**Social Competence in Children and Young People Treated for a Brain Tumour**

Alice Emond, BSc, DClinPsy; Lesley Edwards, BSc, MSc, psychD; Samantha Peacock, BSc, ClinPsyD; Catherine Norman, BSc. DClinPsy, & Michael Evangeli, MA, MSc, ClinPsyD.

*Corresponding Author:*

Dr Alice Emond, Clinical Psychologist.

Email: emondalice@hotmail.com

Address: Children’s Complex Neurodevelopmental Disability Service, Evelina London Children’s Hospital | Children's Neurosciences Centre, 1st Floor, Staircase D, South Wing, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH

**Abstract**

*Purpose* To provide a multi informant assessment of social competence in 8-16 year olds treated for a Brain Tumour (BT) and then to compare these assessment outcomes to peers. *Method*A cross sectional, mixed (within and between group) design was used to compare a paediatric BT survivor group (*n*=33) with an age-matched control group (*n*=34) on two multi-informant (self-report, parent, teacher) social competence questionnaires: Social Skills Improvement System (SSIS); Social Responsiveness Scale (SRS). Demographic factors (age, gender, Social Economic Status (SES), intellectual ability and emotional/behavioural difficulties were investigated as potential non insult related risk factors. *Results*Compared to controls, the BT group were reported to have difficulties in social adjustment, interactions and information processing, on both social competence questionnaire measures by parents and teachers, but not self-report. Social Competence scores for the BT group were broadly distributed within the normal-severe clinical range, with 40% of BT survivors scoring in the clinical range for social competence difficulties on the SRS. Lower intellectual ability and emotional/behavioural difficulties accounted for some of the group differences in social competence, but group effects remained once estimated IQ and emotional/behavioural difficulties were controlled for. *Conclusions* Paediatric BT survivors were reported by parents and teachers to have significant difficulties at all three levels of social competence: adjustment, interaction and information processing. The results highlight the importance of routine assessment in clinic settings for social competence and emotional/behavioural difficulties in BT survivors, to promote early identification and to ensure that survivors are referred for appropriate services and intervention as part of their multi-disciplinary care package.

**Key words:**

Paediatric Brain Tumour; Social Competence; Emotional/Behavioural difficulties; multi-informant

*Introduction*

There are around 500 new paediatric brain tumour cases per year in the UK [1]. As survival rates have improved, concern has focused on long-term adjustment [2]. Paediatric brain tumour (BT) survivors may be at risk for a range of neurocognitive and psychosocial difficulties [3]. In paediatric BT survivors, the ‘Social Brain’ [4], the interconnected network of brain regions associated with social cognitive and affective processes [5] may be damaged directly by the brain tumour or by adverse treatment effects [6]. BT survivors may be also at risk of impairments in social competence due to various stressors associated with the tumour and cancer treatment, disrupting age-appropriate normal social development. Although it is recognised that social competence difficulties increase the risks of adjustment problems in childhood and later life [7] there has been limited published research in BT survivors. Understanding the nature of social competence difficulties is important for effective early intervention to improve social outcomes for paediatric BT survivors.

 ‘Social competence’ refers to the ability to achieve personal goals in social interaction, alongside maintaining positive relationships with others over time and across situations [8]. Yeates and colleagues’ heuristic model of social outcomes in childhood brain disorder [9] is a useful framework for examining the social difficulties in the paediatric BT population. The model hypothesises that children with brain disorders are likely to show impairments at all three separate but inter-related levels of social competence: 1)*social adjustment* (self perceptions, perceptions of others) 2) *social interaction*(affiliative, aggressive, withdrawn behaviour) and 3) *social information processing* (social affective functions, social problem solving and cognitive executive functions). Yeates et al. distinguish between the evaluation of social adjustment by the ‘self’ versus ‘others’. This is a pertinent distinction for paediatric BT survivors who may be more likely than peers, parents and teachers to underestimate peer relationship difficulties [3, 10]. The extent of social difficulties may vary across each level of social competence according to the mix of brain insult-related (e.g. neurological dysfunction) and non-insult (e.g. environmental factors) risk and resilience factors.

