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ORIGINAL ARTICLE

Mental health-care utilization in survivors of childhood cancer and siblings: the Swiss childhood cancer survivor study

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Abstract
Purpose We aimed to (1) describe the utilization of mental health-care in survivors and siblings, the association with severity of distress, and visits to other professionals in distressed survivors not utilizing mental health-care; and (2) identify factors associated with utilization of mental health-care in distressed survivors.
Methods Within the Swiss Childhood Cancer Survivor Study, we sent postal questionnaires to all participants aged <16 years at diagnosis (1976–2003), who survived ≥5 years after diagnosis and were aged ≥16 years at study. Survivors and siblings could indicate if they utilized mental health-care in the past year. Psychological distress was assessed with the Brief Symptom Inventory-18 (BSI-18). Participants with scores $T \geq 57$ on two of three scales or the Global Severity Index were considered distressed.
Results We included 1,602 survivors and 703 siblings. Overall, 160 (10 %) and 53 (8 %), utilized mental health-care and 203 (14 %) and 127 (14 %) were considered distressed. Among these, 69 (34 %) survivors and 20 (24 %) siblings had utilized mental health-care. Participants with higher distress were more likely to utilize mental health-care. Distressed survivors not utilizing mental health-care were more likely to see a medical specialist than nondistressed. In the multivariable regression, factors associated with utilizing mental health-care were higher psychological distress and reporting late effects.
Conclusions Our results underline the importance of developing interventional programs and implementing psychological screening in follow-up of survivors. It is also important to systematically address siblings' needs. In follow-up, patients at risk should be informed about existing possibilities or advised to visit mental health professionals.

Keywords Cancer · Oncology · Mental health care · Childhood cancer survivors

Introduction

Research on psychological late effects after childhood cancer has shown that a substantial number of survivors suffers from a variety of psychological problems [1–3]. Similar to the general population [4], the most frequent problems among survivors include depression, anxiety, somatization, and posttraumatic stress [1, 5–8]. Psychological problems can have debilitating consequences in daily life, both on the individual and social level, and can considerably decrease health-related quality of life [9]. According to the World Health Organization, depression is one of the leading causes of disability in the world [10].

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Psychotherapy, in all its forms, is one of the recognized treatments utilized to reduce symptoms in the acute phase of a psychological disorder [11] to prevent recurrence and, for childhood cancer survivors in particular, to deal with their cancer history. Moreover, cancer survivors in general have to deal with their increased risk of developing physical late effects such as hormone deficiencies, second malignancies, and others [12]. For these reasons, survivors who experience psychological difficulties or are at risk for developing them should be followed by mental health specialists or should be advised to participate in an internet-based program [1, 2]. Regular psychological follow-up is also recommended in the Children's Oncology Group Long-Term Follow-up guidelines and in recent literature [13–15].

Despite this, research on childhood cancer survivors' utilization of mental health care is scarce. Up until now, studies have focused on health-care services without paying particular attention to mental health-care. Moreover, no study has so far investigated health-care utilization of survivors with psychological distress: it remains unclear whether they utilize mental health care as a resource, or whether they visit their pediatric oncologist or other medical professionals. Finally, research on this topic is lacking for siblings, who also are at risk for developing psychological distress as a consequence of the trauma of childhood cancer experienced in the family [16].

According to Andersen and Newman's “model of health services utilization” [17], three types of factors influence mental health-care utilization: (1) *predisposing* (individual characteristics that exist prior to the illness such as gender and migration background), (2) *enabling* (features that influence the health-care delivery and attitudes, e.g., availability of care, attitudes toward seeking care, income, and education), and (3) *needs-related factors* (physical and mental health assessment and include features such as severity of symptoms and perceived need for support). Based on this framework, we investigated factors associated with mental health-care utilization in childhood cancer survivors.

We therefore aimed to (1) describe the mental health-care utilization in survivors and siblings, in particular, (a) mental health-care utilization in survivors and siblings overall and in distressed participants and (b) utilization of other health-care services in distressed and nondistressed survivors not utilizing mental health care; and (2) identify factors associated with the utilization of mental health care among distressed survivors. We hypothesized that both nondistressed and distressed survivors reported to utilize mental health-care services more often than both nondistressed and distressed siblings; furthermore, distressed survivors who did not report to utilize mental health-care attended more visits to other medical professionals than nondistressed survivors. Based on previous research [18] and the model of health services utilization [17, 18], we also hypothesized that a combination of individual sociodemographic and clinical factors (e.g., gender, education, diagnosis and treatment, and presence of late effects) would be associated with survivors' mental health-care utilization.

