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ORIGINAL ARTICLE

Psychosexual development, sexual functioning and sexual satisfaction in long-term childhood cancer survivors: DCCSS-LATER 2 sexuality substudy

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Abstract

Objectives: Childhood cancer may negatively impact childhood cancer survivors' (CCS) sexuality. However, this is an understudied research area. We aimed to describe the psychosexual development, sexual functioning and sexual satisfaction of CCS, and identify determinants for these outcomes. Secondarily, we compared the outcomes of a subsample of emerging adult CCS to the Dutch general population.

Methods: From the Dutch Childhood Cancer Survivor Study LATER cohort (diagnosed 1963–2001), 1912 CCS (18–71 years, 50.8% male) completed questions on sexuality, psychosocial development, body perception, mental and physical health. Multivariable linear regressions were used to identify determinants. Sexuality of CCS age 18–24 (N = 243) was compared to same-aged references using binomial tests and t-tests.

Results: One third of all CCS reported hindered sexuality due to childhood cancer, with insecure body the most often reported reason (44.8%). Older age at study, lower education, surviving central nervous system cancer, poorer mental health and negative body perception were identified as determinants for later sexual debut, worse sexual functioning and/or sexual satisfaction. CCS age 18–24 showed significantly less experience with kissing (p = 0.014), petting under clothes (p = 0.002), oral (p = 0.016) and anal sex (p = 0.032) when compared to references.

Eline van Dulmen-den Broeder and Martha Grootenhuis shared last authorship.

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No significant differences with references were found for sexual functioning and sexual satisfaction, neither among female CCS nor male CCS age 18–24.

Conclusions: Emerging adult CCS reported less experience with psychosexual development, but similar sexual functioning and sexual satisfaction compared to references. We identified determinants for sexuality, which could be integrated in clinical interventions for CCS at risk for reduced sexuality.

KEYWORDS
childhood cancer, pediatric oncology, psychosexual development, sexual functioning, sexual satisfaction

1 | BACKGROUND

Positive sexual health is fundamental for a person's quality of life (QoL) and well-being,[1] but less is known about the late effects of childhood cancer on different aspects of survivors' sexuality. The World Health Organization defines sexuality as "[…] expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships […]."[2] Mental and physical health have a large influence on various aspects of sexuality[1,3] and because the health of survivors of childhood cancer (CCS) may be affected by their former disease,[4] it is essential to question how and to what extent childhood cancer and its treatment might influence survivors' sexual lives.

Some studies have focused on the impact childhood cancer has on survivors' psychosexual development as part of their sexuality. CCS reported delays in reaching sexual milestones when compared to references, with CCS describing postponed debut of sexual intercourse, lower numbers of sexual partners and less experience with relationships or sexual intimacy.[5–11] Some factors were shown to be associated with these delays. Patients treated for cancer during their teenage years described postponed achievement of various milestones, like dating, masturbation or touching under clothes.[6] In addition, CCS who were exposed to higher levels of treatment toxicity or those who had central nervous system (CNS) cancer were less sexually experienced and less likely to be in a relationship at the time of study.[8–10,12] Moreover, childhood cancer might have an influence on survivors' social development. CCS seem to be less autonomous, reach later or less social milestones than their healthy peers and report fewer friends, more social isolation and less social activities,[7,13–15] with one study reporting these delays especially in CNS survivors.[12] Social development plays an important role in sexuality[7] and the social limitations described by CCS might lead to less opportunities to explore their sexuality and more delays compared to healthy peers.

Examining sexual functioning and sexual satisfaction as further aspects of sexuality, some studies described higher sexual dysfunction[5,16–19] and lower sexual satisfaction[5,6,20] in CCS compared to references. More problems with sexual functioning were reported by female CCS, CCS who were older at study, those who were older when diagnosed with cancer and CCS of CNS cancer.[5,8,17,18,21] Furthermore, previous studies have reported worse sexual functioning being associated with survivors' distress level, lower health-related QoL, health problems, fatigue, infertility, negative perception of own body and scarring.[6,16–19,21,22] Similar factors were shown to be associated with decreased sexual satisfaction, that is, having no partner, surviving CNS cancer, but also experiencing fertility problems and body dissatisfaction.[5,6,16,23]

Considering the importance of a healthy sexual life and the complexity of surviving childhood cancer, the first aim of this study was to describe the psychosexual development, sexual functioning and sexual satisfaction of CCS, and identify determinants for these outcomes. The selection of determinants was based on the literature and consisted of sociodemographic information, cancer-related factors and current level of functioning. The second aim of the paper was to compare the psychosexual development, sexual functioning and sexual satisfaction of a subsample of emerging adult CCS to the available data on the Dutch general population.

2 | METHODS

2.1 | Study design

The current paper relies on data collected within the Dutch Childhood Cancer Survivor Study LATER part 2 (DCCSS-LATER 2).[24,25] The DCCSS-LATER 2 is a nationwide cross-sectional cohort study which integrates 16 substudies in CCS diagnosed between 1963 and 2001 in one of the seven former pediatric oncology centers in the Netherlands. The present report is based on the sexuality substudy and includes in addition data on psychosocial development, physical and mental health from the psycho-oncology substudy.[12] The substudies were approved by the ethic commission of Amsterdam University Medical Centers, location AMC, under numbers MEC2013_357 and MEC2013_115, respectively.

