



# University of Groningen

# Disclosing a history of childhood cancer to romantic partners

Bos-van den Hoek, Danique W.; Tuinman, Marrit A.; Hillen, Marij A.; Huijgens, Fiorella L.; Kurpershoek, Elisabeth; Calaminus, Gabriele; Kaatsch, Peter; Hagedoorn, Mariët; Lehmann, Vicky

Published in: Psycho-oncology

10.1002/pon.6130

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version Publisher's PDF, also known as Version of record

Publication date: 2023

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

Bos-van den Hoek, D. W., Tuinman, M. A., Hillen, M. A., Huijgens, F. L., Kurpershoek, E., Calaminus, G., Kaatsch, P., Hagedoorn, M., & Lehmann, V. (2023). Disclosing a history of childhood cancer to romantic partners. Psycho-oncology, 32(6), 904-912. https://doi.org/10.1002/pon.6130

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: https://www.rug.nl/library/open-access/self-archiving-pure/taverneamendment.

**Take-down policy**If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

# **ORIGINAL ARTICLE**

WILEY

# Disclosing a history of childhood cancer to romantic partners

Danique W. Bos-van den Hoek<sup>1,2,3</sup> | Marrit A. Tuinman<sup>4</sup> | Marij A. Hillen<sup>1,2,3</sup> | Fiorella L. Huijgens<sup>1,2,3</sup> | Elisabeth Kurpershoek<sup>1,2</sup> | Gabriele Calaminus<sup>5</sup> | Peter Kaatsch<sup>6</sup> | Mariët Hagedoorn<sup>4</sup> | Vicky Lehmann<sup>1,3</sup> •

### Correspondence

Danique W. Bos-van den Hoek. Email: d.w.bos@amsterdamumc.nl

### **Funding information**

The German Cancer Aid [Deutsche Krebshilfe], Grant/Award Number: 70112102

### **Abstract**

**Objective:** To describe young adult childhood cancer survivors' disclosure of their cancer history (i.e., disclosure behavior, difficulty, and timing), perceived partner responses, and associations with relationship status satisfaction.

**Methods:** German long-term survivors of childhood cancer (N = 509; response rate: 31.3%, age 21–26, 59.7% female) completed a registry-based nationwide survey (embedded mixed methods design, including closed and open-ended questions) on measures about disclosure history (behavior, difficulty, and timing), partner responses, and relationship status satisfaction. Statistical ( $\chi^2$ -, t-, or F-tests) and qualitative analyses were conducted.

Results: Half of all survivors always disclosed their cancer history to romantic partners. Thereby, three themes for considering (non-)disclosure were identified: Survivors' attitudes, having integrated cancer as part of their identity, and anticipated effects on romantic relationships. About 40% indicated having no difficulties with disclosing their cancer history. The timing of disclosure varied, with most survivors disclosing after a few dates. Facilitators of disclosure were the visibility of their former illness (e.g., scars), having trust in a (potential) partner, getting older/ mature, and previous positive experiences with disclosure. Few survivors (13.8%) had ever experienced negative responses from dating partners. Yet, those who had negative experiences, found it more difficult to disclose their cancer history. Survivors were overall rather satisfied with their relationship status, with partnered survivors reporting greater satisfaction than singles (Hedge's g = 1.68); and particularly partnered survivors with past positive responses being most satisfied. **Conclusions:** Young adult childhood cancer survivors appear rather open in disclosing their cancer history to (potential) romantic partners, and few experienced negative responses. Psycho-educational programs may emphasize such findings in helping to prevent fear of disclosure or avoidance of dating and disclosure among survivors.

### KEYWORDS

 $childhood\ cancer,\ disclosure,\ oncology,\ psycho-oncology,\ romantic\ relationships,\ survivorship,\ young\ adulthood$ 

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. Psycho-Oncology published by John Wiley & Sons Ltd.

<sup>&</sup>lt;sup>1</sup>Department of Medical Psychology, Amsterdam UMC location University of Amsterdam, Amsterdam, The Netherlands

<sup>&</sup>lt;sup>2</sup>Quality of Care Program, Amsterdam Public Health Research Institute, Amsterdam, The Netherlands

<sup>&</sup>lt;sup>3</sup>Cancer Center Amsterdam, Cancer Treatment and Quality of Life, Amsterdam, The Netherlands

<sup>&</sup>lt;sup>4</sup>Department of Health Psychology, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

<sup>&</sup>lt;sup>5</sup>Department of Pediatric Hematology and Oncology, University Hospital Bonn, Bonn, Germany

<sup>&</sup>lt;sup>6</sup>German Childhood Cancer Registry (GCCR), Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI), University Medical Center Mainz, Mainz, Germany

# **BACKGROUND**

Cancer during childhood can have major long-term effects on survivors' subsequent lives, including their psychosocial functioning and romantic/psychosexual development during puberty and emerging adulthood. 1-9 Initiating or maintaining romantic relationships may be disrupted by physical impairments, worries about infertility, body image concerns, sexual dysfunction, stigmatization, impaired social skills and prolonged time away from peers during treatment. 1-3,10-13 Qualitative studies showed that young adult survivors of childhood cancer sometimes felt unfit as dating partners, unattractive, or less sexually adventurous than healthy peers. 12,14-17 Even after survivors successfully initiate relationships, they often worry about breakups.<sup>18</sup>

