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# Psychosocial functioning of parents of Dutch long-term survivors of childhood cancer

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## Abstract

**Objective:** To describe health-related quality of life (HRQoL), post-traumatic stress and post-traumatic growth of parents of long-term survivors of childhood cancer (CCS) and study associated factors.

**Methods:** Parents of survivors of the Dutch Childhood Cancer Survivor Study LATER cohort below 30 years and diagnosed 1986–2001 were invited to complete the TNO-AZL Questionnaire for Adult's HRQoL (e.g., sleep and aggressive emotions), Self-Rating Scale for Post-traumatic Stress Disorder, Post-traumatic Growth Inventory, and Illness Cognition Questionnaire. HRQoL domain scores were compared to references using Mann-Whitney U tests. Correlations between post-traumatic stress, growth and HRQoL were evaluated. Medical characteristics of their child and illness cognitions were studied as associated factors of HRQoL, post-traumatic stress and growth.  $p < 0.05$  was considered statistically significant.

**Results:** Parents ( $n = 661$  of  $n = 448$  survivors, 56% female, mean time since child's diagnosis: 21.3 [SD: 3.3] years) reported better HRQoL in social functioning and aggressive emotions than references ( $r = .08$ – $0.17$ ). Mothers additionally reported better HRQoL in pain, daily activities, sexuality, vitality, positive and depressive emotions ( $r = .07$ – $0.14$ ). Post-traumatic stress was symptomatic in 3%, and associated with worse HRQoL ( $r = -0.27$ – $0.48$ ). Post-traumatic growth was positively associated to post-traumatic stress and better HRQoL ( $r = 0.09$ – $0.12$ ). Cancer recurrence was associated to better HRQoL ( $\beta = 0.37$ – $0.46$ ). Acceptance illness

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cognitions were associated to better ( $\beta = 0.12$ – $0.25$ ), and helplessness to worse outcomes ( $\beta = 0.14$ – $0.38$ ).

**Conclusions:** HRQoL of parents of young adult survivors of CCS is comparable to references or slightly better. Only a small proportion reports symptomatic post-traumatic stress. Improving acceptance and reducing feelings of helplessness may provide treatment targets for parents with psychosocial problems.

**KEYWORDS**

health-related quality of life, illness cognitions, parents, pediatric oncology, post-traumatic growth, post-traumatic stress, psycho-oncology, psychosocial outcomes, survivors of childhood cancer

## 1 | BACKGROUND

The diagnosis of cancer of their child has a major impact on the psychosocial functioning of parents.<sup>1,2</sup> Stressors change from the initial shock of diagnosis, to the disruption of daily life because of treatment, fear of recurrence<sup>3</sup> and late effects that may await their child after treatment.<sup>4</sup> These stressors may affect the mental and physical health of parents, that is, cause psychological distress. As described in the integrative trajectory model of pediatric medical traumatic stress and substantiated in empirical studies in pediatric oncology, psychological distress is typically high around diagnosis and decreases over time to normal some years after treatment ends.<sup>2,5,6</sup> However, some parents continue to report elevated psychological distress.<sup>1</sup>

The psychological distress caused by their child's cancer diagnosis and treatment was found to impact parents' health-related quality of life (HRQoL).<sup>2,7</sup> Parents sometimes experience the diagnosis and treatment of their child to be traumatic,<sup>8</sup> causing post-traumatic stress problems in 6%–30% of parents,<sup>1</sup> but also resulting in post-traumatic psychosocial growth.<sup>1</sup> Post-traumatic growth and stress were previously described to be related<sup>9</sup> and both can impact HRQoL.<sup>6,10</sup> However, most research results stem from studies including parents of a child during active treatment or young survivors of childhood cancer (CCS) (aged <18 years). A rather small study suggested ongoing psychological distress in parents of adult CCS.<sup>11</sup> On the other hand, parents of Swiss CCS 24 years after diagnosis reported post-traumatic stress rates similar to the general population.<sup>12</sup> Systematic knowledge of psychosocial functioning of parents of CCS on the very long-term is lacking.

Several factors were found to be associated to psychosocial outcomes of parents of children with cancer closer to diagnosis and treatment. Mothers of children with cancer were described to have more psychological distress<sup>13</sup> and more post-traumatic growth than fathers.<sup>14</sup> Also, parents with a lower level of education were found to have lower psychological function.<sup>2</sup> Previous research identified relapse and central nervous system (CNS) tumor diagnosis of their child as indicators for potentially impaired psychosocial functioning of parents.<sup>2,15</sup> Finally, parents' cognitions are important to consider, following the model that Wallander and Varni proposed, where coping skills (e.g., cognitions) mediate the relation between a stressful event and the psychosocial outcomes.<sup>5,16,17</sup>

To improve knowledge on parents' psychosocial functioning on the long-term, we aimed to describe HRQoL, post-traumatic stress and post-traumatic growth of parents from a large nationwide cohort of Dutch long-term CCS, compare HRQoL to a general population reference sample and study associations between post-traumatic stress and growth, and between these constructs and HRQoL. To be able to identify and help the parents that continue to experience elevated stress, we aimed to identify which sociodemographic factors, medical factors of the child and parental illness cognitions are associated with HRQoL, post-traumatic stress and post-traumatic growth.

