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Psychosocial Impact of Sarcoma

Study 1: Psychosocial Impact of Sarcoma: Challenges & Adaptation, A Meta-Synthesis

Study 2: Psychosocial Impact of Sarcoma: Psychosocial Predictors of Distress in Adults with Sarcoma, A Cross-Sectional Study

Thesis submitted by

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In partial fulfilment of the requirement for the degree of Doctor of Clinical
Psychology

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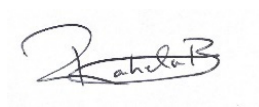
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Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

A handwritten signature in black ink, appearing to read 'Rahela B', is positioned above a horizontal line.

Rahela Beghean

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Abbreviations and Terminology

BIS	Body Image Scale
BS	Bone Sarcoma
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CFT	Compassion-Focused Therapy
DASS-21	Depression Anxiety Stress Scales – 21 items
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
EORTC QLQ-C30	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
GAD-7	Generalised Anxiety Disorder 7-item Scale
GIST	Gastrointestinal Stromal Tumour
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare Professional
HIV	Human Immunodeficiency Virus
HRQoL	Health-Related Quality of Life
MSPSS	Multidimensional Scale of Perceived Social Support
NCCN	National Comprehensive Cancer Network
NFQ	National Framework of Qualifications
NOS	No otherwise specified
PHQ	Patient Health Questionnaire
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROM	Patient-Reported Outcome Measure
PROMIS-PI	Patient-Reported Outcomes Measurement Information System – Pain Interference
PROSPERO	International Prospective Register of Systematic Reviews
PTG	Post-Traumatic Growth
QoL	Quality of Life
SCS-SF	Self-Compassion Scale – Short Form
SCI	Sarcoma Cancer Ireland
SF-36	Short Form Health Survey – 36 item version
SSIN	St. Vincent’s Sarcoma Ireland Network
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
STS	Soft Tissue Sarcoma

Chapter 1: Extended Literature Review

1.1 Overview of Chapter 1

This chapter reviews the literature relevant to the psychosocial impact of sarcoma and sets out the rationale for the studies presented in this major research project. It begins by considering psychosocial burden in cancer more broadly, before narrowing to rare cancers. This section shows that cancer-related distress is shaped not only by disease and treatment, but also by wider psychological, social, and relational consequences. It also highlights how cancer rarity may add further challenges through delayed diagnosis, limited clinician familiarity, fragmented care pathways, and unmet informational and supportive care needs. This provides the broader context for understanding sarcoma as both a cancer diagnosis and a rare disease experience.

The chapter then turns to sarcoma itself, outlining its epidemiology, diagnosis, and treatment to clarify the clinical setting in which psychosocial burden arises. Attention is given to the heterogeneity of sarcoma, the difficulties often associated with diagnosis, the complexity and intensity of treatment, and the visible and functional consequences that may follow surgery, rehabilitation, and long-term surveillance. It also considers why sarcoma may present distinct psychosocial challenges in comparison with more common cancers, particularly through the combined effects of rarity, bodily change, functional limitation, prolonged recovery, and uncertainty about recurrence or progression.

The final part reviews the literature on psychosocial impact of sarcoma, including review literature, studies examining factors associated with distress and

wellbeing, and qualitative work exploring lived experiences. It provides an overview of what is currently known about sarcoma along with highlighting the identified limitations in the literature. The chapter concludes by identifying the key gaps and providing a rationale for the current research project.

1.2 Cancer, Rare Cancers, and Psychosocial Burden

Cancer is widely recognised as an illness whose consequences extend beyond physical disease and treatment alone. Pain, fatigue, impaired physical function, visible bodily change, and the need for rehabilitation may all arise as direct consequences of illness and treatment, but these effects often happen alongside broader psychological and social disruption (Lai et al., 2012; Mehnert et al., 2018; Wang & Feng, 2022). A substantial body of psycho-oncology research has shown that cancer has an effect on emotional wellbeing, self-concept, interpersonal relationships, occupational functioning, and assumptions about continuity, control, and the future (Gorman, 2018; Mehnert et al., 2018; Tack et al., 2022; Wang et al., 2018). Cancer burden is therefore not limited to biomedical morbidity, but spans physical, psychological, social, and existential domains, each of which may shape how the illness is experienced and managed over time. Consideration of these wider dimensions is therefore necessary in order to understand cancer not only as a condition that produces bodily morbidity, but also as one that may involve longer-term psychological, relational, and social consequences beyond the period of active treatment (Gorman, 2018; Lai et al., 2012; Pitman et al., 2018; Wang et al., 2018; Wang & Feng, 2022; Yao et al., 2023).

Psychological distress is among the most consistently reported psychosocial outcomes in cancer populations (Ghiglieri et al., 2023; Lai et al., 2012). Large-scale

evidence suggests that approximately half of patients with cancer experience clinically significant distress. Depression has been found to affect up to one-fifth and anxiety around one-tenth of cancer patients, however estimates vary according to disease type, stage, and method of assessment (Grassi et al., 2023; Mehnert et al., 2018; Pitman et al., 2018). Importantly, these difficulties do not arise in isolation. They are frequently associated with symptom burden, pain, fatigue, sleep disturbance, treatment side effects, and functional limitation, indicating that psychosocial and physical outcomes are closely interrelated (Grassi et al., 2023; Wang & Feng, 2022). These wider consequences can be understood within a biopsychosocial framework, which holds that illness is shaped by biological disease processes, psychological, interpersonal, and social factors (Engel, 1980). More recent developments of this model have further emphasised that these influences are dynamic and reciprocal, unfolding over time and varying in importance across the illness trajectory (Lehman et al., 2017). From this perspective, psychosocial distress in cancer is not separate from disease or treatment, but emerges through their interaction with symptoms, coping, relationships, support, and broader contextual conditions.

Cancer may also disrupt family roles, social relationships, occupational identity, body image, and expectations about the future (Gorman, 2018; Wang & Feng, 2022). Bodily changes associated with treatment, including fatigue, pain, visible change, sexual difficulties, or reduced physical capacity, may affect how individuals relate to their bodies and participate in daily life, while longer-term survivorship may involve an ongoing renegotiation of identity rather than a simple return to pre-illness functioning (Pearce et al., 2020; Tack et al., 2022). In addition, psychosocial outcomes are not uniform across cancer populations. Younger age,

lower socioeconomic status, greater symptom burden, reduced social support, body image distress, and active treatment have all been associated with poorer adjustment and lower levels of wellbeing (Horick et al., 2017; Mehnert et al., 2018; Ruiz-Rodríguez et al., 2022), while self-compassion has been associated with lower anxiety, depression, and stress levels among cancer patients (Bitan et al., 2025), suggesting that cancer-related psychological burden is shaped by an interaction between disease-related, interpersonal, and contextual factors. At the same time, positive and negative consequences may coexist, with some patients also reporting changed priorities, strengthened relationships, or greater appreciation of life, indicating that wellbeing in cancer cannot be understood simply as the absence of distress (Lai et al., 2012; Yao et al., 2023).

However, much of the psycho-oncology evidence has been generated in more common cancers, particularly breast, colorectal, lung, prostate, and gastrointestinal cancers, as well as mixed-site oncology samples (Ghiglieri et al., 2023; Low et al., 2024; Maculaitis et al., 2023; Smith et al., 2017). These are populations in which diagnostic pathways are generally more familiar, treatment protocols are often more standardised, and disease-specific information and support are more widely available. Such features do not necessarily apply in the same way to rare cancers (Low et al., 2024). The psychosocial evidence base in cancer has therefore been shaped largely by populations whose clinical and support pathways differ in important ways from those associated with rarer malignancies and may not fully capture the additional difficulties associated with rare forms of cancers.

Psychosocial burden may be intensified in rare cancers when cancer-related distress is compounded by rarity-related challenges. Diagnostic difficulty is one of

the most frequently cited problems (Low et al., 2024). Rare cancers are encountered less often in healthcare settings, symptoms may not fit familiar diagnostic scripts, and referral pathways may be less straightforward than for common cancers resulting in more delays (Gatta et al., 2011; Low et al., 2024). Such delays have clinical implications, but they are also likely to affect psychosocial outcome by prolonging uncertainty, increasing frustration, and reinforcing the experience of not being understood or recognised early in the illness trajectory (Dufresne & Olivier, 2025; Low et al., 2024).

A related issue concerns the organisation of care and access to expertise. Rare cancers often require specialist diagnosis and treatment, with expertise concentrated in relatively few centres. While centralisation is clearly important for clinical quality, it may also generate fragmented pathways, geographical burden, and discontinuity between local and specialist services (Horick et al., 2017; Von Der Lippe et al., 2017). Patients with rare cancers have been found to be more likely than those with common cancers to be diagnosed and treated across different hospitals, to seek care on the basis of institutional expertise, and to report difficulties relating to referral, communication, and coordination across multiple sites (Low et al., 2024). The requirement for specialist care may therefore produce an additional layer of burden, particularly where healthcare systems are poorly integrated (Horick et al., 2017; Von Der Lippe et al., 2017).

The more limited evidence base associated with rare cancers introduces a further challenge. Smaller and more dispersed patient populations make it more difficult to conduct large trials or develop standardised evidence-based pathways, and rare cancers have historically been under-represented relative to more common

malignancies (Dufresne & Olivier, 2025; Gatta et al., 2011). In clinical practice, this may mean greater reliance case studies, observational evidence, specialist consensus, and extrapolation from related conditions (Dufresne & Olivier, 2025). This matters psychologically as well as medically. Where treatment pathways are less clearly defined and prognostic information is more uncertain, the ambiguity surrounding illness may be heightened by both the disease itself and also by the limits of available evidence (Dufresne & Olivier, 2025; Gatta et al., 2011).

For all these reasons, increasing empirical attention has also been given to the psychological burden experienced by people with rare cancers. A recent systematic review and meta-analysis found that patients with rare cancers had significantly elevated risks of depression and anxiety compared with healthy controls and also found elevated suicide incidence and a higher prevalence of post-traumatic stress disorder among patients with rare cancers relative to those with more common cancers (Low et al., 2024). Poorer physical and psychological health in rare cancer populations is associated with younger age at diagnosis, active treatment, lower social support, and loneliness (Horick et al., 2017).

Moreover, patients with rare cancers have frequently reported difficulty obtaining clear, relevant, and trustworthy information about diagnosis, treatment, prognosis, and survivorship (Heus et al., 2021). A systematic review of in rare cancers found that healthcare system and information needs were the most commonly reported unmet supportive care needs, followed by psychological needs and physical or daily living concerns (Heus et al., 2021). Qualitative research on rare disorders such as haemophilia, cystic fibrosis, or Wilson's disease, more broadly has described similar themes of social invisibility, uncertainty, limited professional

knowledge, and the burden of becoming an “expert patient” in order to secure appropriate care (Von Der Lippe et al., 2017). Although not specific to oncology, these findings are conceptually relevant because they illustrate how rarity can shape illness experience through service fragmentation, limited recognition, and the need to repeatedly explain one’s condition to others.

Overall, this evidence suggests that psychosocial burden in rare cancers arises at the intersection of cancer-related distress and rarity-related difficulty. The emotional, social, and existential challenges associated with cancer may be amplified in rare cancers by delayed diagnosis, limited clinician familiarity, fragmented pathways, a more limited evidence base, unmet informational and supportive care needs, and greater social isolation, including fewer opportunities to encounter others with the same diagnosis or access diagnosis-specific peer support (Horick et al., 2017; Low et al., 2024; Von Der Lippe et al., 2017). Sarcoma is a clear example of a rare form of cancer. The following section will focus on sarcoma.

1.3 Sarcoma: Epidemiology, Diagnosis & Treatment

Sarcoma is a rare and heterogeneous group of malignant tumours arising from mesenchymal tissues, that is, connective and supporting tissues such as bone, muscle, fat, blood vessels, and fibrous tissue (Damerell et al., 2021). Although often referred to as if it were a single disease, sarcoma is better understood as an umbrella term encompassing numerous biologically and clinically distinct malignancies. In adult oncology, sarcomas account for less than 1% of all cancers, although they constitute a larger proportion of cancers diagnosed in children, adolescents, and young adults (Burningham et al., 2012). This rarity has important implications for

awareness, diagnosis, treatment, and research, particularly because most non-specialist clinicians encounter sarcoma only rarely in practice (Hayes et al., 2025).

A defining feature of sarcoma is its heterogeneity. More than 100 subtypes have been identified, differing in histology, anatomical site, biological behaviour, prognosis, and treatment response (Fletcher et al., 2013; Hayes et al., 2025). Sarcomas are most commonly divided into Soft Tissue Sarcoma (STS) and Bone Sarcoma (BS). Soft tissue sarcomas arise in muscle, fat, tendons, blood vessels, nerves, and other connective structures, and can occur almost anywhere in the body, although the limbs, trunk, retroperitoneum, uterus, and head and neck are among the more common sites (Gronchi et al., 2021; Hayes et al., 2025). Bone sarcomas including osteosarcoma, chondrosarcoma, and Ewing sarcoma, arise within bone and they differ in pathology and in age distribution, treatment response, and prognosis (Gerrand et al., 2025; Strauss et al., 2021). This diversity means that two people with a diagnosis of sarcoma may, in practice, face very different illnesses. Approximately 85% are classified as soft tissue sarcomas and around 15% as bone sarcomas, highlighting the predominance of soft tissue disease within the wider sarcoma group (Anttila & Boffetta, 2020; Zhao & Yue, 2012). In some sarcoma groups, disease progression is further shaped by the risk of recurrence and metastasis. Metastatic disease accounts for around one-third of sarcoma-related deaths and is more frequently observed in patients with local recurrence (Serban et al., 2023).

Sarcoma represents a small but clinically important proportion of cancer diagnoses internationally. Estimating incidence precisely has been complicated by the large number of subtypes and by changes in classification over time, but available evidence consistently shows that sarcoma remains a distinct and uncommon cancer group across global and national contexts (Burningham et al.,

2012). Recent Global Burden of Disease analyses estimated approximately 96,000 new cases of STS worldwide in 2021 and approximately 91,000 new cases of BS (Wu et al., 2025; Zhou et al., 2025). In the UK sarcoma accounts for around 1.4% of all cancers, with approximately 5,300 new diagnoses each year, the majority of which are STS rather than BS (Gerrand et al., 2025; Hayes et al., 2025). In Ireland, it is estimated that approximately 280 people are diagnosed with sarcoma each year (Irish Cancer Society, 2024). Hayes et al. (2025) noted that a general practitioner may encounter only one sarcoma case during an entire professional career, which illustrates how rarity translates into limited routine familiarity outside specialist services.

