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## ONCOLOGY

## Psychosexual Development and Sexual Functioning in Young Adult Survivors of Childhood Cancer



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## ABSTRACT

**Background:** Childhood cancer and its treatment can impair survivors' development throughout life, particularly psychosexual development, which can be affected in complex ways and is crucial for survivors' well-being. Yet, research is scarce.

**Aim:** This study assessed psychosexual development (milestone attainment, age at attainment, perceived timing) in young adult survivors of childhood cancer. It further examined sexual satisfaction and sexual functioning, and whether survivors' perceived timing of sexual debut was related to satisfaction or functioning.

**Methods:** A registry-based nationwide survey was completed by N = 492 German survivors of childhood cancer (age 21–26 years, 6–26 years postdiagnosis). They completed standardized measures of psychosexual milestones (eg, first kiss, sexual debut), sexual satisfaction, and sexual functioning. Psychosexual development was compared to normative data (N = 1,533).

**Outcomes:** Psychosexual development, sexual satisfaction, and sexual functioning were the primary outcome measures. Psychosexual development was characterized in three ways: milestone attainment (yes/no), age at attainment, perceived timing ("right" time, too early/late).

**Results:** Milestone attainment was comparable to normative data, except for sexual debut: Survivors were less often experienced (82.5% vs 88%;  $P = .002$ ) and older at sexual debut (17.4 vs 16.2 years;  $g = 0.55$ ), but most survivors (58.3%) perceived their timing as "right." Survivors of brain tumors were least likely to have had their sexual debut, but if experienced age at sexual debut was similar to other survivors. Female survivors were somewhat more experienced than males (eg, first kiss, first relationship; <10% difference), but they were somewhat older when they first kissed ( $g = 0.26$ ). Age at diagnosis was unrelated to milestone attainment. Perceived early/late sexual debut was related to lower satisfaction in female survivors ( $P = .026$ ), but unrelated to sexual dysfunction. Instead, partnered men reported particularly low dysfunction whereas women reported similar levels of sexual dysfunction irrespective of their relationship status ( $P = .049$ ). Overall, sexual functioning was favorable (60.2%: not/barely problematic).

**Clinical implications:** Most survivors reported favorable sexual satisfaction and functioning, but a minority of survivors may need supportive services.

**Strengths & Limitations:** This project represents one of few large-scale studies on psychosexual development in childhood cancer survivors relative to normative data, and is the first to link development to sexual satisfaction/functioning. Assessing satisfaction/functioning with validated, but brief measures limits detailed insights, but was inclusive of any sexual orientation. Medical background information based on registry data was limited.

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**Conclusion:** Results showed normative psychosexual development (except for sexual debut) in most survivors. A self-determined attitude toward sexuality (ie, engaging in sexual activities at the “right” time) may generally determine positive sexual experiences. **Lehmann V, Gerhardt CA, Baust K, et al. Psychosexual Development and Sexual Functioning in Young Adult Survivors of Childhood Cancer. J Sex Med 2022;19:1645–1654.**

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**KEY WORDS:** Cancer Survivorship; Young Adulthood; Childhood Cancer; Psychosexual Development; Sexual Satisfaction; Sexual Functioning

## INTRODUCTION

Cancer treatment in childhood (ie, before the age of 18 years) can affect survivors' development throughout life, and particularly psychosexual development can be influenced in complex ways. Physical effects of cancer and its treatment,<sup>1,2</sup> body image concerns, or social set-backs due to missing time with peers<sup>3</sup> can negatively influence psychosexual development. Although sex is a crucial part of general health and well-being,<sup>4</sup> studies on psychosexual development in young adult survivors (ie, age 18–39 years) are scarce.

At the onset of puberty, psychosexual development entails starting to become romantically interested in others and to explore and engage in sexual activities, alone or with someone else.<sup>5</sup> This includes attaining milestones of psychosexual development, such as falling in love, kissing, or engaging in sexual intercourse for the first time (ie, sexual debut). Initial studies among childhood cancer survivors concluded that survivors were less likely to attain milestones (eg, sexual debut) or that they delay such milestones to a later age.<sup>6–8</sup> Other studies indicated normative psychosexual development by finding no differences relative to controls.<sup>9–12</sup> The underlying factors driving such mixed findings remain poorly understood and may partly be due to small samples. Moreover, merely assessing the attainment of such milestones falls short, as it does not consider the subjective experience of survivors. One study examined the perceived timing of milestone attainment and highlighted that although some childhood cancer survivors were delayed, most (~60%) felt they had reached psychosexual milestones at the “right” time.<sup>13</sup> These findings challenge previous research that focused solely on milestone attainment (yes/no) and suggest that conclusions about delays offer limited insights into the lived experiences of survivors.