2.2 | Participants

Eligible participants received a diagnosis of malignancy covered by the ICCC3 between 1963 and 2002 and were diagnosed before the

age of 18. Data collection took place between 2016 and 2020 and all participants gave written informed consent.

2.3 | Measurements

2.3.1 | Outcomes

For the assessment of the outcomes psychosexual development, sexual functioning and sexual satisfaction, CCS filled out the same items (Table S1) that were applied to the references in the general population.[26] Adult CCS of all ages completed these questions, but reference data was available only for 18–24 years old Dutch peers, therefore the comparison to the general population was done only with CCS age 18–24.

Psychosexual development was assessed in two ways. First, we asked participants if they achieved a list of sexual milestones and if so, at what age. The included milestones were: sexual arousal, sexual fantasies, masturbation, being in love, dating, stable relationship, kissing, petting under clothes, naked petting, intercourse, oral and anal sex. Second, age at sexual debut was used as an additional outcome for psychosexual development and it was defined as the youngest age of first vaginal, oral or anal sex.

Sexual functioning was operationalized by applying 5-Point Likert scale (1–5) questions about problems with sexual desire, sexual arousal, the ability to achieve orgasm, reaching orgasm too early and experiencing pain during intercourse. The individual items were dichotomized into "regularly/often/always" versus "never/sometimes." A mean scale score was computed from all items except early orgasm (Cronbach's $\alpha = 0.78$).

For *sexual satisfaction*, 5-Point Likert scale (1–5) questions were used to evaluate satisfaction with frequency of sex, contact with sexual partner(s), pleasantness of having sex and sex life in general. The individual items were dichotomized in "very satisfied/satisfied" versus "neutral/dissatisfied/very dissatisfied." A mean scale score was calculated which had a high reliability (Cronbach's $\alpha = 0.89$).

Finally, an item evaluating the *impact of childhood cancer* was applied: "Do you find that you are hindered in your sexual life because you had childhood cancer in the past?". If they answered yes, CCS could choose from a predefined list of reasons for their hindered sexuality.

2.3.2 | Determinants

Sociodemographic information was collected through questions regarding participants' age, gender identity, educational level, relationship status and having biological children.

Cancer-related factors were retrieved from the DCCSS-LATER registry and consisted of age at diagnosis, cancer type and abdominopelvic radiotherapy.

Survivors' *psychosocial development* was assessed retrospectively by using the Course of Life Questionnaire (CoLQ).[7,12] Two subscales of the CoLQ were included in the analysis, that is, social development (Cronbach's $\alpha = 0.76$) and autonomy development (Cronbach's $\alpha = 0.54$).

Physical health was assessed with four subscales of the SF-36 Health Survey, namely physical functioning, bodily pain, vitality and general health (Cronbach's $\alpha = 0.85$; 0.91).[27] For *mental health*, scale scores of depression and anxiety from the Hospital Anxiety and Depression Scale were included (Cronbach's $\alpha = 0.81$; 0.83).[28]

Body perception was evaluated using six items from de Graaf[26] about satisfaction with own appearance on a 5-Point Likert Scale (1–5) with a satisfactory scale score reliability (Cronbach's $\alpha = 0.70$).

2.4 | Statistical analysis

Differences between participants and non-participants were assessed with chi-square tests and Cramer's V's. The 50% median age for milestones, proportions of problems with sexual functioning and proportions of sexual satisfaction were described for all items for the total group, and by gender and age.

Multivariable linear regression analysis was conducted on the total CCS sample (age 18–71) to identify determinants for psychosexual development, sexual functioning and sexual satisfaction. One model was calculated for psychosexual development using the age at sexual debut as the dependent variable and including the following factors as determinants: sociodemographic factors (gender, age), current functioning (education), cancer-related factors (age at diagnosis, CNS cancer, abdominopelvic radiotherapy) and psychosocial development (CoLQ-autonomy, CoLQ-social). Two multivariable linear models were run for both the scale scores for sexual functioning and sexual satisfaction. The first model (A) included as determinants: sociodemographic factors (gender, age), cancer-related factors (age at diagnosis, CNS cancer, abdominopelvic radiotherapy), and age at sexual debut. The second model (B) included in addition a block on current functioning (education, having children, being in a relationship, mental health, physical health, body perception). For dichotomous independent variables, standardized regression coefficients up to 0.2 were considered small, while regression coefficients 0.5 and 0.8 were considered medium and large. For continuous independent variables, standardized regression coefficients of 0.1, 0.3, 0.5 were considered small, medium and large, respectively.[29] *p*-values smaller than 0.05 were considered statistically significant.

