

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

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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 survivors aged ≤ 16 years at diagnosis and ≥ 20 years at study. Population-based comparisons were derived from a random sample of the general population (≥ 1 child aged ≥ 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 (response rate: 44.0%) and 471 comparison parents 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: Long after the diagnosis of cancer in their child, parents' relationship appears similar as in parents of the general population. The increased dependency

reported by parents of survivors suggest that they managed 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 members¹⁻³. 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 for⁴.

A recent 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 mixed⁵.

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^{6,7}. 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 cancer⁸. 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 unknown⁵. In this population-based questionnaire survey, we aimed to i) compare the civil 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 (two dimensions: *Security* and *Dependency*).

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)^{10,11}. 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^{10,11}. 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 and covered quality of life, psychological well-being, psycho-social functioning, support needs, and socio-demographic information. 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). Informed consent was provided by all study participants.

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 self-reported 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 settings¹². 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)¹⁴, employment status (unemployed; employed; retired), and monthly household income (≤6000 Swiss Francs; >6000 Swiss Francs)¹⁵. 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 hierarchically 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-being-married 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 ≥ 1 missing item for 56 (5.2%) participants [39 (5.7%) parents of survivors; 17 (4.3%) comparison parents]. For *Dependency*, ≥ 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. ≥ 3 items) and *Dependency* (i.e. ≥ 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 ≥ 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, parents of survivors reported a higher perceived dependency within the partner relationship than comparison parents.

The devastating experience of having a child with cancer is an enormous challenge for the parental relationship^{2,18,19}. Yet, in line with our findings, a large

registry-based study from Norway found no evidence for increased parental divorce rates²⁰. The authors further concluded that the divorce risk was not associated with cancer diagnosis, prognosis or time since diagnosis²⁰. 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 person's marital status may also be influenced by the respective socio-cultural background²¹ and other partnership arrangements such as cohabitation without being married (which is nowadays increasingly established in Switzerland)²². However, even after standardizing for socio-demographic 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 rates²³.

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 satisfaction⁵. Yet, difficulties in communication, sexuality, or role changes have been observed shortly after diagnosis^{5,24-26}. 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. Additionally, parents of survivors reported having more children than comparison parents. This might contribute to an increased perceived dependency within the partner relationship. Previous studies 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 functioning², an aspect we could not account for in our study.

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 cancer²⁹. 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^{15,17}. Mothers typically adopt 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 responsibilities²⁷ may have contributed to different perceptions of the relationship between mothers and fathers of children with cancer.

Study Limitations

A limitation of our study is the response rate of 44% among parents of survivors, which is lower than the median participation rate of 65% reported in a recent systematic review on studies including childhood cancer survivors³⁰. Our study directly approached the parents who may perceive a lower commitment or motivation to participate in research. Other potential reasons for non-participation may include the time burden to complete the relative comprehensive questionnaire, avoidance of

unpleasant memories, lack of perceived relevance due to the long time since diagnosis, or the general decline in participation rates over the last decades³⁰. However, our non-responder analysis revealed no significant differences according to cancer-related characteristics such as diagnosis or treatment. A recent analysis from the SCCSS further concluded that non-response bias plays only a minor role in regard to the prevalence of outcomes such as somatic health, mental health, or health behaviours in Swiss childhood cancer studies³¹. The cross-sectional study design precluded establishing causal inferences and no information on pre-cancer couple-functioning or relationship duration 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 strength was that our study included a large number of fathers (41%) and thus parent-dyads, who are underrepresented in psycho-oncological research³². 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. More than 20 years after the child's cancer diagnosis, the partner relationship of Swiss parents of survivors was not adversely affected. The observed increased dependency within the relationship suggests that in Switzerland, the child's disease is managed in a collective effort by the parents. Two aspects may contribute to these encouraging findings: First, Swiss paediatric oncology settings

provide comprehensive family-centred care during as well as after the acute treatment phase in the context of long-term follow-up care; second, specifically trained psycho-oncologists have been part of the care team for many years in order to address potential psycho-social consequences of the child's disease. Based on our findings, the development or implementation of additional interventions focusing on the parental relationship (e.g. marital counselling) may be in imbalance in regard to costs and benefits in Switzerland. However, parents of children with cancer facing problems in the partner relationship should be identified early in the cancer trajectory and offered additional guidance in order to optimize parent, child, and family outcomes in the long term³³⁻³⁶.

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Conflict of interest statement

No conflict of interest stated for any of the authors.

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Tables

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 [†] (n=471)	
Characteristics of parents	n(% [‡])	%	<i>P</i> -value [§]
Sex			n.a. [†]
Male	322(41.1)	41.5	
Female	462(58.9)	58.5	
Age at study			n.a. [†]
<65 years	501(64.2)	63.9	
≥65 years	279(35.8)	36.1	
Migration background			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	
Employed	429(56.3)	51.1	
Retired	267(35.0)	38.8	
Household income			0.282
≤6000 CHF	233(34.1)	37.3	
>6000 CHF	451(65.9)	62.7	
Characteristics of childhood cancer survivors (n=512)	n(% [‡])		
Age at diagnosis			
<5 years	195(38.1)		
5-10 years	178(34.8)		
>10 years	139(27.1)		
Diagnosis			
Leukaemia	175(34.2)		
Lymphoma [¶]	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)
<i>Treatment</i>	
Surgery	64(12.5)
Chemotherapy	275(53.8)
Radiotherapy	145(28.4)
Stem cell transplantation	27(5.3)
<i>Time since diagnosis</i>	
<20 years	142(27.7)
20-30 years	271(52.9)
>30 years	99(19.3)
<i>Relapse</i>	
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.

