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“I wish someone had once asked me how I’m doing”: Disadvantages and support needs faced by parents of long-term childhood cancer survivors

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Abbreviations:

ARFEC	Association Romande des Familles d'Enfants atteints d'un Cancer
CCS	Childhood cancer survivor
CI	Confidence interval
CNS	Central nervous system
ICCC-3	International Classification of Childhood Cancer – Third Edition
OR	Odds Ratio
SCCR	Swiss Childhood Cancer Registry
SCCSS	Swiss Childhood Cancer Survivor Study
SCT	Stem cell transplantation
SD	Standard deviation

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“I wish someone had once asked me how I’m doing”: Disadvantages and support needs faced by parents of long-term childhood cancer survivors

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Abstract

Background: Childhood cancer affects the whole family and can have a lasting impact on parents of childhood cancer survivors (CCS). We aimed to 1) describe parents' perspective of currently experienced disadvantages, and of their support needs during treatment, after treatment, and today, 2) identify characteristics associated with disadvantages and support needs, and 3) describe the use of existing support services.

Procedure: In this population-based study, we identified parents of CCS (diagnosed ≤ 16 years of age, ≥ 5 years since diagnosis, aged ≥ 20 years at study) through the Swiss Childhood Cancer Registry (SCCR). Parents completed a questionnaire on perceived disadvantages (e.g. job-related, financial, etc.), support needs (e.g. job-related, financial, etc.), and socio-demographics. Cancer-related characteristics were available from the SCCR. We used multivariable multilevel logistic regression to identify characteristics associated with disadvantages and support needs.

Results: An average of 24 years after diagnosis, one fifth of parents ($n=59/308$; 19.2%) reported disadvantages, and 7.1% reported support needs. Many parents had desired more support during (66.9%) or after (34.4%) their child's cancer treatment. Parents whose child experienced late effects ($OR=26.6$; 95%CI:2.9-241.0), or was dependent on parents ($OR=10.6$; 95%CI:2.1-53.7) reported greater current need for more support. Almost half of parents (43.5%) reported having used existing support services.

Conclusions: Many parents need more support during and after active treatment of their child's cancer, and some experience support needs and disadvantages long into survivorship. Better promotion of existing services for parental and familial support and setting up new services, where needed, may help parents in the long term.

Key words: parents; childhood cancer; survivor; disadvantage; support; cancer registry

Introduction

Cancer of a child is an extremely distressing event for the whole family.¹⁻⁷ Parents struggle to balance the multiple needs of all family members: being at the hospital with the ill child, school and childcare for siblings, work-related responsibilities, and their own partnership.^{1,4,5,8} To cope with the demands of caring for a child with cancer additionally to existing family, social, and work duties, many parents may seek support from their social network.⁹ Close family and friends are usually the first providing emotional or instrumental support.¹⁰ However, the treatment for childhood cancer can be long and may exhaust the resources of the primary network. In the long run, parents may need more specific emotional and informational support, e.g. support from other affected parents or health care professionals.^{9,10} A lack of support might contribute to parents experiencing disadvantages, e.g. in their professional lives or financial situation.¹¹⁻¹³ Therefore, it is vital that parents' support needs are met during and after their child's cancer treatment.

Previous research has shown that parents are in need for support during and shortly after their child's treatment,¹⁴⁻¹⁷ and support to be a key factor for family and parental resilience.^{1-4,7} Studies have found that social support decreased in the five years after diagnosis,^{18,19} and that parents' need for support decreased equally.¹⁴ However, parents' support needs in the long term (>5 years after treatment) remain largely unknown and it is unclear whether parents receive enough support to meet their needs.¹⁴⁻¹⁷

Parents of children with cancer experience a broad range of psycho-social and socio-economic disadvantages during the child's acute treatment phase and early survivorship^{11,12,20-24} However, little is known about the disadvantages experienced many years after the child's treatment is completed. Furthermore, it is unknown whether the support needs of CCS' parents in Switzerland are met with standard care and if there are subgroups which require additional support. In a representative sample of CCS parents, we aimed to 1) describe parents' perspective on currently experienced disadvantages, and their support needs during treatment, after treatment,

and today, 2) identify socio-demographic and cancer-related characteristics associated with experiencing disadvantages and a need for more support, and 3) describe the use of existing support services.

Methods

Study participants

In Switzerland, children and adolescents below the age of 21 years diagnosed with leukaemia, lymphoma, central nervous system (CNS) tumour, malignant solid tumour or Langerhans cell histiocytosis are centrally registered in the Swiss Childhood Cancer Registry (SCCR)^{25,26}. This study is part of the Swiss Childhood Cancer Survivors Study (SCCSS),²⁷ a population-based cohort study on clinical and psychosocial late effects after childhood cancer. Through the SCCR, we identified participants for this cross-sectional study in parents of long-term childhood cancer survivors (SCCSS-Parents). We included parents if they had a valid address in Switzerland, whose child was alive, diagnosed with cancer according to the International Classification of Childhood Cancer – Third Edition (ICCC-3)²⁸ at age ≤ 16 years and between 1976 and 2009, was a Swiss resident at diagnosis, survived for ≥ 5 years after diagnosis, was aged ≥ 20 years at the time of study, and was not currently involved in another ongoing study of the SCCSS. We extracted the parents' address from the SCCR and updated them by searches in online telephone books.

Procedure

Parents were contacted between January 2017 and February 2018. We contacted eligible parents with an information letter from the former treating clinic, all subsequent mailings were sent from the University of Lucerne. We asked the contacted parent to share the study information with the other parent. Approximately two weeks after the information letter, we sent two questionnaires (one for each parent) with pre-paid return envelopes. Up to two reminders were sent to non-responders.

We received ethical approval from the Ethics Committee of Northwest and Central Switzerland (EKNZ 2015-075; 26 March 2015).

Measurements

The questionnaire covered quality of life, psychological health, questions regarding the CCS and family functioning, support and disadvantages of family members, and socio-demographic characteristics.

Disadvantages

We asked parents “Are there domains today where you are disadvantaged by your child's previous disease?”. Parents could indicate “none” or any of seven domains (job-related, financial, social environment/friends, family, physical, psychological, or other). Multiple answers were possible. We additionally asked parents to describe the perceived disadvantages in more detail using open-ended questions.

Support needs

We asked parents “Have you ever wished for more support for yourself and/or your family?”. Parents could indicate on six domains (job-related, financial, family, psychological, medical, or other) whether they had needed more support during the treatment, after the treatment, today or never. Multiple answers were possible. We additionally asked parents to describe the desired support in more detail using open-ended questions.

Existing services

We asked parents whether they had ever used the service of parent organizations such as *Kinderkrebshilfe Schweiz* (<https://www.kinderkrebshilfe.ch>) or other local parent organizations. Parents could indicate “No”, “Yes, during treatment”, “Yes, after treatment” and “Yes, still today”. Multiple answers were possible. If they indicated that they had used an existing service, we additionally asked parents to describe by which organization they had been supported.