## 2 | METHODS

### 2.1 | Participants

The cohort of Dutch survivors diagnosed between 1963 and 2001 has been studied in the Dutch Childhood Cancer Survivor Study (DCCSS) LATER 1 (registry linkage and questionnaires) and LATER 2 (clinical visit and questionnaires) studies.<sup>18</sup> This paper presents results from the psychosocial substudy of LATER 2, in which we invited parents of adolescent and young adult CCS (aged <30 years) who were diagnosed between 1986 and 2001 (cohort of CCS  $n = 1362$ ) for a psychosocial questionnaire study. Parents of survivors younger than 18 years ( $n = 49$ ) were directly approached via an attachment to the patient information regarding their child's participation in the DCCSS LATER 2 study. Parents of survivors 18–30 years were invited to participate by mail if their child gave consent and provided the address of their parents. In total, 996 parents (of 588 CCS) were invited. The medical ethics board of Amsterdam University Medical Centers, location AMC (ref: 2010/332) approved the study protocol.

### 2.2 | Psychosocial outcomes and measures

Participants could complete questionnaires on HRQoL, post-traumatic stress and post-traumatic growth digitally or on paper. Additional questionnaire information can be found in Table A1.

## 2.2.1 | Health-related quality of life: TNO-AZL Questionnaire for Adult's HRQoL (TAAQOL)

The TAAQOL was developed by the departments prevention and health and the pediatric department of the Leiden university Medical Center to assess HRQoL in people aged 16 years and older.<sup>19</sup> The TAAQOL measures health status problems weighted by their impact on well-being in the past month in 12 domains, each represented by 2-4 items. We included 10 domains: cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive emotions, depressive emotions, and aggressive emotions, but we left out fine and gross motor functioning. Domain sum scores range from 0 to 100, and higher scores indicate better HRQoL (e.g., less pain, better social function). The TAAQOL has been validated in a random general population sample and a sample of people with chronic illness. Conceptual, convergent and criterion validity and reliability of the TAAQOL are satisfactory.<sup>19</sup>

Dutch general population reference data from 2004 are available from the TAAQOL reference study in two samples from the general population, that were randomly drawn from the national telephone registry.<sup>19</sup> To obtain an age-matched sample we included reference data from adults aged 48-64 years for this study ( $n = 1221$ , 48% female, mean [SD] age: 55.4 [5.0] years).

## 2.2.2 | Childhood cancer-specific post-traumatic stress: Self-rating scale for post-traumatic stress disorder (SRS-PTSD)

The Self-rating scale for post-traumatic stress disorder (SRS-PTSD) assesses post-traumatic stress symptoms that correspond to the diagnostic DSM-IV symptoms in three subscales: re-experiencing (range: 0-5 symptoms), avoidance (range: 0-7 symptoms), and hyperarousal (range: 0-5 symptoms), adding up to a total score (range 0-17). Parents were instructed to think of the childhood cancer that their child had when answering questions on symptom occurrence over the past 4 weeks. Psychometric properties are adequate.<sup>20</sup>

## 2.2.3 | Childhood cancer-specific post-traumatic growth: Post-traumatic growth inventory (PTGI)

The PTGI assesses post-traumatic growth (i.e. positive change) in 21 items from the subscales: relating to others (range: 0-35), new possibilities (range: 0-25), personal strength (range: 0-20), spiritual change (range: 0-10) and appreciation of life (range: 0-15). Parents were asked to think of the childhood cancer that their child had when answering questions. Total scores range from 0 to 105, and higher scores reflect more growth. Psychometric properties are adequate.<sup>21</sup>

## 2.3 | Associated factors and measures

### 2.3.1 | Sociodemographic and medical characteristics of the child

Parents' age, sex, level of education and number of children were the included sociodemographic characteristics. The latter two were obtained from their survivor child in either DCCSS LATER two or DCCSS LATER 1.<sup>22</sup> Child medical characteristics were CNS diagnosis (vs. other diagnoses), recurrence, age at diagnosis and time since diagnosis, and were obtained from the DCCSS LATER registry.<sup>22</sup>

### 2.3.2 | Illness cognitions: Illness cognition questionnaire (ICQ)

The 18-item Illness cognition questionnaire (ICQ) assesses parents' cognitions on their child's disease in three scales: helplessness, acceptance and disease benefits. Higher scores indicate a stronger presence of the illness cognitions (range 6-24).<sup>17</sup> Psychometric properties are good.<sup>17</sup>

## 2.4 | Statistical methods

Descriptive statistics were used to describe the outcomes and associated factors. Within invited parents, age, sex and level of education of participants were compared to non-participants using a t-test and chi-square tests, with Cramer's V as effect size. Characteristics of the sample of CCS of whom one or both parents participated were compared to the total cohort of survivors <30 years using one-sample t-tests and one-sample chi-square tests. HRQoL scores of the parents were compared to the general population for males and females separately using Mann Whitney U-tests with effect size  $r$ , since the assumption of normality was not met. Post-traumatic stress and post-traumatic growth were evaluated in the context of childhood cancer, so they were not comparable to the general population. Associations between post-traumatic stress and growth and the other outcomes were assessed with Pearson's correlation coefficient ( $r$ ).

