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2023

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### How to cite

CHRISTEN, Salome et al. Worries and anxiety in parents of adult survivors of childhood cancer : A report from the Swiss Childhood Cancer Survivor Study-Parents. In: Pediatric blood & cancer, 2023, vol. 70, n° 5, p. e30246. doi: 10.1002/pbc.30246

This publication URL: <https://archive-ouverte.unige.ch/unige:176695>

Publication DOI: [10.1002/pbc.30246](https://doi.org/10.1002/pbc.30246)

## RESEARCH ARTICLE

# Worries and anxiety in parents of adult survivors of childhood cancer: A report from the Swiss Childhood Cancer Survivor Study-Parents

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## Funding information

Swiss National Foundation, Grant/Award Number: 100019153268/1; Kinderkrebshilfe Schweiz; Research Commission of the University of Lucerne; Vontobel-Stiftung; Krebsliga Zentralschweiz; Avenir Stiftung; anonymous foundation

**Objective:** Having a child diagnosed with cancer is distressing for parents. We aimed to compare worries and anxiety in parents of adult childhood cancer survivors with parents of the Swiss general population (GP-parents), and to evaluate characteristics associated with worry in parents of survivors.

**Methods:** We conducted a nationwide, population-based study in parents of survivors (survivors aged  $\geq 20$  years at study,  $\leq 16$  years at diagnosis,  $> 5$  years post diagnosis) and GP-parents ( $\geq 1$  child aged  $\geq 20$  years at study). We used the Worry and Anxiety Questionnaire (WAQ), and computed the WAQ total score (*worries*; possible range 0–80) and caseness for generalized anxiety disorder (*anxiety*), *cognitive*, *somatic*, and *any criteria*. We used multilevel, multivariable linear regression to identify characteristics associated with *worries* in parents of survivors.

**Results:** We included 787 parents of 513 survivors (41.0% fathers) and 478 GP-parents (42.3% fathers). Parents of survivors and GP-parents did not differ regarding *worries* (16.6 vs. 17.1,  $p = .977$ ), *anxiety* (2.7% vs. 3.6%,  $p = .536$ ), *cognitive* ( $p = .440$ ), and *somatic criteria* ( $p = .067$ ). Less parents of survivors met *any criteria* (17.7% vs. 24.0%,  $p = .039$ ). Half of parents reported current cancer-related worries. Higher cancer-related *worries* were reported by mothers ( $\beta = 4.1$ ; 95% CI: 2.0–6.2), parents with one child ( $\beta = 5.9$ ; 95% CI: 2.0–9.7), currently experiencing disadvantages because of their child's former disease ( $\beta = 7.3$ ; 95% CI: 4.0–10.6), or with support needs ( $\beta = 9.0$ ; 95% CI: 3.9–14.2;  $p = .001$ ).

**Conclusions:** It is encouraging that most parents of adult survivors report similar worries and anxiety as GP-parents, but cancer-related worries are still prevalent. Efforts should be made to empower parents to seek psycho-social support if required.

## KEYWORDS

anxiety, cancer survivors, fathers, mothers, Switzerland, worry

**Abbreviations:** CCS, childhood cancer survivor; ChCR, Childhood Cancer Registry; GAD, general anxiety disorder; GP, general population; ICC-3, International Classification of Childhood Cancer—Third Edition; WAQ, Worry and Anxiety Questionnaire.

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## 1 | INTRODUCTION

Having a child diagnosed with cancer is distressing for parents. The illness confronts parents with their child's mortality, and parents worry about their child's health.<sup>1–3</sup> In addition, families' lives are completely disrupted, and parents often struggle to balance different needs, such as work, school, caring for siblings, and hospital visits.<sup>1,2,4</sup> Therefore, many parents experience increased levels of psychological distress and anxiety.<sup>5–9</sup>

For most parents, levels of distress and anxiety decrease with time since diagnosis.<sup>5,7,10–12</sup> However, parents' concerns or worries do not disappear when treatment ends. Parents report being worried about the child's health, including cancer-related health (e.g., late mortality, relapse, late effects), and minor diseases (e.g., cold, cough, fever), but also about their child's school performance, or social contacts.<sup>13–16</sup> Additionally, some parents also report being worried about siblings of the childhood cancer survivor (CCS).<sup>2</sup> It has been hypothesized that the cancer experience can trigger a prolonged state of elevated alertness, which may result in increased worries, anxiety, and negative emotions.<sup>14</sup> Additionally, intolerance of uncertainty may contribute to a vicious cycle of hypervigilance and thereby continuous distress.<sup>17</sup> Several studies found elevated levels of anxiety in parents many years after cancer diagnosis of their child.<sup>15,18,19</sup>

Previous studies have shown that a cancer diagnosis of a child can affect many aspects of parents' lives in the long-term, for example, their relationship, financial situation, and involvement in healthcare of child.<sup>20–24</sup> However, only few studies have investigated worries and anxiety in parents of adult or very long-term CCS. They found that parents of adult CCS think about the cancer of their child more often,<sup>25</sup> and were more worried about the child's health than CCS themselves.<sup>25,26</sup> A pilot study found that more parents of long-term CCS survivors experienced anxiety as compared to parents of children undergoing active treatment.<sup>27</sup> Another study found that parents of long-term CCS did not attend hospitals more often due to anxiety than comparison parents.<sup>28</sup> We conducted a nationwide, population-based study aiming to (1a) compare general worries and anxiety of parents of CCS with parents of the Swiss general population (GP-parents), (1b) evaluate socio-demographic characteristics associated with general worries in parents of CCS and GP-parents, and (2a) provide an overview of and (2b) evaluate socio-demographic and clinical characteristics associated with cancer-related worries in parents of CCS.

