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REVIEW ARTICLE

Social competence in childhood brain tumor survivors: a comprehensive review

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Abstract
Purpose To review the literature investigating the social competence outcomes of child and adolescent survivors of brain tumors.
Methods Twenty articles published between 2000 and 2009 were accessed using PsycInfo and PubMed and reviewed for their findings related to three hypothesized levels of social competence (i.e., social adjustment, social performance, social skills).
Results Current evidence indicates that childhood brain tumor survivors experience decreased social adjustment following treatment. Inconsistencies among studies continue to be an obstacle for advancing the field. The operationalization of social competence requires greater attention to facilitate comparability between studies (e.g., social adjustment, social performance, social skills). The effects of child, familial, and treatment factors and their relationships are still not well understood. There is a lack of theory driven research.
Conclusions Many childhood brain tumor survivors experience deficits in social competence at the level of social adjustment. These deficits worsen with time. Little is known about more rudimentary levels of social competence such as social skills or social performance. This information is needed to guide the development of social intervention programs.

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The survival rate for childhood brain tumors has improved over the last several decades facilitated by continuing medical advances in diagnosis and treatment [1, 2]. Survival has not come without a cost, however, and the presence of late effects such as neurocognitive deficits are now well established [3, 4]. Evidence is similarly mounting for late effects in psychosocial adjustment, defined as social, emotional, and behavioral outcomes, demonstrated in a recent review of the literature published between 1969 and 1999 on childhood brain tumor survivors [5]. Marked social competency deficits were found among these survivors although inconsistencies in evidence were noted [5]. Since publication of this earlier review of psychosocial outcomes, there has been an escalation in studies focused on the social competence outcomes in childhood brain tumor survivors. There is no review that has yet focused specifically on the social competency outcomes among this population. It is critical that social competence outcomes among pediatric brain tumor survivors be reviewed because social competence is necessary to ensure optimal health and well-being. The absence of social competence is a significant risk factor for internalizing problems such as major depressive disorder as well as externalizing behavior problems including conduct disorder [6]. The purpose of the current review, therefore, was to evaluate this new cohort of studies focused on the social competency outcomes in childhood brain tumor survivors.

Definition of terms

Social competence has been defined as "the ability to achieve personal goals in social interaction while simulta-

neously maintaining positive relationships with others over time and across situations" [7]. Such a definition is too broad in scope, however, leading to difficulties in the operationalization and subsequent interpretation, application, and comparison of research findings. In response to criticisms about the breadth of the social competence construct, a more explicit definition of social competence has been offered by Cavell [8] who proposed that social competence be defined as the umbrella under which: (1) social adjustment, defined as the quality of interactions and the extent to which individuals are achieving developmentally appropriate, societally determined goals; (2) social performance on specific tasks, or the social exchange between individuals; and (3) social skills, the specific abilities needed to enable an individual to successfully perform social tasks, have been hypothesized to fall. These components are said to exist in a hierarchy as separate, but interrelated constructs, with social adjustment existing at the top, followed by social performance, and social skills forming the base of this hierarchy. Social competence outcomes in the current review will be evaluated based on Cavell's [8] framework.

Consistent with the views of the National Cancer Institute, the term *survivor* has been used to describe anyone who has been diagnosed with cancer [9]. For the purposes of the current review, therefore, the term survivor will be used to describe any participant diagnosed with a brain tumor.

Determinants of social competence

The source of social competency deficits among child and adolescent brain tumor survivors is unclear. Although the previously conducted review on psychosocial outcomes considered correlates of psychosocial adjustment (e.g., demographic, clinical variables) [5] these were not explicit to social competency outcomes and therefore little was elucidated with respect to variables important to social competence outcomes. Potential determinants surrounding the source of social competence deficits, however, have been identified, including direct treatment effects such as surgery and/or cranial radiation therapy (CRT). CRT is known to affect cognitive abilities [3, 4], which may thereby affect social skills and subsequently social competence [10, 11].

Other variables in addition to disease/treatment factors may also influence social competence outcomes. The transactional stress and coping model posited by Thompson and Gustafson [12] emphasizes the association between chronic illness and psychological adjustment as a function of the transactions among child characteristics (e.g., age, intellectual functioning) in addition to biomedical variables (e.g., chronicity of disease). Moreover, Bronfenbrenner's social ecological model [13] proposes that a multiplicity of personal and environmental factors contribute to child development and social outcomes. In order to better understand social competence outcomes in brain tumor survivors, child and developmental characteristics should be acknowledged, as well as familial/environmental factors [14–16]. There is little research that has been conducted among child and adolescent brain tumor survivors that has attempted to consider these external variables and the interrelationships among each in the context of social competence outcomes.

Objectives

This manuscript aimed to comprehensively evaluate the current literature on the social competence of child and adolescent brain tumor survivors. A new review of the literature on the social competence of brain tumor survivors was needed given the pervasiveness of social competence deficits among this population [5]. Social competence deficits present a risk for compromising long-term adjustment [6]. Greater understanding of these deficits and examination of factors that may contribute to these deficits are warranted so that appropriate intervention strategies may be developed. Focus was given to the literature published between 2000 and 2009. The way in which social competence was operationalized was given special consideration. In addition, consistent with the transactional stress and coping and the social ecological models [12, 13], disease/treatment factors, child, and environmental characteristics were examined as they related to these outcomes.