1.3.1 Sarcoma Diagnosis

Diagnosis is often challenging because symptoms are frequently non-specific and may resemble far more common benign conditions. Soft tissue sarcoma may present as an unexplained lump, especially one that is enlarging, deep, painful, or larger than 5 cm, whereas bone sarcoma more often presents with persistent bone pain, swelling, or, in some cases, pathological fracture (Gerrand et al., 2025; Strauss et al., 2021). However, these criteria fail to discriminate reliably from much more common benign lesions such as lipomas, cysts, or haematomas (Hayes et al. 2025). As such, a substantial proportion of patients experience delays, misattribution of symptoms, or initial reassurance that symptoms are benign. Delayed diagnosis in sarcoma is a recurring problem. For example, a systematic review by Soomers et al., (2020) found substantial variation in the length of the interval from first symptom to histological diagnosis and concluded that sarcomas are particularly prone to late diagnosis because of rarity and symptom ambiguity.. Current diagnosis pathways both in Ireland and UK emphasises early referral to specialist sarcoma

multidisciplinary teams and careful planning of biopsy and imaging, since poorly planned biopsy or unplanned excision can compromise subsequent treatment and increase morbidity (Gronchi et al., 2021; Strauss et al., 2021).

1.3.2 Sarcoma Treatment

Treatment is typically multimodal, involving more than one type, and highly individualised according to tumour subtype, anatomical site, grade, stage, and whether the tumour can be safely removed surgically (Gronchi et al., 2021; Strauss et al., 2021). Surgery remains the principal curative treatment for most localised sarcomas, but the procedures required vary considerably. In soft tissue sarcoma, treatment generally aims to remove the tumour while preserving as much function as possible. In bone sarcoma, surgery may involve limb-salvage procedures, reconstruction, or amputation, depending on tumour site and extent (Gerrand et al., 2025; Gronchi et al., 2021; Strauss et al., 2021). Chemotherapy and radiotherapy also play important but subtype-specific roles. Treatment may therefore involve prolonged admissions, repeated cycles of therapy, complex surgery or reconstruction, and prolonged rehabilitation.

The implications of treatment extend well beyond tumour control. Sarcoma surgery may require removal of bone, muscle, soft tissue, and sometimes neurovascular structures, with consequent effects on mobility, endurance, communication, swallowing, independence, and daily functioning, depending on tumour site and extent of resection (Popovich et al., 2023; Sarcoma UK, 2023). These procedures have major implications for subsequent mobility, pain, body image and overall quality of life and wellbeing (Almeida et al., 2021; McDonough et al., 2019). Rehabilitation is therefore often prolonged and complex. Patients may also

require long-term surveillance and repeated investigations due to the ongoing risk of recurrence or progression, which can prolong the burden of illness well beyond primary treatment (Serban et al., 2023). As a result, patients may require long-term surveillance, repeated investigations, and may face ongoing uncertainty about disease progression. In soft tissue sarcoma, treatment failure may present as local recurrence, metastatic spread, or death. Local recurrence rates are particularly high following surgery with inadequate or positive margins, with some reports suggesting rates of 80 to 90% (Serban et al., 2023). These features position sarcoma as a rare cancer characterised not only by biological diversity, but also by substantial complexity in diagnosis, treatment, and survivorship.

1.4 Why Sarcoma May Present Particular Psychosocial Challenges

Sarcoma differs from more common cancers in several important respects. Firstly, its rarity means that it occupies a far less visible position in both public and clinical contexts. This reduced visibility has consequences for awareness, recognition, and support. Lower public familiarity may make the diagnosis feel more obscure and isolating for patients, while more limited exposure among non-specialist clinicians can contribute to delayed diagnosis, prolonged referral pathways, and less confidence in early management (Popovich et al., 2023; Sarcoma UK, 2023; Weaver et al., 2020). By comparison, cancers such as breast, lung, colorectal, and prostate cancer tend to be accompanied by greater public recognition, more established diagnostic pathways, and a wider range of disease-specific informational and support resources (McDonough et al., 2019; Weaver et al., 2020). In this way, the rarity of sarcoma has implications that extend beyond epidemiology, shaping how the illness is recognised, explained, and experienced by patients (Meek & Baliouis, 2025; Wang et al., 2025). A biopsychosocial perspective is particularly relevant to sarcoma

because rarity, uncertainty, treatment burden, bodily change, and functional limitation may interact over time to shape both illness experience and psychosocial outcome (Engel, 1977; Lehman et al., 2017).

Secondly, sarcoma is exceptionally heterogeneous, making it more difficult to generate standardised pathways, evidence bases and patient narratives (Burningham et al., 2012). Although breast and colorectal cancer also have clinically important subtypes, heterogeneity is especially pronounced in sarcoma, where classification, prognosis, and treatment are highly dependent on histology, anatomical site, grade, and molecular features (Gronchi et al., 2021; Strauss et al., 2021). This makes research synthesis more difficult and weakens the generalisability of research findings and support resources. Burningham et al. (2012) argued that the rarity and diversity of sarcoma have historically hindered large-scale research and slowed progress in treatment development.

Thirdly, sarcoma treatment is often associated with particularly visible and functionally significant consequences. What distinguishes sarcoma treatment from many more common cancer pathways is both its complexity and the extent to which it must be individualised according to tumour location, anatomical structures involved, and likely functional outcome (Popovich et al., 2023). Patients may require extensive surgery, complex reconstruction, prolonged chemotherapy, radiotherapy, repeated surgery for recurrence, or combinations of these approaches (Serban et al., 2023). The consequences of treatment may also be particularly visible and functionally significant, especially where surgery affects limbs, mobility, appearance, or prosthetic use. Limb-salvage surgery, amputation, prosthetic adaptation, extensive scarring, and long-term musculoskeletal impairment are

therefore especially relevant in sarcoma (Hikmet et al., 2025). In some subtypes, treatment may also be prolonged and intensive and involve multi-agent chemotherapy delivered over many months, often in repeated inpatient cycles, with substantial psychosocial implications such as feelings of isolation and increased distress (Almeida et al., 2021; Gronchi et al., 2021; Strauss et al., 2021; Weaver et al., 2020). This degree of variability in sarcoma care means that it is often less predictable and less easily comparable across patients when compared with more common cancers (Hayes et al., 2025).

In summary, sarcoma may involve a distinctive psychosocial burden, shaped not only by cancer-related distress but also by rarity, heterogeneity, visible and functionally significant treatment consequences, and prolonged uncertainty across diagnosis, treatment, and survivorship.

1.5 Psychosocial Burden in Sarcoma: Review of Evidence

Research examining the impact of sarcoma has expanded considerably over the past decade, encompassing survivorship (Franzoi et al., 2023), quality of life (Winnette et al., 2017), psychosocial functioning (McDonough et al., 2019), patient-reported outcomes and symptom burden (Soomers et al., 2020), unmet needs (Weaver et al., 2020), and increasingly, the lived experience of sarcoma (Meek & Baliousis, 2025; Wang et al., 2025). This growing body of work has made it increasingly clear that the consequences of sarcoma extend beyond disease and treatment alone, affecting emotional wellbeing, function, participation, self-perception, and everyday life across the illness trajectory. However, the evidence base has developed unevenly, with some areas examined in depth and others

remaining conceptually and methodologically underdeveloped (Franzoi et al., 2023; Sebio et al., 2025; Weaver et al., 2020).

One of the earliest systematic reviews to provide a broader account of survivorship burden in sarcoma was that of Ng Kee Kwong et al., (2014), which focused on sarcoma in the extremities (arms and legs). Physical functioning was the most extensively documented domain, with survivors generally reporting poorer physical functioning than healthy controls. The review also identified evidence of psychological morbidity and highlighted social and practical difficulties relating to employment, sexual health, pain, and return to work. Importantly, the authors noted considerable heterogeneity in outcome measures and relatively limited use of comparison groups, which constrained direct comparison across studies. Nonetheless, the review was important in showing that sarcoma survivorship extended beyond disease control or surgical success, but instead involved interrelated physical, psychological, and social consequences with clear implications for rehabilitation and longer-term supportive care.

The patient perspective was considered more directly in Winnette et al., (2017) whose systematic review focused on soft tissue sarcoma. Their review showed that soft tissue sarcoma was associated with poorer quality of life compared to population norms across several domains, including emotional wellbeing, body image, post-surgical functional deficit, and practical difficulties relating to work and childcare. However, the review also highlighted the limited evidence base at that time. It was noted that few studies examined patient experience directly, qualitative evidence was limited, and the patient-reported outcome measures used in clinical studies were not specific to soft tissue sarcoma. Consequently, although the review

identified a measurable impact on patient wellbeing, it also suggested that the published literature provided only a partial account of that impact and may not have captured concerns especially salient to this population. Winnette et al. (2017) therefore helped establish both the presence of psychosocial burden in soft tissue sarcoma and the methodological limitations that constrained understanding of it.

McDonough et al., (2019) provided a broader psychosocial synthesis in their review of health-related quality of life, psychosocial functioning, and unmet health needs in sarcoma. Compared with healthy populations, patients with sarcoma generally reported poorer physical and psychological health-related quality of life, together with greater self-image difficulties, depression, and suicide-related outcomes. Comparisons with other cancer groups were more mixed, suggesting that psychosocial burden in sarcoma is substantial, but not necessarily uniformly more severe than that observed across cancer populations more generally. This is an important distinction, because it shifts the argument away from whether sarcoma is always more burdensome and towards whether its psychosocial profile may be differently configured. The review also suggested some variation in psychosocial outcomes over time and across patient groups. Anxiety appeared to be more prominent around diagnosis, whereas depressive symptoms were more often reported during treatment. Lower health-related quality of life was also more common among patients who were older, female, and socially isolated. In relation to unmet needs, the review found very limited sarcoma-specific evidence, identifying only one study, which suggested needs in information provision, symptom control, psychological support, and return-to-work support, particularly among patients treated with amputation. Yet the review also showed how limited the evidence remained, no sarcoma-specific health-related quality-of-life measure was identified, and all

included studies relied on generic instruments. McDonough et al., (2019) therefore showed not only that psychosocial burden in sarcoma is considerable, but also that the evidence base remained limited in its ability to capture that burden, and associated unmet needs, in a sarcoma-specific way.

These findings also highlight the need to clarify what is meant by quality of life. Quality of Life (QoL) is a broad construct, referring to a person's perceived wellbeing and functioning across multiple areas of life. In psycho-oncology research, this is often examined as health-related quality of life (HRQoL), where the focus is on how illness and treatment affect physical functioning, symptoms, emotional wellbeing, independence, social relationships, role participation, and everyday life. For example, the EORTC QLQ-C30 assesses functional health, symptom burden, and HRQoL in cancer, including physical, role, emotional, cognitive, and social functioning, as well as symptoms such as fatigue and pain (Cocks et al., 2023). In sarcoma, HRQoL has similarly been described as patients' perceptions of the impact of disease and treatment on physical or biological, psychological, and social functioning in daily life (den Hollander et al., 2020). This is particularly relevant because sarcoma-related QoL may include several overlapping constructs, including pain, fatigue, physical restriction, disability, altered mobility, visible bodily change, prosthetic use, scarring, rehabilitation demands, uncertainty, self-esteem, social confidence, and disruption to everyday roles. A systematic review of soft tissue and bone sarcoma HRQoL found that patients reported lower HRQoL than the general population, with outcomes varying by tumour location across symptoms, physical functioning, disability, and psychosocial wellbeing; the same review also identified substantial variation in measurement, with 54 different questionnaires used across 87 studies, most commonly generic or cancer-generic measures (den Hollander et al.,

2020). den Hollander et al. (2021) further noted that generic and cancer-generic questionnaires may miss sarcoma- or treatment-specific issues, such as altered appearance, limping or needing a crutch, effects on self-esteem and social life, and concerns specific to amputation. Evidence comparing limb salvage and amputation in lower extremity tumour patients similarly shows that QoL may vary across physical, functional, emotional, and social domains (Banskota et al., 2024). This highlights the value of QoL research in demonstrating the broad burden of sarcoma, while also showing why more specific psychosocial constructs need to be examined more directly.

Storey et al., (2019) examined the field more critically in their review of sarcoma and psychosocial wellbeing. The review found that quality of life was the most frequently assessed domain, appearing in 80% of included studies, whereas other aspects of psychosocial wellbeing, including mental health, social support, coping, and intervention, were examined less consistently. Physical aspects of quality of life appeared to improve over time, but similar improvement was not evident for psychosocial function or mental health. A critical contribution of this review lies in its emphasis on what the literature could not yet show. Similar to McDonough et al., (2019), it emphasised how the heterogeneity in methods, outcome measures, and populations prevented definitive conclusions, but particularly with regard to factors that might predict or influence psychosocial wellbeing. In this respect, the review was especially important in showing that the existing evidence base did not yet provide a sufficiently clear or consistent account of how the impact of sarcoma should be understood or what factors shape it most.

Defining and measuring psychosocial outcomes was examined more directly by Almeida et al., (2021) in their scoping review of patient-reported outcomes in sarcoma. The outcomes most commonly assessed were health-related quality of life, functional outcomes, aspects of mental health, and specific symptoms such as pain, fatigue, and sleep disturbance. Almeida et al., (2021) also showed that studies often used multiple patient-reported outcome measures within the same design, reflecting attempts to capture different aspects of sarcoma experience across the disease trajectory. However, the measures most frequently used were largely generic including the SF-36 and EORTC QLQ-C30, rather than being sarcoma-specific. Their review is important because it clarifies both what has been measured and how the field has been organised conceptually. Psychosocial burden in sarcoma has often been captured through broad multidimensional outcome frameworks such as health-related quality of life, rather than through more discrete psychological constructs such as anxiety, depression, body-image issues, and coping processes. This has been useful in showing that multiple areas of life are affected, but less useful in clarifying which psychosocial domains are most affected, how they relate to one another, and whether they differ according to tumour site, treatment, or disease stage. This is important because sarcoma is highly heterogenous and existing measures may not adequately capture these differences. As such, Almeida et al., (2021) argued for more sarcoma-sensitive approaches to measurement that better reflect patient's experiences, reinforcing concerns already apparent in earlier reviews.

