

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 networks approach (3 qualitative experts)
- Descriptive data analyzed with NVivo 10 (QSR International Pty Ltd) qualitative software
 - Creation of codes
 - Reflecting on emerging thematic patterns

"I am so scared of having another sarcoma, or even worse, chest cancer"

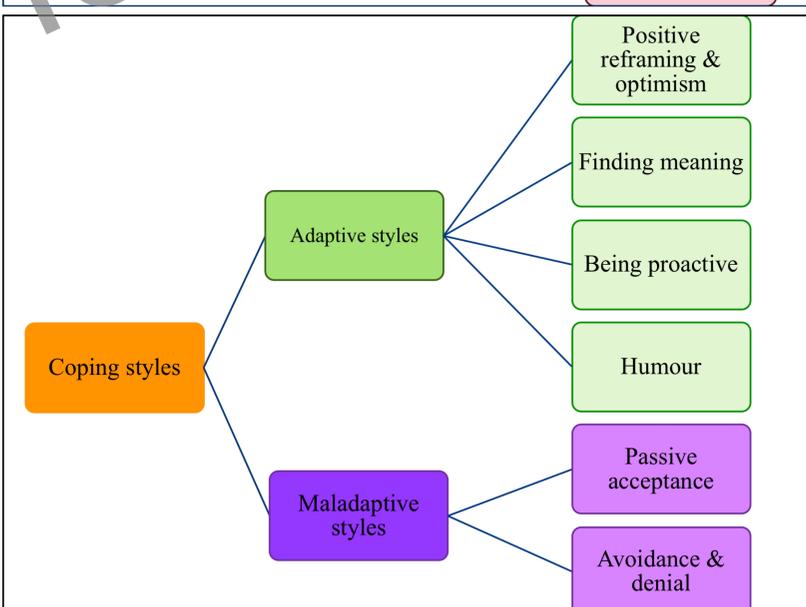
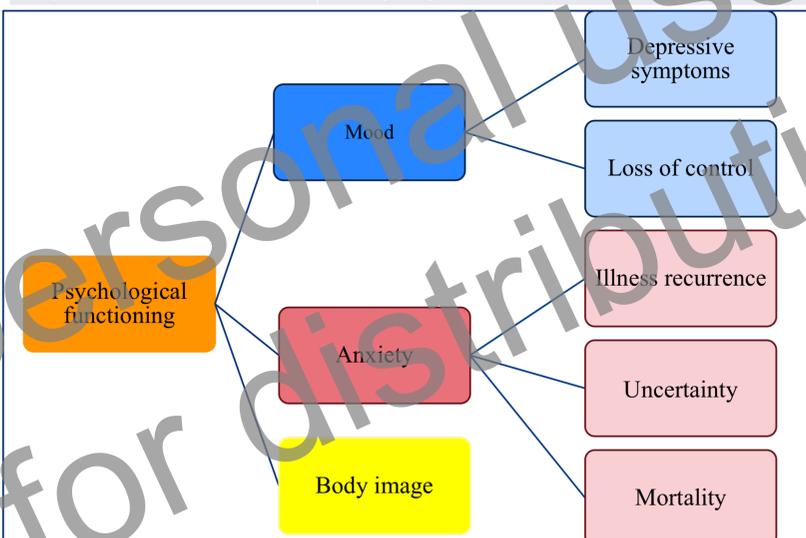
Basic Theme
Worries about recurrence of disease

Organizing Theme
Experiencing anxiety

Global Theme
Psychological functioning

DEMOGRAPHICS (n=28)

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



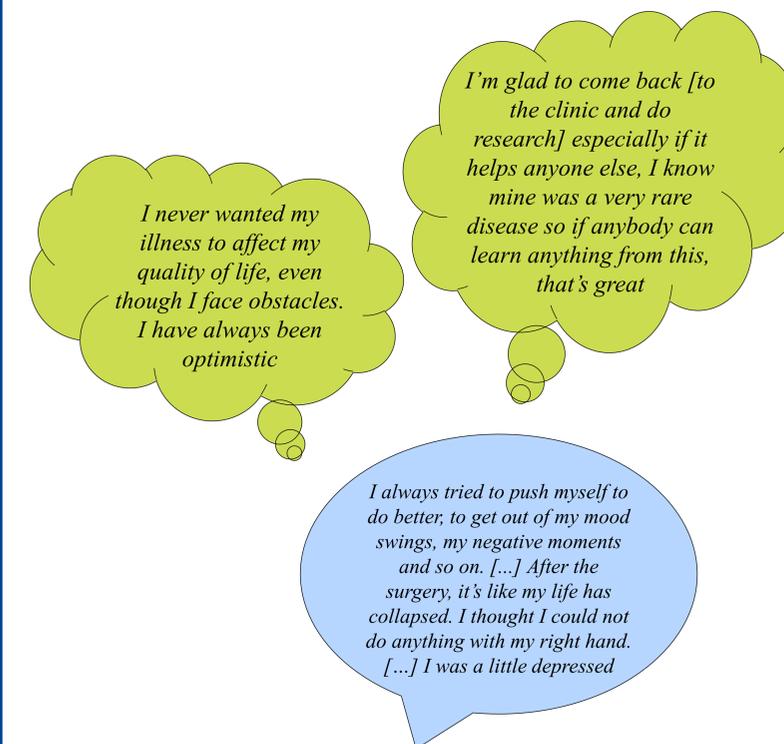
PATIENT IMPACT

- 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



TRANSLATION ACROSS THE RCN

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