Whether the perceived timing of psychosexual development is linked to sexual *functioning* (ie, physical sexual functioning, pleasure, interest, satisfaction) in adult survivors of childhood cancer has not been tested. Instead, studies focused on assessing impaired sexual functioning, which was found more often in childhood cancer survivors than controls.<sup>14</sup> Rates of sexual *dys*-function range between 20% and 57% in young adult survivors,<sup>15–19</sup> with problems being more frequent in female than male survivors.<sup>16,17,19</sup> Qualitative studies offered insights into

the nature of sexual dysfunction in young adult survivors of childhood cancer: Sexual functioning can directly be affected by physical side effects of cancer treatment, along with concerns, insecurities, pressure to perform, body image issues, and missed opportunities to engage with peers.<sup>3,10,20</sup> Yet, some survivors do not experience or anticipate any effects of childhood cancer on their sex life.<sup>20,21</sup> Assessments of sexual *satisfaction*, as one aspect of sexual functioning, produced mixed findings. Some studies reported lower<sup>22,23</sup> or comparable sexual satisfaction to controls,<sup>24</sup> others reported lower satisfaction in male but not female survivors relative to controls,<sup>25</sup> while studies in exclusively female survivors reported lower satisfaction than controls.<sup>15,26</sup> Overall, female sex has most often been identified as related to impaired sexual functioning,<sup>16,17,19</sup> but other factors remain poorly understood.<sup>14</sup> Potential risk factors likely include central nervous system (CNS) tumors,<sup>25</sup> older age at study,<sup>15,26</sup> and diagnosis during adolescence as opposed to childhood.<sup>26</sup> Yet, research is limited and findings may vary due to diverse measures and methodologies.<sup>17</sup>

Sexual experiences in adulthood are an important indicator of whether survivors of childhood cancer thrive later in life. Therefore, it is important to link survivors' psychosexual milestones to their sexual experiences in adulthood. This study will characterize the psychosexual development of young adult survivors of childhood cancer by means of (i) milestone attainment, (ii) age at attainment, and (iii) perceived timing (right time, too early/late). It will be examined whether these 3 characterizations differ by background factors (eg, sex, type of diagnosis), and milestone attainment will be compared to available normative data. This study will further assess sexual satisfaction and sexual functioning, and differences by background factors. Differences by survivors' perceived timing of sexual debut regarding sexual satisfaction and sexual functioning will be tested.

## METHODS

### Procedures

This study is part of larger collaboration called E-Surv, which included 2 surveys: *VIVE* (PI: Calaminus) focusing on medical late effects of childhood cancer and *InRel* (PI: Lehmann)

focusing on intimate relationships among survivors of childhood cancer.

The German Childhood Cancer Registry (GCCR) registers any new case of childhood cancer (ie, before age 18) in Germany. The GCCR randomly selected  $N = 2,000$  survivors and invited them to participate in both studies in a counterbalanced manner (ie, half were invited to VIVE first, the other half to InRel first). Information packets were mailed to survivors, followed by a written reminder, in case of nonresponse. After 3 months, survivors were invited to participate in the second survey (ie, either InRel or VIVE).

Every survivor was assigned an identifying code (ID) that they provided in the survey. This allowed to link responders to clinical data at the GCCR. Only the GCCR had the ID key code, and survey responses were stored separately from identifying information. Thus, personal data and the identity of participants were protected at all times.

Participants provided written informed consent on paper (returned to the GCCR) or online, depending on whether they participated online or on paper-pencil. Online, participants also had the opportunity to withdraw their answers at the end of the survey, and participants who discontinued completing the survey were also excluded from further analyses. All procedures had been approved by the Medical Ethical Committee (#138/17) and data protection officer of the University Medical Center Bonn, Germany and were in accordance with the Declaration of Helsinki.

## Eligibility

Eligible survivors were diagnosed with any type of cancer before age 18, were long-term survivors ( $\geq 5$  years postdiagnosis), were emerging/young adults (ie, age 20–25 years), were registered at the GCCR, and living in Germany at the time of this study. Due to logistical delays after eligible survivors had been identified, participants were age 21–26 years at participation.

Out of  $N = 2,000$  survivors, 622 responded to InRel (31.1%), of which  $n = 89$  actively opted out,  $n = 4$  discontinued completing the survey online, and  $n = 3$  completed the survey but withdrew their participation. Thus,  $N = 526$  survivors completed the survey. Completers were somewhat younger (23.3 vs 24.0 years;  $P < .001$ ) and more often female (39.6% female vs 24.2% male;  $P < .001$ ) than the initial pool of 2,000 eligible participants, but they did not differ by type of diagnosis ( $P = .463$ ). Throughout the survey, participants were able to skip questions. For the current analyses, we retained any survivor with complete data on psychosexual milestones, resulting in a final sample of  $N = 492$ .

## MEASURES

Sociodemographic data (eg, sex, relationship status: single/partnered) were self-reported by survivors. Age and medical data (ie, age at diagnosis, type of diagnosis) were supplied by the GCCR.

*Psychosexual development.* The psychosexual development subscale of the Course of Life Questionnaire (CoLQ)<sup>7</sup> consists of 4 items that assess *age* of reaching 4 psychosexual milestones: first boyfriend/girlfriend, first physical intimacy (without intercourse), sexual debut, and first time in love. We added another milestone: age at first kiss. We further extended the CoLQ by asking survivors how they perceived the *timing* of attaining each milestone: *Yes, it was the right time for me*; *No, I wish it had happened earlier* (ie, too late); *No, I wish I had waited* (ie, too early). If participants had *not* reached a certain milestone, they were able to indicate this accordingly. This was followed by the question of how much they wanted this particular milestone to occur on a scale from 0 to 10 (*not at all*–*very much*; see Appendix for an overview).

