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

Swiss Childhood Cancer Registry

Since 1976: Registration of all children diagnosed with a malignant tumor or benign tumor of the head

Swiss Childhood Cancer Survivor Study (SCCSS)

Survey on late effects after childhood cancer

Control group: siblings

≥ 5 years survival

≥ 16 years at survey
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)
Results

Study Population

Table 1: Characteristics of survivors and siblings

<table>
<thead>
<tr>
<th></th>
<th>Survivors n (%)</th>
<th>Siblings* n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Response Rate</strong></td>
<td>1602 (74)</td>
<td>703 (46)</td>
</tr>
<tr>
<td><strong>Sex (Male)</strong></td>
<td>850 (53)</td>
<td>372 (53)</td>
</tr>
<tr>
<td><strong>Age at study</strong></td>
<td>25.1 8.1</td>
<td>25.2 5.7</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td>17.4 6.9</td>
<td>- -</td>
</tr>
</tbody>
</table>

*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

<table>
<thead>
<tr>
<th></th>
<th>Survivors</th>
<th>Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using of psychological care</td>
<td>10%</td>
<td>8%</td>
</tr>
<tr>
<td>Not using of psychological care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

p = 0.106

<table>
<thead>
<tr>
<th></th>
<th>Distressed Survivors</th>
<th>Distressed Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using of psychological care</td>
<td>34%</td>
<td>12%</td>
</tr>
<tr>
<td>Not using of psychological care</td>
<td></td>
<td></td>
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</tbody>
</table>

p < 0.001
### Results

#### Risk factors for not using psychological care

<table>
<thead>
<tr>
<th>Factor</th>
<th>% not using PC</th>
<th>OR</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity of distress</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(continuous GSI)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.88</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td><strong>Parents’ education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>51</td>
<td>1</td>
<td>0.002</td>
</tr>
<tr>
<td>Secondary</td>
<td>14</td>
<td>2.71</td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>13</td>
<td>0.55</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>22</td>
<td>2.51</td>
<td></td>
</tr>
<tr>
<td><strong>Late effects</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Late effects</td>
<td>52</td>
<td>1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Late effects</td>
<td>48</td>
<td>0.27</td>
<td></td>
</tr>
</tbody>
</table>

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

Not associated:
- Sex
- Migration background
- Language region
- Relapse status
- Residence place
- Diagnosis
- Therapy
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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