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CLINICAL STUDY

Disability, body image and sports/physical activity in adult survivors of childhood CNS tumors: population-based outcomes from a cohort study

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Abstract Childhood CNS tumor survivors risk health and functional impairments that threaten normal psychological development and self-perception. This study investigated the extent to which health and functional ability predict adult survivors' body image (BI) and self-confidence regarding sports and physical activity. The study cohort covered 708 eligible $\geq$18 year old CNS tumor survivors, and data from 528 (75 %) were analyzed. Disability was estimated using the Health Utilities Index^{TM} Mark2/3, a multidimensional self-report instrument. Physical self-confidence in terms of BI and sports/physical activity-related self-confidence (SPAS) were assessed using the BI and the Sports/Athletics modules of a standardized self-report assessment scale. In adjusted regression models, global health and functional status (GHFS) predicted BI ($B = 0.94$, 95 % CI 0.69–1.19) and SPAS ($B = 0.79$, 95 % CI 0.55–1.04). Emotion and pain, and to a lesser degree cognition, speech and vision disability, were associated with poorer BI and SPAS. Gender, sub-diagnosis, and time since diagnosis influenced the relationship between health status and physical self-confidence outcomes. Females had poorer GHFS, BI and SPAS than males. Decreased health and functional ability following childhood CNS cancer intrudes on physical self-confidence, with females being at heightened risk for both disability and negative self-confidence. Identified disability and gender-related risk calls for a follow-up plan that integrates treatment of psychological sequelae in lifetime monitoring of childhood CNS tumor survivors to restore and protect self-image and self-confidence, essential mental health correlates. An expanded plan should recognize the need for such services, optimizing life-long quality of survival for CNS tumor survivors.

Keywords Childhood CNS tumors · Adult survivors · Late effects follow-up · Body image · Self-confidence · Sports activities

Introduction

Central nervous system (CNS) tumors constitute the second most common cancer in children, and the most common solid tumor [1]. Increased survival has prompted studies addressing the late adverse effects of illness, treatment, follow-up and intervention needs. These studies confirm that post-treatment morbidity and heightened risk of harmful social consequences are common among brain tumor survivors after otherwise successful tumor treatment [2–4].

Tumor and treatment-related impairments among CNS tumor survivors include neuro-cognitive, emotional, and psychological sequelae [1, 5, 6]. In addition, late effects involve functional and sensory impairments, some of

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which aggravate with time [3, 7]. Childhood CNS tumor survivors demonstrate rates of disability exceeding not only those of the general population, but also of survivors of other childhood malignancies [3, 4, 7]. Prior findings also indicate that childhood cancer survivors in general have an increased risk for psychological sequelae, sometimes due to changes in physical appearance and bodily concerns [6, 8–11], factors that impinge on survivors' perception of themselves [12–17]. BI and physical capability have been found to be related to psychological adjustment and quality of life [14, 18, 19], while physical activity has been found to mitigate treatment-related sequelae and promote quality of life [20]. In the following, the term physical self-confidence (PSC) will be used for the summary concept that covers both patients' body-image (BI) and sports and physical activity-related self-evaluation (SPAS).

Broad and unspecific screening of quality of life, or health-related quality of life, has been common in the evaluation of psychological status in mixed study populations, resulting in a lack of detailed knowledge about psychological late effects and their determinants in subgroups at particular risk. While neurocognitive consequences have been thoroughly addressed in studies, the effects of childhood CNS tumor and treatment-related disability on vital dimensions of psychological development have not been investigated. Self-perception in terms of body image (BI), sports and physical capability has not been addressed in large population-based studies of adult survivors of childhood CNS tumors.

BI and SPAS play an important role in normal psychological development during childhood and adolescence [16, 18, 21]. In childhood cancer, studies of comparable outcomes have primarily examined mixed diagnostic groups, and younger patients. Findings have been divergent, demonstrating poorer, equal, or even superior outcomes to those of comparison groups [6, 9–11, 16, 22], although negatively correlated with physical late effects [17]. Physical activity per se has been found to be associated with health-related quality of life in adolescent mixed-diagnoses survivors [20].

