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# Relationship status and quality of the partner relationship in parents of long-term childhood cancer survivors: the Swiss Childhood Cancer Survivor Study - Parents

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#### **Short title:**

Partner relationship in parents of childhood cancer survivors

#### **Abstract**

Objective: The intensive and long-lasting experience of childhood cancer is a tremendous stressor for the parental relationship. We aimed to i) compare civil status and partner relationship of parents of long-term childhood cancer survivors with population-based comparisons, ii) identify cancer-related characteristics associated with not-being-married, and iii) evaluate the quality of the partner relationship.

Methods: We sent questionnaires to parents of childhood cancer survivors aged  $\leq 16$  years at diagnosis and  $\geq 20$  years at study. Population-based comparisons were derived from a random sample of the general population ( $\geq 1$  child aged  $\geq 20$  years) and standardized by socio-demographic characteristics of survivor parents. We used logistic regression to identify cancer-related characteristics associated with not-being-married. The quality of the partner relationship was evaluated using the Relationship-specific attachment scale for adults assessing the dimensions Security (secure-fearful) and Dependency (dependent-independent).

Results: A total of 784 parents (58.9% mothers) of 512 survivors and 471 comparison parents (58.5%) completed the questionnaire. Parents of survivors were less often divorced/separated (9.0% vs. 17.5%, P<0.001) and more often in a partner relationship (89.9% vs. 85.0%, P=0.010) than comparisons. Not-being-married was not associated with cancer-related characteristics. Parents of survivors reported similar Security (P=0.444) but higher Dependency (P=0.032) within the partner relationship than comparisons. In both populations, fathers indicated higher Security and Dependency than mothers.

Conclusions: Parenting a child with cancer did not adversely affect parents' relationship in the long term. The cancer experience appeared to increase the dependency within the relationship suggesting that parents manage their child's disease as a team.

## **Background**

"Childhood cancer is family cancer! Our family, our partner relationship did not function well for many years. The partner relationship remained affected until today!" (father of renal tumour survivor, 36 years after diagnosis). This comment in our questionnaire survey including parents of long-term childhood cancer survivors in Switzerland highlights that the intensive and long-lasting experience of childhood cancer affects the psycho-social functioning of all family members<sup>1-3</sup>. Managing the child's disease alongside other everyday activities is challenging for the parents. After diagnosis, parents are confronted with the potential fatality of the disease and conflicting caregiving, emotional, and practical demands they were not prepared for Arecent review concluded that

although most parent-dyads adapt well to the crisis of having a child with cancer, findings related to conflicts in the parental relationship are mixed<sup>5</sup>.

Even years after successful treatment, parents may experience uncertainties related to cancer relapse or late effects and continue to play an active role in the child's long-term care<sup>6,7</sup>. A majority of parents indicated that they felt well prepared for the child's cancer treatment, however, fewer reported feeling prepared for the life after cancer<sup>8</sup>. This points towards a persistent impact on parents' psycho-social functioning including the partner relationship even years after the child's recovery. However, the long-term impact of childhood cancer on the partner relationship from the perspectives of both parents remains largely unknown<sup>5</sup>. In this population-based questionnaire survey, we aimed to i) compare the civil

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status and partner relationship of parents of long-term childhood cancer survivors aged ≥20 years with comparison parents of the general population of Switzerland, ii) identify cancer-related characteristics associated with not-being married, and iii) evaluate the quality of the partner relationship.

#### Methods

#### Parents of childhood cancer survivors

This study is part of the Swiss Childhood Cancer Survivor Study (SCCSS)9 and includes a sample of parents of long-term childhood cancer survivors (SCCSS-Parents) derived from the Swiss Childhood Cancer Registry (SCCR)<sup>10,11</sup>. The SCCR centrally registers children and adolescents aged <20 years, who were diagnosed with leukaemia, lymphoma, central nervous system (CNS) tumour, malignant solid tumour or Langerhans cell histiocytosis in Switzerland<sup>10,11</sup>. Parents were eligible if the child was diagnosed with cancer at age ≤16 years, diagnosed between 1976 and 2009, had survived ≥5 years, and was ≥20 years old at study. Parental names and addresses at diagnosis were extracted from the SCCR and updated using an online telephone directory. Parents with a valid address received an information letter about the purpose of the study. After two weeks, mothers and fathers each received a questionnaire together with pre-paid return envelopes. The questionnaire was available in German, French, and Italian. Non-respondents received up to two reminders after approximately 4 and 12 weeks. We collected data between January 2017 and February 2018. Ethical approval was granted through the Ethics Committee of Northwest and Central Switzerland (EKNZ 2015-075; 26 March 2015).