To study associated factors of the outcomes, multivariable mixed effects linear regression was used with TAAQOL subdomain scores, and SRS-PTSD and PTGI total scores as dependent variables and sociodemographic characteristics, medical characteristics of the child and illness cognitions as independent variables. A random intercept was included to account for dependency of outcomes of parents of the same child. Age of the survivor and of the parent at time of data collection were not included in the models because of multicollinearity with time since diagnosis and child's age at diagnosis. Other assumptions for mixed effects linear regression models were

met. To obtain standardized coefficients ( $\beta$ ) with confidence intervals, continuous variables were standardized.

A  $p$ -value  $<0.05$  was considered statistically significant. A Bonferroni correction was applied for the comparison of 10 domains of HRQoL to reference values ( $0.05/10 = 0.005$ ). After Cohen, mean differences between two groups (regression coefficients of categorical variables) of 0.2, 0.5 and 0.8 and correlations (regression coefficients of continuous variables, Cramer's  $V$  and  $r$ ) of 0.1, 0.3 and 0.5 were considered small, medium and large.<sup>23</sup>

### 3 | RESULTS

661 parents of the 996 invited parents (response rate 66%, 56% female, mean age 57 years) of 448 CCS (33% of total cohort) provided written informed consent and participated. Table 1 describes sociodemographic characteristics and child medical characteristics of participants. Participants had somewhat higher levels of attained education than non-participants (low/middle/high: 23%/36%/41% vs. 29%/41%/31%,  $V: 0.10$ ,  $p = 0.027$ ), but sex (male/female: 44%/56% vs. 48%/52%) and age (57.0 [3.5] vs. 56.5 [3.6] years) were not significantly different. Table A2 shows the characteristics of survivors of whom one or more parents participated in this study ( $n = 448$ ) and the total LATER 2 cohort  $<30$  years. Characteristics of these groups were not significantly different.

Table 2 shows the psychosocial outcomes and illness cognitions of the total group and of mothers and fathers separately. Compared to sex-specific reference values, mothers of survivors had higher HRQoL in all domains except cognitive functioning and sleep and fathers of survivors also had better social functioning and less aggressive emotions (Table 2). HRQoL was never lower than reference values. Effect sizes of the differences were small ( $r: 0.07$ – $0.17$ ). 3% had symptomatic post-traumatic stress and the mean PTGI score was 45.9 (SD: 21.2).

Table 3 presents the associations between post-traumatic stress and growth and the other outcomes. We found a small positive association between post-traumatic stress and post-traumatic growth ( $r: 0.12$ ). Post-traumatic growth also had small associations with higher HRQoL in social functioning, daily activities and positive emotions ( $r: 0.09$ – $0.12$ ). Post-traumatic stress had medium to large negative associations with all domains of HRQoL ( $r: -0.27$ – $-0.48$ ).

Table 4 presents the results of multivariable models. Parents with more than one child had less post-traumatic stress symptoms than parents for whom the survivor child was their only child ( $\beta: -0.44$ ,  $p < 0.01$ ). Regarding medical characteristics, recurrence of their child's cancer related to better HRQoL in social functioning, positive emotions and aggressive emotions with a small to medium effect size ( $\beta: 0.37$ – $0.46$ ,  $p < 0.05$ ). Helplessness related most strongly to post-traumatic stress ( $\beta: 0.39$ ,  $p < 0.001$ ) and more depressive emotions ( $\beta: -0.26$ ,  $p < 0.001$ ), and acceptance to more positive emotions ( $\beta: 0.25$ ,  $p < 0.001$ ) and less post-traumatic stress symptoms ( $\beta: -0.23$ ,  $p < 0.001$ ).

**TABLE 1** Sociodemographic characteristics of participating parents ( $n = 661$ ) and medical characteristics of their survivor child

	% (n) or mean (SD)	Missing cases
Age (years) <sup>a</sup>	57.0 (3.5)	86
Sex		82
Male	44% (254)	
Female	56% (325)	
Attained level of education <sup>b</sup>		128
Low	23% (122)	
Middle	36% (194)	
High	41% (217)	
Number of children	2.5 (0.9)	49
1	10% (61)	
>1	90% (551)	
Child medical characteristics		
Survivor age	25.4 (3.5)	4
Follow-up time since diagnosis (years)	21.3 (3.3)	4
Age at diagnosis (years)	4.1 (3.0)	4
0–4	68% (451)	
5–9	25% (165)	
10–14	6% (41)	
14–17	0% (0)	
Recurrence of primary tumor	12% (77)	4
Primary childhood cancer diagnosis		
Hematologic cancers	55% (365)	
CNS tumor	8% (53)	
Solid tumor	36% (238)	
Treatment period		
1980–1989	1% (4)	
1990–1999	69% (455)	
2000–2001	30% (198)	

<sup>a</sup>Age was estimated as the age at invitation of the survivor child with the best available mean age of women and men at child birth from national data of Statistics Netherlands (CBS) in the median birth year of survivors.

