


RESEARCH ARTICLE

Psychological functioning, coping styles and their relationship to appraisal of physical limitations following invasive surgical procedures for soft-tissue sarcoma: A qualitative study

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Abstract

Background and Objectives: This study explored psychological functioning and coping styles in adult patients with soft-tissue sarcoma who underwent surgical procedures in a single expert sarcoma medical center in Canada.

Methods: This is a qualitative study with three formats of data collection. The interview guide was based on theoretical health-related quality of life model. We began the investigation with 2 online and 2 in-person focus groups. Four individual semistructured interviews were added to further explore emerging themes. Data were analyzed using inductive thematic networks approach.

Results: Twenty-eight adults (13 female, 24–75 years of age) participated. In the domain of psychological functioning we identified three main themes; changes in mood, worry, and body image concerns. In the domain of coping styles, we identified four adaptive coping styles; positive reframing and optimism, finding a purpose, being proactive, and using humor. Among the maladaptive coping styles, we found passive acceptance, and avoidance and denial.

Conclusions: Psychological well-being can be contingent on physical functioning and coping styles in adults with soft-tissue sarcoma. Both psychological and physical function impact quality of life. Patients with more physical limitations, psychological distress and maladaptive coping styles should be monitored for their well-being.

KEYWORDS

adult, coping styles, psychological functioning, qualitative study, quality of life, soft-tissue sarcoma

As a surgeon, I was happy with the range of motion the patient regained after a tumor resection. But it broke my heart to see them sad because they were unable to lift their child.

—Surgical resident

1 | INTRODUCTION

Soft-tissue sarcomas are a rare and heterogeneous group of solid malignant tumors, which originate from the mesenchymal cells, and can occur in any soft-tissue within the body; in any location of

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fat, muscle, or connective tissues.¹ Though the prevalence of STS is low, about 1% of all adult cancer cases,² the impact of this rare tumor on one's person, family, and the health care system remains significant.³

With overall increasing survival rates of patients with cancer, the focus of treatment has expanded from optimizing function to psychological rehabilitation and quality of life.⁴ Compared to other types of tumors, patients with STS still face lower survival rates, around 50%-60% 5 years following the diagnosis.^{5,6} Additionally, a significantly higher proportion of patients with STS compared to cancer-free population report medical comorbidities such as cardiovascular disease,⁷ and up to 50% of patients with STS report long-term disability status.⁸ Patients with STS also report lower quality of life (QOL), and suffer from depression more often than patients with other forms of cancer.⁹⁻¹¹

Patients with STS typically undergo a combination of invasive surgery and radiation therapy, which can result in disfigurement, wound complications, or amputation.^{1,2,12} While these procedures have a curative intention and are largely limb-sparing, these medical interventions come with a high burden to patients.⁹ High levels of psychological distress are often recorded in the initial phases of cancer diagnosis and treatment¹³⁻¹⁶ and can compromise long-term outcomes if left unattended.^{17,18}

Physical and psychological function are two interlinked domains of health-related quality of life.¹⁹ Physical function tends to improve in the initial postoperative phase until it reaches a plateau. Interventions such as physical and occupational therapy are predominantly targeted to this stage of treatment and recovery. Psychological functioning also includes modifiable factors that present an opportunity for intervention, for instance: coping mechanisms. An example of the relationship between the two domains is body image. Visible scarring might be an unavoidable result of a life-saving treatment, however, an individual's appraisal of such scarring will greatly influence their sense of identity and even social life.²⁰ In fact, the existing literature suggests that patients' understanding and perceptions of cancer carry more weight in psychological adaptation than objective clinical or sociodemographic factors.²¹

Psychological functioning is an important patient-reported outcome (PRO) in quality of life, and PROs are important components of patient-centered research and care.^{22,23} Because sarcoma patients experience a high disease burden in respect to their incidence,^{10,24} there is a need to develop novel tools, which will offer better holistic rehabilitation for patients with soft-tissue sarcoma.

Qualitative methods allow for an in-depth exploration of patient-reported outcomes, which include personal experiences, psychological functioning, and coping styles.²⁵ Our analyses in this study were driven by three main goals: 1) to develop a better understanding of the affective responses and psychological functioning in patients who face this rare illness, 2) to identify coping mechanisms, which impact appraisals of surgical and treatment outcomes, and 3) to describe how these areas could be addressed in clinical settings.

