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Health-Related Quality of Life in Parents of Pediatric Brain Tumor Survivors at the End of Tumor-Directed Therapy

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Introduction

Brain tumors are the second most common malignancy in childhood, with an estimated 4,620 new diagnoses each year (American Brain Tumor Society, 2015). Improvements in treatment and greater participation in clinical trials have substantially increased the 5-year survival rate from 59% in 1975-79 to 75% for children with brain or central nervous system (CNS) tumors (American Cancer Society, 2014). However, treatment-related side effects leave many pediatric brain tumors survivors (PBTS) with a variety of challenges, including physical, cognitive, and psychological deficits that may require care and management over the survivor's lifetime (Chien et al., 2003; Robison et al., 2005). Parents of PBTS may experience increased caregiving demands related to survivor physical and neurodevelopmental sequelae that impact parental health-related quality of life (HRQL). Prior research on parents of children with cancer has highlighted risks for poor parental psychosocial and HRQL outcomes (Rosenberg et al., 2014), yet few studies have focused on parents of PBTS and examined associations between parental HRQL and aspects of PBTS functioning, including neurocognitive functioning, and other potentially relevant factors.

A conceptual model of caregiving (Figure 1) offers a framework to understand the experiences and challenges of parents of PBTS and identify the key constructs associated with parental HRQL (Raina et al., 2004). The model includes five constructs that influence caregiver physical and psychosocial health outcomes: (1) background/context, (2) child characteristics, (3) caregiver strain, (4) intrapsychic factors, and (5) coping/supportive factors. *Background/context* factors address the setting in which caregiving takes place, including social and economic characteristics of the family. *Child characteristics* refer to the child's condition and/or problem behaviors and reflect actual care demands. *Caregiver strain* reflects the perception of daily caregiving demands and formal care. *Intrapsychic factors* relate to the caregiver's internal state as measured by self-perception and sense of mastery of

condition-related demands. Last, *coping/supportive factors* constitute the caregiver's access to and use of coping factors, such as social support, family function, and stress management. The model suggests that factors within each construct influence the physical and psychosocial health of caregivers. Research with caregivers of children with critical and chronic conditions, including cancer and brain tumors, has supported associations between caregiver health and subsequent domains proposed in the model (Deatrick et al., 2014; Klassen et al., 2011; Raina et al., 2005).

Background/context factors may relate to a family's access to external resources, and thereby the extent to which the child's condition is viewed as burdensome. Particularly for parents of children with serious or chronic illnesses (Kazak, 1989), including parents of PBTS, caregiving occurs within the context of a family's lifestyle and resources. Sociodemographic variables, such as household income and parental educational attainment, have been shown to influence HRQL for patients and caregivers of family members with a variety of conditions including cancer (Hacalioglu, Ozer, Yilmaz Karabulutlu, Erdem, & Erci, 2010), asthma (Erickson et al., 2002), cerebral palsy, and Autism Spectrum Disorder (Tekinarslan, 2013). Being in a partnered relationship also is associated with greater caregiver psychosocial HRQL (Litzelman, Catrine, Gangnon, & Witt, 2011).

PBTS exhibit a host of *child characteristics*, including physical, neurocognitive, and behavioral difficulties (Ness & Gurney, 2007; Robinson, Fraley, Pearson, Kuttess, & Compas, 2013; Turner, Rey-Casserly, Liptak, & Chordas, 2009), as a result of their tumor and tumor-directed treatments that may influence the degree of care and supervision required of parents. Research on children with complex disabilities suggests that their families face added challenges often resulting in lower parental HRQL (Isa et al., 2013). Studies of children with non-progressive neurodevelopmental disorders (King, King, Rosenbaum, & Goffin, 1999) and ADHD (Harrison & Sofronoff, 2002) highlight child behavior problems as an important predictor of parent well-being. The contributions of PBTS' *child characteristics* to parental HRQL following the completion of treatment remains unexplored.

