

Childhood Cancer Survivors: Self-Reported Quality of Life during and after the Cancer Trajectory

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ABSTRACT

Objective: This cross-sectional study aimed to present how the unique cancer experience in childhood influences young adults' quality of life (QOL). **Methods:** Qualitative and quantitative methods were used to code and analyze a study-specific questionnaire (133 items). These data are presented in accordance with a conceptual QOL/health-related QOL model. **Results:** The participants included 34 women and 28 men ($n = 62$) diagnosed with solid tumors/lymphoma in the period 1983–2003, who had been treated at the same childhood cancer center in Sweden. The current mean age was 28.7 years (range: 18–45, standard deviation [SD]: 6.3, median value: 28.5), the mean age at diagnosis was 12.9 years (range: 8–17, SD: 2.3, median value: 13), and the mean time elapsed since treatment was 15.7 years (range: 4–28, SD: 2.4, median value: 15). The response rate was 65%. Higher levels of psychological maturity were reported by women versus men ($P = 0.01$) and by survivors diagnosed with cancer during adolescence versus school age ($P = 0.04$). Male participants

reported lower levels of physical limitations ($P = 0.03$) and emotional distress when being of treatment and in contact with health care services ($P = 0.04$). The strongest factor influencing QOL during therapy was parental support (97%), while the strongest factors after therapy were to live a life similar to peers (82%) and to be satisfied with one's life situation (81%). During treatment, limitations influencing QOL were related to lack of school support (2%), and after treatment, to deteriorated relationships with siblings (5%). **Conclusions:** Life-threatening diseases at young ages have long-term psychosocial effects with ambiguous results at multiple levels. To capture these experiences, we recommend clinical studies that are based on conceptual clarifying frameworks and adopt a quantitative and qualitative research approach.

Key words: Childhood cancer survivors, pediatric cancer, psychosocial issues, quality of life

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Introduction

The story of pediatric oncology is one of remarkable and promising success regarding survival from life-threatening diseases. Today, approximately 80% of children and adolescents diagnosed with cancer are cured if adequate treatment is given.^[1,2] The populations of long-term survivors are rapidly growing and there is a great need for research concerning survivorship issues and potential sequelae.^[3] Studies have reported that there is an increased lifetime risk of developing adverse health outcomes^[1,2,4] and premature mortality^[5,6] among these survivors. Certain sociodemographic and economic factors such as lower educational attainment, female gender and lower income have been associated with adverse health status and psychological stress.^[7] The development of autonomy, independence, social skills and gender differences has been studied, presenting diverse results in comparison with adolescents not diagnosed with cancer.^[8] Survivors report worries and fears about the previous illness, illness recurrence and their future,^[9] and a relationship has been found among survivors' self-image, life outlooks and health-related worries.^[10] Several studies have shown that the negative and challenging experiences may be compensated by positive expectations regarding life.^[11-13] The above-mentioned challenges and psychologically strengthening factors are all essential aspects of an individual's quality of life (QOL)/health-related QOL (HRQOL). The concepts of QOL and HRQOL are regarded as multidimensional and have a large number of definitions; however, there is still a lack of consensus on the definition of QOL/HRQOL and no clear distinction between these concepts.^[14-16] QOL focuses on subjective judgments regarding mental, social, emotional, and behavioral well-being and function, as well as performance in daily life.^[14-16] HRQOL emphasizes an individual's self-perceived health status or the way health influences QOL.^[16] Several investigations of how the unique experience of being treated for cancer in childhood affects QOL/HRQOL in survivors have been performed, but the results were inconclusive.^[2,7,17]

In the work presented by Anthony *et al.*, 2014,^[15] the authors present a model of QOL/HRQOL with the aim of focusing on the subjective experience during and after childhood cancer treatment. The authors have performed a thorough review of all patient-reported outcome (PRO) measurements used for research on pediatric oncology and long-term survivors. Anthony concludes that there is "a lack of conceptual clarity and consensus in item content comparatively across PRO instruments".^[15] The above-mentioned model has inspired us to systematically analyze a study-specific questionnaire which was designed for a survey regarding QOL of childhood cancer

survivors. The aims of the present study were to analyze factors influencing QOL and to show which ones have the greatest impact during and after childhood cancer treatment.

The following research questions were posed:

- How do the participants express general, physical, social, and psychological health aspects?
- Are there any significant differences between demographic variables (sub-groups) in relation to QOL factors?
- Which factors influence QOL during and after cancer treatment in childhood?