2 | MATERIALS AND METHODS

2.1 | Participants and recruitment

Participants were recruited from a high-volume sarcoma referral center in Montreal, Canada. All eligible participants were adult patients with biopsy-proven localized or metastatic STS of the extremity, diagnosed and treated between January 2007 and April 2018. Eligible participants registered within a prospective database of all sarcoma patients since 2003 were first approached by phone and invited to participate by medical personnel and research assistants. Purposive sampling was employed with the aim to ensure approximately representative distribution of patients across demographic (gender, age) and disease variables (surgery type, tumor site), compared to the prospective database.²⁶ Focus groups were matched in size and language. Convenience sampling was used for semistructured interviews. The final sample size was determined when data saturation was reached, and no new themes emerged from the semistructured individual interviews. For more details please see Tables 1 and 2.

2.2 | Design and procedure

This study is a part of a larger sequential, exploratory mixed-methods study on health-related quality of life (HRQoL) in adult patients with extremity STS. The study was approved by the institutional Research Ethics Board (Protocol #2018-4405).

First step to data collection included electronic (e)-focus groups, in-person focus groups in English and French. The online focus group was done via e-mail. Participants provided written responses to one question at a time. The responses were shared on the chain e-mail by the moderator (GDL). Before posing a new question, participants had a chance to respond to other's comments and responses. The e-focus group resembled a well-moderated and organized group chat, which allowed for adequate interpersonal exchange. In-person focus groups were held in private rooms at the study site. Online mode of participation allowed us to recruit participants living far from the study side, those unable to travel, or those who had other commitments and were only able to participate on their own time.

Data were examined and analyzed sequentially. After the focus group data collection was completed we added individual interviews to further explore emerging themes arising from the focus groups.²⁷

The interview guide was based on the existing theoretical models of health-related quality of life^{19,28} and refined with advisory group that included patient advocates, sarcoma experts, members of the sarcoma unit, as well as the research team. All participants were asked about (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. All formats of data collection relied on the

TABLE 1 Participants included in three modes of data collection. Their participant numbers are associated with the quotations in text

E-focus group (n = 12)	In-person focus group (n = 12)	Individual in-person interview (n = 4)
1. Participant 1 (ENG)	1. Participant 8 (ENG)	1. Participant 25
1. Participant 2 (ENG)	1. Participant 9 (ENG)	1. Participant 26
1. Participant 3 (ENG)	1. Participant 10 (ENG)	1. Participant 27
1. Participant 4 (ENG)	1. Participant 11 (ENG)	1. Participant 28
1. Participant 5 (ENG)	1. Participant 12 (ENG)	
1. Participant 6 (ENG)	1. Participant 13 (ENG)	
1. Participant 7 (ENG)	1. Participant 19 (FRA)	
1. Participant 14 (FRA)	1. Participant 20 (FRA)	
1. Participant 15 (FRA)	1. Participant 21 (FRA)	
1. Participant 16 (FRA)	1. Participant 22 (FRA)	
1. Participant 17 (FRA)	1. Participant 23 (FRA)	
1. Participant 18 (FRA)	1. Participant 24 (FRA)	

Note: (ENG) indicates individuals who participated in English and (FRA) indicates participants who participated in French focus groups.

same open-ended questions: *Can you tell me about your feelings and experience of being diagnosed/treated for soft tissue sarcoma? How has sarcoma affected your psychological state? What has been the impact on your appearance and body image?*

All participants provided written consent. Researchers trained in qualitative methods (UK, GDL, AT) were responsible for moderating the focus groups and conducting semistructured individual interviews. The data from the e-focus group were collected over the span of 5 weeks. The in-person focus groups lasted on average 95 minutes, while individual interviews lasted on average 45 minutes. Data collection occurred between May and July 2018. Individual interviews and focus group discussions were audio recorded. Audio recordings were later transcribed verbatim and the excerpts used in this manuscript are not corrected for grammar. Translations from French were carried out by GDL and checked by AT. Names or other personal information was omitted for confidentiality.

