



Psychological Care After Childhood Cancer: Results from the Swiss Cancer Childhood Survivor Study

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Background on childhood cancer

- Rare disease
- 2nd most frequent cause of death in children
- High burden of disease

Childhood cancer ranks 3rd in years of life affected because of the young age of diagnosis (Bleyer, 1992)

- Survival reached 80% → increasing population of survivors
- 60% have physical or psychological late effects

Focus of research on

- Further increasing survival
- Assuring quality of survivorship

Why study psychological care?

- Somatic & psychological late effects affect quality of life
- We found 14-25% of survivors with high psychological distress (Michel, JCO, 2010; Gianinazzi, Psy-Oncol, 2012)
- Untreated psychological distress is associated
 - Inability to manage health care (Carlson, Health and Quality of Life Outcomes, 2003)
 - Higher costs (Carlson, Health and Quality of Life Outcomes, 2003)
 - Unemployment (Krull, JCS, 2010)
 - Substance abuse (Krull, JCS, 2010)

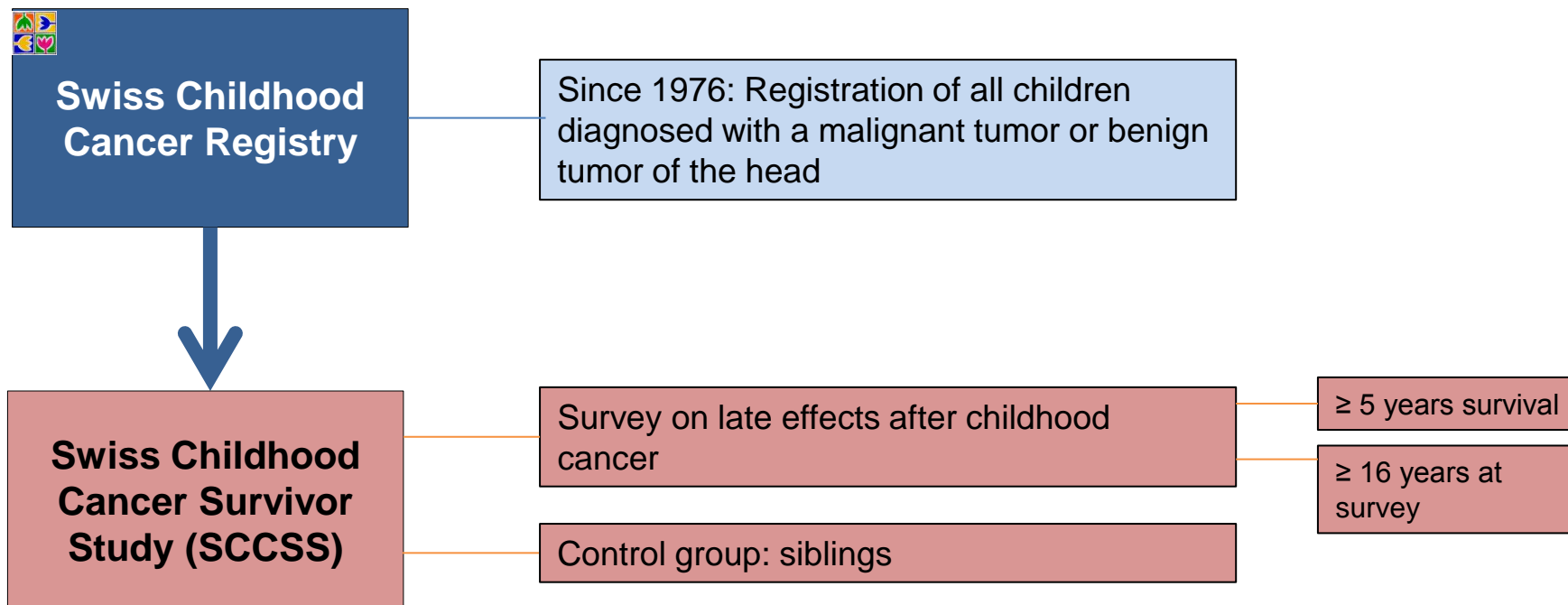
→ Do survivors use psychological care?

