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Experiences and needs of patients with sarcoma: a qualitative meta-synthesis

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ABSTRACT

Purpose: To systematically identify, summarize, and synthesize qualitative evidence on the experiences and needs of patients living with sarcoma, providing insights into their multidimensional challenges.
Methods: This qualitative meta-synthesis follows the ENTREQ guidelines. Seven electronic databases (PubMed, Web of Science, Scopus, Embase, Cochrane Library, CINAHL, and PsycINFO) were searched up to November 2024. Two reviewers independently conducted the study screening and data extraction. The quality was evaluated using the Joanna Briggs Institute's Qualitative Research Standard Assessment tool. Thematic analysis was used for data synthesis.
Results: Twenty-seven studies were included in this meta-synthesis. Three analytical themes emerged: (1) "Self-perceived health challenges after diagnosis" highlighting the physical and emotional challenges faced by patients; (2) "Mixed experiences during social interactions" reflecting the complex dynamics in relationships with friends, family, and healthcare providers; and (3) "Unfriendliness in the society towards sarcomas" emphasizing societal barriers such as employment limitations, financial burdens, and stigma.
Conclusions: Sarcoma patients face significant challenges that extend beyond the individual health condition, impacting their interpersonal relationships and social wellbeing. A comprehensive understanding of the experiences and needs of sarcoma patients on their disease journey can help provide effective management for patients with this rare disease. Addressing these challenges requires a holistic approach involving healthcare providers management, organizational change, community support, and public policy reform.

1. Introduction

Sarcomas represent a group of malignancies that originate from connective tissues and other supportive structures. They are broadly classified into soft tissue sarcoma (STS) and bone sarcoma (BS) (Generaal et al., 2024). According to a report from the Bone and Soft Tissue Cancer Charity (https://sarcoma.org.uk/), sarcomas account for approximately 0.8 % of all newly diagnosed cancers. In the UK, there are roughly 4000 new cases annually and a prevalence of about 7 per 100,000 people in Europe (Stiller et al., 2013). In the Asia-Pacific region, Hong Kong recorded 3746 cases of sarcoma between January 2004 and March 2018. The estimated all-cause mortality rate was 14.5 deaths per 100 person-years among eligible patients with sarcoma (Loong et al., 2020). The disease can affect individuals across all age groups,

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representing 6 %–15 % of pediatric cancers, 11 % of cancers in adolescents and young adults (AYA), and 1 %–2 % of cancers in adults worldwide (van der Graaf et al., 2017). Such tumours can occur in virtually any part of the body, and there are over 100 identified histological subtypes (Eichler et al., 2023). Treatment strategies for sarcomas involve complex pathways that may include surgery, pre or post-operative radiotherapy or chemotherapy, or combined radiotherapy and chemotherapy, depending on each patient's clinical situation (den Hollander et al., 2020). Being diagnosed with a sarcoma is associated with 17 life years lost per patient on average, which is three times more compared to people diagnosed with lung and breast cancer (Weaver et al., 2020). Consequently, the unique characteristics of sarcomas—-being rare, more common in younger age groups, diverse, and complex—suggest that the experiences and needs of this vulnerable group may differ from patients with other cancers.

Quality of life (QoL) of patients with sarcomas is significantly impacted throughout their survivorship, particularly physical, psychological and social wellbeing in the survivorship (Winnette et al., 2017). This underscores the necessity of measuring patients' experience living with sarcomas to facilitate tailored management strategies and ultimately improve health outcomes. Patient-reported outcomes (PROs) provide valuable insights into the health conditions of patients and are essential for capturing their experiences (Skalicky et al., 2017). Recently, various reviews have emerged that aim to summarize patient-reported outcome measures (PROMs) to better capture and understand the experience and QoL of patients with sarcomas. However, these reviews consistently indicate that existing PROMs primarily designed for generic cancer populations, and hence may not accurately reflect the experiences and challenges faced by sarcoma patients due to the unique characteristics of this malignancy (Almeida et al., 2021; Hassani et al., 2023). Unlike other carcinomas, the histological origins of sarcomas include bone, cartilage, fat, and muscle, that influence not only the tumour's characteristics and locations but also treatment strategy and patient experience (van Eck et al., 2020). The most recent COSMIN guided systematic review further highlighted the insufficiency in specific PROMs to effectively assess the specific experiences and needs of sarcoma patients (Generaal et al., 2024). Therefore, the quantitative data collected through current PROMs may inadequately represent the experiences and needs for this population.

In recent years, there has been an increasing number of qualitative studies exploring sarcoma patients' experience needs (Dewhurst et al., 2020). Research indicates that fatigue is a prominent physically debilitating and distressing symptom for sarcoma patients (Almeida et al., 2021). Despite the symptom is debilitating, patients have reported a lack of support to help them manage their fatigue (Dewhurst et al., 2020). Additionally, many patients express experiencing intolerable pain due to major surgery or scarring, which adversely affect their sleep quality (Beghean and Coffey, 2021). Decline in physical ability is common after complex treatment, yet patients feel uncertain about what they need to do to remain active, especially they have poorer physical function than those being diagnosed with other types of cancer, resulting a high degree of disability (Dewhurst et al., 2020). Psychosocially, more than half of sarcoma patients experience fear and shock upon receiving their diagnosis. A high prevalence of depression and anxiety is also noted from the time of diagnosis through treatment and rehabilitation, with these mental health challenges potentially persisting over time (Košir et al., 2020). Furthermore, psychosocial well-being has emerged as an unmet need and remains one of the most critical issues for adolescents and young adults (AYAs) with cancer, particularly among sarcoma patients (Kosir et al., 2020). In terms of social well-being, a diagnosis of sarcoma may lead to social isolation and affect relationships and sexual functioning due to changes in body image and low mood (Gerrand and Furtado, 2017).

Qualitative studies have explored the experiences and needs of patients with sarcoma and highlighted the impact on the patients' well-being in terms of physical, psychological and social domains. Heterogeneous subtypes of sarcomas and invasive treatment strategies can bring different experiences and needs for patients which may not have been fully reflected in individual qualitative studies. To date there has been no qualitative meta-synthesis exploring the experiences and needs of sarcoma patients. There is a need to combine existing qualitative data to summarize the physical, psychological, and social experience of patients with sarcoma. A comprehensive understanding of experiences and needs can help healthcare professionals to better care for and align interventions and health services to meet the unique needs for this patient group. Therefore, this qualitative meta-synthesis aimed to provide a comprehensive understanding of the experiences and needs of patients living with sarcoma.

1.1. Aim

The aim of this review is to systematically identify, summarize and synthesize qualitative evidence on the experiences and needs of patients with sarcoma. This study addressed the following questions.

1) What are the experiences and views of patients living with sarcoma?
2) What are the support needs of patients living with sarcoma?

2. Methods

2.1. Study design

This study was a qualitative synthesis and followed the Thomas and Haddon's three-stage synthesis of thematic synthesis (Thomas and Harden, 2008). This methodology can address people's experiences and perspectives through synthesizing qualitative research findings. The meta-synthesis protocol has been registered on PROSPERO system (registration number: CRD42024615424). The reporting of this manuscript followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement (ENTREQ) guidelines.

2.2. Eligibility criteria

The PICoS strategy (Population, Phenomena of interest, Context, Study design) was utilized to develop the eligibility criteria. The inclusion criteria for studies were as follows: (1) patients who have been diagnosed with any subtypes of sarcoma; (2) phenomena of interest focused on patients' experiences related to physical, psychological, social well-being and needs; and (3) context was at any time after the diagnosis of sarcoma and in any environment, such as being hospitalized for treatment or after discharge. To obtain adequate data, we didn't limit the methodology of qualitative research. Qualitative results from mixed-methods studies were also included. For pediatric patients, reports from themselves or proxy report were both included. Systematic reviews, conference abstracts, editorial letters, case reports and protocols were excluded. Additionally, studies without full-text or not published in English were excluded.

2.3. Search strategy

We systematically searched seven electronic databases, including PubMed, Web of Science, Scopus, Embase, Cochrane Library, CINAHL (EBSCO) and PsycINFO (ProQuest) without restrictions on the year of publication until November 2024. The search terms included five concepts based on the PICoS framework: sarcoma, experience of illness, care needs, information needs and qualitative research. Mesh terms and free terms were combined to use for comprehensive search. The initial search strategy is presented in Supporting file 1.

2.4. Study selection

All studies through database retrieval were uploaded to the EndNote

21.4 software, and duplicate studies were deleted. Two researchers (WQ and GYW) screened the studies independently against the inclusion and exclusion criteria based on the title and abstract. Any disagreements were resolved through discussions with a third researcher (MT). The full texts of all potentially relevant studies were included for further review. Two researchers (WQ and GYW) reviewed full texts and removed articles based on the eligibility criteria. Any reasons for exclusion were recorded. Disagreements during this process were also resolved by the discussion with a third researcher (MT). We followed the PRISMA flow diagram to report our selection process.

2.5. Quality assessment

Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (JBI, 2014) was used to assess the quality of the included studies. This critical appraisal checklist contains 10 items, each of them can be rated as “Yes”, “No”, “Unclear” or “Not applicable”. High quality was achieved when the above criteria were fully met. Moderate likelihood of bias was resulted if the criteria were only partially met. The highest likelihood of bias was resulted if none was achieved. Two researchers (WQ and GYW) reviewed the full texts and evaluated them independently based on the appraisal tool. If there was any disagreement, a third reviewer (MT) was required to make a judgement. The purpose of quality appraisal was to systematize and standardize the process to assess the quality of evidence on the topic (Vanderspank-Wright et al., 2018). Since no study was rated as the highest likelihood of bias, we did not exclude any study in the synthesis.

2.6. Data extraction

Key descriptive features from all included studies were listed using a predesigned form based on JBI QARI Data Extraction Tool (JBI, 2014). The key features included author, publication year, title, country, study descriptions involving methodology, phenomena of interest, setting, participants (e.g., sample size, age, time since diagnosis and treatment), data collection and analysis method, main findings and conclusions. Data was extracted by one reviewer (WQ), and then was verified for accuracy by a different researcher (LQ) not involved in the previous screening process. Any discrepancies were resolved through group discussion hosted by Professor Yorke.

2.7. Data synthesis

We employed Thomas and Haddon’s thematic synthesis approach (Thomas and Harden, 2008) to organize and synthesize qualitative research data. We chose this approach as it can address key questions, with an aim to provide information to understand the patients’ real comprehensive experience and caring needs, and inform tailored nursing practice. This synthesis approach has also been used commonly in qualitative meta-synthesis studies (Cho et al., 2024). During the thematic synthesis, an inductive approach was adopted because it enables us to understand the underlying meaning and experiences of participants by focusing on the similarities and differences of qualitative text, allowing themes to emerge organically. The analysis included three stages: coding text ‘line by line’, constructing ‘descriptive themes’ and developing ‘analytical themes’. In the first stage, all descriptions about illness experiences and caring needs of the patients with sarcoma were aggregated and coded. In the second stage, new descriptive subthemes were created by comparing similarities and differences among the codes from the first stage, making explicit connections, merging similar data and grouping the codes. In the third stage, descriptive themes from the stage 2 were reviewed. Similar subthemes were categorized into analytical themes that were beyond the original research and provided clarified meaning to describe or explain the descriptive topic. In this process, descriptive subthemes and analytical themes were generated, and new explanations of the phenomena were identified. The synthesis was conducted by two researchers (WQ and GYW) and reconciled by a third independent evaluator with experience in thematic analysis (LQ). Finally, our research team scrutinized the analysis and synthesis process to ensure the consistency and adequacy of synthesized evidence.

2.8. Theoretical framework

Theoretical framework is essential in qualitative research, particularly in inductive analysis, where it offers a structured approach and guides researchers to better understand complex phenomena while allowing for flexibility in data interpretation. The Best Practice Guide for Conducting and Reporting Meta-syntheses (Siddaway et al., 2019) stated that the best reviews synthesize studies to draw broad theoretical conclusions about what a literature means, linking theory to evidence and evidence to theory. The Socio-Ecological Model (SEM) is a health promotion framework underscoring the interactive consequence of individual and environmental factors, which can be categorized into multidimensional levels, including individual level (e.g., biologic characteristics), interpersonal level (e.g., interaction in social networks), institutional level (e.g., organizations or settings for interaction), and community and policy level (e.g., social atmosphere) (Bronfenbrenner, 1977; Bronfenbrenner and Ceci, 1994). Previous qualitative studies have successfully explored characteristics, experiences or needs in cancer survivors based on socio-ecological model, providing insights into specific issues at multidimensional levels (Hu et al., 2021; Wang et al., 2024; Wondimagegnehu et al., 2024). Sarcoma patients constitute a special group in cancer populations. It is important to go beyond the individual level which mainly addresses the biological characteristics of symptoms, but address the experience and needs of sarcoma patients in multidimensional level, e.g., interpersonal and community levels. Hence, this model was deemed to be appropriate to guide us to obtain a greater understanding of sarcoma patients’ experiences and needs in multiple levels.