The above approach of supplementing the CoLQ with face-valid questions has been successfully done in previous research.<sup>13</sup> All aspects, that is *attainment* (yes/no), *age* at milestone attainment, perceptions of *timing*, and *wishes* of reaching certain milestones (if applicable) are reported for each of the 5 milestones.

*Sexual satisfaction.* The 5-item Global Measure of Sexual Satisfaction (GMSEX)<sup>27</sup> uses bipolar anchors to describe sexual satisfaction (eg, *good-bad*, *comfortable-uncomfortable*). Between those anchors, a 7-point Likert scale is presented to participants to indicate how they perceive their sex lives. It was specified that any sexual or arousing activity, with a partner or alone, could be considered to expand the scope and making it applicable to partnered and unpartnered sexual activities (incl. masturbation, petting/making out, kissing, or oral sex). Scores on all 5 items are averaged to 1 total score with higher scores indicating greater satisfaction. Cronbach's alpha was excellent with  $\alpha = .941$  in this study ( $\alpha = .931/.949$  for male/female survivors).

*Sexual functioning.* Survivors were asked whether they had been sexually active with someone in the past 6 months. If endorsed, they were presented with the 4-item Medical Outcome Study (MOS) Sexual Functioning Scale.<sup>28</sup> It consists of 3 generic items to assess sexual interest, pleasure, and arousal problems, as well as 1 sex-specific item referring to erectile or orgasmic problems for male and female participants respectively. Items are answered on a 4-point Likert scale (*totally disagree*–*totally agree*), and scores are transformed to a scale of 0–100 and combined to an average score.<sup>29</sup> Higher scores indicate greater sexual *dys*function, where scores below  $\leq 25$  are considered as not/ barely problematic functioning and scores  $\geq 75$  as very problematic.<sup>30</sup> Cronbach's alpha was sufficient in this sample with  $\alpha = .725$  ( $\alpha = .634/.704$  in male/female survivors).

## Statistical Analyses

*Psychosexual development.* Descriptive statistics of *attainment* of the 5 milestones were conducted.  $T$ - and  $\chi^2$ -tests were used to test whether attainment differed by background factors (ie, sex, type of, age at, years since diagnosis). Normative data from a representative sample of Germans age 18–25 year were available

(N = 2,476; 64% female),<sup>31,32</sup> which included N = 1,533 participants who were 21–25 years old and used for comparisons, using  $\chi^2$ -tests. Normative data included percentages of experiences with kissing (94%), physical intimacy/fondling (breast: 87%; genitals: 77%–82%), sexual debut (88%), and no sexual experiences (5%; Table 2) personal communication with Sara Scharmski.<sup>31</sup> Descriptive statistics of wishes to attain certain milestones among survivors who were inexperienced were examined. Differences of survivors' age at milestone attainment by background factors (ie, sex, type of, age at, and years since diagnosis) were examined using independent *t*- and *F*-tests, depending on the examined factor. Regarding age at milestone attainment, German normative data were only available for sexual debut (*M* = 16.2 years),<sup>33</sup> which was compared to survivors, using a *t*-test. Proportions of survivors' perceived timing of each milestone (right time, too late/early) were calculated.

*Sexual satisfaction and functioning.* Descriptive statistics were calculated for sexual satisfaction and functioning, and examined for differences by background factors (sex, type of, age at, years since diagnosis, current relationship status). Two separate analyses of covariance (ANCOVAs) tested differences in sexual function and sexual satisfaction by survivors' perceived timing of sexual debut (right time, too late/early). Covariates included any background factor identified as significantly related to sexual satisfaction or functioning (*P* < .05).

Post-hoc power analyses indicated ample power (>.9) for the above analyses to detect even small effects (*g* = .2/*r* = .2) given a sample of N = 492 survivors. Therefore, all comparisons are accompanied by calculations of effects sizes (Hedges' *g*) for continuous variables, and percentages are used to better guide interpreting the clinical significance of the findings. Hedge's *g* is

interpreted like Cohen's *d*, where values of  $\geq .2$ ,  $\geq .5$ , and  $\geq .8$  are interpreted as small, moderate, and large effects respectively.<sup>34</sup> Hedge's *g* has the advantage of using a correction and therefore not overestimating effects.<sup>35</sup>

## RESULTS

### Participants

The sample included 60.2% female and 39.8% male survivors, who were 21–26 years old, and about half were in a relationship/married (51.8%). Survivors were diagnosed around the age of 8 years (range: 0–17). Years since diagnosis ranged between 6 - 26 years. Male and female survivors did not differ on background characteristics, except female survivors were somewhat more often diagnosed with leukemia than lymphoma relative to males (Table 1).

### Milestone Attainment

Three-quarters of survivors (*n* = 378/492; 76.8%) had attained all 5 milestones of psychosexual development. Most survivors reported having been in love (94.9%), and the fewest had experienced their sexual debut (82.5%; Table 2). Sixteen survivors (3.3%) had no experience with any of the investigated milestones.