In addition to potential effects of cancer and treatment on dating, survivors' behaviors of (not) disclosing their cancer history (i.e., communicating facts, thoughts, and feelings about the cancer experience), may also directly affect their romantic relationships. In general, disclosing personal life events, emotions, or experiences when dating can enhance closeness and intimacy with a (potential) partner. 19-22 Yet, such disclosure may be particularly difficult when one has to disclose a cancer history, as indicated in qualitative studies in young adult survivors. 1,2,13,20 They were unsure about when and which information to disclose, 13 while also worrying about partners' responses, being rejected, and being perceived as different or vulnerable. 2,13,20,21,23 Another qualitative study reported that survivors felt dismissed, disappointed, or frustrated by responses after disclosing their cancer history.<sup>2</sup> At the same time, survivors might feel obliged to share such information with potential partners. 13

Disclosing or withholding a cancer history may also influence survivors' satisfaction with their relationship status (i.e., how happy they are being single or partnered), which could also affect their general well-being and satisfaction with life.<sup>24</sup> Survivors who hesitate to disclose may avoid dating<sup>13,25</sup> and remain single unintentionally. Survivors who are partnered may strain their existing relationships by hesitating or delaying disclosure of their cancer history, 13 potentially jeopardizing partners' trust, their own satisfaction, or quality of life.

Although the aforementioned qualitative studies have yielded some insights into childhood cancer survivors' experiences and concerns surrounding romantic relationships and disclosure, large-scale systematic data are missing. Such insights are needed to offer evidence-based psychosocial counseling and patient education materials, to support survivors in their psychosexual/psychosocial development later in life.<sup>26</sup> Therefore, this study will extend the previous literature by describing childhood cancer survivors' disclosure history (i.e., disclosure behavior, difficulty, timing), perceived partner responses, and relationship status satisfaction. Associations between these variables and differences by background factors will be tested. Moreover, these quantitative responses will be substantiated by qualitatively analyzing open-ended comments of survivors.

# **METHODS**

### **Procedures**

An embedded mixed methods design was adopted, which entailed the simultaneous collection of qualitative data to enrich quantitative data.<sup>27</sup> Presented data are part of a larger collaboration (E-Surv), containing two study parts: VIVE (focus: medical late effects) and InRel (focus: intimate relationships of childhood cancer survivors).<sup>28</sup> Data were collected by mailing information packages and reminders between April-August 2018 through the German Childhood Cancer Registry (GCCR). Survivors were randomly assigned to complete an online or paper questionnaire, and provided informed consent accordingly. Survivors were assigned an anonymized ID and only the GCCR had access to the key code linking IDs and survivors. Thus, survey responses and identifiable information were stored separately and personal data were protected at all times. The Medical Ethical Committee and data protection officer of the University Medical Center Bonn approved the study (#138/17).

Eligible participants had been diagnosed with any type of cancer before age 18, were long-term survivors (≥5 years post-diagnosis), emerging adults (age 20-25 years), and lived in Germany at the time of study. Based on these criteria, the GCCR randomly selected N = 2000 eligible survivors (note: participants were age 21–26 years at participation due to logistical delays).

A total of n = 622 survivors responded (31.1%), of whom n = 89refused to participate and n = 7 withdrew participation (see InRel).<sup>28</sup> Responders were somewhat younger (23.3 vs. 24.0 years; p < 0.001) and more often female (39.6% female vs. 24.2% male; p < 0.001) than the initial pool of 2000 eligible participants, but they did not differ by type of diagnosis (p = 0.463) nor age at diagnosis (p = 0.369). Responders (n = 526) were able to skip any question throughout the survey and, for the presented analyses, we retained any survivor with complete data on disclosure, resulting in a final sample of N = 509. One quarter of these survivors (n = 126/509) shared additional open-ended comments about disclosure for qualitative content analyses.

# Measures

### 2.2.1 | Background information

Relationship status and sex were self-reported. Age and clinical data (incl. age at and type of diagnosis) were supplied by the GCCR.

# Disclosure history and responses

Face-valid multiple choice questions (Supporting Information S1: Appendix A) were completed by survivors assessing (a) disclosure behaviors, that is, whether they typically disclose their cancer

experience to romantic partners (never; always; not to everyone; see all response options in Supporting Information S1: Appendix A), (b) disclosure difficulty was measured on a visual analogue scale, ranging from 0 to 10 (not at all-very much), and (c) disclosure timing, that is, when survivors typically disclose (never; around the first date; after a few dates; and an open-response option). Two items assessed (d) positive and (e) negative perceived responses from potential partners (never; once/several times/always; Supporting Information S1: Appendix A). Finally, survivors were able to provide (f) any additional comments about their experiences of disclosing cancer to (potential) partners.

### Relationship status satisfaction

The Relationship Status Satisfaction Scale (ReSta)<sup>24</sup> measures satisfaction with either being in a relationship/married or being single, depending on a person's relationship status. ReSta consists of five items answered on a 4-point Likert scale, which are summed to one total score with higher scores indicating greater satisfaction. ReSta was previously found to have sound psychometric properties.<sup>24,29</sup> Cronbach's alpha was 0.94 in this study.

#### 2.3 Analyses

Descriptive statistics of survivors' disclosure history (behaviors, difficulty, timing) and perceived partner responses were reported. Associations of disclosure variables with each other and differences by background factors were tested, using  $\chi^2$ -, t-, or F-tests depending on the used factors. Open-ended responses were qualitatively analyzed by means of thematic content analysis.<sup>30</sup> Initial coding was independently done by two authors (DWBH, VL), and subsequently discussed among all authors until agreement was reached.

Descriptive statistics of ReSta were reported and tested for differences by background factors. Three subsequent models utilizing Analyses of Variance were conducted: The first model tested the effects of disclosure on relationship status satisfaction. Second, positive and negative partner responses and interaction terms with significantly related disclosure variables were added. In the third model, background factors, which were significantly (p < 0.05) related to ReSta at the univariate level, were added along with their interaction terms.