Several parental variables specified in the model are relevant in the context of pediatric brain tumor survivorship. Parental perception of caregiver demands may vary among individual caregivers and contribute to the level of *caregiver strain*. Parents who experience fewer demands report more optimal health (King et al., 1999; Klassen et al., 2008; Klassen et al., 2011; Raina et al., 2004). Additionally, *intrapsychic factors*, such as self-perceptions of one's ability to manage condition-related demands (i.e., caregiver competence) have important implications for parents' self-esteem, adjustment, and HRQL (Deatrick et al., 2014; Guillaumon et al., 2013; Klassen et al., 2011). Greater levels of caregiver competence relate to more effective coping and influence perceptions of greater social support and better family functioning (Raina et al., 2004). Research on parents of children diagnosed with cancer has demonstrated that parental perception of illness-related demands and confidence in their ability to manage these demands, rather than the child's health, are the strongest predictors of parental distress (Sloper, 2000).

Coping/supportive factors comprise the last component of the model predicting parental HRQL. Ineffective parental coping efforts have been associated with depressive symptoms and emotional distress in parents of children with cancer (Compas et al., 2015). Supportive factors, such as social support and family functioning, may affect parents' efforts to cope or manage caregiving responsibilities, particularly during key transition periods (e.g., conclusion of cancer treatment) that are known to be challenging and stressful (Rosenberg et al., 2014; Sloper, 2000). Prior research has demonstrated the influence of family functioning on the physical and psychosocial HRQL of caregivers (King et al., 1999; Raina et al., 2005; Sloper, 2000). Furthermore, lack of social support may exacerbate caregivers' feelings of isolation in managing their child's condition and tendency to neglect their own needs following the completion of treatment, thus increasing their risk for poor HRQL (Gibbins, Steinhardt, & Beinart, 2012; Klassen et al., 2008).

Few studies have examined the HRQL of parents of children with brain tumors. This group of parents may be particularly vulnerable to reduced HRQL due to the neurological, physical and neurodevelopmental sequelae seen in PBTS (Hocking & Alderfer, 2012). The only known study to examine this among PBTS found that caregivers of children with brain tumors had significantly lower HRQL compared to normative scores for healthy adults (Chien et al., 2003). Studies of children with cancer indicate that caregivers experience low quality of life or well-being (Klassen et al., 2008; Witt et al., 2010), however there is limited research on predictors of parental HRQL, particularly in pediatric brain tumor populations. The primary objectives of this study are to describe the physical and psychosocial HRQL of parents of PBTS within four months of the conclusion of tumor-directed therapy and to examine the associations between parental HRQL and parent, survivor, and family variables pertinent to the conceptual model of caregiving (Lancashire et al., 2010; Raina et al., 2004). Little is known about parental functioning during this critical transitional period as PBTS complete tumor-directed treatment and evaluating parental HRQL during this time frame is important due to the transfer of primary care from the medical team to the parents. We hypothesized that (1) greater household income (*background factors*) and better PBTS functioning (*child characteristics*), including neurocognitive, physical, and behavioral functioning, will be related to greater parental physical and psychosocial HRQL, (2) lower *caregiver strain*, greater caregiver competence (*intrapsychic factors*), better family functioning and greater social support (*coping/support factors*) will be associated with better parental physical and psychosocial HRQL; and (3) caregiving strain, caregiver competence and coping/supportive factors will account for significant variance in parental physical and psychosocial HRQL while controlling for pertinent background and child characteristics.

Method

Participants

PBTS aged 6-16 years who had transitioned off tumor-directed treatment and their parents were recruited from a pediatric neuro-oncology program in the northeast United States. Survivors were eligible if they had received a form of tumor-directed treatment, including any combination of resection, chemotherapy, and cranial or craniospinal irradiation, had finished all tumor-directed treatment within the previous 4 months, and were expected to

live at least 6 months. Survivors with a history of cognitive or developmental delays prior to brain tumor diagnosis and those from non-English speaking families were excluded. Only survivors between the ages of 6 and 16 years were included due to age restrictions on the selected measures of neurocognitive functioning.