Female survivors were somewhat more likely to have had their first relationship, first kiss, and experience with physical intimacy relative to male survivors (<10% difference; complete overview in Table 2). Notably, proportions of sexual debut did not differ between male and female survivors. The rather low number of inexperienced survivors in combination with type of diagnosis

**Table 1.** Sociodemographic and clinical background data of all survivors (N = 492)

	Whole sample N = 492 <i>M(SD), range</i>	Female survivors <i>n</i> = 296 (60.2%) <i>M(SD), range</i>	Male survivors <i>n</i> = 196 (39.8%) <i>M(SD), range</i>	<i>comparison</i>
Age at study	23.3 (2.5), 21–26	23.3 (1.5), 21–26	23.5 (1.5), 21–26	<i>t</i> (490) = 1.856, <i>P</i> = .064
Age at diagnosis	7.9 (4.8), 0–17	7.6 (4.9), 0–17	8.2 (4.8), 0–17	<i>t</i> (490) = 1.320, <i>P</i> = .187
Years since diagnosis	15.0 (5.0), 6–26	15.1 (5.1), 6–26	14.7 (4.8), 6–26	<i>t</i> (490) = -0.889, <i>P</i> = .374
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Relationship status*				$\chi^2(1) = 2.580, P = .108$
Single	234 (47.6%)	132 (44.9%)	102 (52.3%)	
Partnered/married	255 (51.8%)	162 (55.1%)	93 (47.7%)	
Type of diagnosis				$\chi^2(3) = 8.807, P = .032$
Leukaemia	195 (39.6%)	129 (43.6%)	66 (33.7%)	
Lymphoma	101 (20.5%)	49 (16.6%)	52 (26.5%)	
CNS tumour	94 (19.1%)	58 (19.6%)	36 (18.4%)	
Other	102 (20.7%)	60 (20.3%)	42 (21.4%)	
Age at diagnosis				$\chi^2(1) = 0.120, P = .729$
Childhood ( $\leq 12$ )	378 (76.8%)	229 (77.4%)	149 (76.0%)	
Adolescence (13+)	114 (23.2%)	67 (22.6%)	47 (24.0%)	

Values printed in bold indicate statistically significant differences.

\* *n* = 3 missing



**Table 2.** Psychosexual milestones among all survivors in comparison to German normative data, and split by sex

Milestones	Whole sample N = 492	Normative data N = 1,533	Comparisons*	Female survivors n = 296	Male survivors n = 196	Sex differences
<b>1st relationship</b>			–			$\chi^2(1) = 4.955, P = .026$
experienced	407 (82.7%)	–		254 (85.8%)	153 (78.1%)	
not experienced	85 (17.3%)	–		42 (14.2%)	43 (21.9%)	
<b>1st kiss</b>			$\chi^2(1)=3.30, P = .069$			$\chi^2(1) = 10.374, P = .001$
experienced	451 (91.7%)	94%		281 (94.9%)	170 (86.7%)	
not experienced	41 (8.3%)	6%		15 (5.1%)	26 (13.3%)	
<b>1st intimacy/ petting</b>			[see below]†			$\chi^2(1) = 5.217, P = .022$
experienced	421 (85.6%)	77-87%†		262 (88.5%)	159 (81.1%)	
not experienced	71 (14.4%)	23-13%		34 (11.5%)	37 (18.9%)	
<b>1st intercourse (debut)</b>			$\chi^2(1) = 9.68, P < .001$			$\chi^2(1) = 2.671, P = .102$
experienced	406 (82.5%)	88%		251 (84.8%)	155 (79.1%)	
not experienced	86 (17.5%)	12%		45 (15.2%)	41 (20.9%)	
<b>1st time in love</b>			–			$\chi^2(1) = 0.732, P = .392$
experienced	467 (94.9%)	–		283 (95.6%)	184 (93.9%)	
not experienced	25 (5.1%)	–		13 (4.4%)	12 (6.1%)	
<b>Age at milestone</b>						
<b>1st relationship</b>	16.4 (2.6), 6-25			16.5 (2.7), 6–24	16.3 (2.5), 9–25	$F(1,405) = 0.57, P = .452$
<b>1st kiss</b>	14.9 (3.1), 4-25			15.2 (2.9), 5–23	14.4 (3.5), 4–25	$F(1,449) = 7.00, P = .008$
<b>1st intimacy/ petting</b>	16.4 (2.3), 8-26			16.5 (2.4), 8–26	16.3 (2.1), 10–25	$F(1,419)=0.87, P = .353$
<b>1st intercourse (debut)</b>	17.4 (2.2), 11-25	16.2	$t = 11.13, P < .001, g = 0.55$	17.3 (2.2), 13–24	17.5 (2.1), 11–25	$F(1,404) = 0.69, P = .407$
<b>1st time in love</b>	14.4 (3.1), 3-24			14.7 (3.1), 3–24	13.8 (3.0), 6–23	$F(1,465) = 8.98, P = .003$
<b>Sexual satisfaction</b> ‡	5.5 (1.3), 1-7			5.5 (1.3), 1–7	5.6 (1.3), 2–7	$t(454)=0.782, P = .435$
<b>Sexual dysfunction</b> §	25.1 (23.3), 0-83.3			32.3 (23.3), 0–83.3	12.6 (17.3), 0–66.7	$t(340)=-8.24, P < .001$

Values printed in bold indicate statistically significant differences.

\*Comparisons are based on reported percentages of N = 1,533 German 21–25 year-olds, based on references #31 and personal communication with S. Scharmanski.