With N = 509 survivors, post hoc power analyses indicated ample power (>0.9) for the intended analyses to detect even small effects (Hedge's g = 0.2). Therefore, comparisons for continuous variables were accompanied by effect size calculations ( $g \ge 0.2$ considered small,  $\geq 0.5$  moderate, or  $\geq 0.8$  large effect), whereas percentages were used for categorical variables to better guide interpreting the clinical significance of findings.

# 3 | RESULTS

#### 3.1 **Participants**

Survivors (N = 509) were on average age 23.3 years, mostly female (59.7%), and partnered (51.6%). They had been diagnosed around age 8.9 years, and most were diagnosed during childhood (age  $\leq$ 12; 76.8%) and with leukemia (39.5%). Years since diagnosis ranged between 6 and 26 years (Table 1).

#### 3.2 Disclosure behaviors

About half of survivors (n = 252, 49.5%) indicated to always disclose their cancer history to (potential) partners, whereas n = 191 (37.5%)disclosed not to everyone (including n = 11 who had not disclosed to their current partner), and n = 66 (13.0%) typically never/not yet disclosed to any romantic partner (Table 1). Such disclosure behaviors differed by relationship status ( $\chi^2(2) = 55.53$ , p < 0.001), sex  $(\chi^2(2) = 9.28, p = 0.009)$ , and type of diagnosis  $(\chi^2(2) = 15.69,$ p < 0.001). Specifically, 36.3% single versus 61.7% partnered survivors had always disclosed their cancer history. Male survivors reported more often to never disclose (18.5% vs. 9.2% females) as well as survivors of CNS-tumors (24.8% vs. 10.0% of all other diagnostic groups). Age at diagnosis was significant when dichotomized (i.e., childhood vs. teenage years;  $\chi^2(2) = 7.16$ , p = 0.028; see Table 1), with survivors diagnosed during childhood being more likely to never disclose than those diagnosed as teenagers (15.1% vs. 5.9%). However, when treated as continuous variable, age at diagnosis was unrelated to disclosure; as well as years since diagnosis.

Qualitative analyses indicated three main considerations for whether survivors disclosed their cancer history (see quotes in Supporting Information S1: Appendix B). First, survivors' attitude toward disclosure determined their subsequent behaviors: Some perceived cancer as taboo in society and feared misperceptions/ prejudices, making it difficult to disclose. Others regarded openness toward (potential) partners as vital. Second, survivors' disclosure behaviors were influenced by the extent to which cancer had become part of their identity/self-image. For example, even if negative, cancer had shaped them, changed their perspective on life, and sometimes made them proud. Others were hesitant to disclose due to worrying about being perceived as sick or weak. Thereby, the extent of late effects affecting survivors' daily life varied, which also affected their self-image and disclosure behaviors. Third, anticipated effects on romantic relationship influenced survivors' decisions about disclosure. Some experienced disclosing their cancer history as a test for the relationship or an opportunity to gain a deeper connection and understanding. Few survivors called their cancer history an asset while dating, because they felt they were more interesting for dates. In contrast, others mentioned refraining from disclosure because it felt burdensome for the relationship or they were afraid of negative responses (see also Supporting Information S1: Appendix B).

Disclosure history, partner responses, and relationship status satisfaction for all survivors and by subgroups based on background factors. TABLE 1

