



UvA-DARE (Digital Academic Repository)

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

Vaarwerk, B. ; Schoot, R.A.; Maurice-Stam, H.; Slater, O.; Hartley, B.; Saeed, P.; Gajdosova, E.; van den Brekel, M.W. ; Balm, A.J.M.; Hol, M.L.F.; Jaarsveld, S.; Kremer, L.C.M.; Ronckers, C.M.; Mandeville, H.C.; Pieters, B.R.; Gaze, M.N.; Davila Fajardo, R.; Strackee, S.D.; Dunaway, D.; Smeele, L.E.; Chisholm, J.C.; Caron, H.N.; Grootenhuis, M.A.; Merks, J.H.M.

DOI

[10.1002/psc.27498](https://doi.org/10.1002/psc.27498)

Publication date

2019

Document Version

Other version

Published in

Pediatric Blood & Cancer

License

CC BY-NC

[Link to publication](#)

Citation for published version (APA):

Vaarwerk, B., Schoot, R. A., Maurice-Stam, H., Slater, O., Hartley, B., Saeed, P., Gajdosova, E., van den Brekel, M. W., Balm, A. J. M., Hol, M. L. F., Jaarsveld, S., Kremer, L. C. M., Ronckers, C. M., Mandeville, H. C., Pieters, B. R., Gaze, M. N., Davila Fajardo, R., Strackee, S. D., Dunaway, D., ... Merks, J. H. M. (2019). Psychosocial well-being of long-term survivors of pediatric head-neck rhabdomyosarcoma. *Pediatric Blood & Cancer*, 66(2), [e27498]. <https://doi.org/10.1002/psc.27498>

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).

Supplementary tables

Table S1: Comparison of participating and non-participating survivors

| | | Participants (n=65) | Non-participants (n=15) | p-value |
|----------------------------------|----------------|---------------------|-------------------------|-------------------|
| Age at diagnosis (yrs) | Median (range) | 6.0 (0.5-13.4) | 4.5 (0.1-13.6) | 0.35* |
| Sex, n (%) | Male | 42 (65%) | 11 (73%) | 0.76 [#] |
| | Female | 23 (35%) | 4 (27%) | |
| Histology, n (%) | ERMS | 53 (82%) | 13 (87%) | 1 [#] |
| | ARMS | 8 (12%) | 2 (13%) | |
| | RMS NOS | 4 (6%) | 0 | |
| Primary site, n (%) | PM | 30 (46%) | 7 (47%) | 0.74 [#] |
| | ORB | 22 (34%) | 7 (47%) | |
| | ORB&PM | 4 (6%) | 0 | |
| | HNNPM | 9 (14%) | 1 (7%) | |
| Side, n (%) | Left | 28 (43%) | 5 (33%) | 0.71 [#] |
| | Right | 30 (46%) | 8 (53%) | |
| | Midline | 7 (11%) | 2 (13%) | |
| Treatment protocol, n (%) | MMT 89 | 20 (31%) | 2 (13%) | 0.56 [#] |
| | MMT 95 | 31 (48%) | 10 (67%) | |
| | MMT 98 | 1 (2%) | 0 | |
| | RMS 2005 | 11 (17%) | 3 (20%) | |
| | Other | 2 (3%) | 0 | |
| Number of RT Tx , n (%) | 0 | 4 (6%) | 2 (13%) | 0.25 [#] |
| | 1 | 54 (83%) | 10 (67%) | |
| | Multiple | 7 (11%) | 3 (20%) | |