A total of 76 survivors were contacted about the study and 50 (65.8%) agreed to participate. Reasons given for not participating were too much going on at the time ($n = 3$), scheduling conflicts ($n = 9$), lack of interest ($n = 8$) and passive refusal ($n = 9$). Survivor race, age, and tumor type did not differ between consenting and non-consenting families. The final sample included 50 survivor/parent dyads. Only one parent per survivor participated in the study. For survivors with two parents, the parent who self-identified as the primary caregiver for the survivor was asked to participate. On average, survivors were 10.50 years of age ($SD = 2.79$), 1.32 years ($SD = 1.66$) from diagnosis and 2.69 months ($SD = 1.33$) from the end of tumor-directed therapy. The majority of survivors received multi-modal tumor-directed therapies. Parents were on average 40.98 years old ($SD = 5.97$), primarily mothers (96.0%) and generally in a partnered relationship (76.0%). Complete sample characteristics are presented in Table 1.

Procedure

The current data represent baseline data from of a longitudinal study investigating survivor and family outcomes for PBTS. Following institutional review board approval, eligible families were contacted via letter and phone and scheduled for a study visit, which typically occurred in conjunction with regular medical follow-up appointments. After obtaining informed consent and assent, parents completed measures of demographics, family functioning, parental HRQL, parent perceptions of condition management effort and ability, survivor physical functioning, and survivor behavior problems. Survivors completed neurocognitive tasks assessing intellectual functioning (IQ), working memory, and processing speed. Study visits typically lasted 60 minutes. Participants received a gift card and summary of their performance on the neurocognitive and behavioral measures following the evaluation.

Measures

Background and Context—Parents provided demographic information on the child's current age, gender, and race/ethnicity. Parents also reported their own age, gender, relationship status, highest obtained education level, current employment status, and annual household income. Parents reported their highest level of education by selecting one of ten choices ranging from "Less than 8th grade" to "Graduated from graduate/professional school". Similarly, parents reported total annual income by selecting one of eight choices ranging from "Less than \$10,000" to "Over \$125,000". Information on tumor type and time since diagnosis was obtained from medical records.

Child Characteristics—Survivors completed the two-subtest version of the Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011), which includes the Vocabulary and Matrix Reasoning subtests, yielding an estimate of IQ. The two-subtest version is highly correlated with the full version of the WASI-II ($r = 0.83$; Wechsler,

2011). Survivors also completed select subtests of the Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV; Wechsler, 2003), including Digit Span, Coding and Symbol Search. The Digit Span Backward (DSB) score assessed *auditory working memory* and Coding and Symbol Search subtests comprised the *Processing Speed Index* (PSI). The DSB and PSI scores have strong internal reliabilities of .80 and .88, respectively (Wechsler, 2003).

Parents completed the Behavior Assessment System for Children – Second Edition (BASC-2; Reynolds & Kamphaus, 2006), as a measure of survivor internalizing (e.g., depression, anxiety, and somatization) and externalizing (e.g., hyperactivity, aggression, and conduct problems) behavior problems. The Internalizing Problems and Externalizing Problems T scores were used in analyses with higher values representing greater problem behaviors. The Cronbach alpha for this sample for the Internalizing Problems composite was .91 for ages 6-11 and .80 for ages 12-21, and the Cronbach alpha for the Externalizing Problems composite was .95 for ages 6-11 and .84 for ages 12-21.

Survivor physical functioning was measured using the physical functioning score from the widely-used PedsQL 4.0 (Varni, Seid, & Kurtin, 2001). Parents rated the level of difficulty their child has had with eight different physical activities over the past month on a 5-point scale ranging from “never a problem” to “almost always a problem”. Items were reverse scored and linearly transformed to a 0-100 scale, with higher scores representing better survivor physical functioning. The internal consistency for the physical functioning scale score in the current sample was .91.