Franzoi et al., (2023) widened the scope of earlier reviews by synthesising psychological outcomes in adult sarcoma across seven domains: quality of life, worries and distress, anxiety and depression, suicidal ideation, financial and occupational consequences, unmet needs, and coping strategies. Across the studies

reviewed, sarcoma was associated with impaired quality of life, distress, anxiety and depressive symptoms, suicide-related outcomes, financial and occupational burden, unmet needs, and coping difficulties. The review also highlighted broader psychological sequelae, including feeling discouraged, demoralisation, helplessness, anxiety and depression, social withdrawal, and difficulties in decision-making. This made an important contribution by broadening the field beyond quality of life alone. However, the conclusions were once again mixed and limited by the highly heterogeneous set of studies using varied measures across domains. The review therefore expanded the psychosocial frame of sarcoma literature, but continued to highlight the challenges of integrating an evidence base marked by methodological diversity, heterogeneous samples, and varied outcome measures.

A similar problem is visible in a more recent systematic review of quality of life and patient-reported outcomes in osteosarcoma, Sebio et al., (2025) which again identified marked heterogeneity in study aims, populations, follow-up periods, and outcome measures. Despite focusing on a single bone sarcoma diagnosis, the review found that no single questionnaire adequately captured the range of outcomes relevant across different age groups, and that most measures remained generic or cancer-generic rather than sarcoma-specific. Important domains, including body image, self-esteem, and broader survivorship concerns, were not consistently represented. In this respect, Sebio et al., (2025) reinforce a pattern already identified in earlier reviews: sarcoma research has documented burden across multiple domains, but often through broad and methodologically variable outcome frameworks. The review is therefore important in showing that the challenge is not confined to heterogeneity across the wider sarcoma family. Even within osteosarcoma, there remains limited precision regarding which psychosocial

domains are most salient and how they are best assessed. This continues to support the need for greater conceptual clarity in relation to psychosocial impact, and for more focused examination of the factors associated with distress and wellbeing in sarcoma.

These reviews provide a clearer understanding of what is currently known about the psychosocial burden in sarcoma but they also show where the evidence remains limited. Across the review literature, sarcoma is associated with poorer physical functioning, lower quality of life, and a range of psychological and social difficulties, including distress, self-image concerns, unmet needs, and disruption to everyday functioning. Where comparison groups were available, psychosocial outcomes were generally poorer in sarcoma patients than those of healthy or general population samples, while comparisons with other cancer populations were more mixed. The review literature does not suggest that sarcoma is uniformly more burdensome than all other malignancies across every psychosocial domain. Rather, it suggests that burden in sarcoma may assume a somewhat distinctive profile, shaped by the consequences of treatment, long-term functional restriction, visible bodily change, and the wider demands of recovery and survivorship (Franzoi et al., 2023; Sebio et al., 2025; Wang & Feng et al., 2022).

However, the review literature also points to several recurring limitations. Much of the evidence has been generated through broad quality-of-life and patient-reported outcome frameworks, which have been useful in demonstrating burden across multiple areas of life but offer less precision regarding which psychosocial domains are most salient and how they relate to one another. This has been compounded by substantial heterogeneity in tumour type, anatomical site, age group,

treatment phase, survivorship stage, and outcome measurement, together with continued reliance on generic or cancer-generic instruments. The literature is therefore stronger in demonstrating that psychosocial burden is present than in clarifying how that burden is experienced, how it varies across the illness trajectory, and which factors most consistently shape poorer outcome.

1.6 Factors Associated with Psychosocial Distress & Wellbeing in Sarcoma

The above reviews discussed have established that sarcoma is associated with substantial psychosocial burden, but it has also shown that less is known about the influences that shape this burden and contribute to variation in outcome across patients. Primary empirical studies are therefore important both because they document burden in more specific areas and because they begin to indicate which aspects of sarcoma may be most relevant to distress, wellbeing, and adjustment. This is broadly consistent with a biopsychosocial understanding of illness, in which physical, psychological, and interpersonal influences are treated as interdependent rather than separate domains of outcome (Engel, 1977; Lehman et al., 2017).

Physical and functional consequences are a central feature of the sarcoma literature. This is unsurprising given the nature of sarcoma treatment, which may involve major surgery, limb or pelvic involvement, reconstruction, and prolonged recovery, all with implications for mobility, independence, and participation in daily life (Andrews et al., 2020). Reduced physical functioning has been identified repeatedly in survivorship research and often alongside broader psychosocial difficulty. For example, Ng Kee Kwong et al., (2014) reported that individuals with sarcoma generally had poorer physical functioning than healthy controls years after treatment, together with evidence of psychological distress. Similarly, Storey et al.,

(2019) identified physical functioning and quality of life as among the most frequently examined outcomes in sarcoma research. The important point here is that physical burden appears to form part of the context in which psychosocial burden develops. The literature remains stronger in documenting the presence of functional limitation than in clarifying exactly how physical impairment translates into emotional or social outcome.

This is reflected in studies comparing limb-salvage surgery and amputation. These studies show that psychosocial outcome cannot be inferred from surgical category alone. In a systematic review and meta-analysis, Mei et al., (2014) found that functional outcomes and quality of life varied across studies and were not explained consistently by whether treatment involved amputation or limb salvage. What seems to matter more is the extent of pain, complications, mobility restriction, prosthetic adaptation, and limitation in participation that follows treatment (Barrett et al., 2023; Mei et al., 2014). The psychosocial significance of surgery therefore lies less in the procedure itself than in its consequences for everyday functioning and longer-term adaptation.

Pain and fatigue have emerged as particularly prominent and burdensome aspects of sarcoma, both during treatment and after its completion, affecting sleep, endurance, physical activity, and everyday functioning, and have also been identified as key symptoms in research developing soft tissue sarcoma-specific patient-reported outcome measures (Barrett et al., 2023; Eliason et al., 2022). Moreover, Suhag et al., (2024) similarly found that anxiety, depression, and stress co-occurred with pain, fatigue, insomnia, nausea, anorexia, cognitive difficulties, emotional difficulties, and financial strain in patients with sarcoma. These findings suggest that psychological

difficulties in sarcoma are closely embedded within wider symptom and functional burden. However, there is limited evidence on whether particular symptoms, such as pain or fatigue, have independent effects on distress in sarcoma, or whether their influence is mediated by factors such as sarcoma type, stage, age and other potential covariates.

Body image forms another important domain, particularly where treatment involves scarring, asymmetry, limb difference, or altered posture and movement. Quantitative studies suggest that body image issues are clinically meaningful in sarcoma (Franzoi et al., 2023; McDonough et al., 2019). Compared with healthy controls, patients treated for primary malignant bone tumours have reported significantly poorer body image and poorer physical aspects of quality of life (Holzer et al., 2020). Similar concerns appear in young adult sarcoma survivors, among whom negative body image has been associated with poorer psychological and behavioural outcomes (Wei et al., 2024). This suggests that bodily change has psychosocial significance beyond physical impairment alone. Yet body image remains more often identified as an area of burden than examined as a factor that may help explain anxiety, depression, or wellbeing more directly.

Evidence on psychological distress in sarcoma also indicates that burden is not confined to one stage of illness. Srikanthan et al., (2019) found substantial distress around diagnosis, including anxiety, depression, and suicidal ideation, together with prominent concerns about understanding illness and treatment, fear and worry, and family. Tang et al., (2015) reported that distress remained evident in approximately one-third of patients from diagnosis to one year after surgery, while Day et al., (2022), found that physical and functional wellbeing improved over time

in young adults, but social and emotional wellbeing did not change significantly. Longer-term studies point in a similar direction, with depressive symptoms and recurrence-related worry remaining relevant in survivorship (Robinson et al., 2025). They also identified clinically significant depressive symptom burden in a notable minority of sarcoma survivors and found that younger age and lower household income were associated with greater risk, indicating that depressive outcomes are shaped by social and demographic context as well as by illness-related factors. Similarly, Younger et al., (2020) found that sarcoma-related worry and uncertainty about sarcoma recurrence were associated with lower emotional functioning. These findings suggest that emotional burden in sarcoma is not confined to diagnosis or active treatment alone. Rather, it may persist across the illness trajectory and appears to be shaped by both the physical consequences of disease and treatment and by uncertainty, available support, and wider psychosocial factors.

Only a smaller group of studies has examined factors associated more directly with variation in distress, depression, and wellbeing. Paredes et al., (2012a) found that different forms of perceived social support were associated with depression and overall quality of life, although not consistently with anxiety, and that these relationships varied in part according to disease phase. In a separate longitudinal study, (Paredes et al., 2012b) found no significant change in mean anxiety and depression scores from diagnosis to treatment, but showed that a clinically important subgroup continued to report anxiety or depression within the clinical range across both phases. Higher baseline distress predicted poorer emotional adjustment during treatment, while greater denial and lower use of humour were associated with poorer psychological outcome. These findings suggest

that psychosocial outcome in sarcoma is shaped by a combination of social support, coping, and wider contextual influences rather than by any single factor.

Other studies have linked distress with pain and poorer physical function (Tang et al., 2015), depressive symptoms with younger age and lower socioeconomic status (Robinson et al., 2025), and recurrence-related worry with lower psychological flexibility (Petrella et al., 2023). This evidence is important because it begins to move beyond description and towards explanation. However, it remains fragmented. There is also considerable variation in the variables examined, the outcomes used, and the stages of illness on which they focus, which makes it difficult to identify with confidence which factors most consistently shape distress and wellbeing in sarcoma. Overall, this evidence base suggests that psychosocial burden in sarcoma is closely tied to functional loss, symptom burden, bodily change, and uncertainty across the illness trajectory. What it does not yet provide is a sufficiently clear or consistent account of how these influences relate to one another, or which factors are most central in shaping distress, wellbeing, and adjustment. In that respect, the current literature is stronger in demonstrating psychosocial burden in sarcoma than in explaining it.

1.7 Qualitative Evidence on Psychosocial Experiences in Sarcoma

In recent years, there has been a rapid increase in studies exploring the lived experience of sarcoma. This has added important depth to the literature because qualitative studies have shown more clearly how sarcoma burden is experienced across diagnosis, treatment, rehabilitation, and survivorship (Košir et al., 2020; Martins et al., 2019, 2024; Soomers et al., 2020).

Viewed through a biopsychosocial lens, this literature has been especially important in showing that the consequences of sarcoma are experienced through the body, through everyday function, and through changes in identity and social life. Patients describe pain, fatigue, restricted mobility, rehabilitation demands, altered appearance, and difficulty returning to valued roles, but they describe these at the same time as changes in confidence, independence, identity, and participation in daily life (Dean, 2025; Denissen et al., 2025; Fauske et al., 2016; Van Kouswijk et al., 2024). Pain, in particular, is described not simply as a symptom, but as something that affects sleep, activity, endurance, and ordinary functioning, and that becomes bound up with frustration, dependency, and loss of normality (Vetchy et al., 2025). Body image research has similarly shown that altered appearance after treatment can affect self-esteem, social confidence, and the wish to appear normal, attractive, or healthy to others, suggesting that bodily change may carry both functional consequences and also self-consciousness and, for some, shame (Fauske et al., 2016).

The rapid growth of this literature has led to two qualitative meta-syntheses. Meek & Baliousis (2025) brought together studies of psychological impact across the illness trajectory, identifying issues such as delay, shock, fears and anxieties, sadness and loss, relationships, coping, and growth. Wang et al., (2025) synthesised studies of patients' experiences and needs more broadly, highlighting self-perceived health challenges, mixed social experiences, and wider societal barriers such as stigma, financial strain, and limited understanding. Both reviews make an important contribution because they show more clearly the emotional, relational, and social burden associated with sarcoma.

More recent studies published since those syntheses suggest that this area is continuing to develop and that living with and after sarcoma is becoming a more explicit focus of attention. Fauske et al., (2025) showed that survivors valued oncological follow-up, but wanted more holistic communication, more continuous information about late effects, and better recognition of psychosocial concerns during follow-up care. Halkett et al., (2025a) found that people with sarcoma and carers continued to report unmet needs in relation to psychosocial support, credible information, and sarcoma-specific support pathways. Halkett et al., (2025b) further showed that people wanted better resources about both diagnosis and treatment and about living with sarcoma, emotional support, family support, financial strain, palliative care, bereavement, and coping. Lorimer et al., (2025) similarly showed that post-treatment survivorship involves continuing emotional, social, and practical challenges for both adults with sarcoma and informal carers, including the need to renegotiate roles and navigate life after treatment. Peairs et al., (2025) added another dimension by showing how transport, employment, insurance, financial security, and social support shape patients' experiences of care and survivorship. Collectively, these studies suggest that the literature is moving beyond documenting burden alone and is increasingly concerned with what it means to live with the longer-term consequences of sarcoma.

Moreover, these studies also bring adaptation more clearly into view. In this thesis, adaptation is understood as the ongoing process through which individuals respond to and live with the emotional, physical, relational, and practical consequences of sarcoma across the illness trajectory (Kosir et al., 2020). Across follow-up care, survivorship, rehabilitation, and support research, patients are describing an ongoing effort to live with altered bodies, persistent uncertainty,

disrupted routines, and changed roles, while trying to establish a life after treatment (Dean, 2025; Denissen et al., 2025; Lorimer et al., 2025). In that sense, the literature is beginning to show that surviving sarcoma is only part of the issue; living with and after sarcoma has become equally important.

1.8 Gaps in the Sarcoma Psychosocial Literature & Rationale for Thesis

The available evidence indicates that sarcoma is associated with substantial psychosocial burden across physical, emotional, social, and functional domains (Franzoi et al., 2023; McDonough et al., 2019; Ng Kee Kwong et al., 2014; Storey et al., 2019). Systematic reviews on sarcoma have consistently identified poorer physical functioning, lower quality of life, psychological distress, body-image concerns, unmet needs, and disruption to everyday life (Franzoi et al., 2023; McDonough et al., 2019; Sebio et al., 2025). These difficulties have also been linked with symptom burden, functional loss, uncertainty, age, coping strategies such as use of humour and denial, and wider social supports and context (Holzer et al., 2020; Paredes et al., 2012b; Petrella et al., 2023; Robinson et al., 2025; Srikanthan et al., 2019; Tang et al., 2015). More recent qualitative studies have added further depth by showing how these consequences are experienced across diagnosis, treatment, rehabilitation, and survivorship (Meek & Baliousis, 2025; Wang et al., 2025). However, the literature remains stronger in showing that psychosocial burden is present, and in describing the range of difficulties associated with sarcoma, than in clarifying how patients adapt to these experiences over time, how psychosocial burden varies across the illness trajectory, and which factors most consistently shape distress, wellbeing, and adjustment (Franzoi et al., 2023; Kosir et al., 2020).