<sup>b</sup>Low: primary education, lower vocational education, lower and middle secondary education; middle: middle vocational education, higher secondary education, pre-university education; high: higher vocational education, university.

### 4 | DISCUSSION

We found that HRQoL was comparable to references or slightly better in parents of young adult CCS, who were on average 21 years after their child's cancer diagnosis. Also, the proportion of parents

TABLE 2 Psychosocial outcomes and illness cognitions of parents of survivors of childhood cancer (CCS)

	Total group (n = 543–581) Mean (SD) or % (n)	Mothers (n = 269–294) <sup>b</sup> Mean (SD) or % (n)	Female references (n = 590) Mean (SD)	r <sup>a</sup>	Fathers (n = 208–226) <sup>b</sup> Mean (SD) or % (n)	Male references (n = 631) Mean (SD)	r <sup>a</sup>
<b>Health-related quality of life (HRQoL)</b>							
Cognitive functioning	81.2 (23.2)	80.4 (23.6)	79.4 (24.9)	0.02	82.8 (21.1)	82.3 (22.6)	0.005
Sleep	69.0 (25.0)	63.9 (25.4)	64.1 (28.3)	−0.02	75.1 (22.2)	78.0 (25.0)	−0.09
Pain	71.5 (22.0)	69.8 (21.4)	64.4 (27.4)	0.07*	73.0 (21.9)	73.7 (24.5)	−0.04
Social functioning	86.7 (16.9)	87.1 (17.1)	80.0 (21.5)	0.17*	86.5 (16.5)	84.0 (16.8)	0.08*
Daily activities	85.7 (22.5)	84.3 (24.3)	78.8 (28.9)	0.09*	87.2 (20.1)	86.6 (22.5)	−0.02
Sexuality	84.3 (24.1)	86.8 (21.8)	80.2 (28.3)	0.11*	79.2 (27.2)	81.4 (28.2)	−0.05
Vitality	66.6 (21.7)	65.1 (22.4)	59.2 (25.6)	0.10*	68.6 (20.3)	68.7 (22.4)	−0.03
Positive emotions	64.9 (20.9)	64.1 (21.0)	59.8 (22.2)	0.09*	65.2 (21.3)	63.6 (20.8)	0.04
Depressive emotions	80.3 (17.8)	77.8 (18.4)	71.8 (22.5)	0.11*	83.4 (16.6)	81.5 (19.0)	0.03
Aggressive emotions	92.5 (12.7)	93.3 (11.8)	88.5 (16.2)	0.14*	91.3 (14.0)	87.3 (17.6)	0.10*
<b>Posttraumatic stress</b>							
Total score	2.1 (2.3)	2.3 (2.4)			1.9 (2.2)		
Symptomatic post-traumatic stress	3% (19)	3% (9)			2% (6)		
Symptomatic re-experience	60% (357)	64% (188)			53% (118)		
Symptomatic avoidance	4% (26)	5% (13)			4% (9)		
Symptomatic hyperactivity	10% (61)	10% (30)			10% (22)		
<b>Posttraumatic growth<sup>a</sup></b>							
Total score	45.9 (21.2)	49.1 (20.6)			42.3 (21.8)		
Relating to others	17.0 (7.9)	17.8 (7.9)			16.2 (8.0)		
New possibilities	8.5 (6.0)	9.2 (6.1)			7.9 (5.9)		
Personal strength	10.4 (5.1)	11.5 (4.9)			9.1 (5.2)		
Appreciation of life	7.9 (3.9)	8.4 (3.7)			7.3 (4.1)		
Spiritual change	2.0 (2.6)	2.2 (2.6)			1.7 (2.6)		
<b>Illness cognitions</b>							
Helplessness	8.1 (2.4)	8.1 (2.3)			8.0 (2.4)		
Acceptance	19.1 (3.6)	19.1 (3.5)			19.2 (3.7)		
Disease benefits	17.8 (4.2)	18.1 (4.1)			17.4 (4.3)		

<sup>a</sup>Effect size for differences from the reference sample; effect sizes were calculated with  $r = Z\text{-score of the difference}/(\sqrt{N})$ .

<sup>b</sup>Number of mothers and fathers do not add up to total because of missing values in sex.