Methods

Study design

The study has a retrospective descriptive mixed methods design. Data have been collected by means of a study-specific questionnaire. Items from the questionnaire were categorized by deductive content analysis, reduced and validated by factor analysis, and described by statistical analysis.

Study participants and context

The participants were former patients diagnosed with cancer in 1983–2003, who had been treated at the same childhood cancer center in Sweden. The overall annual incidence of new child cancer cases in this country is 300–350.^[3] The inclusion criteria were: The patient had been diagnosed with solid tumors or lymphoma; was aged eight years at diagnosis; was over 17 years when answering the questionnaire; and at least three years had elapsed since the patient had completed cancer treatment. The oncological treatment methods included cytotoxic treatment and/or surgery and/or extra-cranial irradiation.

Patients diagnosed with brain tumors and leukemia, which are groups that may have received cranial irradiation, were excluded because of the well-known long-term consequences including neurocognitive sequelae and reduced QOL.^[18,19]

Data collection

In 2007-2013, the target group was invited by mail or telephone to take part in this cross-sectional study. In all, 96 former patients were eligible. After the informed consent process, a study-specific questionnaire was distributed by mail and returned in a pre-paid envelope. Three reminders were sent. Thirty-four individuals did not participate in the study, that is 15 could not be reached, ten declined to participate, and nine did not return the questionnaires despite being reminded.

Study-specific questionnaire

A study-specific questionnaire was created for the present study. The questionnaire was developed based on 11 individual interviews, together with a literature review. The interviews were performed with survivors of childhood cancer treated in the late 1970s to 1993 and were recorded and transcribed. The participants' expressed feelings and thoughts in these interviews formed the basis of the design of the questions for the survey, and interview contributors were asked to comment on the suggestions for further revision. Answers were given on a five-point Likert scale from "I disagree" (1) to "I fully agree" (5). In all, the questionnaire comprised 225 items, of which 133 dealt with QOL issues. The questionnaire focused on retrospective data relating to thoughts about the disease at diagnosis and medical and psychosocial issues during treatment, as well as aspects of the participants' present daily life situation after completion of therapy.

Study-specific questionnaire-Deductive content analysis

Using a deductive content analysis process, based on Anthony's model^[15] as a matrix, each of the items in the study-specific questionnaire was categorized [Figure 1].^[15] All items in the study-specific questionnaire dealing with QOL ($n = 133$) were read through several times to get an overview of the content. In accordance with the principal of deductive content analysis as described by Elo and Kyngäs,^[20] each item was labeled with a theoretical code according to the subdomains^[15]/subcategories^[20] presented in Figure 2.

Study-specific questionnaire-construct validation and item reduction by factor analysis

When the qualitative categorization process [Figure 1] was completed, a dichotomization procedure was performed for every item ($n = 133$) in the study-specific questionnaire. First, each single item was defined as having a positive or negative consequence for the participants.

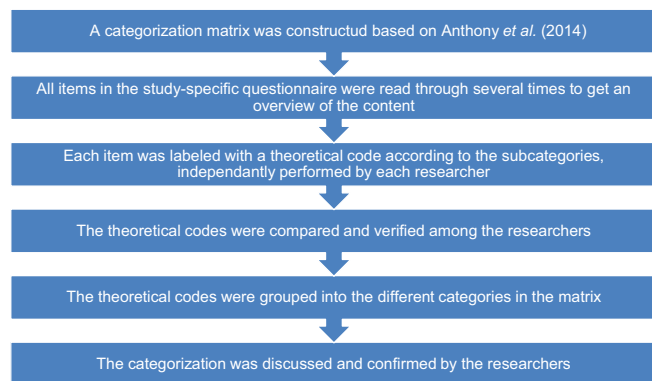


Figure 1: Overview of the deductive qualitative content analysis process

Secondly, each single positive and negative item was classified according to its ranking in the study-specific questionnaire, that is Likert scales one to three were defined as low ranking, and Likert scales four and five were defined as high ranking. To identify clusters of related items and to detect virtual or latent variables, exploratory factor analyses were performed using the statistical software Mplus 7.31 (Muthén and Muthén, 3463 Stoner Avenue, Los Angeles, USA).^[21,22] These statistical procedures were intended to ensure construct validation.^[23] Furthermore, this process reduced the number of items ($n = 133$) in the study-specific questionnaire. Subdomains/subcategories containing at least five items were included [Figure 2]. Missing values were replaced by the median value for each item. In the factor loading process (*Rotation Geomin/Oblique*) the first two resulting factors (Factor 1 and Factor 2) were further analyzed. The factors' model fit scores evaluated with the Root Mean Square of Approximation (RMSEA¹) were lower than 0.05, which were defined as good. The comparative fit index (CFI²) scores were 0.92–1.0, which were good except for the factor Social Health (SoH).