#### **Comparison parents**

The Swiss Federal Statistical Office provided a representative population-based sample of 3000 households including 7052 individuals according to the distributions of age, sex, and language in Switzerland. Individuals aged 18-75 years were eligible and contacted between May 2015 and June 2016. We used similar contact procedures as for parents of survivors. For this study, we restricted the sample to parents having ≥1 child aged ≥20 years.

#### **Outcome measures**

Civil status and partner relationship

Parents of survivors and comparison parents selfreported their civil status (single; married; divorced/separated; widowed) and separately whether they were living in a partner relationship (yes; no).

Quality of the partner relationship

The quality of the partner relationship was evaluated using the *relationship-specific attachment scale for adults* by Asendorpf et al. (1997), which showed satisfactory psychometric properties in German settings<sup>12</sup>. The instrument consists of 14 items assessing the dimensions *Security* (secure-fearful; 6 items) and *Dependency* (dependent-independent; 8 items). Participants indicated their level of agreement with each item using Likert scales (1=not at all to

5=completely). If necessary, items were reverse-coded with higher scores indicating higher Security and higher Dependency. In our sample internal consistency was satisfactory for the dimensions Security (Cronbach's  $\alpha$ =0.73) and Dependency ( $\alpha$ =0.72) $^{13}$ .

# **Explanatory variables**

Socio-demographic characteristics

For parents of survivors and comparison parents, we assessed the following socio-demographic characteristics: sex, age at study (<65 years; ≥65 years [official retirement age in Switzerland]), language region (German; French/Italian), migration background (yes; no), number of children (1 child; ≥2 children), education (compulsory/vocational training; upper secondary/university education)<sup>14</sup>, employment status (unemployed; employed; retired), and monthly household income (≤6000 Swiss Francs; >6000 Swiss Francs)<sup>15</sup>. Participants were considered to have a migration background if not born in Switzerland or not having a Swiss citizenship since birth.

#### Cancer-related characteristics

The following cancer-related characteristics were extracted from the SCCR: cancer diagnosis, treatment, age at diagnosis (<5 years; 5-10 years; >10 years), time since diagnosis (<20 years; 20-30 years; >30 years), and relapse (yes; no). Cancer diagnoses were classified according to the International Classification of Childhood Cancer – Third Edition  $(ICCC-3)^{16}$ and categorized into leukaemia, lymphoma (including Langerhans cell histiocytosis), CNS tumour, and solid tumour (neuroblastoma, retinoblastoma, renal tumour, hepatic tumour, bone tumour, soft tissue sarcoma, and germ cell tumour). Treatment was categorized into: surgery only, chemotherapy (may have had surgery), radiotherapy (may have had surgery and/or chemotherapy), and stem cell transplantation.

# Statistical analysis

All analyses were performed using Stata version 14.2 (StataCorp LP, College Station, TX). As a persons' relationship status may be associated with socio-cultural background, we weighted comparison parents on age, sex, and migration background according to the distribution in parents of survivors 15,17. Socio-demographic characteristics of comparison parents before weighting are presented in Supplementary table 1. Subsequent analyses were based on weighted comparisons. We used descriptive statistics to compare socio-demographic characteristics, civil status, and partner relationship between parents of survivors and comparison parents. We determined associations between not-beingmarried and cancer-related characteristics using logistic regression models adjusted for parental age. A multilevel modelling approach with random intercepts was used to account for family clustering. To evaluate the quality of the partner relationship, we used means and 95% confidence intervals to describe the dimensions Security and Dependency. We compared means between parents of survivors and comparison parents, mothers and fathers, and separately between mothers and fathers of survivors, where both parents

responded to the questionnaire using adjusted Wald tests. The analysis of mean scores was restricted to parents who reported living in a partner relationship and completed all items of the respective scale. For *Security*, we observed  $\geq 1$  missing item for 56 (5.2%) participants [39 (5.7%) parents of survivors; 17 (4.3%) comparison parents]. For *Dependency*,  $\geq 1$  missing item was identified in 59 (5.5%) participants [39 (5.7%) parents of survivors; 20 (5.1%) comparison parents]. A sensitivity analysis was conducted by imputing missing items using the mean value of the available items if at least half of the items of the dimensions *Security* (i.e.  $\geq 3$  items) and *Dependency* (i.e.  $\geq 4$  items) were available.

# Results

## Characteristics of the study population

In total, parents of 1227 survivors were eligible, and parents of 1167 survivors could be contacted (Supplementary figure 1). Among them, 787 parents of 513 survivors (44.0%) returned the questionnaire. We excluded 3 (0.4%) parents with missing relationship status resulting in a final sample of 784 parents of 512 survivors (462 mothers; 322 fathers; 273 parent-dyads). Cancer-related characteristics were similar between survivors with participating and non-participating parents (Supplementary table 2; all *P*>0.05). Among 1255 population-based comparisons who participated in our survey (response rate: 23.6%), 471 parents (272 mothers; 199 fathers) were included in the analysis (Supplementary figure 2).