Methods

Sample and procedure

Since 1976, the population-based Swiss Childhood Cancer Registry (SCCR) collects data on all cancer patients younger than 21 years, who were diagnosed with leukemia, lymphoma, central nervous system (CNS) tumors, other malignant solid tumors, or Langerhans cell histiocytosis [19, 20]. The Swiss Childhood Cancer Survivor Study (SCCSS) is a national long-term follow-up study including all patients registered in the SCCR who survived for ≥5 years and were diagnosed <16 years of age between 1976 and 2003. Details of the study are presented elsewhere [21]. For the present study, we included all persons aged ≥16 years at the time of study.

Between 2007 and 2010, eligible participants received an information letter on the study from their former treating pediatric oncology clinic. Two weeks later, they received a questionnaire with a prepaid return envelope. Nonresponders were sent a reminder letter with a questionnaire 4–6 weeks later. If they still did not reply, they were contacted by phone after another 4–6 weeks.

Siblings of survivors, also aged 16 or older, were recruited as a comparison group. Every survivor was asked to list his/her siblings in the questionnaire. In 2010–2011, we asked survivors for consent to contact their siblings and then sent a questionnaire to siblings who consented. Siblings received the same questionnaire as survivors without the cancer-related questions. We sent only one reminder letter to siblings.

Ethics approval was provided through the general cancer registry permission of the SCCR (The Swiss Federal Commission of Experts for Professional Secrecy in Medical Research) and a non-obstat statement was obtained from the ethics committee of the canton of Bern.

Measures

The SCCSS used an extensive questionnaire similar to those of the US and UK childhood cancer survivors studies [22, 23]. The questionnaire covered various domains including utilization of health services, psychological distress, quality of life, fertility, somatic health, health behaviors, current medication, as well as sociodemographic questions.

Variables assessed by questionnaire

To assess information on “mental health-care,” we asked survivors and siblings to indicate if they visited a psychologist or a psychiatrist in the past year. We also asked whether they visited other health-care professionals in the past year and we coded them: "visits to generalist" if it was a pediatrician or a general practitioner, "visits to oncologist" if it was a pediatric or an adult oncologist, and "visits to specialists" in the case of visits to a cardiologist, neurologist, gastroenterologist, or endocrinologist.

Psychological distress was assessed using the Brief Symptom Inventory-18 (BSI-18) [24]. The inventory yields three scales (somatization, depression, and anxiety) and a Global Severity Index (GSI). Patients were asked to report their degree of distress in the past 7 days using a four-point scale ranging from "not at all" to "a lot." To categorize individuals with psychological distress, sum raw scores were standardized into T scores according to the manual's norm population and survivors with a score $T \geq 57$ were considered as distressed as utilized before by the studies of Zabora and Liptak [25–27]. Sensitivity analyses showed that the utilization of this cutoff better represented the expected proportions of distress in this population [27]. Survivors and siblings who had scores $T \geq 57$ on two scales or the GSI were considered "with psychological distress" (case rule) [24]. Higher scores on the BSI-18 represent higher levels of distress.

Participants were classified as having a migrant background if they were not Swiss citizens since birth, not born in Switzerland, or had at least one parent who was not a Swiss citizen. Language region was coded into German, French, and Italian. For survivors, we also assessed self-reported late effects by asking survivors whether they experienced any late effect of their illness.

Information extracted from the SCCR

We extracted information on baseline demographics and prospectively collected medical information on diagnosis and treatment of survivors from the SCCR including current age, sex, cancer diagnosis, age at diagnosis, treatment, and time since diagnosis. Diagnosis was classified according to the International Classification of Childhood Cancer (third edition) [28]. In the analysis, we grouped diagnoses into leukemia/lymphoma, CNS tumors, and other solid tumors. Treatment was classified as having had surgery (yes/no), having received chemotherapy (yes/no), having had radiotherapy (no radiotherapy, body and limb irradiation, cranio-spinal irradiation), and having had autologous or allogeneic bone marrow transplantation (BMT; yes/no). We also assessed the occurrence of one or more relapses, and we coded place of residence into urban and rural [29].