BI and physical capability of survivors can vary depending on type and/or intensity of treatment, localization of tumor [9, 12, 13, 15, 23], and length of time to follow-up [16, 24]. Poorer BI and heightened bodily concerns have thus been confirmed in acute lymphoblastic leukemia survivors who received both cranial radiotherapy (CRT) and chemotherapy, compared with those who received chemotherapy alone [9]. Childhood CNS tumor survivors commonly treated with CRT, known to be particularly associated with neurotoxicity, constitute a risk group regarding BI disturbance and impact on physical activity [14, 18]. However, the extent to which such consequences are transferred through specific tumor and treatment-related health and function impairment has not been investigated in large scale studies.

Against this background, in a nation-wide cohort of adult CNS tumor survivors we investigated the extent to which health and functional status, as indicator of persistent late effects in specified domains, contributes to disturbances in BI and SPAS. An understanding of the impact of specific health/function sequelae on these essential aspects of self-identity and mental health informs us of the need for and kinds of prophylactic and compensatory measures required to reduce the burden of psychological sequelae in these patients.

Methods

Patients and methods

Participants were identified through the Swedish childhood cancer registry covering patients diagnosed with a primary childhood/adolescent malignancy, classified according to the International Classification for Childhood Cancer [25], diagnostically specified and morphologically verified at one of six university hospital pediatric cancer centers [26]. Survivors $\geq$8 years old, diagnosed between 1982 and 2001 before their 19th birthday, and for whom >5 years had elapsed since diagnosis, were eligible.

Assessments

Health and functional status in specific domains was assessed using the 15-item Health Utilities Index^{TM} Mark2/3 (HUI2/3), which provides patients' self-reported outcomes regarding health and functional abilities [27]. The HUI2/3 provides utility scores derived from general population preferences [27–29]. HUI2/3 covers nine single health/function attributes that can be combined into three comprehensive outcomes: *sensation* (vision, hearing, speech), *mobility* (ambulation, dexterity), and *global health* (here termed global health and functional status, GHFS, based on vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain). For an overview of HUI2/3 outcomes, see Supplementary online Fig. 1. Sensation and mobility scores range from 0.00 (most severe impairment) to 1.00 (perfect health). GHFS summary scores range from 0. 00 to 1.00, where 0.00 = death, and 1.00 = perfect health [27], i.e., higher scores indicate less disability.

Dependent psychological outcomes were assessed using the Body Image sub-scale for BI and the Sports/Athletics sub-scale for SPAS, two modules of the standardized multidimensional Self-Esteem Questionnaire (SEQ-42) [30]. Together they comprise ten items appearing as statements on a four-point Likert scale, response alternatives ranging from *strongly agree* to *strongly disagree*, high scores reflecting positive and low scores negative self-confidence. The outcomes are represented by the sub-scale means. A mid-scale cut-off limit (score 2.5) allows for distinguishing between negative and positive PSC [30]. For HUI2/3 structure and PSC-assessment scale items, see online Supplementary Figs. 1 and 2.

A mail-back questionnaire was used for data collection after written informed consent. The study was approved by the Regional Research Ethics Committee.

Analysis

Correlation was used for exploring associations between the primary study variables and background variables considered as potential mediating factors (confounders). Health/function outcomes (HUI2/3 predictors), and BI and SPAS (dependents) were presented with measures of central tendency and dispersion for the entire group, and for males and females separately. Proportions were compared using Fisher's exact test.

The extent to which health/functional status predicted PSC outcomes was first evaluated in univariable linear regression models with sensation, mobility, and GHFS analyzed separately as predictor factors, and BI and SPAS as dependent outcomes. The significance of potential confounders was analyzed in adjusted regression models with the summary GHFS measure as predictor. Non-categorical background variables that were significantly correlated with primary study variables were included in the adjusted analyses. The significance of sub-diagnosis for the relationship between health/functional status and PSC was analyzed using ANOVA and post hoc Bonferroni correction. To specifically examine whether the *impact of* GHFS on BI varied with time passed since diagnosis, an analysis of interaction effect of time from diagnosis and GHFS (ANOVA; time × GHFS) on self-perception outcomes was carried out. An α of 0.05 was applied for statistical significance in other analyses. The SPSS statistical package 20.0 for Windows (SPSS Inc., Chicago, IL) was used for all calculations.

