Health-related quality of life in young survivors of childhood cancer

A report from the Swiss Childhood Cancer Survivor Study

Wengenroth L¹, Gianinazzi ME², Rueegg CS², Lüer S³, Bergstraesser E⁴, Kuehni CE¹, Michel G¹,²

¹ Institute of Social and Preventive Medicine, University of Bern, Switzerland;
² Department of Health Sciences and Health Policy, University of Lucerne, Switzerland;
³ Division of Pediatric Hematology/Oncology, University Children’s Hospital, Inselspital, Bern, Switzerland;
⁴ Department of Pediatric Oncology, University Children’s Hospital Zürich, University of Zurich, Switzerland
Childhood Cancer
Diagnosis in children aged 0-14 years

200 new cases per year in Switzerland

Adapted from Swiss Childhood Cancer Registry, Annual Report 2011-2012
Survival increased drastically

Late effects:
- Physical limitations
- Psychological well-being

Swiss Childhood Cancer Registry, Annual Report 2011-2012
Health-related quality of life

- Few studies on young survivors, specific diagnostic groups only\textsuperscript{1-3}
- KIDSCREEN instrument suitable to measure HRQoL in healthy and sick children\textsuperscript{4,5}
- Normative data is available retrieved from 1’701 children in Switzerland\textsuperscript{6}

\textsuperscript{1}Bhat, 2005, J Clin Oncol; \textsuperscript{2}Laffond, 2012, Brain In; \textsuperscript{3}van Dijk, 2007, Health Qual Life; \textsuperscript{4}Mohler-Kuo, 2012, Qual Life Res; \textsuperscript{5}Everts, 2008, Child Neuropsychol \textsuperscript{6}Michel, 2009, Qual Life Res
Study Aims

1. Describe HRQoL in a representative sample of survivors in Switzerland, compared to healthy peers.

2. Determine predictors for HRQoL in survivors
Study population N=403

✓ Registered in the Swiss Childhood Cancer Registry
✓ Aged <16 years at diagnosis
✓ Living in Switzerland at diagnosis
✓ Alive, ≥5 years past diagnosis
✓ For this study: Aged 8-16 years at survey
Methods: HRQoL measurement

- **KIDSCREEN-27**\(^1\) (5 dimensions of self-reported HRQoL):
  - physical well-being
  - psychological well-being
  - autonomy and parents
  - peers and social support
  - school environment

- Compared to Swiss norms\(^2\): T-standardized range: 0-100, mean: 50, SD=10

- Higher scores \(\rightarrow\) better HRQoL

\(^1\)Ravens-Sieberer, 2007, Qual Life Res; \(^2\)Michel, 2009, Qual Life Res
Procedures

- **Questionnaire** sent to all eligible survivors, resulting in 403 completed questionnaires (response 67%)
- We used **multivariable linear regressions** to analyze the association of **socio-demographic** and **cancer-related factors** with each HRQoL dimension.
Results 1: Survivors’ HRQoL similar to norm

Mean HRQoL with 95% confidence intervals

Ranges

- 1 SD from expected mean

+ 1 SD from expected mean
## Results 2: Socio-demographic factors associated with HRQoL

<table>
<thead>
<tr>
<th></th>
<th>Physical well-being</th>
<th>Psychological well-being</th>
<th>Autonomy and Parents</th>
<th>Peers and Social Support</th>
<th>School Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Girls</strong></td>
<td>+0.7</td>
<td>-0.1</td>
<td>+2.2</td>
<td>+2.1</td>
<td>**+2.6 ***</td>
</tr>
<tr>
<td><strong>Adolescents (age 13-16)</strong></td>
<td>-1.1</td>
<td>+1.3</td>
<td>+3.0 **</td>
<td>+0.3</td>
<td>-1.3</td>
</tr>
<tr>
<td><strong>Ita./French Language region</strong></td>
<td>-0.6</td>
<td>+2.0</td>
<td>-1.0</td>
<td>-1.9</td>
<td>+0.1</td>
</tr>
<tr>
<td><strong>Migration background</strong></td>
<td>+1.1</td>
<td>+1.8</td>
<td>+3.7</td>
<td>+2.7</td>
<td>+3.3</td>
</tr>
</tbody>
</table>

*** p<0.001   ** p<0.01   * p<0.05
## Results 2: Clinical factors associated with HRQoL

<table>
<thead>
<tr>
<th></th>
<th>Physical well-being</th>
<th>Psychological well-being</th>
<th>Autonomy and Parents</th>
<th>Peers and Social Support</th>
<th>School Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymphoma</td>
<td>-2.0</td>
<td>+0.6</td>
<td>+2.3</td>
<td>+0.9</td>
<td>+1.0</td>
</tr>
<tr>
<td>CNS tumor</td>
<td>-5.9 *</td>
<td>-3.5</td>
<td>-1.0</td>
<td>-3.0</td>
<td>-1.6</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>-2.0</td>
<td>-1.0</td>
<td>+0.5</td>
<td>+0.9</td>
<td>+0.7</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>+0.6</td>
<td>-1.9</td>
<td>+1.0</td>
<td>-2.9</td>
<td>+3.3</td>
</tr>
<tr>
<td>Nephroblastoma</td>
<td>-6.1 *</td>
<td>-2.1</td>
<td>+0.1</td>
<td>-1.1</td>
<td>+0.1</td>
</tr>
<tr>
<td>Soft tissue sarcoma</td>
<td>-4.9</td>
<td>-1.4</td>
<td>+2.5</td>
<td>-0.6</td>
<td>-1.7</td>
</tr>
<tr>
<td>Other tumors</td>
<td>-4.7</td>
<td>-1.8</td>
<td>-2.1</td>
<td>-3.0</td>
<td>-0.5</td>
</tr>
<tr>
<td>Surgery</td>
<td>+2.5</td>
<td>+1.6</td>
<td>+0.3</td>
<td>+2.0</td>
<td>+0.3</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>+0.5</td>
<td>-0.3</td>
<td>-3.5 *</td>
<td>-0.8</td>
<td>-0.2</td>
</tr>
<tr>
<td>BMT</td>
<td>+1.9</td>
<td>+0.8</td>
<td>+1.2</td>
<td>+2.8</td>
<td>-4.7</td>
</tr>
<tr>
<td>Relapse</td>
<td>-4.1 *</td>
<td>-1.1</td>
<td>+2.2</td>
<td>-3.0</td>
<td>+0.5</td>
</tr>
<tr>
<td>Late effects</td>
<td>-5.7 ***</td>
<td>-4.0 **</td>
<td>-4.0 **</td>
<td>-3.9 **</td>
<td>-1.4</td>
</tr>
</tbody>
</table>
First study on HRQoL in children who survived childhood cancer in Switzerland

Overall HRQoL in survivors comparable to healthy peers!

But some survivors reported decreased HRQoL (physical dimension, CNS tumors, nephroblastoma, radiotherapy, relapse, late effects)

Focus to reduce adverse late effects from cancer treatments
Aknowlegements

Survivors and their Families

Sponsors
SPOG
Krebsliga Schweiz
Krebsliga Aargau
Bernische Krebsliga
Krebsliga Zürich
Krebsforschung Schweiz
Swiss National Science Foundation
Graduate schools: SSPH+, GCB Bern

Herzlichen Dank!