2.3 | Data analysis

Analysis was done using an inductive thematic networks approach.²⁹ The principals of interpretative description guided the analysis, which entailed reflection, critical examination, and informed questioning, to gain insight on the impact of the diagnosis and treatment of STS on the patient and their families.³⁰ Researchers (UK and GDL) read the transcripts repeatedly and independently generated codes that captured key thoughts and concepts referring to psychological functioning and coping mechanisms from the focus groups. Data from individual interviews and from focus groups was analyzed using the same approach,^{27,31} and inductive content analysis was used to consolidate findings.³²

The primary author (UK) kept a reflexive journal to explore the concepts and emerging themes. To account for participants' and researchers' cultural context and understanding of the interviews, meanings were produced jointly. Interpretations on both sides enabled confirmation or rejection of researchers' perceptions of data.³³ To further maximize reliability, any discrepancies in coding and face validity of the emergent themes were resolved or discussed in a meeting with the entire research team.

Data analyses were done using NVivo 12 software.

3 | RESULTS

3.1 | Participants

From 615 patients from the prospective data based held at the study site, 64 participants who met our purposive sampling criteria were contacted. Twenty-eight responded positively and participated in our study. For those not wishing to participate reasons for doing so varied, but were not systematically recorded.

Participants were included in two online focus groups (total n = 12, English n = 6), 2 in-person focus groups (total n = 12, English n = 6), and individual semistructured interviews (n = 4). Table 1 shows in which modality participants were included. The mean age of our sample was 56 years (range, 24 to 75), and mean time since diagnosis was 31 months (range, 2 to 92). Thirteen participants (46%) were women. The majority (68%) of our sample had a lower extremity STS; 7 (25%) participants developed a local recurrence, six (21%) had metastatic disease, and 5 (18%) had been amputated. Descriptive data and other demographic and medical information of our sample can be found in Table 2.

TABLE 2 Demographic and medical information of the participants

		Prospective database (n = 866)
Gender		
Male	15 (54)	55%
Female	13 (46)	45%
Age		
<40 y	4 (14)	27%
41-64 y	15 (54)	33%
>65 y	9 (32)	40%
Tumor site		
Lower	19 (68)	74%
Upper	9 (32)	26%
Surgery type		
Minor	7 (25)	
Moderate	11 (39)	
Major	10 (36)	
Radiation		
Yes	28 (100)	99%
Chemotherapy		
Yes	4 (14)	15%
No	24 (86)	
	No	85%
Recurrence		
Yes	7 (25)	10%
No	21 (75)	90%
Metastasis		
Yes	6 (21)	14%
No	22 (79)	86%
Amputation		
Yes	5 (18)	4.5%
No	23 (82)	
Other cancer		
Yes	2 (7)	
No	26 (93)	
Months since diagnosis		
	Mean (SD; range)	
	31.2 (21.5; 2-92)	

Note: Tumor site: upper = upper extremity; lower = lower extremity. Surgery classification: minor surgery = subcutaneous and superficial; moderate surgery = involves muscle resection; skin graft; major surgery = involves nerve/vessel reconstruction, bone resection, plastic surgery, other cancer = participants who had multiple cancer diagnoses.

3.2 | Psychological functioning

Our analyses of psychological well-being and functioning of adult participants with soft-tissue sarcoma revealed three organizing themes; *changes in mood*, *worry*, and *body image concerns*. These emergent themes overlapped and were not mutually exclusive.

Patients accounts related these themes to their treatment procedures, physical functioning and impairments.

3.3 | Changes in mood

3.3.1 | Experiencing low mood

Low mood reported around the time of diagnosis was accompanied by fear and shock in 18/28 (64%) participants. Additionally, majority of participants who reported feeling low mood during the phase of treatment and recovery, linked their low mood to unpleasant physical symptoms and physical limitations due to surgical procedures. One participant expressed how direct the impact of physical limitation on her mood has been:

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.

(Participant 16; female, 58 years, major surgery)

Participants emphasized that the psychological impact of their disease impacted their perceived QOL. One woman who reported experiencing lower mood also reported more difficulty controlling her emotions:

I used to be strong before but while I am going for radiation I used to cry for stupid things. At the end I told the doctor I don't want to continue I cannot take it anymore. [...] I became extremely sensitive, and I am usually not. I would cry for stupid things. My tears would fall like a waterfall.

(Participant 3; female, 39 years, major surgery)

Two participants who reported experiencing distress before receiving their diagnosis of STS reported having a particularly hard time.

I am already naturally a stressed and anxious person, and a little more pessimistic in life. So, all the news in the last few months, like the possibility of amputation and cancer, they affect me enormously.