Aims

1. Compare proportions of survivors and siblings who have seen a psychologist/psychiatrist during the past year
 - Overall
 - In distressed survivors and siblings
2. Identify factors associated with not using psychological care among distressed survivors.

Methods

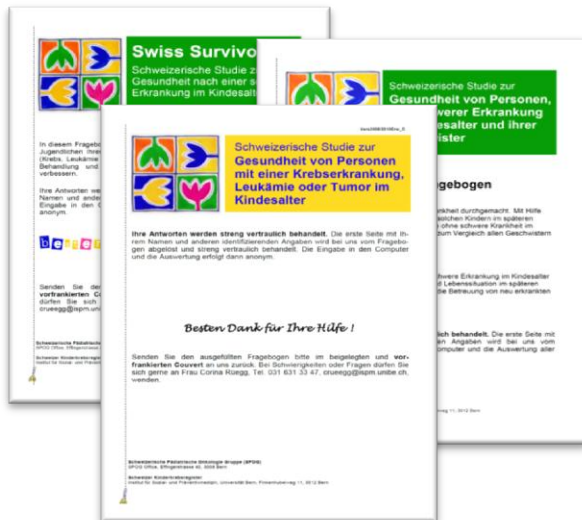
Study population



Methods Questionnaires

Survivors & Siblings

- Postal Questionnaire
- Standardized questions (for siblings without cancer history)
 - General Health
 - Health Behavior
 - Quality of Life
 - Medical Visits (1)
 - Psychological Distress (BSI-18) (2)



1

Besuche bei Haus- oder Kinderarzt in den letzten 12 Monaten	Alle	Einige	Keine
<input type="checkbox"/> beim Hausarzt (Allgemeinpraktiker, Internist o.ä.)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Kinderarzt: Onkologe/Hämatologe (Krebspezialist)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> anderer Kinderarzt (kein Krebspezialist)	—	<input type="checkbox"/>	<input type="checkbox"/>
Besuche bei Spezialisten in den letzten 12 Monaten			
<input type="checkbox"/> Endokrinologe (Hormon-Stoffwechselfach)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Gastroenterologe (Spezialist für Magen-Darmkrankheiten)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Gynäkologe (Frauenarzt)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Kardiologe (Herzspezialist)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Neurologe (Spezialist für Nervenkrankheiten)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Onkologe/Hämatologe (Spezialist für Krebs-Blutkrankheiten)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Ophthalmologe (Augenarzt)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Orthopäde (Knochen- und Gelenkspezialist)	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Psychiater/ Psychologe	—	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Pneumologe (Lungenspezialist)	—	<input type="checkbox"/>	<input type="checkbox"/>

2

72. Wie sehr haben Sie in den letzten 7 Tagen gelitten unter

	Gar nicht	Ein wenig	Ziemlich	Stark	Sehr stark
1 Nervosität oder innerem Zittern	□ 1	□ 2	□ 3	□ 4	□ 5
2 Ohnmachts- und Schwindelgefühl	□ 1	□ 2	□ 3	□ 4	□ 5
3 Herz- oder Brustschmerzen	□ 1	□ 2	□ 3	□ 4	□ 5
4 Gedanken, sich das Leben zu nehmen	□ 1	□ 2	□ 3	□ 4	□ 5
5 plötzlichem Erschrecken ohne Grund	□ 1	□ 2	□ 3	□ 4	□ 5
6 Einsamkeitsgefühle	□ 1	□ 2	□ 3	□ 4	□ 5
7 Schweißausbrüche	□ 1	□ 2	□ 3	□ 4	□ 5
8 dem Gefühl, sich für nichts zu interessieren	□ 1	□ 2	□ 3	□ 4	□ 5
9 Furchtsamkeit	□ 1	□ 2	□ 3	□ 4	□ 5
10 Übelkeit oder Magenverstimmung	□ 1	□ 2	□ 3	□ 4	□ 5
11 Schwierigkeiten beim Atmen	□ 1	□ 2	□ 3	□ 4	□ 5
12 Taubheit oder Kribbeln in einzelnen Körperteilen	□ 1	□ 2	□ 3	□ 4	□ 5
13 einem Gefühl der Hoffnungslosigkeit gegenüber der Zukunft	□ 1	□ 2	□ 3	□ 4	□ 5
14 Schwächegefühl in einzelnen Körperteilen	□ 1	□ 2	□ 3	□ 4	□ 5
15 dem Gefühl, angespannt oder aufgeregt zu sein	□ 1	□ 2	□ 3	□ 4	□ 5
16 Schreck- oder Panikattacken	□ 1	□ 2	□ 3	□ 4	□ 5
17 Ruhelosigkeit, so dass Sie kaum stillsitzen können	□ 1	□ 2	□ 3	□ 4	□ 5
18 dem Gefühl, wertlos zu sein	□ 1	□ 2	□ 3	□ 4	□ 5