Statistical analyses

We performed all analyses using Stata 12.0 (StataCorp, College Station, TX). To compensate for the differences between the two samples of siblings and survivors, we utilized a weighting factor based on age, sex, language region, and migrant background. Hence, we could match the siblings to the distribution of survivors. We also controlled for family clustering using a logistic regression. We found no differences and we presented data not including clustering [30].

First, we utilized Wald statistics to compare the proportions of survivors and siblings who reported having visited a psychologist/psychiatrist, first by considering the whole sample and second by running the analysis separately in distressed survivors and siblings only. Third, we utilized chi-square statistics to compare proportions of distressed and nondistressed survivors who visited other health-care professionals than psychologists. We then looked whether visiting one of these health-care professionals was associated with one of the BSI-18 scales (somatization, depression, or anxiety) using logistic regressions.

We computed univariable logistic regressions to evaluate crude associations between risk factors and the utilization of mental health-care. In the multivariable logistic regression, we included all variables that were significant ($p \leq 0.05$) in the univariable regressions. The outcome was "utilization of mental health-care." All variables that were significantly associated ($p \leq 0.05$) with the outcome in the univariable logistic regression were included in the multivariable analysis. Additionally, because of established explanatory power or relevance, sex, diagnosis, and treatment were included in all models regardless of their statistical significance. Likelihood ratio tests were used to calculate global p values.

Results

Characteristics of the study population

Of 2,621 survivors who were eligible for the SCCSS, we could trace and send a questionnaire to 2,328 survivors of whom 1,729 participants replied (response rate: 74 %) (Fig. 1). Of those, 127 (7 %) completed an abridged questionnaire not containing information on the outcome and were not included in the analysis. In the final analysis, we could include 1,602 survivors. Compared to nonparticipants (Table 1), participants were more often female (47 vs. 39 %), from rural regions (30 vs. 20 %), were more often diagnosed with leukemia (36 vs. 28 %), and were more often treated with chemotherapy (all p values <0.001). Participants were also younger at study (mean age 25.1 vs. 27.2; $p < 0.001$) and had a slightly longer follow-up than nonparticipants (mean time since diagnosis 20.5 vs. 19.1; $p < 0.001$). There was no difference in the rate of cranio-spinal radiotherapy between both groups.

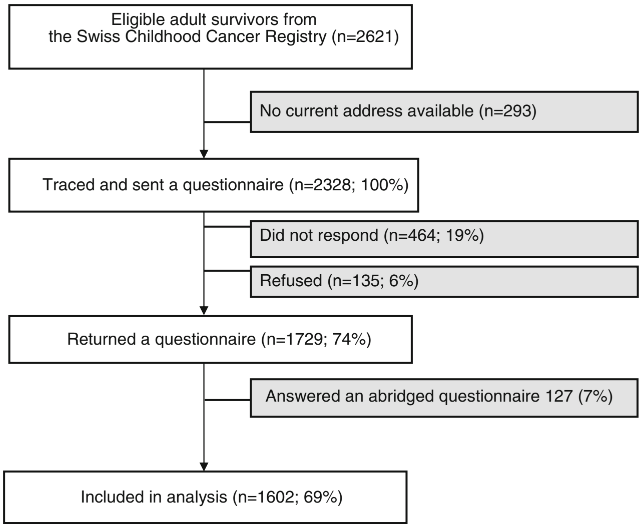

Fig. 1 Participants and response rate of survivors in the Swiss Childhood Cancer Survivor Study. It shows the flow diagram of our study population starting from those eligible to those included in the analysis

We were allowed to contact 1,821 siblings. Of those, 835 (46 %) returned a questionnaire and 703 had information on mental health-care and could be included in the final analysis. Survivors and siblings did not differ in their demographic characteristics (Table 1).