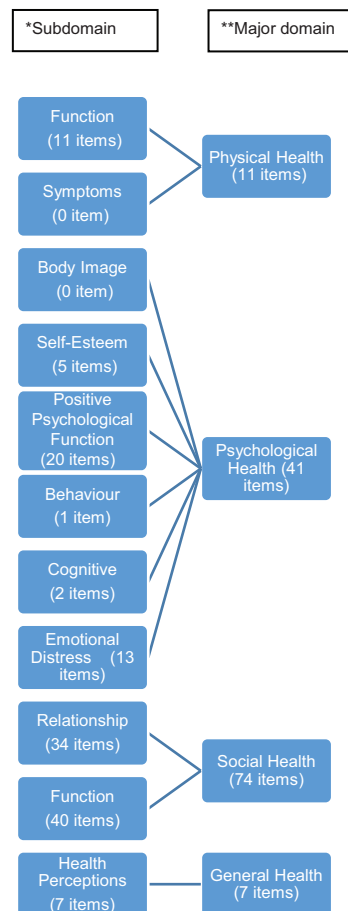


Figure 2: Overview of the categorization matrix based on Anthony et al. (2014) and the distributions of the items from the study-specific questionnaire. *Described as Subcategory in Elo and Kyngäs (2007). **Described as Generic Category in Elo and Kyngäs (2007)

Relationship with the value of 0.72, which was regarded as acceptable. The standardized Root Mean Square (SRMR³) scores were 0.02–0.08, which were good except for the factor SoH-Relationship with the value 0.14, which was acceptable. Statistical significance was attained at $P < 0.05$ and items with correlations above 0.5 were organized into factor groups describing their correlation to the QOL model^[15] and with median values. The factors and their labels are presented with frequencies in Figures 3 and 4. Values above 25% were defined as indicating factors having a high impact on QOL among the participants.

1. An RMSEA value of about 0.05 or less would indicate a close fit of the model in relation to the degrees of freedom
2. CFI presents the proportion of variance explained by the proposed model. (In this case the factor model explains between 92% and 100% of the input data except for factor SoHr, which explains 72% percent)
3. SRMR presents the standardized square root of the average squared amount by which the sample variances and covariances differ from their estimates obtained under the assumption that your mode is correct. A value close to zero is desired.

Statistical analysis

Descriptive statistics are presented as frequencies, mean values, median values, and percentages. To compare proportions of categorical variables between demographic variables, Chi-square statistics were obtained. When more than 15% of the cells had an expected value of <5 , Fisher’s exact test was used. The Mann–Whitney test was performed in order to compare the values between two independent variables. When comparing three independent variables, the Kruskal–Wallis test was used. The limit of statistical significance was set at $\alpha = 0.05$. Tendencies were defined as P values above 0.05 but <0.10 . The statistical analyses

were performed using IBM SPSS Statistics version 22.0 (IBM Corp, Armonk, New York, USA).

Ethical approval

The Regional Research Ethics Board approved the study (Approval No. Dnr 289-07).

Results

Study population

The final study group consisted of 62 persons (34 women and 28 men). The response rate was 65%. The mean current age of the participants was 28.7 years (range: 18–45, standard deviation [SD]: 6.3, median value: 28.5 years), mean age at diagnosis was 12.9 years (range: 8–17, SD: 2.3, median value: 13 years), and the mean time elapsed since treatment was 15.7 years (range: 4–28, SD: 2.4, median value: 15 years). The most common diagnosis was lymphoma (Hodgkin’s disease [HL] and Non-Hodgkin’s disease [NHL]). The rest of the group, defined as “other diagnosis”, included miscellaneous sarcomas and rare malignant disorders, for example ovarian tumors, thyroid and nasal-pharyngeal cancers. Subgroup analyses were performed including gender, diagnosis (HL, NHL, other solid tumors), treatment with or without extra-cranial irradiation, being diagnosed pre-teenage or being a teenager at diagnosis, time since treatment (cut off: median value 15 years), being a teenager/young adult (ages 15–29)^[24] or older when answering the questionnaire, and diagnosed in 1983–1989 or 1990–2003, that is before or after the early 1990s when the HL treatment was changed, in particular regarding radiotherapy^[25] [Table 1].