We also asked parents whether they would use a hypothetical contact point for CCS parents' questions on health or disability insurance, legal issues, and other topics (yes/no). If they answered yes, we additionally asked parents about their wishes and expectations on what should be offered.

Explanatory variables

Sociodemographic characteristics. We assessed sex, age of parent at study, migration background, partnership (yes/no), educational achievement (compulsory schooling or vocational training/upper secondary education

or university education)²⁹, employment situation (employed/unemployed/retired), number of children (1 or 2/≥3), and household income

(≤6000CHF/month/>6000CHF/month). 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.

Parent-reported characteristics of the survivors. We asked parents, whether their child suffers from late effects of the cancer (yes/no). We assessed survivors' independence from their parents (yes/no). We classified survivors as independent if parents indicated that the survivor did no longer live with the parents, was financially independent and did not need support in carrying out daily tasks.

Characteristics of survivors extracted from the SCCR. We extracted information on sex, diagnosis (coded as leukaemia/lymphoma/CNS tumours/other tumours), age at diagnosis, time since diagnosis, age at study, treatment (coded hierarchically as “surgery only”, “chemotherapy (may have had surgery, but not radiotherapy)”, “radiotherapy (may have had surgery and/or chemotherapy)”, “stem cell transplantation (SCT; may have had surgery and/or chemotherapy and/or radiotherapy)”, and relapse (yes/no).

Analysis

We used Stata version 15.1 (StataCorp LP, College Station, TX). We used descriptive statistics, Chi² tests and Wilcoxon rank-sum test to compare participants and non-participants. For aim 1, we used descriptive statistics and content analysis. Answers to open-ended questions were coded according to their content by one researcher, and checked by a second researcher. Disagreement was resolved by discussion. Answers to open-ended questions were used to qualitatively describe domains, and to identify additional disadvantages and support needs. An overall binary variable for disadvantages (yes/no) was coded “yes” if the participant reported a disadvantage in at least one of the seven domains. We generated four binary variables (yes/no): “support needs during treatment”, “support needs after treatment”, “current support needs” and an overall variable “no support needs”. The first three variables were

coded “yes” if the participant reported a support need at that time point for ≥ 1 domain. “No support needs” was coded “yes” if the participant reported no support needs at all time points. For aim 2, we first ran univariable multilevel logistic regression models for the main outcomes *current disadvantages*, *support need during treatment*, and *support need after treatment* (**Supplemental table S1**; one model for each outcome). All variables that were statistically significant at $p < 0.1$ in the univariable model were included in the multivariable multilevel logistic regression model (one for each outcome). For the outcome *support need today*, we used logistic regression, because the number of parents with current support needs was too small to use multilevel analysis. Again, variables that were statistically significant at $p < 0.1$ in the univariable model (**Supplemental table S1**) were included in the multivariable logistic regression model. We used likelihood-ratio tests to calculate overall p -values of categorical variables in all regression models. For aim 3, we used descriptive statistics, χ^2 tests and content analysis.

Results

Study population

We contacted parents of 574 eligible survivors. Parents of 308 survivors responded (53.7%). The final sample consisted of 478 parents (196 fathers, 41.0%) of 308 CCS (**Figure 1**; **Supplemental table S2**). Participating parents had a mean age of 62.3 years at study ($SD=6.9$ years, **Table 1**). Most parents were employed ($n=256$, 53.6%) or retired ($n=164$, 34.3%), and in a partnership ($n=421$, 88.1%). The child's mean age at diagnosis was 6.9 years ($SD=4.5$ years) with a mean time of 24.0 years ($SD=7.1$ years) since diagnosis. Main diagnoses were leukaemia ($n=105$, 34.1%), lymphoma ($n=55$, 17.9%), and CNS tumour ($n=37$, 12.0%). CCS of participating and non-participating parents did not differ regarding diagnosis, age at diagnosis, time since diagnosis, and relapse status. However, survivors of participating parents had more often received chemotherapy or stem cell transplantation, but less often radiotherapy ($p=0.014$; **Table 1**).

Aim 1: Disadvantages and support needs of parents

Current disadvantages. Parents of most survivors ($n=247$, 80.2%) reported no current

disadvantages because of their child's former disease. However, parents of 59 survivors (19.2%) reported current disadvantages: *mental health issues* (parents of 26 survivors, 8.4%; e.g. anxiety, depression), disadvantages in their *social* ($n=15$, 4.9%; e.g. small circle of friends) or *familial environment* ($n=14$, 4.5%; e.g. family planning, divorce from other parent, relationship with relatives) and *physical disadvantages* ($n=14$, 4.5%; e.g. sleep disturbances, fatigue; **Table 2**).

Answers to the open questions revealed additional perceived disadvantages: CCS's *lack of independence* (“My life is oriented towards my daughter; I arrange my life around her.” (mother of CNS tumour survivor)), and that their *parenting* had been affected by the disease (“We wanted to be really good parents, but this is impossible with a fatally ill child!” (father of renal tumour survivor); **Supplemental table S3**).

Support needs of parents. A minority reported to have a current need for more support (parents of 22 survivors, 7.1%; **Supplemental table S4**). However, most parents would have needed more support during (parents of $n=206$ survivors, 66.9%) or after treatment ($n=106$, 34.4%). Most families ($n=226$, 73.4%) reported a need for more support at least at one time point. Parents who reported a current need for more support mostly needed more *financial* (parents of 13 survivors, 4.2%) or *psychological* ($n=9$, 2.9%) support (**Figure 2**; **Supplemental table S4**). During treatment, parents would have needed more *family* support (parents of 133 survivors, 43.2%), *psychological* support ($n=116$, 37.7%), *job-related* support ($n=79$, 25.6%), and *financial* support ($n=69$, 25.6%). After treatment, parents would have needed more *psychological* support (parents of 63 survivors, 20.5%), *medical* support ($n=25$, 8.1%) and *financial* support ($n=24$, 7.8%).

Some parents described their need for support in detail: *Psychological support* ($n=42$): They would have needed more psychological support for themselves, their partner or family, for the child with cancer or the siblings (**Supplemental Table S5**); *Financial support* ($n=17$): transport costs, overnight stays near the hospital, financial loss due to reduction of working hours, and drug treatment that was not paid by

the health insurance; *Family support*: domestic help and childcare for the siblings or the ill child ("I would have liked childcare for the sick child so that the rest of the family could make a day trip once in a while." (mother of malignant bone tumour survivor)); *Job-related support* (n=18): reduction of working hours and more flexibility to take time off; *Medical support* (n=14): more and open information from health-care professionals ("Someone who just had time and explained everything to us" (mother of neuroblastoma survivor)).

Answers to the open-ended questions also revealed additional support needs: *Parenting an ill child*: Parents expressed their wish to participate in parent support groups, to be treated empathetically by health-care professionals, and a need for personal support ("I wish, a treating doctor had once asked me how I'm doing." (mother of renal tumour survivor)); *School and education* for their ill child ("Our child was very forgetful in the beginning." (father of a leukaemia survivor)).

