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Quality of Life Among Parents of Adolescent and Young Adult Brain Tumor Survivors

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Abstract

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We aimed to describe the quality of life (QOL) among parents of adolescent and young adult (AYA) brain tumor survivors as well as parent, survivor, and diagnosis/treatment-related factors associated with adverse QOL. A cross-sectional study of 28 parents of AYA brain tumor survivors (who were on average 10 years post-diagnosis) was used to assess QOL. Parent QOL was measured using the Patient-Reported Outcomes Measurement Information System Global Health measure. Factors associated with adverse parent QOL were explored using logistic regression including: parent, survivor, and diagnosis/treatment-related factors. Parent QOL was within the normal range; however, 40% scored below the clinical threshold of 0.5 SD below the mean for physical and mental health. Parent perceptions of greater family impact, survivor emotional/behavioral health problems, improved cognitive function, and recurrence were associated with adverse parent physical health. Parent anger/sorrow, uncertainty, survivor emotional/behavioral health problems, speech/language problems, and recurrence were associated with adverse parent mental health. Parental emotional resources and perceptions of improved survivor peer relationships were associated with greater parent physical and mental health. The impact of a brain tumor diagnosis and treatment on the QOL of parents may be significant. Interventions are needed to ensure that the needs of parents are met.

Keywords

brain tumor; psychosocial; survivor; parent

BACKGROUND

As of 2013, there were over 420,000 childhood cancer survivors in the United States [1]. Over 50,000 of these were brain tumor survivors; comprising the largest proportion [2]. Endocrine, neurologic, and sensory problems are commonly reported among brain tumor survivors [3–4]. Neurocognitive deficits such as impairment in attention, memory, and executive functioning are also debilitating [5]. Chronic health conditions and neurocognitive impairments may undermine the psychosocial health of brain tumor survivors as they reach adolescence and young adulthood resulting in an inability to achieve important milestones (e.g., academic success, employment, independence) [6–11].

Parents of childhood brain tumor survivors may experience distress as they continue to deal with disabilities. Parents provide a substantial amount of aftercare for aging brain tumor survivors across a variety of domains [12]. Caregiving demands experienced by parents contribute to the quality of life (QOL) of caregivers [13]. Meeting the practical day-to-day needs of the survivor creates challenges for parents. Worries and uncertainties focused on future expectations with respect to disease (e.g. recurrence) and psychosocial (e.g. independence) aspects of care serve as examples. To date, few interventions have been developed and tested in this at-risk group of parents. Characterization of parent QOL and factors which may impact parent QOL is necessary to inform the development of such an intervention.

The primary aim of this study was to describe the QOL among parents of adolescent and young adult (AYA) brain tumor survivors compared to normative data. The secondary aim

was to explore parent, survivor, and diagnosis/treatment-related factors that may be associated with adverse parent QOL.

METHODS

Study Design and Participant Recruitment

This cross-sectional study recruited participant families from CHOC Children's Hospital in Orange County, California. Families were asked to participate in this study from May 2014 through February 2015 at CHOC Children's Hospital. Parents of AYA (age ≥ 10 years) brain tumor survivors (≥ 2 year post diagnosis) who were English or Spanish speaking were eligible for participation. The study was approved by the Institutional Review Board of CHOC Children's Hospital. Informed consent and study measures were completed in-person. Parent participants also signed a release granting access to their child's medical records. Diagnostic and treatment-related information was abstracted from the survivors' medical record using a defined protocol.

Measures

Outcome Measure

NIH PROMIS Global Health Short Form: Parent physical and mental health was assessed using the National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health measure [14]. The measure consists of 10 items which assess physical functioning, bodily pain, general health, vitality, social functioning, and mental health. Item responses are 1= "Excellent" to 5= "Poor". Global physical and mental health subscale scores were calculated and converted to T-scores with a mean of 50, standard deviation (SD) of 10, and a range of 0–100. A higher T-score represents greater perceived physical and/or mental health.

Independent Variables

Parent Factors: Parent distress associated with the AYA brain tumor experience was assessed using the Parent Experience of Child Illness (PECI) [15]. The PECI measures the subjective distress and emotional resources of parents impacted by having a child with a chronic illness. The measure consists of 25 items which assess guilt and worry, unresolved sorrow and anger, long-term uncertainty, and emotional resources. Item responses are 0= "Never" to 4= "Always". Items in each subscale were summed and divided by the number of items contained within the subscale. Subscale scores ranged from 0–4. A higher score on the PECI subscales reflect greater distress and emotional resources.