Reviews of research show that paediatric BT survivors are at risk of social adjustment deficits (e.g. social isolation, peer relationship problems), relative to healthy controls, siblings, and chronic illness groups, including those with non-brain cancers [11,12,13]. The prevalence of social adjustment difficulties reported in the paediatric BT population range from 23-46% [3]. Although no studies have assessed social interaction per se in those with paediatric BT, deficits in ‘affiliative behaviours’ such as engagement have been indirectly assessed by studies that have used the Social Skills Rating System questionnaire (SSRS). [14]. Assessment of social competence at the level of Social Information Processing has received little examination in this population; Bonner and colleagues [14] showed deficits in survivors’ facial expression recognition skills, but an intervention study with survivors did not find deficits in social problem solving abilities [15].

Social competence research with this population can be criticised for limited assessment of social competency (use of brief social subscales of social adjustment, neglecting social interaction and social information processing), the use of single rather than multiple informants, small heterogeneous samples and inadequate controlling for non-insult and insult related risk factors (see [13] for a review). Whilst social interaction and social information processing are typically measured using peer observation and assessment of social cognitive functioning respectively, social competence questionnaires, such as the SSRS and the Social Responsiveness Scale (SRS) include items that also measure these areas of social competence. Multi-informant ratings are particularly important in the assessment of social competence to measure social difficulties in both home and school settings and to increase accuracy and reliability of assessment.

We examined social competence at the level of social adjustment, and measured social interaction and social information processing using multi informant social competence questionnaires in 8-16 year olds treated for a BT, and compared them to a school control group. We explored non-insult related risk factors previously identified in the paediatric BT literature to be associated with poorer social competency; namely older (adolescent) age and male gender [16], low Social Economic Status (SES) [17], lower IQ [3] and emotional/behavioural difficulties [17, 18]. In light of the various insult and non-insult related pathways to social competence deficits [9] the main hypothesis was that, after controlling for non-insult related covariates, the BT group would show greater impairments on measures of social competence than their peers.

*Method*

*Study design* A cross sectional, mixed (within and between group) design was used, with a paediatric survivor group (n=33) and an age matched mainstream school control group (n=34). Ethical approval for the study was obtained from a local NHS Research Ethics Committee, participant Hospital Research and Development Committee and a University ethics committee. *Eligibility criteria* Inclusion criteria were: children aged 8-16 years attending mainstream education; fluent in English; child and one parent willing to participate. Exclusion criteria were: significant impairment in global intellectual ability (operationalised as attending a special school, or Full Scale IQ estimated score below 70); significant visual, hearing or motor impairment; history of documented CNS injury or neurological disorder, or known Autism Spectrum Disorder (ASD). *Sampling method and response rates.* The BT group were identified from the NHS site paediatric oncology database. Of 107 BT paediatric survivors considered for eligibility, 76 individuals met the inclusion criteria. Of these 76 eligible individuals who were approached via letter to participate in the study, 37 (49%) agreed to take part and 33 (43%) completed the study. 16/33 (48%) teachers from the BT group (form tutors if at secondary school; class teachers from primary school) agreed to take part and 10/33 (30%) returned the questionnaires. Time since diagnosis ranged from 2.1 years – 9.8 years (mean 5.9 years) and all survivors were off treatment and medically stable for at least one year. The School Control group was recruited using stratified random sampling (by age and gender to match the BT group) from a large mainstream primary school and an inner city secondary school. Response rates for pupil and parent participation in the School Control group was 17%. 21/34 (62%) of teacher questionnaires in the School Control group were returned/completed. Parents and teachers were sent a follow-up letter after two weeks and one month if questionnaire measures were not returned.

*Demographic information* (Table I.).An Index of Multiple Deprivation (IMD) from participant postcodes was used as a measure of SES [19]. Higher IMD scores indicate higher levels of deprivation in the postcode area. *Medical information* for the BT group was obtained from the NHS site database (Table II.).