Methods

Articles published between 2000 and 2009 were accessed using PsycInfo and PubMed. The following medical subject headings terms were used as keywords in search criteria: "brain neoplasms" and "pediatrics" combined with terms thought to capture social competence: "social behavior", "social adjustment", and "social isolation". In addition, reference lists from retrieved articles were reviewed to locate any other potentially relevant literature. Articles that were included for the current review met the following criteria: (1) study participants were diagnosed before the age of 18 years; and (2) study objectives included an assessment of children's social competence following brain tumor diagnosis or treatment. A total of 25 were identified from the literature search, and 20 of those articles met the aforementioned criteria. These studies are summarized in Table 1.

Table 1 Studies investigating social outcomes in child and adolescent brain tumor survivors published between 2000 and 2009

Study	Number	Participant characteristics	Mean age at time of study	Mean age at diagnosis	Mean time since diagnosis	Study design	Measures	Personal/Clinical variables	Findings
Aarsen et al. [27]	38	Diagnoses: low-grade or pilocytic astrocytoma. Treatment: 24 surgery (SG); 8 chemotherapy (CT); 2 radiation therapy (RT); 2 SG+CT; 1 SG+RT, 1 SG+CT+RT	N/A	Ranged from 1 year 3 months to 14 years 7 months.	Mean time since diagnosis was 7.7 years (3.7–11.4 years)	Cross-sectional study design. Parents (76%) and teachers (57%) completed the CBCL/TRF and children older than 11 years (81%) completed the YSR. Parents (92%) and children older than 8 (95%) completed the TACQOL-P/TACQOL-C. Data collected rom questionnaires were compared with normative values	CBCL/YSR/TRF TACQOL-P/TACQOL-C	Age at diagnosis, tumor location	Parents scored lower on competency subscales of the CBCL indicating more difficulty in this domain. Survivors also reported significantly lower social functioning on the YSR Parents, teachers and children reported significantly more problems on CBCL/TRF/YSR scales for social problems compared with norms TACQOL measure revealed significantly decreased social function compared with normative values Teachers reported more social problems for those with infratentorial tumors compared with those with supratentorial tumors Survivors with a diagnosis in adolescence reported lower TACQOL social functioning than younger survivors
Barrera et al. [24]	122	Diagnoses: variety of CNS tumors and were part of a larger, national survey on childhood cancer (n=800). Of the larger cohort, 42.1% were <2 years at diagnosis, 45.4% were 2–4 years at diagnosis and 12.5% were ≥5 years at diagnosis; 51.5% of survivors were 6–12 years at time of study and 48.5% were 13–16 years at time of study. 70.8% were 6–10 years since diagnosis and 29.2% were 11–16 years since diagnosis				Cross-sectional study design. Parent proxies completed standardized questionnaires. Scores were compared with a healthy control group (n=923)	CBCL OCHS		Parents reported survivors were significantly more likely to report having no close friends and to not use friends as confidents compared with healthy controls
Bhat et al. [30]	134	Diagnoses: variety of CNS tumors. Treatment: 79.9% SG; 53% RT; 41.8%	11.82 years	7.56 years	4.26 years	Cross-sectional study design. Parent proxies and survivors completed	PedsQL	Time since diagnosis, shunt, tumor type, tumor location,	Survivor and parent proxy reports indicated significantly lower functioning on social

Table 1 (continued)

Study	Number	Participant characteristics	Mean age at time of study	Mean age at diagnosis	Mean time since diagnosis	Study design	Measures	Personal/Clinical variables	Findings
		CT; 18.7% were currently receiving treatment				the PedsQL. Scores were compared with normative values		treatment	functioning subscale compared with normative values
									Parents of survivors with low-grade glioma reported highest PedsQL functioning compared with other diagnoses
									Parents of survivors with a shunt reported lower social functioning compared with those without
									Survivors with a shunt reported lower psychosocial functioning
									Parent proxies receiving radiotherapy reported lower social functioning than those receiving other treatments
									There was no effect of tumor location
Bonner et al. [23]	51	Diagnoses: variety of CNS tumors	12.4 years (SD=3.13)	6.4 years (SD =3.68)	6.1 years (SD= 3.62)	Cross-sectional study design. Parents and survivors completed standardized questionnaires. Survivors also completed a non-standardized test of nonverbal social skills. Scores were compared with children with Juvenile Rheumatoid Arthritis (JRA)	CBCL	Age at diagnosis, IQ, treatment	Parents rated survivors as having significantly more social problems as reported by the SSRS and CBCL and more deficits in the use of nonverbal social behaviors compared with children with JRA
							SSRS		Survivors' did not report any significant social problems compared with children with JRA
							DANVA2		Survivors' made significantly more errors interpreting adult facial expression, and there was a trend towards more errors for child facial expressions
							EDI		Children who were younger at diagnosis at received radiation made more errors
							WISC II		Facial recognition was related to parent-reported social problems
Boydell et al. [36]	17	Diagnoses: variety of CNS tumors				Cross-sectional study design. 14 survivors and 22 family members (parents and siblings) were used	Qualitative Interview (devised by authors)		Survivors expressed a desire to fit in and the need for friends

