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


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

<table>
<thead>
<tr>
<th>Age at diagnosis (yrs)</th>
<th>Participants (n=65)</th>
<th>Non-participants (n=15)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median (range)</td>
<td>6.0 (0.5-13.4)</td>
<td>4.5 (0.1-13.6)</td>
<td>0.35*</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td>Male</td>
<td>42 (65%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>23 (35%)</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Histology, n (%)</td>
<td>ERMS</td>
<td>53 (82%)</td>
<td>13 (87%)</td>
</tr>
<tr>
<td></td>
<td>ARMS</td>
<td>8 (12%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td></td>
<td>RMS NOS</td>
<td>4 (6%)</td>
<td>0</td>
</tr>
<tr>
<td>Primary site, n (%)</td>
<td>PM</td>
<td>30 (46%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td></td>
<td>ORB</td>
<td>22 (34%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td></td>
<td>ORB&amp;PM</td>
<td>4 (6%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>HNNPM</td>
<td>9 (14%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Side, n (%)</td>
<td>Left</td>
<td>28 (43%)</td>
<td>5 (33%)</td>
</tr>
<tr>
<td></td>
<td>Right</td>
<td>30 (46%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td></td>
<td>Midline</td>
<td>7 (11%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Treatment protocol, n (%)</td>
<td>MMT 89</td>
<td>20 (31%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td></td>
<td>MMT 95</td>
<td>31 (48%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td></td>
<td>MMT 98</td>
<td>1 (2%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>RMS 2005</td>
<td>11 (17%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2 (3%)</td>
<td>0</td>
</tr>
<tr>
<td>Number of RT Tx , n (%)</td>
<td>0</td>
<td>4 (6%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>54 (83%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td></td>
<td>Multiple</td>
<td>7 (11%)</td>
<td>3 (20%)</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>United Kingdom</th>
<th>United Kingdom</th>
<th>United Kingdom</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>HNRMS</td>
<td>Reference^a</td>
<td>HNRMS</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>8-17 years</td>
<td>16</td>
<td>50.00</td>
<td>9.29</td>
<td>51.26</td>
</tr>
<tr>
<td>18+ years</td>
<td>19</td>
<td>49.30</td>
<td>7.95</td>
<td>50.70</td>
</tr>
<tr>
<td>All ages</td>
<td>35</td>
<td>49.62</td>
<td>8.47</td>
<td>50.96</td>
</tr>
</tbody>
</table>

Kidscreen scale: mean = 50, SD = 10.
^a Country specific weighted norm, adjusted for sex and age
^b 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