## 2 | METHODS

### 2.1 | Sample and procedure

#### 2.1.1 | Parents of CCS

We obtained the sample from the population-based Childhood Cancer Registry (ChCR) in Switzerland.<sup>29,30</sup> Parents were eligible if they had a valid address in Switzerland, if their child was diagnosed with cancer

according to the International Classification of Childhood Cancer—Third Edition (ICCC-3)<sup>31</sup> between 1976 and 2009 at age less than or equal to 16 years, the child was a Swiss resident at diagnosis, greater than or equal to 5 years after diagnosis, and alive and aged 20 years and above at the time of study. We randomized parents into two groups: CCS-parents and CCS-parents-controls, as we hypothesized that mentioning the child's cancer diagnosis in the questionnaire might affect response behavior. CCS-parent-controls received the same questionnaire as GP-parents (general questionnaire) and did not know that they were contacted as parents of a CCS. CCS-parents filled in the general questionnaire, and additionally answered cancer-related questions, for example, about late effects of CCS, follow-up care, support needs and disadvantages (Figure 1). We sent parents study information before sending them two copies of the questionnaire, to be filled out by each parent separately. CCS-parents received the study information from their child's former treating center. We sent a first and second reminder to nonrespondents 4–6 and 12–14 weeks later, respectively. We collected data from January 2017 to February 2018.

#### 2.1.2 | GP-parents

The Swiss Federal Statistical Office provided a representative random sample of 3000 households, according to the distributions of age, sex, and language in Switzerland. Individuals aged 18–75 years in 2015 were eligible to participate in the survey (for details see Roser et al., 2019<sup>32</sup>). For the current analysis, we included individuals who indicated having at least one child aged 20 years and above. GP-parents received the same study material as CCS-parent-controls, and we followed the same procedure as for parents of CCS. We collected data from May 2015 to June 2016.

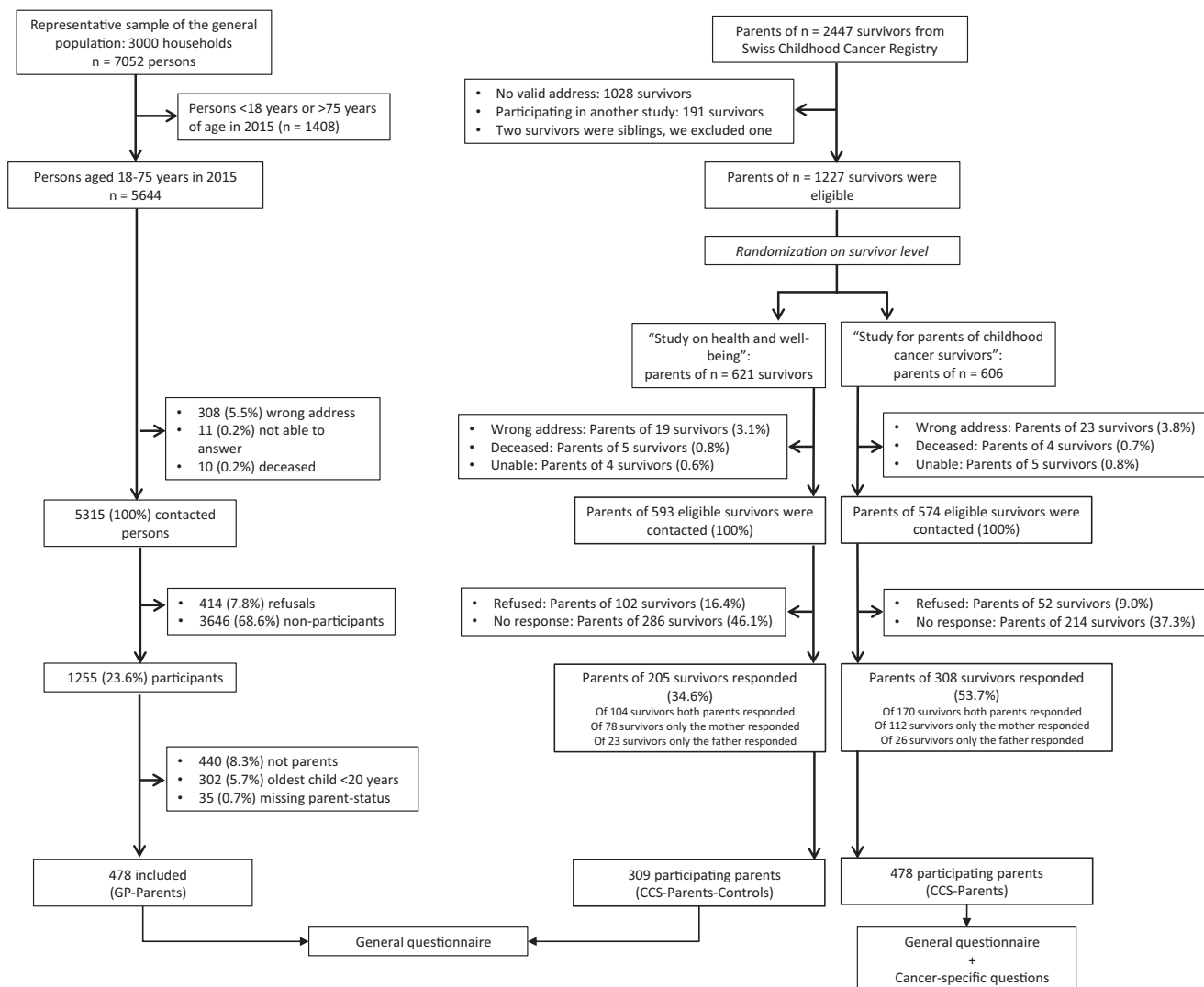
### 2.2 | Ethical committee approval

Ethics approval was granted through the Ethics Committee of Northwest and Central Switzerland (EKNZ 2015-075; March 26, 2015) and all participants provided informed consent.