Aim1: Mental health-care

a. Utilization of mental health-care in all participants and in distressed participants only

Overall, 160 survivors (10 %) and 53 siblings (8 %) reported to have used mental health care in the past year ($p=0.085$). With the BSI-18, we identified 204 survivors (14 %) and 127 siblings (12 %) with psychological distress (T score≥57 on two scales or GSI). Among those who were distressed, 69 (34 %) survivors and 20 (24 %) siblings had utilized mental health-care in the past year ($p<0.001$). Among survivors who utilized mental health-care, 15 (38 %) said that all visits were cancer-related, 16 (40 %) said that some of the visits were cancer-related, and 9 (22 %) said that no visit was cancer-related.

b. Mental health-care and severity of distress

When looking at severity of distress, we found that survivors and siblings utilizing mental health-care tended to be more distressed (Fig. 2). The difference between survivors utilizing mental health-care and survivors not utilizing mental health-care was seen in all four scales, reaching significance in three of them: depression (mean T score 62.25, 95 % confidence interval (CI) 60.21–64.28 vs. 59.37, CI 58.15–60.59), anxiety (61.00, CI 59.12–62.88 vs. 57.34, CI 56.09–58.59), and GSI (63.30 CI 61.96–64.64 vs. 60.39, CI 59.66–61.11). The same pattern was found in siblings; additionally, siblings showed different scores in somatization depending on their mental health-care utilization (58.75, CI 54.73–62.77 in users vs. 53.77, CI 51.82–55.71 in nonusers) (Fig. 2).

c. Utilization of other health-care services in distressed and nondistressed survivors not seeking mental health-care

Among survivors who did not seek mental health-care, 46 % of nondistressed vs. 45 % of distressed survivors visited a general practitioner ($p=0.325$), 14 vs. 7 % visited an oncologist ($p<0.001$), and 19 vs. 35 % another medical specialist ($p<0.001$) (Fig. 3). In survivors, whether distressed or not, visiting a general practitioner or an oncologist, there was no association with either BSI-18 scale. However, among distressed survivors visiting other health-care specialists, high level of somatization (T score ≥57) was associated with more visits to a gastroenterologist (OR=3.81, CI 1.23–7.89) or a neurologist (OR=3.19, CI 1.38–7.34).

Aim2: Factors associated with utilizing mental health-care in distressed survivors

In univariable logistic regressions, determinants for utilizing mental health-care were severity of distress, higher parental education, being aged 25–29 years at study, shorter time since diagnosis, and self-reported late effects (Table 2). Rural place of residence as well as secondary or unknown parental education was associated with not utilizing mental health-care (Table 2). There was no significant association with sex, language region, migration background, diagnosis, treatments, and relapse.

In the multivariable model, age at study, residing in rural regions, time since diagnosis, and parental education were no longer significantly associated with the mental health-care utilization. Only the associations with self-reported late effects and distress severity remained statistically significant (Table 2).

Discussion

Considering the whole population of cancer survivors and siblings, we found that, in the overall sample, only a small proportion of them reported to have utilized mental health-care (10 and 8 %, respectively). When looking at participants considered distressed, the numbers were, as expected, higher with 34 % of survivors and 24 % of siblings having utilized mental health-care. Factors associated with the utilization of mental health-care among distressed survivors were the presence of self-reported late effects and the severity of the

Table 1 Demographic characteristics of cancer survivors comparing participants, nonparticipants, and siblings