2.9. Confidence analysis

Confidence of synthesized findings was assessed using the CERQual appraisal tool (WQ) which focuses on establishing how much plausibility to place in findings from qualitative evidence syntheses. The summary of review findings and CERQual assessments were presented according to the guideline and guidance of this tool (Lewin et al., 2015). The appraisal criteria contain four concepts: methodological limitation, relevance, coherence and adequacy of data.

3. Results

3.1. Search results

The initial search identifies 5748 studies, 4879 studies were remained after removing the duplicates. Following a review of titles and abstracts, 4805 studies were excluded and 74 studies were left to be reviewed for full-texts. Eventually, a total of 27 qualitative studies met the eligibility criteria and were included in this meta-synthesis. The study selection process is visually represented in the PRISMA flow diagram (Fig. 1).

3.2. Characteristics of included studies

All of the included studies were published between 2008 and 2024, with the sample sizes of 6–121. The included patients aged from 13 to 85 years. Their type of sarcoma included gastrointestinal stromal tumour, soft tissue sarcoma, bone sarcoma and tumour location involved limb, hip, pelvis, spine, thorax, abdominal organ, gastrointestinal, retroperitoneal, craniofacial and cervical regions, and head and neck. Time since their diagnoses ranged from less than 1 year to over 20 years.

Seven studies were from the UK (van de Wal et al., 2023a,b; Martins

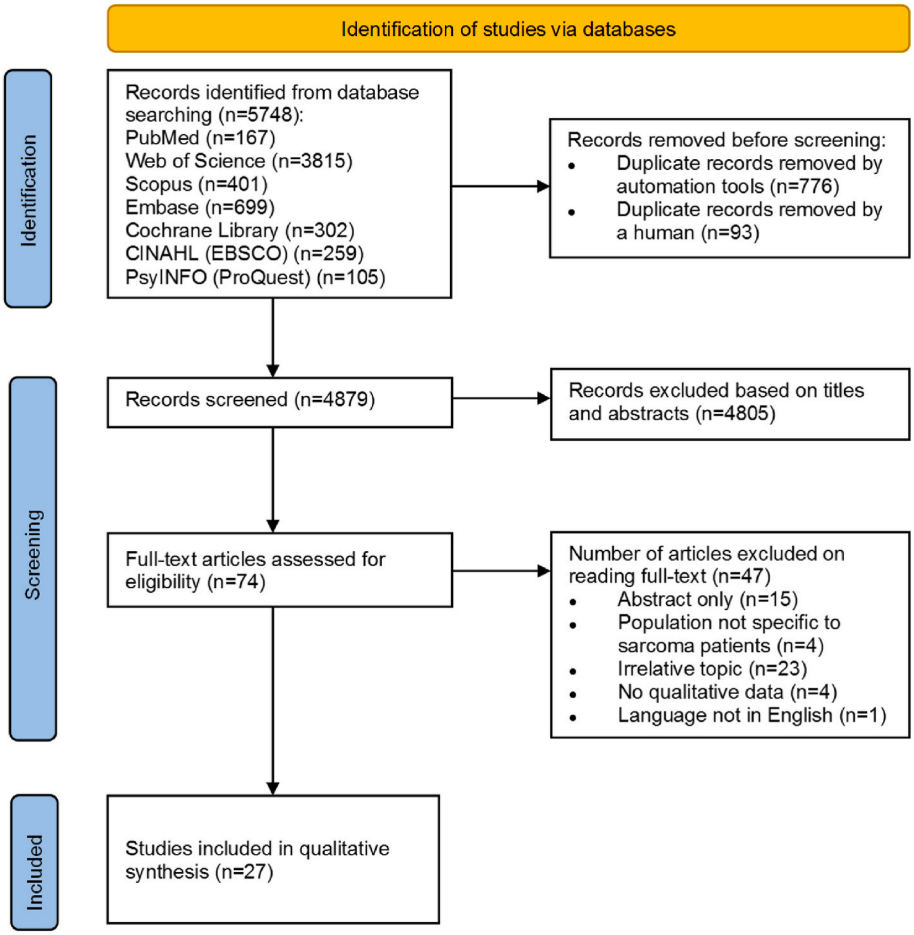

Fig. 1. PRISMA flow diagram.

et al., 2019, 2020, 2024; Vindrola-Padros et al., 2023; Dewhurst et al., 2020; Kosir et al., 2020), six from Norway (Fauske et al., 2015a,b, 2016, Fauske et al., 2019, 2022, 2023), three from the Netherlands (Denissen et al., 2024; van Eck et al., 2021; van de Wal et al., 2023a,b) and three from the USA (Macdonald et al., 2012; Kain et al., 2017; Donovan et al., 2021), two from Canada (Košir et al., 2020; Parsons et al., 2008) and two from Australia (Weaver et al., 2020, 2021), and one each from India (Suhag et al., 2024), Indonesia (Priyanto et al., 2024), Portugal (Almeida et al., 2024) and Ireland (Beghean and Coffey, 2021). Fourteen included studies were generic qualitative study (van de Wal et al., 2023a,b; Martins et al., 2019, 2020, 2024; Vindrola-Padros et al., 2023; van Eck et al., 2021; Suhag et al., 2024; Kain et al., 2017; Kosir et al., 2020; van de Wal et al., 2023; Košir et al., 2020; Parsons et al., 2008; Weaver et al., 2021; Beghean and Coffey, 2021), six were hermeneutic phenomenology (Fauske et al., 2015a,b, 2016, 2019, 2022, 2023), 1 was interpretive phenomenology (Weaver et al., 2020), three were descriptive phenomenology (Dewhurst et al., 2020; Priyanto et al., 2024; Donovan et al., 2021), one was grounded theory study (Denissen et al., 2024), one was ethnographic study (Macdonald et al., 2012) and one was mixed-methods study (Almeida et al., 2024), in which only qualitative data were extracted. Most of the interviews were conducted in hospitals either face-to-face or over the telephone. The characteristics of the included studies are displayed in Table 1.

3.3. *Quality assessment of included studies*

The appraisal scores of the included studies ranged from 7 to 9. All included studies were aligned in terms of research methodology, research objective, data collection method, data analysis method, quotes presentation, ethical issue and interpretation of results. About half of the studies (N = 15) (van de Wal et al., 2023a,b; Martins et al., 2019, 2020, 2024; Vindrola-Padros et al., 2023; van Eck et al., 2021; Suhag et al., 2024; Kain et al., 2017; Priyanto et al., 2024; Kosir et al., 2020; van de Wal et al., 2023; Košir et al., 2020; Weaver et al., 2020; Almeida et al., 2024; Beghean and Coffey, 2021) did not clearly explain the issues related to philosophical perspective. Most studies (N = 24) (van de Wal et al., 2023; Martins et al., 2024; Fauske et al., 2016; Fauske et al., 2015a,b; Martins et al., 2020; Vindrola-Padros et al., 2023; Denissen et al., 2024; Fauske et al., 2023; Dewhurst et al., 2020; van Eck et al., 2021; Suhag et al., 2024; Fauske et al., 2022; Kain et al., 2017; Fauske et al., 2019; Priyanto et al., 2024; Kosir et al., 2020; Košir et al., 2020; Martins et al., 2019; Parsons et al., 2008; Donovan et al., 2021; Weaver et al., 2020; Almeida et al., 2024; Weaver et al., 2021) failed to locate the researcher culturally or theoretically, ignoring potential influence of their beliefs and values. Only seven studies reported the influence of the researcher on the research (Denissen et al., 2024; Dewhurst et al., 2020; Priyanto et al., 2024; van de Wal et al., 2023; Košir et al., 2020; Donovan et al., 2021; Beghean and Coffey, 2021). (see Table 2)

3.4. *Confidence in the findings*

CERQual was used to assess the confidence in the results of each included study (Zhu et al., 2024): four sub-themes were rated as high confidence, one sub-theme was rated as moderate confidence and eight sub-themes were rated as low confidence (see Table 3).

Table 1
Characteristics of included studies.

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
(van de Wal et al., 2023), UK	Patient's perspective on the side effects of tyrosine kinase inhibitors in the treatment of advanced and metastatic gastrointestinal stromal tumours	gastrointestinal stromal tumour patient's perspective on side effects of tyrosine kinase inhibitors	Qualitative interview	Sample size: 24 Age: 38–82 years Time since diagnosis: 4 months-24 years	University Hospital Southampton, Royal Marsden Hospital	Semi-structured interviews and focus groups (face to face or over the telephone), Thematic analysis	1 Gastrointestinal problems 2 Tiredness 3 Edema 4 Skin, eye, mouth & hair problems 5 Cramps, muscle & joint pain & weakness 6Cognitive problems 7 Psychological problems 8 Trouble sleeping 9 Shortness of breath 10 Impact of side effects 11 Management of side effects	These results underline the importance of including the patient's perspective, as there is a gap in symptom reporting between patients and healthcare professionals.
(Martins et al., 2024), UK	A Qualitative Study of the Factors Influencing Patients' Experience of Soft Tissue Sarcoma in the United Kingdom	Patients' experience of being diagnosed with soft tissue sarcoma	Secondary analysis of a descriptive qualitative study	Sample size: 68 Age: >15 years Time since diagnosis: 1 year – over 20 years	UK (unknown location)	Semi-structured interviews (telephone) and focus groups (sarcoma support group meetings), Adapted framework analysis to incorporate content analysis at the charting stage	1 Life transitions and gender differences 2 Coping and finding the "new" normal 3 Social support 4 Specialist services-trust and reassurance 5 Rehabilitation services and adverse/late effects management 6 Transition points in the disease trajectory	We describe factors that both negatively and positively influenced the experience of patients with soft tissue sarcoma. Access to specialist soft tissue sarcoma and rehabilitation services and support tailored to patients' age and disease trajectory are needed to improve these experiences.
(Fauske et al., 2016), Norway	Changes in the Body Image of Bone Sarcoma Survivors Following Surgical Treatment—A Qualitative Study	Bone cancer survivors' experiences of their altered bodies	Qualitative phenomenological and hermeneutic design	Sample size: 18 Age: 18–60 years Time since diagnose: 3–10 years	Norwegian Radium Hospital, Oslo University Hospital	Semi-structured interviews, Inductive thematic analysis	1 Hiding bodily deviations 2 Exposing bodily deviations	Healthcare providers who guide bone sarcoma survivors during follow-up should develop a comprehensive understanding of what it means to cope with a changed and challenging body.
(Fauske et al., 2015b), Norway	Cured of Primary Bone Cancer, But at What Cost: A Qualitative Study of Functional Impairment and Lost Opportunities	Physical and psychosocial late effects 3–7 years after they underwent treatment for primary bone sarcoma in the hip/pelvic region	Qualitative, phenomenological and hermeneutic design	Sample size: 10 Age: 18–60 years Time since diagnosis: 3–10 years	Norwegian Radium Hospital, Oslo University Hospital	Semi-structured interviews, inductive thematic analysis	1 The Impracticalities of Daily Life 2 Lost opportunities and an altered future 3 I am no longer the person I once was	Patients cured of bone cancer in the hip/pelvic region pay a significant price in terms of functional impairment, practical challenges, exclusion from important aspects of life, and loss of previous identity.
(Martins et al., 2020), UK	Development of a patient-reported experience questionnaire for patients	Experiences of being diagnosed, treated and living with sarcoma	Qualitative study	Sample size: 121 Age: 13–82 years Time since	20 hospitals in England and Scotland	Semi-structured interviews and focus groups (telephone or face	1 Physical wellbeing 2 Emotional wellbeing 3 Social wellbeing 4 Financial wellbeing	SAM comprises of 22 items reflecting physical, emotional, social, financial wellbeing and sexuality.

