Body image in adolescent survivors of childhood cancer: the role of chronic health conditions

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Abstract

Background: Cancer diagnosis and its treatment may impair the long-term body image of childhood cancer survivors. This may be particularly relevant in adolescence, a critical period of psycho-social development. We compared the body image between adolescent cancer survivors and their siblings, and determined whether survivors' body image is associated with socio-demographic characteristics, clinical characteristics, and health conditions. Procedure: As part of the nationwide Swiss Childhood Cancer Survivor Study, we sent questionnaires to adolescents (aged 16-19 years), who survived >5 years after having been diagnosed with childhood cancer between 1976-2010. Siblings received the same questionnaire. We assessed the level of agreement with three body image statements referring to body satisfaction and preferences for changes. Chronic health conditions were classified into cardiovascular, pulmonary, endocrine, musculoskeletal, renal/ digestive, neurological, and hearing or vision impairment. We used ordered logistic regression models to identify determinants of a more negative body image. Results: Our study included 504 survivors (48% female) with a median age at study of 17.7 years (IQR 16.8-18.6) and 136 siblings. Survivors and siblings reported overall comparable levels of the three body image statements (all p>0.05). Female survivors (all ORs [?] 1.7), survivors treated with haematopoietic stem cell transplantation (all ORs [?] 2.2), and survivors with [?] 2 chronic health conditions (all ORs [?] 1.4) reported a more negative body image. This was particularly pronounced for survivors suffering from musculoskeletal or endocrine conditions. Conclusion: Clinicians should address body image concerns in adolescent survivors with chronic conditions and offer psycho-social support if necessary.

Introduction

A cancer diagnosis during childhood and its intensive treatment requiring frequent hospitalizations and invasive procedures raises a broad range of medical and psycho-social challenges for the affected children.[1] Despite steadily increasing survival rates, reaching 85% in Switzerland,[2] childhood cancer survivors have a lifelong increased risk of chronic health conditions.[3,4]The treatment's immediate impact on the body, visible and invisible late consequences such as scars, amputations or endocrine problems such as growth hormone deficiency may interfere with survivors' psycho-sexual development and body image.[5-7] Growth hormone deficiency is a common consequence of childhood cancer treatment and has been previously shown to impair linear growth, reduce cardiac muscle mass, and increase fat mass.[8] The cancer experience may further disrupt social interactions with peers and survivors may perceive their bodies as something that has failed them or as a source of pain.[9] A healthy body image is of particular importance during adolescence which is a critical developmental period characterized by many challenges such as puberty, establishing autonomy, first partner relationships, and realization of own sexuality.[10-12]

Understanding the impact of childhood cancer on the body image of adolescent survivors is critical to guide adequate support strategies and to mitigate adverse consequences on survivors' future quality of life and psycho-social well-being.[13,14]Qualitative studies suggest negative effects of childhood cancer on survivors' body image.[15-18] However, a systematic review from 2009 concluded that there is no consistent evidence regarding differences in body image between children and adolescents with cancer and healthy controls.[19] A recent study from Sweden indicated higher body image disturbance in adult women who survived childhood cancer compared to the cancer-free women[20] while another study from the Netherlands found no differences.[9] However, evidence from studies including adolescent childhood cancer survivors is sparse and it remains unclear how chronic health conditions affect the body image of long-term survivors. In this study, we therefore aimed to compare the body image between adolescent cancer survivors and their siblings and to determine whether survivors' body image is associated with socio-demographic characteristics, clinical characteristics, and chronic health conditions.