### 2.3 | Measurements

#### 2.3.1 | Worries and anxiety

We used the *Worry and Anxiety Questionnaire* (WAQ).<sup>33</sup> The WAQ has acceptable psychometric properties for assessing general anxiety disorder (GAD).<sup>33,34</sup> The first item assesses worry topics ("What subjects do you worry about most often?"; free-text answer). For items 2–6, participants rated on a 5-point Likert scale (1 "not at all" to 5 "very severely," recoded into 0–8 as in the original WAQ<sup>33</sup>): excessiveness (item 2) and frequency of worries in the past 6 months (item 3), difficulty controlling worries (item 4), interference of worries with life (item 6), and physical symptoms associated with worries (restlessness,



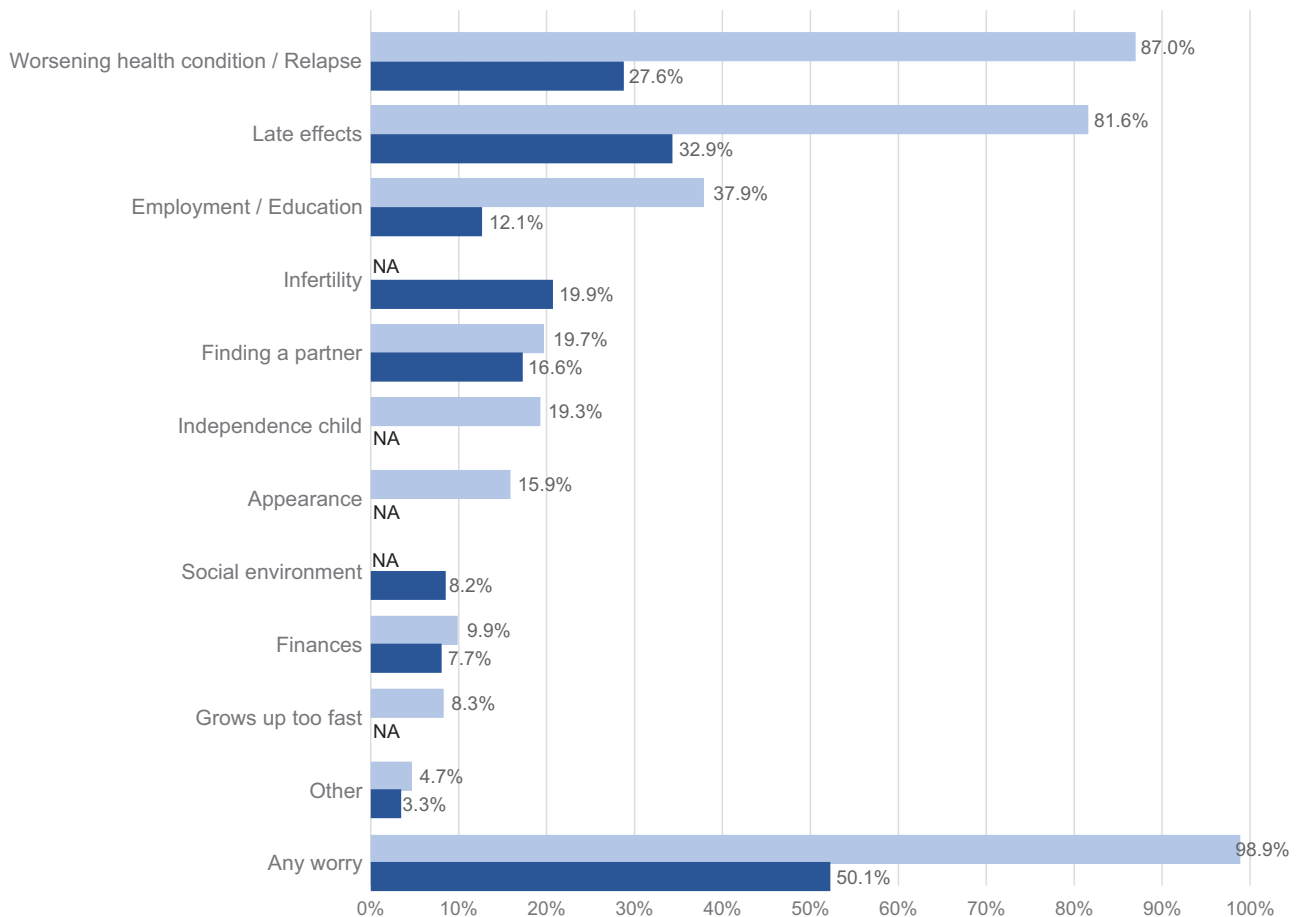
**FIGURE 1** Study flowchart.

fatigue, difficulty concentrating, irritability, muscle tension, sleep disturbance; items 5a–5f). For CCS-parents, we slightly adapted the WAQ items so that they referred to the child's cancer illness, including item 1 to assess what cancer-related worries parents had *during treatment* and *currently* (multiple choice; Figure 2). In addition to the WAQ, we developed questions to assess whether parents' *worries and anxiety influence family life* (positively/negatively; 1 “not at all” to 5 “strong influence”).

### 2.3.2 | Socio-demographic characteristics

We assessed sex (male, female), parental age at study, language region (German, French, Italian), migration background (yes, no), number of children (1, 2, 3,  $\geq 4$ ), education (compulsory schooling, vocational training, upper secondary education, university education),<sup>35</sup> employment status (employed, unemployed, retired), partnership (yes, no), and monthly household income (low:  $\leq 6000$  CHF [Swiss Franc], medium/high:  $>6000$  CHF). Language region was derived from the

questionnaire language. We classified parents as having a migration background if they were not Swiss citizens, had moved to Switzerland after birth, or were not Swiss citizens since birth. Current health status was assessed with item 1 of the SF-36<sup>36</sup>: participants rated their health on a 5-point Likert scale (1 “excellent” to 5 “poor”). We recoded values of 1–3 into “excellent to good,” and values of 4–5 into “fair to poor.” Pain was assessed with item 7 of the SF-36: participants rated their pain in the past 4 weeks on a 6-point Likert scale (1 “no pain” to 6 “very severe pain”). We recoded values of 1–3 into “no to little,” and values of 4–6 into “moderate to very severe.” For CCS-parents, we additionally assessed current perceived *disadvantages* because of the child's disease (yes, no) and current *support needs* (yes, no). Parents were considered to experience *disadvantages* if they indicated “yes” on any of the seven domains (job-related, financial, social environment/friends, family, physical, psychological, or other). Parents were considered to experience *support needs* if they indicated “yes” on any of the six domains (job-related, financial, family, psychological, medical, or other).<sup>23</sup>



**FIGURE 2** Proportion of parents of adult childhood cancer survivors (CCS-parents) reporting specific cancer-related worry topics. *Note:* light blue = proportion of parents indicating they worried about this topic during treatment; dark blue = proportion of parents indicating they worried about this topic currently; NA = not applicable, as this worry topic was not available in the questionnaire as an answer for this time point.