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Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
	with sarcoma: the Sarcoma Assessment Measure (SAM)			diagnosis: <1 year –38 years		to face), Content analysis	5 Sexuality	This systematic process of using patient experience to develop the content of SAM will ensure that it measures what is important to patients.
(Macdonald et al., 2012), USA	Experiences and perspectives on the GIST patient journey	experiences and emotions of patients through GIST diagnosis, treatment initiation, disease control, and in some patients, loss of response and therapy switch	Ethnographic investigations	Sample size: 50 Age: 21–80 years	North American (United States and Canada) and global patients (Brazil, France, Germany, Russia, and Spain)	Ethnographic approach (in home), Unreported analysis method	1 Crisis 2 Hope 3 Adaptation 4 New normal 5 Uncertainty	Physicians and support staff can manage patient expectations and encourage adherence to therapy, which may facilitate optimal patient outcomes. Patient education about current GIST developments and adherence across all phases of the patient journey are of benefit.
(Vindrola-Padros et al., 2023), UK	Experiences of fear of recurrence in patients with sarcoma	An initial understanding of FCR in patients with all types of sarcoma	A secondary analysis of qualitative semi-structured interview	Sample size: 121 Age: 13–82 years Time since diagnosis: <1 year - 38 years	UK (unknown location)	Semi-structured interviews (telephone or face to face), Framework analysis	1 Triggers 2 Discussing FCR 3 Consequences 4 Strategies for dealing with FCR	Patients with sarcoma reported a FCR at different stages of treatment and how these fears played a role in their daily lives. Despite these experiences, the identification and management of FCR have not been reported as a core component of routine clinical practice.
(Denissen et al., 2024), Netherlands	Explaining needs for rehabilitation in patients with bone sarcoma and a megaprosthesis: a qualitative, grounded theory study	The needs for rehabilitation of patients with bone sarcoma before and after surgical resection and reconstruction with megaprosthesis.	Constructivistand interpretative qualitative grounded theory study	Sample size: 13 Age: 19–78 years Time since surgery: 30–204 months	Radboudumc (one out of four university medical centers in the Netherlands)	Semi-structured interviews (at home, in the hospital or online), Grounded theory data-analysis	1 Patients have the need to achieve a new normal 2 Patients have the need to be understood 3 Patients have the need to be prepared 4 Patients have a need for optimal conditions for rehabilitation 5 Patients have a need for trustworthy physical therapists 6 Patients have a need for a clear closure from rehabilitation 7 Patients have a need for access to expertise in the hospital	Patients with bone sarcoma need rehabilitation to achieve a new normal life. With the understanding of needs regarding rehabilitation now gained, the care for patients with bone sarcoma should be better tailored.
(Fauske et al., 2023), Norway	Exploring the Patient Perspective of Bone Sarcoma Survivors Who Have Undergone Particle Radiotherapy Abroad	Individual experiences of medical and psychosocial challenges related to proton and carbon therapy	Phenomenological and hermeneutical approach	Sample size: 12 Age at diagnosis: 14–56 years Time since diagnosis 2–16 years	Norwegian Radium Hospital, Oslo University Hospital and Haukeland University Hospital	Semi-structured interviews (in the hospital, in a participant's office or by phone), Thematic synthesis	1 Importance of being prepared 2 Treatment and stay abroad	Oncologists who inform and refer patients to particle therapy abroad must have sufficient experience of this treatment modality, prognoses, acute side

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Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
							3 Basically healthy, but with health problems and challenges	effects, and late complications.
(Dewhurst et al., 2020), UK	Factors influencing people's ability to maintain their activity levels during treatment for soft tissue sarcoma – A qualitative study	Factors that affect people's ability to be physically active while undergoing treatment	Phenomenological approach	Sample size: 6 Age: 53–69 years	Oncology Centre	semi-structured interviews, Thematic analysis	1 Physical activity as an indicator of normality 2 The implications, loss and uncertainty for the future 3 The challenge of recognising support needs as physical activity declines	This suggests there is a gap in their knowledge of the health benefits gained by continuing to be active as they undergo treatment and the support that might be available to them.
(van Eck et al., 2021), Netherlands	Health-Related Quality of Life Issues Experienced by Thoracic and Breast Sarcoma Patients: A Rare and Understudied Group	The HRQoL issues experienced by a small group of thoracic and breast sarcoma patients	Qualitative study	Sample size: 23 Mean age: 56 years (thoracic sarcoma), 60 years (breast sarcoma) Mean time since diagnosis: 43 months (thoracic sarcoma), 53 months (breast sarcoma)	Germany, Norway, Netherlands, Italy, Cyprus, UK	Semi-structured interviews, Thematic analysis	1 Physical health 2 Mental health 3 Social health	Results of this qualitative study will guide personalized supportive care for breast and thoracic sarcoma patients and help in determining the best possible HRQoL measurement strategy for sarcoma patients with different primary sarcoma locations.
(Suhag et al., 2024), India	Health-related quality of life, psychological issues and concerns among sarcoma survivors: a mixed method study	The health-related quality of life (HRQoL), psychological issues and concerns among sarcoma survivors	Qualitative study	Sample size: 10 Age: 15–60 years	Tertiary care facility	Focused group discussion, Thematic analysis	1 Body image, physical appearance, low self-esteem and acceptance 2 Discrimination by society and support from family, relatives and colleagues 3 Socio-economic impact of sarcoma 4 Marriage concerns, denial of marriage and fertility issues 5 Marriage concerns, denial of marriage and fertility issues 6 Satisfaction with the doctor, nurses and healthcare professionals	Our study emphasizes the importance of holistic survivorship care, involving nurses in post-treatment support, and addressing societal discrimination and psychosocial concerns to enhance their quality of life.
(Fauske et al., 2022), Norway	Hope as a Lifeline: Imatinib Discontinuation in Patients With Oligometastatic Gastrointestinal Stromal Tumours	Experiences of individual GIST patients in their specific life contexts	Phenomenological and hermeneutical approach	Sample size: 9 Age: 50–85 years Time since diagnosis: 6–21 years	Norwegian Radium Hospital, Oslo University Hospital	Semi-structured interviews, Thematic analysis	1 Getting one's life back 2 Fear of recurrence 3 Hope as a lifeline 4 Participating in the study	Use of a qualitative approach in clinical trials can result in a better understanding of patients' perspectives and therefore lead to improved clinical practice.
(Kain et al., 2017), USA	Lessons and advice from our patients: a focus group of sarcoma survivors	Patient experience over the course of sarcoma treatment and recovery,	Qualitative study	Sample size: 20 Age: 22–79 years Time since	Clinic conference room in University of	Focus group, Thematic analysis	1 Information at diagnosis	We identified several areas that can be addressed to enhance patient counseling,

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Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
		how sarcoma patients obtain information, and what information is important to them at different points in their treatment and survivorship		surgery: 0.6–4.8 years	Iowa Hospitals and Clinics		2 Relationship with care team 3 Social support 4 Restoration to “normal”	emotional understanding, and expectations of treatment. These can serve as a guide for future research endeavors and program development.
(Fauske et al., 2015a), Norway	Negative and Positive Consequences of Cancer Treatment Experienced by Long-term Osteosarcoma Survivors: A Qualitative Study	How survivors of osteosarcoma of the lower extremity experience physical and psychosocial late effects several years after undergoing arduous treatment	Qualitative, phenomenological and hermeneutic approach	Sample size: 8 Age: 18–50 years Time since diagnosis: 3–10 years	Norwegian Radium Hospital, Oslo University Hospital	Semi-structured interviews, Thematic analysis	1 Negative consequences of osteosarcoma treatment 2 Lack of energy 3 Body image concerns 4 Changes and losses in leisure time and social life 5 Infertility concerns 6Existential considerations 7 Still struggling 8 Positive changes as a consequence of cancer experience 9 Changed sense of life and self 10 Compassion for others 11 Ambivalence	It is important to understand osteosarcoma survivors’ own experiences in order to assist those who struggle to reorient in life and to construct a new identity for themselves.
(Fauske et al., 2019), Norway	Perspectives on treatment side effects in patients with metastatic gastrointestinal stromal tumour: a qualitative study	How patients with metastatic gastrointestinal stromal tumour (GIST) experience the adverse effects of treatment	Qualitative, phenomenological and hermeneutic design	Sample size: 20 Age: 36–85 years Time since diagnosis: 2–22 years	Norwegian Radium Hospital, Oslo University Hospital	Semi-structured interviews, Thematic analysis	1 Self-reported adverse treatment effects 2 The paradoxical self	We observed a gap between the biomedical perspective on disease that health professionals typically adopt and the individual experiences of patients living with metastatic GIST. A vital goal should hence be to improve communication between healthcare professionals and GIST patients so as to secure an individualized follow-up with guidance on coping with, and adapting to, their new normal.
(Priyanto et al., 2024), Indonesia	Physical Well-Being Needs of Bone Cancer Patients during Treatment in the Hospital: A Qualitative Study	Physical well-being needs of patients with bone cancer undergoing hospitalization	Phenomenological approach	Sample size: 14 Majority of participants aged: 18–65 years	Three major referral hospitals in Central Java	Semi-structured interviews, The Creswell method	1 Goals and needs for physical wellbeing 2 Need for pain management 3 Need for physical mobility 4 Need for sleep and rest 5 Need for self-care	This study shows the significance of addressing pain management, physical mobility, sleep and rest, and self-care for the physical well-being of bone cancer patients. Nurses should be able to identify various physical complaints and

(*continued on next page*)

Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
							6 The meaning of physical well-being for patients	help improve the physical well-being of bone cancer patients.
(Kosir et al., 2020), UK	Psychological adaptation and recovery in youth with sarcoma: a qualitative study with practical implications for clinical care and research	A dynamic understanding of psychological adaptation and recovery in AYA with sarcoma	Qualitative study	Sample size: 30 Age: 15–39 years 29 of them is less than 6 years after treatment and 1 patient is more than 6 year after treatment	National Health Service hospitals	Semi-structured interviews (face to face or online), Framework analysis	1 Function 2 Activity 3 Participation 4 Lived experience 5 Family and social circle 6 Medical team and care takers 7 Health care system at large	This study demonstrates that young people with sarcoma report an array of both positive and negative factors related to their illness experience. The route to recovery is a multifactorial process and a one-size-fits all approach to psychosocial care proves inadequate.
(van de Wal et al., 2023), Netherlands	Psychological and social challenges of patients with locally advanced and metastatic gastrointestinal stromal tumours (GIST) on long-term treatment with tyrosine kinase inhibitors: a qualitative study with patients and medical oncologists	Psychological and social life challenges of GIST patients with locally advanced and metastatic disease on ≥ 5 years TKI treatment	Qualitative study	Sample size: 15 Mean age: 61.3 years Mean time since diagnosis: 13.2 years	Netherlands Cancer Institute/Antoni van Leeuwenhoek Amsterdam, the Erasmus MC Rotterdam, and Radboud UMC Nijmegen in The Netherlands	Semi-structured interviews (face-to-face or online), Thematic analysis	1 Psychological health 2 Social health	The reported psychological and social challenges can significantly hamper the overall quality of life of GIST patients. Some challenges were clearly underreported and hardly recognized by medical oncologist, as they may tend to focus on the physical side effects and clinical outcomes of treatment.
(Košir et al., 2020), Canada	Psychological functioning, coping styles and their relationship to appraisal of physical limitations following invasive surgical procedures for soft-tissue sarcoma: A qualitative study	Psychological functioning and coping styles in adult patients with soft-tissue sarcoma who underwent surgical procedures	Qualitative study	Sample size: 28 Age: 24–75 years Time since diagnosis: 2–92 months	A single expert sarcoma medical center	Semi-structured interviews and focus group (in hospital or online), Inductive thematic networks approach	1 Changes in mood 2 Worry 3 Body image concerns 4 Positive reframing and optimism 5 Finding a purpose 6 Being proactive 7 Using humor 8 Passive acceptance 9 Avoidance and denial	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.
(Martins et al., 2019), UK	Qualitative study exploring patients experiences of being diagnosed and living with primary bone cancer in the UK	Experiences of patients with primary bone cancer	Qualitative study	Sample size: 26 Age:13–77 years Age at diagnosis: 8–77 years	Hospitals across the UK and recruitment through UK sarcoma charities and support groups	Semi-structured interviews and focus groups (face to face or over telephone), Framework analysis	1 Physical well-being: it was literally the worst pain I'd ever experienced 2 Emotional well-being: I think emotional has been equally hard and challenging as the physical one 3 Social well-being: Everyone was very supportive. Everyone came around	This study described the impact of primary bone cancer on patients' well-being and adjustment over time with the identification of influencing factors of better/worse experiences. It showed that impact was felt after end of treatment and affected patients at different life stages. Holistic models of survivorship care are needed.

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Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
							4 Relationships: I've got very frustrated about things; she's dealt with that and supported me 5 The role of healthcare professionals: They were experts in what they were doing	
(Parsons et al., 2008), Canada	"So, are you back to work yet?" Re-conceptualizing 'work' and 'return to work' in the context of primary bone cancer	Lived experiences of illness and resuming vocational pursuits in the context of osteosarcoma	Qualitative narrative methodology	Sample size: 14 Age at diagnosis: 16–35 years	Based on respondent preference	Semi-structured interviews, Thematic analysis	1 Illness work 2 Identity work 3 Vocational work	This study suggests that the answer is instead highly complex, and that patients could be seen as having been 'working' all along.
(Donovan et al., 2021), USA	The Role of Social Media in Providing Support from Friends for Adolescent and Young Adult (AYA) Patients and Survivors of Sarcoma: Perspectives of AYA, Parents, and Providers	How psychosocial factors influence resilience outcomes in AYAs with cancer	Phenomenological qualitative approach	Sample size: 10 Age: 13–25 years Time since treatment: within 6 years	A pediatric sarcoma clinic in Los Angeles	Semi-structured interviews (in person or by phone), Theory-driven immersion/ crystallization	1 Social media provides a way to feel normal and connected to friends 2 Social media accentuates the frustration of being left behind 3 Social media facilitates the need to be understood by peers who have experienced sarcoma 4 Social media can lead to despair, and also provide hope for the future	Connecting with peers through social media can play an important role in providing support for AYAs with sarcoma, but it may also amplify feelings of frustration and anxiety. Future work is needed to determine intervention components that can maximize the benefits of social media for social support of AYAs with sarcoma.
(Weaver et al., 2020), Australia	The unmet needs of patients with sarcoma	Unmet needs of patients who have been diagnosed with sarcoma	Exploratory qualitative research	Sample size: 22 Age: >16 years Age at diagnosis: 15–78 years	A metropolitan teaching hospital	Semi-structured interview (face to face or by phone), Thematic analysis	1 Daily living, financial needs 2 Lack of information 3 Need for a community 4 Navigating the healthcare system	Sarcoma patients have fundamental needs that affect their capacity to live their life in the best possible way. Health services need to better facilitate sarcoma patients at each stage of their experience by providing individualized referrals, support, and coordination. Support interventions are needed to help patients adjust to sarcoma and to improve their quality of life as an outpatient. Connecting patients with sarcoma support groups may provide them with more relevant and intimate support.