(Participant 13; male, 43 years, moderate surgery)

3.3.2 | Loss of control and independence

In addition to the disruption of a normal routine during treatment, participants felt that their life was being scheduled for them by secretaries and other clinic personnel, which contributed to the feeling of loss of independence.

You feel like you're getting on a train and you can't get off, and it's appointments and scans, and appointments and scans and the wait time [...] once you get sucked into the system then suddenly you are not your own boss anymore.

(Participant 28; male, 67 years, major surgery)

Similarly, the invasive surgical procedures resulted in a lack of or reduced mobility in 21 of 28 (75%) participants and made them dependent on others in their everyday endeavors. Participants reported having to adjust their routines and let go of activities and hobbies, which were physical in nature. Three young adult participants and those who made a full recovery reported the loss of independence to be limited to the time in treatment and recovery from the surgery. However, participants whose disease has returned, or those who experienced medical complications reported ongoing struggles with loss of independence.

I cannot work at present; family and close friends come to my home for a few hours and help me out. A few people have stayed with me for several days. I have become the delivery queen: I get deliveries from the pharmacy, from a food service and from Amazon.

(Participant 6; female, 66 years, major surgery)

Losing independence was reported to be burdensome and difficult for some participants to accept.

The most difficult effect of sarcoma was the temporary loss of independence, [...] to this day, I think I would prefer death to being a burden on my loved ones, i.e. requiring help for my basic daily activities.

(Participant 2, male, 29 years, moderate surgery)

3.4 | Worry

3.4.1 | Worry related to illness recurrence

Worries about illness recurrence were reported by 27 of 28 (96%) participants. These worries were particularly pronounced in participants who had already experienced local recurrence or metastatic disease. In addition to worry, some level of self-reported anxiety was often reported in relationships to follow-up appointments.

I used to come down every 3 months, now it's every 6 months, and when I come down there's a little bit of anxiety because you are not sure what the tests are going to show.

(Participant 27; male, 58 years, major surgery)

One of the participants recounts that the first year after treatment was hard psychologically, but his anxiety subsided as more time passed.

I would say that the first 4 years after the operation I was really paranoid and I made several visits to my family doctor because any small health problem was, for me, associated with cancer.

(Participant 13; male, 43 years, moderate surgery)

3.4.2 | Uncertainties about the future

Varying degrees of uncertainty were present across different stages of the illness, from the initial diagnosis and treatment, when patients wondered what would happen to them, through to survivorship when, despite being in remission, participants wondered if they would be diagnosed with cancer again. This uncertainty was expressed as frustration, and as the participant points out, having a routine and concrete plans was difficult

One thing that's been hard, is trying to organize and plan things in advance because there is so much uncertainty and nobody gives us clear answers.

(participant 28; male, 67 years, major surgery)

A total of 18 of 28 (64%) of the participants in our study who identified as caregivers, reported feelings of sadness that accompanied the uncertainty about the future. They reported fear of missing out on their children's development, as well as fear of failing to provide and to continue to take care of their offspring.

3.4.3 | Facing one's own mortality

Thoughts and mentions of death were reported by all participants. These thoughts were present at the time of diagnosis and persisted through to the survivorship phase. Participants expressed a heightened awareness of their own mortality, which, in some, led to further appreciation of life, while in others caused a great level of distress and anxieties. A participant who was unsure if he would require an amputation, tried appreciating his mobility prior his surgical procedure:

I started thinking that it could be serious, then I started realizing, um, that my life would possibly change in the future, so I started making a point of working around and appreciating the, appreciating what I am seeing, what I am doing.

(Participant 28; male, 67 years, major surgery)

For a few participants, the word *cancer* instantly led to thoughts about death. They dreaded the idea of being subjected to invasive medical care, but felt they had no other recourse.

I did not receive a diagnosis, I received a death sentence.

(Participant 19; male, 58 years, moderate surgery)

One young participant dreaded the idea of being operated on, however, she was also worried about dying. She decided to follow the treatment because the major surgery, though extremely distressing, was the lesser evil:

I think that's my worst fear, dying. That's why I did the operation; I knew that otherwise it [death] was pretty guaranteed.