Results

General

Of 5,443 children diagnosed with cancer in Sweden 1982–2001, 1,535 had a CNS tumor. At the time of this study, 449 patients had died. Of the 708 meeting the inclusion criteria, an additional 11 had died since the last update of the register. Of the remaining 697, fully or partly completed questionnaires were returned by 528. Non-responders were similar to responders regarding time passed since diagnosis, age at study invitation, sex, and sub-diagnosis. Three responders with <50 % of completed items in a questionnaire were excluded from analyses, leaving 526–528 patients for calculations, depending on the occurrence of missing responses in individual data sets. For survivor characteristics, see Table 1.

Correlations between the GHFS main predictor, self-confidence outcomes, and the potential confounders are presented in Table 2.

Female survivors had poorer BI and SPAS than males ($p < 0.00001$, Table 3), and nearly half (48 %) had a borderline or negative (score $\leq$2.5) BI, while the corresponding proportion among males was 31 % ($p < 0.0.001$). Regarding SPAS, the proportions of borderline or negative self-confidence was females: 65 %; males: 47 % ($p < 0.0.0001$). Although GHFS was lower in females ($p = 0.043$), the differences in PSC outcomes between sexes remained when controlling for GHFS.

Associations between health/function domains and PSC outcomes are presented in Table 4. Emotion and pain were most strongly associated with the BI and sports/physical activity outcomes, followed by cognition, vision and speech.

Health/function and self- confidence outcomes

Body image

At the entire group level, the compound sensation and GHFS outcomes significantly predicted BI outcomes (sensation $R^2 = 0.02$, 95 % CI 0.25–0.03, $p = 0.0012$; GHFS $R^2 = 0.12$, 95 % CI 0.80–1.30, $p < 0.0001$, Table 5), whereas mobility did not. Both were positively related, i.e. more of indicated impairment predicted poorer BI. GHFS predicted BI in both sexes (males, $p < 0.0001$; females, $p < 0.00001$). Furthermore, sensation predicted BI in males ($p = 0.005$). The most influential single attributes that contributed to the predictive significance of GHFS for BI were emotion, pain, and sensory functions (vision and speech, but not hearing), while motor functioning and ambulation where less influential (Table 4).

Sports and physical activity

In the entire group, sensation (95 % CI 0.13–0.90, $p = 0.009$), mobility (95 % CI 0.01–1.12, $p = 0.047$), and GHFS (95 % CI 0.65–1.15, $p < 0.0001$) significantly predicted SPAS (Table 5). GHFS predicted SPAS in both males and females (males, $p < 0.00001$; females, $p < 0.0001$). In males, an association was found between sensation and SPAS ($p = 0.003$). A non-significant

Table 1 Medical characteristics of the study population

	All survivors m (SD)	Male m (SD)	Female m (SD)	p[a]
Age at follow-up (assessment)	26.29 (4.98)	26.31 (5.13)	26.28 (4.82)	0.906
Age at diagnosis (m, SD)	10.54 (4.42)	10.88 (4.40)	10.17 (4.43)	0.086
Time elapsed from diagnosis	15.71 (5.03)	15.39 (5.10)	16.06 (4.96)	0.145
Diagnosis		Study cohort [% (N)]	Diagnosed with a CNS tumor (%)[b]	
Astrocytoma		46.8 (247)	43.0	
Germ cell—intracranial and intraspinal		4.2 (22)	9.6	
Oligodendroglioma		4.0 (21)	2.4	
Other specified incl. fibrosarcoma and CNS unspecified		12.7 (67)	13.0	
Craniopharyngioma		8.5 (45)	5.4	
Medulloblastoma/PNET		12.9 (68)	18.0	
Ependymoma		8.5 (45)	10.0	
Mixed and unspecified gliomas		2.5 (13)	2.4	