The mean age of parents of survivors and weighted comparison parents was 62.3 years (SD=6.9) and 61.7 years (SD=7.7), respectively. Parents of survivors were more likely to have  $\geq$ 2 children (P<0.001) than comparisons (Table 1). Mean time since diagnosis was 24.0 years (SD=6.9) and survivors were on average aged 6.9 years (SD=4.5) at diagnosis.

# Civil status, partner relationship and determinants of marriage

Parents of survivors were less likely to be divorced/separated (Figure 1; 9.0% vs. 17.5%, P<0.001) and more likely to be married (83.4% vs. 75.1%, P=0.002) or in a partner relationship (89.9% vs. 85.0%, P=0.010) than comparison parents. There were no associations between not-being-married and cancer-related characteristics while adjusting for parental age and family clustering (all P>0.05; Supplementary table 3).

## Quality of the partner relationship

Parents of survivors reported similar *Security* of the partner relationship as comparison parents (Table 2; all P>0.05 for *Security*). Parents of survivors indicated a higher *Dependency* within the relationship than comparison parents (P=0.032). Parents of survivors less strongly agreed with the statement *It is important for me to be independent of my partner* (P<0.001) and *I avoid being dependent on my partner* (P=0.004). Yet, we observed no significant differences in reported *Security* and *Dependency* when separately comparing mothers of survivors to comparison mothers and fathers of survivors to comparison fathers

(Table 3; all P>0.05). Both, fathers of survivors and comparison fathers indicated a higher Security (P=0.037; P<0.001) and a higher Dependency (P<0.001; P=0.005) than mothers of survivors and comparison mothers, respectively. In the analysis restricted to parent-dyads of survivors, where both the child's mother and father responded, fathers reported a higher Dependency (P=0.032), but similar Security (P=0.556) as mothers. We observed similar results in sensitivity analyses using imputed missing scale scores.

## **Discussion**

This study highlights that parenting a child with cancer does not adversely affect parents' civil status or partner relationship in the long term. More than 20 years after the child's diagnosis, parental marriage was not related to the child's cancer diagnosis or treatment. However, the cancer experience appeared to have increased the dependency within the partner relationship, particularly among fathers.

The devastating experience of having a child with cancer is an enormous challenge for the parental relationship<sup>2,18,19</sup>. Yet, in line with our findings, a large registry-based study from Norway found no evidence for increased parental divorce rates<sup>20</sup>. The authors further concluded that the divorce risk was not associated with cancer diagnosis, prognosis or time since diagnosis<sup>20</sup>. Similarly, parental marriage was not related to cancer-related characteristics in our study, suggesting that the burden going along with the child's cancer diagnosis may not necessarily be reflected in parents' marital status. A persons' marital status may also be influenced by the respective socio-cultural background<sup>21</sup> and other partnership arrangements such as cohabitation without being married (which is nowadays increasingly established in Switzerland)<sup>22</sup>. However, even after standardizing for sociodemographic characteristics, our study revealed that parents of survivors were more often in a partner relationship than comparison parents. Similarly, a Danish study concluded that childhood cancer did not affect parental separation rates<sup>23</sup>.

Collectively, these findings suggest that many parent-dyads adapt well to the crisis of having a child with cancer. Indeed, a recent review concluded that childhood cancer does not necessarily affect parent's functioning in terms of emotional closeness, support, and marital satisfaction<sup>5</sup>. Yet, difficulties in communication, sexuality, or role changes have been observed shortly after diagnosis<sup>5,24-26</sup>. In our study, parents of survivors reported similar security and higher dependency within the partner relationship as comparison parents many years after the child's diagnosis. One explanation may be that parents of survivors feel more comfortable with this dependency or more often allow it to happen as they manage the child's disease in a collective effort that lasts long into survivorship. Previous studies further indicated that having a child with cancer resulted in increased mutual commitment and strengthened parental bonds 19,20,26-28. However, the impact of the cancer diagnosis on the

parental relationship also largely depends on the couple's pre-cancer functioning<sup>2</sup>.

We further showed that both, fathers of survivors and comparison fathers, reported a higher dependency within the relationship than mothers. This pattern was confirmed among parent-dyads of survivors, where we directly compared the perceptions of the survivors' mother and father. This is in contrast to a review that observed only few gender differences in perceived marital functioning among parents of children with cancer<sup>29</sup>. One explanation may be the rather traditional division of parental tasks in Switzerland. We previously showed that fathers of survivors were more often engaged in work and in charge of guaranteeing the household's financial stability than mothers<sup>15,17</sup>. Mothers typically adopts the role of the child's primary caregiver thereby contributing to fathers' perceived dependency, particularly if the child is suffering from a severe disease. Alternatively, fathers may feel more comfortable reporting dependency due to their role as the families' breadwinner. Such diverging roles or responsibilities<sup>27</sup> may have contributed to different perceptions of the relationship between mothers and fathers of children with cancer.