(Participant 26; female, 34 years, major surgery)

3.5 | Body image concerns

A total of 21 of 28 (75%) of our participants underwent moderate to major surgical procedures (see Table 2 for definition), and 5 of 28 (18%) received an amputation. All participants underwent surgery and these procedures resulted in varying levels of disfigurement and scarring, with majority 21 of 28 (75%) reporting visible and permanent changes in appearance and functionality. A total of 7 of 28 (25%) participants reported that their surgeons were not able to predict whether an amputation would be necessary until they started the surgery. One participant recounts her disbelief after she had awoken from the surgery:

I kept touching my leg to make sure that it had not been amputated.

(Participant 1; female, 70 years, minor surgery)

The unpredictability of surgical outcomes provoked distress and feelings of anxiety, however, at the time before the surgery participants reported being more concerned about the functionality of their limb rather than physical appearance.

I don't wanna lose my arm. How am I going to work? That's the first thing, that's the first thing that struck me.

(Participant 9; female, 51 years, moderate surgery)

While most participants reported relief in retaining their limbs and regaining strength after physiotherapy, majority (16 of 21, 76%) of participants who underwent moderate to major surgical procedures reported feeling self-conscious about scars and disfigurements.

The only thing my arm looks different, I don't like anyone to see it, so even in a hot day I wear long sleeves or something covering the scar.

(Participant 3; female, 39 years, major surgery)

Body image concern was described as a significant impact on participant's quality of life:

The only thing that really impacts my life is this, this sort of skin flap, I can't, or, I don't wear shirt, anymore

short sleeves, I always wear long sleeve, and um, I guess I'm a little bit, um, I guess embarrassed about it.

(Participant 27; male, 58 years, major surgery)

3.6 | Coping with illness

We identified four adaptive coping styles—*positive reframing and optimism, finding meaning, being proactive, and using humor*—and two maladaptive coping styles—*passive acceptance, and avoidance and denial* (see Figure 1).

3.6.1 | Positive reframing and optimism

Many participants reported feeling optimistic, particularly when hearing positive news about their illness or treatment outcomes, or when feeling supported by their friends and family. Some participants identified with a “glass half-full perspective” of their experience;

It's really funny because the illness has brought gifts, you know, people I don't know or even neighbors dropping food by, you know, all the beautiful gestures.

(Participant 11; female, 67 years, minor surgery)

Participants reported that staying positive during a life-threatening illness was not easy, however, those who reported having trust in their medical team seemed to have accepted their diagnoses more readily and felt as though they were not alone in their battle against cancer.

I am talking to the doctor and she is confident that she will be able to take care of my problem and I, I see her confidence and that gives me confidence.

(Participant 28; male, 67 years, major surgery)

3.6.2 | Finding meaning

A total of 8 of 28 (29%) participants explicitly reported endorsing a new identity as cancer survivors, which gave them a sense of purpose and helped them accept the illness. They adopted a positive stance, accepting challenges and the illness as part of who they became. They found strength in being good parents, or grandparents, and reported gratification in participating in research:

I'm glad to come back 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.

(Participant 27; male, 58 years, major surgery)

