

PAPER 15

The Sarcoma-Specific Quality of Life Study (SARC-QoL): Identifying key domains of Health-Related Quality of Life in adult patients with extremity soft tissue sarcoma

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Background:

The patient's subjective experience of disease is an increasing focus in health care delivery [1, 2]. Health-related quality of life (HRQoL) is defined as a "functional effect of a medical condition and its consequent treatment" [18]; it is both self-reported and multi-dimensional [3-5]. While functional outcome is well researched among the soft tissue sarcoma (STS) population, few studies have focused on HRQoL [6-13], which gives a broader understanding of the psychological, somatic, social and physical toll of cancer and its treatment from the patient's viewpoint. The biologic and anatomic heterogeneity of sarcomas are considerable: a patient treated with soft tissue resection and free flap will have vastly different needs than an individual treated with an amputation or rotationplasty, for example [14, 6, 7, 15]. A recent systematic review (SR) highlights a small, heterogeneous group of QOL studies in STS, but fails to identify any sarcoma-specific measures [16]. A second SR of 31 articles on HRQoL in sarcoma reported lack of sarcoma-specific outcomes that capture psychosocial impacts and unmet needs to people with sarcoma across healthcare spectrum [17]. Just as the treatments are diverse, we surmise that the indicators of patient HRQoL differ and are not captured in existing generic HRQoL tools for cancer.

Questions/purposes:

The study objectives were to explore the domains of HRQoL and functioning in adult patients diagnosed with extremity STS from the patient's perspective from active care through survivorship through qualitative inquiry, so as to form the basis for the development of a patient-derived, sarcoma-specific, preference based HRQoL tool.

Patients and Methods:

Study design is a sequential exploratory mixed methods study of patient experience in localized or metastatic adult extremity STS (2007 and 2017). The study was conducted at a high-volume sarcoma centre. Qualitative descriptive design was grounded in an integrated knowledge translation approach and aimed at identifying HRQoL domains through in-person and electronic focus groups, and individual semi-structured interviews in both English and French (N=28). The interview guide topics were selected based on existing knowledge about PROs and HRQoL life [24], including (a) impact of diagnosis on employment or acquisition of academic/vocational skills; (b) physical and psychological functioning; (c) symptom burden; (d) treatment preferences; (e) knowledge of and use of existing resources; (f) impact on family time and resources; and (g) overall experience. Data was analyzed using inductive thematic networks approach using the qualitative software N-Vivo 12. Codes were generated by 2 independent qualitative experts capturing key concepts of HRQoL that is impacted by STS. Basic themes were clustered into organizing themes, and merged into global domains. Attention was paid to deviant cases and within-group dynamics during focus group discussion analysis. Discrepancies or inconsistencies in coding were resolved in consensus meetings. Final sample size was determined when data saturation was reached and no new themes emerged. Qualitative reduction of identified items to reach a consensus framework was facilitated by a moderator during multi-disciplinary panel meetings comprised of sarcoma experts, patient partners, allied health staff and other stakeholders.

Results:

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Twenty-nine patients with biopsy-proven localized or metastatic STS of the extremity participated (69% lower extremity STS; mean age 56 years, 25% with local recurrence, 21% metastatic, 18% amputation). Inductive thematic network analysis revealed five domains and subdomains of HRQoL for patients with STS: 1) physical domain (subdomain: physical symptoms, treatment complications), 2) psychological domain (anxiety, distress, mood, body image and identity), 3) medical support (emotional support, practical support, confidence in positive outcome and reluctance to medical personnel), 4) social life (family and social support), and 5) daily living (disruption of routine and finances).

Conclusion:

Patient-centered research is crucial to understanding the impact of surgery, adjuvant therapy and the associated complications for patients with extremity STS, and thereby improving the quality of care provision. This study offers a unique perspective on what domains and sub domains are most impactful on HRQoL and provides the basis for our on-going development of a disease-specific, preference-based HRQoL measure.

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