For the comparison with the Dutch general population, we used data presented in national reports on representative samples of young people in the Netherlands.[26,30] Psychosexual development was compared with data of emerging adults (age 18–24) published in 2017 ($N = 13{,}408$),[30] while sexual functioning and sexual satisfaction with data of emerging adults (age 18–24) from 2012 ($N = 4020$).[26] Reference data was weighted for the distribution of age and gender in the CCS sample. For psychosexual development, the median age when 50% of CCS reached a milestone was calculated and is further referred to as 50% median age. Furthermore, proportions of CCS

reaching sexual milestones were compared to references[30] using binomial tests. Due to differences in item-wording, comparison with references on proportions of reached sexual milestones was possible only for the following milestones: being in love, masturbation, dating, kissing, petting under clothes, intercourse, oral and anal sex. For sexual functioning, proportions of CCS experiencing at least one problem with sexual functioning regularly, often or always were compared to references with binomial tests.[26] For sexual satisfaction, mean scale scores were compared to references using one-sample *t*-tests.[26]

For sexual functioning and sexual satisfaction, comparison with references and identification of determinants were conducted only on participants with sexual experience (91.6%, *N* = 1752). In concordance with the definition of de Graaf,[26] participants were considered to be sexually experienced when achieved at least one of the following sexual milestones: petting under clothes, naked petting, intercourse, oral or anal sex.

3 | RESULTS

3.1 | Participants

From the total childhood cancer survivor LATER cohort (*N* = 6165, *N* = 5455 alive), 4643 adult CCS were invited for LATER 2. The 2485 adult CCS participating in the LATER 2 cohort study were eligible for the current sexuality substudy, of whom 1912 took part; 50.8% were male (Table 1). Significant differences between participants and non-participants were found for gender, CNS cancer and treatment type, with fewer males, fewer CNS cancer survivors and more radio- and chemotherapy among participants.

3.2 | Psychosexual development

The 50% median age at debut in the total CCS sample (age 18–71) was: 15 years for sexual arousal, sexual fantasies and masturbation; 16 for first kiss and petting under clothes; 17 for dating; 18 for relationship, naked petting, intercourse and oral sex (Table S2). For additional descriptive information see Tables S3–S5.

3.3 | Sexual functioning and sexual satisfaction

From the total CCS sample, 19.9% described problems with sexual desire, 14.3% with sexual arousal, 16.4% with achieving orgasm, 13.8% with reaching orgasm too early and 7.3% experiencing pain during sex. Overall, 41.4% reported having at least one problem with sexual functioning regularly, often or always (Table S6). Regarding sexual satisfaction, large proportions of CCS reported to be satisfied: 55.6% with their frequency of sex, 81.6% with contact with sexual partner(s), 80.9% with pleasantness of sex and 61.4% with sex life in general (Table S7).

3.4 | Impact of childhood cancer

Among all CCS, 31.1% (*N* = 569) found that their sex life was hindered to at least some extent due to their former illness, of whom 44.8% identified body insecurity as the main reason, 27.4% difficulties in expressing feelings, 25.0% having scars, 23.8% dealing with physical limitations, 21.8% proven or suspected infertility and 21.0% no sexual desire. For other reasons consult Table S8.

3.5 | Determinants of sexuality

3.5.1 | Psychosexual development

All factors included in the regression model for age at sexual debut were significant except age at diagnosis and abdominopelvic radiotherapy (Table 2). Survivors who reported a later sexual debut were male, older than 24, higher educated, survived CNS cancer and scored lower on social and autonomy development.

3.5.2 | Sexual functioning and sexual satisfaction

Older CCS, CCS with worse mental health and with negative body perception experienced both problems with sexual functioning and less sexual satisfaction (Table 3). More problems with sexual functioning, but also more sexual satisfaction was described by CCS having a relationship. Female CCS, CCS with no children and CCS with a later sexual debut reported more problems with sexual functioning, while higher educated CCS reported only lower sexual satisfaction. Survivors of CNS cancer showed a small significant effect for both outcomes in model A, but no significant effect in model B.

3.6 | Comparison with references

3.6.1 | Psychosexual development

When compared to references, significantly fewer CCS age 18–24 reported experience with kissing (CCS = 84.5% vs. references = 89.6%, $p = 0.014$), petting under clothes (CCS = 82.6% vs. references = 88.9%, $p = 0.002$), oral (CCS = 74.2% vs. references = 80.8%, $p = 0.016$) and anal sex (CCS = 22.2% vs. references = 29.0%, $p = 0.032$, Table 4). Experience with being in love, masturbation, dating and intercourse did not differ significantly between CCS age 18–24 and references.

3.6.2 | Sexual functioning and sexual satisfaction

Within the age group 18–24, proportions of having at least one problem with sexual functioning for male CCS of 27.1% (95% CI: 18.0%–37.8%) was lower than the expected 30.9%, but not

TABLE 1 Sociodemographic, cancer-related and current functioning characteristics.