Caregiver Strain—The Condition Management Effort (CME) subscale from the Family Management Measure (FaMM; Knafl et al., 2011) measured caregiver strain by assessing parental perception of the time and work needed to manage the condition. The CME subscale includes 4 statements, such as “it takes a lot of organization to manage our child’s condition”, to be rated on a 5-point scale ranging from strongly disagree to strongly agree. Higher values signified greater caregiver strain. Internal consistency for the CME subscale was .74.

Intrapsychic Factors—The Condition Management Ability (CMA) subscale from the FaMM (Knafl et al., 2011) assessed parents’ perceptions of their competence to care for their child’s condition. The CMA subscale includes 12 statements, such as “we have some definite ideas about how to help our child live with the condition”, to be rated on a 5-point scale ranging from strongly disagree to strongly agree. Higher values signified that the parent viewed their survivor’s condition as more manageable. The CMA subscale has been shown to be a valid and reliable measure of caregiver competence in parents of children with chronic illness (Knafl et al., 2011). The Cronbach alpha for the CMA subscale in this sample was .61.

Coping/Supportive Factors—The 12-item General Functioning Scale from the McMaster Family Assessment Device (FAD GFS) measured general family functioning (Taylor et al., 2001). The FAD GFS is a well-established measure used in many pediatric populations (Alderfer et al., 2008) that encompasses the seven dimensions of McMaster’s

model of family functioning, including problem-solving, communication, roles, and affective responsiveness (Miller, Ryan, Keitner, Bishop, & Epstein, 2000). The FAD GFS generates scores from 1-4 with higher scores indicating higher levels of general family dysfunction and scores above 2.0 representing poor family functioning. Internal consistency for the FAD GFS was .83. Parents also reported on the level of emotional and practical support that they receive from any source in their efforts to care for their PBTS on a four-point Likert scale ranging from “none” to “a lot”.

Health Outcomes—Parental HRQL was measured using the total physical functioning and psychosocial functioning scores from the PedsQL Family Impact Module (FIM; Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). The FIM consists of 36 items, in which parents self-report on their own functioning and family functioning as impacted by their child’s health condition on a 5-point Likert scale ranging from 0 (“never a problem”) to 4 (“always a problem”). Scores are then reverse scored and transformed to a 0-100 point scale, where higher scores indicate better functioning. Physical HRQL scores were calculated by averaging the 6 items of physical functioning and psychosocial HRQL scores were calculated by averaging the 14 items across emotional, social, and cognitive domains. The PedsQL FIM is well-validated and has been used in studies of parental HRQL in pediatric chronic pain (Jastrowski Mano, Khan, Ladwig, & Weisman, 2011), ADHD (Limbers, Ripperger-Suhler, Boutton, Ransom, & Varni, 2011), sickle cell (Panepinto, Hoffmann, & Pajewski, 2009), and disabled populations (Isa et al., 2013). The Cronbach alpha was .92 for the physical HRQL score and .94 for the psychological HRQL score.