Aim 2: Characteristics associated with disadvantages and support needs

Current disadvantages. Having a migration background (OR=3.6, 95%CI:1.3-9.8), need for more support during treatment (OR=3.3, 95%CI:1.4-8.1), late effects of the CCS (OR=7.1, 95%CI:2.7-18.9) and dependence of the CCS on parents (OR=3.3, 95%CI:1.4-7.5) were associated with a perceived current disadvantage (**Table 3**).

Support needs. During treatment, older age of the survivor at diagnosis was associated with lower likelihood for a need for more support (OR=0.9, 95%CI:0.8-0.99; **Table 3**). After treatment, mothers (compared to fathers; OR=1.9, 95%CI:1.1-3.2), and parents needing more support during treatment (OR=3.0, 95%CI:1.6-5.4) were more likely to have a need for more support. Late effects of the CCS (OR=26.6, 95%CI:2.9-241.0) and dependence of the CCS on the parents (OR=10.6, 95%CI:2.1-53.7) were associated with increased likelihood for current need for more support.

Aim 3: Use of existing services

Almost half of parents reported to have ever used support services from a local or national parent organization (parents of 134 survivors, 43.5%; **Supplemental Table S6**). Services

were mainly used during treatment (parents of 109 survivors, 35.4%) or shortly after (n=60, 19.5%). Parents whose child had been diagnosed before 1992 were less likely to have ever used any services compared to parents whose child was diagnosed later ($p<0.001$). Parents who experienced disadvantages or current support needs were more likely to use existing services today than those without disadvantages and current support needs ($p<0.05$). Parents reported to be supported by different cancer-specific organizations in Switzerland, all of which offer a wide range of services: *Association Romande des Familles d'Enfants atteints d'un Cancer* (ARFEC), *Kinderkrebshilfe Schweiz*, *Vereinigung zur Unterstützung krebskranker Kinder*, *Krebsliga*, *Stiftung für krebskranke Kinder Basel* and various self-help groups. Parents of 169 survivors (54.9%) agreed that they would like to use a contact point for questions about health insurance, disability insurance, legal basics or other issues. Answers to the open-ended question revealed that parents wished for a permanent contact person at the hospital. Parents would like to receive easily accessible help and information (address lists, checklists) and advice on: childcare/domestic help, insurances, finances, medical information, legal information, contact to parents of survivors, and psychological support/helpline for parents.

Discussion

We found that one fifth of parents perceive disadvantages due to the former disease of their child on average 24 years after diagnosis. The need for more support was highest during treatment, and decreased over time in all domains. However, some parents are currently still in need for more support. Overall, three quarter of families would have needed more support in the course of their child's cancer-survivorship trajectory. Late effects and dependence of the CCS on parents were consistently identified as main determinants of perceived current disadvantages and more support needs. Unmet support needs during treatment were associated with current disadvantages. Almost half of parents had ever used a support service.

Although it is known that parents need support during, and also after their child's cancer

treatment,¹⁴⁻¹⁷ the large proportion of parents expressing unmet support needs in our study was surprising. A reason might be that, more than 20 years ago, support services for parents, such as social services or psycho-oncological services, might not have been common at the paediatric oncological clinics. Also, most Swiss support organizations for childhood cancer patients and their families were founded around 1990, which means that almost half of our sample had been diagnosed before these organizations were founded. This might also explain why parents whose child was diagnosed before 1992 were less likely to have used a support service. Parents may have been largely on their own coping with the disease of their child and its impact on family life. Another reason might be that, although we asked parents whether they would have needed more support (indicating only unmet needs), parents might have understood “what support did you need or use” (indicating a met or unmet need).

Similar to another study,¹⁴ we found that need for more support decreased over time, but that there is a subgroup of parents who still need support. Another study found that the amount of social support decreases in the first year after diagnosis and then remains stable.¹⁹ In contrast, an Australian study emphasized that families of children who completed treatment need the same level of support as during the treatment phase.¹⁵ It is therefore important to assess parents' support needs regularly; they may differ from one family to another, and may change over time.¹⁷

We found a high need for more *psychological support* (38% during treatment, 20% after treatment, 3% currently), which is similar to other studies (during treatment: 33-72%^{16,17}; after treatment 7-30%^{14,15}). However, comparability is limited as different measures for assessing support were used. Some assessed general need for support,^{14,16} whereas others assessed need for additional support,^{15,17} but used different measures to those used in our study. The psychological barrier to ask for psychological support may still be high for many parents. In Switzerland, hospitals with paediatric oncological wards nowadays offer psycho-oncological services to patients and families. Psycho-oncologists provide organizational, informational or emotional support and help to strengthen the family

members' personal resources.³⁰ Psycho-oncologists try to stay in contact with parents after the end of cancer treatment to provide continuous support. However, this might not apply to the same extent for parents included in our sample due to the long time since diagnosis.

During treatment, the parents in our study needed mostly more *family support*, e.g. help with housekeeping or childcare. In Switzerland, 57% of families use extra-familial childcare, either by relatives or institutions.³¹ The large proportion of families that do not use extra-familial childcare might contribute to an additional need for childcare during the time of diagnosis and treatment. Once childcare is reorganized, the need for family support decreases, as reflected in our results. Similarly, many parents reported needing more *job-related support* during, whereas only few need more support after treatment. After treatment completion, the CCS spends less time at the hospital and the family can gradually return to a more normal family life.³²

Although need for *financial support* also decreased over time, some parents reported to still need financial support more than 20 years after diagnosis. This is in line with our previous research, showing a lasting impact of the childhood cancer diagnosis on the income and employment situation of parents in Switzerland.^{12,23} Together, these results may indicate a need for additional support structures for parents of childhood cancer patients and survivors in Switzerland. Interventions and policies that facilitate the balancing act between caring for a child with a life threatening disease and the parents' professional lives may contribute to mitigate potentially adverse effects on the parents' financial situation in the long term.

A Swedish study found that not working, higher level of education and being foreign-born were associated with a need for support after end of treatment.¹⁴ We found that late effects of the CCS and dependence of the CCS are the main determinants for current support needs and perceived disadvantages. Our study found that unmet support needs during treatment are associated with perceived disadvantages long after diagnosis. Future studies should investigate the influence of the child's health status and ongoing dependence on the parents

in the long-term, particularly in regard to their financial situation, working situation and psychological status.

A limitation of our study is its retrospective design. Parents may have over- or underestimated their need for support during and after the treatment of their child resulting in recall bias. However, due to the distance to their child's diagnosis parents might also have focused on the major needs that they had at that time. Because we only had one contact address for parents, we relied on parents forwarding the study information to the other parent if they did no longer live together. Questions on disadvantages, support needs, and late effects of survivors were self-reported and are therefore an expression of parents' perspective. A few families were not contacted due to another questionnaire survey to their children at the same time.