*Table I. Demographic Variables by Group*

*Table II. Medical Variables in BT Group*

*Social competence measures.* Two multi-informant questionnaires were used to assess social adjustment and indirect measurements of social interaction and social information processing. The *Social Skills Improvement System (SSIS) Rating Scales* [20], a revised version of the *Social Skills Rating System [SSRS*, 21],is a multi-rater (self-report, parent, teacher) questionnaire, assessing positive social behaviour of 3-18 year olds. The SSRS is recommended to assess social competence in paediatric brain tumour survivors, due to its good construct validity, internal consistency and responsiveness to social competency interventions in this population [22]. It has also been shown to correlate with direct measures of social information processing, namely survivors’ facial expression recognition skills [14], providing evidence of concurrent validity. Informants completed the Social Skills domain (46 items) assessing the perceived frequency of a child’s positive social behaviours – communication, cooperation, assertion, responsibility, empathy, engagement and self-control. This questionnaire measures social adjustment (e.g. ‘*is liked by others’*) and social interaction focusing on affiliative behaviours (e.g. ‘*gives compliments to friends or other children in the family’*), with higher scores indicating less social impairment. Cronbach’s α’s for the Social Skills total score ranged from .91 to .96 across informants and group. The *Social Responsiveness Scale (SRS)* [23] is a 65-item questionnaire, completed by parents and teachers, about reciprocal social behaviour over the past six months for 4-18 year olds. The SRS subscales (Social Awareness, Social Cognition, Social Communication, Social Motivation and Autistic Mannerisms) assess social adjustment (e.g. *‘gets teased a lot’*) and include items that measure social interaction (e.g. *‘Is awkward in turn taking interactions with peers’*) and social information processing (e.g. *‘Is able to understand the meaning of other people’s tone of voice and facial expressions’*), with higher scores indicating increased social impairment. The SRS was developed as a screening tool for mild-severe social impairments characteristic of ASD. Its authors claim that it can quantify subtle differences in degrees of social impairment with a lack of floor effects, which allows it to assess symptomatology throughout the full range of social impairments. Although the SRS has not previously used in the paediatric brain tumour population it has been used to assess reciprocal social behaviour in paediatric neurofibromatosis [24], mood and anxiety disorders [25], child psychiatric patients [23] and also validated on a large sample of typically developing children and adolescents [23]. The tool was selected to provide more detailed information on social interaction and social information processing than assessed in this population to date using questionnaire measures. Cronbach’s α’s for the SRS Total Score across informants was .97 and treatment subscales ranged from .85 - .93, except for the Social Awareness subscale (.65 parent; .69 teacher), suggesting good internal consistency. Scores on the SRS and SSIS were strongly negatively correlated with each other, providing evidence of concurrent validity. *Secondary measures.* The two-subtest version of *The Wechsler Abbreviated Scale of Intelligence (WASI)* [26] was used. Vocabulary, a single test of verbal abilities is a prototypical measure of crystallised intelligence (i.e., acquired knowledge). Matrix Reasoning, a single subtest of nonverbal abilities is regarded as a measure of fluid intelligence [27]. The *Strengths and Difficulties Questionnaire (SDQ)* [28],a brief multi-rater (parent, teacher, self-report) screening questionnaire, assessing the emotional and behavioural adjustment of children aged between 3-16 years old over the last six months, was used. The study used three of the four SDQ subscales. (Emotional Problems, Conduct Problems and Hyperactivity/Inattention) to calculate an emotional/behavioural difficulties total score. The ‘Peer Problems’ scale was omitted as it was considered to measure social adjustment and not emotional/behavioural problems. Although this abbreviated total difficulties scale has not been previously operationalised, it showed good internal consistency across groups (Self-report =. 77, Parent = .88, Teacher = .86).

*Procedure***.** Eligible children and their parent/guardian who assented/consented to take part attended a 60-90 minute research appointment at the hospital (BT group) or school (school control group). The child completed the SSIS, SDQ and WASI. The parent completed the SSIS, SRS, SDQ and a demographic information form. With parental and head teacher consent, the child’s class teacher was invited via letter to take part in the study and given the same questionnaires as the parent to complete.

*Data analysis.*

 *Preliminary analyses.* Univariate analyses (Independent sample t-tests, Pearson’s correlations) were carried out between (a) demographic factors, intellectual ability and emotional/behavioural difficulties scores and (b) social competence data, to identify potential covariates for hypothesis testing. A conservative approach to the analysis of potential covariates was taken. Covariates were only included in the analysis of the relationship between diagnostic group and social competence data, after a group difference had already been established, if they were (a) significantly (p<. 05) correlated with social functioning and (b) if there were not group differences on these variables that could be attributed to having a BT [29]. Estimated IQ and emotional/behavioural difficulties met both of these criteria so were included as covariates in analyses (see Table IV.) *Hypothesis testing* To conserve power and minimise type 1 errors, MANOVAs were used for SRS subscales to avoid multiple comparisons. Independent *t*-tests were used for measures with one outcome variable (e.g. SSIS Social Skills) and analyses were carried out separately for each informant (self-report, parent & teacher). MANCOVAs and ANCOVAs were carried out when covariates were included.