Parent perceived impact of the AYA brain tumor survivor experience on family members was assessed using the Impact on Family (IOF) Scale [16]. The IOF scale consists of 15 items reflecting the impact of chronic childhood illness on social and family functioning. Item responses are 1= "Strongly Agree" to 4="Strongly Disagree". The items were summed to compute a total impact score that ranged from 15 to 60. Higher scores reflect a more negative impact of the survivor experience on the family.

Parent sociodemographic information, such as parent gender, age (continuous), Latino (yes vs. no), employment status (Full or part-time vs. other), marital status (Married vs. single), and educational attainment (grade school or high school completion vs. college or greater) was also self-reported.

Survivor Factors: The PROMIS Emotional Distress – Depression Short Form 6 and the Peer Relationships Short Form 8 were used [17–18]. The Emotional Distress – Depression Short Form 6 is a parent-completed questionnaire that contains 6 items which measure negative mood, views of self, social cognition, as well as decreased positive affect and engagement. The Peer Relationships Short Form 8 is a parent-completed questionnaire that contains 8 items which measure the quality of relationships with friends and acquaintances. The response scales for the PROMIS measures are 0= “never” to 4= “almost always”. The items were summed to generate total scores, ranging from 0–100. The total scores were converted to standardized T-scores with a normalized mean of 50 and SD of 10. A higher T-score represents greater depression or greater peer relationship quality; respectively.

The Pediatric Symptom Checklist (PSC) - 17 is a psychosocial screen designed to facilitate the recognition of emotional and behavioral problems in children [19–20]. A parent completed version of the PSC-17 was used which consists of 17 items. Item responses are 0=“Never,” 1=“Sometimes,” and 2=“Often”. Items were summed to compute a total problem score ranging from 0 to 34.

The PedsQL Cognitive Functioning Scale (CFS) parent-proxy report questionnaire contains 6 items which measure cognitive functioning over the last month [21]. Item responses are 0=“never” to 4=“almost always”. Items were reverse-coded and transformed generating a total score ranging from 0–100. A higher score represents fewer cognitive difficulties.

All measures utilized demonstrated acceptable reliability and validity [14–21].

Diagnosis and Treatment-related Factors: Brain tumor survivor disease and treatment-related factors were obtained from a medical chart review. This included the current survivor age, survivor gender, survivor age at the time of diagnosis, time elapsed since diagnosis, diagnosis, and treatment details including exposures to chemotherapy, surgery, radiation, and a history of recurrence.

The presence of late effects was reported by parents including hearing problems, vision problems, speech/language problems, chronic pain, endocrine problems, and weight problems using a 5-point response scale which was subsequently dichotomized (none/mild vs. moderate, severe, very severe).

Analysis

Descriptive statistics were generated for the sample and study measures. Comparisons were made with normative data using a one-sample T-test (null hypothesis of the sample mean=50). Parent QOL (physical and mental health) was dichotomized at 0.5 SD below the mean (T score $\leq$ 45) which represents a minimally important difference to create a dichotomous outcome variable reflecting compromised QOL versus normal QOL [22].

Associations were explored between parent QOL as measured by the NIH PROMIS Global Health measure and parent factors including age, gender, and race/ethnicity (Latino yes vs. no), adjustment (PECI subscales of worry, unresolved anger/sorrow, long-term uncertainty, and emotional resources), and perceived family impact (IOF total score) using univariate logistic regression. Associations were then explored between parent QOL and survivor factors including perceived survivor emotional/behavioral health (PSC-17, PROMIS Emotional Distress – Depression Short Form 6), parent perceived survivor social health (PROMIS Peer Relationships Short Form 8), and cognitive functioning (CFS). Lastly, associations were explored between parent QOL as well as diagnosis/treatment-related factors such as survivor age at diagnosis (continuous), time since diagnosis (continuous), diagnosis (medulloblastoma vs. other), radiation therapy (yes vs. no), the presence of late effects such as hearing problems (yes vs. no), and recurrence (yes vs. no). Adjusted odds ratios accompanied by 95% confidence intervals were reported.

RESULTS

A total of 318 participants were screened for participation. Of these, 269 individuals were excluded (260 were diagnosed with malignancies other than brain tumors and 9 were brain tumor survivors that were < 10 years of age). Of the 49 potentially eligible participant families a total of 9 visits were canceled, 4 were missed, 5 families declined to participate, and in 2 cases a parent was not present at the visit. Of the 5 families who declined, reasons included: not wanting to fill out questionnaires during clinic visit as it would interfere with bonding time, having a headache, and not being interested. A total of 29 families provided consent. We received questionnaires from N=31 parents representing 28 participant families. For the three families in which both parents returned questionnaires, one parent from each family was randomly selected in order to avoid overrepresentation from any single family. Table 1 provides a description of the parent respondents and AYA brain tumor survivor characteristics.