Methods

Design, study population and research setting

The Swiss Childhood Cancer Survivor Study (SCCSS) is a nationwide follow-up study of all patients registered in the Swiss Childhood Cancer Registry (SCCR), who were diagnosed with cancer between 1976 and 2010 before the age of 21 years, and who survived at least 5 years after diagnosis.[21] The SCCR centrally registers all children and adolescents, who are diagnosed with leukaemia, lymphoma, central nervous system (CNS) tumours, malignant solid tumours, or Langerhans cell histiocytosis in Switzerland.[22,23]As part of the SCCSS, we sent questionnaires to adolescent survivors of childhood cancer aged 16-19 years at study between 2007 and 2017. The SCCSS questionnaires were developed based on the questionnaires used in North American and British childhood cancer survivor studies to increase international comparability.[24,25]We added questions on socio-economic characteristics adapted to the Swiss context.[26,27]We asked survivors for consent to contact their siblings as comparison group. Adolescent siblings of the same age range (16-19 years) received the same questionnaire between 2009 and 2012 without cancer-related questions. Ethical approval of the SCCR and the SCCSS was granted by the Ethics Committee of the Canton of Bern (166/2014; 2021-01462).

Outcome measures – body image

We assessed the body image of survivors and siblings with three statements in the questionnaire: i) *I am satisfied with my body image* , ii) *I would like to change a few things regarding my body* , and iii) *I would like to change many things regarding my body* . These questions have been previously used in healthy adolescents in Switzerland as part of the Swiss multicentre adolescent survey on health in 2002 (SMASH-2002).[28]Survivors and siblings were asked to indicate their level of agreement with these statements on a 4-point Likert scale (0=completely agree; 1=slightly agree; 2=slightly disagree; 3=completely disagree). For analysis purposes we reverse coded statements ii) and iii) with higher scores indicating a more negative body image.

Socio-demographic characteristics

For survivors and siblings, we assessed the following socio-demographic characteristics in the questionnaire: age at study (16-17 years; 18 years; 19 years), sex, language region in Switzerland (German; French or Italian), migration background, and whether they currently have a boyfriend or girlfriend (no; yes). We considered survivors as having a migration background if they were not living in Switzerland since birth, were not Swiss citizens since birth, or have another nationality than or in addition to the Swiss nationality.

Clinical characteristics and chronic health conditions

We obtained the following clinical characteristics from the SCCR: age at diagnosis (<5 years; 5-10 years; >10 years), cancer diagnosis according to the International Classification of Childhood Cancer - Third edition (ICCC-3)[29], treatment, time since diagnosis (5-10 years; 10-15 years; >15 years), and history of relapse (no; yes). For analyses, cancer diagnoses were categorized into leukaemia (ICCC-3 Group I), lymphoma (II), CNS tumour (III), bone tumour and soft tissue sarcoma (VIII, IX), and other tumours (IV, V, VI, VII, X, XI, XII, and Langerhans cell histiocytosis). Treatment modalities were coded hierarchically into surgery only, chemotherapy (may have had surgery), radiotherapy (may have had surgery or chemotherapy), and haematopoietic stem cell transplantation (HSCT; may have had surgery, chemotherapy, or radiotherapy).

In the questionnaire we collected information on chronic health conditions involving the cardiovascular, pulmonary, and endocrine system, hearing and vision problems, and musculoskeletal, renal or digestive, and neurological conditions. Chronic health conditions were asked using questions from the North American[24] and British[25] Childhood Cancer Survivor Studies. Survivors had to indicate whether they suffer from symptoms/ diseases involving the respective body systems. Survivors were classified as having the chronic health condition if at least one of the corresponding symptoms/ diseases was reported. If information on symptoms/ diseases was missing, we assumed the condition is not present or at least not serious, as done previously.[30] We then created a sum score based on the number of body systems affected by chronic health conditions for each survivor.

Statistical analysis

We used descriptive statistics to describe the study population and chi-squared tests to compare clinical characteristics between participating and non-participating survivors. To increase the comparability between survivors and siblings, we standardized siblings for age at study and sex according to the distribution in survivors as previously done.[31-33]We used multivariable logistic regression with being a sibling as outcome to calculate appropriate weights. The weight for survivors was set to 1 and all subsequent analyses were based on weighted siblings.