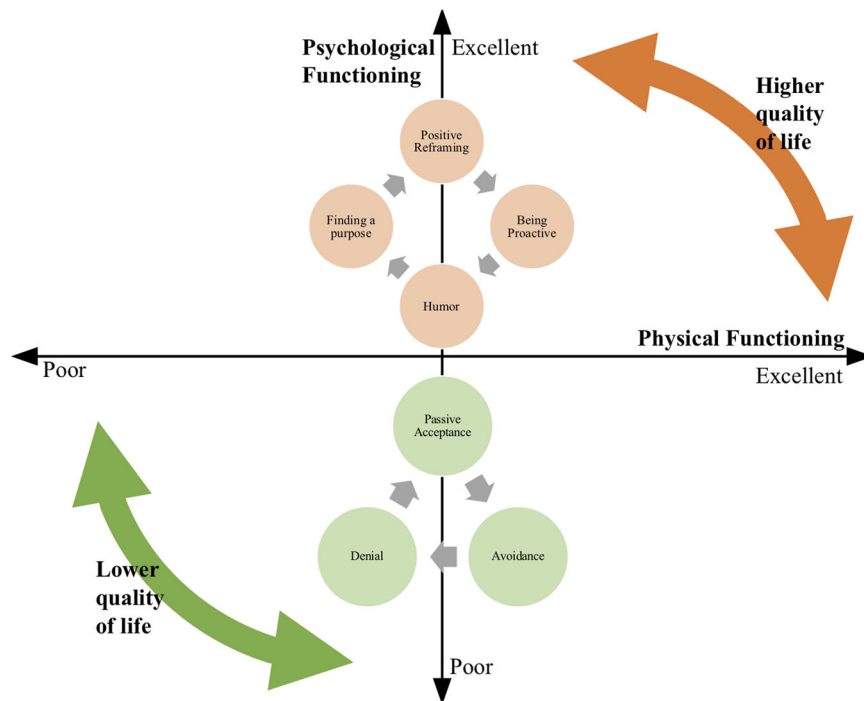


FIGURE 1 Psychological and physical functioning are two interrelated domains of health-related quality of life (HRQoL). The x-axis shows relative levels of physical functioning, from poor (severe impairment) to excellent (no impairment). The y-axis shows a relative level of psychological functioning, from poor (severe psychological distress) to excellent (no signs of psychological distress). Those who find themselves in excellent levels of psychological and physical functioning report higher HRQoL, and individuals who find themselves in poor levels of psychological and physical functioning report lower levels of HRQoL. Adaptive coping mechanisms (light orange, positive are on the y-axis) can contribute to better psychological functioning as well as better coping with physical limitations. Maladaptive coping mechanisms (light green, negative on the y-axis) can contribute to psychological distress and poorer acceptance of surgical and physical outcomes [Color figure can be viewed at wileyonlinelibrary.com]

3.6.3 | Being proactive

As a way of regaining the independence lost due to their illness, participants reported being more proactive in their everyday life, or other domains not impacted by their illness. Those who reported being proactive about their health and well-being were more hopeful and optimistic about the future and long-term outcomes. Adherence to preventative guidelines (such as using sunscreen or avoiding smoking) was noted as a way of staying proactive and taking care of their health.

3.6.4 | Using humor

The use of humor was recorded on multiple occasions, in focus groups and individual interviews alike. Sometimes the use of humor came with a sense of bitterness, however, humorous way of coping was most commonly observed in the participants who also held a positive outlook. Participants enjoyed recounting anecdotes from their encounters with medical teams and reported a lightened atmosphere when doctors utilized humor as well.

Now, it's been 35 years later and I've got my second cancer and my thing is, I made it through again; my next

one is gonna be at 105 and at that point I won't care anymore.

(Participant 8; male, 73 years, major surgery)

3.6.5 | Passive acceptance

Contrary to the proactive nature of some of the participants, those, 7 of 28 (25%) who experienced recurrence or complications after the surgery, or were severely limited in their mobility reported more apathy as well as moderate levels of demoralization. Accepting their illness was more difficult to do, and phrases as “*what will be, will be*” were commonplace. One participant (Participant 25; female, 58 years, major surgery) who was experiencing serious wound complications around the groin area and had been hospitalized for a prolonged period felt as though the outcomes were no longer in her hands and felt at the mercy of the medical team and treatments.

3.6.6 | Avoidance and denial

Avoidance and denial were present in majority of participants before receiving the diagnosis. Many participants reported having noticed

growths, however, lack of other symptoms delayed their follow-up, even upon doctors' suggestions to do so. One participant believed that thinking about his illness would make it worse and thus referred to cancer as a *problem* or a *thing*. He also reported not wanting to be too informed:

I don't do absolutely no research of cancer. I don't need to know. If I can't change it, I don't need to know.

(Participant 10; male, 58 years, minor surgery)

One of the younger participants also reported having doubts about his diagnosis, and 1.5 years after his diagnosis still reports having a hard time accepting it:

Some details didn't make sense, angiosarcoma is very rare in young patients and it very rarely—if at all—affects feet. This created certain doubts about the accuracy of my diagnosis and some part of me still wanted to believe it was not cancer.

(Participant 2; male, 29 years, moderate surgery)

4 | DISCUSSION

Qualitative study of the unique needs and challenges of patients with extremity STS is lacking in the literature. This study provides invaluable insight into subjective patient experience, which will inform the development of new PRO measures. Our study investigated psychological functioning and coping mechanisms in adults with extremity STS. Majority of the research in STS to date focused on oncologic survival and functional outcomes.^{8,34} Particularly we addressed the relationship between physical and psychological function, two areas that have been described as the most prominent in patients with sarcoma and carry implications for the HRQoL.^{35,36} While the disease and clinical factors are stable in nature, the psychological functioning appears to be more malleable, dynamic, and dependent on individuals' circumstances and coping mechanisms. This is promising as existing psychosocial approaches have been shown to improve psychological functioning in cancer patients.^{37,38}

Consistent with the existing literature, our results indicate that patients with STS undergo a significant amount of subjective stress and report feelings of low mood, however, patients with fewer physical symptoms also report lower levels of subjective psychological distress.^{10,11} According to our participants' accounts, low mood was often present around the time of diagnosis and in the initial phases of illness and tended to subside after active treatment. Those who had been most limited in their everyday life, physically dependent on others, or hospitalized reported more changes in their mood, and experiencing lower mood. Based on participants' descriptions, their low mood could largely be due to loss of independence and isolation resulting from treatment and hospitalization.