# Limitations and strengths

A limitation of our study is the response rate of 44% among parents of survivors. This may be largely explained by the long time since diagnosis. However, non-respondents were not significantly different from respondents according to cancer diagnosis, treatment, age at and time since diagnosis. A recent analysis from the SCCSS concluded that non-response bias plays only a minor role in Swiss childhood cancer studies<sup>30</sup>. cross-sectional study design precluded establishing causal inferences; no information on precouple-functioning was available. Additionally, the response rate of the comparison group was relatively low (23%). However, we maximized comparability of the two populations by using similar inclusion criteria and procedures, and by weighting comparison parents according to parents of survivors. Both surveys further used the same questions to evaluate the partner relationship. A major

# References

- Van Schoors M, Caes L, Knoble NB, Goubert L, Verhofstadt LL, Alderfer MA, Guest Editors: Cynthia A. Gerhardt CABDJW, Grayson NH. Systematic Review: Associations Between Family Functioning and Child Adjustment After Pediatric Cancer Diagnosis: A Meta-Analysis. J Pediatr Psychol 2017;42(1):6-18.
- Long KA, Marsland AL. Family adjustment to childhood cancer: a systematic review. Clin Child Fam Psychol Rev 2011;14(1):57-88.
- 3. Lindahl Norberg A, Montgomery SM, Bottai M, Heyman M, Hoven EI. Short-term and long-term effects of childhood cancer on income from employment and employment status: A national cohort study in Sweden. Cancer 2016;123:1238-48.
- Sulkers E, Tissing WJ, Brinksma A, Roodbol PF, Kamps WA, Stewart RE, Sanderman R, Fleer J. Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of

strength was that our study included a large number of fathers (41%) and thus parent-dyads, who are underrepresented in psycho-oncological research<sup>31</sup>. This enabled a detailed evaluation of the quality of the partner relationship from both parents' perspectives.

#### **Clinical implications**

Understanding the impact of childhood cancer on the parental relationship is crucial to develop appropriate family support strategies along the child's cancer trajectory. In Switzerland, parenting a child with cancer did not appear to adversely affect parents' relationship in the long term. An important aspect in this context is the provision of family-centred care in Swiss paediatric oncology settings during and after the acute treatment phase with psycho-oncologists being an important component of the care team. The need for a family system approach in paediatric oncology has been further underscored in a recent meta-analysis revealing a significant association between family functioning and patient or sibling adjustment following childhood cancer<sup>1</sup>. Moreover, an ongoing assessment of parental mental health (e.g. by a psychooncologist) has recently been suggested as a standard of care in pediatric oncology<sup>32</sup>. Parents of children with cancer facing problems in the partner relationship should be identified early in the cancer trajectory and offered anticipatory guidance in order to optimize parent, child, and family outcomes in the long term<sup>33-</sup>

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# **Conflict of interest statement**

No conflict of interest stated for any of the authors.

- caregiving stress during the first year after diagnosis. Psychooncology 2015;24:318-24.
- Van Schoors M, Caes L, Alderfer MA, Goubert L, Verhofstadt L. Couple functioning after pediatric cancer diagnosis: a systematic review. Psychooncology 2017;26(5):608-16.
- Doshi K, Kazak AE, Hocking MC, DeRosa BW, Schwartz LA, Hobbie WL, Ginsberg JP, Deatrick J. Why mothers accompany adolescent and young adult childhood cancer survivors to follow-up clinic visits. J Pediatr Oncol Nurs 2014;31(1):51-7.
- Vetsch J, Rueegg CS, Mader L, Bergstraesser E, Rischewski J, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Follow-up care of young childhood cancer survivors: attendance and parental involvement. Support Care Cancer 2016;24(7):3127-38.
- Greenzang KA, Cronin AM, Mack JW. Parental preparedness for late effects and long-term quality of life in survivors of childhood cancer. Cancer 2016;12:2587-94.