It is a major strength of our study that we were able to assess parents' needs for support and perceived disadvantages long after their child's cancer diagnosis. We are not aware of other studies that have assessed the support needs and disadvantages faced by parents of CCS such a long time after diagnosis. Another strength of our study is the representative sample based on a population-based cohort of parents including a large number of fathers and parent couples.

Our study confirmed that many parents need more support during and after their child's cancer treatment. Study findings also showed that some parents experience support needs and disadvantages long into survivorship. Late effects of the child and ongoing dependence of the child on the parents were identified as the main determinants for perceived disadvantages and current support needs in parents. It is crucial that existing services for parental and familial support are promoted actively by healthcare professionals in order to avoid disadvantages for survivors' families in the long-term.

Conflict of interests

No conflicts of interest for any of the authors.

Data sharing 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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TABLE 1 Description of participating parents and comparison of survivors of participating and non-participating parents.

Characteristics of parents		Participants		Non-participants		
		N=478	%			
Sex	Male	196	41.0	—	—	
	Female	282	59.0	—	—	
Migration background	No	394	82.4	—	—	
	Yes	58	12.1	—	—	
Partnership	Yes	421	88.1	—	—	
	No	48	10.0	—	—	
Educational achievement	Compulsory schooling	54	11.3	—	—	
	Vocational training	232	48.5	—	—	
	Upper secondary education	77	16.1	—	—	
	University education	71	14.9	—	—	
Employment	Not employed	39	8.2	—	—	
	Employed	256	53.6	—	—	
	Retired	164	34.3	—	—	
Number of children	1	8	1.7	—	—	
	2	211	44.1	—	—	
	3	135	28.2	—	—	
	≥4	83	17.4	—	—	
Characteristics of survivors		N=308 ^a	%	N=266	%	p-value ^b
Diagnosis	Leukaemia	105	34.1	85	32.0	0.905
	Lymphoma	55	17.9	44	16.5	
	CNS tumour	37	12.0	44	16.5	
	Neuroblastoma	13	4.2	12	4.5	
	Retinoblastoma	9	2.9	6	2.3	
	Renal tumour	20	6.5	20	7.5	
	Hepatic tumour	6	1.9	2	0.8	
	Malignant bone tumour	15	4.9	12	4.5	
	Soft tissue sarcoma	23	7.5	17	6.4	
	Germ cell tumour	10	3.2	10	3.8	
	Langerhans cell histiocytosis	15	4.9	14	5.3	
Treatment	Surgery only	37	12.0	37	13.9	0.014
	Chemotherapy	170	55.2	115	43.2	
	Radiotherapy	81	26.3	99	37.2	
	Stem cell transplantation	19	6.2	12	4.5	
Relapse	No	270	87.7	226	85.0	0.410
	Yes	38	12.3	40	15.0	
Characteristics of parents and survivors		Mean	SD	Mean	SD	p-value ^c
Parents: Age at study		62.3	6.9	—	—	—
Survivors: Age at study		32.4	6.4	32.6	6.7	0.741
Survivors: Age at diagnosis		6.9	4.5	6.7	4.6	0.476
Survivors: Time since diagnosis		24.0	7.1	24.4	7.0	0.618

Abbreviations: CNS=central nervous system, SD=standard deviation; Note: Number of observations may not add up to total N due to missing values

^a Number of survivors with at least one parent responding to this survey

^b p-value from Chi² statistics, missings not included

^c p-value from Wilcoxon rank-sum test

TABLE 2 Perceived current disadvantages faced by parents of childhood cancer survivors. Numbers are presented on family level (478 parents from N=308 families).

	Overall (N=308 families):				Only one parent of family responded (n=138 families):				Both parents of family responded (n=170 families):							
	Parents of ... families reported disadvantage		Parents of ... families reported no disadvantage		Mother reported disadvantage		Father reported dis-advantage		Both reported disadvantage		Only mother reported disadvantage		Only father reported disadvantage		Both reported no disadvantage	
	n	% ^a	n	% ^a	n ^b =112	% ^c	n ^d =26	% ^e	n	% ^f	n	% ^f	n	% ^f	n	% ^f
Any	59	19.2	247	80.2	22	19.6	1	3.8	8	4.7	17	10.0	11	6.5	134	78.8
Job-related	13	4.2	293	95.1	3	2.7	1	3.8	0	0.0	7	4.1	2	1.2	161	94.7
Financial	10	3.2	296	96.1	3	2.7	1	3.8	0	0.0	1	0.6	5	2.9	164	96.5
Social	15	4.9	291	94.5	8	7.1	0	0.0	2	1.2	5	2.9	0	0.0	163	95.9
Family	14	4.5	292	94.8	5	4.5	0	0.0	0	0.0	6	3.5	3	1.8	161	94.7
Physical	14	4.5	292	94.8	6	5.4	0	0.0	0	0.0	5	2.9	3	1.8	162	95.3
Psychological	26	8.4	280	90.9	11	9.8	0	0.0	2	1.2	8	4.7	5	2.9	155	91.2
Other	14	4.5	292	94.8	6	5.4	0	0.0	1	0.6	3	1.8	4	2.4	162	95.3

Note: Numbers may not add up to the total n or 100% due to missing data.

^a"Overall:" N=308 families equal 100%

^bFor 112 families, only the mother responded to the questionnaire

^c"Only one parent responded:" n=112 families equal 100%

^dFor 26 families, only the father responded to the questionnaire

^e"Only one parent responded:" n=26 families equal 100%

^f"Both parents responded:" n=170 families equal 100%

TABLE 3 Associations with need for more support and perceived current disadvantages (from multivariable multilevel logistic regression)

	Need for more support: During treatment			Need for more support: After treatment			Need for more support: Current ^a			Current disadvantage		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
Sex			–			0.017			0.721			0.097
Male	–	–		1.00			1.00			1.00		
Female	–	–		1.89	1.12–3.19		1.26	0.35–4.54		2.01	0.88–4.58	
Age (parent)^b [years]		–	–	0.97	0.93–1.01	0.087	–	–	–	–	–	–
Migration background			–			–			0.101			0.012
Yes	–	–		–	–		2.87	0.81–10.10		3.62	1.33–9.84	
No	–	–		–	–		1.00			1.00		
Employment			–			–			0.058 ⁺			–
Employed	–	–		–	–		1.00			–	–	
Unemployed	–	–		–	–		7.73	1.39–43.10		–	–	
Retired	–	–		–	–		0.98	0.18–5.31		–	–	
Support need during treatment			–			<0.001			0.107			0.008
Yes	–	–		2.97	1.64–5.39		3.47	0.76–15.73		3.32	1.36–8.12	
No	–	–		1.00			1.00			1.00		
Support need after treatment			–			–			0.218			0.094
Yes	–	–		–	–		2.00	0.66–6.06		1.96	0.89–4.30	
No	–	–		–	–		1.00			1.00		
Diagnosis (survivor)			0.133 ⁺			–			–			–
Lymphoma	0.32	0.11–0.96		–	–		–	–		–	–	
Leukaemia	1.00			–	–		–	–		–	–	
CNS	1.18	0.36–3.88		–	–		–	–		–	–	
Other tumours ^c	0.69	0.29–1.61		–	–		–	–		–	–	
Age at diagnosis (survivor)^d [years]	0.91	0.84–0.99	0.032	–	–	–	–	–	–	–	–	–