The participants’ descriptions of their quality of life

In Tables 2-4, items and corresponding major domains and subdomains according to the model

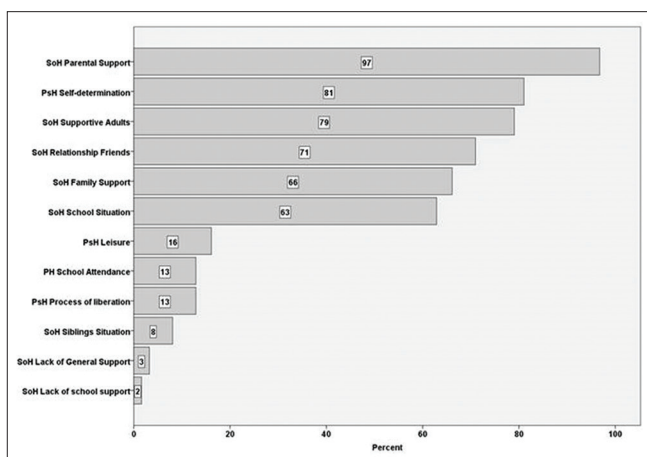


Figure 3: Factors influencing quality of life during treatment

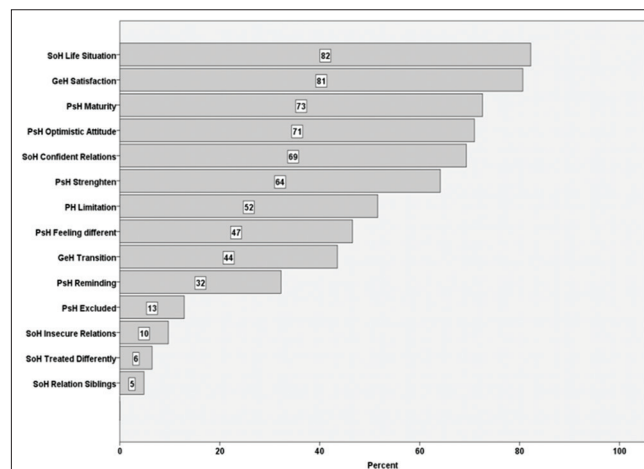


Figure 4: Factors influencing quality of life after treatment

of Anthony,^[15] are presented along with the factors used in Figures 3 and 4. All dichotomized items with correlations above 0.5 are elevated and presented with numerical data and frequencies (high ranking, 4–5). In total, 64 items out of 133 fulfilled the correlation criteria. In total, six missing values were detected within the general health domain and four missing values within the psychological domain. These values were replaced

by the median value for each item. No missing values were detected in the physical and social domains. The results revealed that the vast majority of these items dealt with social ($n = 32$) and psychological ($n = 20$) aspects during and after treatment.

Table 1: Demographics of the study population of responding childhood cancer survivors ($n=62$)

Demographics	Total, n (%)	Female, n (%)	Male, n (%)
Number of CCS	62	34 (54.8)	28 (45.2)
Diagnosis			
Hodgkin's disease	28 (45.2)	14 (41.2)	14 (50.0)
Non-Hodgkin's disease	14 (22.6)	4 (11.8)	10 (35.7)
Other solid tumours	20 (32.3)	16 (47.1)	4 (14.3)
Treatment			
Radiotherapy	37 (59.7)	22 (64.7)	15 (53.6)
No radiotherapy	25 (40.3)	12 (35.3)	13 (46.4)
Age at diagnosis (years)			
8-12	24 (38.7)	9 (26.5)	15 (53.6)
13-17	38 (61.3)	25 (73.5)	13 (46.4)
Years since treatment (years)			
≤15	33 (53.2)	18 (52.9)	15 (53.6)
>15	29 (46.8)	16 (47.1)	13 (46.4)
Participant's age (years)			
<30	34 (54.8)	19 (55.9)	15 (53.6)
≥30	28 (45.2)	15 (44.1)	13 (46.4)
Year of diagnosis			
1983-1989	21 (33.9)	12 (35.3)	9 (32.1)
1990-2003	41 (66.1)	22 (64.7)	19 (55.9)
Education			
High school	27 (43.5)	15 (44.1)	12 (42.9)
University	35 (56.5)	19 (55.9)	16 (57.1)
Marital status			
Married/has a partner	34 (54.8)	24 (70.6)	10 (35.7)
Single/not stated	24 (38.7)/4 (6.5)	8 (23.5)/2 (5.9)	16 (57.1)/2 (7.1)