Statistical Power and Data Analyses

Descriptive and preliminary analyses were conducted to describe demographic characteristics, tumor-related variables, survivor characteristics, caregiving demand, caregiver competence, family functioning and HRQL outcomes. The distribution of scores for all primary variables was checked for violations of normality. Annual household income was grouped into three categories in analyses: “Less than \$34,000”; “\$34,000 - \$100,000”; or “Greater than \$100,000”. Parental education also was combined into three groups: “High school degree or less”; “Some college/vocational school”; or “Graduated from 4 year college or higher”. Due to the few number of families reporting “None” ($n = 2$) or “A little” ($n = 8$), social support, responses on this scale were combined to form two groups: “None or some support” and “A lot of support”. See Table 1 for distribution of the sample across the values for income, education and support. Differences in parental HRQL related to household income, parental education, employment status, partner status, and social support were examined using either t-tests or one-way ANOVAs with post-hoc t-tests following the LSD method. Pearson bivariate correlations examined associations between parental HRQL and parent, survivor, and family variables. Variables significantly related to parental physical and psychosocial HRQL in these correlational analyses were entered into two separate two-step hierarchical regression analyses to test the strength of parent and family variables as predictors of parental psychosocial and physical HRQL over and above background and child characteristic variables. For each model, significant background and child characteristics were entered in the first step and significant caregiver strain, caregiver competence, and coping/supportive factors were entered in the second step. R^2 change was

calculated to determine the degree of improvement in accounting for variance in HRQL when adding family and caregiver variables into the model with pertinent background and child characteristics. Effect sizes were calculated using R^2 and Cohen's f^2 and interpreted as small (0.1), medium (0.3), or large (0.5; Cohen, 1988). Power analyses revealed that a sample size of 39-72 participants was needed to detect anticipated effect sizes ranging from .3 - .5 for multiple regression analyses with three to five predictors and a sample size of 42-84 participants was needed to detect anticipated effect sizes ranging from .35 - .5 for one-way ANOVAs with three predictors (Soper, 2006). All data were analyzed using SPSS version 22 with an alpha level set to $p = 0.05$.

Results

Descriptive and Preliminary Analyses

Means and standard deviations for all study variables are presented in Table 2. Parental physical HRQL scores ranged from 12.50 to 100 ($M = 62.77$, $SD = 23.22$) and parental psychosocial HRQL scores ranged from 17.08 to 100 ($M = 66.07$, $SD = 20.90$). Survivor IQ ($M = 96.08$, $SD = 16.58$), working memory ($M = 9.20$, $SD = 3.08$), and processing speed ($M = 90.71$, $SD = 18.55$) were in the average range, however parent-rated survivor physical functioning ($M = 62.39$, $SD = 26.43$) was low compared to published norms for healthy samples, $t = -5.91$, $p < .01$ (Varni, Limbers, & Burwinkle, 2007). Parent-rated survivor internalizing (mean T score = 54.46, $SD = 10.16$) and externalizing problems (mean T score = 44.74, $SD = 10.40$) also were in the average range. Parent-reported general family functioning was in the normal range ($M = 1.57$, $SD = .39$). Neither parental physical nor psychosocial HRQL varied by parent education, partner status or employment status. Pearson bivariate correlations revealed that survivor age and time since diagnosis were not significantly associated with any study variables.

Hypothesis 1

Parental physical HRQL significantly differed by household income, $F(2, 38) = 3.36$, $p < .05$, and had a large effect (Cohen's $f^2 = .42$), with parents in the highest income level reporting better physical HRQL than those in the lowest income level $t = -2.70$, $p < .05$. Parental psychosocial HRQL did not differ by household income, $F(2, 38) = 2.58$, $p = .09$. Greater survivor internalizing problems and better survivor physical functioning also were significantly correlated with greater physical HRQL (Table 2). No child characteristics were significantly associated with parental psychosocial HRQL.

Hypothesis 2

Greater caregiver competence and lower caregiver strain were significantly correlated with better physical HRQL (Table 2). Additionally, better family functioning, greater caregiver competence, and lower caregiver strain were significantly correlated with better psychosocial HRQL. Neither parental physical, $t = -.66$, $p = .51$, nor psychosocial HRQL, $t = -.17$, $p = .87$, varied by level of perceived support.