Characteristic	Cancer survivors							
	Participants ($n=1,602$)		Nonparticipants ($n=1,019$)			Siblings ($n=703$)[a]		
	n	(%)	n	(%)	p^b	n	(%)	p^b
Sex					<0.001			n.a.[c]
Male	850	(53)	620	(61)		372	(53)	
Female	752	(47)	399	(39)		331	(47)	
Language					0.329			n.a.[c]
German	1,180	(74)	728	(71)		541	(77)	
French	367	(23)	259	(25)		140	(20)	
Italian	55	(3)	32	(4)		22	(3)	
Migration background					<0.001			n.a.[c]
Swiss	1,462	(91)				654	(93)	
Immigrant	140	(9)				49	(7)	
Place of residence at study					<0.001			0.489
Urban	1,000	(70)	624	(80)		492	(70)	
Rural	426	(30)	157	(20)		211	(30)	
Parents' education								0.145
Primary	150	(9)	–	–		70	(10)	
Secondary	1,057	(66)	–	–		471	(67)	
Tertiary	287	(18)	–	–		127	(18)	
Unknown	30	(7)				35	(5)	
Diagnosis (ICCC-3 main groups)					<0.001			n.a.[c]
I Leukemias	574	(36)	289	(28)		–	–	
II Lymphomas	291	(18)	203	(20)		–	–	
III CNS tumors	212	(13)	169	(17)		–	–	
IV Neuroblastomas	69	(4)	43	(4)		–	–	
V Retinoblastomas	38	(2)	28	(3)		–	–	
VI Renal tumors	108	(7)	42	(4)		–	–	
VII Hepatic tumors	10	(1)	4	(1)		–	–	
VIII Bone tumors	77	(5)	41	(4)		–	–	
IX Soft tissue sarcomas	90	(6)	70	(6)		–	–	
X Germ cell tumors	45	(3)	42	(4)		–	–	
Langerhans cell histiocytosis	69	(4)	52	(5)		–	–	
Other[d]	19	(1)	36	(4)		–	–	
Surgery					0.357			n.a.[c]
No	691	(58)	432	(60)		–	–	
Yes	505	(42)	289	(40)				
Chemotherapy					<0.001	–	–	n.a.[c]
No	256	(16)	291	(29)		–	–	
Yes	1,346	(84)	728	(71)		–	–	
Radiotherapy								n.a.[c]
No	986	(62)	677	(66)		–	–	
Body & Limbs radiation	318	(20)	180	(18)		–	–	
Cranio-spinal radiation	298	(18)	162	(16)		–	–	
BMT								n.a.[c]
No	1,534	(96)	981	(96)	0.514	–	–	
Yes	68	(4)	38	(4)		–	–	
Self-reported late effects								n.a.[c]
Without late effects	996	(64)	–	–		–	–	

Table 1 (continued)

Characteristic	Cancer survivors							
	Participants (n=1,602)		Nonparticipants (n=1,019)			Siblings (n=703)[a]		
	n	(%)	n	(%)	p[b]	n	(%)	p[b]
With late effects	558	(36)	–	–		–	–	
Relapse								n.a.[c]
No	1,331	(89)	–	–		–	–	
Yes	163	(11)	–	–		–	–	
Psychological Distress[e]								0.923
Not Distressed	1,304	(86)	–	–		576	(86)	
Distressed	204	(14)	–	–		127	(14)	
	mean	(SD)	mean	(SD)	p[f]	mean	(SD)	p[f]
Age at study	25.1	(8.1)	27.2	(7.8)	<0.001	25.2	(5.7)	n.a.
Age at diagnosis	7.7	(4.7)	8.1	(4.8)	0.178	–	–	
Time since diagnosis	20.5	(7.4)	19.1	(7.9)	<0.001	–	–	

Percentages are based upon available data for each variable

ICCC-3 International Classification of Childhood Cancer Third Edition, *CNS* Central nervous system, *SD* Standard Deviation, *BMT* bone Marrow transplantation

[a] Matched proportions and numbers of siblings according to the marginal distribution in survivors on age, gender, language, and migration background

[b] P value calculated on chi-square statistics

[c] Populations are standardized on these variables to make them comparable

[d] Other malignant epithelial neoplasms, malignant melanomas and other or unspecified malignant neoplasms

[e] Participants with scores $T \geq 57$ on two scales or the Global Severity Index were considered as distressed

[f] P value calculated on two-sample mean comparison test (t test)

psychological distress. A trend for not utilizing mental health-care could be observed in male survivors, in older survivors, in participants coming from rural areas and with lower levels of parental education. Distressed survivors not seeking psychological support reported more often to have visited another health-care specialist than nondistressed survivors.