One of the clearest limitations concerns the extent to which psychosocial outcomes have been examined through broad health-related quality-of-life and patient-reported outcome measures (Almeida et al., 2021; McDonough et al., 2019; Sebio et al., 2025). These approaches have been valuable in showing that sarcoma affects multiple areas of life simultaneously, including physical functioning, symptoms, emotional functioning, and social participation (Almeida et al., 2021; McDonough et al., 2019; Ng Kee Kwong et al., 2014). However, they often provide limited precision regarding which psychosocial domains are most affected. In practice, broad outcome measures may capture the combined effects of pain, fatigue, disability, social restriction, emotional distress, and reduced wellbeing without distinguishing clearly between them (Storey et al., 2019; Almeida et al., 2021). This has made it more difficult to determine whether poorer psychosocial outcomes in sarcoma are driven primarily by symptom burden, functional loss, altered body image, uncertainty, social context, or combinations of these factors (McDonough et al., 2019; Storey et al., 2019; Sebio et al., 2025). This is an important limitation because, although such measures can demonstrate that sarcoma burden is present, they are less helpful in identifying which psychosocial processes are most salient and therefore which domains should be prioritised in assessment to provide a tailored intervention for individuals with sarcoma (Franzoi et al., 2023; Low et al., 2024). As a result, the quantitative literature is relatively strong descriptively, but less well developed in explanatory and clinically actionable terms.

A related limitation concerns the inconsistent examination of factors associated with psychosocial outcome. Previous studies have linked distress or poorer wellbeing with pain, physical function, social support, coping style, age, income, psychological flexibility, and phase of illness (Paredes et al., 2012b; Tang et

al., 2015; Petrella et al., 2023; Robinson et al., 2025; Eichler et al., 2023). However, the range of variables examined differs substantially across studies, as do the measures used to assess them. This makes findings difficult to integrate and limits clarity about which factors are most consistently associated with distress, diminished wellbeing, or poorer adjustment in sarcoma (Franzoi et al., 2023; Storey et al., 2019). Although recent studies have begun to move beyond description and toward explanation, the evidence remains fragmented across different outcomes, different sarcoma groups, and different stages of illness (Eichler et al., 2023; Petrella et al., 2023; Robinson et al., 2025).

This limitation is especially important for psychosocial variables that appear relevant in sarcoma but remain underexplored. Body image disturbance has been shown to be a meaningful difficulty in sarcoma, particularly where treatment involves visible and functionally significant bodily change (Holzer et al., 2020; Wei et al., 2024). Yet body image has been more often described as an outcome than examined as a factor that may help explain anxiety, depression, or wellbeing more directly (Holzer et al., 2020; Wei et al., 2024). Similarly, although the literature has identified associations between pain, social support, and coping with psychological distress (Paredes et al., 2011, 2012b; Tang et al., 2015), other potentially relevant psychological processes remain largely unexamined in sarcoma. Self-compassion is one such example. In broader cancer populations, self-compassion has increasingly been linked with lower distress and more adaptive psychological adjustment (Bitan et al., 2025; Krok et al., 2025), yet it has not been adequately explored in sarcoma despite the likely relevance of bodily change, shame, uncertainty, and self-critical responses in this population (Franzoi et al., 2023; Meek & Baliousis, 2025). More generally, there is still limited understanding of how symptomatic, functional,

interpersonal, and intrapersonal factors combine to shape distress and wellbeing in adults with sarcoma (Franzoi et al., 2023; Kosir et al., 2020).

The qualitative literature addresses some of these limitations by showing more clearly how living with sarcoma is managed in everyday life. It has increasingly highlighted patients' experiences of uncertainty, bodily change, disruption to daily life, social disconnection, altered identity, fear of recurrence, and difficulties navigating care (Kosir et al., 2020; Martins et al., 2019, 2024; Meek & Baliousis, 2025; Wang et al., 2025). The two qualitative meta-syntheses have begun to consolidate some of this literature, with Meek and Baliousis (2025) focusing more explicitly on psychological impact and Wang et al. (2025) taking a broader experiences and needs perspective. However, several aspects of sarcoma experience remain less clearly understood. Both reviews included wide age ranges spanning adolescence to older adulthood, which may limit clarity regarding adult-specific experience given the likely importance of developmental stage in shaping how illness is understood and managed (Fantozzi et al., 2022).

Moreover, although existing studies highlight both psychological and broader social challenges, they offer less understanding of how emotional, social, relational, and functional disruptions interact in adult life, and how adults respond and adapt to them over time. Viewed from a biopsychosocial perspective, this suggests a need to understand adaptation in sarcoma as a dynamic process shaped by interacting bodily, psychological, interpersonal, and contextual influences rather than by any single domain alone (Engel, 1977; Lehman et al., 2017). This is increasingly important as survival improves and attention shifts not only to surviving sarcoma, but also to living with and beyond it. Recent qualitative studies suggest that living with and

beyond sarcoma often involves managing altered bodies, uncertainty, disrupted routines, changed roles, and uneven support, alongside ongoing efforts to cope, self-manage, remain resilient, and establish a new normal (Dean, 2025; Denissen et al., 2025; Fauske et al., 2025; Kosir et al., 2020; Lorimer et al., 2025). In the mixed cancer psycho-oncology literature, adaptation is understood as a dynamic process involving coping, connection, meaning-making, and other adaptive resources (Zhu et al., 2024), yet these processes remain underexplored in sarcoma research. An adult-focused synthesis may therefore provide a more coherent psychosocial understanding of sarcoma and clarify how adults experience and adapt to its longer-term consequences.

A further gap concerns intervention development. Although psychosocial burden and unmet needs have been documented with increasing consistency, this has not been matched by the development or evaluation of sarcoma-relevant psychosocial interventions (Franzoi et al., 2023; Kosir et al., 2020). Current psycho-oncology guidelines and service frameworks emphasise the importance of tailored, evidence-based psychosocial care, yet the evidence informing psychosocial intervention remains drawn mainly from mixed cancer samples and more common malignancies rather than sarcoma-specific populations (Hwang et al., 2023; Semenenko et al., 2023). This matters because sarcoma may involve distinctive combinations of rarity, functional limitation, body-altering treatment, and prolonged rehabilitation that are not well represented in broader psycho-oncology evidence (Low et al., 2024; Weaver et al., 2020). As a result, the current literature provides limited guidance regarding which psychosocial targets are most relevant for intervention in sarcoma and how support might best be tailored for this group. This limits the extent to which the current literature can inform tailored psychosocial care

and reinforces the importance of better understanding which factors are most relevant to distress and wellbeing in this population.

Overall, two related gaps become clear. The first concerns the need for a more focused synthesis of qualitative research on sarcoma in adults. Although recent meta-syntheses have advanced understanding of lived experience (Meek & Baliouris, 2025; Wang et al., 2025), they provide less clarity about the overall psychosocial impact of sarcoma in adult life and about how adults adapt to its emotional, social, relational, and functional consequences over time. A more focused adult synthesis is therefore needed to clarify both psychosocial impact and adaptation in sarcoma. The second concerns the relative lack of empirically focused research examining factors associated with both distress and wellbeing in adults with sarcoma. Existing studies suggest that psychosocial outcomes are shaped by interacting physical, social, and psychological influences (Paredes et al., 2012a, 2012b; Petrella et al., 2023; Robinson et al., 2025; Tang et al., 2015), but these influences have not been examined in a sufficiently integrated or consistent way. In particular, variables such as body image distress and self-compassion remain underexplored despite their likely relevance to adjustment in sarcoma (Bitan et al., 2025; Holzer et al., 2020; Krok et al., 2025; Wei et al., 2024). More precise evidence is therefore needed to clarify which factors are most strongly associated with psychosocial distress and wellbeing, and which may represent meaningful targets for assessment and intervention.

The present thesis was developed in response to these gaps in the literature. Study 1 addresses the need for a more focused and up-to-date synthesis of qualitative research on sarcoma in adults, clarifying the psychosocial impact of the disease and

how adults respond and adapt to its emotional, social, relational, and functional consequences over time (Meek & Baliousis, 2025; Wang et al., 2025). Study 2 addresses the need for more clearly specified empirical evidence on factors associated with psychosocial distress and wellbeing in adults with sarcoma (Franzoi et al., 2023; Paredes et al., 2012a, 2012b; Robinson et al., 2025; Tang et al., 2015). Together, these studies address both conceptual and empirical limitations in the existing literature: first, by clarifying psychosocial impact and adaptation in adult sarcoma, and second, by examining which psychosocial factors may help explain variation in distress and wellbeing within this population.

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Chapter 2: Qualitative Systematic Review – Study 1

Psychosocial Impact of Sarcoma: Challenges & Adaptation, A Meta-Synthesis

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Title: Psychosocial Impact of Sarcoma: Challenges & Adaptation, A Meta-Synthesis

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Abstract:

Objectives: Sarcoma is a rare and heterogeneous cancer frequently associated with significant psychosocial burden. This review aims to synthesise qualitative research to examine the psychosocial impact of sarcoma in adults, focusing on how individuals experience and make sense of disruption across diagnosis, treatment, recovery, and survivorship, the ways they adapt to these challenges, and the psychosocial needs they identify throughout the sarcoma trajectory.

Methods: A preregistered systematic review (PROSPERO CRD42024571502) was conducted following PRISMA and ENTREQ guidance. Four databases were searched (PsycINFO, MEDLINE, CINAHL, and Web of Science), and peer-reviewed qualitative studies involving adults with sarcoma were included. Updated search conducted on 30/12/2025. Study quality was appraised using CASP, and data were synthesised using inductive thematic synthesis to integrate experiential accounts and generate analytical insights.

Results: Forty studies published between 2008 and 2025 involving 538 participants were included, with most rated high methodological quality. Five themes captured sarcoma as a cumulative psychosocial disruption, beginning with diagnostic delay and uncertainty, intensifying through invasive treatment and prolonged recovery, and extending into enduring changes in body image, function, identity, and social participation. Adaptation emerged as a dynamic, ongoing process involving self-management, meaning-making, selective information engagement, and reliance on relational and professional support. Persistent unmet needs were identified, particularly regarding specialist, coordinated care and sarcoma-informed rehabilitation.

Conclusions: Experiences of sarcoma as adults are characterised by prolonged psychosocial disruption requiring adaptation across all stages of the illness. Findings highlight the importance of specialist, continuous, and rehabilitation-focused sarcoma care to support long-term adjustment and wellbeing.

Keywords: Sarcoma, Soft Tissue Sarcoma, Bone Cancer, Psychosocial Impact, Adaptation, Challenges, Qualitative Research, Thematic Synthesis, Cancer

2.1 Background

Sarcoma is a rare heterogeneous group of malignant tumours arising in bone, cartilage, and soft tissue ¹. It accounts for approximately 1% of adult malignancies and includes more than 70 histological subtypes across diverse anatomical sites ². Sarcoma's rarity and clinical heterogeneity contribute to diagnostic delay, limited awareness, and disrupted care pathways, further compounding patients' distress ^{3,4}.

While representing a small proportion of cancers, sarcoma can be associated with disproportionate psychosocial burden relative to more common cancers ^{5,6}. Individuals consistently report lower quality of life, elevated distress, anxiety, depression, and fear of recurrence ^{6,7}. Functional impairment, altered body image, and social disruption are also common alongside unmet informational and psychosocial needs ^{8,9}. Franzoi et al⁷ provided strong evidence of sarcoma's substantial psychosocial burden; however, that review, along with others, also highlighted major methodological limitations. Clinical heterogeneity, varied patient experiences, lack of disease-specific tools, and inconsistent outcome measures constrain accurate assessment and interpretation of its impact ^{2,10}.

In recent years, there has been a rapid surge of qualitative studies exploring the lived experiences of sarcoma, illuminating the emotional and social dimensions of living with a rare cancer. Two recent meta-syntheses have synthesised this literature. Meek & Baliousis ¹¹ explored the psychological impact of sarcoma along the illness trajectory, identifying themes of uncertainty and identity change and comparing these experiences with those of people with Kaposi sarcoma. Wang et al.,¹² described broader lived experiences and unmet needs, including stigma, financial strain, and social barriers.

However, several aspects of sarcoma experience remain less clearly understood. First, both reviews included wide age ranges spanning adolescence to older adulthood (13-85 years), potentially obscuring adult-specific experiences as developmental stage can influence how people relate to illness ¹³. Second, although existing evidence highlights both psychological and broader social challenges, these domains have largely been examined separately, leaving limited understanding of how emotional, social, relational, and functional disruptions interact in adults' lives. An adult-focused synthesis that integrates these domains may therefore provide a more coherent psychosocial understanding of sarcoma. Finally, although coping and emotional responses have been described in previous syntheses ^{11,12}, less is known about how adults with sarcoma adapt to these wider psychosocial challenges. In the broader cancer literature, adaptation is understood as a dynamic process with cancer survivors highlighting coping strategies, social connection, spirituality, and meaning making as key adaptive processes ¹⁴, yet these mechanisms remain underexplored in sarcoma research.

This review addresses these gaps by synthesising most up to date qualitative research on the psychosocial impact of sarcoma in adults. Specifically, it focuses on adult experiences, integrates psychosocial impact across emotional, social, relational, and functional domains, and examines adaptation as an ongoing dynamic process rather than a fixed outcome. The review therefore aims to deepen understanding of how individuals experience, make sense of, and respond to the disruptions associated with sarcoma, and the psychosocial needs they identify. The review is guided by the following research questions:

1. How do individuals describe the psychosocial impact of sarcoma?

2. How do individuals describe making sense of and adapting to the psychosocial challenges associated with sarcoma?
3. What psychosocial needs do individuals identify across their experiences of sarcoma?

Through addressing these questions, the review seeks to provide an integrated understanding of the lived psychosocial experience of sarcoma.

2.2 Methods

This systematic review was preregistered with PROSPERO International Register of Systematic Reviews (CRD42024571502, 27/08/2024) and reported in accordance with PRISMA guidelines¹⁵, with adaptations for qualitative synthesis¹⁶ guided by the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines¹⁷ (Supplementary Material 1).

2.2.1 Design

A qualitative meta-synthesis was conducted aiming to generate new understandings and identify conceptual gaps, following the principles of thematic synthesis¹⁸. This involved four stages: (1) systematic searching, (2) study selection, (3) quality appraisal, and (4) thematic synthesis. An inductive analytic stance guided the interpretation and grounded analysis in participant's accounts.