[a] t test for differences between males and females

[b] Proportion of sub-diagnoses among all children diagnosed with a CNS tumor in Sweden between 1984 and 2005 [26]

Table 2 Pearson r correlations between background factors and study variables

	Gender[a] r (N)	Age at diagnosis r (N)	Age at assessment r (N)	Time elapsed from diagnosis r (N)	GHFS[b] r (N)	BI[c] r (N)
Gender[a]	1 (527)					
Age at diagnosis	−0.077 (527)	1 (527)				
Age at assessment	−0.004 (527)	0.438** (527)	1 (527)			
Time elapsed from diagnosis	0.067 (527)	−0.437** (527)	0.608** (527)	1 (527)		
GHFS[b]	−0.125** (515)	0.028 (515)	−0.117** (515)	−0.138** (515)	1 (515)	
BI[c]	−0.212**** (528)	0.055 (528)	−0.109* (528)	−0.160*** (528)	0.346**** (516)	1 (527)
SPAS[d]	−0.202**** (528)	0.007 (528)	−0.130** (528)	−0.141** (528)	0.298**** (516)	0.552**** (527)

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$, **** $p < 0.0001$

[a] Females scored 1, males scored 2

[b] A higher score indicates less impairment/late effects

[c] A higher score indicates a better outcome

[d] Higher score indicates a better outcome

tendency ($p < 0.068$) indicated that mobility was also, to some extent, influential regarding SPAS in males. As with BI, emotion, pain, and sensory functions contributed most to the effect of health/function on SPAS, motor functioning and ambulation being less influential (Table 4).

Adjusted regression

Correlations verified significant associations between gender and the primary study variables (Table 2). Therefore, the two adjusted regression models were applied for the entire group, and for males and females separately. As initial analyses verified that time from diagnosis to assessment and age at diagnosis were both associated with BI and SPAS, and inter-correlated, only time since diagnosis was used in adjusted regressions. Being unrelated to health/function and BI/SPAS, age at assessment was excluded from adjusted analyses. Thus, Model I was adjusted for gender, while Model II was adjusted for gender and time elapsed from diagnosis. In both models, GHFS significantly predicted both BI and SPAS in all separately analyzed groups (males, females, all survivors, $p < 0.0001$ throughout). For details of adjusted regression analyses outcomes, see online Supplementary Table 1.

Table 3 Mean values in entire group and by sex for physical self-confidence outcomes, and health/function predictor factors

	All survivors, $N = 528$ m (SD)	Female, $N = 254$ m (SD)	Male, $N = 274$ m (SD)	t[a]	df	p
Self-evaluation outcomes						
BI	2.79 (0.77)	2.61 (0.78)	2.94 (0.72)	4.977	526	<0.00001
SPAS	2.47 (0.75)	2.31 (0.75)	2.62 (0.73)	4.734	526	<0.00001
Health/function predictors						
Sensation	0.88 (0.17)	0.87 (0.17)	0.89 (0.17)	1.319	518	ns
Mobility	0.97 (0.13)	0.97 (0.12)	0.98 (0.11)	0.488	520	ns
GHFS	0.75 (0.26)	0.75 (0.26)	0.81 (0.24)	2.874	514	0.0043

BI body image; *SPAS* sports and physical activity self-assessment, *GHFS* global health and functional status, *ns* non-significant

[a] t test for differences between male and female survivors

Table 4 Pearson r correlations between single functional domains and BI and SPAS

	BI	p	SPAS	p
Vision	0.137	0.0016	0.117	0.0072
Hearing	0.059	ns	0.013	ns
Speech	0.105	0.0167	0.120	<0.01
Ambulation	0.030	ns	0.095	0.03
Dexterity	0.040	ns	0.109	0.012
Cognition	0.152	0.0004	0.124	0.0047
Emotion	0.361	<0.0001	0.227	<0.0001
Pain	0.300	<0.0001	0.301	<0.0001
Sensation[a]	0.142	0.0012	0.115	0.008
Mobility[b]	0.015	ns	0.087	0.048
GHFS[c]	0.346	<0.0001	0.298	<0.0001