- Kuehni CE, Rueegg CS, Michel G, Rebholz CE, Strippoli MP, Niggli FK, Egger M, von der Weid NX, Swiss Paediatric Oncology G. Cohort profile: the Swiss childhood cancer survivor study. Int J Epidemiol 2012;41(6):1553-64.
- Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni CE. The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001-2005. Swiss Med Wkly 2007;137(35-36):502-9.
- Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MP, Kuehni CE, Swiss Paediatric Oncology G. Incidence of childhood cancer in Switzerland: the Swiss Childhood Cancer Registry. Pediatr Blood Cancer 2008;50(1):46-51.
- 12. Asendorpf JB, Banse R, Wilpers S, Neyer FJ. Beziehungsspezifische Bindungsskalen für Erwachsene und ihre Validierung durch Netzwerk-und Tagebuchverfahren [Relationship-specific attachment scales tor adults and their validation with network and diary procedures]. Diagnostica 1997;43(4):289-313.
- Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. Quality criteria were proposed for measurement properties of health status questionnaires. Journal of clinical epidemiology 2007;60(1):34-42.
- 14. Kuehni CE, Strippoli MP, Rueegg CS, Rebholz CE, Bergstraesser E, Grotzer M, von der Weid NX, Michel G, Swiss Pediatric Oncology G. Educational achievement in Swiss childhood cancer survivors compared with the general population. Cancer 2012;118(5):1439-49.
- Mader L, Roser K, Baenziger J, Tinner EM, Scheinemann K, Kuehni CE, Michel G. Household income and risk-of-poverty of parents of long-term childhood cancer survivors. Pediatr Blood Cancer 2017;64(8):1-12.
- Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005;103(7):1457-67.
- Mader L, Rueegg CS, Vetsch J, Rischewski J, Ansari M, Kuehni CE, Michel G. Employment Situation of Parents of Long-Term Childhood Cancer Survivors. PloS one 2016;11(3):e0151966.
- Vrijmoet-Wiersma CM, van Klink JM, Kolk AM, Koopman HM, Ball LM, Egeler RM. Assessment of Parental Psychological Stress in Pediatric Cancer: A Review. J Pediatr Psychol 2008;33(7):694-706.
- Ljungman L, Cernvall M, Gronqvist H, Ljotsson B, Ljungman G, von Essen L. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. PloS one 2014;9(7):e103340.
- Syse A, Loge JH, Lyngstad TH. Does Childhood Cancer Affect Parental Divorce Rates? A Population-Based Study. J Clin Oncol 2010;28(5):872-7.
- Mader L, Vetsch J, Christen S, Baenziger J, Roser K, Dehler S, Michel G. Education, employment and marriage in long-term survivors of teenage and young adult cancer compared with healthy controls. Swiss Med Wkly 2017;147:w14419.
- Bundesamt für Statistik. Newsletter Demos 1/2017 -Paarbeziehungen [Newsletter Demos 1/2017 - Partner

- relationships]. Neuchâtel: Bundesamt für Statistik, 2017.
- Grant S, Carlsen K, Bidstrup PE, Bastian GS, Lund LW, Dalton SO, Johansen C. Parental separation and pediatric cancer: a Danish cohort study. Pediatrics 2012;129(5):e1187-91.
- da Silva FM, Jacob E, Nascimento LC. Impact of childhood cancer on parents' relationships: an integrative review. J Nurs Scholarsh 2010;42(3):250-61
- Lavee Y, Mey-Dan M. Patterns of change in marital relationships among parents of children with cancer. Health Soc Work 2003;28(4):255-63.
- Silva-Rodrigues FM, Pan R, Pacciulio Sposito AM, de Andrade Alvarenga W, Nascimento LC. Childhood cancer: Impact on parents' marital dynamics. Eur J Oncol Nurs 2016;23:34-42.
- Moules NJ, Estefan A, McCaffrey G, Tapp DM, Strother D. Taking One for the Team: Examining the Effects of Childhood Cancer on the Parental Subsystem-Part 2. Journal of family nursing 2016;22(4):540-58.
- Wijnberg-Williams BJ, Van de Wiel HB, Kamps W, Hoekstra-Weebers JE. Effects of communication styles on marital satisfaction and distress of parents of pediatric cancer patients: a prospective longitudinal study. Psychooncology 2015;24(1):106-12.
- Clarke NE, McCarthy MC, Downie P, Ashley DM, Anderson VA. Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature. Psychooncology 2009;18(9):907-15.
- Rueegg CS, Gianinazzi ME, Michel G, Zwahlen M, von der Weid NX, Kuehni CE. No evidence of response bias in a population-based childhood cancer survivor questionnaire survey - Results from the Swiss Childhood Cancer Survivor Study. PloS one 2017;12(5):e0176442.
- 31. Jones BL, Pelletier W, Decker C, Barczyk A, Dungan SS. Fathers of children with cancer: a descriptive synthesis of the literature. Soc Work Health Care 2010;49(5):458-93.
- Kearney JA, Salley CG, Muriel AC. Standards of Psychosocial Care for Parents of Children With Cancer. Pediatr Blood Cancer 2015;62 (Suppl 5):S632-83.
- Alderfer MA, Long KA, Lown EA, Marsland AL, Ostrowski NL, Hock JM, Ewing LJ. Psychosocial adjustment of siblings of children with cancer: a systematic review. Psychooncology 2010;19(8):789-805.
- James K, Keegan-Wells D, Hinds PS, Kelly KP, Bond D, Hall B, Mahan R, Moore IM, Roll L, Speckhart B. The care of my child with cancer: parents' perceptions of caregiving demands. J Pediatr Oncol Nurs 2002;19(6):218-28.
- 35. Klassen A, Raina P, Reineking S, Dix D, Pritchard S, O'Donnell M. Developing a literature base to understand the caregiving experience of parents of children with cancer: a systematic review of factors related to parental health and well-being. Support Care Cancer 2007;15(7):807-18.

