocol using the *Medical Late Effects Rating* (interrater reliability Kappa = 0.94). The ratings for both are noted in Table 2.

Mothers rated the survivors' cognitive ability after treatment using a single item 0-10 rating (0=no change; 10=poorest functioning). (See Table 2).

The qualitative interviews of the larger study were conducted face to face, by one of two authors (MSL or JD), in a private setting in the survivors' home setting while the mother was being interviewed in another space within the home. These research participants like others discussing sensitive topics tolerated the process well.³⁵ None of the participants in this study demonstrated prolonged distress. While several survivors did cry for one to two minutes, the survivors were given time and encouraged to continue at their own pace. Two mental health professionals were involved in the study and available on-call to react to any emerging psychological effects of the research. In addition, the interview guide was carefully constructed to avoid excessively probing questions.

The interviewers prepared a case summary of demographic and treatment data, as well as data from Phase 1, to orient them to the survivor and their family before the interview. These case summaries were further developed after the interviews with additional field notes. The interviews were audio recorded with digital recorders and lasted an average of 46 minutes. After the interview, the survivors received \$20 for their participation in the interview.

Analysis of Data

Directed content analysis was used to identify descriptive or topical categories using the conceptualization of HRQOL (e.g. physical and emotional functioning) to organize the analysis but not restrict the analysis. Categories were added or expanded to reflect what the survivors reported.^{36, 37} Categories were developed by the investigators who independently read through one interview transcript and derived preliminary categories. After comparing their categories they came to an agreement on a general coding scheme, which they applied to two more interviews. They then compared the additional categories in order to identify ambiguities, incompleteness, lack of clarity, and any overlap in categories. Following this review, the investigators finalized a coding structure that was applied to the rest of the interview data. Based on the category structure, a "code book" was drafted that contained a definition of each category, guidelines for its application, and excerpts of data exemplifying the category. Two members of the research team met to compare their application of the categories and resolve any differences in their analyses as well as code each interview independently.

The research team met biweekly to resolve any differences in their coding in order to refine and clarify the categories and strengthen the rigor of the study.³⁸ Atlas.ti 6.2™ software accommodated changes and additions to the coding structure. Two matrix displays of data in each category across all subjects and for all categories for each subject (case summaries) were constructed to further assist in the analysis.³⁹ These matrix displays also allowed examination of data according to Phase 1 HRQOL measures in terms of high or low physical and emotional HRQOL.⁵ Through constant comparative analysis,⁴⁰ the qualitative categories were refined for conceptual flow and consistency and were incorporated into the data analysis.

Results

The results are communicated in three sections. First, the demographic characteristics of the survivors are described. Second and third, two typical cases (same tumor and treatment with different demographics) are presented in order to facilitate a holistic understanding of the survivors and are followed by an examination of their HRQOL.

Sample Characteristics

The characteristics of the survivors who participated in the study are described in Table 2. They had varied diagnoses, tumor locations and types, late-effects, school and work histories, and ages. This sample consisted of 41 survivors of brain tumors: ages 15-36 years ($m = 23$ [s.d.4.86]), 61% male, 83% white, 20% did not go to school or work and 10% volunteered only. Tumors were most often located in the posterior fossa (50%), and low grade glioma (43%) and medulloblastoma (32%) were the most common histologies. Treatment intensity included 27% minimal, 29% average, 10% moderate, 29% intensive, and 5% most intensive. Medical late effects ratings revealed 17% with minimal to no limitations, 19% with mild restrictions, 59% with moderate restrictions and 5% with several restrictions of daily living. Post treatment cognitive functioning was rated 5 and above by 48% and below 5 by 52% of the mothers.

No significant differences were found ($p>.05$) between this sample and the larger sample.

Cases

The survivors described their everyday life in terms of their physical health, emotional health, social functioning, cognitive functioning, and self-care abilities. These five broad areas are used to demonstrate how HRQOL is manifested in the survivors' lives.