### 2.3.3 | Characteristics of CCS

The following characteristics were extracted from the ChCR: sex (male, female), age at study, cancer diagnosis, treatment (surgery only, chemotherapy [may have had surgery], radiotherapy [may have had surgery and/or chemotherapy], stem cell transplantation), age at diagnosis, time since diagnosis, and relapse (yes, no). Cancer diagnoses were classified according to ICC-3,<sup>31</sup> and categorized into leukemia, lymphoma, central nervous system (CNS) tumor, and other tumor. Among CCS-parents, we additionally assessed *late effects* (yes, no) and *CCS' independence* (yes, no) in the questionnaire. We classified CCS as independent if parents indicated that the CCS did no longer live with the parents, was financially independent, and did not need support in carrying out daily tasks.

## 2.4 | Statistical analysis

We used Stata (Version 16.1) for all quantitative analyses and Atlas.TI (Version 8) for content analysis of the free-text answer on worry topics (WAQ item 1 in questionnaire of CCS-parent-

controls and GP-parents). For the content analysis, three researchers (Michaela Kaufmann, Pauline Holmer, Anica Illic) assigned codes to participants' answers. In a second step, four researchers (Salome Christen, Katharina Roser, Michaela Kaufmann, Grit Sommer) grouped the codes into worry topics (examples can be found in Table S1).

Scoring of the WAQ total score, cognitive, somatic, any and no criteria were performed as defined by the authors of the WAQ<sup>33</sup>: we generated the WAQ *total score* by adding up the scores for each of the 10 items (items 2, 3, 4, 5a–5f, 6). Participants were classified as meeting criteria for: *GAD* if they reported at least one worry topic (item 1), reported a score greater than or equal to 4 on items 2, 3, 4, and 6, and a score greater than or equal to 4 on at least three of items 5a–5f; *cognitive criteria* if they had a score greater than or equal to 4 on items 2, 3, and 4; *somatic criteria* if they had a score greater than or equal to 4 on at least three of the items 5a–5f; and *any criteria* if they met any of the above criteria.

In case of missing values, we imputed the median of the available items if at least half of the items were completed (WAQ *total score*: items 2, 3, 4, 5a–5f, 6; *GAD* and *cognitive criteria*: items 2, 3, 4, 6; *somatic criteria*: items 5a–5f).

For aim 1, we included CCS-parent-controls and GP-parents. For aim 2, we included CCS-parents only. We used descriptive statistics to describe worries and anxiety. We used Pearson chi-square tests (or Fisher's exact tests if  $df = 1$ , or cell frequency  $< 5$ ) to test differences between CCS-parent-controls and GP-parents for worry topics, GAD, cognitive criteria, somatic criteria, any criteria, influence on family life, and Mann-Whitney  $U$  tests for WAQ single items and WAQ total score. We ran three multilevel linear regression models with random intercepts to evaluate characteristics of parents associated with WAQ total score: model 1 included socio-demographic characteristics of the combined samples of CCS-parent-controls and GP-parents, model 2 included clinical characteristics of CCS-parent-controls only, and model 3 included socio-demographic and clinical characteristics of CCS-parents only. Variables that were associated with WAQ total score in the univariable models ( $p < .1$ ) were included in the multivariable model. Sample (included only for models 1 and 2: CCS-parent-controls, GP-parents), sex, and age were a priori defined to be included in the multivariable model. All tests were two-sided and considered statistically significant if  $p < .05$ . No correction for multiple testing was done.

### 3 | RESULTS

Overall, 787 parents of CCS (response rate combined: 44%; 478 CCS-parents [response rate: 54%], 309 CCS-parent-controls [response rate: 35%]) were included in this study. From GP, 1255 persons participated in our survey (response rate: 23.6%), of which 478 GP-parents were included in this study (Figure 1). Parents of CCS and GP-parents were similar regarding sex (41% and 42% fathers, respectively), age (mean 62.3 vs. 62.1 years), language region, educational achievement, employment, household income, and the pain experienced (Table 1).

#### 3.1 | General worries and anxiety in CCS-parent-controls and GP-parents

Most parents reported at least one worry (CCS-parent-controls: 85.8%; GP-parents: 87.7%;  $p = .450$ ; Table 2). Content analysis of WAQ item 1 showed that CCS-parent-controls and GP-parents had similar worries and were most often worried about health and well-being, social relationships, and world affairs (Table 3; Figure S1).

Means of all WAQ single items (Table 3) and WAQ total score (16.6 vs. 17.1,  $p = .977$ ) were similar for CCS-parent-controls and GP-parents. Fewer CCS-parent-controls than GP-parents met any criteria (17.7% vs. 24.0%,  $p = .039$ ). Similar proportions of CCS-parent-controls and GP-parents met GAD criteria (2.7% vs. 3.6%,  $p = .536$ ), cognitive criteria (7.8% vs. 9.6%,  $p = .440$ ), and somatic criteria (14.7% vs. 20.0%,  $p = .067$ ). We found no gender differences for the four WAQ criteria in CCS-parent-controls ( $p > .05$ ). In GP-parents, more mothers met somatic ( $p = .001$ ) and any criteria ( $p < .001$ ) when compared to fathers.

There was no difference between CCS-parent-controls and GP-parents in how worries influenced their family life (positively: 21.8% vs. 20.4%,  $p = .696$ ; negatively: 20.9% vs. 20.0%,  $p = .772$ ; Table 2).