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Table 1 (*continued*)

Author, year, country	Title	Phenomena of interest	Methodology	Participants characteristics	Setting	Data collection and analysis method	Themes	Authors conclusions
(Almeida et al., 2024), Portugal	Understanding quality of life's challenges in sarcoma patients: A mixed-methods study	Experiences of living with the disease and their specific care requirements	Mixed-methods study	Sample size: 7 Age: 22–78 years	A private room of an oncologic hospital	Semi-structured interviews, Thematic analysis	1 Disruption of daily life 2 Adaptation to life with sarcoma 3 The demand for more personalized care	The results underscore the significance of delivering care that enhances the quality of life for sarcoma patients, addressing both their physical and psychosocial needs, and providing personalized support throughout all stages of the disease.
(Weaver et al., 2021), Australia	"We're on a Merry-Go-Round": Reflections of Patients and Carers after Completing Treatment for Sarcoma	Patients' and carers' reflections on life after treatment for sarcoma	Qualitative research	Sample size: 21 Age: 15–78 years	A mutually convenient location	Semi-structured interview (face to face or by phone), Thematic analysis	1 This journey is never going to be over 2 But what happens when I am better 3 Finding a silver lining	This study highlight the heterogeneous and ongoing needs of sarcoma survivors and their families. Patients and carers strove to translate their experiences in a meaningful way, such as by improving outcomes for other people affected by sarcoma. Parental carers in particular attempted to protect the patient from the ongoing stress of managing the disease.
(Beghean and Coffey, 2021), Ireland	"You either sink or you swim, and you're better off swimming": A qualitative study exploring the self-management experiences of soft tissue sarcoma survivors	Consequences of soft tissue sarcoma and its treatment experienced by survivors, the self-management strategies they use to deal with these consequences, and any factors that may act as barriers or facilitators to their self-management	Qualitative study	Sample size: 7 Age: 25- over 65 years Time since diagnosis: 7–10 years	Participants' choosing location	Semi-structured interviews (home, a local café, hotel lobby), Thematic analysis	1 Consequences of STS 2 Self-management strategies employed 3 Perceived facilitators 4 Perceived barriers	The findings of this study suggest that soft tissue sarcoma survivors, especially those who are younger and experience physical limitations, may find the immediate post-treatment period particularly challenging and may benefit from nurse-led self-management support.

Table 2
Critical appraisal of included studies.

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
van de Wal et al. (2023)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Martins et al. (2024)	U	Y	Y	Y	Y	N	Nq	Y	Y	Y
Fauske et al. (2016)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Fauske et al. (2015b)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Martins et al. (2020)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Macdonald et al. (2012)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Vindrola-Padros et al. (2023)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Denissen et al. (2024)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Fauske et al. (2023)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Dewhurst et al. (2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
van Eck et al. (2021)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Suhag et al. (2024)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Fauske et al. (2022)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Kain et al. (2017)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Fauske et al. (2015a)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Fauske et al., 2019	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Priyanto et al. (2024)	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Kosir et al. (2020)	U	Y	Y	Y	Y	N	N	Y	Y	Y
van de Wal et al. (2023)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Košir et al. (2020)	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Martins et al. (2019)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Parsons et al. (2008)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Donovan et al.(2021)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Weaver et al. (2020)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Almeida et al. (2024)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Weaver et al. (2021)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Beghean and Coffey (2021)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note: Y, Yes; N, No; U, Unclear; NA: Not applicable.
Q1. Is there congruity between the stated philosophical perspective and the research methodology?.
Q2. Is there congruity between the research methodology and the research question or objectives?.
Q3. Is there congruity between the research methodology and the methods used to collect data?.
Q4. Is there congruity between the research methodology and the representation and analysis of data?.
Q5. Is there congruity between the research methodology and the interpretation of results?.
Q6. Is there a statement locating the researcher culturally or theoretically?.
Q7. Is the influence of the researcher on the research, and vice-versa, addressed?.
Q8. Are participants, and their voices, adequately represented?.
Q9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?.
Q10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?.

3.5. *Main findings of the meta-synthesis*

Thirteen subthemes were extracted from the included 27 qualitative studies. Three themes were identified through grouping and comparative analysis of thirteen descriptive subthemes. The three themes were: (1) self-perceived health challenges after diagnosis; (2) mixed experiences during social interactions; (3) unfriendliness in the society towards sarcomas. A summary of these themes and results of meta-synthesis for experiences, views and support needs of patients living with sarcoma is presented in Fig. 2 and Table 4.

3.5.1. *Theme 1: self-perceived health challenges after diagnosis*

Individuals could experience significant changes in their health status starting from the sarcoma diagnosis. During the interviews, patients often described symptoms or functional impairments they perceived, Three sub-themes were categorized from the patient reported physical and mental health outcomes.

3.5.1.1. Subtheme 1: negative physical experience. Patients typically encountered a range of adverse physical issues resulting from different treatments, such as limb amputation, limb-salvage surgery, chemotherapy, radiotherapy, and a combination of multiple treatments. These physical issues subsequently led to a decreased quality of life.

A major physical concern was impaired mobility in which most sarcoma patients concerned the most after the treatment. For example, limb-salvage surgery could lead to muscle impairment; while amputation contributed to the limb loss. For patients receiving chemotherapy or radiotherapy, swelling and weakness also limited their mobility and hindered movement (from Andrews et al., 2019). As indicated by a quote from an interviewee,

> “The legs are sometimes difficult to move, and it is a bit difficult to move for too long, so I have to use U-shaped crutches.” (from Priyanto et al., 2024)

The limitations in mobility directly resulted in patients’ dysfunction in performing activities of daily living (ADLs), such as walking, bathing and dressing, which severely impacted their quality of life. One of the interviewees said,

> “At first I pretty much couldn’t do anything a normal person would be able to do. I wasn’t able to go to the toilet without assistance, in the sense that I wasn’t able to wipe certain areas. I wasn’t able to shower by myself.” (from Martins et al., 2020)

Patients who received surgery disclosed their permanent changes in appearance and functionality. Visible scar was an unavoidable result of a life-saving treatment. Moreover, destruction of structural integrity of the body caused by surgical removal made patients have to wear long or loose-fitting clothes to cover their strange body image. Also, other therapies could bring hair loss, face swelling and vulnerable skin (Košir et al., 2020).

> “The scars are not the worst thing, the hernia is. The scars are not too bad. The problem is the thing that protrudes from my hip/pelvic region [hernia]. I don’t have a pelvic bone, as it was removed in the front, and they moved a muscle from the stomach down to my hip/pelvic area. Now I feel that my abdomen has caved in and that it

Table 3
Summary of findings and CERQual assessments.

Summary of review finding	Studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual Assessment of Confidence	Explanation of judgement
Self-perceived health challenges after diagnosis *Negative physical experience* Patients experienced physical problems including limited mobility, dysfunction, body image, pain, sleep disturbance, fatigue, loss of fertility, loss of sexuality, digestive problems, cognitive problems and dyspnea.	(Priyanto et al., 2024) Martins et al. (2020) Fauske et al. (2016) Košir et al. (2020) van Eck et al. (2021) Dewhurst et al. (2020) van de Wal et al. (2023) Fauske et al. (2023) Fauske et al., 2019 Fauske et al. (2022)	Minor methodological limitations as all studies with minor methodological limitations	Minor methodological limitations as studies were from five countries including UK, Norway, Canada, Netherlands and Indonesia	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Minor concerns about adequacy as ten studies together offered relatively rich data overall	High confidence	This finding was graded as high confidence because of minor concerns of all aspects.
Emotional distress Patients experiences emotional problems including shock, fear, uncertainty, depression, anxiety and irritability	(Almeida et al., 2024) van de Wal et al. (2023) Martins et al. (2019) Martins et al. (2024) Vindrola-Padros et al. (2023)	Minor methodological limitations as all studies with minor methodological limitations	Minor methodological limitations as studies were from three countries including Portugal, Netherlands and UK	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Minor concerns about adequacy as five studies together offered relatively rich data overall	High confidence	This finding was graded as high confidence because of minor concerns of all aspects.
Positive attitude towards adjustment Positive attitude towards disease and recognize the effects of treatment	(Fauske et al., 2015a) Kain et al. (2017) Denissen et al. (2024)	Minor methodological limitations as studies with minor methodological limitations	Minor concerns about relevance as studies were from three countries including Norway, USA and Netherlands	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Minor concerns about adequacy as three studies together offered relatively rich data overall	High confidence	This finding was graded as high confidence because of minor concerns of all aspects.
Mixed experiences during social interactions *Difficulty in returning to previous social interactions* Reduced social activities and feel isolated from friends	()Fauske et al. (2015b) Weaver et al. (2021) Weaver et al. (2020)	Minor methodological limitations as studies with minor methodological limitations	Moderate concerns about relevance as studies were from two countries including Norway and Australia	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Minor concerns about adequacy as three studies together offered relatively rich data overall	Moderate confidence	This finding was graded as moderate confidence because of moderate concerns regarding relevance.
Peer support Individuals who had similar experiences were supportive for sarcoma patients	Martins et al. (2019) (Donovan et al., 2021)	Minor methodological limitations as studies with minor methodological limitations	Moderate concerns about relevance as studies were from two countries including UK and USA	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Moderate concerns about adequacy as only two studies offered thin data	Low confidence	This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy.
Changes of roles in family They could not take care of family members and became burden on family.	Kosir et al. (2020) Dewhurst et al. (2020)	Minor methodological limitations as studies with minor methodological limitations	Moderate concerns about relevance as studies were from one country (UK)	Minor concerns about coherence as data shows a reasonable level of consistency across all studies	Moderate concerns about adequacy as only two studies offered thin data	Low confidence	This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy.
Family support Family members could help to care for patients which provided support to them. *Limited information from medical professionals* Patients failed to access detailed and updated	(Suhag et al., 2024) Martins et al. (2019) (Fauske et al., 2023) Macdonald et al. (2012) (Suhag et al.,	Minor methodological limitations as studies with minor methodological limitations Minor methodological limitations as	Moderate concerns about relevance as studies were from two countries including India and UK Moderate concerns about relevance as studies were from two countries including	Minor concerns about coherence as data shows a reasonable level of consistency across all studies Minor concerns about coherence as data shows a	Moderate concerns about adequacy as only two studies offered thin data Moderate concerns about adequacy as only two studies	Low confidence Low confidence Low confidence Low confidence Low	This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy.

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Table 3 (*continued*)

Summary of review finding	Studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual Assessment of Confidence	Explanation of judgement
information regarding their health status and treatment strategy. *Supportive care from medical team members* Professional treatment and follow-ups provided patients strong support. ***Unfriendliness in the society towards sarcomas*** *Limiting employment* Limited companies were willing to hire individuals who had sarcoma history or physical impairments. *Challenging financial issues* Difficulties in finding employment and the high costs of ongoing treatment caused financial burdens. *Feel stigmatised* Patients felt stereotypes and discrimination from the public. *Need for empathy from living environment* People's understanding of sarcoma was insufficient that made sarcoma patients difficult to deal with reactions of others.	2024) Fauske et al. (2023) Fauske et al. (2015b) Parsons et al. (2008) (van de Wal et al., 2023) Martins et al. (2024) (Beghean and Coffey, 2021) Fauske et al. (2016) Suhag et al. (2024) (Martins et al., 2020) van Eck et al. (2021)	studies with minor methodological limitations Minor methodological limitations as studies with minor methodological limitations Minor methodological limitations as studies with minor methodological limitations Minor methodological limitations as studies with minor methodological limitations Minor methodological limitations as studies with minor methodological limitations Minor methodological limitations as studies with minor methodological limitations	Norway and USA Moderate concerns about relevance as studies were from two countries including India and Norway Moderate concerns about relevance as studies were from two countries including Norway and Canada Moderate concerns about relevance as studies were from two countries including Netherlands and UK Minor concerns about relevance as studies were from three countries including Ireland, Norway and India Moderate concerns about relevance as studies were from two countries including UK and Netherlands	reasonable level of consistency across all studies Minor concerns about coherence as data shows a reasonable level of consistency across all studies Minor concerns about coherence as data shows a reasonable level of consistency across all studies Minor concerns about coherence as data shows a reasonable level of consistency across all studies Minor concerns about coherence as data shows a reasonable level of consistency across all studies Minor concerns about coherence as data shows a reasonable level of consistency across all studies	offered thin data Moderate concerns about adequacy as only two studies offered thin data Moderate concerns about adequacy as only two studies offered thin data Moderate concerns about adequacy as only two studies offered thin data Minor concerns about adequacy as three studies together offered relatively rich data overall Moderate concerns about adequacy as only two studies offered thin data	confidence High confidence Low confidence	This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy. This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy. This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy. This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy. This finding was graded as high confidence because of minor concerns of all aspects. This finding was graded as low confidence because of moderate concerns regarding relevance and adequacy.