Characteristics	Participants, *N* = 1912	Non-participants, *N* = 2731[a]	Cramer's V[b]
Gender by age group (years)			
Total	100% (50.8% male)	100% (61.3% male)	0.11***
18–24	12.7% (43.2% male)	17.1% (62.4% male)	
25–40	57.9% (52.5% male)	58.4% (62.1% male)	
41–50	23.2% (51.7% male)	19.7% (58.9% male)	
51–71	6.2% (47.5% male)	4.8% (56.7% male)	
Age at diagnosis (years)			0.01
0–11	81.0%	82.0%	
12–18	19.0%	18.0%	
Cancer type			
Leukemia	34.6%	33.7%	0.01
Lymphomas	18.9%	19.2%	0.004
Renal tumors	11.5%	10.9%	0.01
CNS	9.4%	11.7%	0.04*
Soft tissue sarcoma	7.4%	7.5%	0.002
Bone tumors	6.1%	5.1%	0.02
Neuroblastoma	5.7%	4.8%	0.02
Germ cell tumors	3.5%	4.0%	0.01
Hepatic tumors	0.9%	1.1%	0.01
Retinoblastoma	0.5%	0.7%	0.01
Other	1.6%	1.4%	0.01
Treatment			
Surgery	50.1%	51.1%	0.03
Radiotherapy	39.3%	30.1%	0.10***
Abdominopelvic area	8.6%	6.5%	0.04*
Chemotherapy	87.3%	81.0%	0.09***
Hematopoietic cell transplantation			0.06**
Autologous transplant	2.4%	1.6%	
Allogeneic transplant	4.2%	2.6%	
Level of education			
Low[c]	14.0%		
Middle[d]	42.7%		
High[e]	43.4%		
Having children			
Yes	39.7%		
No	60.3%		

[a]Information available only for 2025 non-participants.

[b]Range Cramer's V [0–1] with 0 = no association and 1 = perfect association.

[c]Primary, lower vocational, lower and middle general secondary education.

[d]Middle vocational, higher general secondary, pre-university education.

[e]Higher vocational, university education.

Significant results are presented with *p-value <0.05, **p-value <0.01, ***p-value <0.001.

TABLE 2 Multivariable analysis of determinants for psychosexual development.[a]

Determinants	Age at sexual debut $N = 1394$, $R^2 = 0.151$ ($p < 0.001$) β (95% CI)
Sociodemographic factors	
Female gender[b]	−0.217*** (−0.314; −0.120)
Age (reference: 18–24)	
25–40[b]	0.208* (0.046; 0.370)
41–50[b]	0.545*** (0.362; 0.727)
51–71[b]	0.608*** (0.368; 0.847)
Current functioning factors	
Education (reference: Low)	
Middle[b]	0.326*** (0.161; 0.491)
High[b]	0.579*** (0.415; 0.742)
Cancer-related factors	
Age at diagnosis >12[b]	−0.010 (−0.136; 0.116)
CNS cancer[a]	0.324** (0.134; 0.514)
Abdominopelvic radiotherapy[b]	0.125 (−0.052; 0.302)
Psychosocial development	
Social development[c]	−0.232*** (−0.284; −0.180)
Autonomy development[c]	−0.074* (−0.125; −0.024)

[a]The dependent variable psychosexual development was measured by sexual debut, defined as the youngest age of first sexual intercourse (vaginal, oral, or anal).

[b]Regression coefficients up to 0.2 small, 0.5 medium, 0.8 large.

[c]Regression coefficients up to 0.1 small, 0.3 medium, 0.5 large.

Significant results are presented with *p-value <0.05, **p-value <0.01, ***p-value <0.001.

significant ($p = 0.522$). Similarly, the proportion for female CCS of 47.2% (95% CI: 37.5%–57.1%) was higher than the expected 39.2%, but also not significant ($p = 0.108$). Regarding sexual satisfaction, no significant differences in scale scores were found for male CCS age 18–24 (CCS = 3.9 vs. references = 4.0, t(84) = 1.258, $p = 0.212$) nor for female CCS age 18–24 (CCS = 3.9 vs. references = 3.9, t (110) = −0.193, $p = 0.847$) when compared to same-aged references.

4 | DISCUSSION

This large nationwide cohort study provides needed insight in CCS sexuality. We found that a third of survivors had at least some hindrance in their sex life because of their childhood cancer and that CCS age 18–24 reported less experience with different sexual milestones when compared to the general population. Nevertheless, the emerging adult CCS and same-aged references had similar sexual functioning and sexual satisfaction. The identified determinants of declined sexuality provide insight in subgroups at risk and targets for treatment.

4.1 | Psychosexual development

Emerging adult CCS (age 18–24) had less often achieved various sexual milestones compared to same-aged references. Especially survivors who were male, older, higher educated, had survived CNS cancer and CCS with delayed psychosocial development had a later sexual debut. The later sexual debut reported by male CCS compared to female CCS is consistent with the pattern observed in the Dutch general population.[30] Concerning the psychosocial development, this may be explained by survivors taking less risk behaviors,[7,12] experiencing more parental dependency[31–33] and participating in less social activities with peers than healthy controls,[13,14] which might lead to less opportunities for CCS to engage in sexual activities. Healthy Dutch teenagers, whose parents had a greater knowledge about their whereabouts, similarly reported delays in reaching sexual milestones compared to teenagers with less monitoring parents.[34] Therefore, more encouragement toward social exploration might result in similar levels of sexual experience for CCS compared to healthy peers.