Carey et al. [19]	15	Diagnoses: variety of CNS tumors	10.31 years (range, 8–12).	Mean time since treatment was 3.66 years (range, 0.76–10 years)		Cross-sectional study design. Parents, survivors and teachers completed standardized questionnaires. Scores were compared with normative values	CBCL/YSR/TRF SSRS	IQ	Parent proxies reported significant social problems (CBCL, SSRS) compared with normative values Survivors did not report any significant social problems (YSR, SSRS) compared with normative values Teachers did not report any significant social problems (TRF) compared with normative values
Foley [21]	29	Diagnoses: hypothalamic/chiasmic brain tumors	12.5 years (range, 7–17)	6.7 years	Minimum 6 months	Cross-sectional study design. Survivor and parent proxies completed questionnaires. Scores were compared with same-age survivors of other brain tumors and normative values	CBCL FAD		Parent reports of social competence indicated significantly more problems in the brain tumor group compared with normative values There was no difference between parent reports for hypothalamic brain tumors and other tumors Older age at diagnosis was related to higher social competence as reported by father report, but not mothers Special education was related to poorer social competence as reported by mothers
Holmquist and Scott [38]	54	Diagnoses: variety of CNS tumors. Treatment: 80% RT; 67% CT; 91% SG. Only 18% received some form of monotherapy	10.45 years	6.45 years	47.2 months. All survivors were off treatment at least 39.5 months	Cross-sectional study design. Parents proxies completed standardized questionnaires. Scores were compared with those obtained from parent proxies of children with leukemia (n=24) as well as to normative values	CBCL CRS		Chemotherapy treatment was related to CBCL social withdrawal and anxious/depressive symptomatology
Kullgren et al. [37]	40	Diagnoses: variety of CNS tumors. Mean time between Time 1 and Time 2 was 27 months. Treatment: 35% SG; 7.5% RT; 5% CT; 27.5% SG+RT; 15% SG+RT+CT; 5% CT+RT; 2.5% SG+CT; and 1 survivor received no treatment	8.3 years (Time 1); 10.3 years (Time 2)	6.8 years	1.4 years (Time 1); 3.5 years (Time 2)	Longitudinal, retrospective study design. Parents completed standardized questionnaires at two time points: Time 1, 1–2 years post-diagnosis; and Time 2, 3–4 years post-diagnosis.	VABS CBCL FILE	SES, IQ, age at diagnosis, type of tumor, tumor site, treatment	CBCL social competence was significantly lower than normative values at both time points Multiple treatments and low social competence at Time 1 predicted social competence at Time 2
Mabbott et al. [20]	43	Diagnoses: malignant posterior fossa tumors. Treatment:		6.84 years	2.9 years (3.6 years for teachers) at	Longitudinal, retrospective study design. Parents and	CBCL/TRF	Extent of resection, shunt, radiation, age at diagnosis	Parent proxy reports were stable over time, although there was a significant

Table 1 (continued)

Study	Number	Participant characteristics	Mean age at time of study	Mean age at diagnosis	Mean time since diagnosis	Study design	Measures	Personal/Clinical variables	Findings
		RT			first assessment	teachers completed standardized questionnaires. 13 survivors were seen for only one assessment, 40 survivors were seen for serial assessments. Scores were compared with normative values.			increase in reports of social problems. ▪ Teacher reports indicated significant increases in social problems and social withdrawal over time
Meeske et al. [32]	86	Diagnoses: variety of CNS tumors. 42% of brain tumor children were receiving active treatment, 30% were off treatment for less than 12 months and 20% were off treatment for more than 12 months	9.7 years (range, 2–18).	5 years		Cross-sectional study design. Parent proxies completed questionnaires. Scores were compared with parent proxy reports of children with ALL (n=170) as well as to normative values.	PedsQL		Parent proxy reports indicated survivors with a brain tumor scored significantly lower on social functioning compared with parent proxy reports of survivors with ALL 63% of brain tumor survivors had a total PedsQL score below 1 SD of the normative sample PedsQL Psychosocial health was improved for children who had been off treatment for less than 12 months, but decreased for children who had not had treatment for more than 12 months
Palmer et al. [31]	99	Diagnoses: variety of CNS tumors. Treatment: 61.6% RT; 83.3% SG; 87.9% CT; 5.1% bone marrow transplant.	9.75 years (range, 2–18)	Children were on treatment (46.5%), off treatment< 12 months (19.2%) or off treatment> 12 months (34.3%).		Cross-sectional study design. Parent proxies and survivors completed questionnaires. Scores were compared with 9565 healthy controls	PedsQL		Parent proxy reports and survivors reported significantly lower social functioning compared with healthy controls
Poggi et al. [18]	76	Diagnoses: variety of CNS tumors. Treatment: 92.1% SG; 88.2% RT	11.9 years	7.4 years	Mean time since diagnosis was 5.2 years	Cross-sectional study design. Parent proxies completed the CBCL and the VABS. Scores were compared with normative values as well as to study defined age categories	CBCL VABS	Sex, IQ, time since diagnosis, tumor type, tumor location, treatment	CBCL parent reports revealed 22.6% were above the mean based on normative values for social problems A longer time since diagnosis was associated with more problems on the CBCL withdrawn, social problems There was no significant difference between CBCL scores and type of diagnosis or site of tumor VABS scores indicated impairment in each of four