CCS: Childhood cancer survivors

General health domain (six items)

The major domain “General health” contains perceptions of the participants’ overall health after the treatment was completed. In particular, a strong satisfaction with current life was presented (80.7%) [Table 2].

Physical health domain (six items)

“Physical health” contains aspects of physical function and the effects of the former illness and treatment, and the role of school attendance was highlighted (77.2%) [Table 2].

Social health domain (32 items)

The category “SoH” includes how the disease and the treatment had affected the young persons’ social relations. Support from mothers (95.2%), fathers (86.0%), friends (72.9%), other adults (61.0%), and healthcare professionals (75.9%) were highly ranked [Table 3].

Psychological health domain (20 items)

PsH reflects self-esteem, positive psychological function, cognitive function, and emotional distress. Many items related to maturity and an optimistic attitude toward life were highly ranked, in particular the insight not to take everything in life for granted (86.2%) [Table 4]).

Demographic variables (sub-groups) and quality of life factors-in comparison

All of the demographic variables in Table 1 were compared with QOL factors, showing that female participants reported higher levels of psychological maturity, but also more physical limitations. Participants diagnosed in the 1980s and female participants stated they had higher

Table 2: Description of quality of life, general and physical health, based on the model of Anthony et al. [Figure 2]

Major domain	Subdomain	Factors presented in Figure 3 and Figure 4	Corresponding items (study-specific questionnaire) with correlations >0.5	High ranking, n (%)
GeH	Health perception	GeH satisfaction	I am satisfied with my present life situation	46 (80.7)
			I feel completely healthy	45 (75.0)
GeH	Health perception	GeH transition	It took a long time before life was similar to before the disease	29 (50.0)
			Life never became similar to before the disease	37 (63.8)
			I felt healthy after completion of treatment	29 (50.9)
			Despite recommendations to be careful, I lived like everyone else	24 (46.2)
PH	Function	PH ability	I have felt challenged by authorities and insurance companies	3 (5.3)
			My possibilities concerning work has been reduced	8 (13.6)
			My possibilities concerning education has been reduced	8 (13.6)
PH	Function	PH school attendance	I attended school whenever possible	44 (77.2)
PH	Function	PH limitation	I have physical limitations due to my disease and treatment	20 (32.8)
			I did not perform military service even though I wanted to	7 (14.9)

GeH: General health, PH: Physical health

Table 3: Description of quality of life, social health, based on the model of Anthony *et al.* [Figure 2]

Major domain	Subdomain	Factors presented in Figure 3 and Figure 4	Corresponding items (study-specific questionnaire) with correlations >0.5	High ranking, n (%)
SoH	Function	SoH lack of school support	I had to repeat a grade in school The school did not take enough account of my situation	4 (6.6) 11 (19.6)
SoH	Function	SoH siblings situation	Grandparents took care of my siblings Relatives took care of my siblings Adults outside our family took care of my siblings	9 (17.3) 9 (17.3) 4 (7.8)
SoH	Function	SoH lack of general support	I wished we had talked more openly about my disease	6 (10.7)
SoH	Function	SoH family support	We talked openly about my disease at home I talked openly about the disease with my mother I talked openly about the disease with my father I talked openly about the disease with my siblings I talked openly about the disease with my friends I talked openly about the disease with adults outside my family	50 (86.2) 52 (91.2) 40 (75.5) 28 (59.6) 36 (65.5) 31 (57.4)
SoH	Function	SoH school situation	I managed to recoup subjects on my own	37 (61.7)
SoH	Relationship	SoH relationship friends	I missed contact with friends I needed to contact friends in order to be included in activities My friends distanced themselves when they heard about my disease Friends supported me in my situation I participated in most of the activities among friends	34 (55.7) 44 (74.6) 44 (74.6) 43 (72.9) 29 (48.3)
SoH	Relationship	SoH relation siblings	My relationship with my siblings was negatively affected by the disease	10 (21.7)
SoH	Relationship	SoH parental support	My mother supported me during the period of treatment My father supported me during the period of treatment	59 (95.2) 49 (86.0)
SoH	Relationship	SoH supportive adults	Teachers supported me during the period of my disease Other adults supported me during the period of my disease Healthcare professionals supported me during the period of my disease	35 (62.5) 36 (61.0) 41 (75.9)
SoH	Relationship	SoH insecure relations	I find it hard to feel safe together with other persons	13 (21.0)
SoH	Relationship	SoH confident relations	My relationships with family members have not been affected by my disease	22 (53.7)
SoH	Relationship	SoH treated differently	I am treated differently by colleagues due to my experiences I am treated differently by new contacts due to my experiences I feel lonely	5 (8.6) 6 (10.3) 14 (22.6)