Emerging adult survivors showed an interesting pattern regarding the different milestones when compared to references. CSS engaged in less oral and anal sex, but we found no significant differences for the experience with intercourse, which might suggest that survivors are less inclined in sexual experimenting. The differences are rather small though, and in contrast with previous literature.[6–9,11] Despite the delayed start on some milestones, CCS might show similar sexual behavior to the general population later in their lives. More research including older CCS and older references than in the current study is needed to determine if the small differences we found disappear, stay small or increase with the age of survivors.

4.2 | Sexual functioning & sexual satisfaction

We found worse sexual functioning and less sexual satisfaction in CCS with poorer mental health, an association which was also described in the general population.[21] Furthermore, survivors of CNS cancer had a higher age at sexual debut compared to survivors of other types of cancers and CNS contributed to small account to more problems with sexual functioning and less satisfaction. This corroborates previous studies which found CNS cancer survivors at risk for various impaired sexuality outcomes.[5,8–10] Interestingly, in our study, the effect of CNS cancer on the outcomes disappeared when adding the current-functioning factors in the regression model. This might be explained by an indirect effect of CNS cancer on sexuality through its primarily influence on survivor's current level of functioning. CNS cancer survivors are a subgroup that generally presents more late effects and lower health-related QoL.[35] Our results underline the importance of paying attention to CNS cancer survivors and CCS

TABLE 3 Multivariable analysis of determinants for scale scores of problems with sexual functioning and sexual satisfaction.

Determinants Model A	Problems with sexual functioning $N = 1617$, $R^2 = 0.244$ ($p < 0.001$) β (95% CI)	Sexual satisfaction $N = 1637$, $R^2 = 0.024$ ($p < 0.001$) β (95% CI)
Sociodemographic factors		
Female gender[a]	0.944*** (0.860; 1.027)	−0.027 (−0.120; 0.065)
Age (reference: 18–24)		
25–40[a]	0.014 (−0.123; 0.152)	−0.139 (−0.293; 0.014)
41–50[a]	−0.009 (−0.165; 0.147)	−0.273** (−0.446; −0.099)
51–71[a]	0.230* (0.025; 0.435)	−0.547*** (−0.774; −0.321)
Cancer-related factors		
Age at diagnosis >12[a]	−0.001 (−0.110; 0.108)	0.043 (−0.078; 0.163)
CNS cancer[a]	0.180* (0.019; 0.341)	−0.199* (−0.377; −0.021)
Abdominopelvic radiotherapy[a]	0.106 (−0.046; 0.257)	−0.006 (−0.173; 0.161)
Psychosexual development		
Age at sexual debut[b]	0.047* (0.003; 0.090)	−0.038 (−0.086; 0.010)
Model B	**Problems with sexual functioning** **$N = 1409$, $R^2 = 0.359$ ($p < 0.001$)** **β (95% CI)**	**Sexual satisfaction** **$N = 1409$, $R^2 = 0.339$ ($p < 0.001$)** **β (95% CI)**
Sociodemographic factors		
Female gender[a]	0.847*** (0.761; 0.934)	−0.009 (−0.094; 0.076)
Age (reference: 18–24)		
25–40[a]	0.038 (−0.107; 0.183)	−0.219** (−0.362; −0.077)
41–50[a]	0.055 (−0.116; 0.226)	−0.368*** (−0.536; −0.199)
51–71[a]	0.251* (0.037; 0.465)	−0.608*** (−0.819; −0.397)
Current functioning factors		
Education (reference: Low)		
Middle[a]	−0.021 (−0.157; 0.116)	−0.190** (−0.325; −0.055)
High[a]	0.038 (−0.100; 0.175)	−0.303*** (−0.438; −0.167)
Having children[a]	−0.234*** (−0.328; −0.140)	−0.085 (−0.177; 0.008)
Being in a relationship[a]	0.186** (0.075; 0.296)	0.942*** (0.834; 1.051)
Mental health		
Anxiety[b]	0.092** (0.037; 0.147)	−0.039 (−0.093; 0.016)
Depression[b]	0.121*** (0.058; 0.184)	−0.129*** (−0.191; −0.068)
Physical health		
Physical functioning[b]	−0.006 (−0.065; 0.053)	−0.009 (−0.067; 0.049)
Pain[b]	0.019 (−0.037; 0.074)	−0.037 (−0.092; 0.018)
Vitality[b]	−0.031 (−0.096; 0.035)	0.057 (−0.008; 0.121)
General health[b]	−0.039 (−0.099; 0.022)	−0.008 (−0.068; 0.051)
Body perception[b]	−0.146*** (−0.193; −0.098)	0.250*** (0.203; 0.297)
Cancer-related factors		
Age at diagnosis>12[a]	0.024 (−0.080; 0.129)	−0.021 (−0.124; 0.082)
CNS cancer[a]	0.094 (−0.067; 0.256)	0.028 (−0.130; 0.187)
Abdominopelvic radiotherapy[a]	0.034 (−0.117; 0.185)	−0.044 (−0.191; 0.104)

(Continues)

TABLE 3 (Continued)

Model B	Problems with sexual functioning $N = 1409$, $R^2 = 0.359$ ($p < 0.001$) β (95% CI)	Sexual satisfaction $N = 1409$, $R^2 = 0.339$ ($p < 0.001$) β (95% CI)
Psychosexual development		
Age at sexual debut[b]	0.012 (−0.033; 0.056)	−0.010 (−0.054; 0.034)

[a]Regression coefficients up to 0.2 small, 0.5 medium, 0.8 large.