Case A.—JW is a 27 year old who was diagnosed with medulloblastoma at three years of age. His treatment consisted of surgery, chemotherapy and craniospinal radiation. He did well and completed therapy without any major complications. JW attended high school and was in a self-contained classroom with multiple supports in place. JW has short stature secondary to growth hormone deficiency and scoliosis. He has a small cranium and partial alopecia at the base of his skull with thinned scalp hair throughout. JW has bilateral hearing aids and cataracts.

After graduation from high school, JW attempted to go to Occupational Vocational Rehabilitation (OVR) for training with a job coach. He was not successful in completing the program due to fatigue, poor concentration, lack of organization, and poor social skills. He spends most of his time alone or with his parents or siblings. He watches TV and plays computer games. JW has no friends outside his immediate family and recognizes this as a concern. He considers his dog his best friend.

JW relies on his mother and older sister for his medication, transportation and making healthcare appointments. He is unable to manage his self-care and activities of daily living (ADLs). His meals are prepared for him and he often chooses to sleep if family members are not around. Although JW states that he is content, he recognizes that he is reliant on his

family and wishes he was more independent. He would like to date and live on his own; however he does not think about how he could support himself.

Case B—LC is a 24 year old female who was diagnosed at 14 years of age with medulloblastoma. Her treatment consisted of surgery, chemotherapy and craniospinal radiation. She did well, completed therapy and has been disease free since the completion of treatment. LC attended a rigorous private school prior to her diagnosis, where she was doing exceptionally well academically, athletically and socially. Post treatment, she returned to her high school and struggled in all aspects of her life. She felt as though no one understood how challenged she was given her prior performance.

LC is a pleasant, attractive, well-spoken young adult. She wears a wig to cover her alopecia and is well groomed. After graduation from high school, LC applied to and started college. She is currently in her 6th year of attempting to complete the requirements to graduate without success. She is unable to drive and relies on public transportation.

Socially, LC is lonely. She lives at home, commutes to college and does not have friends. She tried to work part time but had trouble with memory, organization, speed, and multitasking. LC is very close with her family and spends a lot of time with her younger brother. Her faith is an important part of her life and she attends church regularly. She would like to have friends and date. She recently reached out to her treatment team to inquire about volunteering so that she could give back to others. LC struggles to meet the expectations of others. Her limitations are not visible and unrealistic expectations of her ability cause her great distress.

These two cases represent typical profiles describing each of the five areas of functioning described by the survivors. AYA childhood brain tumor survivors who have received cranial radiation have many challenges, although the extent that treatment and late effects impact HRQOL varies from patient to patient. In Case A would most likely endorse a lower physical and emotional HRQOL. JW struggles with the simple tasks of daily living. He is completely reliant on his family to provide for his daily needs including meals, medication and entertainment. His understanding of a world where he functions differently is not apparent to him since he was diagnosed. His insight into what he would like to do with his life is childlike. He wants to date and live on his own, yet he has no insight/understanding as to what this would require and how he would go about achieving such goals. He just knows he wants these things.

In contrast, LC (Case B) would most likely endorse a relatively higher physical and lower emotional HRQOL. This young woman has a clear understanding of life before and after cancer. She has a sense of isolation and attributes this to the fact that others do not see or understand her disability from her tumor and late effects. She finds comfort in her religion, but lacks the peer and social connections she once experienced. Although from the outside she appears developmentally on target, but, is aware that she does not have the necessary skills.

Components of HRQOL for AYA Childhood Brain Tumor Survivors

As illustrated in the two cases, survivors shared in their own words some meaningful insights into their worlds. **Physical health issues** consisted of differences in appearance, such as short stature, baldness, hypoplasia and neurologic functioning and included sensations and balance issues. One survivor related: "In high school...they thought I was funny 'cause my head was shaped weird, and called me all weird names. I didn't like it." Another survivor shared: "I don't like to wear my hearing aids. I don't like the way they look."