		Relationship status <sup>a</sup>	status <sup>a</sup>	Sex		Type of diagnosis <sup>b</sup>	osis <sup>b</sup>	Age at diagnosis <sup>c</sup>	sis <sup>c</sup>	
	Total N (%)	Partnered n (%)	Single n (%)	Female n (%)	Male n (%)	CNS n (%)	Other n (%)	≤12 years n (%)	13+ years n (%)	Years since diagnosis Mean (SD), range
	509 (100.0)	0.0) 261 (51.6)	245 (48.4)	304 (59.7)	205 (40.3)	101 (19.8)	408 (80.2)	391 (76.8)	118 (23.2)	14.9 (4.9), 6–26
Disclosure behavior										
Always	252 (49.5)	5) 161 (61.7)	89 (36.3)	156 (51.3)	96 (46.8)	45 (44.6)	207 (50.7)	186 (47.6)	66 (55.9)	14.7 (5.0)
Not to everyone <sup>d</sup>	191 (37.5)	5) 91 (34.9)	99 (40.4)	120 (39.5)	71 (34.6)	31 (30.7)	160 (39.2)	146 (37.3)	45 (38.1)	14.8 (5.0)
Never/not yet	66 (13.0)	9 (3.4)	57 (23.3)	28 (9.2)	38 (18.5)	25 (24.8)	41 (10.0)	59 (15.1)	7 (5.9)	15.8 (4.3)
Subgroup comparisons		$\chi^2(2) = 55.5$	$\chi^2(2) = 55.53, p < 0.001$	$\chi^2(2) = 9.48, p = 0.009$	p = 0.009	$\chi^2(2) = 15.69, p < 0.001$	p < 0.001	$\chi^2(2) = 7.16, p = 0.028$	0 = 0.028	F(2,506) = 1.40, p = 0.247
Difficulty disclosing $(n = 504)$	504)									
(Somewhat) difficult	311 (61.7)	7) 153 (58.8)	156 (64.7)	203 (67.2)	108 (53.5)	62 (62.6)	249 (61.5)	244 (63.2)	67 (56.8)	14.8 (5.2)
Not at all	193 (38.3)	3) 107 (41.2)	85 (35.3)	99 (32.8)	94 (46.5)	37 (37.4)	156 (38.5)	142 (36.8)	51 (43.2)	15.0 (4.8)
Subgroup comparisons		$\chi^2(1) = 1.83, p = 0.176$	p = 0.176	$\chi^2(1) = 9.69, p = 0.002$	p = 0.002	$\chi^2(1) = 0.04, p = 0.834$	<i>γ</i> = 0.834	$\chi^2(1) = 1.58, p$	0 = 0.208	t(502) = -0.35, p = 0.724
Partner responses										
Negative $(n = 442)^e$										
Yes	70 (15.8)	32 (12.7)	37 (19.6)	43 (15.9)	27 (15.8)	15 (18.5)	55 (15.2)	50 (15.2)	20 (17.9)	14.4 (5.5)
°N N	372 (84.2)	2) 219 (87.3)	152 (80.4)	228 (84.1)	144 (84.2)	66 (81.5)	306 (84.8)	280 (84.8)	92 (82.1)	14.9 (4.9)
Subgroup comparisons	s	$\chi^2(1) = 3.80, p = 0.051$	p = 0.051	$\chi^2(1) = 0.00, p = 0.983$	p = 0.983	$\chi^2(1) = 0.54, p = 0.465$	<i>i</i> = 0.465	$\chi^2(1) = 0.46, p = 0.498$	0 = 0.498	t(440) = 0.78, p = 0.436
Positive $(n = 440)^{e}$										
Yes	386 (87.7)	7) 231 (92.4)	154 (81.9)	240 (88.9)	146 (85.9)	62 (77.5)	324 (90.0)	288 (87.5)	98 (88.3)	14.7 (5.0)
N <sub>O</sub>	54 (12.3)	19 (7.6)	34 (18.1)	30 (11.1)	24 (14.1)	18 (22.5)	36 (10.0)	41 (12.5)	13 (11.7)	15.2 (4.8)
Subgroup comparisons	S	$\chi^2(1) = 11.0$	$\chi^2(1) = 11.09, p = 0.001$	$\chi^2(1) = 0.88, p = 0.349$	p = 0.349	$\chi^2(1) = 9.50, p = 0.002$	، = 0.002	$\chi^2(1) = 0.04, p = 0.835$	0 = 0.835	t(438) = 0.66, p = 0.509
Satisfaction with Relationship Status Scale (ReSta)	Mean (SD)	Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)		
	15.8 (4.3)	18.5 (2.3)	12.9 (4.2)	16.2 (4.3)	15.2 (4.4)	14.3 (4.7)	16.2 (4.2)	15.6 (4.4)	16.4 (4.2)	•
Subgroup comparisons		t(504) = -18.86, p < 0.001	p < 0.001	t(507) = -2.51, p = 0.013	p = 0.013	t(140.48) = 3.	t(140.48) = 3.65, p < 0.001	t(507) = -	t(507) = -1.67, p = 0.097	r = 0.004, p = 0.928

<sup>&</sup>lt;sup>a</sup>Partnered survivors included n = 239 in a committed relationship and n = 22 married (n = 3 missings).

<sup>&</sup>lt;sup>b</sup>Other types of diagnoses: leukemia (n = 201, 39.5%), lymphoma (n = 101, 19.8%) and other (n = 106, 20.8%); Dichotomizing CNS versus other diagnostic groups was based on the finding that if differences occurred it was always between CNS-tumor survivors versus all others.

<sup>&#</sup>x27;Mean (SD) age at diagnosis: 7.9 (4.8), range: 0-17 years; Mean (SD) age at study: 23.3 (1.5), range: 21-26 years.

 $<sup>^{</sup>d}$ Including n=11 who indicated they disclosed in the past, but not to their current partner (not warranting separate analyses).

 $<sup>^{\</sup>rm e}n=20$  missings (negative), n=22 missings (positive); n=47 never told anybody.

# 3.3 | Disclosure difficulty

Although measured on a VAS-scale, 38.3% of survivors indicated having no difficulties to disclose (score: 0, n=193). Remaining response options (1–10) were chosen by about 5%–10% each and combined into "(some) difficulties" (Table 1). The resulting dichotomized variable showed that disclosure difficulties differed by sex ( $\chi^2(1) = 9.69$ , p=0.002), but no other background factors. More female than male survivors found it difficult to disclose their cancer history to romantic partners (67.2% vs. 53.5%).

Disclosure behaviors and survivors' experienced difficulties were significantly related ( $\chi^2(2) = 41.93$ , p < 0.001). Those who *never* disclosed or *not to everyone* found it more often difficult (81.0% and 73.7%, respectively) than those who *always* disclosed their cancer history (i.e., 47.8% found it difficult).

# 3.4 | Disclosure timing

Survivors' timing varied, but most disclosed after a couple of dates (n = 278, 55.6%). Added open-ended responses specified that disclosure was also dependent on whether it came up in a conversation (e.g., when asked about scars; n = 53, 10.6%), whether it felt right (n = 40, 8.0%), or once relationships became serious/felt closer (n = 41, 8.2%). Timing was excluded from further analyses due to indicating different aspects (timing vs. reasoning) and unequal distributions.

Qualitative analyses largely substantiated the above results. Survivors found it difficult to find the right time to disclose, but some chose specific moments: On the first/after a few dates, when the relationship became more serious, or upon becoming physically intimate. Other survivors could not intentionally choose when to disclose their cancer history because of its visibility (e.g., scars, spasms). In those cases, conversations were automatically steered toward disclosing their cancer history. Next to visibility, other facilitators of disclosure included: trust in a (potential) partner, getting older/passing of time and becoming more mature; and previous disclosure experiences that felt like practicing (Supporting Information S1: Appendix B).