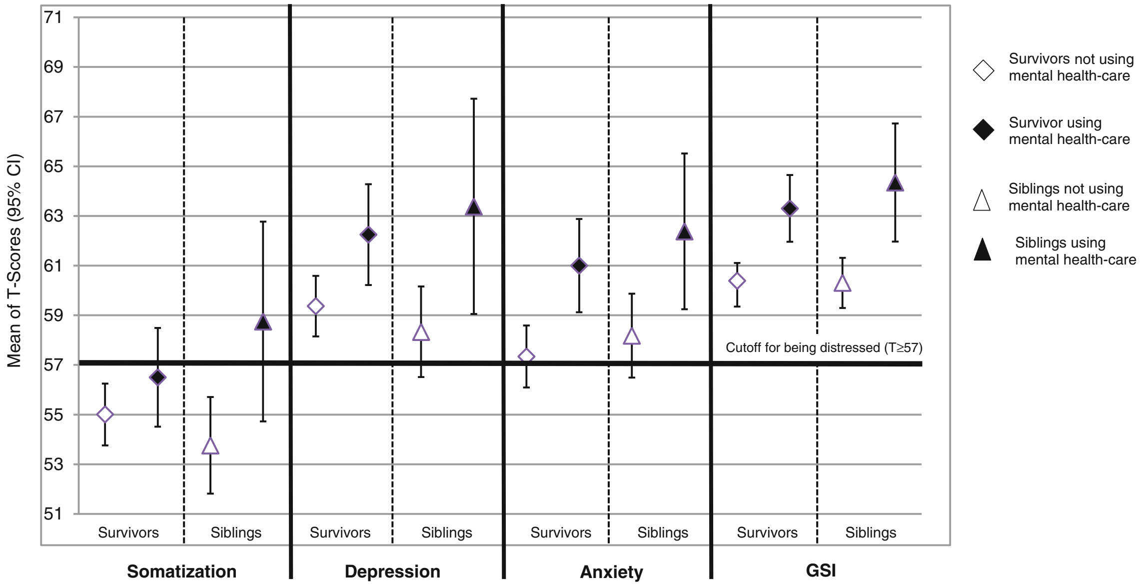

Fig. 2 Psychological distress in survivors and siblings using mental health-care vs. survivors and siblings not using mental health-care. It shows mean T scores and 95% confidence intervals for the three BSI-18 scales and the GSI

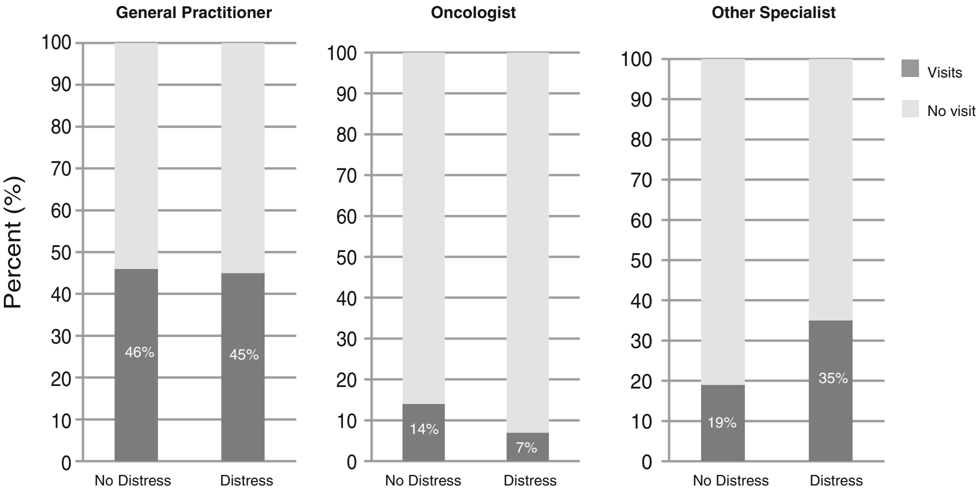

Fig. 3 Proportions of distressed and nondistressed survivors not utilizing mental health-care, who visited a general practitioner, an oncologist, or another specialist (gastroenterologist, neurologist, cardiologist, or endocrinologist)

This is the first study which investigated the utilization of mental health-care in childhood cancer survivors with psychological distress. A previous study assessing the more general utilization of health-care among survivors found that 12 % of survivors and 8.7 % of controls reported to have seen a psychologist, a psychiatrist, or a social worker in the past year [31]. These proportions are similar to the ones we found in the overall sample. That study, however, did not investigate the utilization of mental-health care among survivors or siblings with psychological distress. Another study which focused on adult survivors of adolescent cancer reported that only 3 % of the overall sample and 12 % of survivors with a psychological condition were receiving mental health-care [32].