Treatment (survivor)	—	—	—	—	—	1.18	0.17–7.93	0.935 ⁺	1.20	0.34–4.30	0.422 ⁺
Surgery ^e	—	—	—	—	—	1.18	0.17–7.93		1.20	0.34–4.30	
Chemotherapy ^e	—	—	—	—	—	1.00			1.00		
Radiotherapy ^e	—	—	—	—	—	1.07	0.30–3.91		1.98	0.82–4.77	
SCT ^e	—	—	—	—	—	1.70	0.34–8.61		0.85	0.19–3.85	
Age at study (survivor)^d	—	—	—	—	—	0.98	0.87–1.09	0.673	—	—	—
[years]	—	—	—	—	—						
Late effects (survivor)	—	—	—	—	—			0.004			<0.001
Yes	—	—	—	—	—	26.58	2.93–241.0		7.09	2.66–18.90	
No	—	—	—	—	—	1.00			1.00		
Independence of survivor	—	—	—	—	—			0.004			0.005
Independent	—	—	—	—	—	1.00			1.00		
Not independent	—	—	—	—	—	10.58	2.08–53.74		3.27	1.43–7.50	

Abbreviations: CI=confidence interval, CNS=central nervous system, OR=odds ratio, SCT=stem cell transplantation

Notes: Statistically significant variables at $p < 0.05$ are highlighted in bold

^a The results for this outcome are from multivariable logistic regression (multilevel analyses not possible due to small number of observations in certain categories)

^b Age (parent) is a continuous variable: OR<1 indicates lower odds for support need with older age of parent

^c The category “other tumours” consists of neuroblastoma, retinoblastoma, renal tumours, hepatic tumours, malignant bone tumours, soft tissue sarcoma, germ cell tumours and Langerhans cell histiocytosis

^d Age at diagnosis (survivor) and Age at study (survivor) are continuous variables: OR<1 indicates lower odds for support need/disadvantage in parents with survivor's older age at diagnosis/study

^e Treatment was coded hierarchically as “surgery only”; “chemotherapy (may have had surgery, but not radiotherapy)”; “radiotherapy (may have had surgery and/or chemotherapy)”; “stem cell transplantation (may have had surgery and/or chemotherapy and/or radiotherapy)”

⁺ overall p-value from likelihood-ratio test

FIGURE 1 Study flow chart: Participating and non-participating parents of long-term childhood cancer survivors.

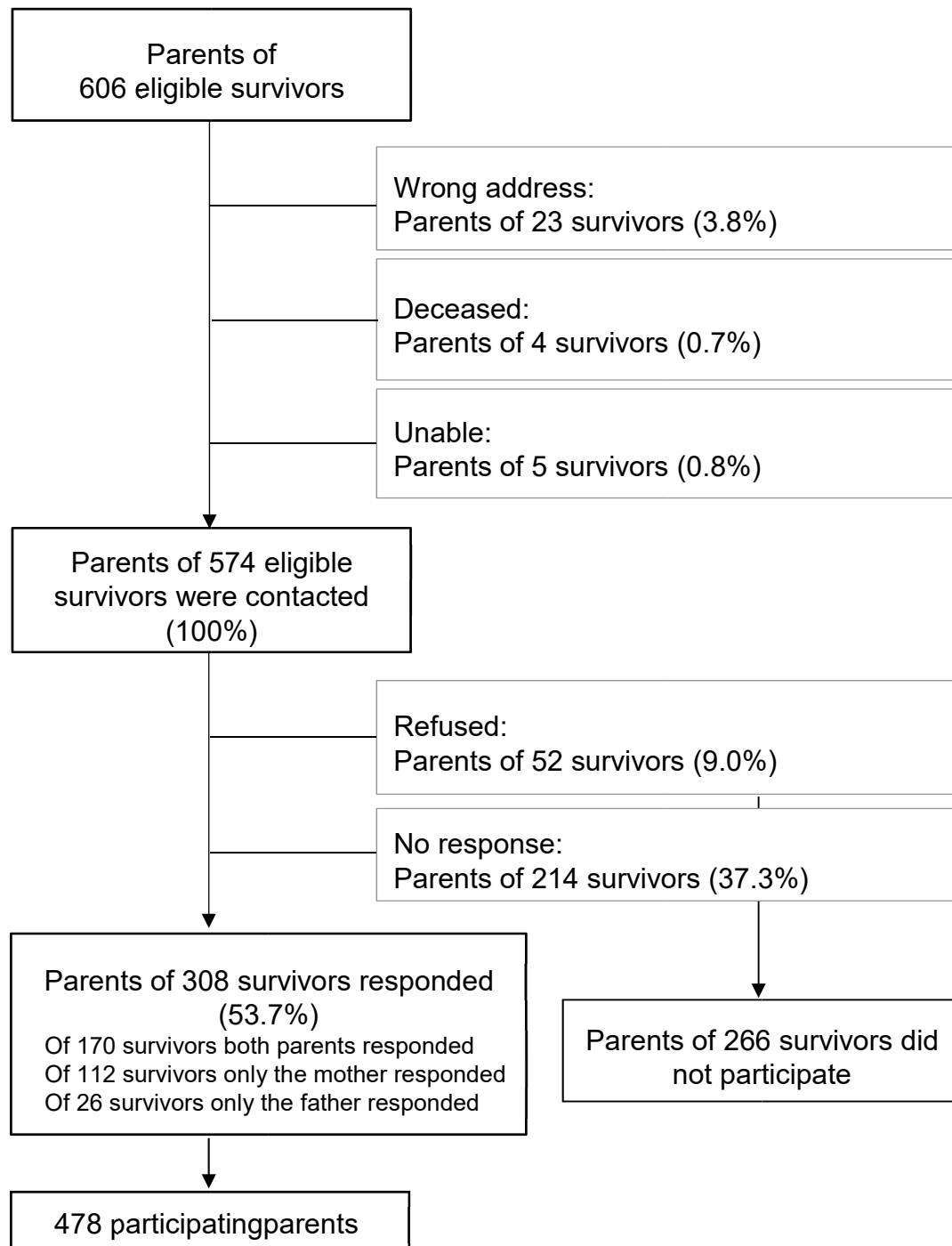
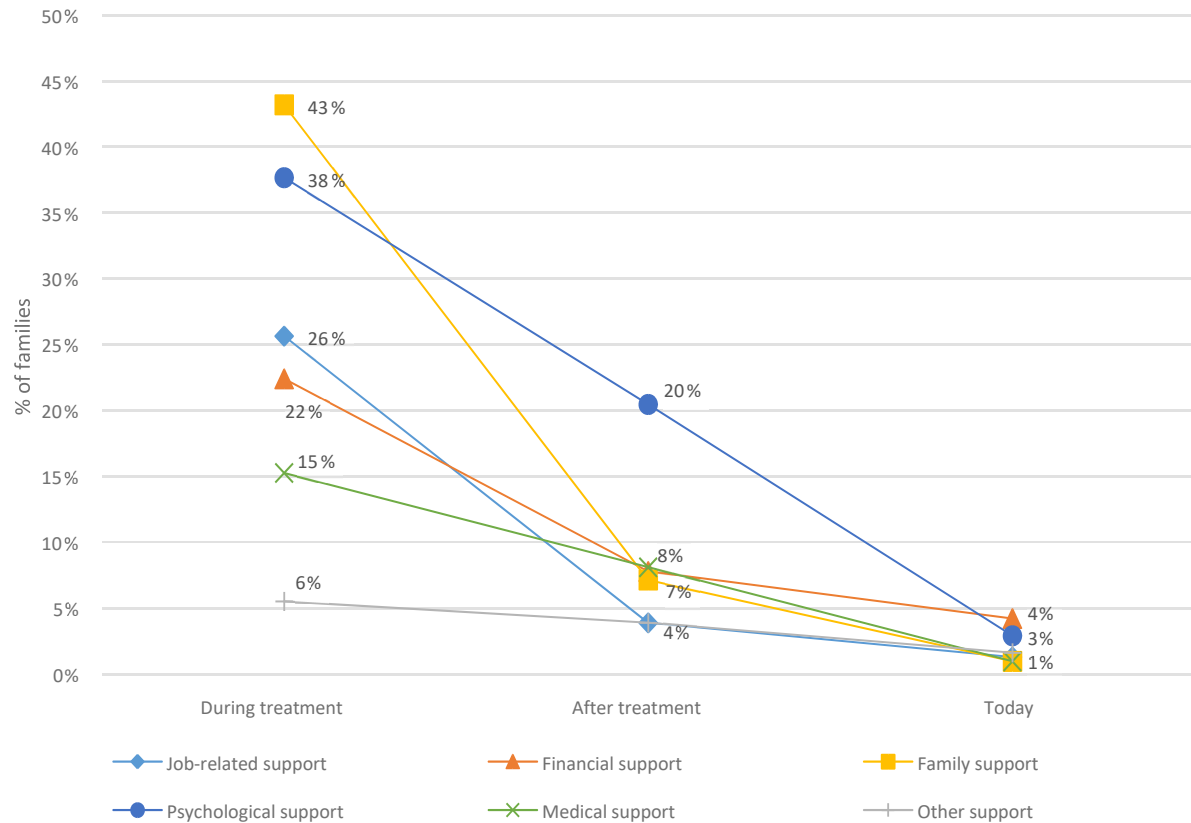