# 3.5 | Partner responses

Most survivors (n = 386/509, 75.8%) had experienced *positive* responses from partners when disclosing their cancer history, whereas few (n = 70/509, 13.8%) reported *negative* responses. Note that those who never told any date were excluded from subsequent analyses (Table 1).

Survivors who experienced *positive* partner responses were more likely to be partnered (92.4% vs. 81.9% of singles;  $\chi^2(1) = 11.09$ , p < 0.001) and less often CNS-tumor survivors (77.5% vs. 90.0% other diagnoses;  $\chi^2(1) = 9.50$ , p = 0.002). However, both findings are likely intertwined as CNS-tumor survivors were also more often single (67.3% vs. 43.7%,  $\chi^2(1) = 18.06$ , p < 0.001). No other

background factors were associated with positive responses, while *negative* responses were unrelated to all background factors.

Survivors who ever perceived negative responses found it more often difficult to disclose their cancer history (78.6% vs. 56.1% without negative responses;  $\chi^2(1) = 12.39$ , p < 0.001); whereas difficulty was unrelated to previous positive responses from dating partners (p = 0.295).

Qualitative analyses further showed that positive responses included sympathy, understanding, and curiosity. Negative responses were pity, shock, fear, or becoming distant. Pity was described as particularly burdensome. Survivors specified that negative responses were often caused by lacking knowledge or misperceptions about cancer. A few mentioned that responses were neither positive nor negative, and that some dates did not know how to react at all.

### 3.6 | Satisfaction

Survivors were satisfied with their relationship status (M=15.8, range: 5–20; Table 1), but partnered survivors much more than singles (M=18.5 vs. 12.9; t(504)=-18.86, p<0.001; g=1.68). Female survivors reported slightly higher satisfaction than males (M=16.2 vs. 15.2; t(507)=-2.51, p=0.013; g=0.23) and survivors of CNS-tumors reported lower satisfaction than others (M=14.3 vs. 16.1; t(507)=3.95, p<0.001; g=0.44).

In the first model, relationship status satisfaction differed by survivors' disclosure behaviors (F(2,498) = 16.61, p < 0.001; Table 2) with post hoc tests indicating that all groups significantly differed from another: Survivors who *always* disclosed their cancer history reported highest levels of satisfaction (M = 16.8), followed by those who do *not disclose to everyone* (M = 15.4) and those who *never* disclose (M = 12.8, all p's < 0.002; g = 0.34-0.98). Difficulty and the interaction with disclosure behaviors were unrelated to relationship status satisfaction (Table 2).

Second, when positive and negative partner responses were added, disclosure behaviors remained significant. Additionally, the interaction of difficulty and negative responses was significant (F(1,429)=6.09; p=0.014), indicating that for survivors who found it (somewhat) difficult and who had received negative responses, status satisfaction was lowest (Figure 1). For survivors without previous negative responses, finding it difficult to disclose or not was unrelated to status satisfaction.

Lastly, background factors which were significantly related to relationship status satisfaction (sex, relationship status, CNS diagnosis) and selected interactions (Table 2) were added to the final model. The significant effect of relationship status at the univariate level was reiterated (F(1,416)=47.53, p<0.001; g=1.67). More importantly, its interaction with positive partner responses was also significant (F(1,416)=5.66, p=0.018). Partnered survivors who had received positive responses reported higher status satisfaction than partnered survivors without positive responses. In contrast, singles' satisfaction did not differ by whether or not having received positive responses (Figure 2).

TABLE 2 Tested effects of disclosure variables and background characteristics on relationship status satisfaction

	First model	Second model	Third model
actors			
Disclosure behavior	F(2,498) = 16.61, p < 0.001	F(1,429) = 6.23, p = 0.002	F(2,416) = 0.82, p = 0.443
Always (mean [SD])	16.8 (3.9)	16.8 (3.9)	16.9 (3.9)
Not to everyone (mean [SD])	15.4 (4.3)	15.5 (4.3)	15.5 (4.3)
Never/not yet (mean [SD])	12.8 (4.7)	13.8 (5.0)	13.8 (5.0)
Difficulty disclosing	F(1,498) = 0.02, p = 0.876	F(1,429) = 0.58, p = 0.445	F(1,416) = 0.48, p = 0.488
Positive responses		F(1,429) = 3.25, p = 0.072	F(1,416) = 1.62, p = 0.206
Negative responses		F(1,429) = 0.31, p = 0.580	F(1,416) = 0.00, p = 0.99
Sex			F(1,416) = 0.15, p = 0.70
Relationship status			F(1,416) = 47.53, p < 0.0
Partnered (mean [SD])			18.5 (2.3)
Single (mean [SD])			13.1 (4.1)
CNS diagnosis (vs. all other)			F(1,416) = 2.06, p = 0.15
nteractions			
Disclosure behavior $\times$ difficulty	F(2,498) = 1.00, p = 0.366	F(2,429) = 0.20, p = 0.816	F(2,416) = 0.76, p = 0.46
${\sf Difficulty} \times {\sf negative} \ {\sf responses}$		F(1,429) = 6.09, p = 0.014	F(1,416) = 2.07, p = 0.15
Disclosure behavior $\times$ sex			F(2,416) = 1.40, p = 0.24
$Difficulty \times sex$			F(1,416) = 0.12, p = 0.73
Disclosure behavior $\times$ relationship status			F(2,416) = 1.33, p = 0.26
Positive responses $\times$ relationship status			F(1,416) = 5.66, p = 0.01
Positive responses $\times$ CNS diagnosis			F(1,416) = 1.10, p = 0.29
Relationship status × CNS diagnosis			F(1,416) = 0.03, p = 0.85

*Note*: Values printed in bold are significant at  $p \ \langle \ 0.01$ .