									areas, the most impaired being the socialization subscale A longer time since diagnosis was associated with the VABS socialization subscale
Pompili et al. [44]	20	Diagnoses: Cerebellar pilocytic astrocytoma Treatment: SG	27 years (range, 18–40 years).	8 years (range, 2–16 years)		Cross-sectional study design. Self-report questionnaire was administered to survivors. Scores were compared with an age and sex matched healthy control group	QOL Questionnaire (modified from Mackworth et al. (1992) by authors)		Survivors reported decreased QOL socializing
Poretti et al. [28]	25	Diagnoses: craniopharyngioma Treatment: SG.	20 years 7 months (range, 4 years 6 months–32 years 5 months)	9 years (range, 2 years 10 months–15 years 11 months)	Mean time since surgery was 11 years 3 months	Cross-sectional study design. Survivor and parent proxies completed the questionnaires. Scores were compared with normative data	Semi-structured interview (devised by authors)		Survivors reported greatest problems on the YSR social problems subscale
							CBCL/YSR		Survivors reported PedsQL scores to be significantly lower compared with normative values—with functioning be lowest on social subscales
							PedsQL		PedsQL psychosocial health was rated to be lower than PedsQL physical health
Ribi et al. [33]	18	Diagnoses: Medulloblastoma	18.9 years (range, 8.5–31.9 years).	6.8 years (range, 1.1–14.7 years).	Mean follow-up time was 12.2 years (range 3.0-24 years).	Cross-sectional study design. Survivor and parent proxies completed standardized questionnaires. Survivors participated in the semi-structured interview	Semi-structured interview (devised by authors)		Interview revealed 37% of survivors reported having difficulty in making friends, 44% experienced rejection by peers and 100% of those over 18 did not have an intimate relationship
							CBCL/YSR		Parents reported significantly lower PedsQL functioning in all domains compared with normative values
							PedsQL		Survivors reported significantly lower PedsQL social functioning compared with normative values
Sands et al. [22]	29	Diagnoses: craniopharyngioma	Unspecified	8.03 years (range, 0.91–15.17 years)	Mean time since diagnoisis was 71.5 months (range 8.4-178.4 months)	Cross-sectional study design. Survivor and parent proxies completed self-report questionnaires. Score were compared with normative data	CBCL	Tumor type (retrochiasmatic vs. prechiasmatic)	CBCL parent proxy reports indicated survivors had significantly increased social problems compared with normative data
							CHQ-PF50/SF-36		Scores on social functioning subscales from QOL measures were reported to be ‘low average’
Schultz et al. [25]	376	Diagnoses: variety of CNS tumors				Cross-sectional study design. Parent proxies completed	PBI		Survivors demonstrated significantly lower social competence compared with

Table 1 (continued)

Study	Number	Participant characteristics	Mean age at time of study	Mean age at diagnosis	Mean time since diagnosis	Study design	Measures	Personal/Clinical variables	Findings
						questionnaires for survivors and siblings. Scores were compared between survivors and siblings			siblings Survivors were 1.9 times more likely to have diminished social competence compared with siblings
		Part of a larger, national survey on childhood cancer (n=2979); 14.8% were <2 years at diagnosis; 53.3% were 2–4 years at diagnosis; and 17.9% were≥5 years at diagnosis. 42.6% of survivors were 12–14 years at time of study and 57.4% were 15–17 years at time of study							
Upton and Eiser [34]	40	Diagnoses: variety of CNS tumors Treatment: 87.5% SG; 62.5% RT; 37.5% CT	12 years 2 months (range from 6–16 years)	6 years 4 months (range 3 months to 13 years)	Time since treatment completion ranged from 2 years to 12 years 5 months	Cross-sectional study design. Mothers and teachers completed questionnaires. Scores were compared with normative values	Semi-Structured Interview (devised by authors) SDQ		Semi-structured interview conducted with parent indicated 42.5% of survivors were socially isolated Parent proxies reported survivors as having more peer relationship problems, and poorer pro-social behavior on SDQ compared with normative data Teachers reported survivors as having more peer relationship problems on SDQ compared with normative values
Vance and Eiser [35]	8	Diagnoses: variety of CNS tumors	Age ranged from 8-20 years.	Age at diagnosis ranged from 0.69 to 9.51 years.	Time since diagnosis ranged from 3.85 to 12.35 years	Cross-sectional study design. Parents were asked to describe their child's illness history and current functioning	Qualitative Interview (devised by authors)		Parents reported their children had significant difficulties with respect to peer relationships. In particular, parents spoke of peer exclusion, and bullying

Note: *Normative values* were used to describe scores that have been obtained in previous research and considered standard scores for that particular measure. *Healthy controls* were used to refer to control subjects recruited for the particular research study in question and these scores are then compared with the target population

CBCL Child Behavior Checklist [17], *YSR* Youth Self-Report [17], *TRF* teacher report form [17], *TACQOL-P/C* Netherlands Organization for Applied Scientific Research/Academic Hospital Leiden Center Children's Quality of Life questionnaires parent form/child form [62], *OCHS* Ontario Child Health Study [63], *PedsQL* Pediatric Quality of Life Inventory [29], *SSRS* Social Skills Rating Scale [64], *HUI2* Health Utilities Index 2 [65], *BASC* Behavioral Assessment System for Children [66], *FAD* McMaster Family Assessment Device [67], *CRS* Conners' Rating Scales [68], *VABS* Vineland Adaptive Behavior Scales [69], *FILE* Family Inventory of Life Events and Changes [70], *QLI* Ferrans and Powers Quality of Life Index [71], *SCL-90-R* Symptom Checklist-90-Revised [72], *FMH* Fertigkeitenskala Münster-Heidelberg [73], *PGWB* Psychological General Well-being Schedule [74], *AGHDA* Adult GH-deficiency assessment [75], *RCMAS* Revised Children's Manifest Anxiety Scale [76], *SMFQ* Short Mood and Feelings Questionnaire [77], *C-GAS* Children's Global Assessment Scale [78], *SF-36* 36-item Short Form Health Survey [79], *SDQ* Strengths and Difficulties Questionnaire [80], *BSI-18* Brief Symptom Inventory 18 [81]