2.2.2 Literature search

Searches were conducted on 21st of November 2024 across PsycINFO, MEDLINE, CINAHL, and Web of Science, with an update on 30th of December 2025. The search strategy was developed by the lead reviewer with supervision from Senior Lecturers in Clinical Psychology, a Principal Psycho-oncologist, and librarian support.

Search terms combined two main concepts: (1) Sarcoma and (2) Psychosocial impact (e.g., mental health, wellbeing, adjustment, coping, relationships, stigma, see Supplementary Material 2). Backward and forward citation searching of included studies was also conducted.

2.2.3 Study eligibility criteria

Studies were included if they: (1) involved adults (≥ 18 years) with confirmed sarcoma; (2) explored psychosocial experiences; (3) used qualitative methods; (4) were peer-reviewed; and (5) were published in English. To support a focused and coherent synthesis, Gastrointestinal Stromal Tumours (GIST) and Kaposi sarcoma were excluded due to their distinct treatment pathways and psychosocial challenges, including long-term targeted therapy in GIST and virus-related stigma and care pathways in Kaposi sarcoma ^{19,20}. No limits were placed on publication date. See Supplementary Material 3 for full eligibility criteria

2.2.4 Study Selection & Data Extraction

Records were managed in Rayyan, a systematic review tool, for screening and management ²¹. Following duplicate removal, 100% of titles and abstracts were independently screened by two reviewers (RB and ER) against the eligibility criteria. Full-text articles were 100% assessed independently by the same reviewers. Discrepancies were resolved through discussion with a third reviewer (FOK), with decisions documented.

Data extraction was conducted by one reviewer (RB) for 100 % of included studies using a pre-designed template and independently checked for accuracy by two reviewers (ER and PC), each verifying 50% of the studies. Extracted information included authors, year, country, study aims, design, analytic method, and

sample characteristics (e.g., gender age, sarcoma type, treatment status, sarcoma stage). Psychosocial findings were recorded at two levels:

1. First-order constructs: participant quotations;
2. Second-order constructs: authors' interpretations and thematic statements

Data were tabulated in Microsoft Excel. Where information was unclear, authors were contacted and given one month to respond; if no response was received, studies were retained without the missing data.

2.2.5 Quality Appraisal

Quality assessment was conducted using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist ²². One reviewer (RB) assessed 100% of studies, with independent assessment by two reviewers (ER and PC), each assessing 50%. The 10-item CASP tool evaluates methodological rigour and validity across three domains: Section A evaluates study design and methodological integrity; Section B assesses clarity and credibility of findings; and Section C considers the value and applicability of results.

In line with Long et al²³ recommendation, particular attention was given analytic rigour ('Was the data analysis sufficiently rigorous'). Following Butler et al²⁴ guidelines, each item was rated as Yes (1 point), Can't tell (0.5 points), or No (0 points), producing a total score (maximum 10). Studies were categorised as: High quality (≥ 9), Moderate (7.5-8.5), or Low (< 7.5).

Low-quality studies were not automatically excluded unless significant ethical or methodological flaws undermined data credibility (a score of < 1 on item 7 [Have ethical issues been taken into consideration?]). Final quality ratings were determined by consensus.

2.2.6 Data Synthesis

A thematic synthesis approach¹⁸, was used to inductively translate diverse qualitative data into descriptive and analytical themes grounded in participant's perspectives.

It involved three stages: (1) line-by-line coding of first- and second-order data; (2) development of descriptive themes through comparison and grouping of codes; and (3) generation of analytical themes to produce new conceptual insights. Coding and analysis were conducted in NVivo 15 by three reviewers (RB, ER, and PC) with experience in thematic analysis.

2.2.7 Rigour & Reflexivity

Rigour and reflexivity were supported through independent coding, transparent documentation, and iterative team discussions. Reflexive meetings were used throughout the synthesis to examine assumptions, compare interpretations, and enhance analytic consistency. The lead reviewer (RB), a Trainee Clinical Psychologist, also brought prior research experience in sarcoma, which informed familiarity with the clinical and psychosocial complexities of this population. In addition, lived experience of sarcoma within a close family context emerged during the course of this research. This combination of research and personal experience sensitised the analysis of themes of diagnostic uncertainty, mistrust, family impact, disability, and the role of healthcare systems in shaping adaptation. In particular, it heightened sensitivity to how prolonged uncertainty, fragmented care, and visible functional decline may shape meaning-making for both patients and families across sarcoma trajectory. It also informed attention to adaptation not as a discrete outcome, but as an ongoing process unfolding in the context of cumulative disruption and shifting support needs. These influences were actively reflected upon during analysis

through research supervision meetings and reflective journaling, in which assumptions, emotional responses, and emerging interpretations were explicitly discussed and documented to consider how they may have shaped what was foregrounded in the data, particularly themes relating to uncertainty, trust, bodily change, and system-level support. FOK, an academic Clinical Psychologist with expertise in the intersection of physical and mental health and experience in systematic reviews and thematic analysis, contributed methodological and psychosocial perspectives. LOD, a Principal Specialist Psycho-oncologist with extensive clinical experience in sarcoma care, contributed specialist insight into the clinical, rehabilitative, and survivorship context of sarcoma. Bringing these perspectives together supported a reflexive analytic process in which interpretations were discussed, challenged, and refined across the team, helping ensure that the conceptual framing remained grounded in participants' accounts rather than in any one professional or personal perspective.

2.3 Results

2.3.1 *Study inclusion*

The article selection process can be seen in the PRISMA diagram (Figure 1). A total of 40 studies were included in the final synthesis. Articles were published from 2008-2025. There was a total of 538 sarcoma participants across the included articles (age range 18-80+ yrs, 43% male (N= 230), 48% female (N= 258), and 9% not specified (N= 50). See Table 1 for study characteristics.

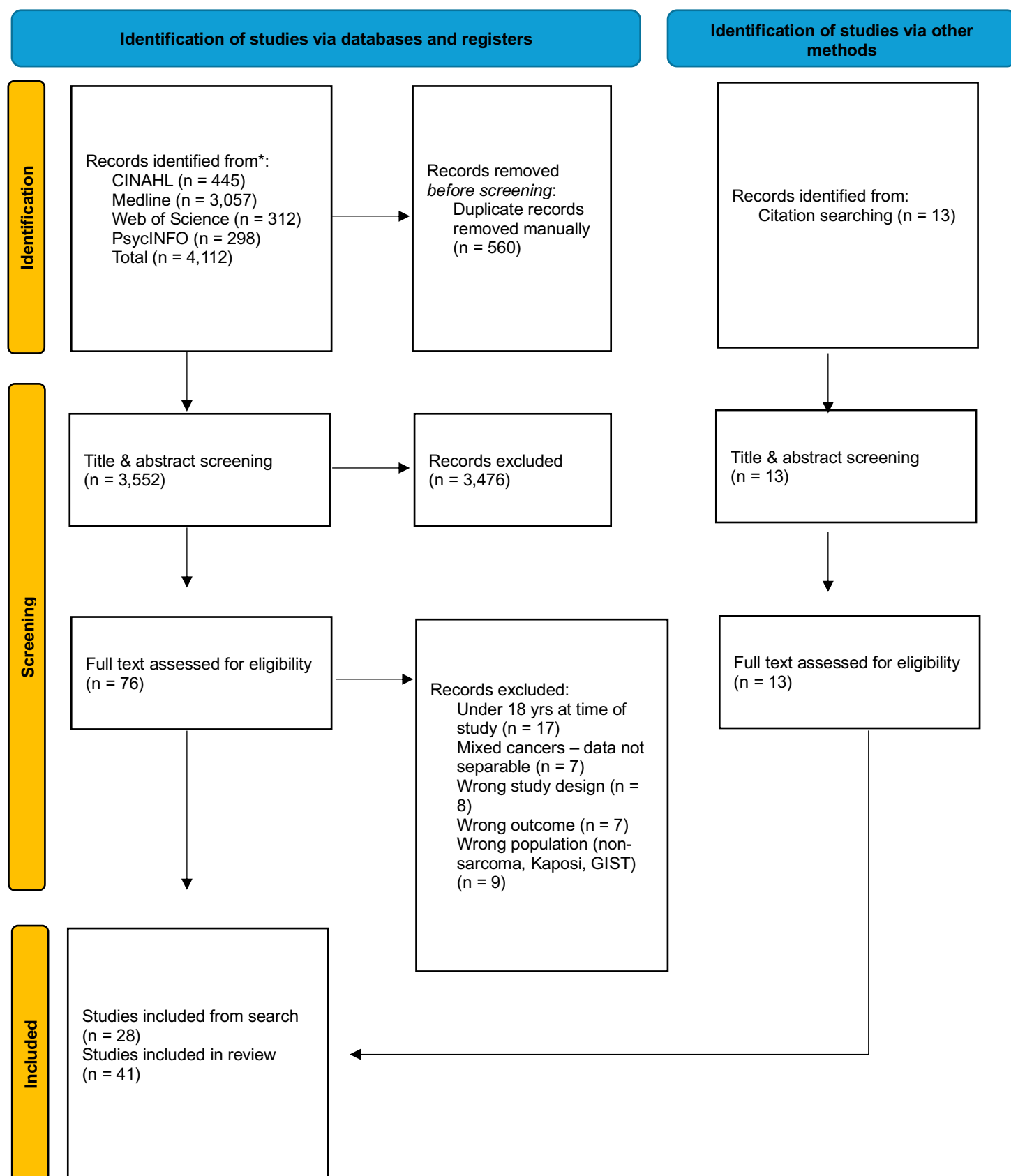
Figure 1*PRISMA Flow Diagram*

Table 1*Characteristics of Included Studies*

ID	Author(s) (Year)	Country/ Study setting	Aim	Findings/Themes	Participants	Treatment Status	Data Collection	Data Analysis
1	Almeida et al (2024)	Portugal / Oncology Hospital	To enhance the understanding of the QoL challenges of Portuguese individuals with sarcoma.	(1) Interrupted life, (2) Learning to live with the sarcoma and (3) Need for more individualised care.	N = 7; Age = 22-78yrs; Gender = 3(M), 4(F); Type = STS (3), BS (4) - (Leiomyosarcoma, Ewing's sarcoma, Other sarcoma)	NR	Mixed method - Semi-structured interview.	Thematic analysis
2	Antalis et al (2019)	USA / Universit y of Michigan Rogel Cancer Centre	To examine patient perceptions of Survivorships Care Plans (SCPs) and the role of SCPs in overall health management.	1) Addressing information needs, 2) Monitoring for reoccurrence evokes fear 3) SCP as a health management tool	N = 8; Age = >18yrs; Gender = NR; Type = NR	NR	Mixed method – open-ended questions via telephone interview	Thematic Analysis

3	Beghean & Coffey (2021)	Ireland/ Irish Sarcoma Group	To explore biopsychosocial consequences of STS, self-management strategies, and barriers/facilitators to same.	1) Consequences of STS and its treatment, 2) Perceived facilitators and barriers to self-management post-treatment, and 3) Self-management strategies employed	N = 7; Age = 26-65+yrs; Gender = 2(M), 5(F); Type = STS (Myxofibrosarcoma, Myxoid liposarcoma, Synovial sarcoma, Angiosarcoma)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Thematic analysis
4	Benedict et al (2016)	USA/ Metropolitan Cancer Center	To explore young adult's discussions of fertility.	1) Fertility concern, 2) Emotions raised when discussing fertility, and 3) Managing fertility concerns	N = 2; Age = 21-24yrs; Gender = 1(M), 1(F); Type = BS (Osteosarcoma, Ewing sarcoma)	Post-treatment/survivors	Qualitative study - semi-structured interview and focus group	Grounded theory
5	Burgers et al (2022)	Netherlands / University Medical Centers & Netherlands Cancer Institute	To examine the psychosocial challenges in daily life of the growing group of AYAs (Adolescents & Young Adults) with a UPCP (Uncertain or Poor Cancer Prognosis).	1) Feeling inferior to previous self and others, 2) Feeling of being alone, 3) Sense of grief about life, and 4) Loss of control over the future	N = 7; Age = >18yrs; Gender = NR; Type = Sarcoma unspecified	NR	Qualitative study - Semi-structured interview.	Grounded Theory by Corbin and Strauss - constructivist philosophical perspective

6	Burgers et al (2023)	Netherlands / University Medical Centers & Netherlands Cancer Institute	To explore the care experiences of AYAs with a UCP, with a focus on areas of improvements and to provide oncology HCPs with examples and tools to provide the best possible care.	1) Trust, 2) Tailored communication, and 3) Holistic, empathic and open approach.	N = 3; Age = 28-41yrs; Gender = 0(M), 3(F); Type = STS (leiomyosarcoma, rhabdomyosarcoma), BS (osteosarcoma)	Mixed	Qualitative study - semi-structured interview and focus group	Grounded theory
7	D'Alessandro et al (2025)	USA / Quaternary Care Children's Hospital	To characterise the experiences of individuals living with incurable and indolent STS for more than two years.	1) Managing physical symptoms related to disease/treatment side effects, 2) Navigating feelings of guilt and inadequacy, 3) Changing illness experience over time, and 4) Self-reflection generating gratitude	N = 5; Age = 23-45yrs; Gender = 2(M), 3(F); Type = STS (low-grade fusion-driven sarcoma; alveolar soft part sarcoma; deficient epithelioid sarcoma; extra-skeletal myxoid chondrosarcoma; and epithelioid hemangioendothelioma)	Mixed	Mixed method-questionnaire with open-ended questions	Thematic analysis (inductive)

8	Dean et al (2025)	UK / Sarcoma Specialist Centre - Royal Marsden Hospital	To explore patient experience of rehabilitation in the surgical pathway for lower limb STS.	1) Accessing the right services at the right time; 2) “Communication is key” - providing knowledge and support to navigate uncertainty; and 3) The importance of person-centred rehabilitation.	N = 8; Age = 32-80yrs; Gender = 4(M), 4(F); Type = Lower limb STS (Well-differentiated/de-differentiated liposarcoma; Undifferentiated pleomorphic sarcoma; Pleomorphic sarcoma; Synovial sarcoma; Extrasosseous Ewing sarcoma; Solitary fibrous sarcoma)	Post-treatment/survivors	Qualitative study - Semi-structured interview.	Thematic analysis (inductive)
9	den Hollander et al (2022)	Multiple countries (Germany, Italy, Jordan, Netherlands, UK)	To gain more insight in the HRQoL issues that individuals with uterine STS face.	1) Physical health, 2) Mental health, and 3) Social health	N = 13; Age = 39-61yrs; Gender = 0(M), 13(F); Type = STS (leiomyosarcoma, endometrial stromal sarcoma, rhabdomyosarcoma, Sarcoma NOS, Other (adenosarcoma, PEComa, undifferentiated spindle cell sarcoma)	Mixed	Mixed method - semi-structured interview	Thematic analysis