* 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

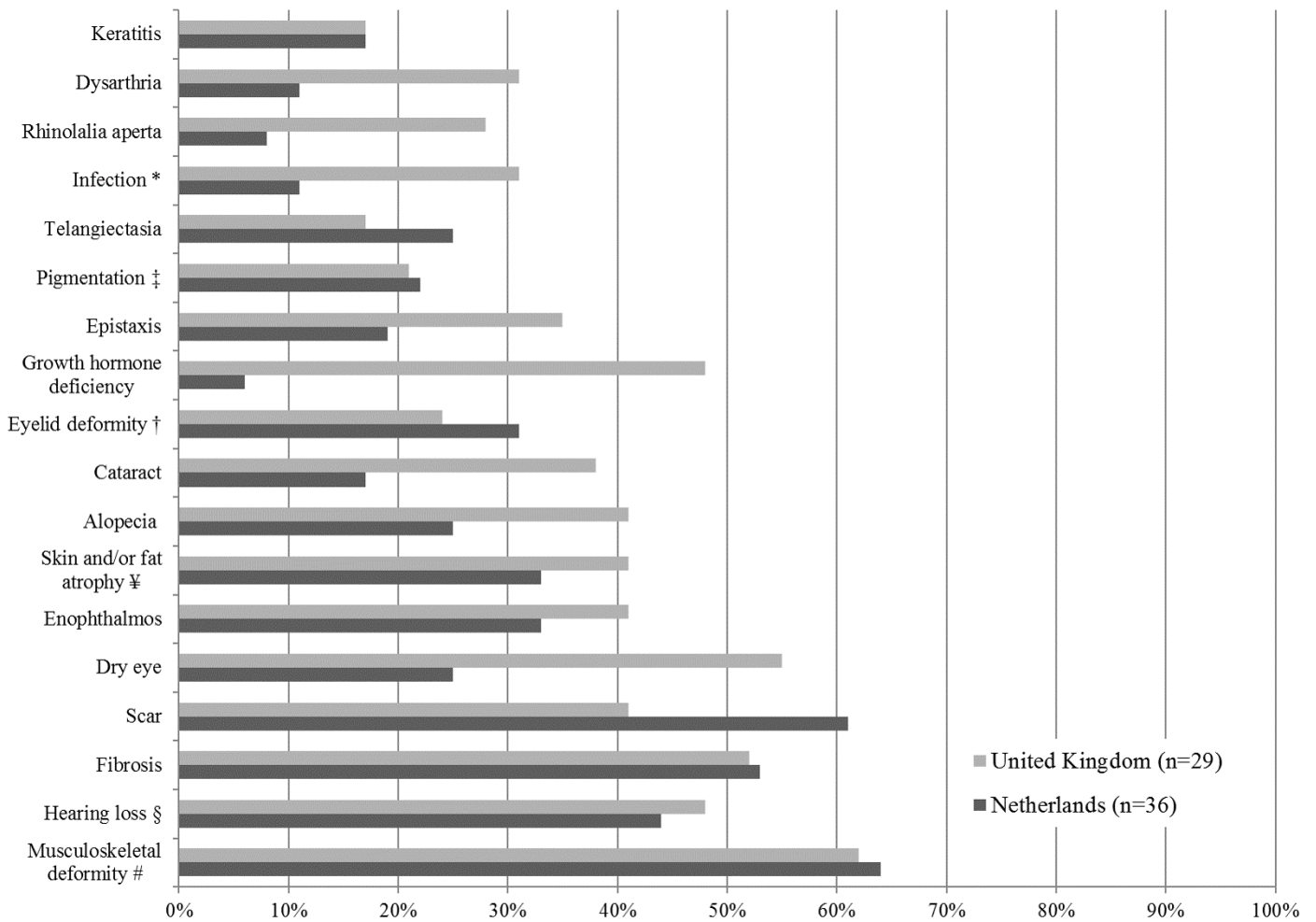
| | Netherlands | | | | | | | United Kingdom | | | | | | |
|-------------------|-------------|-------|------|------------------------|------|--------------------|----------------------|----------------|-------|-------|------------------------|------|--------------------|----------------------|
| | HNRMS | | | Reference ^a | | HNRMS vs reference | | HNRMS | | | Reference ^a | | HNRMS vs reference | |
| | n | Mean | SD | Mean | SD | Effect size | p-Value ^b | n | Mean | SD | Mean | SD | Effect size | p-Value ^b |
| 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.

^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)

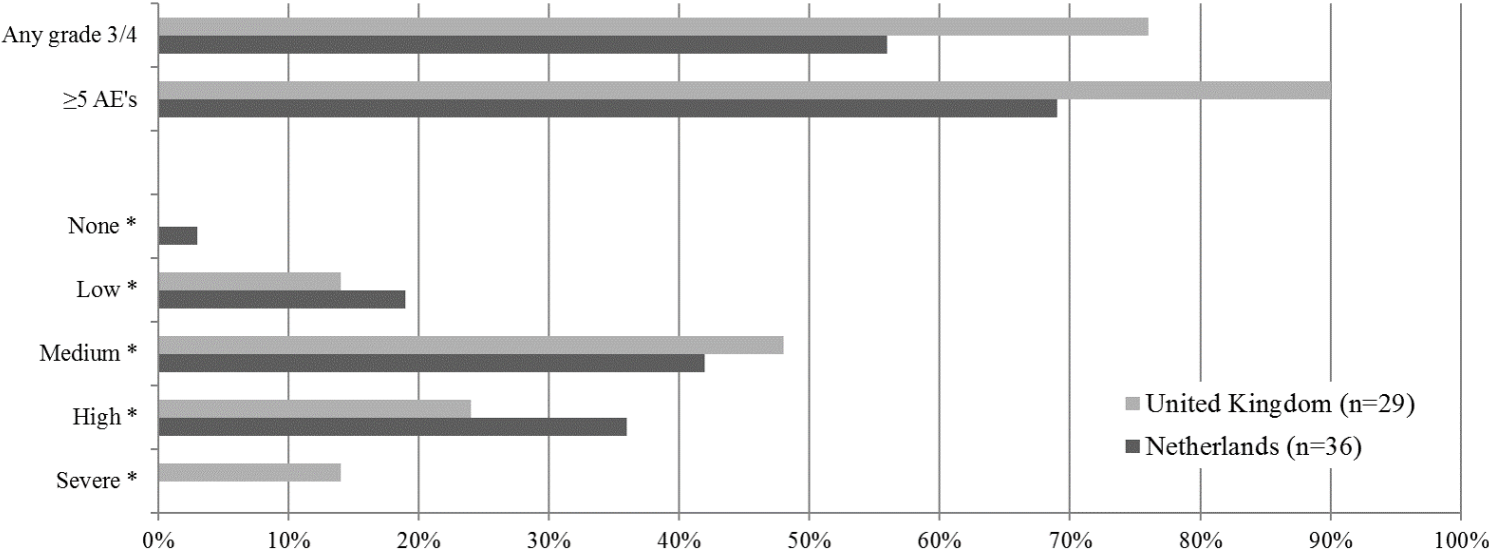
‡ Skin and/or fat atrophy comprises: fat atrophy, skin atrophy

† 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