FIGURE 2 Support needs of parents of childhood cancer survivors: Percentages are presented on family level, indicating the percentage of families of which one or both parents reported a need for more support (parents from N=308 families) in the respective domain and at the respective time point.



Note: Percentages per time point may exceed 100%, as parents could indicate more than one domain.

SUPPLEMENTAL TABLE S1 Associations with more support needs and current disadvantages (from univariable multilevel logistic regression)

	Need for more support: During treatment			Need for more support: After treatment			Need for more support: Current ^a			Current disadvantage		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
Sex			0.231			0.008			0.030			0.035
Female (Ref. Male)	1.38	0.81–2.34		1.98	1.19–3.29		2.78	1.02–7.60		2.15	1.06–4.38	
Age (parent)^b	0.97	0.92–1.02	0.298	0.96	0.92–1.00	0.030	0.95	0.89–1.02	0.152	0.98	0.93–1.04	0.544
Migration background			0.991			0.218			0.068			0.011
Yes (Ref. No)	0.99	0.39–2.51		1.57	0.77–3.22		2.67	1.00–7.14		3.94	1.37–11.39	
Partnership^c			–			–			0.327			0.321
No (Ref. Yes)	–	–		–	–		1.81	0.59–5.54		1.82	0.56–5.91	
Educational achievement			0.700			0.751			0.587			0.784
Compulsory school/ Vocational training	1.00			1.00			1.00			1.00		
Upper secondary/ University education	0.88	0.46–1.70		0.92	0.53–1.58		1.29	0.52–3.24		1.11	0.53–2.35	
Employment^c			–			–			0.064⁺			0.293 ⁺
Employed	–	–		–	–		1.00			1.00		
Unemployed	–	–		–	–		2.79	0.94–8.28		0.68	0.18–2.51	
Retired	–	–		–	–		0.56	0.20–1.58		0.53	0.23–1.19	
Number of children			0.250			0.635			0.806			0.277
≥3 (Ref. 1 or 2)	1.53	0.74–3.19		0.88	0.51–1.50		0.89	0.35–2.24		0.61	0.25–1.50	
Household income^c			–			–			0.910			0.425
≤6000CHF	–	–		–	–		0.95	0.39–2.30		1.44	0.59–3.50	
>6000CHF	–	–		–	–		1.00			1.00		
Support need during treatment			–			<0.001			0.015			0.002
Yes (Ref. No)	–	–		3.12	1.75–5.57		3.36	1.13–10.00		3.92	1.63–9.41	
Support need after treatment			–			–			0.003			0.003
Yes (Ref. No)	–	–		–	–		3.59	1.56–8.25		3.34	1.50–7.40	
Diagnosis (survivor)			0.067⁺			0.334 ⁺			0.387 ⁺			0.414 ⁺
Lymphoma	0.24	0.08–0.71		0.75	0.35–1.61		0.41	0.09–1.93		0.63	0.18–2.20	
Leukaemia	1.00			1.00			1.00			1.00		
CNS	0.99	0.30–3.23		1.63	0.73–3.66		1.59	0.51–4.97		2.25	0.64–7.91	
Other tumours ^d	0.68	0.29–1.60		1.29	0.72–2.33		0.81	0.30–2.15		1.09	0.43–2.79	
Age at diagnosis (survivor)^e	0.90	0.83–0.97	0.009	0.97	0.92–1.03	0.291	0.97	0.88–1.06	0.478	1.04	0.95–1.13	0.407
Treatment (survivor)			0.516 ⁺			0.804 ⁺			0.042⁺			0.019⁺
Surgery ^f	2.09	0.66–6.60		1.28	0.59–2.75		1.09	0.23–5.28		1.07	0.30–3.78	
Chemotherapy ^f	1.00			1.00			1.00			1.00		
Radiotherapy ^f	0.88	0.39–2.00		0.95	0.52–1.73		2.43	0.91–6.47		4.07	1.62–10.21	
SCT ^f	1.63	0.35–7.59		1.49	0.51–4.30		5.71	1.59–20.56		3.31	0.71–15.35	
Age at study (survivor)^e	–	–	–	–	–	–	0.93	0.86–1.01	0.052	0.95	0.89–1.02	0.146
Late Effects (survivor)^c			–			–			<0.001			<0.001
Yes (Ref. No)	–	–		–	–		16.67	3.87–71.82		8.87	3.48–22.59	
Independence of survivor^c			–			–			<0.001			<0.001
Independent	–	–		–	–		1.00			1.00		
Not independent	–	–		–	–		20.52	4.76–88.47		7.12	2.73–18.58	