We found that mothers ( $\beta = 2.9$ , 95% CI: 1.1–4.8), parents from the French-speaking language region ( $\beta = 3.2$ , 95% CI: 0.9–5.5), parents with fair to poor health ( $\beta = 9.9$ , 95% CI: 6.2–13.7), and parents who experienced pain ( $\beta = 5.2$ , 95% CI: 2.8–7.6) reported higher WAQ total scores (Table S2).

#### 3.2 | Cancer-related worries and anxiety in CCS-parents

Among CCS-parents, most reported at least one worry during the treatment of their child (98.9%). The most frequently reported worries were that the medical condition of the child could worsen (87.0%), there is risk of late effects (81.6%), and that the child may have difficulties at school (37.9%; Figure 2).

Half of parents (50.1%) reported current cancer-related worries about their child. The most frequently reported worries were about late effects or health of child (32.9%), a relapse or second malignancy (27.6%), and that the child may be infertile (19.9%). When comparing worries during treatment to current worries, the proportion of parents who reported worries decreased for all topics, but only marginally for "finding a partner" and "finances" (Figure 2).

Mean WAQ total score was 13.3 (SD = 1.98). Overall, 16.2% of parents met any criteria ( $n = 76$ ), 10.7% somatic criteria ( $n = 49$ ), 7.2% cognitive criteria ( $n = 34$ ), and 1.5% met criteria for GAD ( $n = 7$ ). Some parents reported that worries and anxiety influenced their family life—positively ( $n = 58$ , 13.9%) or negatively ( $n = 60$ , 14.5%).

Compared to both CCS-parent-controls and GP-parents, fewer CCS-parents reported a positive or negative influence on their family life ( $p < .05$ ; Table 2).

We found that mothers ( $\beta = 4.1$ , 95% CI: 2.0–6.2), parents with one child ( $\beta = 5.9$ , 95% CI: 2.0–9.7), parents who experienced pain ( $\beta = 3.2$ , 95% CI: 0.2–6.2), or disadvantages ( $\beta = 7.3$ , 95% CI: 4.0–10.6), and those who reported a need for support ( $\beta = 9.0$ , 95% CI: 3.9–14.2) reported higher WAQ total scores (Figure 3; Table S3).

### 4 | DISCUSSION

On average 24 years after a cancer diagnosis in their child, parents of CCS reported worries and anxiety similar to those of parents of the Swiss GP. Parents of CCS were less likely to meet any caseness criteria of the WAQ. However, they remained worried about their child: half of parents reported current cancer-related worries. Mothers, parents of an only child, parents who experienced pain, disadvantages, or support needs had increased cancer-related worries.

Our results add to the evidence that anxiety is similarly prevalent in parents of very long-term CCS and comparisons from GP. Our results are in line with a study from Denmark that found incidence of hospital contacts for anxiety did not differ in parents and comparisons more



**TABLE 1** Characteristics of participating parents of adult childhood cancer survivors (CCS-parents, CCS-parent-controls) and participating parents of the Swiss general population (GP-parents)

		CCS-parents		CCS-parent-controls		GP-parents	
		N	%	N	%	N	%
<b>Total</b>	No. of participating parents	478	100.0	309	100.0	478	100.0
<b>Sex</b>	Male	196	41.0	127	41.1	202	42.3
	Female	282	59.0	182	58.9	276	57.7
<b>Parent participation status</b>	One parent participated	138	28.9	101	32.7	234	49.0
	Both parents participated	340	71.1	208	67.3	244	51.0
	Missing	0	0.0	0	0.0	0	0.0
<b>Language region</b>	German	351	73.4	239	77.3	350	73.2
	French	110	23.0	55	17.8	110	23.0
	Italian	17	3.6	15	4.9	18	3.8
<b>Migration background</b>	No	394	82.4	255	82.5	395	82.6
	Yes	58	12.1	38	12.3	83	17.4
	Missing	26	5.4	16	5.2	0	0.0
<b>Partnership</b>	Yes	411	86.0	277	89.6	395	82.6
	No	48	10.0	29	9.4	71	14.9
	Missing	19	4.0	3	1.0	12	2.5
<b>Educational achievement</b>	Compulsory schooling	54	11.3	32	10.4	41	8.6
	Vocational training	232	48.5	158	51.1	243	50.8
	Upper secondary education	77	16.1	56	18.1	80	16.7
	University education	71	14.9	47	15.2	77	16.1
	Missing	44	9.2	16	5.2	37	7.7
<b>Employment</b>	Employed	256	53.6	174	56.3	229	47.9
	Not employed	39	8.2	27	8.7	45	9.4
	Retired	164	34.3	103	33.3	190	39.7
	Missing	19	4.0	5	1.6	14	2.9
<b>Number of children</b>	1	49	10.3	17	5.5	77	16.1
	2	211	44.1	136	44.0	246	51.5
	3	135	28.2	97	31.4	101	21.1
	≥4	83	17.4	53	17.2	54	11.3
	Missing	0	0.0	6	1.9	0	0.0
<b>Household income (monthly)</b>	Low (<6000 CHF [Swiss Franc])	145	30.3	88	28.5	157	32.8
	Middle/high (≥6000 CHF)	263	55.0	189	61.2	254	53.1
	Missing	70	14.6	32	10.4	67	14.0
<b>Health status</b>	Fair to poor	21	4.4	21	6.8	40	8.4
	Excellent to good	453	94.8	285	92.2	433	90.6
	Missing	4	0.8	3	1.0	5	1.0
<b>Pain</b>	No to little	390	81.6	245	79.3	366	76.6
	Moderate to very severe	82	17.2	62	20.1	108	22.6
	Missing	6	1.3	2	0.6	4	0.8
<b>Current perceived disadvantage</b>	No	396	82.8	-	-	-	-
	Yes	67	14.0	-	-	-	-
	Missing	15	3.1	-	-	-	-

(Continues)

TABLE 1 (Continued)