*Results*

*Descriptive statistics*The BT group and control group were of comparable age. The gender difference between groups was not statistically significant. The control group were more likely to belong to ethnic groups other than ‘White’, and to live within an area of higher deprivation (Table I). Both groups had comparable estimated IQ scores, with group means in the average range, with scores ranging from borderline/low average to the superior range. There were no group differences in overall emotional/behavioural difficulties rated by self-report and teachers (Table III). Parents rated BT survivors as having significantly more emotional distress, conduct problems and hyperactivity/ inattention, with one third of the BT group reported in the clinical range for emotional distress.

*Table III. Group Comparison on Estimated IQ and Emotional/Behavioural Difficulties*

*Table IV. Group Comparison on Social Competence Variables*

Both groups scored in the average range across informants for the SSIS Total Score. The BT group scored in the clinical range (>60T) on parent report for the SRS Total Score and on three of the treatment subscales: Social Communication, Social Motivation and Autistic Mannerisms.

*Risk factors for social functioning difficulties*. No significant relationships were found between demographic variables (age, gender, ethnicity, SES) and social competence scores. Participants with lower estimated IQ scores had lower Teacher SSIS Social Skills Scores and higher Parent SRS Scores.

Increased emotional/behavioural difficulties were associated with lower SSIS scores across all informants and higher SRS scores in parents and teachers (Table V).

No medical variables were significantly associated with SRS scores, except ‘no surgery’ but this finding needs to be interpreted with caution due to the small number in the no surgery group (see Table II).

*Table V: Table V. Pearson’s Correlations between non-insult risk factors and social competence measures by informant across groups*

*Hypothesis testing*There was a significant group effect for the parent and teacher report SSIS Social Skills (parent - *t*(55) = 2.30, *p*<.05); teacher- *t*(29) = 2.45, *p*<.05) and SRS Total Score (parent – Λ=0.72, *F*(5, 51) = 3.94, *p*<.01, Partial η2 = .28; teacher - (Λ=0.59, *F*(1, 28) = 3.33,*p*<.05, partial η2 =.41)), but not on the self-report SSIS Social Skills (*t*(59) =.69, *p*>.05). The main effects remained after controlling for the covariates of estimated IQ and emotional/behavioural difficulties (Table IV.).

*Secondary analyses***.** Group differences on the SRS subscales were explored using univariate ANOVAs to ascertain the type of social competence difficulties exhibited by group. The clinical significance of social competence results was investigated by comparing SRS Total Scores by group with clinical cut offs thresholds using Chi squared analysis. *Type of social competence difficulties.* The main group effects were significant across all of the SRS subscales completed by parents and teachers. The main group effect remained on all parent and teacher report SRS subscales after controlling for estimated IQ and emotional/behavioural difficulties respectively (Table IV), except for the teacher social motivation subscale. *Clinical significance of social functioning scores. (Table VI).* Participants who had been treated for a brain tumour were significantly more likely to score in the clinical range (60*T* and above) on the SRS Total Score than participants in the control group as rated by parents and teachers. In the BT group, both informants reported around 40% of participants within the clinical range, with scores falling in the mild-severe clinical range across all SRS subscales. Six individuals (18%) were rated in the *severe* clinical range on the SRS Total Score (>76*T*) by parent report. Some participants in the control group scored within the mild clinical range on parent (n=3 (13%)) and teacher (n=1 (5%)) report.

*Table VI. SRS Total T-Scores and Clinical Cut-Offs by Group and Informant*

*Discussion*

We examined social competence in 8-16 year olds treated for a BT compared to a school control group in terms of social adjustment, social interaction and social information processing using multi-rater questionnaires. The hypothesis that the BT group would show greater impairments than the school control group across both social competence measures (SSIS, SRS), after controlling for non-insult risk factors (IQ, emotional/behavioural difficulties) was supported with parent and teacher report, but not on SSIS self-report. Thesignificant group effects, across social competence measures and parent and teacher informants, provides evidence that paediatric BT survivors may be at risk of a range of pervasive social competence difficulties at the level of social adjustment, social interaction and social skills compared to their typically developing peers. Group differences on the SSIS indicate that BT survivors may show poorer social adjustment and exhibit less affiliative behaviours in social interactions than their peers. However, mean SSIS scores in the BT group were within the ‘average’ range compared to normative data, in line with the previous SSRS study in this population [14]. Forty percent of paediatric brain tumour survivors were rated as having clinically significant difficulties on the SRS which focuses on reciprocal social interaction, that is, difficulty ‘engaging in emotionally appropriate, turn-taking social interaction with others’ [23]. However, there was large variability in scores and caution is needed when generalising about the severity of difficulties in the BT group.