SoH: Social health

levels of emotional distress when they were reminded of the treatment and when in contact with healthcare services [Table 5]. Treatment-related differences were reported and the group treated for solid tumors had greater physical limitations [Table 6]. Among those who had received extra-cranial radiotherapy, a tendency to have lower levels of confidence and security in relationships, and lower school attendance was stated. Survivors diagnosed with cancer as teenagers compared to younger ages reported higher levels of psychological maturity and participation in leisure activities, despite restrictions. Participants who were older than 30 reported greater psychosocial challenges regarding the transition-phase (treatment/off-treatment) and being treated differently by colleagues and new contacts [Table 5].

Factors influencing quality of life during and after treatment

The results describing factors influencing QOL during and after treatment are presented in Figure 3 (during treatment, high values were 63% and above) and Figure 4 (after treatment, high values were 32% and above). The

factor having the highest impact during treatment was parental support (97%), while after treatment the highest impact factors were living a similar life to their peers (82%) and being healthy and satisfied with life (81%). Values equal to 16% and below [Figure 3] and equal to 13% and below [Figure 4] were characterized by limitations influencing the QOL in this population. The lowest values were related to lack of school support during treatment [Figure 3] and deteriorated relationships with siblings in the long term [Figure 4].

Discussion

This study presents data concerning the QOL in childhood cancer survivors, based on the working model of Anthony *et al.* 2014.^[15] During the cancer trajectory, easily the strongest factor influencing QOL among survivors was parental support. Factors promoting success after treatment included living like an ordinary teenager, being satisfied with the present life situation, and being healthy. Limitations during treatment were related to lack of school support and reduced openness when talking about the disease and

Table 4: Description of quality of life, Psychological health, based on the model of Anthony *et al.* [Figure 2]

Major domain	Subdomain	Factors presented in Figure 3 and Figure 4	Corresponding items (study-specific questionnaire) with correlations >0.5	High ranking, n (%)
PsH	Positive psychological function	PsH maturity	Today, I am able to live in the present	25 (46.3)
			The disease made me more mature	29 (58.0)
			I feel a greater understanding of other people's problems	40 (72.7)
			The disease has made me humble towards life	38 (66.7)
			I realize what is important in life	40 (70.2)
			I do not take everything for granted	50 (86.2)
			The disease experience has made me more positive as a person	32 (60.4)
PsH	Positive psychological function	PsH optimistic attitude	The disease has affected my values of life	34 (63.0)
			I have managed to survive my disease and I feel I can handle various difficulties	29 (50.0)
			In difficult situations I am able to be rational	33 (66.0)
PsH	Positive psychological function	PsH leisure	I have a positive attitude to life	33 (67.3)
			I have confidence to complete various challenges	29 (50.0)
			I continued with my leisure activities despite of restrictions	50 (83.3)
PsH	Self-esteem	PsH feeling different	I have felt different from my peers because of my illness experience	24 (41.4)
PsH	Self-esteem	PsH strenghten	My self-esteem has been affected and strengthened by my illness experience	34 (64.2)
PsH	Self-esteem	PsH self-determination	I participated in leisure activities just like my peers	47 (81.0)
PsH	Emotional distress	PsH reminding	I feel emotional distressed when being reminded of my treatment and in contact with healthcare services	27 (44.3)
PsH	Emotional distress	PsH excluded	I have a feeling of being excluded by others	14 (23.3)
PsH	Emotional distress	PsH process of liberation	I have an increased attachment to my parents in comparison with peers	30 (52.7)
			My parents slowed the process of liberation during my adolescence	11 (17.7)