Results

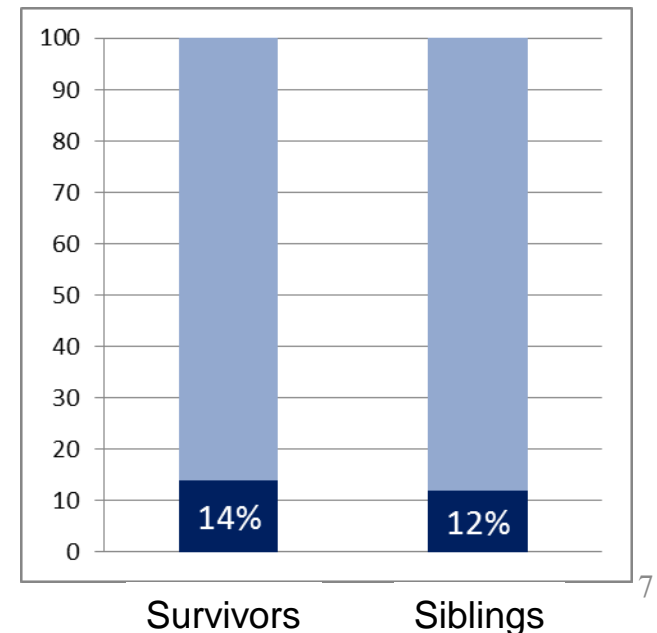
Study Population

Table 1: Characteristics of survivors and siblings

	Survivors n (%)		Siblings* n (%)	
	mean	SD	mean	SD
Response Rate	1602 (74)		703 (46)	
Sex (Male)	850 (53)		372 (53)	
Age at study	25.1	8.1	25.2	5.7
Time since diagnosis	17.4	6.9	-	-

*Standardized proportions of siblings according to the marginal distribution in survivors on: age, sex, migration background

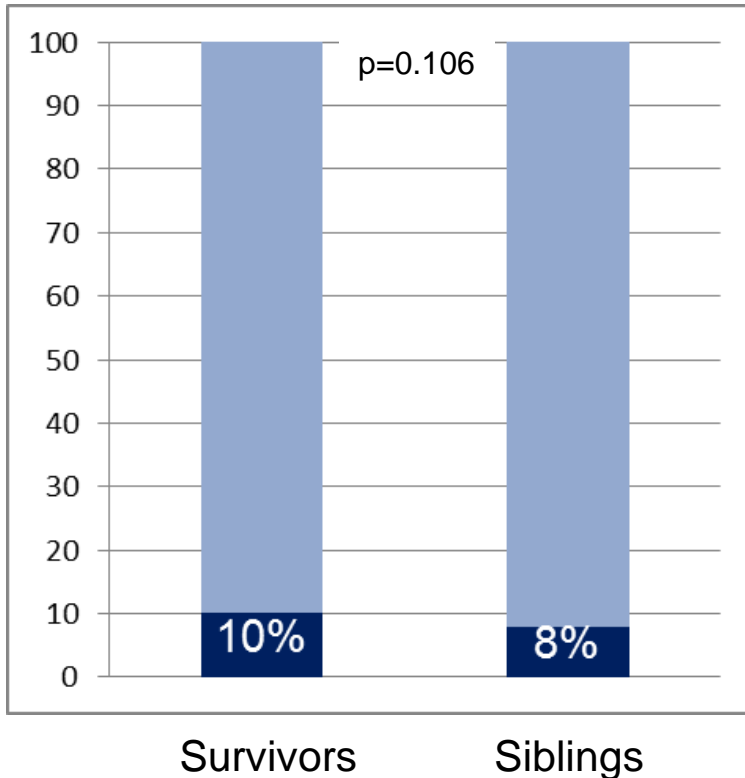
Figure 1: Proportions of distress (survivors and siblings with T-score >57)