[b]Regression coefficients up to 0.1 small, 0.3 medium, 0.5 large.

Significant results are presented with *p-value <0.05, **p-value <0.01, ***p-value <0.001.

TABLE 4 Proportions of reached sexual milestones[a] in CCS versus references[b] age 18–24 (n = 225–236).

	Being in love	Masturbation	Dating	Kissing	Petting under clothes	Intercourse	Oral sex	Anal sex
Age 18–24								
CCS	94.1%	85.6%	80.1%	84.5%	82.6%	76.9%	74.2%	22.2%
References	94.4%	89.3%	83.6%	89.6%	88.9%	79.4%	80.8%	29.0%
p-value	0.934	0.090	0.180	**0.014**	**0.002**	0.398	**0.016**	**0.032**
Male age 18–24								
CCS	98.1%	94.2%	80.4%	80.6%	79.4%	76.7%	75.2%	27.3%
References	94.5%	97.5%	81.0%	86.5%	88.0%	75.0%	79.0%	29.0%
p-value	0.166	0.072	0.984	0.106	**0.012**	0.778	0.416	0.784
Female age 18–24								
CCS	91.0%	78.6%	79.8%	87.6%	85.2%	77.1%	73.4%	18.3%
References	94.4%	82.6%	85.6%	92.1%	89.7%	82.8%	82.1%	28.9%
p-value	0.132	0.286	0.080	0.080	0.120	0.106	**0.094**	**0.012**

Note: Significant results are presented in bold.

Abbreviation: CCS, childhood cancer survivors.

[a]Reference data on sexual arousal, sexual fantasies, relationship and naked petting was not available.

[b]Proportions in references are weighted for the distribution of age and gender in the CCS sample.

with impaired mental health, since these survivors seem to be at risk of reduced sexuality, although the role of CNS cancer and mental health is limited in our sample, especially the contribution of CNS cancer in the explanation of sexual satisfaction.

Cancer treatment may have an impact on the appearance of survivors and can result in physical alterations like amputations, underdevelopment of body parts and scarring.[36] In the literature, CCS described negative body image[37] and identified uncertainty about their own body and having scars as reasons for sexual limitations due to cancer.[6,15,38] Similarly, in our study survivors identified body insecurity as the most common reason for hindered sexuality due to cancer. Screening for negative body perception and addressing this topic as early as during cancer treatment might prevent the development of impaired body image which, in turn, might have a positive effect on survivors' sexuality.

Contrary to our expectations, no significant differences were found between CCS and the references on sexual functioning and sexual satisfaction. This is an encouraging result and in alignment with some studies investigating sexual satisfaction[10,16,23] and one focus group study highlighting that CCS did not necessarily link their sexuality to the former cancer experience.[38] However, in the current study, the comparison with reference data was possible only for CCS age 18–24, who might not yet experience sexuality problems. In previous studies,[5,16–18,20] where significant differences were reported, CCS and references up to age 51 were included in the comparison. Cancer treatments might accelerate aging and put survivors at an increased risk of developing various health conditions earlier than the general population.[39] Therefore, differences between CCS and the general population with regard to problems with sexual functioning and sexual satisfaction may arise at a higher age than we were able to study. More research is needed to investigate the differences in sexuality between older CCS and older healthy population.

4.3 | Study limitations

Considering the representativeness of the results for Dutch CCS, differences between participating and non-participating CCS were found only for some medical characteristics and gender, and gender was accounted for in all analyses. Furthermore, volunteer bias in sexuality related research has been proven in the general population.[40] Sexuality is a sensitive topic and there might be potential

hesitance of CCS to participate in sexuality related studies, especially of CCS with more sexuality problems. This may have led to lower inclusion of CCS with impaired sexuality and therefore to possible optimistic results. Additionally, items used prior in the Dutch general population were applied for the sake of comparison. Cronbach's alphas were satisfactory,[26] but other psychometric characteristics were not known. Besides, the spectrum of sexuality is wider than the outcomes covered in this study and there may be other potential determinants, that is, fertility, biological factors, cultural aspects, which should be addressed in future research.

4.4 | Clinical implications

Our study underlines the need to pay attention to older and CNS cancer survivors, but also survivors with decreased mental health and negative body perception. Identifying the survivors at risk, and then opening the topic of sexuality during their late effect clinic visits and in patient organizations meetings, but also offering interventions and tailored information to CCS in need, might help survivors experience less hindrance in their sexuality.