\*Mann-Whitney  $p < 0.005$  for difference from the general population sample.

with symptomatic post-traumatic stress seemed low. These results reinforce previous insights that the initially elevated levels of distress experienced around the time of their child's diagnosis and treatment eventually return to normal levels in most parents.<sup>2,6</sup> A consideration with these generally reassuring results may be that pediatric oncology care in the Netherlands at the time of treatment (largely 1990–2001) likely included availability of child life specialists and

social workers; this may have helped and prevented long term psychosocial difficulties.<sup>24</sup>

Compared to the literature, our results on HRQoL seem positive. A study in parents who were around 3 years after their child's diagnosis found lower HRQoL in several domains compared to references, and mothers in more domains than fathers.<sup>25</sup> HRQoL of parents was previously found to improve with time since diagnosis,<sup>7</sup>

**TABLE 3** Pearson's *r* (and 95% confidence interval) of associations between post-traumatic stress and post-traumatic growth, and HRQoL and distress

	Post-traumatic stress		Post-traumatic growth	
Post-traumatic stress	X		0.12**	(0.04;0.21)
Post-traumatic growth	0.12**	(0.04;0.21)	X	
Cognitive functioning	−0.30***	(−0.38;−0.22)	−0.03	(−0.11;0.05)
Sleep	−0.37***	(−0.44;−0.29)	−0.02	(−0.10;0.07)
Pain	−0.34***	(−0.42;−0.26)	−0.05	(−0.14;0.03)
Social functioning	−0.32***	(−0.39;−0.23)	0.09*	(0.001;0.17)
Daily activities	−0.35***	(−0.42;−0.27)	−0.10*	(−0.19;−0.02)
Sexuality	−0.27***	(−0.35;−0.19)	−0.08	(−0.16;0.01)
Vitality	−0.40***	(−0.47;−0.32)	−0.02	(−0.10;0.07)
Positive emotions	−0.31***	(−0.39;−0.22)	0.12**	(0.04;0.21)
Depressive emotions	−0.48***	(−0.54;−0.41)	−0.05	(−0.13;0.04)
Aggressive emotions	−0.33***	(−0.41;−0.25)	−0.03	(−0.12;0.06)

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

and other studies evaluating parents' well-being longer after their child's childhood cancer diagnosis also showed relatively high HRQoL in parents of survivors.<sup>26</sup>

A small proportion (3%) of participating parents experienced symptomatic post-traumatic stress, which is similar to that reported for Dutch parents of an ill child (3%).<sup>27</sup> This seems low compared to 6%–30% that previous research described in parents of a younger survivor child,<sup>1</sup> but is in line with the finding that Swiss parents of CCS are not at increased risk for post-traumatic stress on the long-term.<sup>12</sup> Nevertheless, parents who experience these symptoms from their child's cancer on the long-term may be in need of support.<sup>6</sup> This may be especially relevant since we found that post-traumatic stress problems showed moderate associations to HRQoL, and previous research also describes a negative impact on psychosocial functioning.<sup>6</sup> Post-traumatic growth scores were lower than previously reported in parents of children with cancer during treatment (66.1 [19.1])<sup>28</sup> and around 5 years after end of treatment (69.0 [25.5]).<sup>29</sup> Post-traumatic growth may decline in the 2 decades after diagnosis, in line with results that were found in survivors.<sup>9</sup> These results of relatively low post-traumatic stress and growth, which are associated, are in line with the theoretical models: a stressor causes struggle (i.e., post-traumatic stress), which stimulates growth, and this process tapers off with time in most people.<sup>10</sup>

In line with previous studies, mothers had more post-traumatic growth.<sup>14</sup> A higher level of education related to better HRQoL in some domains, which may be explained by similar associations between education level and HRQoL in the general population.<sup>30</sup> Remarkably, having multiple children was a protective factor for post-traumatic stress symptoms.

Previous medical characteristics of their child did not seem to negatively impact parents' psychosocial functioning this long after diagnosis. Remarkably, recurrence was associated to more positive

HRQoL in social and emotional domains. Based on previous research we rather expected a negative impact of factors related to more severe treatment and consequences.<sup>7,31</sup> The contrast may be explained by the time of assessment: previous results concern well-being closer to the time of childhood cancer treatment.<sup>31</sup>

The illness cognition helplessness was associated to worse psychosocial functioning, while the illness cognition acceptance was associated to better psychosocial functioning. Apparently, even this long after their child's cancer, cognitions about that illness were relevant for parents' psychosocial functioning, in line with the model of Wallander and Varni.<sup>16</sup> Helplessness scores were substantially lower and acceptance scores seemed higher in our sample than those from a study on parents of a child during treatment for cancer.<sup>17</sup> In line with this study, these cognitions were associated with most psychosocial outcomes.<sup>17</sup> Similar to results of previous studies, disease benefits only showed small positive associations with positive emotions and social function.<sup>17,32</sup>

#### 4.1 | Clinical implications

Fortunately, psychosocial functioning of parents of children with cancer on average does not seem to be impaired on the long-term. A few parents of survivors experienced post-traumatic symptoms. Our results suggest that illness cognitions may be a target for interventions, for instance using cognitive behavioral therapy or acceptance commitment therapy.<sup>33,34</sup> As previous research suggests that maladaptive coping early on predicts later outcomes,<sup>24</sup> screening in an earlier phase and offering timely intervention may prevent these long-term problems for this small group of parents.<sup>35</sup> Intervention could for example, be provided using the recently developed module for parents of a child with cancer of the psychosocial group intervention Op Koers (in English: on track), which aims

**TABLE 4** Standardized coefficients ( $\beta$ ) of associations of sociodemographic factors, child disease variables and illness cognitions with health-related quality of life (HRQL), distress, posttraumatic stress and posttraumatic growth