PsH: Psychological health

Table 5: Group comparisons of categorical variables/quality of life factors and demographic sub-groups (Mann-Whitney)

Factor	Factors in Figures 3 and 4	Demographic data					
		Median	Q1-Q3	Median	Q1-Q3	P	
							Male
1	PsH reminding	2.0	1.0-3.0	3.0	1.0-4.3	0.04*	
1	PsH feeling different	2.0	1.0-4.0	4.0	2.0-5.0	0.07	
1	PsH maturity	3.5	3.0-4.0	4.0	4.0-5.0	0.01*	
2	PH limitation	3.0	3.0-3.5	3.5	3.0-4.5	0.03*	
2	PsH strenghten	4.0	2.8-4.3	4.0	3.0-5.0	0.10	
Factor	Factors in Figures 3 and 4	Radiotherapy		No radiotherapy		P	
1	SoH insecure relations	2.0	1.0-3.0	1.0	1.0-2.0	0.06	
2	SoH confident relations	4.0	2.0-4.0	4.0	4.0-4.5	0.05	
2	PH school attendance	1.0	1.0-2.0	2.0	1.0-3.5	0.05	
Factor	Factors in Figures 3 and 4	Age at diagnosis 8-12 years		Age at diagnosis 13-17 years		P	
1	PsH maturity	3.5	3.0-4.0	4.0	3.5-5.0	0.03*	
2	PsH strenghten	4.0	2.0-4.8	4.0	3.0-5.0	0.07	
2	PsH leisure	4.5	3.8-5.0	5.0	4.0-5.0	0.048*	
Factor	Factors in Figures 3 and 4	≤ 15 years Since treatment		> 15 years Since treatment		P	
1	SoH relation siblings	1.0	1.0-1.0	1.0	1.0-2.0	0.067	
1	SoH treated differently	1.0	1.0-2.0	1.0	1.0-1.0	0.085	
Factor	Factors in Figures 3 and 4	Participant's age <30 years		Participant's age ≥30 years		P	
1	SoH treated differently	1.0	1.0-2.0	1.0	1.0-1.0	0.045*	
2	PsH self-determination	4.0	4.0-5.0	5.0	4.0-5.0	0.08	
2	GeH transition	3.0	2.0-3.8	3.5	2.8-4.5	0.02*	
Factor	Factors in Figures 3 and 4	Year of diagnosis 1983-1989		Year of diagnosis 1990-2003		P	
1	PsH reminding	3.0	2.5-4.5	2.0	1.0-4.0	0.03*	
1	SoH treated differently	1.0	1.0-1.0	1.0	1.0-2.0	0.067	
1	SoH family supportive	1.0	1.0-1.0	2.0	1.0-4.0	0.092	

*Significant differences are highlighted in bold type. GeH: General health, PH: Physical health, PsH: Psychological health, SoH: Social health

Table 6: Group comparisons of categorical variables/quality of life factors and demographic sub-groups (Kruskal-Wallis)

Factor	Factors in Figures 3 and 4	Demographic data						P
		Median	Q1-Q3	Median	Q1-Q3	Median	Q1-Q3	
		Hodgkin lymphoma		Non-Hodgkin lymphoma		Other solid tumors		
1	PsH excluded	1.0	1.0-2.0	1.0	1.0-4.0	1.0	1.0-1.0	0.08
2	PH limitation	3.0	3.0-3.5	3.0	2.9-3.8	3.8	3.0-4.9	0.03*

*Significant differences are highlighted in bold type PsH: Psychological health, PH: Physical health

its consequences. In the present life, impediments primarily originated from deteriorated relationships with siblings, being alone, and being treated differently by other people.

When a child is diagnosed with cancer the child and his/her parents express feelings of isolation and powerlessness.^[26] Several studies have shown significant parental distress and an adult world in crisis.^[27,28] Still, the parents' worries and anxiety cannot gain the upper hand when they need to prioritize their parental protective role and the welfare of the child.^[25] In line with previous research,^[29] the participants in this study stressed the importance of support from their families, in particular their mothers, including the ability to talk about and share the great stress they were subjected to. Some participants lacked this generous open attitude, but wished it had existed. Outside the family, the participants said that important sources of support were friends, health care professionals, teachers and other adults, and that such care was characterized by comfort, secure relations, and being treated with respect. The importance of both transparency and care has previously been observed, as chronic diseases in childhood are known to generate numerous stressors and to challenge all family members.^[27,28,30]