†normative data specified experience with breast petting (87%), petting of male genitals (85%) and female genitals (77%). Compared to the generic ‘petting and intimacy’ in this study,  $\chi^2$ -test were respectively:  $\chi^2 = 0.66, P = .403$ ;  $\chi^2 = 3.34, P = .067$ , and  $\chi^2 = 16.53, P < .001$ .

‡n = 456 due to missing data; comparisons between males and females are based on all available survivors, as opposed to experienced survivors (n=390) as reported in text.

§n = 342 who were sexually active with a partner in the past 6 month.

**Table 3.** Perceptions of timing

Milestones	Experienced n (%) *	Inexperienced n (%)
<b>1st relationship</b>	407 (82.7%)	85 (17.3%)
right time:	296 (60.2%)	wanted: †
too late:	47 (9.6%)	6.7 (2.8), 0–10
too early:	62 (12.6%)	
<b>1st kiss</b>	451 (91.7%)	41 (8.3%)
right time:	315 (64.0%)	wanted: †
too late:	57 (11.6%)	6.7 (3.3), 0–10
too early:	74 (15.0%)	
<b>1st intimacy/ petting</b>	421 (86.6%)	71 (14.4%)
right time:	298 (60.6%)	wanted: †
too late:	43 (8.7%)	5.5 (3.4), 0–10
too early:	77 (15.7%)	
<b>1st intercourse (debut)</b>	406 (82.5%)	86 (17.5%)
right time:	287 (58.3%)	wanted: †
too late:	55 (11.2%)	5.6 (3.1), 0–10
too early:	59 (12.0%)	
<b>1st time in love</b>	467 (94.9%)	25 (5.1%)
right time:	381 (77.4%)	wanted: †
too late:	24 (4.9%)	6.4 (3.2), 0–10
too early:	50 (10.2%)	

\*percentages may not add to 100% due to 1-10 missings.

†see Appendix for each item wording.

led to small/empty cells in  $\chi^2$ -analyses. Consequently, these tests could only be conducted for 2 of the 5 milestones (ie, first relationship, sexual debut), which showed 1 significant difference: Survivors of CNS tumors were less likely to have had their sexual debut (66.0% vs 82.5%–90.2% of the other 3 groups;  $P < .001$ ). Other comparisons by age at diagnosis or years since diagnosis did not yield significant results ( $ps > .1$ ) with mean differences smaller than 1 year between survivors who had or had not attained each of the 5 milestones.

Relative to normative data (N = 1,533; age 21–25years), similar proportions of survivors and the normative group have had their first kiss (91.7% vs 94%;  $P = .069$ ). Regarding physical intimacy/fondling, normative data were collected in greater detail by separating experiences with breast petting (87%) vs fondling of male (85%) and female genitals (77%). Our more generic assessment of physical intimacy fell in-between these normative data (85.6%; see Table 2). Sexual debut differed between survivors and the normative group, with survivors less likely to have experienced sexual intercourse (82.5% vs 88%;  $P = .002$ ).

The proportion of those with no experience of any milestone was comparable between survivors and the normative group (3% vs 5%;  $P = .103$ ). Inexperienced survivors reported how much they wanted a particular milestone to occur. Highest scores were reported for desiring a relationship ( $M = 6.7$ ) and lowest scores for wanting to engage in sexual intercourse ( $M = 5.6$ ) or physical intimacy ( $M = 5.5$ ; Table 3).

### Age and Perceived Timing

Survivors’ mean ages of attaining each of the 5 milestones of psychosexual development ranged between 14.8 years (first kiss) and 17.4 years (sexual debut; Table 2). Sex differences were indicated for 2 milestones. Female survivors were somewhat older when they had their first kiss (15.2 vs 14.4,  $P = .008$ ,  $g = 0.26$ ) and the first time they fell in love (14.7 vs 13.9,  $P = .003$ ,  $g = 0.28$ ; Table 2). Mean ages of milestone attainment did not differ by type of diagnosis, except for physical intimacy ( $P = .025$ ) where leukemia survivors were younger than survivors with “other” diagnoses when they first experienced physical intimacy (16.1 vs 17.0,  $g = 0.41$ ). Age at diagnosis was uncorrelated with age at any milestone attainment ( $r < 0.1$ ;  $P > .1$ ), even when dichotomizing age at diagnosis (ie, diagnosed during childhood vs. adolescence;  $P > .2$ ).

Relative to normative data, survivors were significantly older at sexual debut ( $M = 17.4$  vs 16.2 years;  $P < .001$ ;  $g = 0.55$ ). Nevertheless, most survivors still thought this was the “right” time (58.3%) or even wished that they had waited longer (12.0%). Overall, survivors’ perceived timing of their milestone attainment was predominantly “right,” which was indicated among 70.6% (first kiss) and up to 83.7% (first time in love). Thus, only a few survivors indicated they had reached their milestones too late (5.3%–13.7%) or too early (11.0%–18.4%; Table 3).