	Cognitive functioning <sup>a</sup>	Sleep <sup>a</sup>	Pain <sup>a</sup>	Social functioning	Daily activities <sup>a</sup>	Sexuality	Vitality <sup>a</sup>	Positive emotions	Depressive emotions	Aggressive emotions <sup>a</sup>	Posttraumatic stress	Posttraumatic growth
Model n	422	420	421	420	421	416	422	422	421	417	407	430
	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)	$\beta$ (95% CI)
Sociodemographic variables												
Sex (female vs. male)	-0.08 (-0.27; 0.11)	-0.48*** (-0.67; -0.30)	-0.09 (-0.28; 0.09)	0.06 (-0.13; 0.24)	-0.15 (-0.34; 0.04)	0.39*** (0.20; 0.58)	-0.14 (-0.33; 0.05)	-0.07 (-0.26; 0.12)	-0.31** (-0.48; -0.13)	0.17 (-0.03; 0.37)	0.12 (-0.05; 0.29)	0.28** (0.10; 0.45)
Level of education (ref. low)												
Middle	-0.19 (-0.45; 0.07)	-0.05 (-0.31; 0.20)	-0.05 (-0.30; 0.20)	0.02 (-0.23; 0.28)	-0.18 (-0.44; 0.09)	-0.07 (-0.34; 0.20)	-0.13 (-0.38; 0.13)	-0.004 (-0.26; 0.27)	-0.05 (-0.31; 0.20)	0.15 (-0.12; 0.41)	0.04 (-0.20; 0.27)	-0.03 (-0.29; 0.24)
High	-0.02 (-0.27; 0.24)	0.07 (-0.19; 0.32)	0.32* (0.06; 0.57)	0.27* (0.02; 0.53)	-0.13 (-0.39; 0.13)	-0.08 (-0.35; 0.19)	0.10 (-0.16; 0.35)	0.01 (-0.25; 0.27)	0.07 (-0.18; 0.33)	0.32* (0.06; 0.58)	0.06 (-0.18; 0.30)	-0.07 (-0.33; 0.20)
Number of children (>1 child vs. 1 child)	-0.10 (-0.42; 0.22)	0.11 (-0.21; 0.43)	0.01 (-0.31; 0.32)	-0.15 (-0.47; 0.16)	-0.06 (-0.38; 0.27)	0.003 (-0.34; 0.35)	0.10 (-0.22; 0.42)	0.15 (-0.18; 0.48)	0.07 (-0.25; 0.40)	0.11 (-0.22; 0.44)	-0.44** (-0.74; -0.13)	-0.05 (-0.40; 0.31)
Child disease variables												
Time since diagnosis	-0.01 (-0.12; 0.10)	0.05 (-0.05; 0.16)	-0.01 (-0.11; 0.10)	-0.02 (-0.14; 0.09)	0.002 (-0.11; 0.11)	-0.07 (-0.19; 0.05)	0.001 (-0.11; 0.11)	-0.05 (-0.17; 0.06)	-0.03 (-0.15; 0.08)	0.02 (-0.09; 0.14)	0.02 (-0.09; 0.13)	0.06 (-0.06; 0.19)
Age at diagnosis (years, ref 0-5)												
5-10	0.05 (-0.18; 0.29)	0.17 (-0.06; 0.40)	0.10 (-0.13; 0.33)	0.25 (0.01; 0.49)	0.16 (-0.08; 0.40)	0.14 (-0.11; 0.40)	0.07 (-0.17; 0.31)	-0.10 (-0.35; 0.14)	0.20 (-0.04; 0.45)	0.28* (0.04; 0.52)	-0.10 (-0.33; 0.12)	-0.17 (-0.44; 0.10)
10-15	-0.15 (-0.56; 0.26)	0.28 (-0.12; 0.68)	0.20 (-0.20; 0.59)	-0.07 (-0.48; 0.34)	-0.15 (-0.57; 0.27)	0.14 (-0.31; 0.60)	-0.35 (-0.75; 0.06)	-0.30 (-0.72; 0.13)	-0.11 (-0.54; 0.32)	0.03 (-0.39; 0.44)	-0.09 (-0.48; 0.30)	0.31 (-0.17; 0.78)
Recurrence (any vs. none)	-0.03 (-0.34; 0.27)	0.07 (-0.23; 0.37)	0.24 (-0.06; 0.54)	0.41** (0.10; 0.72)	-0.02 (-0.34; 0.29)	0.08 (-0.25; 0.42)	0.23 (-0.08; 0.54)	0.46** (0.15; 0.78)	0.18 (-0.14; 0.50)	0.37* (0.05; 0.68)	-0.05 (-0.35; 0.25)	0.12 (-0.23; 0.47)
CNS diagnosis (ref. other diagnoses)	0.16 (-0.18; 0.49)	0.04 (-0.30; 0.36)	-0.13 (-0.46; 0.20)	-0.01 (-0.35; 0.34)	-0.04 (-0.39; 0.30)	-0.33 (-0.69; 0.03)	0.02 (-0.31; 0.36)	0.15 (-0.19; 0.50)	-0.03 (-0.37; 0.32)	-0.12 (-0.46; 0.23)	0.03 (-0.29; 0.35)	0.30 (-0.08; 0.68)
Illness cognitions												
Helplessness	-0.07 (-0.17; 0.04)	-0.08 (-0.19; 0.02)	-0.15** (-0.25; -0.04)	-0.14** (-0.25; -0.04)	-0.15** (-0.26; -0.04)	-0.19** (-0.30; -0.08)	-0.12* (-0.22; -0.01)	-0.07 (-0.18; 0.04)	-0.26*** (-0.36; -0.15)	-0.16** (-0.27; -0.05)	0.39*** (0.29; 0.48)	0.10 (-0.01; 0.20)
Acceptance	0.12* (0.01; 0.23)	0.19** (0.08; 0.30)	0.14* (0.03; 0.25)	0.13* (0.02; 0.24)	0.15** (0.04; 0.27)	0.05 (-0.07; 0.16)	0.19** (0.08; 0.30)	0.25*** (0.13; 0.36)	0.15** (0.04; 0.26)	0.17** (0.05; 0.28)	-0.23*** (-0.34; -0.13)	0.14* (0.03; 0.24)
Disease benefits	0.03 (-0.08; 0.13)	0.01 (-0.09; 0.12)	-0.01 (-0.11; 0.09)	0.12* (0.02; 0.22)	-0.06 (-0.17; 0.04)	-0.06 (-0.17; 0.04)	-0.04 (-0.15; 0.06)	0.11* (0.002; 0.21)	0.03 (-0.07; 0.13)	0.07 (-0.03; 0.18)	0.06 (-0.03; 0.16)	<sup>b</sup>