Differences in **neurocognitive functioning** directly and indirectly influenced every area of functioning and were embedded in the survivor's accounts about their daily life. The direct impact was apparent in everyday tasks; for instance, reading directions or working with money could be challenging and potentially frustrating to a survivor. The indirect impact became evident when their neurocognitive late effects complicated their self-care. For instance, if survivors' had neurocognitive limitations in memory and executive functioning, survivors were not able to manage follow-up self-care and relied on their mothers for related reminders and problem solving. While those who were limited had some awareness that their abilities were different than before their brain tumor and its treatment and different from their peers, the amount and nature of their insight varied.

Emotional health issues involved survivors recognizing that they need to rely on others for day-to-day functioning, a sensitivity to others reactions around them, and loss of independence in terms of the physical challenges that make them more reliant on others. Almost every survivor acknowledged the support of their primary caregiver. One survivor stated, "I love her (mother) very much. She does a lot for me...she is my backbone and support." In contrast, some survivors expressed ambivalence about their reliance on others, "I don't always need the help. If you're willing to help me, great, but I don't always need it." Survivors expressed great sensitivity regarding how others reacted to them. In one poignant example, a survivor felt rejected by his peers at work, "One time they [co-workers] just sat there, you know. They sat there, and they laughed at me. I said, 'Why are you laughing at me?'" The sense of loss was pervasive. One survivor shared, "[It is] hard to think about what my life would have been." Their families were also acknowledged for helping them problem solve their situations. For instance, one survivor recounted that their family's plans for his independence (the goal of the survivor and caregiver) was that he would have his own apartment with its own front door attached to the family home. Another survivor has his own business (window washing) that is actually part of his mother's thriving cleaning business. On the other hand, some survivors and families, such as in Case B, insist the survivor achieve independence using strategies that have not worked in the past and hold little future potential.

A majority of the survivors commented that **social functioning** was most impacted by their brain tumor and treatment. Survivors recognized the difficulty they endured making friends and finding a significant other. Loneliness was a prevailing theme for all of the survivors. At times, the survivors who were most neurocognitively impaired had limited insight as to why they did not have friends or why they could not achieve their goals. What one survivor said

that was typical of others, “The hardest thing in my life is getting along with my friends...people I work with...I want to have friends, but I just can't seem to find them.” As in Case A and B, they were both aware they were without friends, but wanted to date and have friends.

Survivors acknowledged that their family members were their best friends and they had tremendous gratitude for them. One survivor mentioned, “Most of the time I spend with my parents.” Similarly, another said, “I do a lot of things with my brother and his friends.” They acknowledged the importance of family and the interplay between their families and “finding” themselves because of their lack of friends. Community members were also seen as important for survivors and for their families, not only as friends but also for the assistance they could provide. One adolescent said, “In fourth grade I struggled with multiplication and division. The (teachers) were the biggest support and a lot of people at my church, they had a program called ‘Angel Hands’ and they made meals for my family and the amount of support we got was just amazing.”

The consequences of these physical, neurocognitive, emotional, and social differences were inherent in how survivors’ assessed their **self-care abilities** or their abilities to perform their own ADLs and meet developmental milestones. One survivor admitted, “I need my family for everything. They have to remind me about my medications, making doctor's appointments, driving me everywhere, and make my food.” Clearly, this group of AYA survivors of childhood brain tumor, living at home with their parents, has less potential to meet developmental milestones, successfully accomplish typical young adult tasks, and live independently. As one young man said, “I spend most of the day sleeping, then I get up late afternoon and eat. I know my parents will be home soon. I stay up very late ‘til about 4 a.m. and then go to sleep again.”

Discussion

The AYA survivors of childhood brain tumors in this study described their HRQOL that is their physical, emotional, and social functioning. Using HRQOL as conceptual framework, five key aspects of HRQOL were demonstrated by two cases. Survivors of childhood brain tumors were able to convey their concerns and everyday experiences about their sense of self and their relationships with others, including their caregivers, family members and peers. To some degree, most survivors understood they are different and that would not change. As described in the two cases, some AYA survivors have significant neurocognitive impairments that limit their potential for achieving typical developmental milestones. These survivors may have reduced insight and are content, although they are not likely to achieve independence. Other survivors have more insight and know what they have “lost,” know who they were, and know what their potential was prior to diagnosis. They may or may not be able to accept this new baseline. They struggle for normalcy in the face of great adversity as they spoke about how their physical, social, cognitive and emotional abilities changed as a result of their cancer as well as with their late effects of treatment.²⁷ In the best case scenario, these survivors can complete college or become skilled laborers and live independently but may fail to become independent even with college or skills training because they cannot perform independently in a work or home environment.⁴¹