First, we used chi-squared tests to compare the level of agreement with the three body image statements between survivors and weighted siblings. We applied ordered logistic regression to identify potential differences across ordered categories. Among survivors, we then fitted ordered logistic regression models to identify associations between the level of agreement with the three body image statements and socio-demographic characteristics, clinical characteristics, and chronic health conditions. Separate models were created for each body image statement. We *a priori* decided to adjust each model for the potential confounding factors age at study and sex based on previous literature.[34] In addition, we separately analysed the association between body image and growth hormone deficiency due to its relatively high prevalence and direct impact on the body.[8] All analyses were performed using Stata version 15.1 (StataCorp. 2017. *Stata Statistical Software: Release 15* . College Station, TX: StataCorp LLC).

Results

Of 882 eligible survivors aged 16-19 years, 794 received the questionnaire (**Figure 1**). Of those, 543 completed the questionnaire (response rate 68%). We excluded 39 (5%) survivors with missing information on body image and finally included 504 (64%) in the analysis. The final sibling population consisted of 136 participants. Most survivors and siblings were from a German speaking region and did not report a migration background (**Table 1**). Thirty percent of survivors and siblings reported that they currently have a boyfriend or girlfriend. Among survivors, median age at diagnosis was 5.8 years (interquartile range [IQR] 2.6-9.9), median time since diagnosis 11.6 years (IQR 8.2-14.8), and median age at study 17.7 years (IQR 16.8-18.6). The most frequent cancer diagnoses were leukaemia (32%) and CNS tumours (17%). Clinical

characteristics were similar between participating and non-participating survivors (**Supplementary table S1**).

Chronic health conditions were reported by 354 (70%) survivors with 141 (28%) reporting 1 condition and 213 (42%) [?] 2 conditions. Neurological (33%), renal and digestive (23%), and musculoskeletal conditions (23%) were most frequently reported (**Table 2**). The most commonly reported symptoms within these conditions were balance disorders (15%), chronic constipation or diarrhoea (9%), and prolonged pain in bones or joints (9%). Growth hormone deficiency was reported by 49 (10%) of survivors.

Body image in adolescent childhood cancer survivors and their siblings

Survivors and siblings reported overall comparable levels of body image (**Figure 2;** all p from chi-squared tests and ordered logistic regression >0.05). Few survivors (4.6%) and siblings (2.9%) completely disagreed with the statement *I am satisfied with my body image* . Slightly more survivors than siblings completely agreed with the statements *I would like to change a few things regarding my body* (28.9% vs. 24.0%) and *I would like to change many things regarding my body* (7.6% vs. 2.5%).

Determinants of a more negative body image in survivors

In terms of socio-demographic determinants, we found that female survivors were more likely to have a negative body image compared to male survivors (**Table 3**). This was evident for all three body image statements (all ORs [?] 1.7). After adjustment for age at study and sex, we further found that survivors from French or Italian-speaking Switzerland (OR=1.6, 95%-CI: 1.1-2.3) and those with a migration background (OR=1.5, 95%-CI: 1.0-2.1) more often would like to change many things regarding their bodies. We identified cancer treatment as the most important clinical determinant. Compared to surgery only, survivors that received HSCT were more likely to have a negative body image. This was observed for all three body image statements (all ORs [?] 2.2). CNS tumour survivors were less often satisfied with their body image compared to leukaemia survivors (OR=1.6, 95%-CI: 1.0-2.7).

Survivors with [?] 2 chronic health conditions were more likely to have a negative body image compared to survivors without chronic health conditions (**Table 4**). This was observed for all three body image statements (all ORs [?] 1.5). Survivors suffering from musculoskeletal and endocrine conditions consistently reported a more negative body image compared to survivors without such conditions. A separate analysis of growth hormone deficiency revealed particularly pronounced associations. Survivors with growth hormone deficiency were less often satisfied with their body image (OR=3.4, 95%-CI: 1.9-6.0) and more often would like to change few (OR=2.2, 95%-CI: 1.3-3.9) or many things regarding their bodies (OR=2.3, 95%-CI: 1.3-4.1). Survivors with renal and digestive conditions more often would like to change few things regarding their bodies (OR=1.6, 95%-CI: 1.1-2.4). Survivors with neurological conditions were less often satisfied with their body image (OR=1.4, 95%-CI: 1.0-2.0). These associations remained virtually unchanged after adjustment for age at study and sex.