10	Denissen et al (2025)	Netherlands / Radboud University Medical Center	To explain the needs for rehabilitation of patients with BS before and after surgical resection and reconstruction.	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, and 7) Patients have a need for access to expertise in the hospital	N = 13; Age = 19-78yrs; Gender = 7(M), 6(F); Type = BS (Osteosarcoma n=6, Chondrosarcoma n=5, Angiosarcoma n=1, Metastasis n=1)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Constructivist, interpretative qualitative grounded theory study
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11	Dewhurst et al (2020)	UK / Outpatient Clinic - Oncology Center	The aim of this research was to explore factors that might influence the physical activity people with an STS undertake as they receive palliative chemotherapy.	1) Physical activity as an indicator of normality, 2) Implications, loss, and uncertainty for the future due to diagnosis and treatment, and 3) The challenge of recognizing support needs as physical activity decline	N = 6; Age = 53-69yrs; Gender = 2(M), 4(F); Type = STS (6) - (Endometrial Sarcoma, Inferior vena cava Leiomyosarcoma, Abdominal Rhabdomyosarcoma, Retroperitoneal Liposarcoma, Leiomyosarcoma of the uterus, Pleomorphic spindle cell sarcoma adrenal gland)	Active treatment: palliative chemotherapy	Qualitative Study - Semi-structured interview	Inductive approach based on a constructionist perspective
12	Eliason et al (2022)	USA / Sarcoma Oncology Center, California	To characterize patient experiences of symptoms and impacts of mSS through CE questioning and CD interviewing.	1) Physical symptoms: pain, breathing/respiratory, fatigue, and gastrointestinal, and 2) Additional symptoms experienced	N = 8; Age = 21-51yrs; Gender = 5(M), 3(F); Type = STS (metastatic synovial sarcoma - mSS)	Mixed	Qualitative Study - Semi-structured interview was used.	Thematic analysis
13	Fauske et al (2015a)	Norway / Norwegian Radium Hospital, Oslo University Hospital	To understand the experience of illness through qualitative methodology.	1) The impracticalities of daily life due to functional impairment, 2) Lost opportunities, and 3) Identity change.	N = 10.0; Age = 18-60yrs; Gender = 7(M), 3(F); Type = BS (Osteosarcoma n= 2, Ewing's sarcoma n=5, Chondrosarcoma n= 3)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Thematic analysis

14	Fauske et al (2015b)	Norway / Norwegian Radium Hospital, Oslo University Hospital	To understand the long- term experiences of osteosarcoma survivors from a sociocultural and psychosocial perspective.	1) Negative Consequences and 2) Positive Consequences.	N = 8; Age = 18-50yrs; Gender = 4(M); 4(F); Type = BS (Osteosarcoma - lower extremity)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Thematic analysis
15	Fauske et al (2016)	Norway / Norwegian Radium Hospital, Oslo University Hospital	To explore how visible body changes following surgical treatment affect the life and identity of primary bone sarcoma survivors 3–10 years after diagnosis.	1) Hiding and 2) Exposing bodily deviations	N = 18; Age = 18-60yrs; Gender = 11 (M); 7 (F); Type = BS (Osteosarcoma, Ewing's Sarcoma, Chondrosarcoma - hip/pelvis region or lower extremities)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Thematic analysis
16	Fauske et al (2019)	Norway / Norwegian Radium Hospital, Oslo University Hospital	To identify and explore different trajectories that bone sarcoma survivors might navigate during follow-up.	1) Back to normal, 2) A new normal, and 3) Still struggling	N = 18; Age = 18-60yrs; Gender = 11 (M), 7 (F); Type = BS (Osteosarcoma, Ewing's Sarcoma, Chondrosarcoma - hip/pelvis region or lower extremities)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Thematic analysis

17	Fauske et al (2025)	Norway / Sarcoma Centre - Norwegian Radium Hospital Oslo University hospital	To explore how sarcoma survivors experienced communication with and support from healthcare personnel during their outpatient long-term follow-up care.	1) Outpatient follow-up, 2) Psychosocial concerns, 3) Information on side effects, and 4) Feedback on the checklist.	N = 28; Age = 20-73yrs; Gender = 15(M), 13(F); Type = STS and BS, not specified.	Mixed	Qualitative Study - Semi-structured interview	Reflexive thematic analysis
18	Gough et al (2019a)	UK / Royal Marsden (RM) NHS Foundation Trust	To explore qualitatively the individual constituents of HRQoL in two groups of patients with advanced STS	1) Physical domains, 2) Psychological domains, and 3) Social domains	N = 140; Age = 32-82yrs; Gender = 5(M), 9(F); Type = Advanced STS (Leiomyosarcoma, PeComa, Plemorphic, Sarcoma NoS, Synovial, MFH, epithelioid, Liposarcoma, Fibrosarcoma)	Active treatment - advanced STS	Longitudinal mixed methods - Semi-structured interview	Thematic & exploratory analysis
19	Gough et al (2019b)	UK / Royal Marsden (RM) NHS Foundation Trust	To explore patient-centered accounts of the value and timing of prognostic discussions in advanced STS.	1) Rarity causing prognostic uncertainty, 2) Avoiding the negative, and 3) Physical symptoms a better prognostic indicator than physician guess.	N = 24; Age = 19-82yrs; Gender = 8 (M), 16(F); Type = STS (Leiomyosarcoma, liposarcoma, epithelioid sarcoma, pleiomorphic sarcoma, fibrosarcoma, MFH, Other sarcoma)	Mixed	Qualitative Study - Semi-structured interview	Thematic & exploratory analysis

20	Halkett et al (2025a)	Australia / Community organisation	To explore the potential role a helpline could play in supporting people diagnosed with sarcoma and carers.	1) 'The current system is not meeting needs', 2) 'Holistic support,' 3) 'A source of credible information,' 4) 'The helpline operator' and 5) 'Centralised support for my sarcoma'	N= 12; Age: 21-61yrs; Gender = 3(M), 9(F); Type = STS and BS, not specified	NR	Qualitative Study - Semi-structured interview	Reflexive thematic analysis
21	Halkett et al (2025b)	Australia / Community organisation	To determine the information needs from the perspectives of people with sarcoma, carers and HCPs.	1) "Accessing Useful Information About Diagnosis and Treatment"; 2) "Learning to Live with Sarcoma"; 3) "Gaining Access to Psychosocial Support"; 4) "Connecting with the Sarcoma Community"; 5) "Seeking Practical Support and Information"; and 6) "Obtaining Financial Support";	N= 18	NR	Qualitative Study - Semi-structured interview	Thematic analysis
22	Hewitt et al (2019)	UK / Hospital in the North West of England.	To gain a deeper understanding of patients' perceptions of treatment for STS, identify concerns throughout treatment, and consider what patients found helpful.	1) Care process, 2) Coping with treatment, and 3) Social relations throughout treatment.	N = 19; Age = 29-84yrs; Gender = 11(M), 8(F); Type = STS (not specified)	Post-treatment/survivors	Qualitative study - Semi-structured interview	Thematic analysis

23	Kain et al (2017)	USA / University of Iowa Hospitals and Clinics	To determine general categories of information patients want to know at various time points in their care and investigate how patients coped with various physical and psychosocial issues that may occur with sarcoma treatment.	1) Information about diagnosis and treatment, 2) Relationship with the care team, 3) Social support, and 4) Restoration to “normal.”	N = 20; Age = 22-79yrs; Gender = 11(M); 9 (F); Type = BS (Chondrosarcoma and Osteosarcoma) and STS (Undifferentiated pleomorphic sarcoma, Myxofibrosarcoma, Leiomyosarcoma, Malignant peripheral nerve sheath tumor, Fibromyxosarcoma, Synovial sarcoma	Post-treatment/survivors	Qualitative study – Focus group	Scissor-and-sort technique/Content Analysis
24	Košir et al (2020)	Canada / Sarcoma Medical Center, Montreal	(1) To develop a better understanding of the affective responses and psychological functioning and identify coping mechanisms.	1) Changes in mood, (2) Worry, and (3) Body image concerns.	N = 28; Age = 24-75yrs; Gender = 15(M); 13(F); Type = STS (lower and upper extremity)	Post-treatment/survivors	Qualitative study – Focus group & semi-structured interview	Inductive Thematic Networks Approach and Inductive Content Analysis
25	Lidington et al (2021)	UK / Hospital and local charities	To explore the healthcare experiences of YAs with cancer treated in UK hospitals.	1) Delay in diagnosis, 2) Navigating the healthcare system, 3) Health information, 4) Variability in fertility preservation discussion and 5) Signposting to relevant resources	N = 13; Age = 25-42yrs; Gender = NR; Type = Not specified	Mixed	Qualitative study - semi-structured interview and focus group	Thematic analysis

26	Lorimer et al (2025)	Australia / Hospital and local charities	To provide insights into the psychosocial, emotional, and practical challenges that shape the post-treatment journey for informal carers and adults diagnosed with sarcoma.	1) It Takes a Village, 2) I'll Be Strong, and 3) Navigating Life After Sarcoma	N= 5; Age = 21-53yrs; Gender = 2(M), 3(F); Type = STS (Epithelioid, Retroperitoneal Liposarcoma), BS (Chondrosarcoma, Osteosarcoma)	Post-treatment	Qualitative study - Semi-structured interview	Reflexive thematic analysis
27	Magasi et al (2022)	USA / Cancer Centres in Midwestern United States	To examine how survivors of breast cancer, head and neck cancer, and sarcoma negotiate disability understandings and experiences.	1) Long-term effects and 2) Disability Identity	N = 5; Age = 22-67yrs; Gender = 0(M), 5(F); Type = Not specified	Post-treatment/survivors	Qualitative study - Semi-structured interview	Thematic analysis
28	Martin et al (2023)	UK / Hospitals in England and Scotland	To describe pre-diagnostic signs/symptoms and pathways to diagnosis, including where help was sought and what processes were involved prior to the diagnosis.	1) Experience of the diagnosis process.	N = 5; Age = 25-65+yrs; Gender = 5(M), 0(F); Type = BS (not specified)	Post-treatment/survivors	Mixed method - Semi-structured interview.	Thematic analysis

29	Martins et al (2019)	UK / Hospitals	To explore the experiences of patients with PBC across the UK.	1) Physical, 2) Emotional, 3) Social well-being and 3) Role of healthcare professionals.	N = 22; Age = 25-66+yrs; Gender = not specified; Type = BS (not specified)	Mixed	Qualitative study - semi-structured interview and focus group	Framework analysis
30	Martins et al (2024)	UK / Multicenter study in the United Kingdom recruiting through specialist STS clinical teams	To provide an in-depth exploration of patients' experience of being diagnosed with STS to provide context to the developing outcome measure.	2) Impact of STS-individual and social factors, and 2) Context and processes of care.	N = 68; Age = 23-82yrs; Gender = 40(M), 28(F); Type = STS (not specified)	Mixed	Qualitative study - Semi-structured interview and focus group	Framework analysis
31	Parsons et al (2008)	Canada / Mount Sinai Hospital	To characterise the lived experiences of illness of people with osteosarcoma and to characterize the lived experiences of resuming vocational pursuits.	1) Illness work, (2) Identity work and 3) Vocational work	N = 14; Age = 18-38yrs; Gender = 8(M); 6(F); Type = BS (osteosarcoma - 12 lower extremity, 2 upper extremity)	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Narrative Analysis

32	Peairs et al (2025)	USA / Orthopedic oncology clinic	The aim was to explore the lived experiences of patients with sarcoma as pertaining to Social Determinants of Health.	1) Education Access and Quality, 2) Healthcare Access and Quality, 3) Economic Stability, 4) Neighborhood and Built Environment, and 5) Social and Community Context	N = 17; Age = 18+; Gender = 9(M), 8(F); Type = STS and BS, not specified	Mixed	Qualitative Study - Semi-structured interview	Framework Method thematic analysis
33	Soomers et al (2020)	UK & Netherlands / Radboud University Medical Centre (Radboud umc), NL, or the Royal Marsden NHS Foundation Trust, UK	To investigate the route to diagnosis (RtD) experienced by individuals with sarcoma, including factors contributing to the length of the total interval from the perspective of a patient	1) Diagnostic interval: Diagnostic phase and effect of centralisation, 2) Reflection on diagnostic pathway: Satisfaction with care and impact of delay and 3) Recommendations for improvement of the diagnostic pathway	N = 15; Age = 18-69yrs; Gender = 6(M), 9(F); Type = STS & BS (Osteosarcoma, Nerve sheath sarcoma, Solitary fibrous tumour, Leiomyosarcoma uterus, Osteosarcoma, Solitary fibrous tumour, Ewing sarcoma, solitary fibrous tumour groin, Leiomyosarcoma, Endometrial stromal sarcoma uterus, Ewing sarcoma thorax, Ewing like sarcoma thorax, Liposarcoma, Undifferentiated pleomorphic sarcoma,	Pre-treatment and active treatment	Qualitative Study - Semi-structured interview	Content Analysis

					Differentiated liposarcoma)			
34	Spears et al (2008)	UK / Hospital	To explore the emotional support given to individuals with sarcoma by ward-based nurses.	1) Use of humour, warmth and positive attitude, 2) Inappropriate/unprofessional behaviour, 3) Recognition of feelings/needs, 4) Continuity and relationship with nurse, 5) Practical nurse behaviour and 6) Availability and time	N = 5; Age = 24-37yrs; Gender = 3(M), 2(F); Type = Not specified	Not specified	Qualitative study - semi-structured interview	Thematic analysis
35	Taylor & Pooley (2018)	Australia / Hollywood Functional Rehabilitation Clinic	To provide insights into sarcoma survivors' thought patterns which impinge on their psyche and their motivational drive to reshape their lives.	1) Undergoing treatment, 2) Surviving sarcoma, and 3) Looking forward	N = 7; Age = 18-44yrs; Gender = 2(M), 5(F); Type = BS & STS (chondrosarcoma, giant cell [a malignant form of giant cell tumor of bone] or Ewing's sarcoma)	Post-treatment/survivors	Qualitative Study - Reflective Journaling Design	Interpretative Phenomenology Analysis (IPA) and inductive Thematic Analysis