### Sexual Satisfaction

Complete data on sexual satisfaction was available from  $n = 446$  survivors and differed by sexual debut: Survivors who only had experiences with self-pleasure/masturbation (ie, no sexual debut;  $n = 66$ ) reported lower satisfaction than those with previous experiences of sexual intercourse ( $M = 5.8$  vs  $4.3$ ;  $t(454) = 9.16, P < .001, g = 1.22$ ). Among survivors with sexual debut ( $n = 390$ ), sexual satisfaction did not differ by survivors' sex ( $t(388)=1.91, P = .057, g = 0.20$ ), age at diagnosis (childhood vs adolescence;  $t(388) = 1.22, P = .224, g = 0.14$ ), years since diagnosis ( $r = .071, P = .159$ ), or type of diagnosis ( $F(3,386) = 0.15, P = .929, g = 0.03-0.10$ ) at the univariate level. However, it differed by current relationship status, where partnered survivors were more satisfied than singles ( $M = 6.0$  vs  $5.3$ ;  $t(387) = 5.93, P < .001, g = 0.62$ ).

Thus, the final ANOVA assessing potential effects of perceived timing of sexual debut (right, too early/late) on sexual satisfaction included relationship status. Moreover and as indicated above, sex and type of diagnosis were related to psychosexual development and included as well (incl. their interaction with each other and with timing perceptions). This ANOVA reiterated the significant effect of relationship status ( $F(1, 367) = 36.83, P < .001$ ) and showed significant differences by sex ( $F(1,367) = 6.95, P = .009$ ) with men reporting higher satisfaction, and by timing perceptions ( $F(2, 367) = 3.62, P = .028$ ), where survivors who perceived their sexual debut as having happened at the 'right' time reported significantly higher satisfaction ( $M = 5.9$ ;  $n = 277$ ) than those who wished they had waited (too early,  $M = 5.4$ ;  $n = 56$ ) and those who felt it had happened too late ( $M = 5.5$ ;  $n = 54$ ; the latter 2 were similar as indicated by post hoc tests,  $ps < .03$ ). These constitute small to moderate differences ( $g = 0.37-0.43$ ). More importantly, the interaction between sex and timing perceptions was significant ( $F(2,367) = 3.70, P = .026$ ). Male and female survivors who perceived having had their sexual debut at the right time reported the same level of satisfaction. Yet, among those who perceived their debut as having happened too early or too late, female survivors were less satisfied than male survivors (see Figure 2).

### Sexual Functioning

Most survivors (86%,  $n = 349/406$  with sexual debut) were sexually active in the 6 months prior to data collection and were asked to complete the MOS ( $n = 342$  completers). Of these, most (60.2%) indicated not/barely impaired sexual functioning (ie, scores  $\leq 25$ ; Figure 1). Sexual functioning differed between male and female survivors ( $P < .001$ ), where female survivors indicated greater impairment ( $M = 32.3$  vs  $12.6, g = 0.92$ ). Sexual functioning also differed by age at diagnosis ( $t(340) = 2.36, P = .019$ ). Those diagnosed in childhood reported better sexual functioning than those diagnosed in adolescence ( $M = 23.4$  vs  $30.1, g = 0.29$ ). Sexual functioning did not differ by relationship status ( $t(338) = 0.41, P = .681, g = 0.05$ ) or type of diagnosis ( $F(3,338) = 0.61, P = .609, g = 0.00-0.18$ ). It was weakly

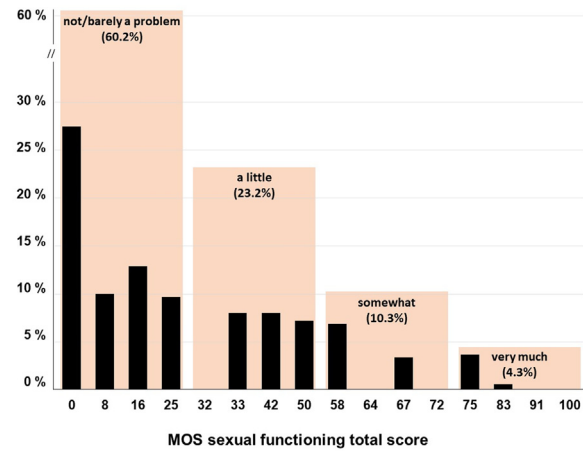


Figure 1. Distribution and categorization of MOS sexual functioning scores. Figure is available in color online at [www.jsm.jsexmed.org](http://www.jsm.jsexmed.org).

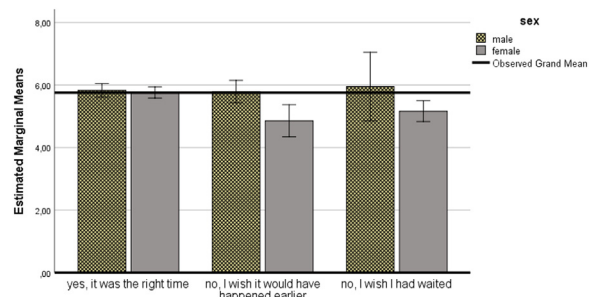
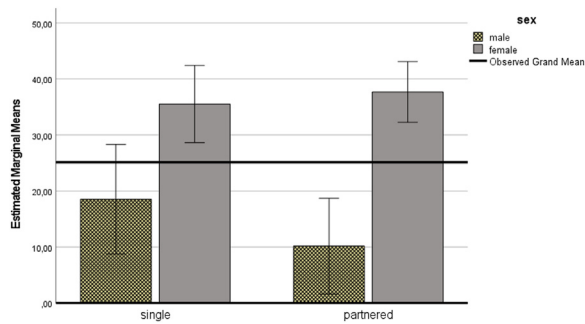


Figure 2. Estimated marginal means of sexual satisfaction (GMSEX) for male and female survivors by timing perceptions of their sexual debut. Figure is available in color online at [www.jsm.jsexmed.org](http://www.jsm.jsexmed.org).

related to years since diagnosis ( $r = -0.149, P = .006$ ), such that a longer time since diagnosis was related to better sexual functioning; whereas age was unrelated to sexual functioning ( $r = -0.095, P = .080$ ).