Abbreviations: CI=confidence interval, CNS=central nervous system, OR=odds ratio, Ref.=reference category (OR=1.00), SCT=stem cell transplantation

Notes: Statistically significant variables at $p < 0.1$ are highlighted in bold

^a The results for this outcome are from univariable logistic regression (not multilevel)

^b Age (parent) is a continuous variable: OR<1 indicates lower odds for support need with older age of parent

^c The variables partnership, employment, household income, late effects of the survivor and independence of the survivor were not assessed for the time points "during treatment" and "after treatment" and were, therefore, only included in the models "current support need" and "current disadvantage"

^d The category "other tumours" consists of neuroblastoma, retinoblastoma, renal tumours, hepatic tumours, malignant bone tumours, soft tissue sarcoma, germ cell tumours and Langerhans cell histiocytosis

^e Age at diagnosis (survivor), and Age at study (survivor) are continuous variables: OR<1 indicates lower odds for support need/discrimination in parents with survivor's older age at diagnosis/study

^f Treatment was coded hierarchically as "surgery only"; "chemotherapy (may have had surgery, but not radiotherapy)"; "radiotherapy (may have had surgery and/or chemotherapy)"; "stem cell transplantation (SCT; may have had surgery and/or chemotherapy and/or radiotherapy)"

* overall p-value from likelihood-ratio test

SUPPLEMENTAL TABLE S2 Description and comparison of participating parents (one parents responded vs. both parents responded), and of survivors of participating and non-participating parents.

Characteristics of parents (N=478)		Participants				p-value ^a	Non-participants		
		One parent responded n=138	%	Both parents responded n=340	%				
Sex	Male	26	18.8	170	50.0	<0.001	—	—	
	Female	112	81.2	170	50.0		—	—	
Migration background	No	102	73.9	292	85.9	0.029	—	—	
	Yes	23	16.7	35	10.3		—	—	
Partnership	Yes	94	68.1	327	96.2	<0.001	—	—	
	No	38	27.5	10	2.9		—	—	
Educational achievement	Compulsory schooling	19	13.8	35	10.3	0.062	—	—	
	Vocational training	71	51.4	161	47.4		—	—	
	Upper secondary	18	13.0	59	17.4		—	—	
	University	12	8.7	59	17.4		—	—	
Employment	Not employed	12	8.7	27	7.9	0.333	—	—	
	Employed	66	47.8	190	55.9		—	—	
	Retired	53	38.4	111	32.6		—	—	
Number of children	1	3	2.2	5	1.5	0.071	—	—	
	2	50	36.2	161	47.4		—	—	
	3	36	26.1	99	29.1		—	—	
	≥4	32	23.2	51	15.0		—	—	
Characteristics of survivors (N=308)		n=138 ^b	%	n=170 ^b	%	p-value ^a	n=266	%	p-value ^c
Diagnosis	Leukaemia	46	33.3	59	34.7	0.135	85	32.0	0.905
	Lymphoma	26	18.8	29	17.1		44	16.5	
	CNS tumour	18	13.0	19	11.2		44	16.5	
	Neuroblastoma	4	2.9	9	5.3		12	4.5	
	Retinoblastoma	1	0.7	8	4.7		6	2.3	
	Renal tumour	7	5.1	13	7.6		20	7.5	
	Hepatic tumour	6	4.3	0	0.0		2	0.8	
	Malignant bone tumour	6	4.3	9	5.3		12	4.5	
	Soft tissue sarcoma	11	8.0	12	7.1		17	6.4	
	Germ cell tumour	6	4.3	4	2.4		10	3.8	
	LCH	7	5.1	8	4.7		14	5.3	
Treatment	Surgery only	14	10.1	23	13.5	0.346	37	13.9	0.014
	Chemotherapy	76	55.1	94	55.3		115	43.2	
	Radiotherapy	36	26.1	45	26.5		99	37.2	
	SCT	12	8.7	7	4.1		12	4.5	
Relapse	No	122	88.4	147	86.5	0.612	226	85.0	0.410
	Yes	16	11.6	23	13.5		40	15.0	
Characteristics of parents and survivors		Mean	SD	Mean	SD	p-value ^d	Mean	SD	p-value ^e
Parents: Age at study		63.1	7.8	62.0	6.5	0.263	—	—	—
Survivors: Age at study		33.5	6.9	31.5	5.8	0.011	32.6	6.7	0.741
Survivors: Age at diagnosis		7.4	4.5	6.5	4.5	0.109	6.7	4.6	0.476
Survivors: Time since diagnosis		24.6	7.6	23.5	6.6	0.231	24.4	7.0	0.618

Abbreviations: CNS=central nervous system, LCH=Langerhans cell histiocytosis; SCT=stem cell transplantation; SD=standard deviation; Note: Number of observations may not add up to total N due to missing values

^a p-value from Chi² statistics, comparing parents with only one parent responding to the survey to parents of which both parent responded

^b Number of survivors with at least one parent responding to this survey

^c p-value from Chi² statistics, comparing all responders to non-responders of the survey

^d p-value from Wilcoxon rank-sum test, comparing parents with only one parent responding to the survey to parents of which both parent responded

^e p-value from Wilcoxon rank-sum test, comparing all responders to non-responders of the survey

SUPPLEMENTAL TABLE S3 Summary of coded answers to the open-ended question regarding parents' perceived disadvantages ("Are there domains today where you are disadvantaged by your child's previous disease? Please describe the disadvantage briefly:")

Topic	Description	Number of parents mentioning disadvantage:
Job-related	Job-related disadvantages	7
Financial	Financial disadvantages	2
Social environment/ friends	Social environment	3
	Few social contacts	4
	Lack of support from relatives	1
Family	Family planning	1
	No grandchildren	1
	Divorce from other parent	4
	Disadvantaged partnership/ disagreements	1
Physical	Physical disadvantage	2
Psychological	Anxiety	9
	Depression	1
	Emotional disadvantage	4
	Psychological distress	4
Lack of independence	Lack of independence from the survivor	10
	Personal development disadvantaged	2
Impaired parenting	Impaired parenting	2

SUPPLEMENTAL TABLE S4 Support needs of parents of childhood cancer survivors. Numbers are presented on family level, indicating the number of families of which one or both parents reported a need for more support (478 parents from N=308 families).