Results

Evidence for deficits in social competence

Social adjustment Most studies evaluated social competence at the level of social adjustment [8]. Specifically, half of the studies characterized social competence as assessed by subscales of the parent report Child Behavior Checklist (CBCL) [17] which reflect social adjustment, although labeled "Social Competence" and "Social Problems". The CBCL parent form is a standardized 118-item inventory summarized into total, internalizing (including social problems) and externalizing scores, as well as three different competence scales (including social competence). Internal consistency reliability ranges for the CBCL from 0.57 to 0.71 for internalizing, 0.70 to 0.86 for externalizing, and 0.69 to 0.82 for total problem behaviors, across ages [17]. Based on these scales, social adjustment was found to be compromised compared with normative values [18–22] or to children with juvenile rheumatoid arthritis (JRA) [23].

Similarly using the parent-reported CBCL, Barrera and colleagues [24] and Schultz and colleagues [25] conducted two large (e.g., greater than 100 participants) national studies to describe psychosocial outcomes among childhood cancer survivors including this population. The first, conducted in Canada [24], evaluated specific items of the CBCL and revealed that child and adolescent survivors of brain tumors were reported by parents to have fewer friends compared with other cancer survivors or a population-based control group. The other, conducted in the USA [25], utilized a subset of questions from the CBCL [26] and found that survivors of brain tumors had decreased social adjustment compared with their siblings [25].

Three studies administered the teacher report form (TRF) [17] of the CBCL to assess social adjustment with conflicting results [19, 20, 27]. Carey and colleagues [19] reported no significant difference to norms whereas Aarsen and colleagues [27] found teachers reported survivors of astrocytoma to have significantly higher social adjustment problems compared with population norms. The third study by Mabbott and colleagues [20], which was retrospective in nature, found teachers reported social adjustment to be within the normal range at first assessment, although social adjustment difficulties significantly increased in later assessments. Three studies reported social adjustment as assessed by the Youth Self-Report of the CBCL [17]; Aarsen and colleagues [27] and Poretti and colleagues [28] reported significantly greater social adjustment problems compared with population norms, whereas Carey and colleagues [19] found no significant difference between survivors and population norms.

Other measures of social adjustment include the social function subscale of the Pediatric Quality of Life Index (PedsQL) [29], a measure of health-related quality of life (HRQL). Using this subscale, Bhat and colleagues [30] found parent proxy reports and child self-reports showed significantly lower social adjustment compared with normative values and Palmer and colleagues [31] replicated these results compared with healthy controls. In Meeske et al.'s study [32], child and adolescent brain tumor survivors self-reported lower social adjustment compared with survivors of acute lymphoblastic leukemia (ALL). The types of treatments received by ALL survivors in this study (e.g., cranial radiation) were not included in this study. More than 10 years from diagnosis, Ribi and colleagues [33] and Poretti and colleagues [28] found parent and survivors of medulloblastoma and craniopharyngioma, respectively, also reported significantly lower scores on the social functioning subscale of the PedsQL compared with normative values. Using other HRQL questionnaires, Sands et al. [22] found parent proxies and survivors of craniopharyngioma reported "low average" social adjustment compared with normative values. Finally, other standardized questionnaires of social adjustment have yielded the same outcomes. Upton and Eiser [34] found parents and teachers reported significantly more difficulties with social adjustment as assessed through peer relationships compared with normative values and Bonner et al. [23] confirmed these findings compared with children with JRA based on parent report. No differences were found based on survivor self-reports.

Qualitative methodology has also been employed to assess social adjustment. Vance and colleagues [35] uncovered two consistent themes after conducting semi-structured interviews: (1) peer exclusion and being bullied; and (2) the discrepancy between their child's social relationships prior to cancer treatment and the subsequent downfall with peers following the return to school. As well, in Upton and Eiser's study, [34] almost half the mothers of children with brain tumors reported their child was socially isolated and half of these mothers felt their child's behavior limited social opportunities. Interviews and focus groups conducted with brain tumor survivors, parents and siblings, Boydell and colleagues [36] similarly uncovered themes of social isolation.

In summary, with the exception of two studies based on self-reports [19, 23], social adjustment as assessed through a range of standardized questionnaires, semi-structured interviews and focus groups with multiple informants, has been found to be compromised in childhood brain tumor survivors compared with population norms, healthy controls, healthy siblings, children with other cancers, and children with other chronic illnesses.

Social performance None of the studies reviewed assessed childhood brain cancer patients on aspects of social performance.

Social skills Bonner and colleagues [23] conducted the only study that assessed social competence at the level of social skills. This study focused on the evaluation of social skills via cognitive assessment and measured facial expression recognition skills. They found that child survivors of brain tumors made significantly more errors interpreting adult facial expressions compared with children with JRA. Such skills are acknowledged to be essential for proficient social communication and interaction as well as to provide critical nonverbal social information to observers [10].

Determinants of social competence deficits

Disease/treatment factors Where assessed, no relationship has been found between social competency outcomes with tumor type or tumor site [30, 37]. Among a population of craniopharyngioma survivors, tumor size did not appear to effect social adjustment outcomes [22].