		CCS-parents		CCS-parent-controls		GP-parents	
		N	%	N	%	N	%
Current support need	No	428	89.5	-	-	-	-
	Yes	24	5.0	-	-	-	-
	Missing	26	5.4	-	-	-	-
Characteristics of CCS		CCS-parents		CCS-parent-controls		GP-parents	
		N	%	N	%	N	%
Total	No. of participating families <sup>a</sup>	308	100.0	205	100.0	-	-
Sex CCS	Male	171	55.5	114	55.6	-	-
	Female	137	44.5	91	44.4	-	-
	Missing	170	55.2	104	50.7	-	-
Diagnosis	Leukemia	105	34.1	70	34.1	-	-
	Lymphoma	70	22.7	44	21.5	-	-
	CNS tumor	37	12.0	33	16.1	-	-
	Other tumor	96	31.2	58	28.3	-	-
Treatment	Surgery only	37	12.0	27	13.2	-	-
	Chemotherapy	170	55.2	105	51.2	-	-
	Radiotherapy	81	26.3	65	31.7	-	-
	Stem cell transplantation	19	6.2	8	3.9	-	-
	Missing	2	0.6	0	0.0	-	-
Relapse	No	269	87.3	181	88.3	-	-
	Yes	39	12.7	24	11.7	-	-
	Missing	0	0.0	0	0.0	-	-
Parent-reported late effects	No	159	51.6	-	-	-	-
	Yes	143	46.4	-	-	-	-
	Missing	6	1.9	-	-	-	-
Parent-reported independence of CCS	Independent	178	57.8	-	-	-	-
	Not independent	129	41.9	-	-	-	-
	Missing	1	0.3	-	-	-	-
Characteristics of parents and CCS		Mean	SD	Mean	SD	Mean	SD
Parents: age at study		62.3 <sup>b</sup>	6.87	62.3	6.87	62.1	7.97
CCS: age at study		32.4	6.42	32.2	6.18	-	-
CCS: age at diagnosis		6.9	4.54	6.9	4.45	-	-
CCS: time since diagnosis		24.0	7.08	23.9	6.64	-	-

Note: We randomized parents into two groups: CCS-parents and CCS-parents-controls. Both groups received questionnaires with the same questions, but the questionnaire for CCS-parents assessed additional cancer-related information. The questionnaire sent to CCS-parent-controls had no reference to the child's cancer diagnosis. CCS-parent-controls and GP-parents received the exact same questionnaires.

Abbreviations: CCS, childhood cancer survivor; CNS, central nervous system; N, sample size; SD, standard deviation.

<sup>a</sup>Number of CCS with at least one parent responding to this survey.

<sup>b</sup>Four missing values.

than 20 years after diagnosis.<sup>28</sup> Another study found higher prevalence of anxiety in parents of CCS (11.1%), on average 18 years after diagnosis, but they included a small sample of parents who still accompanied their child to follow-up care visits.<sup>27</sup> Some studies found that mothers reported more anxiety than fathers.<sup>12,19,37</sup> However, in line with other studies,<sup>15,28,38</sup> we found no gender differences for anxiety,

which is in line with a systematic review that found gender differences in parents of children with cancer to diminish over time.<sup>39</sup>

General worries and topics of worries were comparable between CCS-parent-controls and GP-parents. However, when comparing CCS-parents to CCS-parent-controls, there was some indication that CCS-parents may be less worried, and fewer CCS-parents indicated that



**TABLE 2** Worries and anxiety in parents of adult childhood cancer survivors and parents of the Swiss general population

WAQ		CCS-parents N = 478		CCS-parent-controls N = 309		GP-parents N = 478		p-Value <sup>a</sup>
		Mean	SD	Mean	SD	Mean	SD	
WAQ total score		13.3	11.98	16.6	11.96	17.1	13.14	.977
		n	%	n	%	n	%	p-value <sup>b</sup>
Item 1: parents reporting at least one worry		227	50.1%	265	85.8%	419	87.7%	.450
No. of reported worry topics	Median (range)	2 (0–8)	–	2 (0–5)	–	2 (0–5)	–	–
GAD	All	7	1.5%	8	2.7%	17	3.6%	.536
	Fathers/mothers	2/5	1.0/1.8%	2/6	1.7/3.4%	7/10	3.5/3.7%	
Cognitive criteria	All	34	7.2%	24	7.8%	45	9.6%	.440
	Fathers/mothers	8/26	4.1/9.5% <sup>e</sup>	7/17	5.7/9.4%	14/31	7.0/11.6%	
Somatic criteria	All	49	10.7%	44	14.7%	93	20.0%	.067
	Fathers/mothers	14/35	7.3/13.2% <sup>e</sup>	16/28	13.2/15.6%	25/68	12.6/25.5% <sup>e</sup>	
Any criteria	All	76	16.2%	53	17.7%	112	24.0%	.039
	Fathers/mothers	22/54	11.2/19.8% <sup>e</sup>	19/34	15.7/19.0%	30/82	15.1/30.6% <sup>e</sup>	
Influence of worries and anxiety on family life	Positive influence: yes <sup>c</sup>	58	13.9% <sup>f</sup>	57	21.8%	81	20.4%	.696
	Negative influence: yes <sup>d</sup>	60	14.5% <sup>f</sup>	58	20.9%	80	20.0%	.772

Note: Higher values indicate more worries. We excluded  $n = 20$  participants (WAQ total score, GAD, no criteria),  $n = 21$  participants (somatic criteria), and  $n = 15$  (cognitive criteria), who answered less than half of the items.

Abbreviations: CCS, childhood cancer survivor; GAD, general anxiety disorder; GP, general population; N, sample size; SD, standard deviation; WAQ, Worry and Anxiety Questionnaire.

<sup>a</sup>p-Value from Mann–Whitney *U* test, comparing CCS-parent-controls to GP-parents.

<sup>b</sup>p-Value from Fisher's exact test, comparing CCS-parent-controls to GP-parents.

<sup>c</sup>CCS-parents: 62 missings, CCS-parent-controls: 48 missings, GP-parents: 80 missings; missings were excluded from calculating proportions.

<sup>d</sup>CCS-parents: 63 missings, CCS-parent-controls: 32 missings, GP-parents: 77 missings; missings were excluded from calculating proportions.