The importance of families of AYA survivors of childhood brain tumors in supporting ongoing development and HRQOL went beyond the resources, structure, and support for physical, neurocognitive, emotional, and social functioning. For the most affected, their families provided recognition that survivors were important human beings and their existence mattered to someone. Without other meaningful relationships, the family served as the survivors central social connection and served as the survivor's looking glass enabling them to define themselves.⁴² The outcomes of family management sometimes included creative solutions to difficult problems that reinforced the survivors' positive sense of self.

The most striking information gained from this study was every survivor's overwhelming appreciation for what their mothers and family have done and continues to do for them. They viewed their mothers as special individuals who sacrificed to provide in the best way they could for their child. For this reason, survivors universally wanted to give back to others. They consistently described their desire to do for others since so many had given to them. While generally described in the survivorship literature in the past, connection between the desire to give back and what the family has done for them has not been described. This could be an important motivator for survivors who may not be able to work but who could be channeled into volunteer activities in their community or the cancer/brain tumor community.

While all areas of HRQOL were important to the survivors, neurocognitive issues seemed most compelling in the narratives. As noted in the literature, neurocognitive functions underpin development across all spheres of functioning and any differences between their cognition and that of others may set them apart in every sphere of their existence and can create deep divides of risk and suffering especially for those survivors who are self-aware^{43,44}. While this study did not include neurocognitive testing, a follow-up study on a convenience sample of 34 of the survivors in this study found that survivors' working memory was in the average range and survivor processing speed and long-term memory were in the low-average range. Performance-based measures of executive function revealed borderline mental flexibility abilities and low-average problem-solving abilities.⁴³

Practice Implications

At every step of the survivor's care, nurses and other health care professionals can advocate with the survivors and their families to improve the survivor's physical health, emotional health, social functioning, cognitive functioning, and self-care abilities. First, (re)habilitation may be important in order to maximize the survivors' independence. For instance, the survivorship team found that the 27 year old survivor in Case A who had been diagnosed and treated as a 3-yearold was not able to dress himself. For Case B, work on social skills and perhaps a structured volunteer opportunity might be effective initial interventions to improve HRQOL. Such services may be necessary as treatment ends and over time as a result of developmental and/or pathophysiological changes; therefore, health care providers, the survivor, and family must be educated regarding the necessity of continuing assessment and (re)habilitation. Involvement of the family is paramount in (re)habilitation as family functioning is important to ongoing functioning of the survivor. For instance, survivors who live in disorganized families have poorer executive functions than those with better

functioning families.⁴⁵ Health care providers can help families understand their importance to the survivor and how they can best ask questions of providers that may guide decisions during all phases of development. It is extremely important for all to recognize and acknowledge the significant losses and assist the survivor and family to cope with this sense of loss so that all members of the family can move forward. Clinicians can help families normalize the need for on-going support and counseling as the adolescent/young adult develops into the next life stage which may be important to helping them cope with the numerous losses.