> sticks out when I am not wearing something tight." (from Fauske et al., 2016)

Pain management was a critical aspect of care for sarcoma patients, as they often experienced significant pain due to the tumour and its treatment, which might even need painkillers to control. An interviewee said,

> "At first, it was painful, and then I had difficulty walking and limping, and over time, it got bigger. There was pain, tingling, and heaviness. Every night and morning, I suddenly felt pain. While in the hospital, I was injected with painkillers." (from Priyanto et al., 2024)

Sleep disturbance was subsequently brought by the cramps and pain in the nighttime. As illustrated by two interviewees,

> "… cramps… which I think is quite common. Nighttime incidence and cause of insomnia." (from van de Wal et al., 2023a,b)

> "I can't sleep because of pain, I can't sleep because of myself, not because of the environment, and I often use drugs from the hospital so I can sleep." (from Priyanto et al., 2024)

Fatigue was a prevalent and debilitating symptom experienced by sarcoma patients especially after chemotherapy. Cancer-related fatigue was considered as something different from normal tiredness, which was often described as an overwhelming sense of exhaustion and could not be alleviated by rest or sleep.

> "You just have no energy, it's not that you want to sleep particularly it's just you feel as though your legs won't get you there you know it's just this feeling that you know that you're not going to make it." (from Dewhurst et al., 2020)

Infertility was also a concern raised by some sarcoma patients because chemotherapy and radiation were sometimes near their sex organs. The manifestation of infertility included premature menopause for women and poor sperms for men. As illustrated by one interviewee,

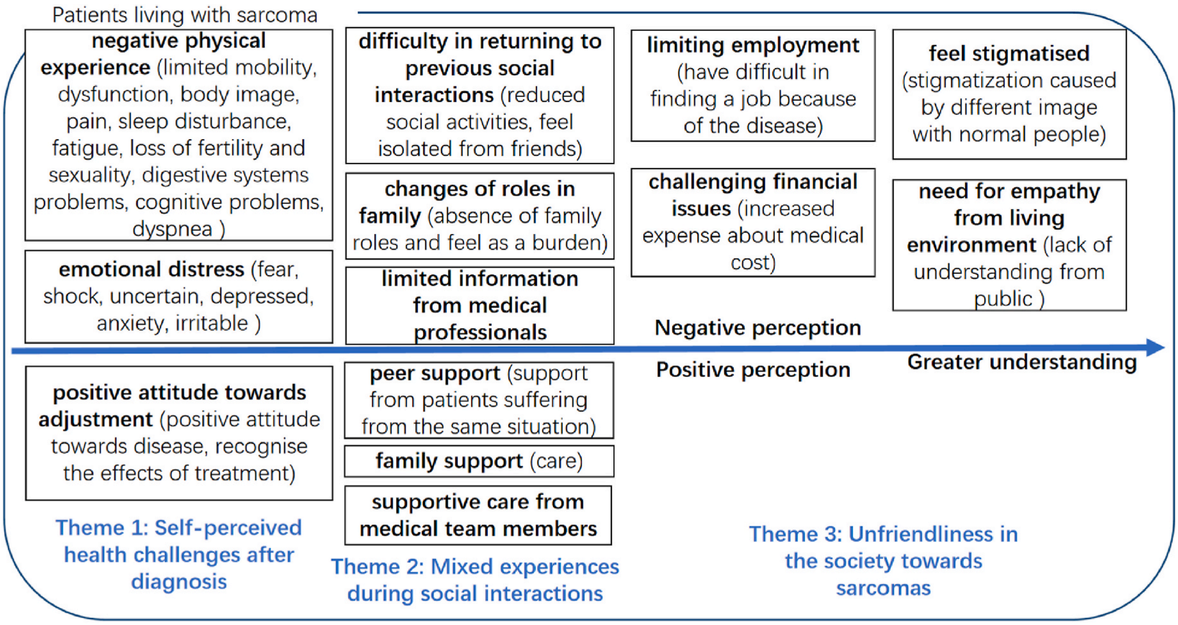

Fig. 2. Descriptive and analytical themes summary.

> "Having children is something that I think is problematic in my current situation." (from van de Wal et al., 2023a,b)

Likewise, the sexual well-being of sarcoma patients was also affected. Due to the nature of sarcoma, tumours could develop in various locations throughout the body. If the tumour was located in or near reproductive organs, the surgery may directly affect sexual function or cause pain or discomfort during sexual activity. One interviewee from the study by Martins et al. (2020) said,

> "Our sex life has, undoubtedly, been affected by this. Because of where the problem was, where my sarcoma was sited, where my operation consequently has been, yes. I mean, I must admit, from a sexual intercourse point of view, it hasn't happened since my operation."

Digestive problems were also common treatment-related side-effects reported by sarcoma patients. The problems included diarrhea, taste change, appetite loss and nausea (from Fauske et al., 2019). As illustrated by an interviewee,

> "Yes, well, some of the side effects during treatment I've mentioned are nausea, mucus in my throat, hair loss, sunburn, and fatigue. I had a doctor available when I started the radiation, and also for regular monitoring during my stay, that was appointments." (from Fauske et al., 2023)

Some sarcoma patients reported cognitive problems which included inability to concentrate and poor memory after the completion of treatment. In the semi-structured interviews, two interviewees reported that,

> "… an inability to concentrate is how I describe it, but that seems to have gone since coming off Glivec." (from van de Wal et al., 2023a,b)

> "I have trouble remembering things. My house is full of notes." (from van Eck et al., 2021)

Dyspnea would be caused if the tumours occurred near the pulmonary and bronchial areas which could directly obstruct airways or compress the lung tissue, as indicated by the following statement from an interviewee with thoracic sarcoma. Also, certain drugs could result in breathlessness (from van de Wal et al., 2023a,b).

> "It is as if I am not getting enough oxygen. I'm a little bit scared about that or panicky sometimes. It is annoying. Normally during the day, I have no problems with it, nor do I suffer from it. But when I am in bed, I am paying attention to it in a different way" (from van Eck et al., 2021)

3.5.1.2. Subtheme 2: emotional distress. Sarcoma patients were found to experience various psychological burden which affected patients' lives in many ways. The psychological burden started with the initial discomfort at the diagnosis, blending with fear, uncertainty and anxiety throughout the active treatment to the subsequent change in attitudes toward the disease, which were challenging and difficult.

Feeling shock was the first feeling when they received a diagnosis of sarcoma because of the sudden shift from a state of normalcy to a life-threatening situation. Some patients expressed being overwhelmed and felt confused why they had this rare disease. In the semi-structured interview, one interviewee said,

> "Because there is a question that I ask constantly, why me? Why must I have so much suffering … I was so young, why me?" (from Almeida et al., 2024)

Fear is another common emotion expressed by sarcoma patients because it had a high possibility of recurrence and metastases. In addition, some patients were required to have multiple treatments and invasive surgery with uncertain prognosis which increased their fear about future.

> "It's the week between the scan and the results that the fear starts to set in again. 'Am I going to be told it's come back?' It's that not knowing." (from Vindrola-Padros et al., 2023)

Uncertainty was also a concern, which was resulted from the complexity and rarity of the disease, varied treatment options and unclear prognosis.

> "You're left in a state of uncertainty, because obviously no-one can give you a definitive five-year outlook. You're constantly having rescans and everything. You've been through a very big thing and it's not really over. It might be, but you don't know, so that level of uncertainty is tricky at first to sort of get to grips with." (from Martins et al., 2019)

Table 4
Results of meta-synthesis for experiences, views and support needs of patients living with sarcoma.

Theoretical underpinning	Analytic themes	Descriptive subthemes	Codes	Example quotations
Individual level	Self-perceived heath challenges after diagnosis	Negative physical experience	limited mobility	The legs are sometimes difficult to move, and it is a bit difficult to move for too long, so I have to use U-shaped crutches. (Priyanto et al., 2024)
			dysfunction	At first I pretty much couldn't do anything a normal person would be able to do. I wasn't able to go to the toilet without assistance, in the sense that I wasn't able to wipe certain areas. I wasn't able to shower by myself. (Martins et al., 2020)
			body image	The scars are not the worst thing, the hernia is. The scars are not too bad. The problem is the thing that protrudes from my hip/pelvic region [hernia]. I don't have a pelvic bone, as it was removed in the front, and they moved a muscle from the stomach down to my hip/pelvic area. Now I feel that my abdomen has caved in and that it sticks out when I am not wearing something tight. (Fauske et al., 2016)
			pain	At first, it was painful, and then I had difficulty walking and limping, and over time, it got bigger. There was pain, tingling, and heaviness. Every night and morning, I suddenly felt pain. While in the hospital, I was injected with painkillers. (Priyanto et al., 2024)
			sleep disturbance	… cramps… which I think is quite common. Nighttime incidence and cause of insomnia. (van de Wal et al., 2023a,b)
			fatigue	You just have no energy, it's not that you want to sleep particularly it's just you feel as though your legs won't get you there you know it's just this feeling that you know that you're not going to make it. (Dewhurst et al., 2020)
			loss of fertility	Having children is something that I think is problematic in my current situation. (van de Wal et al., 2023a,b)
			loss of sexuality	Our sex life has, undoubtedly, been affected by this. Because of where the problem was, where my sarcoma was sited, where my operation consequently has been, yes. I mean, I must admit, from a sexual intercourse point of view, it hasn't happened since my operation. (Martins et al., 2020)
			digestive systems problems	Yes, well, some of the side effects during treatment I've mentioned are nausea, mucus in my throat, hair loss, sunburn, and fatigue. I had a doctor available when I started the radiation, and also for regular monitoring during my stay, that was appointments. (Fauske et al., 2023)
			cognitive problems	I have trouble remembering things. My house is full of notes. (van Eck et al., 2021)
			dyspnea	"It is as if I am not getting enough oxygen. I'm a little bit scared about that or panicky sometimes. It is annoying. Normally during the day, I have no problems with it, nor do I suffer from it. But when I am in bed, I am paying attention to it in a different way. (van Eck et al., 2021)
		Emotional distress	shock	Because there is a question that I ask constantly, why me? Why must I have so much suffering … I was so young, why me? (Almeida et al., 2024)
			fear	It's the week between the scan and the results that the fear starts to set in again. 'Am I going to be told it's come back?' It's that not knowing. (Vindrola-Padros et al., 2023)
			uncertain	You're left in a state of uncertainty, because obviously no-one can give you a definitive five-year outlook. You're constantly having re-scans and everything. You've been through a very big thing and it's not really over. It might be, but you don't know, so that level of uncertainty is tricky at first to sort of get to grips with. (Martins et al., 2019)
			depressed	No, I'm not cured. So that was something difficult to cope with and then, also, after my chemotherapy finished, all of a sudden, I wasn't the center of attention anymore. I became quite depressed because of it, which is probably, I think, you spent all that time looking forward to getting to the end of it, then you've come to the end of it and I went to see the local GP about that. (Martins et al., 2024)
			anxiety	Every time before you get a scan, you always anxiety, you always get worried, it's just a known thing to panic over nothing, like, when you know you've got a scan coming up. (Vindrola-Padros et al., 2023)
			irritable	I do suffer from mood swings. I've always been very even-tempered. I can cope with most things, but now I do have some quite dramatic mood swings. (van de Wal et al., 2023a,b)
		Positive attitude towards adjustments	positive attitude towards disease	Now, I appreciate each day even more. Yes, I do [….]. I say we should be grateful for every day that goes well. (Fauske et al., 2015a)
			recognize the effects of treatment	Every time the physical therapist came [during chemotherapy treatment], I thought, Oh ***, I don't feel like doing that at all. But

(continued on next page)

Table 4 (*continued*)