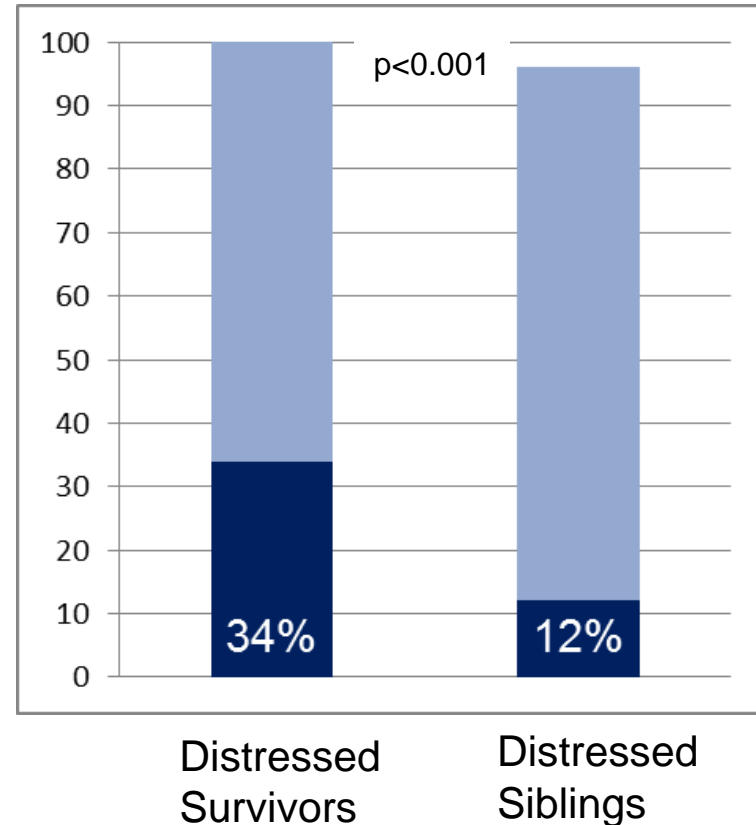
Results

Use of psychological care

a) Overall sample



b) Distressed Survivors & Siblings



- Using of psychological care
- Not using of psychological care

Results

Risk factors for not using psychological care

Factor	% not using PC	OR	p-value
Severity of distress (continuous GSI)		0.88	<0.001
Parents' education			
Primary	51	1	0.002
Secondary	14	2.71	
Tertiary	13	0.55	
Unknown	22	2.51	
Late effects			
No Late effects	52	1	<0.001
Late effects	48	0.27	

Not associated:

- Sex
- Migration background
- Language region
- Relapse status
- **Residence place**
- Diagnosis
- Therapy

Adjusted for: all factors listed, diagnosis, therapy, age, sex and time since diagnosis, language region and place of residence

Conclusions

- Only a small proportion of distressed survivors and siblings seems to be seeking professional help. Positive is that those who use psychological care are those more distressed.
- Factors associated with not using psychological care were no late effects, lower education and less severe distress.
- No systematic psychological surveillance available in Switzerland

What can be done?

- Development of interventions to systematically implement psychological surveillance in follow up of survivors
- Address survivors' families
- Use of new technologies
- Useful for all cancer survivors

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einfach da wenn's schwierig wird