Second, surveillance, assessment, and treatment of late effects of the brain tumor and treatment can be provided using different models of care, including general survivorship clinics, multidisciplinary follow-up clinics (MDC), or consultation of the neuropsychology team with primary care physicians. Due to the multi-organ systems impacted by the treatment for a brain tumor, a multidisciplinary clinic model may have the best potential to meet survivors' varied and complex needs. One such clinic is staffed with a neuro-oncologist; oncologist specializing in survivorship, survivorship nurse practitioner, oncology nurse coordinator, oncology nurses as well as providers from endocrinology, nephrology, cardiology, pulmonary, nutrition, and psychology. This team addresses the physical, psychological and social needs of these survivors and their families. In Case A, JW was reliant on his family and had no independence. The MDC consolidated his trips to the clinic by providing the multidisciplinary care he needed in one setting on one day. This benefitted the family and decreased the burden of missing several days of work. Additionally, in dealing with the fatigue and lack of ability to perform ADL, the team (neuro-oncologist, psychologist and survivorship team member[s])) were able to meet in conjunction with the MDC and design a multifaceted approach for these issues that were implemented during his next clinic visit. This included medication, training sessions for the survivor and family members, and referral to local programs to support and facilitate social interactions. The usefulness of the MDC is further illustrated again in Case B whereby the survivor could not drive and had multiple subspecialists involved in her care. Seeing several subspecialists and completing necessary testing on one day decreased the stressors for the family and decreased LC's concerns about missing school and falling further behind.⁴⁶

Third, the greatest conflicts arise in the clinical arena when the primary caregiver's goals differ from the survivor's goals and when expectations⁴⁷ are not appropriately prioritized. Setting appropriate goals and expectations for self-care, academic, and vocational goals is a very difficult job given the sensitivity around setting realistic goals for an individual without belittling or insulting the survivor and his or her caregivers and family. For example, a survivor knows he/she cannot be successful at college but the parental caregivers do not accept this and insist that the survivor apply and attend college. Open communication among the survivor, parents, family, and treatment team when considering such goals is a most important factor in facilitating quality of life.⁴⁸ Though this process, stepwise solutions focused on the needs of the survivor at any particular point in development can be identified that are respectful to the needs and goals of all involved. In addition, developmental and neurocognitive assessments are essential to this process. Using the results, it is crucial that caregivers advocate for individualized education plans (IEP) and if an IEP is not needed and other issues exist, advocate for special accommodations with a 504 Plan.⁴⁹

When appropriate, survivors should be able to access training to develop self-care, life skills, and independence through the IEP as well as transition plans that are to be embedded within them. For survivors with the greatest impairments, the focus of their education should be on developing skill sets for meeting their activities of daily living (ADL). Many of the survivors in this study did not benefit from either specialized instruction or accommodations because the nature of their difficulties was not well understood at the time they were in school and struggled to meet some of the simplest tasks of ADL. Providing structure to their day and teaching the skills necessary to perform ADLs is important to decrease their dependency on family and create a sense of independence for the survivor. The MDC team works with parents and survivors to devise strategies to facilitate independence and increase ADLs as needed. For instance, the family in Case A was frustrated and didn't understand why JW couldn't get dressed. The psychologist explained this was related to the JW's cognitive limitations. The team and the family used problem solving to find an acceptable structure for teaching the survivor how to get dressed and for reminders to organize this and other ADLs. The given structure to the task and guidance assisted the survivor develop these skills.

Academic and vocational goals and expectations must be examined over time. It cannot be assumed that there are no issues because the survivor is successful at one point in time. Instead, surveillance is necessary to understand potential learning issues. For example, their needs may not be apparent to the school or parents until they reach grades that involve major transitions in learning (e.g. 3rd grade) or until late effects progress. At these times their learning needs can change dramatically and the results of testing can provide the guidance and knowledge needed to give anticipatory guidance and set realistic goals. Another example is a survivor who is able to graduate from high school and who wants to pursue further education, it is imperative that they choose an appropriate program of study and a university/college with available supports and resources in place. We found in our study that some college graduates may experience challenges related to gainful employment or meeting their goals of living independently because of their limitations in neurocognitive functioning.⁴⁴ While colleges may offer various ways to accommodate for the survivor's neurocognitive differences, navigating the work world usually does not offer such accommodations. For those survivors who are not or cannot attend college, OVR should be brought into the treatment plan by nurses and other members of the team as early as possible to help identify and put into place next steps for success. Again, the MDC team is equipped to respond and intervene and make referrals during the clinic visit since all parties are readily available. Neuropsychological testing can be scheduled and the testing psychologist can assist the family with needed advocacy for the AYA. For example in many cases, families are unaware of what the public school system can offer services up to the age of 21.