Discussion

This nationwide population-based study showed that the body image of adolescent survivors of childhood cancer was overall comparable to that of their healthy siblings. Female survivors, survivors treated with haematopoietic stem cell transplantation, and those with a higher burden of chronic health conditions had a more negative body image. This was particularly pronounced for survivors suffering from musculoskeletal or endocrine conditions.

This is one of few population-based studies investigating the body image of adolescent survivors of childhood cancer. Body image is a complex psychological construct including body-related self-perceptions and self-attitudes such as beliefs, feelings, and behaviours.[19] Although cancer and treatment-related changes

in appearance and the high prevalence of physical late consequences after successful treatment would be expected to adversely interfere with survivors' body image,[4] our study showed that the body image of adolescent survivors was overall comparable to that of their healthy siblings. This is in line with a study from the Netherlands including adult survivors[9] and a previous systematic review including also studies with patients on active treatment.[19]Evidence from other studies including adolescent long-term childhood cancer survivors is limited by lack of population-based sampling approaches and restrictions to certain cancer types.[35-37]

Similar to a recent study from Sweden including adult childhood cancer survivors[20] and findings in healthy adolescents in the general population of Switzerland,[28] we found that female survivors were more likely to have a more negative body image than male survivors. This confirms the extensive literature on sex differences in body image indicating that females are more likely to negatively self-evaluate their appearance and report higher levels of body image dissatisfaction than men.[34] Societal pressures and attractive body image expectations may be particularly pronounced in Western cultures.[14] Our findings indicated that survivors from French or Italian-speaking Switzerland were more likely to report a negative body image than survivors from German-speaking parts. However, we are not aware of other studies reporting on within country differences in body image and hypothesize that this may be explained by differential reporting behaviour rather than underlying differences in body image.

We further found survivors treated with HSCT were more likely to have a negative body image. HSCT is often used for high-risk disease or as second-line treatment.[38] Physical side effects and toxicity may occur at various stages of HSCT treatment from intensive pre-transplantation therapy, conditioning regimens, chronic immunosuppression, and acute or chronic graft-versus-host disease (GvHD).[39]Transplanted survivors may also experience unique late consequences such as delayed immune reconstitution leading to recurrent infections and chronic dermatologic conditions as a result of chronic GvHD of the skin that may adversely interfere with their body image in the long-term.[39] However, our study included only 30 survivors treated with HSCT and more research is needed to elucidate the underlying mechanisms.

Chronic health conditions were an important determinant of a more negative body image in our study. Even though we included also mild chronic conditions, we found that the more conditions adolescent survivors experienced, the higher was their risk to report a negative body image. This was particularly pronounced for survivors suffering from musculoskeletal or endocrine conditions. Musculoskeletal conditions such as prolonged pain in bones or joints, scoliosis, or reduced flexibility of joints are visible disabilities and likely to interfere with survivors' everyday life compared to non-visible conditions such as cardiovascular or pulmonary diseases. Indeed, qualitative research indicated that childhood cancer survivors felt negatively about their bodies because of the visible effects of the treatment such as hair loss, weight gain, scarring, or amputations.[9,15-18]The most common endocrine conditions in our study included growth hormone deficiency that may cause short stature, and hypo- and hyperthyroidism leading to hormonal imbalance.[40] Such conditions may directly interfere with survivors' body image and psycho-sexual development particularly during adolescence. Indeed, we found a strong association between growth hormone deficiency and a more negative body image. Treatment with recombinant human growth hormones significantly improves height in children with growth hormone deficiency, however, affected children may still not achieve their genetic potential.[40]Endocrine problems and hormonal imbalances may further interfere with pubertal development. Reduced breast development may to some extent also explain the more negative body image of female survivors compared to male survivors. Collectively, our findings highlight that health care professionals should be aware of the risk of body image concerns in survivors with a high burden of chronic health conditions and therefore address this problem during follow-up care.[41] Additional support and counselling by an interdisciplinary team involving psychologists may help affected survivors to reduce body image concerns.