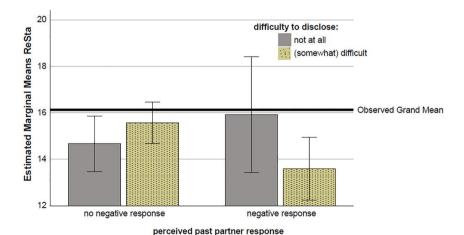


FIGURE 1 Estimated marginal means of relationship status satisfaction by perceived negative partner responses and difficulty to disclose.

# **DISCUSSION**

This study showed that childhood cancer survivors experienced some hesitation and/or difficulty in disclosing their cancer history to romantic partners. Survivors varied in their preferred moment to disclose, with some having little choice due to visible physical reminders of their treatment. Three important considerations for (non-)

disclosure were survivors' attitudes, cancer being part of their identity, and anticipated effects on romantic relationships. Survivors who ever experienced negative responses had more difficulties to disclose. Most survivors were satisfied with their relationship status, with partnered survivors who received positive responses being most satisfied.

Although 38% reported no difficulties disclosing their cancer history, 62% of survivors experienced at least some difficulties, in line with previous research.<sup>26</sup> Difficulty was strongly related to whether survivors disclosed at all (i.e., 80% with difficulties did not disclose). Moreover, male, single, and CNS-tumor survivors were less likely to disclose. Yet, how people deal with (non-)disclosure is highly personal,<sup>20</sup> as further demonstrated in our qualitative analyses. Survivors' values and beliefs determined their disclosure behaviors, which included their (a) attitudes (e.g., "openness is essential" vs. "fearing taboos"), (b) identity (e.g., being proud or perceived as weak), and (c) anticipated effects on relationships ("good test" vs. "too burdensome"), which also corroborates previous qualitative studies.<sup>2,12,13,20,21</sup> More than half of survivors indicated they disclosed after several dates and few disclosed before/around the first date. This aligns with healthy singles' expectations when dating a cancer survivor: 48%-76% would want to know after some dates, but hardly anyone before/at the first date.31

Female survivors were more likely than males to disclose their cancer history, although they also experienced it as more difficult. This corroborates previous qualitative research that women more frequently disclose, 20,21,32 suggesting they may perceive disclosure as essential to building intimacy. 33,34 Notably, survivors' relationship status differed by sex, with female survivors being somewhat more often partnered (56% vs. 44% of men), and partnered survivors disclosed and received positive responses more often. Hence, more research is needed to disentangle the potential role of sex in dating as a cancer survivor (e.g., female survivors may be more successful on the dating market than males). Lastly, and in line with previous findings, CNS-tumor survivors reported greater difficulties disclosing, while they were also more often single, 5,8,26 which may be due to impaired social or cognitive functioning later in life.<sup>35,36</sup>

Most survivors experienced positive responses to their disclosure, which is rather surprising given that only one previous study indicated relatively positive perceived responses,<sup>23</sup> while other research emphasized survivors' confusion and disappointment with (potential) partners' responses and perceived lack of interest in their stories.<sup>2</sup> A possible explanation may be changing societal views on cancer survivorship, which became associated with positive traits like bravery and strength.<sup>31</sup> Thus, potential romantic partners may increasingly respond supportive and positive to survivors' disclosures.

Survivors who always disclosed their cancer history also reported highest satisfaction, while those who experienced difficulty disclosing and who received negative responses had relatively lower relationship status satisfaction. This supports earlier findings showing less intimacy and happiness among survivors who were hesitant to disclose.<sup>37</sup> Yet, when controlling for background characteristics, these effects disappeared: Partnered survivors were more satisfied with their status than singles, which is in line with previous research in healthy people and childhood cancer survivors, 24,38 but partnered survivors who received positive responses were most satisfied. As indicated above, partnered survivors more often disclosed and received positive responses, while such experiences may also led them to being partnered in the first place. Such interplay may encourage open conversations and thus closeness and satisfaction within relationships. Indeed, supportive relationships have been associated with positive disclosure experiences (e.g., increasing closeness/intimacy), and unsupportive relationships may be related to failure to disclose, lower well-being, and anxiety. 13,21,39 At the same time, fear of negative responses might cause singles to avoid dating and disclosure, 10 potentially resulting in dissatisfaction with their relationship status. However, singles' reports of satisfaction did not differ by whether or not having received positive responses. Survivors may benefit from receiving advice or positive examples on how to disclose their cancer history, ideally from peers.<sup>2,20</sup> This should include suggestions about dealing with (concerns about) negative or seemingly uninterested responses to improve or maintain their status satisfaction. Such advice is relevant to young survivors facing various developmental milestones following their disease (e.g., choices about parenthood).4,5,8

#### 4.1 **Study limitations**

Although this large-scale study offered novel insights into disclosure of a heterogeneous sample of young adult survivors of childhood cancer, certain limitations should be considered. Various face-valid items have been used in this study, as no validated measures exist for disclosure and dating experiences. Some subgroup analyses were hampered by low case numbers, sometimes

0991611, 2023, 6, Downloaded library.wiley.com/doi/10.1002/pon.6130 by Bibliotheek Rijksuniversiteit, Wiley Online Library on [11/07/2023]. See the Terms and Conditions (https: ditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

also necessitating the combination of subgroups/categories which may have different experiences or implications (e.g., disclosure "not to everyone"; see Supporting Information S1: Appendix B). Importantly, item responses were substantiated by survivors' open-ended answers, which also corroborated previous qualitative findings. Yet, our cross-sectional design did not allow for testing causal relations, and satisfaction scores are notorious for being skewed. Moreover, this study did not assess how and which information survivors discuss, which may also differ in different cultural contexts, and should be addressed in future research. For example, sharing clinical information about cancer was found easier than sharing emotional experiences.<sup>2,20</sup> and effects on potential partners should be tested. Lastly, our response rate was rather low (31%), but typical for this unique population. Although recruitment through the GCCR allowed for a population-based approach across Germany. some selection bias may have occurred (e.g., non-response due to discomfort with intimate topics).