Hypothesis 3

A hierarchical multiple regression model (Table 3) tested the strength of the associations between identified variables and parental physical HRQL. Household income, survivor internalizing problems, and survivor physical functioning were entered in the first step, followed by caregiver strain and caregiver competence in the second step. The overall model explained 38% of the variance in physical HRQL, $F(5, 35) = 4.27, p < .01$, and had a large effect (Cohen's $f^2 = .61$). Adding caregiver strain and caregiver competence into the model significantly improved the amount of variance explained in physical HRQL, $R^2 = .13, p < .05$. Examination of the individual variables revealed that lower caregiver strain was significantly associated with better physical HRQL, $t = -2.07, p < .05$.

A linear multiple regression model (Table 4) was used to test the strength of the associations between identified variables and parental psychosocial HRQL since no background or child characteristics were significantly correlated with psychosocial HRQL. A model consisting of caregiver strain, caregiver competence, and family functioning explained 44% of the variance in psychosocial HRQL, $F(3, 41) = 10.58, p < .01$, and represented a large effect (Cohen's $f^2 = .79$). Examination of the individual variables revealed that greater caregiver competence and lower caregiver strain were significantly associated with better psychosocial HRQL, $t = 2.45, p < .05$ and $t = -2.06, p < .05$, respectively.

Discussion

The current study highlights specific associations between identified constructs within a model of caregiving and two different aspects of HRQL in parents of PBTS following the completion of tumor-directed treatment. Findings underscore the importance of caregiver perceptions of strain and their own competence in caregiving as factors related to their HRQL. These results support previous research on health outcomes in parents of children with serious chronic conditions (Deatrick et al., 2014; Klassen et al., 2011; Raina et al., 2005) and provide an impetus for future research on parents of PBTS.

Consistent with the theoretical model (Raina et al., 2004), some *background/context factors* and *child characteristics* were significantly associated with parental physical HRQL. Greater household income and better PBTS behavioral and physical functioning were associated with better physical HRQL for parents of PBTS. The association between income and HRQL has been found in prior studies (Erickson et al., 2002; Hacialioglu et al., 2010; Tekinarslan, 2013) and suggests that higher income may increase a family's access to resources and reduce financial worries, resulting in fewer stressors and greater well-being. These findings reinforce recent calls to incorporate the assessment of financial burden as a standard of care within pediatric oncology (Pelletier & Bona, 2015). In terms of child characteristics, PBTS with fewer internalizing problems and greater physical functioning may be able to care for themselves more, limiting the physical demands placed on caregivers.

Contrary to some prior studies (Eiser, Eiser, & Stride, 2005; Klassen et al., 2008), survivor age, time since diagnosis and survivor neurocognitive functioning were not significantly associated with parental physical or psychosocial HRQL. This difference in findings may be

related to the time period of focus for the current study. At the conclusion of tumor-directed therapy, survivor physical and neurodevelopmental late effects likely have not had enough time to develop (Turner et al., 2009) and may not be as relevant to parental HRQL as they would be for parents of long-term survivors. The acute period following the conclusion of tumor directed treatment is an understudied time period for families of PBTS and warrants further study as this may be a potential point for early intervention with PBTS and their families.

Parents reporting lower caregiver strain and greater caregiver competence had better physical HRQL, with caregiver strain in particular accounting for unique variance in physical HRQL, when controlling for household income and survivor internalizing problems and physical functioning. This is consistent with a large study of mothers of adolescent and young adult PBTS that found associations between perceived caregiver strain and maternal physical health (Deatrick et al., 2014). Parents who perceive fewer demands to manage may be better able to direct their efforts to self-care. Alternatively, parents with greater physical functioning may perceive PBTS health-related tasks as less demanding.

Observed associations between parental psychosocial HRQL and *intrapsychic* and *coping/supportive factors* support calls to bolster caregiver and family functioning within the context of managing health outcomes of families affected by pediatric brain tumors (Barakat et al., 2015; Deatrick et al., 2014). In the current study, better family functioning was correlated with better parental psychosocial HRQL. Among caregivers of children affected by brain insults, cohesive, strong family units can support caregivers by integrating caregiving responsibilities into family routines across family members (Deatrick et al., 2014).