Social relationships with friends, school attendance, and leisure activities positively influenced the survivors' well-being and were central themes in the present study. These SoH aspects also had an influence on the young adults' mental health and were prioritized, especially among adolescents, regardless of restrictions and parents who might act to inhibit the process of emancipation. Similarly, current research in pediatric oncology addresses the role of SoH,^[17] including family functioning and relationships with peers and teachers.^[31] The participants stated that whenever it was physically feasible, they went to school, and being in school is known to facilitate social growth in spite of severe circumstances.^[32] However, studies confirm that many children who have been treated for cancer have education-related challenges.^[33] Home-schooling could be suggested as an alternative if the child cannot manage regular schooling, but may generate negative feelings and isolation, influencing QOL.^[34] In our study population, several participants said that they could attend school and leisure activities to a limited extent. Recommendations by health

care professionals regarding restricted school attendance were based on the current medical knowledge concerning the risks of social interactions for infection-prone children. Recent studies have shown that being in school does not lead to more antibiotic treatments or hospital stays.^[35] Today, children in Sweden are encouraged to go back to school and to be open about their diagnosis, supported by consultant nurses. Retrospectively, adult survivors emphasize that attending school during treatment and having social support is associated with living a normal life.^[36]

The young survivors reported that their general present health included feelings of well-being, satisfaction with life, and positive self-esteem even in comparison with those of the same age and without a cancer experience. Self-determination and satisfaction with activities in life are known to be central aspects of QOL in survivors.^[31] Several participants argued that they felt healthy as soon as the treatment was completed but the transition to a normal life took a long time, in particular in the older cohort. Having trustful and sustainable relationships played a major role in adaption to the new life situation. A tendency toward treatment-related impediments was observed in the study-group who had received extra-cranial radiation. Such treatment-related consequences have also been reported earlier.^[37]

A history of having had a malignant disorder is known to deepen and hasten the process of maturity but at the same time it is important to be like everyone else, and not to be an outsider.^[11] In line with previous research,^[11-13] the participants expressed feelings concerning post-traumatic personal growth and strength, their capacity to handle problems, taking control over their own lives, and ranking their problems in comparison with the cancer experience. This positive psychological functioning is a central theme for many survivors, but is insufficiently represented in many PRO instruments.^[31] In the present study, other study participants reported emotional distress and said that their lives had been permanently changed. The cancer experience involved feelings of being different^[11,36] and alienated and this tendency was reported only by female participants.^[7] One out of five expressed the fear of being abandoned and ostracized by others, as previously described,^[11,38]

but unfortunately the present study was not designed to investigate potential underlying explanations more systematically. Restricted physical functioning could be a limiting factor in their professional adult lives, which was reported by more women than men, with a tendency to be more pronounced in the group treated for solid tumors. Several persons in this treatment group had permanent disabilities having been operated upon with limb-saving surgery as well as amputations, and may have faced challenges with insurance accessibility for decades after diagnosis.^[39] Yet, it was the longing to be a part of a group with common interests rather than a specific physical activity that inhibited some participants. These results underline that the sense of belonging is what really matters during as well as after completion of therapy.^[31]

The strength of this study is the long-term follow-up of a cohort of former patients treated at the same childhood cancer center. To strengthen the psychometric properties of the study-specific questionnaire, construct validation was established by performing exploratory factor analyses with categorical factor indicators. The limitations are related to the heterogeneous sample regarding ages, diagnoses and treatment era. By performing subgroup analyses, we have tried to partly compensate for this inconvenience, but conclusions need to be drawn with caution.

Conclusion and clinical implications

In clinical practice, new knowledge with a positive impact on the long-term QOL of childhood cancer survivors can be developed by using a mixed methods approach with a qualitative and quantitative validation.^[15,31,23] The results show that social support during the cancer trajectory was essential to enhance the long-term psychological status for individuals who have ended childhood cancer directed treatment. Healthcare professionals working with childhood cancer patients need to reflect on these results, their supportive role and how they can address children who need extra care, consolation, comfort, and support. Future studies need to focus on vulnerable groups within pediatric oncology and to highlight the role of social support and functioning during treatment. There is also a need to identify childhood cancer survivors who have a long-term risk of psychological disadvantages, as well as groups who would benefit from developing psychological maturity.

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Conflicts of interest

There are no conflicts of interest.

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