With regard to treatment effects, the evidence is conflicting. Holmquist and Scott [38], Mabbott and colleagues [20] and Poggi and colleagues [18] found no effect of CRT on social competency outcomes when employing the CBCL social competence scale as an outcome. On the other hand, when employing the PedsQL, Bhat et al. [30] found that CRT with or without surgery was related to significantly lower social adjustment compared with no treatment, surgery only, or radiation and chemotherapy with or without surgery. The discrepancy in findings may be attributable to the fact that the PedsQL was designed for children with a chronic illness and may be more sensitive to differences in outcomes. Investigation at the level of social skills found a trend for the impact of CRT on the recognition of child facial expressions [23]. More research investigating the impact of CRT on social competence outcomes in brain tumor survivors is warranted.

Regarding chemotherapy effects, Holmquist and Scott [38] found children who received drugs such as vincristine, cytoxan, and VP16, reported greater social adjustment difficulties compared with those who did not receive chemotherapy regimes. Of note, however, there are a number of factors which may have confounded these results. Children receiving chemotherapy are more likely to have medulloblastoma or ST PNET tumors, which are larger volume tumors and similarly require craniospinal radiation followed by focal radiation, known to be a risk factor for hearing, vision, and neurocognitive deficits [39]. Children with brain tumors who do not receive chemotherapy, on the other hand, are more likely to have smaller volume tumors and are more likely to not to receive radiation [39]. Taking this into account, Kullgren et al. [37] examined the effects of having multiple treatments (i.e., surgery and radiation, chemotherapy and radiation, or surgery and chemotherapy) and found that this combined variable was also likely to predict difficulty with social adjustment 3 to 4 years following diagnosis. Disease recurrence was consistently associated with decreased social adjustment compared with survivors without disease recurrence according to Aarsen et al. [27] and Sands et al. [22]. Disease recurrence has also been associated with decreased social adjustment compared with those without disease recurrence in a study of survivors more than 10 years since treatment [28]. Finally, Bhat and colleagues [30] found the presence of a shunt to be related to social adjustment deficits, although this was not confirmed by Mabbott et al. [20].

Age at diagnosis was considered a variable of interest in five of the reviewed studies with contradicting evidence [20, 21, 23, 27, 37]. Kullgren et al. [37] and Mabbott et al. [20] found no relation between age at diagnosis and social adjustment. Aarsen and colleagues [27] found survivors with a diagnosis in adolescence reported lower social adjustment based on a HRQL measure compared with younger survivors. Foley and colleagues [21] found that younger age at diagnosis was related to poorer social adjustment based on father's but not mother's reports. Finally, Bonner et al. [23] found that the children who were younger at diagnosis and had CRT made more errors in facial recognition, compared with older children. Clearly, further research is needed to better understand the relationship between age at diagnosis and social adjustment in this population.

Time since diagnosis, on the other hand, has been found consistently to be related to social adjustment, with the longer the time since diagnosis, the worse the outcome. In Mabbott and colleagues' [20] retrospective study, CBCL social adjustment was found to have significantly decreased over a median follow-up period of 4.17 years from diagnosis. In Kullgren and colleagues' [37] longitudinal study, low CBCL social adjustment was found at 1 to 2 years post-diagnosis and these scores were predictive of lower CBCL social adjustment scores 3 to 4 years later. For self-reported social adjustment, no significant differences were found between survivors and population norms when time since diagnosis was 3.66 years [19]. Significantly worse outcomes, however, were found when time since diagnosis was 7.7 and 11 years [27, 28] providing further evidence that longer time since diagnosis may account for decrements in social adjustment over time.

Child factors Few studies have evaluated the effect of gender or age at study on social competence, and among these no significant relationships have been found [18, 22, 30]. Lower body mass index (BMI), suggestive of underweight, was found to be related to poorer parent-

reported social competence [40]. In the same study, examining the interrelationships among child variables (BMI, self-perception, IQ, and social competence), lower BMI was similarly related to self-perceptions of close friendships in the presence of lower IQ. These findings warrant further investigation to better understand the relationship of child characteristics and their interactions, and the social competence of these survivors.

With respect to the neurocognitive functioning of survivors, some associations with social competence have been found. Lower overall intellectual capabilities [18, 38] and lower nonverbal intelligence [19] were associated with decreased social adjustment. Conflicting reports exist with respect to verbal intelligence, however. Holmquist and Scott [38] found lower verbal memory and verbal fluency was associated with decreased social adjustment whereas, Carey and colleagues [19] found no relationship between verbal intelligence and social adjustment. Finally, Foley et al. [21] found survivor's enrollment in special education was related to mother's but not father's reports of decreased social adjustment.

Environmental factors Kullgren et al. [37] found socio-economic status (SES) to be related to social competence outcomes, although it did not contribute significantly to the variance of social competency when other variables were considered. Except for the examination of SES, there are no studies in the current review that considered the effect of family functioning on social competency outcomes.

Intervention efforts

Three studies have examined the effect of social competence interventions among children with brain tumors [41–43], though randomized control studies have yet to be conducted. DieTrill [41] and colleagues developed a social skills intervention completed by eight boys over 16 sessions. Improvements in social adjustment were reported based on satisfaction questionnaires administered to the families upon completion of the group. Without a baseline assessment, an absence of standardized questionnaires, and a sample of only eight boys, however, little can be derived from these results.