During the treatment					After the treatment					Today					Never										
Overall (N=308):		n	% ^a		n		% ^a		n		% ^a		n		% ^a										
Any support need		206	66.9%		106		34.4%		22		7.1%		66		21.4%										
Job-related		79	25.6%		12		3.9%		4		1.3%		198		64.3%										
Financial		69	22.4%		24		7.8%		13		4.2%		197		64.0%										
Family		133	43.2%		22		7.1%		3		1.0%		152		49.4%										
Psychological		116	37.7%		63		20.5%		9		2.9%		138		44.8%										
Medical		47	15.3%		25		8.1%		3		1.0%		217		70.5%										
Other		17	5.5%		12		3.9%		5		1.6%		260		84.4%										
Only one parent of family responded (n=138 families):		Only mother responded: n=112 ^b		Only father responded: n=26 ^d		Only mother responded: n=112 ^b		Only father responded: n=26 ^d		Only mother responded: n=112 ^b		Only father responded: n=26 ^d		Only mother responded: n=112 ^b		Only father responded: n=26 ^d									
		n	% ^c	n	% ^e	n	% ^c	n	% ^e	n	% ^c	n	% ^e	n	% ^c	n	% ^e								
Any support need		69	61.6%	14	53.8%	33	29.5%	7	26.9%	11	9.8%	1	3.8%	26	23.2%	10	38.5%								
Job-related		13	11.6%	7	26.9%	5	4.5%	1	3.8%	2	1.8%	0	0.0%	85	75.9%	18	69.2%								
Financial		24	21.4%	4	15.4%	7	6.3%	3	11.5%	8	7.1%	1	3.8%	70	62.5%	19	73.1%								
Family		36	32.1%	8	30.8%	5	4.5%	4	15.4%	2	1.8%	0	0.0%	64	57.1%	16	61.5%								
Psychological		43	38.4%	8	30.8%	24	21.4%	3	11.5%	5	4.5%	0	0.0%	46	41.1%	16	61.5%								
Medical		16	14.3%	4	15.4%	6	5.4%	1	3.8%	1	0.9%	0	0.0%	82	73.2%	21	80.8%								
Other		3	2.7%	0	0.0%	4	3.6%	0	0.0%	3	2.7%	0	0.0%	96	85.7%	25	96.2%								
Both parents of family responded (n=170 families):		Both parents reported support need:		Only mother reported support need:		Only father reported support need:		Both parents reported support need:		Only mother reported support need:		Only father reported support need:		Both parents never reported support need:		Only mother never reported support need:		Only father never reported support need:							
		n	% ^f	n	% ^f	n	% ^f	n	% ^f	n	% ^f	n	% ^f	n	% ^f	n	% ^f	n	% ^f						
Any support need		70	41.2	30	17.6	23	13.5	13	7.6	36	21.2	17	10.0	2	1.2	6	3.5	2	1.2	30	17.6	18	10.6	31	18.2
Job-related		17	10.0	19	11.2	23	13.5	0	0.0	3	1.8	3	1.8	0	0.0	1	0.6	1	0.6	95	55.9	30	17.6	23	13.5
Financial		17	10.0	13	7.6	11	6.5	3	1.8	3	1.8	8	4.7	1	0.6	2	1.2	1	0.6	108	63.5	22	12.9	17	10.0
Family		29	17.1	40	23.5	20	11.8	0	0.0	7	4.1	6	3.5	0	0.0	0	0.0	1	0.6	72	42.4	21	12.4	36	21.2
Psychological		17	10.0	30	17.6	18	10.6	5	2.9	22	12.9	9	5.3	1	0.6	2	1.2	1	0.6	76	44.7	24	14.1	36	21.2
Medical		5	2.9	10	5.9	12	7.1	3	1.8	11	6.5	4	2.4	0	0.0	1	0.6	1	0.6	114	67.1	22	12.9	21	12.4
Other		1	0.6	7	4.1	6	3.5	0	0.0	6	3.5	2	1.2	0	0.0	1	0.6	1	0.6	139	81.8	16	9.4	11	6.5

Note: Numbers may not add up to the total n or 100% due to missing data.

^aN=308 families equals 100%, ^bFor 112 families, only the mother responded to the questionnaire, ^cn=112 families equals 100%, ^dFor 26 families, only the father responded to the questionnaire, ^en=26 families equals 100%, ^f“Both parents responded:” N=170 equals 100%.

SUPPLEMENTAL TABLE S5 Summary of coded answers to open-ended questions regarding parents' support needs ("Have you ever wished for more support for yourself and / or your family? Please describe the support you would wish having received in more detail:")

Support need: Topic	Description	Number of parents mentioning needs:
Job-related	Reduction of working hours/Adequate sick leave for parents	18
Financial	Financial support	17
Family/ Siblings/ Organizational/ General	Family support	4
	Received no support at all	2
	General support	4
	Driving service to school	1
	Childcare (general)	8
	Childcare for siblings	6
	Childcare for ill child	2
	Domestic help	16
	Child guidance	4
Psychological/ Partnership	Psychological support	35
	Psychological support for siblings	3
	Partnership	6
	Meeting with former treating medical staff	1
	Family therapy	4
	Drug rehabilitation	1
Medical/ Hospital stays/ Informational/ Follow-up care	Possibility to have meals at the hospital (for parents)	2
	Possibility to stay overnight at the hospital (for parents)	6
	Constant medical team (doctors/medical staff)	2
	Increased participation/More visits of family and friends	1
	Nutritional advice	1
	Medical/Therapeutical follow-up care of the survivor	4
	Notification after follow-up appointments as quickly as possible	1
	Information needs	14
Parenting with an ill child	Understanding/Consideration for the parents	3
	Health status of the parents	2
	Follow-up care for family	1
	Exchange with other parents	5
	Exchange with parents of survivors	1
School/ Education of the ill child	School and education	4
	School support	2

SUPPLEMENTAL TABLE S6 Use of support services from parent organizations by parents of childhood cancer survivors.

Numbers are presented on family level (478 parents from N=308 families).

	Overall (N=308 families):				Only one parent of family responded (n=138 families):				Both parents of family responded (n=170 families):							
	Parents of ... families reported service use		Parents of ... families reported no service use		Mother reported service use		Father reported service use		Both reported service use		Only mother reported service use		Only father reported service use		Both reported no service use	
	n	% ^a	n	% ^a	n ^b =112	% ^c	n ^d =26	% ^e	n	% ^f	n	% ^f	n	% ^f	n	% ^f
Any	134	43.5	169	54.9	41	36.6	9	34.6	51	30.0	14	8.2	19	11.2	86	50.6
During treatment	109	35.4	194	63.0	34	30.4	8	30.8	43	25.3	13	7.6	11	6.5	103	60.6
After treatment	60	19.5	243	78.9	22	19.6	3	11.5	15	8.8	14	8.2	6	3.5	135	79.4
Today	15	4.9	288	93.5	5	4.5	0	0.0	2	1.2	4	2.4	4	2.4	160	94.1

Note: Numbers may not add up to the total n or 100% due to missing data.

^aN=308 families equal 100%

^bFor 112 families, only the mother responded to the questionnaire

^c"Only one parent responded:" n=112 families equal 100%

^dFor 26 families, only the father responded to the questionnaire

^e"Only one parent responded:" n=26 families equal 100%

^f"Both parents responded:" n=170 families equal 100%