Parent QOL

Parents' self-reported NIH PROMIS Global Health measure scores did not differ from normative data. Mean physical health summary T-scores (mean 48.5; 95% CI, 44.6–52.4) were comparable to normative data (one-sample t-test, p=0.46), and mental health summary T-scores (mean 47.8; 95% CI, 44.0–51.7) were also comparable to normative data (one sample t-test, p=0.27). A total of 11 (39%) parent participants reported T-scores for self-reported physical health that were > 0.5 SD below the mean for physical health and 12 (42%) reported scores for self-reported mental health that were > 0.5 SD below the mean for mental health.

Parent Factors Associated with QOL

Results of univariate analyses describing parent factors associated with QOL are provided in Table 2. Perception of greater family impact was associated with adverse physical (OR 1.18; 95% CI 1.03–1.35), and mental health (OR 1.13; 95% CI 1.01–1.27). Unresolved anger/sorrow (OR 4.3; 95% CI 1.30–14.18) as well as long-term uncertainty (OR 3.04; 95% CI 1.01–9.14) was associated with only adverse mental health. Greater emotional resources

were associated with better physical (OR 0.35; 95% CI 0.12–0.99), and mental health (OR 0.35; 95% CI 0.12–1.00).

Survivor Factors Associated with QOL

Results of univariate analyses describing survivor factors associated with QOL are provided in Table 2. Perception of better cognitive function (OR 1.04; 95% CI 1.00–1.07) was associated with adverse physical health. Perceived survivor emotional/behavioral health problems (OR 1.25; 95% CI 1.01–1.56) was associated only with adverse physical health. Perceived survivor depression was associated with both adverse physical (OR 1.12; 95% CI 1.02–1.24) and mental health (OR 1.00; 95% CI 1.00–1.20). Perception of improved survivor peer relationships were associated with better physical (OR 0.90; 95% CI 0.82–0.98), and mental health (OR 0.88; 95% CI 0.80–0.98).

Diagnosis/Treatment-Related Factors Associated with QOL

Results of univariate analyses describing diagnosis and treatment-related factors associated with QOL are provided in Table 2. The presence of speech/language problems was associated with adverse mental health (OR 19.20; 95% CI 1.84–199.94). Recurrence was the only diagnosis and treatment-related factor that appeared to be associated with both adverse physical and mental health (OR 12.5; 95% CI 1.20–130.6).

DISCUSSION

The primary aim of this study was to begin to characterize QOL among parents of AYA brain tumor survivors and to explore potential parent, survivor, and diagnosis/treatment-related factors that may be associated with adverse QOL. This study was limited by a small sample and the results should be considered exploratory for informing future investigation in this area. Contrary to what we expected, we documented that overall parents demonstrated average QOL. We also found that parent factors such as perceptions of greater family impact, unresolved anger/sorrow, and long-term uncertainty were associated with adverse QOL. Greater emotional resources were associated with better QOL. Survivor factors including perceptions of better cognitive function, greater emotional/behavioral problems as well as survivor depression were associated with adverse QOL. Perceptions of improved survivor peer relationships were associated with better QOL. Diagnosis and treatment-related factors such as speech/language problems, and recurrence were associated with adverse QOL.

Approximately 40% of parents scored below the clinical threshold of 0.5 SD below the mean for physical and mental health. Findings of average QOL among parents of childhood cancer survivors have been reported although the majority of studies include a variety of childhood cancer diagnoses often excluding brain tumors [23]. Parents of AYA brain tumor survivors remained at-risk for adverse QOL at an average of 10 years post-diagnosis. One explanation for this finding is that parents of AYA brain tumor survivors continue to deal with disabilities and chronic health conditions which necessitate long-term aftercare and negatively impact QOL [24]. Additional characterization of these high-risk parents across the trajectory of

survivorship care is needed. Our findings underscore the need to provide long-term surveillance for psychosocial problems among these parents [25].

Perceived family impact appeared to be a salient factor which was associated with both diminished physical and mental health among parents of AYA brain tumor survivors. In general, parents of childhood cancer survivors report an absence of adverse changes in the family environment [26]. Some parents of brain tumor survivors report deterioration of the family environment including marital relations and marginalization of family members including healthy siblings [27]. The burden of chronic health conditions and neurocognitive deficits in the survivor may also lead to greater family impact as the parents struggle to deal with time and financial constraints placed upon them due to a need for ongoing survivor care [28].