Barakat and colleagues [43] conducted a pilot study of a social skills intervention for 13 children with brain tumors. The intervention consisted of six sessions targeting social skills such as nonverbal communication and cooperation. Results were based on standardized measures (e.g., CBCL), 1 month prior to the intervention and 10 months following the intervention completed by survivors, their parents, and teachers. Improved social adjustment was reported. The small sample size, lack of control group, and follow-up assessments conducted 10 months post-intervention, however, make it difficult to attribute social adjustment changes to the intervention alone.

More recently, the preliminary outcomes of a social skills program with 32 participants was assessed [42]. The group intervention consisted of eight 2-h weekly sessions focused on social skills including friendship making and managing teasing. Using standardized questionnaires administered twice before the intervention, immediately following the intervention, and at 6-month follow-up, significant improvements in social adjustment were found. These improvements were maintained after 6-month follow-up [42]. No significant change was found for any standardized outcome measures completed by survivors. Although this study improved on previous methodology in terms of the sample size and repeated assessments before and after the intervention, it was limited by a lack of a control group.

Discussion

The literature on the social competence outcomes of child and adolescent survivors of brain tumors was reviewed based 20 identified studies. Consistent evidence was obtained for deficits in social competence. With one exception [23], these social competence deficits have been demonstrated at the level of social adjustment. Social adjustment deficits were found across a variety of data gathering techniques (standardized questionnaires, semi-structured interview), informants (parents, survivors, teachers), and study designs (cross-sectional, longitudinal, retrospective, comparisons to population norms, siblings, or healthy peers). Social adjustment deficits appear to endure into early adulthood and more than 10 years beyond diagnosis [28, 33]. Moreover, social adjustment difficulties seem specific to brain tumor populations as opposed to other cancer (e.g., ALL) [32, 38], or other illness (e.g., JRA) populations [25].

It was disappointing to find that by and large, most studies reporting social adjustment outcomes continue to rely primarily on comparisons to normative values and rarely use control or comparison groups. In fact, even healthy control groups appeared only twice as a comparison group among the studies reviewed [31, 44]. The use of normative values as a comparison in studies was also criticized in the earlier review paper [5] and almost one decade later, no improvement has been made in this area. Relying on normative data is problematic because normative data may overestimate the rates of social competence deficits in this population. Normative samples typically exclude children with adjustment problems and therefore do not represent the general population [45, 46]. At the very

least, an increase in the use of comparison groups matched by age and gender (e.g., healthy peers, siblings, or children with other types of chronic illness), as opposed to population norms, is warranted to enhance validity of findings.

The current review has found an increase in the use of multi-informant assessment methodology (nine of 20 studies, 45%) compared with the previous review where only five studies (38%) included multi-informant assessments, of which the majority were comprised of parent proxy and teacher reports [5]. Teachers were only included as informants in the current review in three out of the 20 studies, each employing the TRF of the CBCL. For the most part, teachers reports tended to resemble that of parents. The increase in multi-informant reporting in the current review, therefore, is largely reflected by an increase in survivor self-reports.

The increase in survivor self-reports has highlighted greater discrepancies between child and parent and teacher reporting. There are several hypotheses for this discrepancy. Survivors of childhood cancer in general have been noted to underreport, or repress, their psychosocial difficulties, which may also account for the lack of significant differences [47, 48]. Within the literature on pediatric oncology, the discrepancy between survivors' subjective reports and others (i.e., parents, teachers,) has been documented for outcome variables including competence (e.g., self-esteem) and distress (e.g., depression, anxiety, behavioral problems, general psychopathology, somatic distress) [48–52]. Alternatively, given cognitive late effects among this population, survivors may lack the insight to understand the basis for socially competent behavior [53]. Finally, parent reports may also be subject to inflation due to parental distress, particularly when dealing with a child with a chronic illness [32]. The discrepancies in reporting between parents (teachers, peers) and survivors in reports of social competence have not been investigated and warrant future research.

In comparing the recent studies of social competence reviewed in this study to the previous review [5], differences in data collection were evident. Specifically, greater utilization of quality of life measures (35% vs. 15%) and a decreased use of sociometric measures was observed. In fact, none of the studies in the current review employed sociometric measures, previously implemented by Noll and colleagues [54, 55], to examine peer relationships among children and adolescents with cancer, including brain tumor survivors. Although sociometric measures have been criticized for relying too heavily on popularity and likeability [56], peer reports are critical to our understanding of brain tumor survivors' social competence, given the importance of returning to normal life after treatment.

There has been some consideration of the determinants of or contextual factors that may influence social competence outcomes. With respect to the effect of disease/treatment variables, only disease recurrence and longer time since diagnosis have been consistently shown to be related to greater social competence difficulties in these survivors [22, 27, 28]. According to Thompson and Gustafson [12], this may reflect the chronicity of illness and treatment demands on the child and family contributing to further isolation from family and friends [12]. Disease recurrence and time since diagnosis might also contribute to increased brain function impairment. Neurocognitive deficits in pediatric brain tumor survivors have similarly been found to worsen with time since diagnosis [57, 58].

Interestingly, the effects of CRT, speculated to be related to social competence difficulties as a result of its known effect on cognitive outcomes [59], have not been confirmed. None of the studies in the current review considered neurological or physical impairments. Again, more research is needed to identify specific disease/treatment variables related to social difficulties in these survivors.