BT survivors were rated by parents and teachers as also having poorer social awareness and social cognitive skills on the SRS; that is relative difficulties in detecting and interpreting social cues, such as tone of voice, facial expressions and awareness of others’ thoughts and feelings, which may underlie their social interaction and adjustment impairments [14].

The finding that individuals treated for a BT did not themselves report any significant social adjustment and social interaction difficulties on the SSIS compared to the control group, is consistent with Bonner et al’s study [14] using the SSRS. Contradictory evidence, however, has been reported from studies using the Youth Self Report from the CBCL, a different measure of social adjustment, compared to population norms [30]. Some survivors may not understand the basis for socially competent behaviour due to cognitive late effects [31] whilst others may adopt a ‘repressive coping style’ to minimise the negative psychosocial effects of their cancer experience [32]. It is of note that survivors reported more social adjustment deficits in studies where the mean time since diagnosis was longer (e.g. 7.7 years, [30]; 11.3 years, [33]) then the current study (5.9 years), which may suggest that survivors may become more aware of their social differences as they become older and face more demanding and complex social situations. Parent and teachers may over-report social difficulties if they become more hypervigilent to difficulties due to concerns for the child [34]. This may be particularly true for parents who experience elevated levels of distress from having a child with a chronic illness [35]. In support of this explanation, no group differences were found on emotional/behavioural difficulties as rated by teachers, in contrast to significant group differences with parental report.

Consistent with theoretical models of social competence and previous research with paediatric BT survivors, lower intellectual ability and emotional/behavioural difficulties accounted for some of the group variance in social competence. Although brain tumour survivors do not universally experience emotional and behavioural difficulties, some individuals may be at risk of clinically significant problems in this area [36]. Emotional/behavioural difficulties may reflect the stressful cancer experience of survivors and may also be a product of poorer social competence itself, which is a significant risk factor for both internalising and externalising behaviour difficulties in children [37]. Attainment of age-appropriate social competence and peer relationships may be important resilience factors that moderate the psychological and behavioural adjustment of brain tumour survivors by increasing their self-esteem and adaptation to their condition [38].

The study’s strengths are the use of detailed standardised social competency measures, multiple informants across home and school settings and inclusion of a comparison control group matched for age and estimated IQ, addressing criticisms of earlier research [13]. Whilst the social competence questionnaire measures used in this study include items that report on social interaction and social information processing, direct clinical observation of survivors’ social interactions may have been preferable. Cognitive assessment of their social information processing is required to confirm the difficulties reported by parents and teachers.

Inclusion of a chronic illness control would have allowed to control for a number of nonspecific illness-related variables, which could have been related to social competence; for example, the experience of illness, time off school and the effects of others’ knowledge and style of interaction with individuals who have a chronic illness. The response rate from teachers in the BT group was poor (30%) and comparatively less than other studies that report teacher data (e.g. 57%, [30]), which limits the conclusions from the teacher data in this study. There were also a number of other potential confounding factors that were not measured in this study, such as language ability and specific cognitive skills (e.g. processing speed [39] and executive functioning [40]), which are often impaired in survivors and recognised as important for social communication.

*Conclusions and implications for practice.* The results highlight the importance of routine assessment in clinic settings for social competence and emotional/behavioural difficulties in BT survivors, to promote early identification and ensure that survivors are referred for appropriate services and intervention as part of their multi-disciplinary care package. However, as the results suggest that survivors report less social difficulties than do their parents and teachers, consideration needs to be given to the survivors’ insight into the social difficulties and their motivation for change to ensure their engagement in any intervention.

Use of multiple informants and social competence screening tools, could improve the accuracy and reliability of assessment procedures, and help to identify target areas of intervention for individuals. Due to the social interaction opportunities, challenges and varying provision of interpersonal support in the school environment, schools could have an important role in monitoring social difficulties and supporting interventions for BT survivors. Service user focus groups would also be helpful to ascertain what psycho-social support would be most helpful from the individual and family perspective (e.g., clinic, home or school interventions), to promote social competence across the course of the illness.

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**Conflict of Interest**

None declared. The author completed the research as part of her doctorate in Clinical Psychology at Royal Holloway University of London and has no financial relationship with the institution. The authors have full control of the primary data and the journal has permission to review the data if requested.

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