Unresolved anger/sorrow and long-term uncertainty was associated with adverse mental health. Previous studies report that parents of childhood cancer survivors demonstrate unresolved anger and sorrow [29]. These feelings of unresolved anger and sorrow may occur secondary to the perception of loss of health among the brain tumor survivor. Long-term uncertainty is associated with psychological distress among parents of childhood cancer survivors [30]. Uncertainty may result from concern about recurrence or the development of a second cancer or a serious chronic health condition. Characterization of parent adjustment including ongoing feelings of anger, sorrow, and uncertainty within the context of providing care for aging brain tumor survivors is needed.

Greater emotional resources were associated with better physical and mental health. Emotional resources among parents of children with childhood cancer including coping styles, appraisals of internal resources, and perceptions of self-efficacy are needed to ensure optimal QOL [31–34]. As an example, coping styles that involve information seeking or problem solving are associated with the ability to apply a positive interpretation and find meaning within the childhood cancer experience. Parents that demonstrate self-efficacy by feeling that they are competent caregivers may also be more likely to demonstrate positive changes in their self-perceived physical and mental health. This may be particularly important for long-term caregivers of brain tumor survivors.

The finding of a positive association between improved cognitive function and adverse parent physical health was surprising. Improved cognitive function among individuals with neurological disorders is positively correlated with greater self-awareness of neurobehavioral symptoms [35]. Greater self-awareness of neurobehavioral deficits may be troublesome for parents. Parents may be troubled by this increased survivor self-awareness. For example, this self-awareness among survivors may serve as a constant reminder of the loss of health of the survivor.

Perceived survivor depression and poor peer relationships were both associated with adverse changes in physical and mental health. It was striking to note that perceptions of peer relationships were significantly perturbed. In fact, the mean T-score was nearly one standard deviation below the norm (data not shown). Previous research documents that parent’s worry about many aspects of survivor health and well-being [28]. Parents may be particularly

concerned about social health as it relates to a lack of friendships and peer relationships. This underscores the necessity to help parents of these survivors address these challenges.

Recurrence appears to be associated with diminished mental and physical health among parents. Brain tumor recurrence is typically associated with a poor prognosis. Treatment of recurrence may require additional surgery, chemotherapy, and radiation therapy leading to greater risk for toxicities. Parents faced with recurrence may experience intensified fears, anxiety, and unhappiness when faced with ongoing disruptions in their lives [36]. In addition, they may be less resilient and less willing and able to access resources [36].

Limitations

This was a cross-sectional study; thus, our ability to explore causal relationships was limited. The sample size was also small; therefore, the study had limited power to detect significant associations between QOL and parent as well as survivor characteristics. Moreover, the sample may have lacked the representativeness of a larger population of brain tumor survivors with respect to diagnoses, treatment exposures, and subsequent toxicities. No adjustment had been made for multiple comparisons; therefore, significant results should be interpreted conservatively as hypotheses to be explored in future studies. The addition of other comparison groups aside from normative data (e.g., other diagnostic groups with risk for neurocognitive dysfunction such as leukemia/lymphoma survivors) might also have added additional depth to the interpretation of the findings. Despite the aforementioned limitations our study allowed for the characterization of QOL among parents of AYA brain tumor survivors (an understudied group) and for the exploration of important potential correlates of parent QOL. The sample did capture families of survivors who are infrequently characterized (e.g., Latinos). Although we did not detect differences in psychosocial outcomes among Latinos they remain underrepresented in the extant literature. Future longitudinal studies are needed which employ larger representative samples of families impacted by brain tumors as well as those that employ additional comparison groups.

CONCLUSION

The findings of this study underscore the need to continue to increase awareness of the impact of the diagnosis and treatment of a brain tumor on the QOL of parents, a potential impact that may be felt for many years following the completion of therapy. The development and testing of theory-based interventions are needed to meet the unique needs of parents of these aging survivors [37].