In Switzerland, to date, there is no tailored national follow-up program and no dedicated late effects clinic for survivors of childhood cancer [33]. However, all survivors are followed up by their pediatric oncologist for the first 5 to 10 years and are then usually transferred to their general practitioner. Psychological screening is not offered systematically within regular follow-up visits. It is thus not entirely surprising that more than half of survivors with psychological distress did not utilize any type of mental health-care. While a similar proportion of distressed survivors utilized general practitioner care as nondistressed survivors, fewer visited an oncologist and more other health specialists. This might also be due to some survivor suffering from posttraumatic stress preventing them from attending oncologist care and instead looking for help at other specialists. We also found that higher levels of somatization were associated with visits to gastroenterologists and neurologists partly confirming previous research: patients with high somatization show increased medical care utilization, but not necessarily mental health-care [34]. A reason for this may lie in the Swiss health-care system, in which patients can see a medical specialist without having to be referred by a general practitioner [35].

Fewer siblings utilized mental health-care than survivors despite their distress. This difference might be due to the fact that childhood cancer survivors have regular medical visits during follow-up, allowing detection of psychological problems and the reference to a psychologist. Furthermore, it is now widely known that cancer survivors may be more prone to psychological distress, but siblings and family members in general are still an under-considered and under-studied group even though, research has shown that they may also be at risk and that offering psychological support to the whole family has positive consequences for both siblings and survivors [36].

Patients in psychotherapy are still stigmatized in many countries [37]. It is therefore possible that even if survivors and siblings were actually advised to start psychotherapy or to visit a mental health specialist, they would not follow the advice or would not report the attendance in the questionnaire. Studies have proposed models to overcome these barriers such as implementing mental health-care in oncological or primary care settings in order to avoid the stigma related to mental illness [15]. However, to our knowledge, nothing alike has yet been implemented in follow-up of childhood cancer survivors in Switzerland.

Furthermore, there are several sociocultural factors playing a role in a person's attitude towards mental health-care as it is clearly pointed out in the model of health services utilization [17]. In the present study, we found for example that sociodemographic factors may play a role in determining whether a survivor utilizes mental health-care or not. We found that male survivors [38], participants older than 35 years, with a rural background, and coming from families with lower education tended not to utilize mental health-care. The same trend was observed for survivors with longer time since diagnosis.

Interestingly, we found no direct association with disease-related factors. However, the association with self-reported late effects suggests that cancers and treatments inducing somatic late effects might indirectly influence the utilization of mental health-care. Survivors reporting late effects may be more prone to see a health professional and have

Table 2 Sociodemographic, health-related, and cancer-related factors associated with the utilization of mental health-care in distressed survivors

	n	% attending	Univariable regression			Multivariable regression		
			OR	95 % CI	*p*	OR	95 % CI	p^a
Age at study, years								
<20	90	19	1		0.037	1		0.208
20–24	84	29	1.72	0.85–3.49		1.07	0.34–3.37	
25–29	51	41	3.01	1.40–6.48		4.54	1.13–18.24	
30–34	41	34	2.23	0.97–5.13		2.38	0.52–10.91	
≥35	36	19	1.04	0.39–2.76		0.56	0.04–7.59	
Sex								
Female	188	29	1			1		
Male	114	25	0.79	0.46–1.34	0.186	0.38	0.14–1.08	0.072
Language								
German	219	59	1		0.145	1		0.767
French/Italian	83	41	1.48	0.88–2.49		0.87	0.36–2.07	
Migration background								
Native Swiss	264	29	1		0.186			
Immigrant	38	18	0.56	0.24–1.32				
Place of residence at study								
Urban	194	31	1		0.009	1		0.213
Rural	77	16	0.40	0.20–0.80		0.63	0.15–3.54	
Parents' education								
Secondary	158	30	1		<0.001	1		0.942
Primary	36	14	0.37	0.14–1.01		0.85	0.21–3.50	
Tertiary	50	44	1.80	0.94–3.46		1.22	0.37–3.98	
Unknown	58	14	0.37	0.16–0.83		0.65	0.07–6.41	
Diagnosis								
Leukemia	105	21	1		0.322	1		0.847
Lymphomas	39	26	1.30	0.55–3.07		1.61	0.34–7.69	
CNS tumors	57	32	1.74	0.84–3.61		0.85	0.12–5.82	
Other	86	31	1.73	0.90–3.32		1.10	0.21–5.75	
Surgery								
No	133	34	1		0.256	1		
Yes	97	27	0.72	0.40–1.27		1.44	0.38–5.44	
Chemotherapy								
No	68	32	1		0.308	1		0.314
Yes	234	26	0.74	0.41–1.33		0.51	0.16–1.89	
Radiotherapy								
No radiotherapy	177	28	1		0.849	1		0.074
Body & limbs radiation	61	25	0.83	0.43–1.62		0.25	0.09–0.98	
Cranio-spinal radiation	64	28	0.99	0.53–1.88		0.98	0.29–3.33	
BMT								
No	286	27	1		0.732	1		0.177
Yes	16	31	1.21	0.41–3.60		0.13	0.07–2.44	
Time since diagnosis								
<10	47	13	1		0.023	1		0.196
10–14	72	33	3.42	1.27–9.17		3.22	0.81–13.71	
≥15	179	30	2.87	1.15–7.18		1.53	0.34–6.87	
Self-reported late effects								
No late effects	122	15	1		<0.001	1		0.021

