Psychological Functioning and Coping Styles in Adults with Extremity Soft Tissue Sarcoma: A Qualitative Analysis from the Soft Tissue Sarcoma Quality of Life (SARC-QoL) Study

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WHY IS THIS IMPORTANT?

- Psychological distress is frequently reported in patients with cancer.
- Soft-tissue sarcoma (STS) is considered an ‘orphan’ cancer due to low prevalence, with patients facing lower survival rates compared to other cancers (50 to 60% 5-year survival) (Jacobs et al., 2015).
- Impact of STS on one’s person, family, and the health care system is significant, with up to 50% reporting some form of long term disability (Parsons & Davis, 2004).

HYPOTHESIS

- Adult patients with extremity STS have a unique experience that is not currently captured in existing generic quality of life (QoL) measures.
- Patient-reported experience and coping styles will provide crucial insights into the psychological functioning QoL-domain in this population.

WHAT DID WE DO?

Three main objectives:
1. To explore affective responses and coping mechanisms of patients diagnosed with an extremity STS at various stages of illness.
2. To identify areas of psychological functioning that most impact these patients;
3. To describe how these areas could be best addressed in clinical settings.

METHODS

Study design: Sequential exploratory mixed methods study of patient experience
Qualitative interviews (n=28):
- Online focus groups (n=12)
- In-person focus groups (n=12)
- Semi-structured interviews (n=4)

Interpretive description content analysis:
- Inductive thematic network approach (3 qualitative experts)
- Descriptive data analyzed with NVivo 10 (QSR International Pty Ltd) qualitative software
  - Creation of codes
  - Reflecting on emerging thematic patterns

DEMOGRAPHICS (n=28)

<table>
<thead>
<tr>
<th>Patient demographics</th>
<th>Mean ± SD or % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56.1 ± 13.6 years</td>
</tr>
<tr>
<td>Gender</td>
<td>46% (13) women; 54% (15) men</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>31 mos ±21</td>
</tr>
<tr>
<td>Tumour location</td>
<td>Lower extremity: 68%; Upper extremity: 32%</td>
</tr>
<tr>
<td>Surgery</td>
<td>Minor: 25%; Moderate: 40%; Major: 35%</td>
</tr>
<tr>
<td>Local recurrence</td>
<td>25% (n=7)</td>
</tr>
<tr>
<td>Metastasis</td>
<td>21% (n=6)</td>
</tr>
<tr>
<td>Amputation</td>
<td>18% (n=5)</td>
</tr>
</tbody>
</table>

PATIENT IMPACT

- Patient-reported QoL measures are crucial to understanding the patient experience.
- Maladaptive coping styles (passive acceptance and avoidance/denial) are endorsed as common experiences among STS patients and negatively impact HRQoL.
- Clinicians and researchers should aim to promote adaptive coping mechanisms (positive reframing, optimism, finding meaning), especially during active treatment and surveillance.

CONCLUSION

- Psychological concerns and distress are prominent among patients with STS, and there is a need to capture their unique experience in future HRQoL measures.
- Targeted psychosocial interventions in STS should be evaluated.

SOME QUOTES FROM THE PARTICIPANTS

I’m glad to come back [to the clinic and do research] especially if it helps anyone else, I know mine was a very rare disease so if anybody can learn anything from this, that’s great.

I never wanted my illness to affect my quality of life, even though I face obstacles. I have always been optimistic.

I always tried to push myself to do better, to get out of my mood swings, my negative moments and so on. [...] After the surgery, it’s like my life has collapsed. I thought I could not do anything with my right hand. [...] I was a little depressed.

TRANSLATION ACROSS THE RCN

Expansion of this methodology to people with head and neck as well as pelvic and retroperitoneal STS.

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