Notably, greater caregiver competence and lower caregiver strain were significantly associated with better psychosocial HRQL, independent of the *coping/supportive factor* of family functioning. These findings support the conceptual model of caregiving (Raina et al., 2004) and complement prior research showing significant associations between caregiver perceptions of their caregiving and caregiver health (Deatrick et al., 2014; Raina et al., 2005). Parents with higher confidence in their ability to manage their survivor's condition and a perception of lower levels of caregiving strain reported better functioning across emotional, social and cognitive domains. Future research with parents of PBTS should examine whether positive changes in caregiver competence and perceptions of caregiver strain impact both caregiver and survivor outcomes over time.

Interestingly, parental psychosocial HRQL was not associated with any of the *background/context factors* or *child characteristics* measured in this study. This null finding, combined with the significant association between caregiver's perceptions of their own competence and level of strain and parental psychosocial HRQL, emphasizes the important role of parental perceptions and self-efficacy in their own psychosocial HRQL. These results suggest the need for providers to attend to caregivers' *intrapsychic factors* and perceptions of strain, in addition to PBTS functioning, when assessing areas of need (Kearney, Salley, & Muriel, 2015).

While the current study provides an important first step in identifying unique factors associated with the HRQL of parents of PBTS, it does have limitations. First, the sample is most representative of Caucasian, partnered, non-Hispanic mothers of PBTS who are employed. While the sample reflects the population of our cancer center's catchment area (U.S. Census Bureau, 2015), greater diversity of participants in terms of demographics and family role would increase the generalizability of findings and improve our understanding of the HRQL of different family members. Second, causal inferences were unable to be made due to the cross-sectional nature of the study. Third, the current study did not contain a control group preventing comparisons to determine the extent to which HRQL is compromised for parents of PBTS. Finally, the internal reliability for the CMA subscale of the FaMM was low compared to prior studies using that measure (Deatrick et al., 2014; Knafl et al., 2011) suggesting that this scale might be measuring more than one construct in this sample.

This study expands upon previous research on the impact of caring for PBTS on parents' physical and psychosocial HRQL by examining aspects of survivor, parent, and family functioning and offers implications for future directions for research and intervention efforts. Components of caregiver psychological processes and family factors appear to play important roles in parental HRQL. Prospective studies from the time of diagnosis can further highlight associations and interactions between parental, survivor and family domains over time. Overall patterns could inform clinical interventions as to the most appropriate time to target caregiver competence and the potential long-term benefits of fostering competence from an early stage. Such efforts could be adapted from existing interventions with children who experienced traumatic brain injury (Wade, Carey, & Wolfe, 2006) and promote the integration of survivor care into daily routines and teach problem-solving strategies to better manage survivor needs and enhance caregiver competence.

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Figure 1.

Conceptual model of caregiving process and caregiver burden among pediatric populations. Recreated from “Caregiving Process and Caregiver Burden: Conceptual Models to Guide Research and Practice,” by P. Raina, M. O’Donnell, H. Schwellnus, P. Rosenbaum, G. King, J. Brehaut, D. Russell, M. Swinton, S. King, M. Wong, S. D. Walter, and E. Wood, 2004, BMC Pediatrics, 4:1. Copyright 2004 to Raina et al. Reprinted with permission.