Thus, the final ANCOVA for sexual functioning and potential effects of timing perceptions included sex, relationship status, age at diagnosis (childhood vs adolescence), and type of diagnosis, while controlling for years since diagnosis (continuous), based on all previously identified differences (and including interaction terms). Sex ( $F(1,312) = 22.48, P < .001$ ) and years since diagnosis ( $F(1,312) = 3.89, P = .049$ ) were significant, but timing perceptions ( $F(2, 312) = 2.13, P = .120$ ), relationship status ( $F(1,312) = 1.18, P = .278$ ), and age at diagnosis ( $F(1,312) = 0.01, P = .960$ ) were not. Importantly, the interaction of sex and current relationship status was related to sexual dysfunction ( $F(1,312) = 3.89, P = .049$ ) where female survivors reported similar levels of sexual dysfunction irrespective of their relationship status, while partnered male survivors reported particularly low dysfunction scores (Figure 3).





**Figure 3.** Estimated marginal means of sexual functioning (MOS) by relationship status for male and female survivors. Figure is available in color online at [www.jsm.jsexmed.org](http://www.jsm.jsexmed.org).

Sexual satisfaction and functioning were moderately correlated ( $r = -0.485$ ,  $P < .001$ ), which appeared to be driven by female survivors. Their satisfaction and functioning were moderately correlated ( $r = -0.572$ ,  $P < .001$ ), while it was weakly associated in male survivors ( $r = -0.229$ ,  $P = .012$ ).

## DISCUSSION

This study adds to the scarce literature of psychosexual development and sexual functioning in young adult survivors of childhood cancer and shows several differences within the large study sample and relative to normative data. Survivors' psychosexual development is comparable to normative data, except for sexual debut which was less often attained and delayed, but survivors perceived it as occurring at the "right" time. Sexual satisfaction in adulthood differed based on survivors' perceived timing of sexual debut, whereas sexual functioning did not. Yet, survivors' sex and current relationship status may play an important role.

Among survivors, attainment of milestones differed between male and female survivors with women being more likely to have experiences with relationships, kissing, and physical intimacy/fondling. Sex differences have barely been tested in previous studies, likely due to limited sample sizes, but one large study also reported more milestone attainment among female survivors.<sup>6</sup> Although more likely to attain, female survivors in our study were somewhat older when they had their first kiss and when falling in love for the first time. This is interesting because some studies indicated that particularly female survivors' may worry about and struggle with (sexual) intimacy,<sup>3,10,21</sup> which could hamper their psychosexual development. However, it is possible that some late effects of treatment (eg, short stature) may hinder the attainment of milestones in male survivors to a greater extent, because these comply less with the Western masculine body ideal.<sup>36-38</sup> Similarly, male survivors seem to live longer with their parents,<sup>6</sup> which could hamper their independence and exploration of sexuality. All potentially contributing to sex differences in milestone attainment between male and female survivors.

Another important finding, in line with previous research, is that survivors of CNS tumors were less likely to have experienced

their sexual debut.<sup>9,12,13</sup> This might also extend other studies among CNS tumor survivors showing impaired social skills and difficulties interacting with peers.<sup>39-41</sup> Notably, CNS tumor survivors who had experienced their sexual debut did so at the same age as other survivors. Thus, the diagnosis itself may be less informative and other indicators need to be considered (eg, neurocognitive treatment toxicity<sup>9</sup> or functioning).

Proportions of survivors who had experience with kissing, fondling, and boy/girlfriends were comparable to normative data. Similarly, the number of survivors and participants from the normative group with no sexual experience (by age 26) was comparable, which echoes previous research highlighting normative development among survivors.<sup>9-11,42</sup> Yet, survivors were less likely to have had their sexual debut and they were older at sexual debut showing moderately sized effects ( $g = 0.55$ ) and replicating previous findings.<sup>6,8</sup> Clinical practice and future research should consider that sexual debut may differ between survivors and the normative group, but other forms of intimacy may not. Different factors that are important to attaining different milestones should also be examined, such as social networks, self-esteem, or independent living. Interestingly, age at cancer diagnosis did not influence psychosexual development. This was unexpected, as cancer diagnoses in adolescence is thought to hamper social development and exploration of sexuality with peers.<sup>3,8,21</sup> However, other studies also highlighted that some survivors try to compensate for missed time with peers by rushing into relationships,<sup>10,43</sup> thus balancing out potential differences.