Future Directions

Barakat and colleagues noted that treatment intensity and medical late effects are important predictors of HRQOL and served as a proxy for predicting outcomes in this patient population.⁵ Such data are potentially important in identifying childhood brain tumor survivors who are at risk and need to be linked to early intervention programs with social and self-management skills training. These types of interventions may serve as a foundation

from which these survivors can “find” their path to acceptance for the losses they have suffered. Often, survivors of brain tumors return to school with supports in place, but to date these have been largely inadequate in preparing survivors for creating productive lives. Identifying individual needs and putting systems into place that can accommodate for the changes following treatment might provide a better foundation for growth and development with the challenges these survivors face.

Programs are needed to help survivors develop and refine social skills so that integrating with their peer group is possible to combat their pervasive sense of loneliness. Appropriate activities need to be identified and will be instrumental in fostering development of skills. An example of this is a of a young brain tumor survivor who wanted to join the Brownies; however, she didn't “fit in” with the troop in her neighborhood. Therefore, her mother established a Brownie troop for girls with special needs, thereby creating an environment where the child could develop a peer group and work on social skills with girls with similar struggles. In addition, healthy lifestyles could hopefully modify risks factors associated with inactivity, obesity and improve overall health by increasing activity level in these survivors and could also serve as an opportunity for socialization. Several caregivers participated in these activities with the survivor initially and some were finding success with the survivor now participating in such informal and formal programs as individuals. Potential programs included Weight Watchers, certain types of exercise classes, and programs tailored specifically for individual with neurologic impairment.

Other than the practical suggestions to improve survivor's HRQOL, future research must focus on developing interventions that focuses on caregivers as well as survivors and families. Since the family unit is critical to the survivor's overall HRQOL and their growth and development, the family must be supported and guided through the long and sometimes arduous task of optimizing a survivor's relationships with others to increase their ability to achieve a sense of purpose and direction into young adulthood.³²

Limitations

Although this study has contributed much to our knowledge regarding the function and perspectives of HRQOL through direct contact with the survivors in their homes, the study has several limitations. First, although we identified all childhood brain tumor survivors in the tumor registry,³² only those who responded to our mail contact and met our inclusion criteria participated in this study and a selection bias was created. In addition, the resulting cohort was predominantly white, non-Hispanic.

Second, the treatment period is over two decades and this may present varying treatment effects based on type of radiation, surgical techniques and chemotherapy regimens. We were, however, able to carefully describe the treatment given to this cohort of survivors using ratings by experienced and expert clinicians.

Finally, 20% of the sample were under the age of 18 and would usually be living at home. While survivors between 18-20 year were selected to match age criteria for the National Cancer Institute for AYA so that typical concerns of emerging YA who do not live

independently could be identified, data from younger survivors may have inadvertently changed the results.

Conclusions

Although neurocognitive issues seemed most compelling in the narratives, all areas of HRQOL were important to the survivors. When dealing with the issues generated from their brain tumor and its treatment, the centrality of the survivors' families went beyond the resources, structure, and support for physical, neurocognitive, emotional, and social functioning. That is, especially for the most affected, their families provided the recognition that they were important beings and their existence mattered to someone. Advocacy for appropriate support is urgently needed to support the HRQOL for survivors and for their families, as well as comprehensive cancer survivorship care.

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Table 1**Sample Questions from the Survivor Interview Guide**

Joining with the interviewee: Sense of self

- Tell me about yourself.

Quality of Life-Overall Importance

- What kinds of things do you do every day? Are they important to you? If not, what is important to you? What are the most important things in your life right now?

Quality of Life-Facilitators and challenges

- Has the brain tumor changed your view of your future path? What do you think the future will hold for you?
- What do you enjoy doing? What are some fun things for you to do? What do you look forward to doing?
- What parts of your life are most challenging?

Individuals who facilitate QOL and meet challenges; mothers role regarding their QOL

- Who assists you with everyday life? Who assists you with what is important to you?
- Tell me a recent example of a particular struggle you faced and how these people helped you.