Worries were endorsed more commonly than low mood, and according to our participants' account they both tended to subside with time, a pattern observed in previous research on adults with sarcoma.³⁹ The Damocles Syndrome, previously described in cancer populations,⁴⁰ marked by high levels of uncertainty, was particularly pronounced. Participants reported being acutely aware of their own mortality, which was primarily associated with learning the diagnosis, but still reported by individuals already years after treatment completion. The acute awareness of one's own mortality further contributed to their subjective levels of distress. Some participants found little comfort in learning more about their illness, perhaps because STS is a rare disease with unknown causes and high morbidity.^{1,2,12} These factors might make worries in patients with STS unique in their nature.

To cope with soft-tissue sarcoma, participants in our sample employed an array of different coping mechanisms. The majority of survivors who reported fewer episodes of low mood and fewer worries utilized adaptive coping styles such as positive reframing and optimism. Adaptive coping styles in STS may bear importance as some research suggests that optimism can improve quality of life in cancer patients.⁴¹ Participants who reported finding a purpose, staying proactive, and using humor tended to express fewer worries and better overall psychological well-being even in light of physical limitations. In line with the previous literature, humor was found to be adaptive and reported by participants who also reported little psychological distress.^{39,42}

Conversely, those who developed metastatic disease, local recurrence, or medical complications recounted having more difficulties adapting to life with illness. Prior sensitivity to distress or multiple life stressors can contribute to higher levels of psychological distress, as well as poorer coping mechanisms, a finding in line with the literature.⁴³ Some participants reported a passive attitude, which resulted in feelings of defeat, and little planning for the future. More commonly, participants utilized avoidance and denial. In our study, more men than women (7 of 15 and 2 of 13, respectively) endorsed denial, and this appears to be in line with other previous studies that document this gender discrepancy in denial behavior.⁴⁴⁻⁴⁶ Though denial may be adaptive in some circumstances,⁴⁷ others found a correlation between denial and higher psychological distress in the diagnostic and treatment phases.³⁹ In our study some individuals were more able to focus on positive aspects of life as a result of denial, while others struggled to accept their illness, and believed they were subjected to unnecessary medical interventions.

5 | LIMITATIONS AND FUTURE DIRECTIONS

Our sample was limited to adult patients from a regional expert sarcoma center, which may limit generalizability of the findings. The range of time since diagnosis was large (from 2 months to over 7 years) and majority of the participants provided retrospective

accounts, which may have resulted in some recall bias. Future studies should attempt to follow patients longitudinally to better understand the effects of time and transitions on psychological well-being. Another limitation was a low number of young adult (YA) participants. Stories of YA facing STS who might be single, have no children, or still dependent on their parents are not fully accounted for in our study. Future studies should aim to recruit more YA with this rare form of cancer and describe their experience in more detail.

6 | CONCLUSION AND CLINICAL IMPLICATION

The patient's subjective experience is at the core of patient-centered health care. Patients with STS face high levels of disease burden, which can result in significant levels of distress. All patients with STS should be routinely screened for psychological functioning, especially when undergoing extensive surgical procedures. Physicians and allied professionals should discuss the extent of possible disfigurement and scarring from surgical procedures, as well as aim to promote the adaptive coping mechanisms such as optimism, humor, finding a purpose, and helping patients to be proactive. On the other hand, further support should be offered to those who employ maladaptive coping mechanisms such as passive acceptance, or avoidance and denial.

Adaptive coping mechanisms can empower patients and attenuate the level of perceived burden on physical functioning of surgical procedures. Early identification of individuals at higher risk for poorer physical and psychological outcomes could assure better HRQoL in the long-term, and higher patient satisfaction.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

DATA AVAILABILITY STATEMENT

Data for this study is available upon request.

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