Sexual *satisfaction* differed by whether survivors have had their sexual debut. Survivors who only ever pleased themselves (ie, masturbation) reported lower satisfaction, which is intuitive given that inexperienced survivors also reported rather moderate levels of wanting to reach this milestone. Singles were less satisfied than partnered survivors, which aligns with findings in the general population<sup>44,45</sup> and childhood cancer survivors.<sup>24</sup> More importantly, sexual satisfaction differed by survivors' perceived timing of sexual debut (small to moderate effects) and in conjunction with survivors' sex. Male and female survivors who felt they had their sexual debut at the "right" time, reported similar and the highest levels of satisfaction. In contrast, if timing was off (ie, perceived as too early or late), female survivors reported lower levels of sexual satisfaction, while men reported the same satisfaction regardless of their perceived timing. Previous studies on male and female childhood cancer survivors' sexual satisfaction<sup>23-25</sup> did not directly compare both sexes as comparisons to control groups were emphasized. Our data suggest that the timing of sexual debut may affect women's sexual experiences later in life differently than men's, but effects may also work the other way around: Survivors who are sexually satisfied in adulthood may think positively of the timing of their sexual debut in hindsight and consider it right for them. Thus, causal testing in longitudinal designs is still needed to better assess adult sexuality after childhood cancer. Our findings may indicate that a self-determined attitude toward the own sexuality (ie, engaging in sexual

activities at a personally “right” time) can determine a generally positive experience of sex.<sup>46,47</sup>

Sexual *functioning* did not differ by timing perceptions nor current relationship status, but by the interplay of relationship status and sex. Female survivors reported more impaired sexual functioning than males, which is in line with previous research,<sup>16,17,19</sup> and which was the case regardless of their current relationship status (single or partnered). In contrast, male survivors reported better sexual functioning than females, with partnered men experiencing the least sexual impairment, particularly relative to partnered women. Mechanisms that explain why relationship status may affect men and women differently remain to be tested. Yet, survivors reported overall rather favorable sexual functioning with most (60.2%) reporting no/barely any problems, whereas only 4.3% of survivors experienced “very problematic” sexual functioning. This is positive and also more favorable than another recent study using the MOS.<sup>30</sup> They reported no problems in 48% and very problematic sexual functioning in 15.4% of survivors of adolescent and young adult (AYA) cancer. The difference in age at diagnosis, as well as the young age of our sample ( $\leq 26$  years) and longer time since diagnosis ( $M = 15$  years) may partly explain such differences. Yet, our results are still more favorable than other studies in childhood cancer survivors,<sup>15–19</sup> potentially due to the young age of our sample. Generally, time since diagnosis should be considered. Although only weakly correlated, longer time since diagnosis may allow for better adjustment and hence better sexual functioning in adulthood. Time since diagnosis can become very long in childhood cancer survivors (ie, up to decades), and sometimes survivors do not recall their time of treatment. Accordingly, survivors themselves may not connect any (sexual) problems to their former disease.<sup>20</sup> While this is overall positive in the sense that many survivors are thriving, they should be made aware of potential sexual problems that can directly arise from their former treatment (eg, symptoms of premature ovarian insufficiency, nerve damage). Additionally, many survivors are sexually inexperienced before diagnosis and they are unable to compare or do not have to adjust to an altered body and sexual self. These aspects may work in favor of young adult survivors protecting them against very negative effects of cancer on sexual functioning.

Besides offering valuable new insights, some limitations should be considered. The response rate was low (31%) but rather typical for this unique population, and this sample of almost 500 survivors is among the largest studies on psychosexual development after childhood cancer. Comparisons to normative data can be highlighted as strength, and although the normative sample was not specifically matched to survivors, both samples were similar in age, sex ( $\sim 60\%$  female), and recruited in similar years (2018–2019) in Germany. The MOS-Sexual Functioning Scale is generic and short, providing little detail, but minimizes the burden of completion for participants. Notably, male and female survivors differed on the MOS-total score and all separate items, meaning that the differences found in functioning were not driven by the sex-specific items assessing either erectile or

orgasm functioning. The MOS is also inclusive of any sexual orientation and any (un)partnered sexual activities. Sexual satisfaction and functioning scores were skewed, which is typical but also limits the robustness of analyses, and hence our addition of effect sizes. Presented data constitute self-report and retrospective reports of psychosexual development potentially introducing recall bias. Yet, and if indicated this would apply to both, survivors and normative data. Finally, medical background information based on registry data was limited and future research should consider more detail (eg, treatment toxicities).

This is the first study to link psychosexual development in young adult survivors of childhood cancer to sexual function and satisfaction, and to assess psychosexual development relative to large-scale normative data. Survivors delayed their sexual debut, but are comfortable with it. Perceived timing of sexual debut can be influential for sexual satisfaction, particularly in female survivors. Perceived timing was not influential for functioning for the entire group, but survivors’ sex and current relationship status may be taken into account. Overall, sexual satisfaction and functioning was favorable in this very young adult sample, but providers may pay attention to female, single, and/or CNS tumor survivors for potential sexual problems. Future research should continue to assess psychosexual development and sexual health in greater detail, and consider additional medical factors (eg, type of treatment) and other social, psychological, and environmental factors (eg, peer groups, self-esteem, autonomy).

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## STATEMENT OF AUTHORSHIP

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## SUPPLEMENTARY MATERIALS

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