With respect to child characteristics, higher intellectual capabilities, nonverbal intelligence, and verbal memory and verbal fluency were all associated with increased social function [18, 19, 38]. No consistent relationship emerged with gender, or age. There is little research that has explored other personal characteristics such as self-concept and social outcomes with this population. Further research on the associations of child characteristics with social outcomes is warranted.

Finally, there is little evidence with regard to the effects of family factors on social outcomes in childhood brain tumor survivors. This is an area that warrants greater attention in future research given recent findings highlighting the importance of the home environment (e.g., maternal age, maternal depression) of children with cancer who survive a stem cell transplantation for cognitive, educational and psychosocial outcomes [60].

As in the previous review, we found that studies herein remain largely cross-sectional with heterogeneous age at time of study and tumor population. In contrast, across the range of studies, mean age at diagnosis remained relatively consistent, ranging from 5 to 9 years of age, with the majority lying in the 6 to 7 years of age range. Only four studies, however, included age at diagnosis in analysis and the evidence for its effect is conflicting. Thus, more research is needed to better understand the relationship between the child's development using age at diagnosis as an index of development and the effect of disease and treatment on social outcomes.

Critique and future directions

There remain some considerable limitations in the research conducted in this field. Although there is now sufficient evidence that social competence difficulties exist in this population, measurement of social competence has focused primarily at the level of social adjustment. Moreover, measures of social adjustment are limited largely to tools that have been designed for use in a healthy population. As highlighted in the previous review paper [5], measures designed for healthy populations have generally been criticized for their applicability in non-healthy children [46], which was similarly. There is a need for future research investigating the psychometric properties of these measures among a population of childhood brain tumor survivors to ensure their validity with this population.

With one exception [23], a major gap in the field is the lack of assessment at the more primary levels of social competence, mainly social performance and social skills. More research on these levels of social competence may help identify important targets for intervention (i.e., reading facial cues). It is time that the research in social outcomes of childhood brain tumors survivors move beyond the simple implementation of standardized questionnaires and instead employ more innovative methodologies to understand this construct.

Most studies lack a conceptual framework to understand the determinants of social competence in the context of a life changing illness such as a childhood brain tumor. There are a multiplicity of factors within the child's environment that influence the developing child, before and after diagnosis and treatment [12–14]. Thus, when investigating social outcomes in children treated for a brain tumor, in addition to disease and treatment variables, the child and adolescents' own characteristics, IQ, and self-esteem, as well as familial and environmental factors must be considered in order to generate a more comprehensive understanding of these social competence outcomes. It may be, for example, that although hypothesized in a number of studies, no consistent relationship has been identified with CRT and social outcomes because it has not yet been considered in conjunction with neurocognitive outcomes. Neurocognitive outcomes may moderate the effect of CRT on social competence when their interrelationships are considered. Currently, studies have examined some isolated child's characteristics and disease factors, but rarely have their interrelations for mediation or moderation been explored.

Familial factors have seldom been studied in the context of social competence, which bears little improvement over the studies included in the earlier review [5]. There is still a lack of research evaluating SES, parental education, and other parental characteristics. Given the increased ethnic diversity in the Western world, ethnicity is also a factor that has yet to be included in studies of social competence, as cultural pattern, values and beliefs play an important role in social behavior and the development of social competence. In fact, not only has ethnicity rarely been investigated as a potential correlate, it was only documented as part of the sample demographics in four studies of the 20 studies reviewed [19, 23, 31, 37]. As well, SES and other parent characteristics need to be considered to better understand the role of these contextual factors and their interrelations to social outcomes in survivors of brain tumors in childhood and adolescence.

A major limitation for examining multiple factors as determinants of social competence outcomes are the small sample sizes available when studying participants with rare conditions such as childhood brain tumors. A small sample size remains a limitation in research conducted among this population, with the exception of two nationally based studies [24, 25]. Understandably, as the prevalence rate of child and adolescent brain tumors is minimal among the population, this is an issue that is difficult to circumvent. Nevertheless, a small sample restricts research not only in the evaluation of contextual factors, but also in the consideration of child and adolescent brain tumor survivors as a homogeneous group, despite in reality being a very heterogeneous group. Collaborations to conduct multi-site evaluations would address this problem. New research designs to investigate social competence outcomes in child and adolescent brain tumor survivors, therefore, should focus on collaborative consortiums from multiple research centers.

Finally, there remains a lack of adequate longitudinal studies to accurately evaluate survivors' social competence over extended periods of time, and different developmental trajectories depending on the age of the child at diagnosis. Although challenging to conduct with high-risk populations, longitudinal studies are necessary to fully understand the long-term scope of the disease, its treatment and related factors. Conducted in the context of child and familial factors, longitudinal research would provide insight into potential predictive and protective mechanisms of long-term social outcomes in survivors of childhood brain tumors. Lastly, a longitudinal design would allow us to predict future social outcomes from early factors [61].

Conclusion

There is consistent evidence to conclude that child and adolescent survivors of brain tumors experience deficits in social competence at the level of social adjustment and that longer time since diagnosis and lower cognitive functioning are associated with social competence deficits. These deficits appear to persist into early adulthood and beyond

and therefore, warrant early intervention. More research is needed, however, to better understand social deficits at the levels of social performance and social skills to uncover more specific sources of social difficulties. This research will guide the development of further evidence based social competence interventions tailored to the specific level of social deficit identified with this population.

Disclosures None.

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