<sup>e</sup>Statistically significant difference between mothers and fathers;  $p < .05$ .

<sup>f</sup>Statistically significant difference between CCS-parents and CCS-parent-controls, and between CCS-parents and GP-parents;  $p < .05$ .

worries and anxiety affected their family life, either positively or negatively. This might have been caused by a response-shift after answering cancer-related questions: CCS-parents were reminded of the time when the child was ill with its challenges, anxiety, and distress, and may have assessed their current situation in relation to this time.

Our study adds to the evidence that cancer-related worries of parents of CCS do not seem to have an “end date.” On average 24 years after diagnosis, at an age of 48–85 years, nearly a third of parents reported currently being worried about late effects or child's health, a quarter was worried about a relapse or second malignancy, and some were worried about infertility, their child finding a partner, or the child's education or job. Similarly, a systematic review found that parents of CCS worry about their child's health, late effects, or a possible relapse but also the child's education, lack of friends, and possible infertility.<sup>13</sup> A more recent study also showed continued parental worries about cancer recurrence or late effects long into survivorship.<sup>15</sup> This is particularly relevant as fear of cancer recurrence was found to be associated with lower health-related quality of life in parents.<sup>15</sup>

A subgroup of parents of CCS is at increased risk for worries. In contrast to anxiety, we found a gender difference for worries. Mothers reported increased worries in all groups, GP-parents, CCS-parent-

controls, and CCS-parents. This is a common finding, and various hypotheses for gender differences have been made: from women being more prone to ruminative thinking, mothers being more involved in child care than fathers, but also men being less likely to disclose their feelings openly.<sup>26,39</sup> Having an only child, experiencing pain, current disadvantages, and support needs were associated with increased cancer-related worries. Parents of an only child may worry more about the child because of a stronger focus on the only child.

Parents at risk for increased worries or those who experience anxiety should be offered psycho-social support. While worrying about adult children is a normal phenomenon of parenthood,<sup>40</sup> our study found specific subgroups of parents of survivors who reported increased cancer-related worries: mothers, parents of an only child, parents who experience pain, disadvantages, or support needs. As a standard of care for affected families, it is recommended that parents' mental healthcare needs are assessed and that access to appropriate interventions is facilitated.<sup>11</sup> This is important and feasible during active treatment, when anxious and distressed parents can be identified and offered psycho-social interventions.<sup>41</sup> Also during follow-up appointments, parents should be offered information adapted to the child's age and risk for late effects.<sup>42</sup> However, with children's

**TABLE 3** Worries and anxiety in parents of adult childhood cancer survivors as compared to parents of the Swiss general population

		CCS-parents N = 478		CCS-parent-controls N = 309		GP-parents N = 478		p-Value <sup>a</sup>
		n	%	n	%	n	%	
Worry topics	Health and well-being	NA	NA	130	42.1%	207	43.3%	0.657
	Personal Life	NA	NA	37	12.0%	86	18.0%	<b>0.027</b>
	Education and work	NA	NA	36	11.7%	60	12.6%	0.739
	Social relationships	NA	NA	88	28.5%	139	29.1%	0.872
	Politics	NA	NA	26	8.4%	18	3.8%	<b>0.007</b>
	Economy	NA	NA	2	0.6%	13	2.7%	0.058
	Finances	NA	NA	33	10.7%	51	10.7%	1.000
	World affairs	NA	NA	62	20.1%	91	19.0%	0.713
	Environmental issues	NA	NA	49	15.9%	62	13.0%	0.294
	Society	NA	NA	43	13.9%	63	13.2%	0.831
		Mean	SD	Mean	SD	Mean	SD	p-Value <sup>b</sup>
Worries and Anxiety Questionnaire	Item 2	1.3	1.71	1.5	1.67	1.4	1.80	0.348
	Item 3	1.9	2.05	2.9	1.74	2.9	1.92	0.790
	Item 4	1.4	1.82	1.7	1.81	1.7	1.85	0.833
	Item 5a	1.4	1.65	1.7	1.71	1.8	1.80	0.328
	Item 5b	1.0	1.62	1.3	1.75	1.5	1.88	0.087
	Item 5c	1.0	1.40	1.2	1.46	1.3	1.65	0.690
	Item 5d	1.1	1.57	1.5	1.64	1.5	1.68	0.679
	Item 5e	1.0	1.59	1.3	1.75	1.4	1.95	0.553
	Item 5f	2.0	2.16	2.1	2.04	2.2	2.12	0.790
	Item 6	1.2	1.54	1.5	1.66	1.4	1.66	0.402

Note: The detailed codes that were grouped into these worry topics can be found in Figure S1.

Abbreviations: CCS, childhood cancer survivor; GP, general population; N/n, sample size.