Table 1

Sample Characteristics of Participants

Variables	<i>n</i> (%) or <i>M</i> ± <i>SD</i>
Survivor age in years (<i>M</i> ± <i>SD</i>)	10.5 ± 2.8
Survivor Gender	
Male	23 (46.0)
Female	27 (54.0)
Survivor Race	
Caucasian	38 (76.0)
African-American	9 (18.0)
Other	3 (6.0)
Parent age in years (<i>M</i> ± <i>SD</i>)	41.0 ± 6.0
Parent Gender	
Male	2 (4.0)
Female	48 (96.0)
Parent Education ^a	
High school degree or less	13 (26.0)
Some college/vocational school	15 (30.0)
Graduated from 4 year college or higher	20 (40.0)
Parent Employment ^a	
Employed	36 (75.0)
Unemployed	12 (25.0)
Total Household Income ^b	
< \$34,000	13 (28.9)
\$34,000 - \$100,000	15 (33.3)
>\$100,000	17 (37.8)
Relationship status	
In partnered relationship	38 (76.0)
Not in partnered relationship	12 (24.0)
Social Support	
None, a little, or some	24 (48.0)
A lot	26 (52.0)
Tumor-related characteristics	
Tumor types	
Astrocytoma	15 (30.0)
Glioma	8 (16.0)
Medulloblastoma	6 (12.0)
Germinoma	4 (8.0)
Ganglioglioma	4 (8.0)
Other	13 (26.0)
Treatment	

Variables	<i>n</i> (%) or <i>M</i> ± <i>SD</i>
Surgical resection only	17 (34.0)
Chemotherapy only	3 (6.0)
Radiation therapy only	4 (8.0)
Resection and chemotherapy	4 (8.0)
Resection and radiation therapy	11 (22.0)
Resection, chemotherapy and irradiation	11 (22.0)
Years since diagnosis (<i>M</i> ± <i>SD</i>)	1.3 ± 1.7

^aNote. N = 48;

^bN = 45

Table 2Means, Standard Deviations, and Bivariate Correlations Among Key Study Variables^a

	Mean (SD)	2	3	4	5	6	7	8	9	10	11
1 Caregiver Physical HRQL	62.78 (23.48)	.81**	-.16	.36*	-.50**	-.31*	-.05	-.07	.05	-.15	.36*
2 Caregiver Psychosocial HRQL	65.73 (21.01)	---	-.44**	.54**	-.54**	-.24	-.15	.05	.06	-.04	.13
3 Family Functioning	1.56 (.40)		---	-.40**	.34*	.14	.31*	-.31*	-.10	-.04	.03
4 Caregiver Competence	47.73 (5.65)			---	-.46**	-.03	.09	.33*	.34*	.27	.13
5 Caregiving Strain	11.92 (3.82)				---	.22	.06	-.30*	-.37**	-.30*	-.29*
6 Child IP	54.59 (10.22)					---	.40**	.15	.04	.08	-.22
7 Child EP	44.81 (10.49)						---	-.14	-.07	-.06	.13
8 Survivor IQ	95.98 (16.75)							---	.68**	.44**	.10
9 Survivor WM	9.24 (3.09)								---	.56**	.19
10 Survivor PSI	90.98 (18.65)									---	.19
11 Survivor PF	63.16 (26.14)										---

Note. IP = Internalizing Problems; EP = Externalizing Problems; WM = Working Memory; PSI = Processing Speed Index; PF = Physical Functioning;

* $p < .05$;

** $p < .01$.

^a N ranges from 44 to 50 due to missing data.

Table 3
Hierarchical Regression Analysis for Variables Predicting Parental Physical HRQL

	Model 1		Model 2	
	β	t	β	t
Household Income	.33	2.26*	.22	1.51
Survivor Internalizing Problems	-.18	-1.21	-.14	-1.03
Survivor Physical Functioning	.25	1.71	.18	1.27
Caregiver Strain			-.33	-2.03*
Caregiver Competence			.11	.70
R^2	.25*		.38**	
R^2			.13*	

* $p < .05$;

** $p < .01$

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Table 4
Multiple Regression Analysis for Variables Predicting Parental Psychosocial HRQL

	β	t	R ²
Caregiver Strain	-.28	-2.06 [*]	.44 ^{**}
Caregiver Competence	.35	2.45 [*]	
Family Functioning	-.20	-1.55	

^{*} $p < .05$;
^{**} $p < .01$