<sup>a</sup>Model without random intercept, as it was redundant.

<sup>b</sup>Excluded because of overlap with the outcome.

\* $p$ -value < 0.05, \*\* $p$ -value < 0.01, \*\*\* $p$ -value < 0.001.



to teach active coping skills using cognitive behavior therapy to prevent psychosocial problems. An effect study of this intervention is currently in progress, but evidence was reported for parents of children with a chronic disease.<sup>36</sup>

## 4.2 | Study limitations

This study is one of the first describing psychosocial functioning in parents of long-term young adult CCS. Recruiting parents from the national LATER cohort provided a large sample of parents and availability of their child's medical characteristics. Nevertheless, there are some limitations regarding determinants and sample selection. Not-included factors, such as parents' health, their child's current functioning, social support or other stressful events,<sup>16</sup> could also have contributed to the psychosocial functioning of the parents. Also, some of the multivariable models could not be adjusted for dependency of parents of the same child. Because the intra-class coefficients of these outcomes were not significant, the non-adjusted models seem acceptable.<sup>37</sup> Furthermore, we estimated parents' age based on their child's age and used reports from their survivor child on education level and number of children, which limited reliability and completeness of these variables. Finally, parents of adult CCS were contacted after obtaining contact information from their child. This may have introduced an unknown selection bias, and consequently, hampers sound conclusions about generalizability of the results. Nevertheless, our sample included at least one parent of a third of the total cohort of CCS with current age 16–30 years, participants had similar characteristics as non-participating parents, their children had similar characteristics as the total CCS cohort and the sample was balanced regarding fathers and mothers.

## 5 | CONCLUSION

HRQoL of parents of long-term CCS is comparable to references or slightly better. A small proportion of parents experiences symptomatic post-traumatic stress. Improving acceptance and reducing feelings of helplessness related to their child's disease may provide treatment targets for parents with psychosocial problems.

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### CONFLICT OF INTEREST

The authors have no relevant conflicts of interest to disclose.