N varied between 516 and 528, depending on variables in analysis and occurrence of missing item responses

[a] Sensation is based on vision, hearing, and speech

[b] Mobility is based on ambulation and dexterity

[c] GHFS is based on vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain

Influence of confounders

In Model I entire group analyses, gender, along with GHFS, predicted BI (B = −0.26, 95 % CI −0.38 to −0.14, $p < 0.0001$), and SPAS (B = −0.25, 95 % CI −0.37 to −0.12, $p = 0.0001$). In Model II, gender predicted both BI (B = −0.25, 95 % CI −0.37 to −0.13, $p < 0.0001$) and PSC (B = −0.24, 95 % CI −0.36 to −0.12, $p = 0.0016$). Similarly, in Model II/entire group analyses, time elapsed from diagnosis predicted BI (B = −0.02, 95 % CI −0.03 to −0.01, $p = 0.0030$) and SPAS (B = −0.02, 95 % CI −0.03 to −0.00, $p = 0.0114$). A main effect of sub-diagnosis on BI/SPAS was found for BI (F = 2.71, df = 7; $p = 0.009$), caused by craniopharyngioma survivors' poorer BI compared to "other specified tumors" survivors.

A marginally significant interaction effect was found for GHFS and time elapsed since diagnosis on SPAS alone (SPAS $F_{516} = 3.34$, $p = 0.057$; BI $F = 1.72_{516}$, ns) Follow-up inspection of data, showed that this was not due to a direct effect of the time factor, but merely due to a variation of the impact of GHFS on SPAS with time. A somewhat stronger impact of GHFS was indicated in patients with shorter time since diagnosis than in those with longer, while no own direct effect of time on SPAS was found.

Discussion

In this population-based cohort of adult childhood CNS-tumor survivors, late effects of tumor and treatment predicted both BI and self-evaluated sports/physical activity (SPAS). On an entire group level, disability (in terms of poorer GHFS and sensation outcomes) predicted poorer BI and SPAS, while mobility outcomes were predictive only of SPAS. Females reported poorer BI and lower SPAS than males. Although GHFS status was worse in females, GHFS was significantly predictive of BI and SPAS for *both* sexes. Sensation was related to BI and SPAS in males only. The most influential functional domains on the studied self-identity-related psychological outcomes were emotion and pain, followed by cognition, vision and speech.

HUI2/3 indications of impairment in motor functioning and ambulation appeared to be less influential, contrary to what might be expected, This suggests that self-perception outcomes are related to survivors' sensory disabilities and psychological factors (cognition and emotion), rather than restrictions in motor capability.

Prior studies show that compromised health and functional impairment are characteristics of CNS tumor patients when compared both with the general population and with survivors of other pediatric malignancies. However, the long-term consequences of disability in specific domains of functioning regarding physical self-perception have not

Table 5 Regression analyses with functional domains and GHFS as predictors, and BI and SPAS as dependent outcomes

Predictor	All[a]				Male[b]				Female[c]			
	R^2	B	t	*p*	R^2	B	t	*p*	R^2	B	t	*p*
BI												
Sensation	0.02	0.64	3.26	0.0012	0.03	0.72	2.84	0.005	0.01	0.44	1.49	ns
Mobility	0.00	0.10	0.34	ns	0.01	0.50	1.28	ns	0.00	−0.33	−0.81	ns
GHFS	0.12	1.05	8.35	<0.00001	0.10	0.95	5.54	<0.0001	0.11	1.03	5.59	<0.00001
Sports and physical activity												
Sensation	0.01	0.51	2.63	0.009	0.03	0.77	3.02	0.003	0.00	0.11	0.39	ns
Mobility	0.01	0.56	1.99	0.047	0.01	0.72	1.83	ns	0.00	0.37	0.93	ns
GHFS	0.09	0.90	7.08	<0.0001	0.08	0.83	4.73	<0.0001	0.08	0.84	4.63	<0.00005