Table 1 Socio-demographic characteristics of parents of childhood cancer survivors, weighted comparison parents,

and cancer-related characteristics of survivors of participating parents

	Parents of survivors (n=784)	Comparison parents <sup>†</sup> (n=471)	
Characteristics of parents	$\frac{(1-784)}{n(\%^{\ddagger})}$	0/ <sub>0</sub>	P-value <sup>§</sup>
Sex	n(70 )	70	n.a. <sup>†</sup>
Male	322(41.1)	41.5	11.4.
Female	462(58.9)	58.5	
Age at study	402(36.9)	36.3	n.a. <sup>†</sup>
<65 years	501(64.2)	63.9	п.а.
	` '	36.1	
≥65 years	279(35.8)	30.1	†
Migration background	(40/97.1)	07.1	n.a.†
No	649(87.1)	87.1	
Yes	96(12.9)	12.9	
Language			0.164
German	588(75.0)	71.4	
French/Italian	196(25.0)	28.6	
Number of children			< 0.001
1 child	25(3.4)	15.8	
≥2 children	714(96.6)	84.2	
Education			0.873
Compulsory schooling/vocational training	476(65.5)	65.0	
Upper secondary/university education	251(34.5)	35.0	
Employment status	_==(==)		0.211
Unemployed	66(8.7)	10.1	0.211
Employed	429(56.3)	51.1	
Retired	267(35.0)	38.8	
	207(33.0)	30.0	0.282
Household income	222(24.1)	27.2	0.282
≤6000 CHF	233(34.1)	37.3	
>6000 CHF	451(65.9)	62.7	
Characteristics of childhood cancer survivors (n=512)	$n(\%^{\ddagger})$		
Age at diagnosis			
<5 years	195(38.1)		
5-10 years	178(34.8)		
>10 years	139(27.1)		
	139(27.1)		
Diagnosis	175(24.2)		
Leukaemia	175(34.2)		
Lymphoma <sup>1</sup>	114(22.3)		
CNS tumour	70(13.7)		
Neuroblastoma	18(3.5)		
Retinoblastoma	14(2.7)		
Renal tumour	34(6.6)		
Hepatic tumour	6(1.2)		
Bone tumour	32(6.3)		
Soft tissue sarcoma	32(6.3)		
Germ cell tumour	17(3.3)		
Langerhans cell histiocytosis	24(4.7)		
Treatment	<del>-</del> ·(···)		
Surgery	64(12.5)		
Chemotherapy	275(53.8)		
	145(28.4)		
Radiotherapy Stom cell transplantation	• • •		
Stem cell transplantation	27(5.3)		
Time since diagnosis	1.40(0==)		
<20 years	142(27.7)		
20-30 years	271(52.9)		
>30 years	99(19.3)		
Relapse			
No	450(87.9)		
Yes	62(12.1)		

CHF, Swiss Francs; CNS, central nervous system; n.a., not applicable. P-values less than 0.05 are indicated in bold. †Weighted according to age, sex, and migration background. ‡Percentages are based upon available data for each variable.

 $^{\S}P\text{-value}$  from chi-square statistics comparing parents of survivors and comparison parents.  $^{\S}Includes$  Langerhans cell histiocytosis (n=24).

**Table 2** Quality of the partner relationship of parents of survivors and weighted comparison parents using the *relationship-specific attachment scale for adults* by Asendorpf et al. (1997)<sup>12</sup>