5 | CONCLUSION

Our study emphasizes the importance of some factors on survivors' sexuality, that is, age, gender, mental health and body perception. Emerging adult CCS described less psychosexual experience, but similar sexual functioning and sexual satisfaction as Dutch general population references. Focus on risk groups and implementation of research-based interventions may support optimal psychosexual development and help survivors to enjoy a healthy sexual life.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from Princess Maxima Center. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the author(s) with the permission of Princess Maxima Center.

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REFERENCES

1. George WH, Norris J, Nguyen HV, Masters NT, Davis KC. Sexuality and Health; 2014.
2. Organization WH. *Developing Sexual Health Programmes: A Framework for Action*. World Health Organization; 2010.
3. Gray PB. Evolution and human sexuality. *Am J Phys Anthropol*. 2013;152:94-118. https://doi.org/10.1002/ajpa.22394
4. Erdmann F, Frederiksen LE, Bonaventure A, et al. Childhood cancer: survival, treatment modalities, late effects and improvements over time. *Cancer Epidemiol*. 2021;71:101733. https://doi.org/10.1016/j.canep.2020.101733
5. Sundberg KK, Lampic C, Arvidson J, Helström L, Wettergren L. Sexual function and experience among long-term survivors of childhood cancer. *Eur J Cancer*. 2011;47(3):397-403. https://doi.org/10.1016/j.ejca.2010.09.040
6. Van Dijk E, Van Dulmen-den Broeder E, Kaspers G, Van Dam E, Braam K, Huisman J. Psychosexual functioning of childhood cancer survivors. *Psycho-Oncology*. 2008;17(5):506-511. https://doi.org/10.1002/pon.1274
7. Stam H, Grootenhuis M, Last B. The course of life of survivors of childhood cancer. *Psycho-Oncology*. 2005;14(3):227-238. https://doi.org/10.1002/pon.839
8. Lehmann V, Gerhardt CA, Baust K, Kaatsch P, Hagedoorn M, Tuinman MA. Psychosexual development and sexual functioning in young adult survivors of childhood cancer. *J Sex Med*. 2022;19(11):1644-1654. https://doi.org/10.1016/j.jsxm.2022.07.014
9. Lehmann V, Keim MC, Ferrante AC, Olshefski RS, Gerhardt CA. Psychosexual development and satisfaction with timing of developmental milestones among adult survivors of childhood cancer. *Psycho-Oncology*. 2018;27(8):1944-1949. https://doi.org/10.1002/pon.4746
10. Lehmann V, Tuinman MA, Keim MC, et al. Psychosexual development and satisfaction in long-term survivors of childhood cancer: neurotoxic treatment intensity as a risk indicator. *Cancer*. 2017;123(10):1869-1876. https://doi.org/10.1002/cncr.30513
11. Dieluweit U, Debatin KM, Grabow D, et al. Social outcomes of long-term survivors of adolescent cancer. *Psycho-Oncology*. 2010;19(12):1277-1284. https://doi.org/10.1002/pon.1692
12. Maurice-Stam H, van Erp LM, Maas A, et al. Psychosocial developmental milestones of young adult survivors of childhood cancer. *Support Care Cancer*. 2022:1-11.
13. Pendley JS, Dahlquist LM, Dreyer Z. Body image and psychosocial adjustment in adolescent cancer survivors. *J Pediatr Psychol*. 1997;22(1):29-43. https://doi.org/10.1093/jpepsy/22.1.29
14. Vannatta K, Gerhardt CA, Wells RJ, Noll RB. Intensity of CNS treatment for pediatric cancer: prediction of social outcomes in survivors. *Pediatr Blood Cancer*. 2007;49(5):716-722. https://doi.org/10.1002/pbc.21062
15. Frederick NN, Recklitis CJ, Blackmon JE, Bober S. Sexual dysfunction in young adult survivors of childhood cancer. *Pediatr Blood Cancer*. 2016;63(9):1622-1628. https://doi.org/10.1002/pbc.26041
16. Ford JS, Kawashima T, Whitton J, et al. Psychosexual functioning among adult female survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2014;32(28):3126-3136. https://doi.org/10.1200/jco.2013.54.1086
17. Hovén E, Fagerkvist K, Jahnukainen K, et al. Sexual dysfunction in young adult survivors of childhood cancer–A population-based study. *Eur J Cancer*. 2021;154:147-156. https://doi.org/10.1016/j.ejca.2021.06.014
18. Haavisto A, Henriksson M, Heikkinen R, Puukko-Viertomies LR, Jahnukainen K. Sexual function in male long-term survivors of childhood acute lymphoblastic leukemia. *Cancer*. 2016;122(14):2268-2276. https://doi.org/10.1002/cncr.29989
19. Bjornard KL, Howell CR, Klosky JL, et al. Psychosexual functioning of female childhood cancer survivors: a report from the St. Jude Lifetime Cohort Study. *J Sex Med*. 2020;17(10):1981-1994. https://doi.org/10.1016/j.jsxm.2020.06.005
20. Gray RE, Doan BD, Shermer P, et al. Psychologic adaptation of survivors of childhood cancer. *Cancer*. 1992;70(11):2713-2721. https://doi.org/10.1002/1097-0142(19921201)70:11<2713::aid-cncr2820701124>3.0.co;2-t