# 5 | CONCLUSIONS

Our finding that most survivors perceived positive reactions to their disclosure should be encouraging to other survivors who may be hesitant. Acknowledging such findings along with healthy singles' positive attitudes may be helpful for survivors and included in psycho-educational materials. Nevertheless, such information may always be balanced, as some respondents experienced negative reactions. Opportunities for survivors to reflect on possible positive and negative partner reactions and to identify with stories from peers may empower them and help them navigate the dating process. More research is needed to gain better insights into communication, content, and effects of disclosure, and survivors' well-being. This large survey study showed that many young adult childhood cancer survivors experienced some hesitation and difficulty disclosing their cancer history to (potential) romantic partners, although many always disclosed regardless of whether they found it difficult. Survivors' preferred moment for disclosing varied. Partnered survivors receiving positive responses were most satisfied with their relationship status. Background factors like female sex and CNS-tumor diagnosis may serve as indicators to identify those with potential struggles. Yet, healthcare providers should always pay attention to possible difficulties in dating among all survivors, given its essential role for overall quality of life.

# **ACKNOWLEDGMENTS**

We would like to thank Katja Baust, Clara von Schweinitz, Fereshteh Shakib, Axel Budde, Michelle Brust, Jana Ellwart, Desiree Grabow, and Irene Jung for facilitating this study and data collection. This study was partially funded by a grant from the German Cancer Aid (#70112102; Calaminus, Kaatsch, Langer).

### CONFLICT OF INTEREST STATEMENT

The authors declare no competing interests.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

#### ORCID

Vicky Lehmann https://orcid.org/0000-0003-4898-3176

### **REFERENCES**

- Nahata L, Morgan TL, Lipak KG, Olshefski RS, Gerhardt CA, Lehmann V. Romantic relationships and physical intimacy among survivors of childhood cancer. *J Adolesc Young Adult Oncol.* 2020;9(3): 359-366. https://doi.org/10.1089/jayao.2019.0114
- Thompson AL, Long KA, Marsland AL. Impact of childhood cancer on emerging adult survivors' romantic relationships: a qualitative account. J Sex Med. 2013;10(supplement\_1):65-73. https://doi.org/10. 1111/j.1743-6109.2012.02950.x
- van Dijk EM, van Dulmen-den Broeder E, Kaspers GJ, van Dam EW, Braam KI, Huisman J. Psychosexual functioning of childhood cancer survivors. *Psychooncology*. 2008;17(5):506-511. https://doi.org/10. 1002/pon.1274
- Dieluweit U, Debatin KM, Grabow D, et al. Social outcomes of longterm survivors of adolescent cancer. *Psychooncology*. 2010;19(12): 1277-1284. https://doi.org/10.1002/pon.1692
- 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
- Puukko LRM, Hirvonen E, Aalberg V, Hovi L, Rautonen J, Siimes MA. Sexuality of young women surviving leukaemia. Arch Dis Child. 1997;76(3):197-202. https://doi.org/10.1136/adc.76.3.197
- Nies M, Dekker BL, Sulkers E, et al. Psychosocial development in survivors of childhood differentiated thyroid carcinoma: a crosssectional study. Eur J Endocrinol. 2018;178(3):215-223. https://doi. org/10.1530/EJE-17-0741
- Maurice-Stam H, van Erp LME, Maas A, et al. Psychosocial developmental milestones of young adult survivors of childhood cancer. Support Care Cancer. 2022;30(8):6839-6849. https://doi.org/10.1007/s00520-022-07113-3
- 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. Psychooncology. 2018;27(8):1944-1949. https://doi.org/10.1002/pon.4746
- Lehmann V, Ferrante AC, Winning AM, Gerhardt CA. The perceived impact of infertility on romantic relationships and singlehood among adult survivors of childhood cancer. *Psychooncology*. 2019;28(3): 622-628. https://doi.org/10.1002/pon.4999
- Lehmann V, Nahata L, Ferrante AC, et al. Fertility-related perceptions and impact on romantic relationships among adult survivors of childhood cancer. J Adolesc Young Adult Oncol. 2018;7(4):409-414. https://doi.org/10.1089/jayao.2017.0121
- 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
- Rabin C. Impact of cancer on romantic relationships among young adults: a systematic review. J Clin Psychol Med Settings. 2019;26(1): 1-12. https://doi.org/10.1007/s10880-018-9566-7
- Benedict C, Shuk E, Ford JS. Fertility issues in adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol. 2016;5(1):48-57. https://doi.org/10.1089/jayao.2015.0024
- Quinn GP, Huang IC, Murphy D, Zidonik-Eddelton K, Krull KR. Missing content from health-related quality of life instruments:

- interviews with young adult survivors of childhood cancer. *Qual Life Res.* 2013;22(1):111-118. https://doi.org/10.1007/s11136-012-0120-z
- Brown M, Pearce M, Bailey S, Skinner R. The long-term psychosocial impact of cancer: the views of young adult survivors of childhood cancer. Eur J Cancer Care. 2016;25(3):428-439. https://doi.org/10. 1111/ecc.12380
- Lehmann V, Tuinman MA, Keim MC, Hagedoorn M, Gerhardt CA. Am I a 6 or a 10? Mate value among young adult survivors of childhood cancer and healthy peers. J Adolesc Young Adult Oncol. 2018;7(1):72-78. https://doi.org/10.1089/jayao.2017.0041
- Crawshaw MA, Sloper P. 'Swimming against the tide'—the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. Eur J Cancer Care. 2010;19(5):610-620. https://doi.org/10.1111/j.1365-2354.2009.01118.x
- Greene K, Derlega VJ, Mathews A. Self-disclosure in Personal Relationships. The Cambridge Handbook of Personal Relationships. Cambridge University Press; 2006:409-427.
- Janin MMH, Ellis SJ, Wakefield CE, Fardell JE. Talking about cancer among adolescent and young adult cancer patients and survivors: a systematic review. J Adolesc Young Adult Oncol. 2018;7(5):515-524. https://doi.org/10.1089/jayao.2017.0131
- Barnett ME, Shuk EM, Conway FP, Ford JS. Cancer-related disclosure among adolescent and young adult cancer survivors: a qualitative study. J Adolesc Young Adult Oncol. 2014;3(3):123-129. https://doi.org/10.1089/jayao.2013.0043
- Laurenceau JP, Barrett LF, Pietromonaco PR. Intimacy as an interpersonal process: the importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. J Pers Soc Psychol. 1998;74(5):1238-1251. https://doi.org/10.1037//0022-3514.74.5.1238
- Rabin C. Self-disclosure to peers by young adult cancer survivors. Psychooncology. 2019;28(1):181-186. https://doi.org/10.1002/pon. 4930
- Lehmann V, Tuinman MA, Braeken J, Vingerhoets AJ, Sanderman R, Hagedoorn M. Satisfaction with relationship status: development of a new scale and the role in predicting well-being. J Happiness Stud. 2015;16(1):169-184. https://doi.org/10.1007/s10902-014-9503-x
- Lehmann V, Grönqvist H, Engvall G, et al. Negative and positive consequences of adolescent cancer 10 years after diagnosis: an interview-based longitudinal study in Sweden. *Psychooncology*. 2014;23(11):1229-1235. https://doi.org/10.1002/pon.3549
- Hamilton R, Zebrack B. Dating and disclosure for cancer survivors.
  In: Mulhall J, Incrocci L, Goldstein I, Rosen, R, eds. Cancer and Sexual Health. Current Clinical Urology. Humana Press; 2011. https://doi.org/ 10.1007/978-1-60761-916-1\_50
- Creswell JW. Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research. Vol 7. Prentice Hall Upper Saddle River: 2002.
- 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
- Adamczyk K. Development and validation of a Polish-language version of the Satisfaction with Relationship Status Scale (ReSta). Curr Psychol. 2017;38(1):8-20. https://doi.org/10.1007/s12144-017-9585-9

- Braun V, Clarke V. Thematic analysis. In: Cooper H, Camic PM, Long DL, Panter AT, Rindskopf D, Sher KJ, eds. APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological. American Psychological Association; 2012: 57–71.
- Tuinman MA, Lehmann V, Hagedoorn M. Do single people want to date a cancer survivor? A vignette study. PLoS One. 2018;13(3): e0194277. https://doi.org/10.1371/journal.pone.0194277
- 32. Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. *Qual Health Res.* 2009;19(6): 744-754. https://doi.org/10.1177/1049732309334737
- Belpame N, Kars MC, Deslypere E, Rober P, Van Hecke A, Verhaeghe S. Living as a cancer survivor: a qualitative study on the experiences of Belgian adolescents and young adults (AYAs) after childhood cancer. *J Pediatr Nurs*. 2019;49:e29-e35. https://doi.org/10.1016/j.pedn.2019.07.015
- Carpentier MY, Fortenberry JD, Ott MA, Brames MJ, Einhorn LH. Perceptions of masculinity and self-image in adolescent and young adult testicular cancer survivors: implications for romantic and sexual relationships. *Psychooncology*. 2011;20(7):738-745. https://doi.org/10.1002/pon.1772
- Annett RD, Patel SK, Phipps S. Monitoring and assessment of neuropsychological outcomes as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S460-S513. https:// doi.org/10.1002/pbc.25749
- Yeates KO, Bigler ED, Dennis M, et al. Social outcomes in childhood brain disorder: a heuristic integration of social neuroscience and developmental psychology. *Psychol Bull.* 2007;133(3):535-556. https://doi.org/10.1037/0033-2909.133.3.535
- Pasipanodya EC, Parrish BP, Laurenceau JP, et al. Social constraints on disclosure predict daily well-being in couples coping with earlystage breast cancer. J Fam Psychol. 2012;26(4):661-667. https:// doi.org/10.1037/a0028655
- 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. *Psychooncology*. 2016; 25(2):210-216. https://doi.org/10.1002/pon.3841
- Figueiredo MI, Fries E, Ingram KM. The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psychooncology*. 2004;13(2):96-105. https://doi.org/ 10.1002/pon.717

### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Bos-van den Hoek DW, Tuinman MA, Hillen MA, et al. Disclosing a history of childhood cancer to romantic partners. *Psychooncology*. 2023;32(6):904-912. https://doi.org/10.1002/pon.6130