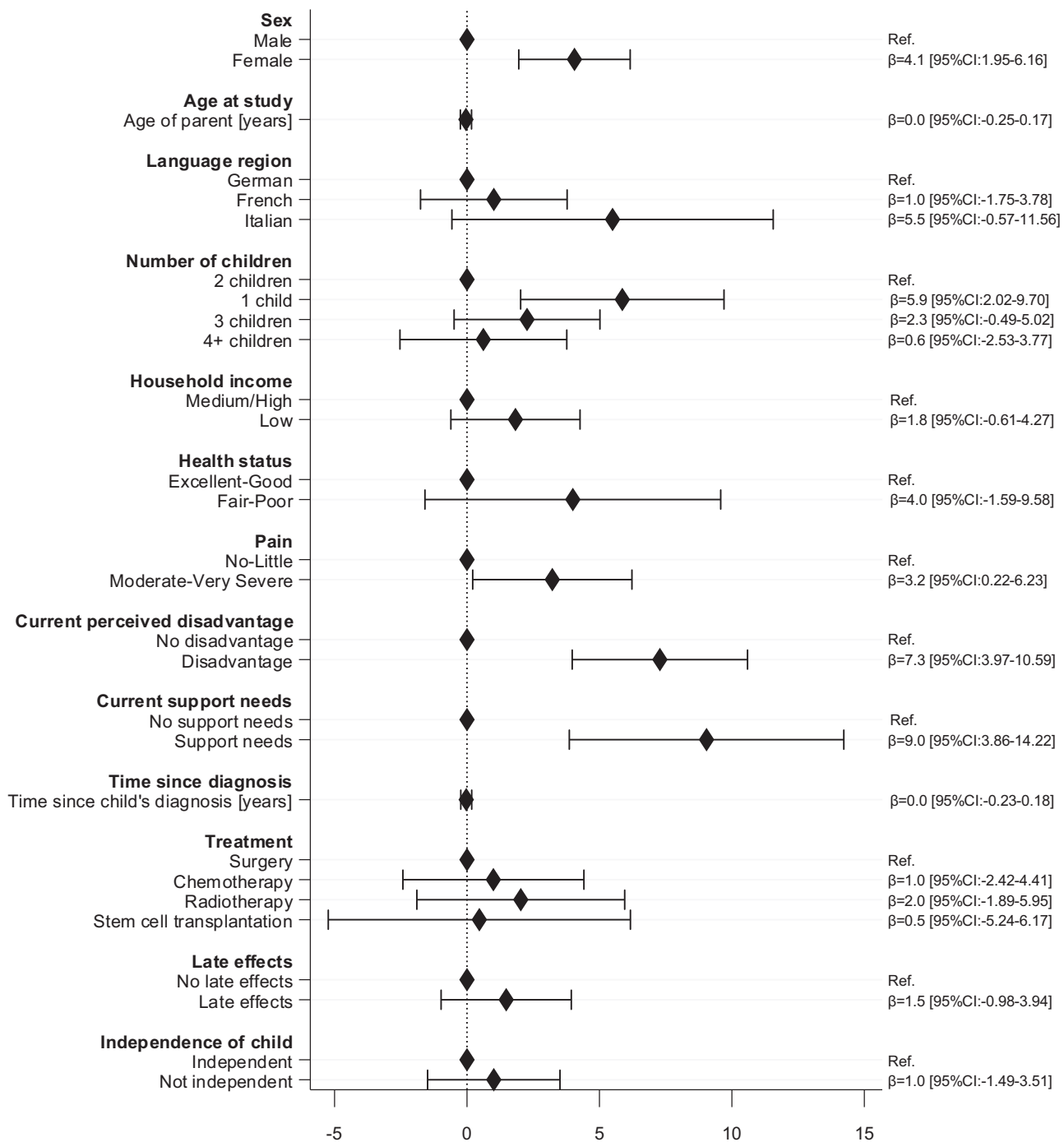
<sup>a</sup>p-value from Fisher's exact test, comparing CCS-Parent-Controls to GP-parents.

<sup>b</sup>p-value from Mann-Whitney-U test, comparing CCS-Parent-Controls to GP-parents

increasing age, parents are less likely to accompany their child to follow-up appointments,<sup>25,43</sup> and it may become difficult to reach parents. The first years after treatment completion may, therefore, be an important time point for healthcare professionals to assess parents' information needs and repeatedly provide information about potential late consequences of the cancer diagnosis and treatment for their child, but also to inform parents of the potential impact on their psycho-social well-being. Online resources might help, especially if they are personalized for the child such as in a survivorship passport. Parents who experience disadvantages or have current support needs were more likely to experience worries and anxiety, and in our previous work we demonstrated that both these characteristics were associated with late effects and dependence of the survivor on the parents.<sup>23</sup> Healthcare professionals should, therefore, be aware that parents of survivors with severe late effects may be at increased risk for poor psycho-social outcomes and offer appropriate support. Additionally, online information or social media platforms may prove useful resources for parents of survivors to find information about the impact of a childhood cancer diagnosis on caregivers, as well

as information about psycho-social support services available for affected families. Overall, healthcare professionals should communicate early to parents of childhood cancer patients that they may experience anxiety or worries and encourage them to seek support if required.

Strengths of our study are the nationwide, population-based design, and the randomization of CCS-parents into two groups, one of which was contacted with the same questionnaire as the general population and the other with reference to their child's cancer diagnosis. We were able to include a considerable proportion of fathers and parent-couples, and the study included a comparison group of the Swiss general population. A limitation of our study is the relatively low response rate, especially in the general population, and the different response rates of the three different groups, which might have resulted in selection bias. However, the two samples were comparable regarding most characteristics, and we restricted the general population sample to parents of similarly aged children as parents of CCS, which improves comparability of the two samples. Recall bias may be a limitation for parents' answers about worries during treatment. Due



**FIGURE 3** Characteristics associated with cancer-related worries in parents of adult childhood cancer survivors (CCS-parents). Note: All displayed variables were included in the multivariable model. Ref. = reference category.

to the cross-sectional design of our study, we were not able to establish causal inference of associations. Overall, the design and methods used in our study allow for generalizability to the population of parents of CCS in culturally similar countries, or countries with a similar healthcare infrastructure.

It is encouraging that most parents of adult CCS report normal levels of worry and anxiety, on average 24 years after the cancer diagnosis of

their child. Cancer-related worries are still prevalent among parents, especially worries about late effects or cancer recurrence. Mothers, parents of an only child, parents who experience pain, disadvantages, or support needs are more likely to experience cancer-related worries and anxiety. Our study suggests that surveillance of worries and anxiety for all parents of adult CCS is not necessary, but efforts should be made to empower parents to seek psycho-social support if required.

## ACKNOWLEDGMENTS

We would like to thank all parents who participated in our study. We would also like to thank Michaela Kaufmann, Pauline Holmer, Anica Ilic, and Grit Sommer for their contribution in coding the open answers.

Open access funding provided by Universitat Luzern.

## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## 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:** Christen S, Roser K, Harju E, et al. Worries and anxiety in parents of adult survivors of childhood cancer: A report from the Swiss Childhood Cancer Survivor Study-Parents. *Pediatr Blood Cancer*. 2023;70:e30246. <https://doi.org/10.1002/pbc.30246>