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Table 1

Characteristics of Parent Participants and Their Adolescent Young Adult Brain Tumor Survivors

Parent Characteristics **(N=28)**	
Mean Age at Assessment	44.0 years (SD 7.0)
Female	13 (46.4)
Hispanic or Latino	12 (42.9)
Full or Part Time Employment	11 (39.3)
Married or Living with Partner	19 (67.9)
High School/GED or College/Grad School	25 (89.3)
Annual Household Income <$40,000 per year	12 (42.9)
Survivor Characteristics	
Mean Age at Assessment	16.3 years (SD 3.2)
Female	13 (46.4)
Diagnosis	
Astrocytoma or Glioma	5 (17.9)
Medulloblastoma	13 (46.4)
Ependymoma	3 (10.7)
Germ Cell Tumor	2 (7.1)
Other **	5 (17.9)
Mean Age at Diagnosis	5.6 years (SD 3.6)
Time Elapsed Since Diagnosis	10.7 years (SD 4.2)
Stem Cell Transplant	7 (25.0)
Chemotherapy	24 (85.7)
Radiation	22 (78.6)
Surgery	27 (96.4)
Recurrence	6 (21.4)
Second Cancer	0 (0.0)

** Pineal tumor (N=1), pineoblastoma (N=2), craniopharyngioma (N=1), choroid plexus carcinoma (N=1)

Table 2

Unadjusted univariate models - parent, survivor, and diagnosis/treatment factors associated with decreased[%] parent physical and mental health scores (N=28)

	Decreased[%] Parent Physical Health PROMIS Global Physical Health Component Score		Decreased[%] Parent Mental Health PROMIS Global Mental Health Component Score	
	OR	**95% CI**	**OR**	**95% CI**
Parent Factors				
Age in Years[b]	0.97	0.87–1.09	0.99	0.89–1.11
Gender				
Male	1.67	0.25–11.07	1.38	0.21–9.24
Female (referent)	1.00		1.00	
Latino				
Yes	0.32	0.07–1.55	0.45	0.10–2.14
No (referent)	1.00		1.00	
Pediatric Experience of Childhood Illness				
Guilt & Worry[a b]	1.87	0.77–4.52	1.85	0.76–4.50
Unresolved Anger & Sorrow[a b]	2.03	0.79–5.20	4.30	1.30–14.18**
Long-term Uncertainty[a b]	2.73	0.98–7.58	3.04	1.01–9.14**
Emotional Resources[a b]	0.35	0.12–0.99**	0.35	0.12–1.00**
Impact on Family Scale				
Total Impact[a b]	1.18	1.03–1.35**	1.13	1.01–1.27**
Surivor Factors				
Age in Years [b]	1.06	0.84–1.35	1.07	0.84–1.36
Gender				
Male	1.29	0.29–5.77	1.71	0.37–7.92
Female (referent)	1.00		1.00	
PROMIS (Parent-Report)				
Depression[a b]	1.12	1.02–1.24**	1.10	1.00–1.20**
Peer Relationship Health [a b]	0.90	0.82–0.98**	0.88	0.80–0.98**
Pediatric Symptom Checklist (Parent-Report)				
Total Problem Score [a b]	1.25	1.01–1.56**	1.12	0.92–1.36
Peds QL (Parent-Report)	1.04	1.00–1.07**	1.00	0.98–1.04
Cognitive Function Scale [a b]				
Diagnosis/Treatment Factors				
Age at Time of Diagnosis in Years [b]	0.90	0.72–1.13	0.96	0.77–1.19
Time Since Diagnosis in Years [b]	1.12	0.92–1.35	1.08	0.89–1.30
Diagnosis				

	Decreased[%] Parent Physical Health PROMIS Global Physical Health Component Score		Decreased[%] Parent Mental Health PROMIS Global Mental Health Component Score	
	OR	**95% CI**	**OR**	**95% CI**
Medulloblastoma	1.40	0.31–6.33	1.07	0.23–4.89
Other (referent)				
Radiation Therapy				
Yes	1.44	0.24–8.84	0.72	0.11–4.82
No (referent)	1.00		1.00	
Hearing Problems				
Yes	1.44	0.24–8.84	0.72	0.11–4.82
No (referent)	1.00		1.00	
Vision Problems				
Yes	0.64	0.14–3.04	1.53	0.32–7.19
No (referent)	1.00		1.00	
Speech/Language Problems				
Yes	5.00	0.77–32.57	19.20	1.84–199.94**
No (referent)	1.00		1.00	
Pain Problems				
Yes	5.00	0.45–55.63	6.00	0.54–67.28
No (referent)	1.00		1.00	
Endocrine Problems				
Yes	1.05	0.22–5.00	2.00	0.41–9.84
No (referent)	1.00		1.00	
Weight Problems				
Yes	1.10	0.22–5.45	2.71	0.53–13.85
No (referent)	1.00		1.00	
Recurrence				
Yes	12.5	1.20–130.60**	12.5	1.20–130.60**
No (referent)	1.00		1.00	

** P≤0.05

% Decreased scores correspond to a T score < 45.

a Greater score corresponds to a greater amount of the respective factor being measured.

b Treated as a continous variable in analysis.