Theoretical underpinning	Analytic themes	Descriptive subthemes	Codes	Example quotations
				then the physical therapist was gone and then I thought, yeah, I did my exercises and it does feel a bit more familiar again, and eventually after every treatment or every exercise session, it was good. (Denissen et al., 2024)
Interpersonal level	Mixed experiences during social interactions	Difficulty in returning to previous social interactions	reduced social activities	I spend less time with friends than I used to do. I feel sad about that. I feel it is the pain that is my biggest problem. (Fauske et al., 2015b)
			feel isolated from friends	A lot of friends do sort of back off from you when they find out that you have cancer. (Weaver et al., 2020)
		Peer support	support from the patient suffering from the same situation	if you hear they're struggling about certain things and you can relate to them, you start realising it's normal. (Martins et al., 2019)
		Changes of roles in family	stop breastfeeding	It was really hard from things like-, so I had to stop breastfeeding. (Kosir et al., 2020)
		Family support	support from familiy and relatives	No one passes wrong comment on me, my family members and relatives supported me with regard to cancer. (Suhag et al., 2024)
		Limited information from medical professionals	need information about treatment	I felt I didn't get enough information, I would have liked to get more (…) about the place I was going to, what to expect, what the treatment's like there, I knew I'd have radiation for a certain period, but it would have been nice to know what would happen on those days. (…). I wasn't prepared for the mask either. (Fauske et al., 2023)
		Supportive care from medical team members	support from health care workers	The doctor, staff nurse and health care workers help me and supported me during my treatment. They give positive reinforcement to patients. (Suhag et al., 2024)
Organizational and community level	Unfriendliness in the society towards sarcoma	Limiting employment	difficult to hire someone on crutches	No one wants to hire anyone on crutches. (Fauske et al., 2015b)
		Challenging financial issues	financial difficulties	I do have financial difficulties due to the Imatinib. As I said, my career has ended and now I am selling puzzles. Well that's definitely not enough to live on. (van de Wal et al., 2023)
		Feel stigmatised	discrimination	A lot of people did sideline, pass comments, mentally disturbed me, they used to say that this is the sin of his past deeds. (Suhag et al., 2024)
		Need for empathy from living environment	lack of understanding from others	I just wasn't expecting something that nobody knew about, because breast cancer and things like that, you can go and talk to somebody. Leiomyosarcoma, they just look at you and go, 'Excuse me?' It's quite disconcerting. (Martins et al., 2020)

Sarcoma patients frequently experienced a high level of depression because they were struggled the possibility of cancer relapse even after the treatment has been completed. Also, the late effect of cancer treatment, i.e., reduced attention also made the patients feel depressed.

> "No, I'm not cured." So that was something difficult to cope with and then, also, after my chemotherapy finished, all of a sudden, I wasn't the center of attention anymore. I became quite depressed because of it, which is probably, I think, you spent all that time looking forward to getting to the end of it, then you've come to the end of it and I went to see the local GP about that." (from Martins et al., 2024)

Anxiety usually came from the uncertainty of the results of the medical tests, particularly, the tests might have abnormal findings which indicated the recurrence of cancer. The anxiety was exaggerated at the time when waiting for each medical test and the results.

> "Every time before you get a scan, you always anxiety, you always get worried, it's just a known thing to panic over nothing, like, when you know you've got a scan coming up." (from Vindrola-Padros et al., 2023)

Besides, patients undergoing treatment for sarcoma often experienced side effects which could lead to irritability as they were required to cope with the altered physical state exacerbating their mood swings.

> "I do suffer from mood swings. I've always been very even-tempered. I can cope with most things, but now I do have some quite dramatic mood swings" (from van de Wal et al., 2023a,b)

3.5.1.3. Subtheme 3: positive attitude towards adjustment. Unlike the initial frustration of being diagnosed with sarcoma, after living with the disease for a longer period of time, some patients changed their attitudes or perceptions. They were able to accept the disease, adapted to it and took a positive approach to life. Particularly, they have started to build up an existential mindset and believed that being alive in the present was a kind of luck. They also accepted the fact that they were ill and they could do the best in the present.

> "Now, I appreciate each day even more. Yes, I do [….]. I say we should be grateful for every day that goes well." (from Fauske et al., 2015a)

> "I know I'll never be back to where I was, I know I will never be back to what I was but as best as I can be now and as happy as I can be now you know." (from Kain et al., 2017)

Although the process of treatment was painful and contributed to various side effects, some patients realized that the experience could bring some benefits to their lives, in particular enhancing their confidence in managing their own health conditions.

> "Every time the physical therapist came [during chemotherapy treatment], I thought, Oh ***, I don't feel like doing that at all. But then the physical therapist was gone and then I thought, yeah, I did my exercises and it does feel a bit more familiar again, and eventually after every treatment or every exercise session, it was good." (from Denissen et al., 2024)

3.5.2. *Theme 2: mixed experiences during social interactions*

Social interaction was an inevitable part for sarcoma patients. Their social relationships primarily involved direct interactions with friends, family, and medical caregivers. Among all the quotes included, patients reported experiencing contradictory feelings, encompassing both positive and negative perceptions, during interactions with friends, family members, and medical caregivers.

3.5.2.1. *Subtheme 1: difficulty in returning to previous social interactions.*

Due to changes of their health condition brought by the disease and treatment, patients experienced a decrease in social activities when compared to the past. Additionally, the shift in their identity from healthy individuals to patients often led to a strain on previous friendships, resulting in the deterioration of some relationships.

Reduced social activities was a key issue. Due to the physical symptoms and functional impairments, the patients were no longer maintain their previous level of activity. Additionally, regular check-up further limited their availability and scheduling.

> "I spend less time with friends than I used to do. I feel sad about that. I feel it is the pain that is my biggest problem." (from Fauske et al., 2015b)

> "[Patient] wanted to get back to school, wanted to get back into the sports team… [The parents] get the documents, find out when the next check is, work out when we had to go in and have the PET scan." (from Weaver et al., 2021)

Feeling isolated from friends is another negative perception in relation to social interactions. The patients said their friends did not contact them anymore, probably due to their cancer diagnosis. They could not be treated as the normal individual by friends and had to quit some social activities with friends such as playing football as their limited physical function.

> "A lot of friends do sort of back off from you when they find out that you have cancer." (from Weaver et al., 2020)

3.5.2.2. *Subtheme 2: peer support.*

Sarcoma patients expressed that connecting with others who have similar experiences was very important because most people, even for the patients of other types of cancer. The sarcoma patients thought the support from people having a similar experience was crucial, making them feel less isolated and different.

> "if you hear they're struggling about certain things and you can relate to them, you start realising it's normal." (from Martins et al., 2019)

> "If you had a support network of people going through those similar drugs and they're going, 'Oh my God, I cannot lift my arm today' you wouldn't feel guilty." (from Donovan et al., 2021)

3.5.2.3. *Subtheme 3: changes of roles in family.*

Due to the compromised functional outcomes, some patients were unable to perform their roles in the families as usual. For example, because of the active cancer treatment, sarcoma patients who were mothers were unable to breastfeed their babies. Although the patients lost their family roles, some strived to behave as normal, avoiding to become a burden to their loved ones and to alleviate family members' concerns about their situation.

> "It was really hard from things like-, so I had to stop breastfeeding." (from Kosir et al., 2020)

> "when somebody tells you, you have cancer, normality flies out of the window, I want to keep things as normal as possible for them, you know, my youngest son is in the last year of his degree and I don't want this to affect his results, um my other son is working but he has um emotional mental anxiety difficulties and I don't want to burden him with too much anxiety so it's important to try and keep as close to normality as possible." (from Dewhurst et al., 2020)

3.5.2.4. *Subtheme 4: family support.*

The understanding of family members served as a crucial support for patients in facing their illness with a positive attitude. Family members could help care for patients and assist with household tasks which were significant support to the patients during their disease journey.

> "No one passes wrong comment on me, my family members and relatives supported me with regard to cancer." (from Suhag et al., 2024)

> "You know, my partner still had to go to work, and so my mum looked after my children for me, and I'm quite fortunate." (from Martins et al., 2019)

3.5.2.5. *Subtheme 5: limited information from medical professionals.*

Most patients expressed a strong need for information about their condition. When healthcare professionals failed to provide detailed information regarding their health status and treatment strategy, patients were left with a sense of confusion and uncertainty. As such, the patients searched the information online. However, they were struggled to find the most up-to-date resources about sarcoma as it is a rare disease.

> "I felt I didn't get enough information, I would have liked to get more (…) about the place I was going to, what to expect, what the treatment's like there, I knew I'd have radiation for a certain period, but it would have been nice to know what would happen on those days. (…). I wasn't prepared for the mask either." (from Fauske et al., 2023)

> "I checked Google with "stromal tumours" or "GIST." Google seemed to show older results, dating back to 2002 or 2003, and that was worrisome." (from Macdonald et al., 2012)

3.5.2.6. *Subtheme 6: supportive care from medical team members.*

Early and accurate diagnosis by healthcare professionals, along with specialized treatment during hospitalization and regular follow-up after discharge, provided patients with a strong sense of support, boosting their confidence in facing the disease. Additionally, the motivational support from medical staff was regarded as essential for patients during their journey.

> "The doctor, staff nurse and health care workers help me and supported me during my treatment. They give positive reinforcement to patients." (from Suhag et al., 2024)

> "Well yes, I felt that it (the polyclinic) was professional. I have confidence in their skill. I feel they know what they're doing (…) and I have a good dialogue with them. I've had various doctors who have called me and followed me up through these almost eight years, but I think they all explain things well. And they're actually personal." (from Fauske et al., 2023)

3.5.3. *Theme 3: unfriendliness in the society towards sarcomas*

As a rare type of cancer, sarcoma often presents patients with significant challenges to re-integrate into the society, as expressed during interviews. The unique locations of tumours could impact the patients' appearance and lead to decreased functional outcomes after treatment. Because of these limitations, patients reported various forms of unfriendliness in their living environment, including reduced employment opportunities, financial burdens, and a lack of understanding from the public.

3.5.3.1. *Subtheme 1: limiting employment.*

Patients with severe physical impairments often found it difficult to secure employment. Moreover, returning to their previous jobs after treatment could be challenging. Deteriorating health condition made it hard for these patients to compete in the job market, as many companies would like to employ capable and high-performing employees.

> “No one wants to hire anyone on crutches.” (from Fauske et al., 2015b)

> “But basically, they weren’t going to give me my old job because I – they weren’t even going to find me another job within the company sitting down. I was trying to get a job everywhere. I had resumes everywhere. And I finally went back to the place that I didn’t want to go because I couldn’t do it.But you know, I would have done it no matter what. But how did I feel? I was disappointed, I was a little upset.” (from Parsons et al., 2008)

3.5.3.2. Subtheme 2: challenging financial issues. Patients reported challenging financial issues primarily due to difficulties in finding employment and the high costs of ongoing treatment. The financial assistance provided by the governments was insufficient to alleviate the financial challenges they faced.

> “I do have financial difficulties due to the Imatinib. As I said, my career has ended and now I am selling puzzles. Well that‘s definitely not enough to live on.” (from van de Wal et al., 2023)

> “I knew I couldn’t really afford hospital, sort of, visits of that sort of cost, so I was concerned about the practical, how am I going to get there?” (from Martins et al., 2024)

> “I feel like the Department for Work and Pension made me feel like I shouldn’t be asking for support …. It’s hard to fight for something when you’re already fighting something so difficult.” (from Martins et al., 2024)

3.5.3.3. Subtheme 3: feel stigmatised. Sarcoma patients also felt being stigmatised by the society. Because of the disrupted body images, some sarcoma patients reported that they were stared by people in the crowd, and some were stigmatised as individuals with physical disabilities. The comments, discrimination, and stigma significantly impacted the mental well-being of these patients.

> “everybody looks at someone in a wheelchair instantly.” (from Beghean and Coffey, 2021)

> “Alarmingly many people have a theory that if you’re in a wheelchair, you must be brain damaged.” (from Fauske et al., 2016)

> “A lot of people did sideline, pass comments, mentally disturbed me, they used to say that this is the sin of his past deeds.” (from Suhag et al., 2024)

3.5.3.4. Subtheme 4: need for empathy from living environment. Sarcoma patients reported that the public lacked in understanding about their challenges as it is not a common cancer, such as lung or breast cancer. Due to the insufficient understanding and societal awareness, the sarcoma patients felt the society was lack of empathy to them.

> “I just wasn’t expecting something that nobody knew about, because breast cancer and things like that, you can go and talk to somebody. Leiomyosarcoma, they just look at you and go, ’Excuse me?’ It’s quite disconcerting.” (from Martins et al., 2020)

> “I remember that I had shown it to a friend who was shocked. I am very open. I take off my shirt and I show it. But it is also difficult how to deal with the reaction of others.” (from van Eck et al., 2021)

4. Discussion

This is the first meta-synthesis to synthesize the experiences and needs of patients living with sarcoma. Due to the lack of specific tools developed for sarcoma patients, qualitative interviews are the most powerful way to tap into the experiences and needs of this rare group of patients. Underpinned by the socio-ecological model, we combined the results from 27 qualitative studies, generating evidence in relation to physical, psychological and social perspectives. Three core analytical themes were eventually identified, including self-perceived health challenges after diagnosis, mixed experiences during social interactions and unfriendliness in the society towards sarcoma.