This is of particular importance as an adverse body image has been previously shown to be associated with psychological distress[14] and sexual dysfunction[13] in childhood cancer survivors. In turn, this may affect survivors' involvement in intimate relationship and family planning and their quality of life in the long-term.[9] While somatic health conditions after childhood cancer are usually well cared for during long-term follow-up care, this may be less standardized for aspects related to mental health such as body image

concerns.[42] In the literature, most body image interventions such as cognitive behavioural therapy, education-based intervention, strength training, and physical exercise have been implemented among survivors of breast cancer and it remains unclear whether such approaches would be efficacious in the childhood cancer survivor population.[14] A promising approach is the recently established Fex-Can Childhood project that includes an interventional approach to advance knowledge in the areas of sexual function and fertility-related distress after childhood cancer including body image as a secondary outcome.[43] If proven efficacious and successfully implemented in survivorship care, such an approach could be particularly beneficial for adolescent survivors with body image concerns and may contribute to mitigate adverse long-term consequences.

A limitation of our study is the relatively small number of siblings. Sibling comparisons are valuable as they offer a possibility to control for possible confounders such as socio-economic background[31] and we further maximized comparability by standardizing for age at study and sex. However, our study may have lacked the statistical power to detect small differences between groups. Another limitation may be reporting bias due to social desirability.[44]Survivors may have reported more favourable outcomes and our study therefore may have underestimated the implications of the cancer diagnosis and related chronic health conditions on survivors' body image. However, this may to some extent also apply to sibling comparisons. Finally, agreement with the statement *I would like to change a few things regarding my body* should not necessarily be interpreted as an adverse outcome but should be seen in light of personal choices such as the wish to build up muscles for example. A strength of our study is the nationwide and population-based sampling approach and the high response rate that supports the representativeness of our study population. We have previously shown that non-response bias may only play a minor role in Swiss childhood cancer survivor studies.[45] In our study, we cover all childhood cancer types and treatment periods from 1976 to 2010. Another strength refers to the use of high quality clinical information based on medical records from the SCCR and the assessment of chronic health conditions based on standardized questions used in other childhood cancer survivor studies.[24,25]

In conclusion, it is encouraging that the body image of adolescent childhood cancer survivors was comparable to healthy siblings. However, a subgroup of survivors with a high burden of chronic health conditions might develop a negative body image during adolescence. These survivors could benefit if health care professionals addressed such concerns in a standardized way during follow-up care and offered psycho-social support.

Conflict of interest statement

No conflicts of interest to declare.

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Data availability statement

The data that support the information of this manuscript were accessed on secured servers of the Institute of Social and Preventive Medicine at the University of Bern. Individual-level sensitive data can only be made available for researchers who fulfil the respective legal requirements. All data requests should be communicated to the corresponding author.

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Figure legends

Figure 1. Flow chart of the study population

Figure 2. Comparison of level of agreement with body image statements between survivors and weighted siblings

*Calculated on weighted analysis (weights on age at study and sex according to the distribution in survivors).

Supplementary material

Supplementary table S1. Clinical characteristics of participating and non-participating survivors in the Swiss Childhood Cancer Survivor Study (SCCSS)

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Table1_BodyImage_PBC.docx available at https://authorea.com/users/484622/articles/570325-body-image-in-adolescent-survivors-of-childhood-cancer-the-role-of-chronic-health-conditions

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