Quality of Life-Community Issues

- Tell me about work? School? Play? (as appropriate)
- How do you communicate with others outside your home?

Quality of Life-Social relationships; how they relate to others

- Who do you spend the most time with? Who else do you spend time with? How has that changed or not since you were treated for your brain tumor?
- How do you feel about dating? Are you dating anyone?
- Do you think others treat you differently because of your brain tumor sometimes? Are you concerned about this?

Quality of Life-Physical

- If so, what kinds of physical differences (or problems) do you experience? Do you think they come from your brain tumor? Are you concerned about them?
- Do you worry about your health now and in the future?

Quality of Life-Psychological

- To whom to you compare yourself? What do you think about yourself when comparing yourself to others?
- What makes you happy? Sad? Nervous?
- Can you think of a time when something did not go well at work? School? Home? Tell me what you think might have helped from your family? School? Health care workers?

Quality of Life-Family Issues-How they relate to family members

- Tell me about your family

Other Factors that may influence Quality of Life

- Are there other issues that affect your everyday life that you feel are important for me to understand?
 - What kinds of advice do you have for health care providers?
 - What advice would you have for someone who was just diagnosed with (or just finished treatment for) a brain tumor?
-

Table 2

Demographic and Medical Data for Survivors (n=41)

	Frequency	Percent
Survivor Race		
African American	4	9.76
Asian and Pacific Islander	2	4.88
White	34	82.93
Multiple	1	2.44
Survivor Ethnicity		
Hispanic	1	2.44
Non-Hispanic	40	97.56
Survivor Education and Work		
No school or work	8	19.51
School	13	31.71
Work with or without school	16	39.02
Volunteer	4	9.76
Insurance Status		
Public insurance	8	19.51
Private insurance	23	56.10
Both	9	21.95
Not Insured	1	2.44
Survivor Gender		
Female	16	39.02
Male	25	60.98
Survivor Age in Years (mean 23; st dev 4.86, range 15-36)		
14-19	10	24.39
20-24	19	46.34
25-29	8	19.51
30-39	4	9.76
Survivor Time Since Diagnosis (years)		
Mean (Standard Deviation)	15 (5.74)	
Median	15	
Range	6.96-27.30	
5-9.99 years	7	17.07
10-14.99 years	11	26.83
15-19.99 years	13	31.71
20-24.99 years	8	19.51
25 or more years	2	4.88
Treatment Intensity		
1. Resection only	11	26.83
2. Focal radiation +/- non-intensive chemotherapy	12	29.27
3. Moderate chemotherapy +/-focal radiation, but no CSI	4	9.76

	Frequency	Percent
4. Craniospinal radiation +/- moderate/non-intensive chemotherapy) Or intensive chemotherapy and stem cell rescue	12	29.27
5. Craniospinal radiation and intensive chemotherapy and stem cell rescue	2	4.88
Medical Sequelae		
1. Minimal to no limitation in activity	7	17.07
2. Mild restriction of daily activity	8	19.51
3. Moderate restriction of daily activity	24	58.54
4. Severe restriction of daily activity; life threatening	2	4.88
Tumor Locations		
Posterior Fossa/Cerebellar	20	48.78
Cortical/Subcortical: all lobes	7	17.07
Suprasellar/Hypothalamic (included Pituitary)	6	14.63
Pineal	4	9.76
Ventricle (supratentorial)	2	4.88
Brain Stem	1	2.44
Optic Nerve/chiasm	1	2.44
Diagnoses		
Low Grade Glioma	18	43.90
Medulloblastoma/Primitive neuroectodermal tumors (PNET)	13	31.71
Craniopharyngioma	3	7.32
High Grade Glioma	3	7.32
Germ Cell Tumor	2	4.88
Choroid Plexus Tumor	2	4.88
Maternal Rating of Survivors' Post Treatment Cognitive Ability		
0 (no change)	5	12
1	6	15
2	3	7
3	1	2
4	0	0
5	5	12
6	4	10
7	4	10
8	5	12
9	2	5
10 (poorest)	6	15