“Self-perceived health challenges after diagnosis” emphasizes on the patients’ perceptionof their health condition after sarcoma which corresponds to the individual level of the socio-ecological model that focuses on changes in the individual’s own situation (Bronfenbrenner, 1977). The findings revealed that the changes were multifaceted, including physical and psychological, arising from both the sarcoma itself and the aggressive cancer treatments. Patients experienced significant disruptions in mobility due to invasive treatments, particularly limb-salvage surgery and amputation. The physical limitations hindered their ability to perform activities of daily living. Additionally, other physical symptoms, e.g., pain, fatigue, loss of fertility and cognitive impairments further exacerbated the individual burden. This is accordance with the results of a national study of sarcoma patients in German in which their symptom burden was high, with physical limitations as one of the most commonly identified issue (Eichler et al., 2020). However, the degree of physical limitation was influenced by different clinical characteristics such as tumour sites, sarcoma types, disease and treatment status, that cannot be explained concretely in the qualitative studies (Fernandez-Pineda et al., 2017). Future interviews should pay attention to the differences in individual characteristics and obtain more accurate physical experiences of sarcoma patients. Apart from the physical changes, emotional distress, including shocked, fear, uncertain, anxious, depressed and irritable, were reported by sarcoma patients. These distresses are also intricately linked to the individual level of the socio-ecological model, explaining the personal experiences, emotions, and psychological responses to the diagnosis and treatment of sarcoma. Previous quantitative studies only observed fear, anxiety and depression in sarcoma patients (Benedetti et al., 2023; Petrella et al., 2023). Our meta-synthesis added to these results and identify the feeling of shock, uncertainty, and irritability in sarcoma patients, aside from fear, anxiety and depression. Through understanding the individual level of the socio-ecological model, healthcare providers can provide better support to sarcoma patients in navigating the complex emotional experiences along the cancer trajectory. Despite the physical and psychological changes, this meta-synthesis identified a positive attitude towards adjustment in some sarcoma patients. The adjustment included personal growth, acceptance, and resilience to cancer and its treatment. This transformation often involved an existentialist mindset, where patients accepted their limitations, embraced the present moment and found gratitude in daily life (Denissen et al., 2024). Given the importance of the existentialist mindset in the transformation, healthcare providers can cultivate patients for this mindset through encouraging them to focus on achievable goals, celebrating small victories, and being thankful to be presence. As such, patients can be empowered to navigate their cancer journey with hope and determination even under the adversity.

“Mixed experiences during social interactions” emphasizes the positive and negative experiences of sarcoma patients with their friends, family members and medical caregivers who are all the important parts in the interpersonal level of the socio-ecological model. As revealed by our meta-synthesis, sarcoma patients encountered substantial challenges to return to the previous social interactions with their friends. Fauske et al. (2015b) found that the reduced social interaction was primarily due to the pain and other physical limitations experienced by the sarcoma patients. The disruption in social activities engagement further led to a profound sense of loss and isolation (Fauske et al., 2015b). Weaver et al. (2020) also indicated that the shift in identity after a cancer diagnosis also strained on the existing friendships. Withdrawing from friends exacerbated the feelings of isolation, leaving sarcoma patients to navigate the disease with diminished support.

Notwithstanding the social withdrawal, our meta-synthesis found that peer support was vital source of comfort for sarcoma patients. As revealed by the qualitative evidence, peer support networks offered a space where sarcoma patients could openly discuss their challenges without fear of judgment or misunderstanding. Unlike the traditional social networks which might falter, peer support was reported as a critical lifeline, offering empathy and shared understanding to sarcoma patients. Therefore, healthcare providers should facilitate the patients to make connections with peer support groups and encourage open communication about social challenges within the groups. Our meta-analysis also identified a complex family dynamic in sarcoma patients. The included qualitative studies showed that the diagnosis and treatment of sarcoma significantly disrupted the family roles and responsibilities of patients. In the interviews, the patients often expressed a strong desire to maintain normalcy to minizine the impact of the disease on their loved ones (Dewhurst et al., 2020). In the meantime, family support was emerged as a vital resource for sarcoma patients, providing both emotional and practical assistance. While patients might struggle with feelings like a burden and loss of role, the support of family members could provide a critical buffer against these challenges. Healthcare providers should recognize this complex family dynamics and offer resources and guidance to both patients and their families. One more important finding from our meta-synthesis was that there was limited information provided by healthcare professionals regarding the patients' medical condition and treatment. In the interviews, sarcoma patients expressed a strong need for detailed and clear information to help them navigate their diagnosis and treatment journey (Macdonald et al., 2012). While the limited information led to confusion and anxiety, the presence of a supportive and communicative medical team could significantly mitigate these challenges.

The theme of "unfriendliness in the society towards sarcomas" underscores the pervasive difficulties sarcoma patients encountered in their living environment, which are exacerbated by the rarity and unique characteristics of their medical condition. This theme corresponds to the organizational and community levels of the socio-ecological model. One of the major subthemes revealed by the meta-synthesis was limiting employment which showed significant barriers to workforce participation for sarcoma patients. The physical impairments resulting from sarcoma and its treatment hindered the patients' ability to secure or return to employment. This was further compounded by organizational practices that prioritized high-performing employees, leaving those with visible disabilities or reduced physical capabilities marginalized (Fauske et al., 2015b). To facilitate sarcoma patients to reintegrate to the society, it is advocated that organizations need to adopt more inclusive hiring practices and provide reasonable accommodation to support the employment of individuals with disabilities. Our meta-analysis also revealed a profound financial challenge in sarcoma patients. The high costs of treatment, coupled with difficulties in maintaining employment and inadequacy of financial support from governments placed a significant economic burden for this population group (Martins et al., 2024). Community-based support systems, including financial assistance programs and local advocacy groups, are therefore crucial in alleviating these burdens. Additionally, raising awareness within communities about the specific needs of sarcoma patients can foster a more supportive environment. Besides, this meta-synthesis highlighted the exclusion and stigmatization of sarcoma patients which underscores the need for public policy interventions that promote inclusivity and understanding. Educational campaigns and policy initiatives which aim at increasing public awareness of rare cancers like sarcoma can help dismantle stereotypes and foster a more empathetic society. Furthermore, policies that ensure equitable access to healthcare and social services for sarcoma patients are essential in mitigating the financial and social challenges they face. In sum, addressing the unfriendliness in the society towards sarcoma requires a comprehensive approach that involves organizational change, community support, and public policy reform. By fostering inclusive employment practices, enhancing community-based support systems, and implementing policies that promote awareness and empathy, we can create a more supportive environment for sarcoma patients. This holistic approach is vital in improving the quality of life for individuals living with this rare and challenging condition.

4.1. *Limitations*

Firstly, due to the insufficient number of the included studies, we were unable to report the experiences and needs of patients by different types of sarcomas. Secondly, the inclusion of only peer-reviewed literature may have resulted in the loss of gray literature. Lastly, this qualitative systematic review only included English literature, so articles in other languages may be missed.

5. Conclusions

This meta-synthesis identifies the experiences and needs of sarcoma patients along their disease journey. Physical and psychological symptoms are the most direct outcome of the disease, resulting in a reduced quality of life. However, an existential mindset can lead to a positive attitude towards the disease, resulting in adjustment and transformation. Sarcoma also results in both positive and negative experiences in interpersonal relationships with friends, family members and healthcare caregivers. The unfriendliness in the society causes employment, economic, and stigmatization issues for patients living with sarcoma. For this rare disease, we call for more research to be conducted in the future, thus formulating a comprehensive management plan to support sarcoma patients throughout the treatment process and survivorship.

CRediT authorship contribution statement

Qi Wang: Writing – original draft, Methodology, Formal analysis, Conceptualization. **Qi Liu:** Writing – review & editing, Methodology. **Ka Yan Ho:** Writing – review & editing, Conceptualization. **Katherine Ka Wai Lam:** Methodology, Formal analysis. **Ting Mao:** Methodology. **Kate Law:** Writing – review & editing. **Kuan Liao:** Conceptualization. **Mian Wang:** Writing – review & editing. **Yuwen Gao:** Methodology. **Hammoda Abu-Odah:** Writing – review & editing. **Naomi Takemura:** Conceptualization. **Herbert Ho Fung Loong:** Supervision. **Janelle Yorke:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

No conflict of interest to declare.

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Appendix A. Supplementary data

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References

Almeida, A.M., Lima, L., Martins, T., 2024. Understanding quality of life's challenges in sarcoma patients: a mixed-methods study. Eur. J. Oncol. Nurs. 70, 102585. https://doi.org/10.1016/j.ejon.2024.102585.

Almeida, A., Martins, T., Lima, L., 2021. Patient-reported outcomes in sarcoma: a scoping review. Eur. J. Oncol. Nurs. 50, 101897. https://doi.org/10.1016/j.ejon.2021.101897.

Andrews, C.C., Siegel, G., Smith, S., 2019. Rehabilitation to improve the function and quality of life of soft tissue and bony sarcoma patients. Patient Relat. Outcome Meas. 10, 417–425. https://doi.org/10.2147/PROM.S130183.

Beghean, R., Coffey, L., 2021. "You either sink or you swim, and you're better off swimming": a qualitative study exploring the self-management experiences of soft tissue sarcoma survivors. Eur. J. Oncol. Nurs. 55, 102062. https://doi.org/10.1016/j.ejon.2021.102062.

Bronfenbrenner, U., 1977. Toward an experimental ecology of human development. Am. Psychol. 32 (7), 513–531. https://doi.org/10.1037/0003-066X.32.7.513.

Bronfenbrenner, U., Ceci, S.J., 1994. Nature-nurture reconceptualized in developmental perspective: a bioecological model. Psychol. Rev. 101 (4), 568–586. https://doi.org/10.1037/0033-295x.101.4.568.

Cho, H.J., Kang, K., Park, K.Y., 2024. Health and medical experience of migrant workers: qualitative meta-synthesis. Arch. Public Health 82 (1), 27. https://doi.org/10.1186/s13690-024-01254-z.

den Hollander, D., Van der Graaf, W.T.A., Fiore, M., Kasper, B., Singer, S., Desar, I.M.E., Husson, O., 2020. Unravelling the heterogeneity of soft tissue and bone sarcoma patients' health-related quality of life: a systematic literature review with focus on tumour location. ESMO Open 5 (5), e000914. https://doi.org/10.1136/esmoopen-2020-000914.

Denissen, J.J., van der Geest, I.C., van Hinte, G., Desar, I.M., van der Wees, P.J., Koenders, N., 2024. Explaining needs for rehabilitation in patients with bone sarcoma and a megaprosthesis: a qualitative, grounded theory study. Disabil. Rehabil. 1–13. https://doi.org/10.1080/09638288.2024.2393440.

Dewhurst, S., Tigue, R., Sandsund, C., Mein, G., Shaw, C., 2020. Factors influencing people's ability to maintain their activity levels during treatment for soft tissue sarcoma – a qualitative study. Physiother. Theory Pract. 36 (8), 923–932. https://doi.org/10.1080/09593985.2018.1519622.

Eichler, M., Hentschel, L., Richter, S., Hohenberger, P., Kasper, B., Andreou, D., Pink, D., Jakob, J., Singer, S., Grützmann, R., Fung, S., Wardelmann, E., Arndt, K., Heidt, V., Hofbauer, C., Fried, M., Gaidzik, V.I., Verpoort, K., Ahrens, M., Weitz, J., Schaser, K. D., Bornhäuser, M., Schmitt, J., Schuler, M.K., The PROSa Study Group, 2020. The health-related quality of life of sarcoma patients and survivors in Germany-Cross-Sectional results of a nationwide observational study (PROSa). Cancers 12 (12), 3590. https://doi.org/10.3390/cancers12123590.

Eichler, M., Hentschel, L., Singer, S., Hornemann, B., Richter, S., Hofbauer, C., Hohenberger, P., Kasper, B., Andreou, D., Pink, D., Jakob, J., Grützmann, R., Fung, S., Wardelmann, E., Arndt, K., Hermes-Moll, K., Schoffer, O., Fried, M., Jambor, H.K., Weitz, J., Schaser, K.D., Bornhäuser, M., Schmitt, J., Schuler, M.K., 2023. Health related Quality of Life over time in German sarcoma patients. An analysis of associated factors - results of the PROSa study. Front. Endocrinol. 14, 1166838. https://doi.org/10.3389/fendo.2023.1166838.

Fauske, L., Bondevik, H., Bruland, Ø.S., Ozakinci, G., 2015a. Negative and positive consequences of cancer treatment experienced by long-term osteosarcoma survivors: a qualitative study. Anticancer Res. 35 (11), 6081–6090.

Fauske, L., Bruland, O.S., Grov, E.K., Bondevik, H., 2015b. Cured of primary bone cancer, but at what cost: a qualitative study of functional impairment and lost opportunities. Sarcoma 2015, 484196. https://doi.org/10.1155/2015/484196.