36	Taylor & Pooley (2017)	Australia / Hollywood Functional Rehabilitation Clinic	To explore sarcoma survivors' thought patterns regarding their post-operative body image, functionality, and quality of life	1) Pre- and post-operative body image experiences and mobility concerns and 2) Reconstructing a future healthier and happier quality of life	N = 7; Age = 18-44yrs; Gender = 2(M), 5(F); Type = BS & STS (chondrosarcoma, giant cell [a malignant form of giant cell tumor of bone] or Ewing's sarcoma)	Post-treatment/survivors	Qualitative Study - Reflective Journaling Design	Interpretative Phenomenology Analysis (IPA) and inductive Thematic Analysis
37	van Eck et al (2021)	Germany, Norway, The Netherlands, Italy, Cyprus, and the United Kingdom	The aim of this study was to assess the unique issues experienced by patients with primary thoracic and primary breast sarcomas.	1) 'Physical health', 2) 'Mental health', and 3) 'Social health'	N = 23; Age = 18-79+ yrs; Gender = 8(M), 15(F); Type = STS (thoracic sarcoma [Liposarcoma, Myxofibrosarcoma, Rhabdomyosarcoma, Sarcoma NOS], breast sarcoma [Angiosarcoma, Sarcoma NOS]), BS (thoracic sarcoma [Chondrosarcoma, Ewing's sarcoma])	Mixed	Qualitative Study - Semi-structured interview	Thematic analysis

38	van Kouswijk et al (2024)	Netherlands / Department of Orthopedics of University Medical Center Groningen	To identify what factors, influence functional recovery after limb-salvage surgery (LSS) for lower extremity musculoskeletal tumours (LEMT) from joint patient and HCP perspectives.	1) Body structures and functions, 2) Activities and participation, 3) Environmental factors, and 4) Expectations	N = 11; Age = 40-59yrs; Gender = 2(M), 2(F); Type = BS (osteosarcoma, chondrosarcoma), STS (myxoid liposarcoma)	Post-treatment/survivors	Exploratory Qualitative Study - Semi-structured interview with open and closed ended questions.	Deductive and Inductive qualitative Content Analysis
39	Vetchy et al (2025)	Austria / Medical University of Vienna, Department of Orthopedics and Trauma Surgery	To explore how patients experience the time following amputation after primary limb salvage surgery due to musculoskeletal malignancies.	1) Prosthesis, 2) Orthopaedic technician, 3) Quality of life, and 4) Amputation	N = 9; Age= 22-65yrs; Gender= 4(M), 5(F); Type = Sarcoma, unspecified	Post-treatment/survivors	Qualitative Study - Semi-structured interview	Maryn content analysis
40	Zambrano et al (2020)	Switzerland / Bern University Hospital	To identify what motivates survivors of extremity sarcoma to return to work (RTW).	1) Searching for distraction and wanting to leave the disease behind, 2) The problems with the 'new' normal, 3) Signs of readiness, and 4) Motivating factors and meaning of returning to work	N = 15; Age = 27-55yrs; Gender = 7(M), 8(F); Type = STS - extremity, BS - extremity	Post-treatment/survivors	Qualitative study - qualitative survey approach to data collection through an open-ended questionnaire	Inductive Thematic Analysis

41 †	Znajda et al (1999)	Canada / Mount Sinai Hospital	To identify psychosocial issues experienced by patients treated with surgery and irradiation for STS of the thigh.	1) Lack of preparedness for the diagnosis, 2) Support sought and given, 3) Need for more information, 4) Changes to daily life, 5) A change in focus from self to "I relating to others, " and 6) Recognition of cancer as a "forever disease."	N = 10; Age = 40-60yrs; Gender = 5(M), 5(F); Type = STS of the thigh	Post-treatment/survivors	Qualitative Study - An unstructured interview was used.	Unknown - Data analysis involved description of the major categories and subcategories with the intention of finding major themes
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Note. STS = soft tissue sarcoma; OS = osteosarcoma; MS = mixed sarcoma; NR = not reported; QoL = Quality of Life; HRQoL = Health Related Quality of Life; Yas = Young Adults.

† Study 41 was excluded from the final synthesis following quality assessment review.

[illegible]

38	van Kouswijk et al (2024)											High
39	Vetchy et al (2025)											High
40	Zambrano et al (2020)											High
41	Znajda et al (1999)											Excluded†

Note. CASP = Critical Appraisal Skills Programme qualitative checklist. Q1–Q10 correspond to checklist items. Papers were categorized into high-quality (score 9.0–10), moderate-quality (7.5–9.0), and low-quality (7–5.5) studies.

†Study 41 has been excluded from the synthesis due to receiving <1 on item 7.

 =Yes  =Can't  =No

- Q1. Was there a clear statement of the aims of the research?
- Q2. Is a qualitative methodology appropriate?
- Q3. Was the research design appropriate to address the aims of the research?
- Q4. Was the recruitment strategy appropriate to the aims of the study?
- Q5. Was the data collected in a way that addressed the research issue?
- Q6. Has the relationship between researcher and participants been adequately considered?
- Q7. Have ethical issues been taken into consideration?
- Q8. Was the data analysis sufficiently rigorous?
- Q9. Is there a clear statement of findings?
- Q10. How valuable is the research?

2.3.3 Review Findings

Using the thematic synthesis approach¹⁸ 5 themes and 13 subthemes were identified. All themes were supported by between 14 and 34 studies, including several of high methodological quality (see Table 3). These themes capture the complex psychosocial dimensions of living with sarcoma across the illness trajectory where disruption begins early in the diagnostic pathway, accumulates across treatment and recovery, and extends into longer-term changes in identity, function, and social life. Across this trajectory, participants also described ongoing efforts to adapt, supported or constrained by the resources, relationships, and systems available to them (see Figure 2). A summary of these themes and quotes is presented in Table 4.

Table 3*Frequency of Studies Contributing to Themes and Subthemes*

Theme	Subtheme	Study IDs (referenced)	Frequency (n)	Total References (Σ)
Theme 1. In the Dark - Delays, Dismissals, Diagnostic Dread & Mistrust	Fragmented diagnostic journey	6, 11, 25, 28, 33, 35	6	42
	Rare & Unprepared - The shock, fear, and uncertainty of a sarcoma diagnosis	1, 9, 11, 19, 20, 24, 32, 33, 35, 36, 37	11	41
	Total of Studies Contributing to Theme 1 (n)		14	83
Theme 2. Treatment as Threat	The Burden of Recovery	1, 3, 5, 7, 8, 9, 10, 13, 15, 16, 17, 18, 23, 24, 26, 27, 29, 30, 32, 35, 38, 39	22	115
	The Invasiveness of Multimodal Treatment	3, 4, 7, 9, 11, 12, 13, 14, 15, 16, 18, 22, 24, 29, 31, 35, 36, 37	18	187
	Total of Studies Contributing to Theme 2 (n)		30	302
Theme 3. No Longer the Same - Identity Loss & Altered Lives	Living in a Changed body - Shame and Visible Scars	1, 3, 4, 9, 13, 14, 15, 16, 24, 27, 29, 30, 31, 36, 37, 38	16	88
	The Weight of Functional Loss - Disrupted Roles & Lost Independence	1, 3, 4, 5, 7, 9, 11, 12, 13, 14, 15, 16, 18, 21, 24, 27, 29, 30, 31, 32, 35, 36, 37, 38, 39, 40	26	301
	Social Disconnection - Isolation, Stigma & Feeling like a Burden	1, 3, 4, 5, 9, 13, 14, 15, 16, 22, 23, 24, 26, 27, 29, 30, 31, 36, 37, 40	20	118

	The Emotional Cost of Sarcoma - Fear of Recurrence & Distress	1, 2, 3, 5, 7, 9, 11, 12, 13, 14, 16, 18, 22, 23, 24, 30, 31, 37, 38	19	90
Total of Studies Contributing to Theme 3 (n)			30	597
Theme 4. What Helped Along the Way -Support & Strength in the Face of Sarcoma				
	Self-Management - Activity, Reframing, & Acceptance	1, 3, 5, 7, 9, 10, 11, 13, 14, 15, 16, 18, 19, 22, 23, 24, 25, 26, 30, 31, 32, 35, 36, 37, 38, 39, 40	27	282
	Relational & System-Level Support - Not Facing Sarcoma Alone	1, 2, 3, 7, 8, 9, 11, 17, 20, 21, 22, 23, 25, 26, 29, 30, 32, 34, 35, 39	20	197
	Choosing Not to Know: Preserving Hope through Selective Engagement	1, 3, 19, 22, 23, 40	6	41
Total of Studies Contributing to Theme 4 (n)			34	520
Theme 5. What do people with sarcoma need				
	Diagnostic improvement	3, 6, 8, 25, 30, 33	6	33
	Specialist, Individualised & Integrated Sarcoma Care across Treatment, Rehabilitation, and Survivorship	1, 2, 3, 6, 8, 10, 11, 17, 20, 21, 22, 23, 25, 26, 29, 30, 32, 33, 37, 38, 39	21	273
Total of Studies Contributing to Theme 5 (n)			21	306

Note. *Frequency (n)* = number of studies contributing to each subtheme; *Total References (Σ)* = total coded instances per subtheme; *Total of Studies Contributing to Theme (n)* = distinct studies represented within each theme (duplicates removed). Study IDs bolded indicate high quality studies.

Figure 2

Conceptual model of psychosocial adaptation in adults with sarcoma

Figure 2 illustrates the conceptual model emerging from the synthesis, showing how psychosocial disruption accumulates across the sarcoma trajectory and how long-term adaptation is shaped by both individual and system-level factors

The model conceptualises psychosocial adaptation as dynamic and iterative, rather than as a linear progression from diagnosis to recovery. Diagnostic disruption and treatment-related threat may contribute to enduring psychosocial disruption, including altered body image, functional loss, identity disruption, distress, social disconnection, and fear of recurrence. These experiences may continue beyond active treatment and shape longer-term adjustment.

Longer-term adaptation is presented as both shaped by earlier disruption and continually influenced by ongoing coping, support, and healthcare experiences. Coping strategies such as acceptance, reframing, self-management, and meaning-making may support adaptation, while relational and system-level factors, including family support, sarcoma-informed professionals, rehabilitation, and tailored information, may either facilitate or constrain adjustment. The model therefore suggests that adaptation in sarcoma is not a fixed endpoint, but an ongoing process that may change in response to later challenges such as surveillance, functional changes, fear of recurrence, or unmet needs.

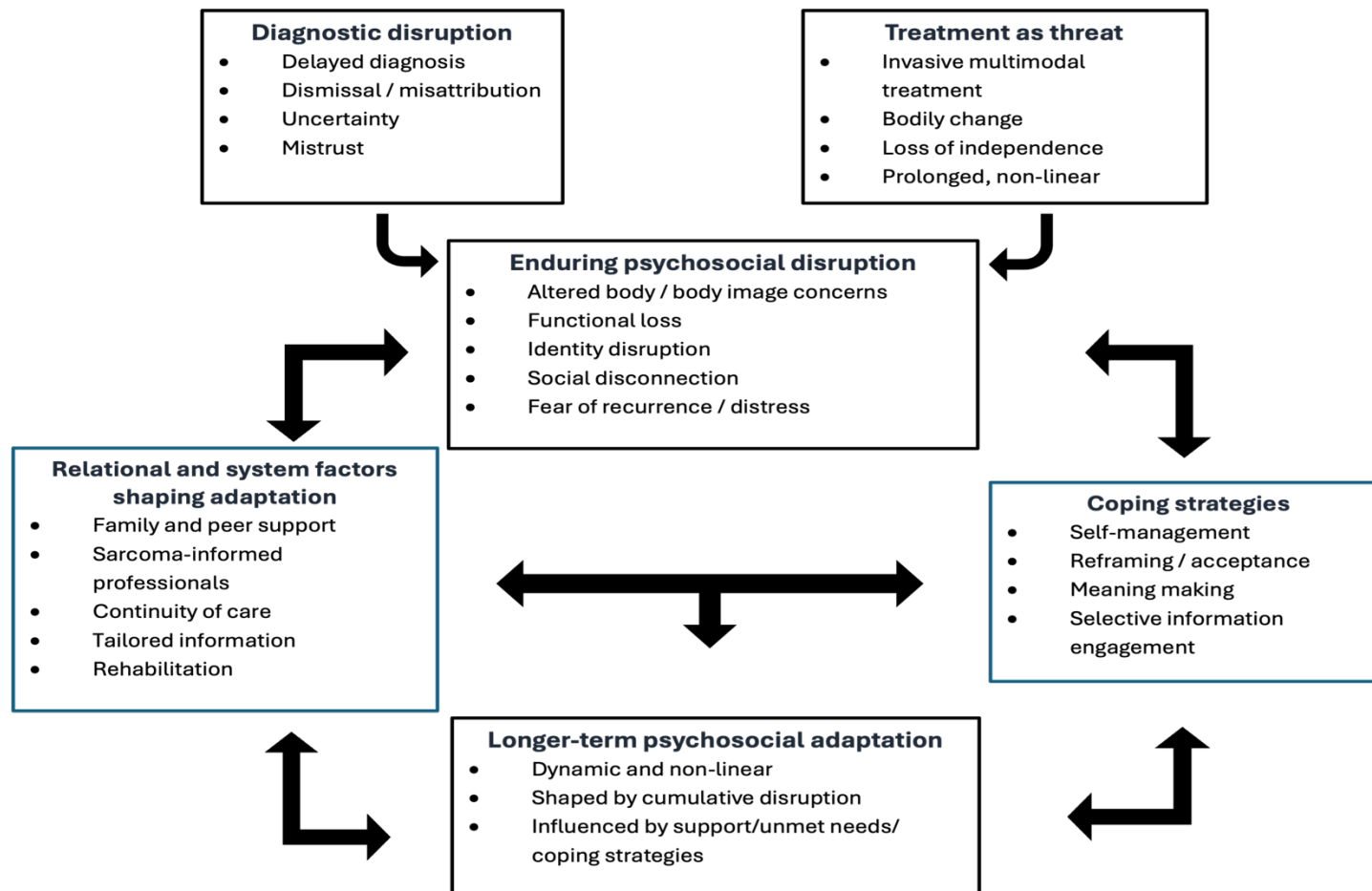


Table 4

Analytical and Descriptive Themes with Representative Codes on the Psychosocial Impact of Sarcoma