21. Zebrack BJ, Foley S, Wittmann D, Leonard M. Sexual functioning in young adult survivors of childhood cancer. *Psycho-Oncology*. 2010; 19(8):814-822. https://doi.org/10.1002/pon.1641
22. Wettergren L, Kent EE, Mitchell SA, et al. Cancer negatively impacts on sexual function in adolescents and young adults: the AYA HOPE study. *Psycho-Oncology*. 2017;26(10):1632-1639. https://doi.org/10.1002/pon.4181
23. Lehmann V, Hagedoorn M, Gerhardt CA, et al. Body issues, sexual satisfaction, and relationship status satisfaction in long-term childhood cancer survivors and healthy controls. *Psycho-Oncology*. 2016;25(2):210-216. https://doi.org/10.1002/pon.3841
24. Teepen JC, Kok JL, Feijen EA, et al. Questionnaire-and linkage-based outcomes in Dutch childhood cancer survivors: methodology of the DCCSS LATER study part 1. *Cancer Med*. 2022;12(6):7588-7602. https://doi.org/10.1002/cam4.5519
25. Feijen EA, Teepen JC, van Dulmen-den Broeder E, et al. Clinical evaluation of late outcomes in Dutch childhood cancer survivors: methodology of the DCCSS LATER 2 study. *Pediatr Blood Cancer*. 2023;70:e30212.
26. De Graaf H. *Seks onder je 25e: Seksuele gezondheid van jongeren in Nederland anno 2012*. Eburon Uitgeverij BV; 2012.
27. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol*. 1998;51(11):1055-1068. https://doi.org/10.1016/s0895-4356(98)00097-3
28. Spinhoven P, Ormel J, Sloekers P, Kempen G, Speckens AE, van Hemert AM. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychol Med*. 1997;27(2):363-370. https://doi.org/10.1017/s0033291796004382
29. Cohen J. Statistical power analysis. *Curr Dir Psychol Sci*. 1992;1(3): 98-101. https://doi.org/10.1111/1467-8721.ep10768783
30. de Graaf H, van den Borne M, Nikkelen S, Twisk D, Meijer S. *Seksuele gezondheid van jongeren in Nederland anno 2017*. Rutgers and Soa Aids Nederland; 2017.
31. Kim MA, Yi J, Wilford A, Kim SH. Parenting changes of mothers of a child with cancer. *J Fam Issues*. 2020;41(4):460-482. https://doi.org/10.1177/0192513x19881191
32. Hillman KA. Comparing child-rearing practices in parents of children with cancer and parents of healthy children. *J Pediatr Oncol Nurs*. 1997;14(2):53-67. https://doi.org/10.1177/104345429701400203
33. Quin S. The long-term psychosocial effects of cancer diagnosis and treatment on children and their families. *Soc Work Health Care*. 2005;39(1-2):129-149. https://doi.org/10.1300/j010v39n01_09
34. de Graaf H, Vanwesenbeeck I, Woertman L, Keijsers L, Meijer S, Meeus W. Parental support and knowledge and adolescents' sexual health: testing two mediational models in a national Dutch sample. *J Youth Adolesc*. 2010;39(2):189-198. https://doi.org/10.1007/s10964-008-9387-3
35. Schulte F, Russell KB, Cullen P, et al. Systematic review and meta-analysis of health-related quality of life in pediatric CNS tumor survivors. *Pediatr Blood Cancer*. 2017;64(8):e26442. https://doi.org/10.1002/pbc.26442
36. White CA. Body image dimensions and cancer: a heuristic cognitive behavioural model. *Psycho-Oncology*. 2000;9(3):183-192. https://doi.org/10.1002/1099-1611(200005/06)9:3<183::aid-pon446>3.0.co;2-l
37. Kyritsi H, Matziou V, Papadatou D, Evagellou E, Koutelekos G, Polikandrioti M. Self concept of children and adolescents with cancer. *Health Sci J*. 2007(3).
38. Jervaeus A, Nilsson J, Eriksson LE, Lampic C, Widmark C, Wettergren L. Exploring childhood cancer survivors' views about sex and sexual experiences-findings from online focus group discussions. *Eur J Oncol Nurs*. 2016;20:165-172. https://doi.org/10.1016/j.ejon.2015.07.009
39. van den Boogaard WM, van den Heuvel-Eibrink MM, Hoeijmakers JH, Vermeij WP. Nutritional preconditioning in cancer treatment in relation to DNA damage and aging. *Annu Rev Cancer Biol*. 2021; 5(1):161-179. https://doi.org/10.1146/annurev-cancerbio-060820-090737
40. Strassberg DS, Lowe K. Volunteer bias in sexuality research. *Arch Sex Behav*. 1995;24(4):369-382. https://doi.org/10.1007/bf01541853

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