### DATA AVAILABILITY STATEMENT

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

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## APPENDIX 1

TABLE A1 Questionnaire information

Measures	Subscales, items and Cronbach's alpha's from the present study	Example items	Scale score computation
TNO-AZL questionnaire for Adult's HRQoL (TAAQOL)	<p>Cognitive functioning (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.88</math></p> <p>Sleep (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.89</math></p> <p>Pain (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.76</math></p> <p>Social functioning (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.84</math></p> <p>Daily activities (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.88</math></p> <p>Sexuality (4 items, 2 parts each: limitation and burden), <math>\alpha = 0.84</math></p> <p>Vitality (4 items), <math>\alpha = 0.84</math></p> <p>Positive emotions (4 items), <math>\alpha = 0.91</math></p> <p>Depressive emotions (4 items), <math>\alpha = 0.76</math></p> <p>Aggressive emotions (4 items), <math>\alpha = 0.66</math></p>	<p><u>Cognitive functioning:</u> "In the past month, did it happen that you had difficulty concentrating on what other said?"</p> <p>No—a little—some—a lot</p> <p>If a little or more: "How much did that bother you?"</p> <p>Not at all—a little—quite a lot—very much</p> <p><u>Vitality:</u> "In the past month, did you feel energetic?"</p> <p>No—a little—quite—very</p>	<p>One score (0–4) is derived from the two scales; a score of 4 is given when there is no health problem or limitation (indicated on the first Likert scale), a score of 3 when there is a limitation (i.e. a little, some or a lot) but when the person is not bothered by the limitation (indicated on the second Likert scale); a score of 2 when there is a limitation and the person is a "a little" bothered, a score of 1 when there is a limitation and the person is "quite a lot" bothered and a score of 0 when there is a limitation and the person is "very much" bothered.</p> <p>Sum scores are calculated by domain and transformed to range from 0 to 100</p>
Self-rating scale for post-traumatic stress disorder (SRS-PTSD)	<p>Re-experiencing (5 symptoms), <math>\alpha = 0.69</math></p> <p>Avoidance (7 symptoms), <math>\alpha = 0.50</math></p> <p>Hyperarousal (5 symptoms), <math>\alpha = 0.43</math></p> <p>Total score (17 symptoms), <math>\alpha = 0.76</math></p>	<p><u>Re-experiencing</u> Symptom intrusive thoughts: a. "I thought about the event regularly, even if I didn't want to." Not at all—less than four times a week—four or more times a week b. "Sometimes images of the event shot through my mind" Not at all—less than four times a week—four or more times a week</p> <p><u>Avoidance</u> Symptom avoidant thoughts or feelings: "Ever since the disaster I have been avoiding people or things (such as shops, restaurants, movies, airports, parties) that remind me of the event" Not at all—a little bit—very much</p> <p><u>Hyperarousal</u> Symptom sleep disturbance: "Ever since the event, I have had trouble sleeping. I have trouble falling asleep, or I wake up in the middle of the night and can't get back to sleep" Not at all—a little bit—very much</p>	<p>Symptoms are evaluated with one or two items that are answered on a 3-point Likert scale. It differs by symptom which answers indicate presence of the symptom).</p> <p>Post-traumatic stress is considered symptomatic if 1 re-experiencing, 3 avoidance and 2 hyperarousal symptoms were reported.</p>
Post-traumatic growth inventory (PTGI)	<p>Relating to others (7 items), <math>\alpha = 0.84</math></p> <p>New possibilities (5 items), <math>\alpha = 0.84</math></p>	<p><u>Relating to others</u> "I more clearly see that I can count on people in times of trouble" I experienced this:</p>	<p>The Likert scales translate to a 0–5 score, which are summed to compute scale and total scores.</p>

TABLE A1 (Continued)

Measures	Subscales, items and Cronbach's alpha's from the present study	Example items	Scale score computation
	Personal strength (4 items), $\alpha = 0.82$ Spiritual change (2 items), $\alpha = 0.53$ Appreciation of life (3 items), $\alpha = 0.80$ Total score (21 items), $\alpha = 0.93$	Not at all—to a very small degree—to a small degree—to a moderate degree—to a great degree—to a very great degree <u>Appreciation of life</u> <i>"I changed my priorities about what is important in life"</i> I experienced this: Not at all—to a very small degree—to a small degree—to a moderate degree—to a great degree—to a very great degree	
Illness cognition questionnaire (ICQ)	Helplessness (6 items), $\alpha = 0.71$ Acceptance (6 items), $\alpha = 0.81$ Disease benefits (6 items), $\alpha = 0.86$	<u>Helplessness</u> Focusing on the negative consequences of the disease and generalizing them to functioning in daily life <i>"Because of my illness I miss the things I like to do most"</i> Not at all—somewhat—to a large extent - completely <u>Acceptance</u> Acknowledging being chronically ill and perceiving the ability to manage the negative consequences of the disease <i>"I can handle the problems related to my illness"</i> Not at all—somewhat—to a large extent - completely <u>Disease benefits</u> Also perceiving positive, long-term consequences of the disease <i>"Dealing with my illness has made me a stronger person"</i> Not at all—somewhat—to a large extent - completely	The Likert scales translate to a 1–4 score, which are summed to compute scale scores.

## APPENDIX 2

TABLE A2 Characteristics of the survivors of participating parents and from the total LATER 2 cohort &lt;30 years\*

	CCS of included parents ( <i>n</i> = 448) <sup>a</sup> % or mean (SD)	LATER 2 cohort <30 ( <i>n</i> = 1362) <sup>a</sup> % or mean (SD)
Survivor age (years)	25.2 (3.7)	25.4 (3.4) <sup>b</sup>
Follow-up time since childhood cancer diagnosis (years)	21.2 (3.3)	21.4 (3.1) <sup>b</sup>
Age at diagnosis (years)	4.0 (2.9)	4.0 (2.9)
0–4	70%	69%
5–9	25%	27%
10–14	5%	5%
14–17	0	0
Recurrence of primary tumor	11%	11%
Primary childhood cancer diagnosis		
Hematologic cancers	55%	53%
CNS tumor	9%	12%
Solid tumor	37%	35%
Treatment period		
1980–1989	1%	1%
1990–1999	69%	71%
2000–2001	30%	27%

<sup>a</sup>Characteristics missing for *n* = 3.

<sup>b</sup>Based on mean participation date of participating parents.

\*Characteristics of both cohorts were not significantly different.