Psychosocial well-being of long-term survivors of pediatric head-neck rhabdomyosarcoma


Published in:
Pediatric Blood & Cancer

DOI:
10.1002/pbc.27498

Link to publication

Creative Commons License (see https://creativecommons.org/use-remix/cc-licenses):
CC BY-NC

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)

Download date: 09 Apr 2020
### Supplementary tables

**Table S1:** Comparison of participating and non-participating survivors

<table>
<thead>
<tr>
<th></th>
<th>Participants (n=65)</th>
<th>Non-participants (n=15)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at diagnosis (yrs)</strong></td>
<td>Median (range)</td>
<td>6.0 (0.5-13.4)</td>
<td>4.5 (0.1-13.6)</td>
</tr>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>42 (65%)</td>
<td>11 (73%)</td>
<td>0.76 *</td>
</tr>
<tr>
<td>Female</td>
<td>23 (35%)</td>
<td>4 (27%)</td>
<td></td>
</tr>
<tr>
<td><strong>Histology, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ERMS</td>
<td>53 (82%)</td>
<td>13 (87%)</td>
<td>1 *</td>
</tr>
<tr>
<td>ARMS</td>
<td>8 (12%)</td>
<td>2 (13%)</td>
<td></td>
</tr>
<tr>
<td>RMS NOS</td>
<td>4 (6%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>Primary site, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PM</td>
<td>30 (46%)</td>
<td>7 (47%)</td>
<td>0.74 *</td>
</tr>
<tr>
<td>ORB</td>
<td>22 (34%)</td>
<td>7 (47%)</td>
<td></td>
</tr>
<tr>
<td>ORB&amp;PM</td>
<td>4 (6%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>HNNPM</td>
<td>9 (14%)</td>
<td>1 (7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Side, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left</td>
<td>28 (43%)</td>
<td>5 (33%)</td>
<td>0.71 *</td>
</tr>
<tr>
<td>Right</td>
<td>30 (46%)</td>
<td>8 (53%)</td>
<td></td>
</tr>
<tr>
<td>Midline</td>
<td>7 (11%)</td>
<td>2 (13%)</td>
<td></td>
</tr>
<tr>
<td><strong>Treatment protocol, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMT 89</td>
<td>20 (31%)</td>
<td>2 (13%)</td>
<td>0.56 *</td>
</tr>
<tr>
<td>MMT 95</td>
<td>31 (48%)</td>
<td>10 (67%)</td>
<td></td>
</tr>
<tr>
<td>MMT 98</td>
<td>1 (2%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>RMS 2005</td>
<td>11 (17%)</td>
<td>3 (20%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2 (3%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>Number of RT Tx , n (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>4 (6%)</td>
<td>2 (13%)</td>
<td>0.25 *</td>
</tr>
<tr>
<td>1</td>
<td>54 (83%)</td>
<td>10 (67%)</td>
<td></td>
</tr>
<tr>
<td>Multiple</td>
<td>7 (11%)</td>
<td>3 (20%)</td>
<td></td>
</tr>
</tbody>
</table>

* Based on Mann Whitney test
# Based on Fisher’s Exact test

Abbreviations: ARMS, alveolar rhabdomyosarcoma; ERMS, embryonal rhabdomyosarcoma; HNNPM, Head and neck non-parameningeal; MMT, consecutive study of International Society of Paediatric Oncology Malignant Mesenchymal Tumour group; ORB&PM, orbital with parameningeal extension; ORB, orbital; PM, parameningeal; RMS 2005, European paediatric Soft Tissue Sarcoma group RMS 2005 protocol; RMS NOS, Rhabdomyosarcoma not otherwise specified; RT, radiotherapy; Tx, treatment; Yrs, years
### Table S2: Self-perception (KIDSCREEN) of HNRMS survivors

<table>
<thead>
<tr>
<th></th>
<th>Netherlands</th>
<th></th>
<th>United Kingdom</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HNRMS</td>
<td>Reference</td>
<td>HNRMS</td>
<td>Reference</td>
</tr>
</tbody>
</table>
|                  | n           | Mean                  | SD             | Mean                  | SD             | Effect size | p-Value
|                  |             |                       |                |                       |                |             | 
| 8-17 years       | 16          | 50.00                 | 9.29           | 51.26                 | 8.83           | -0.14       | 0.60
|                  | 15          | 55.00                 | 11.53          | 49.93                 | 8.66           | 0.59        | 0.11
| 18+ years        | 19          | 49.30                 | 7.95           | 50.70                 | 8.73           | -0.16       | 0.61
|                  | 12          | 47.18                 | 12.31          | 47.85                 | 8.69           | 0.08        | 0.85
| All ages         | 35          | 49.62                 | 8.47           | 50.96                 | 8.97           | -0.15       | 0.36
|                  | 27          | 51.52                 | 12.31          | 49.01                 | 9.14           | -0.27       | 0.30

Kidscreen scale: mean = 50, SD = 10.

* Country specific weighted norm, adjusted for sex and age

* Based on one-sample t-test.
Figure S1: Histogram showing prevalence of most common adverse events (any grade) in survivors of head-neck rhabdomyosarcoma (HNRMS), divided by country (see Schoot et al.6).

Musculoskeletal deformity of the faces comprises: deformity, hypoplasia and asymmetry.

Audiometry data missing for 6/65 survivors (NL survivors n=2, UK survivors n=4)

Skin and/or fat atrophy comprises: fat atrophy, skin atrophy

Eyelid deformity comprises: ectropion, entropion, eyelid retraction and ptosis.

Pigmentation comprises: hypopigmentation, hyperpigmentation.

Infection comprises: ‘gastro-intestinal infection’ and ‘respiratory infection’
Figure S2: Histogram showing prevalence of a grade 3/4 adverse event according to CTC AE, ≥5 adverse events (any grade) and the burden score (see Schoot et al.6).

* Burden score adapted from Geenen et al.24