[§]P-value from chi-square statistics comparing parents of survivors and comparison parents.

[¶]Includes Langerhans cell histiocytosis (n=24).

Accepted

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)¹²

	Parents of survivors			Comparison parents			P-value
	n	Mean score [†]	95%-CI	n	Mean score [†]	95%-CI	
Security (secure-fearful; 6 items)[‡]	649	4.33	4.29-4.38	378	4.30	4.23-4.37	0.444
<i>Secure (3 items)</i>							
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
<i>Fearful (3 items[§])</i>							
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)[‡]	649	3.01	2.96-3.06	375	2.91	2.84-2.98	0.032
<i>Dependent (4 items)</i>							
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
<i>Independent (4 items[§])</i>							
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.

[†]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.

[‡]The original German version was translated into English by the author team.

[§]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)				Dependency (dependent-independent; 8 items)			
	n	Mean [†]	95%-CI	P-value	n	Mean [†]	95%-CI	P-value [†]
Mothers of survivors	360	4.29	4.22-4.36	0.037[‡]	361	2.91	2.85-2.98	<0.001[‡]
Fathers of survivors	291	4.39	4.33-4.46		0.142 [§]	290	3.12	
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		-	170	3.02	

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

[†]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.

[‡]P-value from adjusted Wald tests comparing mothers of survivors with fathers of survivors and comparison mothers with comparison fathers.

[§]P-value from adjusted Wald tests comparing mothers of survivors with comparison mothers and fathers of survivors with comparison fathers.

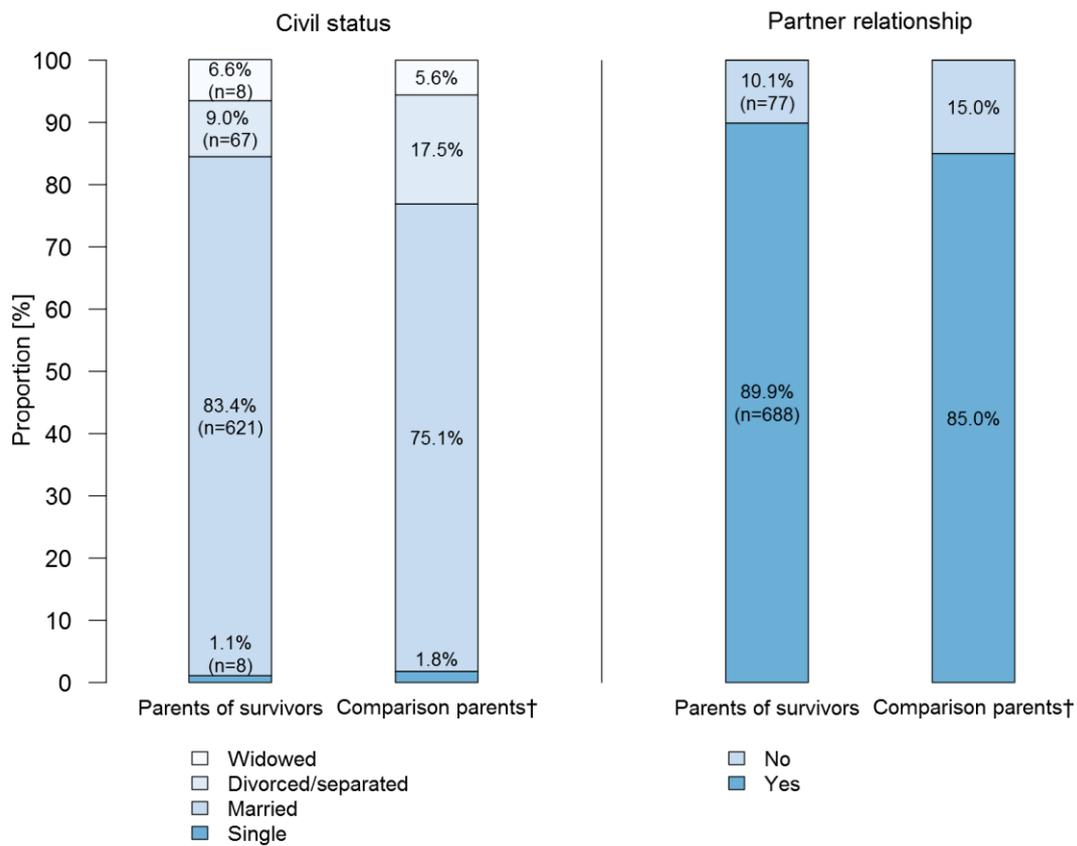


Figure 1 Civil status and partner relationship of parents of survivors and comparison parents

†Weighted proportions according to age, sex, and migration background distribution in parents of survivors