Fauske, L., Lorem, G., Grov, E.K., Bondevik, H., 2016. Changes in the body image of bone sarcoma survivors following surgical treatment—a qualitative study. J. Surg. Oncol. 113 (2), 229–234. https://doi.org/10.1002/jso.24138.

Fauske, L., Hompland, I., Lorem, G., Bondevik, H., Bruland, Ø.S., 2019. Perspectives on treatment side effects in patients with metastatic gastrointestinal stromal tumour: a qualitative study. Clin. Sarcoma Res. 9 (1), 6. https://doi.org/10.1186/s13569-019-0116-3.

Fauske, L., Wærstad, P.H., Hompland, I., Bruland, Ø.S., 2022. Hope as a lifeline: imatinib discontinuation in patients with oligometastatic gastrointestinal stromal tumours. Anticancer Res. 42 (2), 955–963. https://doi.org/10.21873/anticanres.15555.

Fauske, L., Jebsen, N.L., Bondevik, H., Bruland, Ø.S., 2023. Exploring the patient perspective of bone sarcoma survivors who have undergone particle radiotherapy abroad. Anticancer Res. 43 (5), 2031–2039. https://doi.org/10.21873/anticanres.16364.

Fernandez-Pineda, I., Hudson, M.M., Pappo, A.S., Bishop, M.W., Klosky, J.L., Brinkman, T.M., Srivastava, D.K., Neel, M.D., Rao, B.N., Davidoff, A.M., Krull, K.R., Mulrooney, D.A., Robison, L.L., Ness, K.K., 2017. Long-term functional outcomes and quality of life in adult survivors of childhood extremity sarcomas: a report from the St. Jude Lifetime Cohort Study. J. Cancer Surviv. 11 (1), 1–12. https://doi.org/10.1007/s11764-016-0556-1.

Generaal, J.D., Jansen, M.R., van Leeuwen, G.L., van Ginkel, R.J., Been, L.B., van Leeuwen, B.L., 2024. Twenty-five years of experience with patient-reported outcome measures in soft-tissue sarcoma patients: a systematic review. Qual. Life Res. 33 (12), 3189–3211. https://doi.org/10.1007/s11136-024-03755-4.

Gerrand, C., Furtado, S., 2017. Issues of survivorship and rehabilitation in soft tissue sarcoma. Clin. Oncol. 29 (8), 538–545. https://doi.org/10.1016/j.clon.2017.04.001.

Hassani, M., Mate, K.K.V., Turcotte, R., Denis-Larocque, G., Ghodsi, E., Tsimicalis, A., Goulding, K., 2023. Uncovering the gaps: a systematic mixed studies review of quality of life measures in extremity soft tissue sarcoma. J. Surg. Oncol. 128 (3), 430–437. https://doi.org/10.1002/jso.27390.

Hu, Y., Xu, J., Wang, X., Shi, Y., Chen, M., Im, E.O., 2021. Socio-ecological environmental characteristics of young Chinese breast cancer survivors. Oncol. Nurs. Forum 48 (5), 481–490. https://doi.org/10.1188/21.ONF.481-490.

JBI, 2014. Joanna Briggs Institute Reviewers' Manual 2014 Edition. JBI [Internet].

Kain, J., Carlson, A., Kahler, J., Bemboom, J., McDonald, K., Miller, B., 2017. Lessons and advice from our patients: a focus group of sarcoma survivors. Iowa Orthop. J. 37, 139–146.

Kosir, U., Bowes, L., Taylor, R.M., Gerrand, C., Windsor, R., Onasanya, M., Martins, A., 2020. Psychological adaptation and recovery in youth with sarcoma: a qualitative study with practical implications for clinical care and research. BMJ Open 10 (11), e038799. https://doi.org/10.1136/bmjopen-2020-038799.

Košir, U., Denis-Larocque, G., Tsimicalis, A., Freeman, C., Turcotte, R.E., Cury, F., Alcindor, T., Goulding, K., 2020. Psychological functioning, coping styles and their relationship to appraisal of physical limitations following invasive surgical procedures for soft-tissue sarcoma: a qualitative study. J. Surg. Oncol. 121 (8), 1266–1275. https://doi.org/10.1002/jso.25915.

Lewin, S., Glenton, C., Munthe-Kaas, H., Carlsen, B., Colvin, C.J., Gülmezoglu, M., Noyes, J., Booth, A., Garside, R., Rashidian, A., 2015. Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). PLoS Med. 12 (10), e1001895. https://doi.org/10.1371/journal.pmed.1001895.

Loong, H.H., Wong, C.K.H., Wei, Y., Kwan, S.S.C., Zhang, Y., Tse, T., Lau, Y.M., Leung, L K.S., Tang, G.C.H., 2020. Prevalence and prognostic impact of comorbidities and peripheral blood indices in sarcomas. ESMO open 5 (6), e001035. https://doi.org/10.1136/esmoopen-2020-001035.

Macdonald, N., Shapiro, A., Bender, C., Paolantonio, M., Coombs, J., 2012. Experiences and perspectives on the GIST patient journey. Patient Prefer. Adherence 6, 253–262. https://doi.org/10.2147/PPA.S24617.

Martins, A., Bennister, L., Fern, L.A., Gerrand, C., Onasanya, M., Storey, L., Wells, M., Whelan, J.S., Windsor, R., Woodford, J., Taylor, R.M., 2020. Development of a patient-reported experience questionnaire for patients with sarcoma: the Sarcoma Assessment Measure (SAM). Qual. Life Res. 29 (8), 2287–2297. https://doi.org/10.1007/s11136-020-02481-x.

Martins, A., Bennister, L., Fern, L.A., Gerrand, C., Onasanya, M., Storey, L., Wells, M., Whelan, J.S., Windsor, R., Woodford, J., Taylor, R.M., 2024. A qualitative study of the factors influencing patients' experience of soft tissue sarcoma in the United Kingdom. Cancer Nurs. 47 (2), 84. https://doi.org/10.1097/NCC.0000000000001163.

Martins, A., Whelan, J.S., Bennister, L., Fern, L.A., Gerrand, C., Onasanya, M., Storey, L., Wells, M., Windsor, R., Woodford, J., Taylor, R.M., 2019. Qualitative study exploring patients experiences of being diagnosed and living with primary bone cancer in the UK. BMJ Open 9 (9), e028693. https://doi.org/10.1136/bmjopen-2018-028693.

Parsons, J.A., Eakin, J.M., Bell, R.S., Franche, R.-L., Davis, A.M., 2008. "So, are you back to work yet?" Re-conceptualizing 'work' and 'return to work' in the context of primary bone cancer. Soc. Sci. Med. 67 (11), 1826–1836. https://doi.org/10.1016/j.socscimed.2008.09.011.

Priyanto, P., Kamal, A.F., Dahlia, D., Besral, B., 2024. Physical well-being needs of bone cancer patients during treatment in the hospital: a qualitative study. Nurse Media J. Nurs. 13 (3), 342–355. https://doi.org/10.14710/nmjn.v13i3.52696.

Siddaway, A.P., Wood, A.M., Hedges, L.V., 2019. How to do a systematic review: a best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. Annu. Rev. Psychol. 70, 747–770. https://doi.org/10.1146/annurev-psych-010418-102803.

Skalicky, A.M., Ghate, S.R., Perez, J.R., Rentz, A.M., 2017. Results of a qualitative study to develop a patient reported outcome measure for patients with 4 subtypes of soft tissue sarcoma. Sarcoma 2017, 6868030. https://doi.org/10.1155/2017/6868030.

Stiller, C.A., Trama, A., Serraino, D., Rossi, S., Navarro, C., Chirlaque, M.D., Casali, P.G., RARECARE Working Group, 2013. Descriptive epidemiology of sarcomas in Europe: report from the RARECARE project. Eur. J. Cancer 49 (3), 684–695. https://doi.org/10.1016/j.ejca.2012.09.011.

Suhag, A., Sharma, K.K., Tiwari, S.K., Joshi, P., Rastogi, S., Kaur, S., 2024. Health-related quality of life, psychological issues and concerns among sarcoma survivors: a mixed method study. ecancermedicalscience 18. https://doi.org/10.3332/ecancer.2024.1657.

Thomas, J., Harden, A., 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med. Res. Methodol. 8, 45. https://doi.org/10.1186/1471-2288-8-45.

van de Wal, D., Fauske, L., Bruland, Ø.S., Jones, R.L., Kasper, B., Wilson, R., van der Graaf, W.T.A., Husson, O., 2023a. Psychological and social challenges of patients with locally advanced and metastatic gastrointestinal stromal tumours (GIST) on long-term treatment with tyrosine kinase inhibitors: a qualitative study with patients and medical oncologists. Support. Care Cancer 31 (6), 352. https://doi.org/10.1007/s00520-023-07810-7.

van de Wal, D., Venkatesan, S., Benson, C., van der Graaf, W.T., Johnson, C.D., Husson, O., Sodergren, S.C., 2023b. A patient's perspective on the side effects of tyrosine kinase inhibitors in the treatment of advanced and metastatic gastrointestinal stromal tumors. Future Oncol. 19 (4), 299–314. https://doi.org/10.2217/fon-2022-0730.

van der Graaf, W.T.A., Orbach, D., Judson, I.R., Ferrari, A., 2017. Soft tissue sarcomas in adolescents and young adults: a comparison with their paediatric and adult counterparts. Lancet Oncol. 18 (3), e166–e175. https://doi.org/10.1016/S1470-2045(17)30099-2.

van Eck, I., den Hollander, D., Desar, I.M.E., Soomers, V.L.M.N., van de Sande, M.A.J., de Haan, J.J., Verhoef, C., Vriens, I.J.H., Bonenkamp, J.J., van der Graaf, W.T.A., van Houdt, W.J., Husson, O., 2020. Unraveling the heterogeneity of sarcoma survivors' health-related quality of life regarding primary sarcoma location: results from the SURVSARC study. Cancers 12 (11), 3083. https://doi.org/10.3390/cancers12113083.

van Eck, I., den Hollander, D., Lidington, E., Hentschel, L., Eichler, M., Salah, S., Singer, S., Pinto, M., Fauske, L., Fiore, M., Nixon, I., Constantinidou, A., Desar, I.M. E., Bonenkamp, J.J., van Houdt, W.J., Reuvers, M.J.P., Haas, R.L.M., Bruland, Ø.S., Kasper, B., van der Graaf, W.T.A., Husson, O., 2021. Health-related quality of life issues experienced by thoracic and breast sarcoma patients: a rare and understudied group. J. Clin. Med. 10 (22). https://doi.org/10.3390/jcm10225334. Article 22.

Vanderspank-Wright, B., Efstathiou, N., Vandyk, A.D., 2018. Critical care nurses' experiences of withdrawal of treatment: a systematic review of qualitative evidence. Int. J. Nurs. Stud. 77, 15–26. https://doi.org/10.1016/j.ijnurstu.2017.09.012.

Vindrola-Padros, C., Fern, L.A., Gerrand, C., Hulbert-Williams, N.J., Lawal, M., Storey, L., Wells, M., Windsor, R., Woodford, J., Taylor, R.M., 2023. Experiences of fear of recurrence in patients with sarcoma. J. Psychosoc. Oncol. Res. Pract. 5 (4), 113. https://doi.org/10.1097/OR9.0000000000000113.

Wang, Y.C., Miao, N.F., You, M.H., Wang, F.T.Y., Hsu, C.Y., 2024. Care needs, challenges, and experiences of sexual and gender minority cancer survivors in taiwan: findings from a qualitative study. Semin. Oncol. Nurs. 40 (4), 151694. https://doi.org/10.1016/j.soncn.2024.151694.

Weaver, R., O'Connor, M., Carey Smith, R., Sheppard, D., Halkett, G.K.B., 2021. "We're on a merry-go-round": reflections of patients and carers after completing treatment for sarcoma. Curr. Oncol. 28 (4), 3003–3014. https://doi.org/10.3390/curroncol28040263.

Weaver, R., O'Connor, M., Sobhi, S., Carey Smith, R., Halkett, G., 2020. The unmet needs of patients with sarcoma. Psychooncology 29 (7), 1209–1216. https://doi.org/10.1002/pon.5411.

Winnette, R., Hess, L.M., Nicol, S.J., Tai, D.F., Copley-Merriman, C., 2017. The patient experience with soft tissue sarcoma: a systematic review of the literature. Patient 10 (2), 153–162. https://doi.org/10.1007/s40271-016-0200-1.

Wondimagegnehu, A., Assefa, M., Teferra, S., Kantelhardt, E.J., Zebrack, B., Addissie, A., 2024. A qualitative study on psychosocial challenges of patients with cancer in Ethiopia using the social-ecological model. Qual. Health Res. 34 (8–9), 828–841. https://doi.org/10.1177/10497323231219409.

Zhu, X., Chen, S., He, M., Dong, Y., Fang, S., Atigu, Y., Sun, J., 2024. Life experience and identity of spousal caregivers of people with dementia: a qualitative systematic review. Int. J. Nurs. Stud. 154, 104757. https://doi.org/10.1016/j.ijnurstu.2024.104757.