Table 2 (continued)

	n	% attending	Univariable regression			Multivariable regression		
			OR	95 % CI	*p*	OR	95 % CI	p^a
Late effects	158	39	3.63	2.01–6.58		3.33	1.20–9.27	
Relapse								
No	262	27	1		0.446			
Yes	40	33	1.32	0.65–2.70				
Severity of distress[b]								
GSI (*T* score)			1.13	1.06–1.20	<0.001	1.14	1.03–1.26	0.013

OR Odds ratio, *CI* Confidence interval, *BMT* Bone marrow transplantation, *CNS* Central nervous system

[a] Global *p* values calculated with likelihood ratio test

[b] The variable "Severity of distress" is the *T* score (mean=50, SD=10) of the Global Severity Index of the Brief Symptom Inventory 18

psychological distress detected. Beyond late effects, our results, although not statistically significant due to the small sample size of distressed survivors, suggest that a person's sociocultural background may be a stronger predictor for the utilization of mental health-care than the disease history. In other words, the patent's "social anchorage" may be a more important player than the medical illness in determining the mental health-care utilization. Though not empirically assessed, we have reasons to believe that in Switzerland, a rural background works is a proxy for a certain attitude towards psychological distress and utilization of mental health care, rather than being a distance barrier for attending care [39].

Strengths and limitations

A major strength of this study is the large population-based sample of adult survivors with prospectively collected data and information on diagnosis, treatment, and relapse. Despite a rather long questionnaire, the response rate of 74 % was high. Furthermore, thanks to the broad spectrum of questions asked, we could assess mental health-care utilization in survivors and siblings presenting with psychological distress.

The present study has, however, limitations. It is likely that self-selection bias influenced the findings, because survivors of specific groups may have been reluctant to complete the questionnaire or even may not have been able to fill it out due to severe late effects or impairments. Another limitation that our study shares with other questionnaire-based assessments of childhood cancer survivors is the utilization of self-report measures for mental health-care and psychological distress. Admitting to utilizing mental health-care is for many subgroups still problematic, and it is possible that survivors of childhood cancer underreported it [40]. Further, there are currently no Swiss norms available for the BSI-18, and the real prevalence of distress in our sample might be slightly different. These are two possible reasons for the relatively low prevalence of distress found in our sample. The lower response rate in siblings might have influenced results in terms of representativeness. Finally, we were not able to look in more detail which type of mental health-care survivors had sought because it was not the focus of the questionnaire.

Implication for practice and conclusions

Our findings may imply that mental health-care utilization is not yet systematically implemented in Switzerland, especially within follow-up care for survivors of childhood cancer [41]. In a medical setting where time constraints are often dictating the priorities, the development of an appropriate, short screening program with the possibilities to refer patients to adequate psychosocial care seems mandatory. Health-care professionals should also be made aware of the importance of prioritizing mental health issues [15]. Further, knowing the factors associated with the utilization of mental health-care will contribute to develop targeted interventions to reach all patients in need, even those who might be less prone to accept it. Future research will have to investigate whether underreport of psychological distress occurs in the population of childhood cancer survivors. Finally, knowing that siblings suffer from distress due to the traumatic experience with cancer in the family will allow developing specific screening procedures to monitor this vulnerable group more closely.

Our results underline the importance of introducing regular screening for psychological distress and appropriate referral to mental health-care. Our findings also suggest that it is imperative to systematically address siblings' needs. In follow-up, patients at risk for psychological distress should be informed about existing possibilities or advised to visit mental health professionals.

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