		Parents of survivors		(	Compariso		
	n	Mean score <sup>†</sup>	95%-CI	n	Mean score <sup>†</sup>	95%-CI	P-value
Security (secure-fearful; 6 items) <sup>‡</sup>	649	4.33	4.29-4.38	378	4.30	4.23-4.37	0.444
Secure (3 items)							
I feel understood by my partner	678	4.23	4.17-4.30	394	4.15	4.06-4.24	0.144
I can rely on my partner	677	4.66	4.60-4.71	393	4.59	4.51-4.68	0.196
I find it easy to be emotionally close to my partner	674	3.86	3.77-3.94	390	3.84	3.73-3.96	0.821
Fearful (3 items§)							
I have difficulties to completely rely on my partner	670	4.39	4.32-4.47	392	4.37	4.26-4.47	0.687
I feel uncomfortable when I am close to my partner	671	4.52	4.44-4.60	392	4.55	4.45-4.65	0.667
I am worried not to be accepted by my partner	655	4.36	4.28-4.45	387	4.32	4.20-4.43	0.516
Dependency (dependent-independent; 8 items) <sup>‡</sup>	649	3.01	2.96-3.06	375	2.91	2.84-2.98	0.032
Dependent (4 items)							
To enjoy something completely, my partner must always be at my side	673	2.74	2.65-2.84	395	2.85	2.74-2.97	0.151
If I have problems, my partner has to be there for me	671	3.38	3.30-3.46	393	3.29	3.19-3.40	0.178
I can solve problems only with my partner	670	2.91	2.82-3.00	394	2.78	2.66-2.89	0.079
I can never be close enough to my partner	661	2.73	2.64-2.83	383	2.70	2.58-2.82	0.670
Independent (4 items <sup>§</sup> )							
If I have problems, I can easily solve them without my partner	672	2.63	2.56-2.71	393	2.61	2.51-2.71	0.706
I make important decisions without my partner	673	3.73	3.65-3.81	395	3.66	3.55-3.78	0.359
It is important for me to be independent of my partner	671	3.05	2.96-3.15	391	2.76	2.64-2.88	0.000
I avoid being dependent on my partner	669	2.94	2.85-3.03	390	2.72	2.60-2.84	0.004

CI, confidence interval. P-values less than 0.05 are indicated in bold.

<sup>&</sup>lt;sup>†</sup>Analysis based on complete cases. Participants indicated their level of agreement with each item using Likert-scales (1=not at all to 5=completely). Higher mean scores indicate higher Dependency, respectively.

<sup>&</sup>lt;sup>‡</sup>The original German version was translated into English by the author team.

<sup>§</sup>Items were reverse coded for the analysis.

Table 3 Quality of the partner relationship stratified by sex of parents of survivors and weighted comparison parents.

	•	Security (secure-fearful; 6 items)			D	Dependency (dependent-independent; 8 items)				
	n	Mean <sup>†</sup>	95%-CI	P-va	alue	n	Mean <sup>†</sup>	95%-CI	P-va	ılue <sup>†</sup>
Mothers of survivors	360	4.29	4.22-4.36	0.025†	0.142§	361	2.91	2.85-2.98	<0.001 <sup>†</sup>	0.099§
Fathers of survivors	291	4.39	4.33-4.46	0.037‡	$0.403^{\S}$	290	3.12	3.04-3.19	<0.001 <sup>‡</sup>	$0.154^{\S}$
Comparison mothers	208	4.19	4.09-4.30	∠0.001†	-	205	2.82	2.73-2.91	0.005‡	-
Comparison fathers	170	4.44	4.35-4.52	<0.001‡	-	170	3.02	2.92-3.13	0.005*	-

CI, confidence interval. P-values less than 0.05 are indicated in bold.

<sup>&</sup>lt;sup>†</sup>Analysis based on complete cases. Participants indicated their level of agreement with each item using Likert-scales (1=not at all to 5=completely). Higher mean scores indicate higher Security and higher Dependency, respectively.

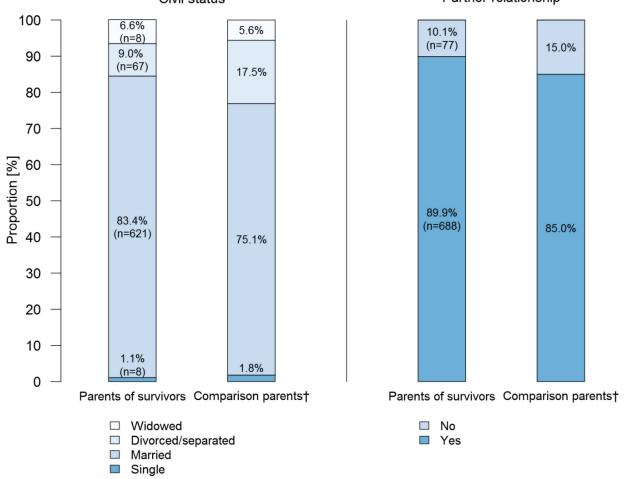
<sup>‡</sup>P-value from adjusted Wald tests comparing mothers of survivors with fathers of survivors and comparison mothers with comparison fathers.

<sup>§</sup>P-value from adjusted Wald tests comparing mothers of survivors with comparison mothers and fathers of survivors with comparison fathers.