[a] *N* varied depending on analysis between 516, and 528

[b] *N* (sensation) = 272; (mobility) = 269; (global health/function status) = 269

[c] *N* (sensation) = 248; (mobility) = 253; (global health/function status) = 247

been studied. The findings from this study show that brain tumor survivors' comparatively common persistent sequelae, which often affect physical appearance and hamper physical performance [10, 11, 15], do transfer into psychological key domains of self-perception and identity. Our findings thus indicate that the impact of illness, treatment and sequelae is pronounced and affects self-perception more regularly in CNS tumor survivors than in survivors of other pediatric malignancies, where, for example, BI has been found to remain intact [10].

The association between indicated disability and physical self-perception was seen in these survivors whose illness and treatment took place many years earlier, a finding which supports other findings indicating that concerns about BI, physical appearance and functioning emerge and even increase with time after completed treatment [18]. Our data also suggested that both health/functional status and psychological self-perception become poorer with increasing age. Pendley et al. [16], in a study of mixed diagnoses survivors, found indications that BI concerns and related social anxiety may not develop until several years after treatment termination.

Some particularly notable findings concerned the way in which physical self-identity outcomes, and the influence of health/function on these outcomes varied with gender. While female CNS tumor survivors are known to present more pronounced late effects [7], here they also displayed poorer BI and sports/physical activity confidence than males. Borderline or negative PSC in terms of BI and SPAS was found in nearly every other female survivor, which was also significantly more than among males. In this respect, it can be concluded that in the long-term perspective, our adult female survivors who were treated and followed up during the actual era in question, and followed up according to past and current clinical and psychosocial surveillance routines, are still at heightened risk for psychological self-identity disturbance. Compared to the medical and neuro-behavioral CNS tumor-related late effects that cannot be fully compensated for by remedial measures, the late effects in self-perception, self–confidence and identity constitute well-suited targets for treatment interventions known from, and practiced in, other areas of psychological treatment and promotion of mental health [31–34]. Our findings, together with repeated feedback from study participants indicate that a formalized follow-up plan should be extended to cover adulthood for these patients, in order to reach those with persistent or late occurring surveillance needs, and protect mental health and optimize quality of long-term survival for all. Follow-up could be effectivized for survivors now left with unmet health care needs [35] and insufficient psychosocial observation.

Degree of health and functional sequelae in this study appeared as determinants of vital elements of self-identity in adult survivors of childhood CNS tumors. The findings indicate a need for further study of how disturbances in BI and self-confidence impinge on mental health in this patient group. Forthcoming research efforts should be expanded to investigate the extent to which unavoidable residual morbidity in survivors instigates disturbances in the normal course of other aspects of psychological development as well.

In interpreting the findings, it should be considered that the main assessments were carried out using self-report assessment, which is subject to the general limitations of patient-reported data. Outcomes may have been influenced by gender-related differences in response style, or by response shift bias; the latter referring to a shift towards a state of greater acceptance in a person's internal standards, values, and conceptualization of the quality of life that can take place in patients with chronic illness or disability [36, 37].

Conclusions

Health status and functional ability predict BI and self-confidence regarding physical capability in adult CNS tumor survivors. Domains of affected health and function act together and predict variation in these outcomes, crucially associated with self-identity and mental health. Female survivors present the poorest outcomes, both regarding health/function and physical self-confidence, but health/function status molds self-confidence in both sexes. The study identifies targets for prophylactic and compensatory remedial measures for protection against psychological sequelae, and for the improvement of surveillance of childhood CNS tumor survivors. In a coordinated approach, integrated medical and psychological rehabilitation should address health- and functional impairments and avoidable adverse psychological consequences, combined with lifetime follow-up.

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Conflict of interest The authors declare that there are no conflict of interests.

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