# **Figures**

Figure 1 Civil status and partner relationship of parents of survivors and comparison parents

Civil status Partner relationship



<sup>&</sup>lt;sup>†</sup>Weighted proportions according to age, sex, and migration background distribution in parents of survivors

# **Supporting information**

Supplementary table 1 Socio-demographic characteristics of parents of survivors and comparison

parents who returned the questionnaire

•	Parents of survivors (n=784)	Comparison parents (n=471)	
Characteristics of parents	n (%†)	n (%†)	P-value <sup>‡</sup>
Sex			0.681
Male	322 (41.1)	199 (42.3)	
Female	462 (58.9)	272 (57.7)	
Age at study			0.213
<65 years	501 (64.2)	286 (60.7)	
≥65 years	279 (35.8)	185 (39.3)	
Migration background			0.048
No	649 (87.1)	391 (83.0)	
Yes	96 (12.9)	80 (17.0)	
Language			0.095
German	588 (75.0)	333 (70.7)	
French/Italian	196 (25.0)	138 (29.3)	
Number of children			< 0.001
1 child	25 (3.4)	75 (15.9)	
≥2 children	714 (96.6)	396 (84.1)	
Education			0.709
Compulsory schooling/vocational training	476 (65.5)	284 (64.4)	
Upper secondary/university education	251 (34.5)	157 (35.6)	
Employment status			0.060
Unemployed	66 (8.7)	45 (9.7)	
Employed	429 (56.3)	229 (49.4)	
Retired	267 (35.0)	190 (40.9)	
Household income			0.166
≤6000 CHF	233 (34.1)	157 (38.2)	
>6000 CHF	451 (65.9)	254 (61.8)	

CHF, Swiss Francs. P-values less than 0.05 are indicated in bold.

 $<sup>^\</sup>dagger Percentages$  are based upon available data for each variable.

<sup>&</sup>lt;sup>‡</sup>P-value from chi-square statistics comparing parents of survivors to comparison parents.

Supplementary table 2 Cancer-related characteristics of survivors of participating and non-

participating parents

	Survivors of participating parents (n=512)	Survivors of non-participating parents (n=715)	
	$n(\%^{\dagger})$	$n(\%^{\dagger})$	<i>P</i> -value <sup>‡</sup>
Age at diagnosis			0.844
<5 years	195 (38.1)	263 (36.8)	
5-10 years	178 (34.8)	248 (34.7)	
>10 years	139 (27.1)	204 (28.5)	
Diagnosis			0.589
Leukaemia	175 (34.2)	240 (33.6)	
Lymphoma <sup>§</sup>	114(22.3)	161 (22.5)	
CNS tumour	70 (13.7)	107 (15.0)	
Neuroblastoma	18 (3.5)	37 (5.2)	
Retinoblastoma	14 (2.7)	13 (1.8)	
Renal tumour	34 (6.6)	49 (6.9)	
Hepatic tumour	6 (1.2)	4 (0.6)	
Bone tumour	32 (6.3)	30 (4.2)	
Soft tissue sarcoma	32 (6.3)	47 (6.6)	
Germ cell tumour	17 (3.3)	27 (3.8)	
Treatment			0.155
Surgery	64 (12.5)	90 (12.7)	
Chemotherapy	275 (53.8)	346 (48.7)	
Radiotherapy	145 (28.4)	243 (34.2)	
Stem cell transplantation	27 (5.3)	31 (4.4)	
Time since diagnosis			0.828
<20 years	142 (27.7)	188 (26.3)	
20-30 years	271 (52.9)	382 (53.4)	
>30 years	99 (19.3)	145 (20.3)	
Relapse			0.305
No	450 (87.9)	614 (85.9)	
Yes	62 (12.1)	101 (14.1)	

CNS, central nervous system. P-values less than 0.05 are indicated in bold.

<sup>†</sup>Percentages are based upon available data for each variable.

<sup>&</sup>lt;sup>‡</sup>P-value from chi-square statistics comparing survivors of participating parents and survivors of non-participating parents.

<sup>§</sup>Includes Langerhans cell histiocytosis.

**Supplementary table 3** Cancer-related determinants of not being married in parents of survivors from logistic regression models adjusted for parental age and family clustering<sup>†</sup>

	Parents of survivors			
	OR‡	95%-CI	P-value	
Age at diagnosis			0.346	
<5 years	1.00			
5-10 years	0.63	0.19-2.04		
≥10 years	0.80	0.22-2.82		
Diagnosis			0.338	
Leukemia	1.00			
Lymphoma§	0.60	0.15-2.42		
CNS tumor	2.05	0.43-9-83		
Solid tumor	1.12	0.33-3.87		
Treatment			0.423	
Surgery	1.00			
Chemotherapy	0.78	0.16-3.85		
Radiotherapy	1.38	0.25-7.59		
Stem cell transplantation	0.52	0.03-7.83		
Time since diagnosis			0.065	
<20 years	1.00			
20-30 years	1.67	0.46-6.13		
≥30 years	6.28	1.11-35.45		
Relapse			0.228	
No	1.00			
Yes	0.70	0.15-3.31		

CI, confidence interval; CNS, central nervous system; OR, odds ratio.

<sup>†</sup>Multilevel modeling with random intercepts.

<sup>‡</sup>Odds ratio for not being married.

<sup>§</sup>Includes Langerhans cell histiocytosis.