Analytical Theme	Descriptive Theme (Subtheme)	Code	Illustrative Quote	Article ID / Author(s)
In the Dark – Delays, Dismissals, Diagnostic Dread & Mistrust	Fragmented diagnostic journey	Misdiagnosis	“It’s a hematoma because you’ve obviously pulled a muscle and you know you’ve pulled a muscle and it looks much like a hematoma” they said. [. . .] You don’t like to dreadfulize, you don’t like to think what ifs. I had pulled muscles in the past and they have been painful, and I have had problems with back muscles in the past through dangerous sports, so I just assumed at the time that they were correct, it was a hematoma.”	33 Soomers et al., 2020
		Long diagnostic process	“...[they took] a biopsy 3 times. They punctured 3 times, so they would have enough, but they hadn’t because it turned out they were still in doubt between a chondrosarcoma and an osteosarcoma.”	33 Soomers et al., 2020
		A waiting game	"... It took lots of tests to determine I’d a giant cell tumour... but that was just the start of the waiting... There was lots more waiting for them to determine what to do and how to make it better... It felt like it took forever."	35 Taylor & Pooley, 2018
		Rarity of sarcoma	“When you dig into the evidence, obviously sarcoma is a rare tumor, but even so, there's a few studies. As a patient, you're always trying to figure out which one of those study groups reflects you, because they don't.”	32 Peairs et al., 2025
	Rare and Unprepared: Shock, Fear & Uncertainty	Shock and emotional distress	"As a surfer and a soccer player for the whole of my life... the biggest initial problem I had when I found out I had a Ewing’s Sarcoma in my lower right leg... was the	36 Taylor & Pooley, 2017

Treatment as Threat	The Invasiveness of Multimodal Treatment		shock... of being told that I'd likely lose my right leg at the knee..."	
		Pervasive sense of uncertainty	"And I think I still don't quite understand what the difference between sarcoma and so-called normal cancer is. Also, specifically to sarcoma, because the other thing that you hear a lot from the doctors, it's not your typical cancer, so what is typical cancer and how...Because the population is so small, it's just understanding how big are the risks if you do this or you don't do that? Because there's just not a lot of data, there's not a lot of knowledge, it's hard to understand myself, but it's also hard to almost talk about it, because you're not quite sure."	9 den Hollander et al., 2022
		Fear	"It was difficult from the moment of the result at the hospital until the scans. Especially after the scans I was wondering: "is it somewhere else, how bad is it?" I thought I was dying."	33 Soomers et al., 2020
		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...."	11 Dewhurst et al., 2020
		Fertility	"That made me feel really isolated from people (...) I've always wanted a family, so that has been probably the biggest thing that I've had to overcome"	29 Martins et al., 2019
		Shortness of breath	"that is simply just walking uphill or if I'm carrying heavy shopping bags then I will get a little bit out of breath, which I didn't used to (pt 12, 54 years, leiomyosarcoma)"	9 den Hollander et al., 2022
		Surgical pain	"The doctor removed the bottom floating ribs and a mat has been placed in it. When I turn around, I can feel it stinging..."	37

			van Eck et al., 2021
The Burden of Recovery	Fear of limb loss	"I kept touching my leg to make sure that it had not been amputated. (Participant 1; female, 70 years, minor surgery)"	24 Košir et al., 2020
	Recovery expectations and challenges	"My expectations were, well, 'you get the prosthesis, you learn to walk again by attending physical therapy, and then it will be all right'. But that is not really how it goes; it is just different"	38 van Kouswijk et al., 2024
	Loss of independence	"I wished the sarcoma had never happened to me... The sarcoma had eaten away my bone and the bone broke. I had to move back in with my mum and dad as I couldn't pick my daughter up let alone dress, feed, or care for her... I couldn't put any weight on my leg. My parents had to do everything and this was a huge loss of my independence."	36 Taylor & Pooley, 2017
	Impairment on day-to-day activities	"These last medications have made me fat, I lost many muscles in the legs, and also a little bit in the arms, but not so much. But basically, I lost my autonomy and mobility. I have more and more difficulty with these normal things in life, like taking a shower."	1 Almeida et al., 2024
	Ongoing complications	"To get physically back and I don't know that I realized the complications of some of the nerve damage, and scar tissue damage and things like that that I have had to do extra kind of alternative massage therapy"	23 Kain et al., 2017
No Longer the Same – Altered Lives & Loss of Self	Living in a Changed Body – Shame & Visible Scars	Negative view of body "I feel, in all reality, very ugly when I am naked. I had girlfriends who say that they like me regardless, but I don't really believe them because they might just say that because they don't want me to be hurt or something like that. [. . .] I am more daring now but still afraid."	16 Fauske et al., 2016

		Afraid that they will reject me because of my ugly scars.”	
	Hiding self	“When people stared out of curiosity that’s when I became very self-conscious of the way I walked. The fact is that back then I limped and walked like an older person and that was embarrassing to me. I felt less confident because my leg looked ‘funny’... And, random strangers would ask me rude questions about my limp. They’d want to know all of the gory details... So that’s when I started to create an appearance of being normal. I wore jeans 365 days a year and tried not draw any attention to myself. I never wore shorts or short skirts”	36 Taylor & Pooley, 2017
	Others’ perceptions of their bodies	“The thing I noticed was how the adults stared at me. The children approached me and asked me what happened, and I said that I had an operation. That was totally fine, and they did not stare at all. How the adults were staring at me, on the other hand, was something that really caught my attention.”	16 Fauske et al., 2016
	Shame of looking different	“I just want to look normal. I don’t want to look like I have one breast. I don’t want to look disabled; I want to be normal. . . . Mentally I was probably at the worst point of my time because I couldn’t stop crying...”	27 Magasi et al., 2022
The Weight of Functional Loss – Disrupted Roles & Disability	Functional impairment	“I have no control. If I go out without crutches, I am afraid of falling. The risk of falling is much greater if I were to lose my foothold with the healthy leg. Then I have no chance of standing up on my feet with just the injured leg.”	13 Fauske et al., 2015a
	Mobility	"I have less muscle power on the left side because I have fewer muscles. I do exercise regularly, but so many muscles were removed at the time, there is simply no room for improvement."	38 van Kouswijk et al., 2024

	Physical disability	"My functional impairment is, in fact, more than what people can see from watching me walk...I cannot get anything done (on crutches). [. . .] I cannot carry anything; I cannot take anything with me. I have to put everything in a rucksack."	14 Fauske et al., 2015b
	Changing roles and relationships	"Um I'm having to accept help with the housework because it's I just you know I mean I'm keeping the basics done um and that would be fine but you know I've got quite a big family...I just can't do all the things I would normally do."	11 Dewhurst et al., 2020
	Losing their identity	"I felt very down. . . I can't always get down on the floor and play with my children. . . I sometimes feel like I'm a bad mom."	7 D'Alessandro et al., 2025
	Work disruptions	"I went back to work probably about a year after.[I] asked them if I could have my job back. The human resources guy said, "Yeah, no problem, sure, says to hire you back." So I waited. He's like, "At the end of the week we'll call you." That week passed. Another week passed...But basically, they weren't going to give me my old job...I was trying to get a job everywhere. I had resumes everywhere..."	31 Parsons et al., 2008
	Experience of loneliness	"It's very lonely because even when you've got all your family around at the end of the day it just comes down to you, doesn't it?"	22 Hewitt et al., 2019
Social Disconnection – Isolation, Stigma & Feeling Like a Burden	Feeling like a burden	'I can't always get everything off my chest, because I don't want to burden my children with it every time'..	37 van Eck et al., 2021

The Emotional Cost of Sarcoma: Fear of Recurrence & Distress	Social life	“No, people forget a little. Planning things that I cannot attend, and those things. [...] I think that it is obvious that people do so because they do not think that I am disabled and cannot manage what they do. And then, I become sad.”	14 Fauske et al., 2015b
	Not feeling understood	I don’t want to play like I’m being the victim, but ... it was just some people just not even acknowledging it [the impact of sarcoma] at all”	26 Lorimer et al., 2025
	Fear of recurrence	“I never felt cured either, it is known that it is a tumour that can come back quickly.”	37 van Eck et al., 2021
	Depression	"I always tried to push myself to do better, to get out of my mood swings, my negative moments and so on. [...] After the surgery, it's like my life has collapsed. I thought I could not do anything with my right hand. [...] I was a little depressed."	24 Košir et al., 2020
	Worry & fear of death	“If I go to bed on time, at 10 PM, I don’t sleep and I am afraid of death. So I sleep badly. I go to bed when I feel tired.”	9 den Hollander et al., 2022
	Lasting negative impact	"I would come here to the hospital to do my treatments, and always ask myself why there were so many	1 Almeida et al., 2024

What Helped along the Way – Support & Strength in the Face of Sarcoma	Self- Management: Activity, Reframing & Acceptance		people without legs ...nothing convinced me, only time helped, and it took two years."	
		Preserving a sense of normality	"when somebody tells 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..., um my other son has um emotional mental anxiety difficulties...so it's important to try and keep as close to normality as possible."	11 Dewhurst et al., 2020
		Increasing exercise	"The gym instructor said to me that my leg's okay and that I just needed to trust my leg because it would support me. She told me what I shouldn't do though was to not rely on my crutch...I asked her if I would need to do my exercises every day for the rest of my life and she replied: Yes... So now I've done more exercises in these last few weeks than I've done over the past 17 years after having my tumour on my left leg..."	36 Taylor & Pooley, 2017
		Accepting the new normal	"You want to be back to normal as fast as possible and it's not that way. I think you know you gotta find your new normal. You know it's not, you're not going to be like you were before but you're going to be a new normal. So you find a good goal where you can cope and you go on with life."	23 Kain et al., 2017
		Active coping vs rumination	"... I think the 'feel good factor' in physically feeling that you have the upper hand is probably as important as an awful lot of other things you are doing... if you are giving all your body the good endorphins and that sort of thing, rather than looking at a (medical) prognosis and saying "It's not good "and" I wonder how long I'm going to last" you know..."	19 Gough et al., 2019b
		Accepting the body	"I've become less aware of the difference and most days I don't think about it at all. I've got used to being slow	36

Relational & System-Level Support – Not Facing Sarcoma Alone		and wonky... and I don't have any issues with the look of my leg. I'm used to it!"	Taylor et al., 2017
	Reframing experiences	"Cancer has shown me how far past my limits I can push myself. . . Real pain, real love, real discipline, real courage. Not just in me, but in others..."	7 D'Alessandro et al., 2025
	Family Support	"My wife is my rock. Sometimes she's also the person that says 'come on, let's not sit around and mope around. Let's try and get going'..."	8 Dean et al., 2025
	Social Support	"I think because they (patient support groups), they sort of understood how I was feeling, whereas nobody else really did, well they can't can they? My family members didn't really understand what was going on in my head"	22 Hewitt et al., 2019
	Positive relationships with Health Care Professionals (HCPs)	"I was about to start bursting into tears and (Patient makes crying noise) and so this lovely nurse came walking by and she says to me, well she looked at me and that was it...we chatted and it just made me feel better..."	34 Spears et al., 2008
Choosing Not to Know: Preserving Hope through Selective Engagement	Avoiding prognosis discussions	"...they never mentioned it, and I've never asked. I don't want to know. I have a treatment plan and I will stick to it. I need to be positive and an 'expiry date' doesn't give me that..."	19 Gough et al., 2019b
	Shifting focus away from negativity	"putting it out of my mind completely ... there's no point in sitting here and biting your nails and thinking".	3 Beghean & Coffey, 2021
	Choosing not to know prognosis information	"I don't recall hearing that and I don't think I would have wanted to know [prognosis]. I just wanted to know	23 Kain et al., 2017

what I was up against, what the plan was and... how to get through it."

What Do People with Sarcoma Need?	Diagnostic Improvement	Lack of awareness of sarcoma	"Possibly my doctor himself should have pushed slightly more rather than saying: yes, that's fine, you can leave it until after your holidays, [the GP] should've possibly said: 'no, let's fix it beforehand'..."	27 Soomers et al., 2020
		Diagnostic delays	"...multiple instances of waiting for doctor, oncologist, and hospital waiting rooms (e.g., waiting for the results...waiting for a referral to an oncologist; waiting for appointment dates to complete the additional tests...waiting for a return appointment with the oncologist to find out the tests results and informed of the likely treatment options"	29 Taylor & Pooley, 2018
		Need for more information about sarcoma	"There should be more information regarding the disease and clear orientations like you will do this, you will do that. Sometimes there is little information, and you must wait two months for the appointment."	1 Almeida et al., 2024
		Fighting for diagnosis	"It makes you feel like they're just as invested in your health and your recovery as you are. So, it makes you feel better, which then makes it feel more important to help prove them right."	25 Lidington et al., 2021
	Specialist, Individualised & Integrated Care Across Treatment and Survivorship	Clear information and guidance	"It actually is important at the start of the trajectory that you actually have a conversation with someone speaking about like, how will the coming treatment trajectory be and what can you expect in the medical area? What can you expect in the rehabilitation area?"	10 Denissen et al., 2024
		Consistent access to information and care	"Me and my parents have a certain difficulty in having the information about my case. There are many professionals in the team and it's a little tricky to have	1

	the information about my situation ... to have all the information. One thing my mom suggested was to have one person who should be responsible for communication with the patient, always the same person who gives you all the information."	Almeida et al., 2024
Trust in HCPs	"... I was halfway through the trajectory [of rehabilitation] before you actually find out. If you go to the physical therapist for the first time, you cannot judge, because he needs to get a chance. But afterwards I thought, they are not specialized in this, they don't completely know."	35 Taylor & Pooley, 2018
Inadequate access to specialised rehabilitation	"The primary care physical therapist is too inexperienced. Sounds tough, but it is true. Don't get me wrong, I was very glad about him, he helped me back on my feet. (.) But I missed training stability there. I'm missing quite a few muscles, so other muscles had to take over. (...) I didn't train that enough back then. A rehabilitation centre is better qualified for that."	37 van Kouswijk et al., 2024
Lack of follow-up	"Even post getting home, again no psychology recommendation given or asked: "Would you like [access to services]?"...I went and hunted for all that stuff myself and I just thought how so little follow-up there has been. It's all about while you're in there and it's the afterwards your kind of left."	20 Halkett et al., 2025
Time for conversations	"There should be someone with more time for conversation or more prepared to understand what's going on"	1 Almeida et al., 2024

Theme 1: In the Dark – Delays, Dismissals, Diagnostic Dread & Mistrust

Across studies, participants described the diagnostic process as prolonged, confusing, and saturated with uncertainty. Two subthemes captured these experiences:

Fragmented Diagnostic Journey

The pathway to diagnosis was often characterised by misattributed symptoms, repeated consultations, and delayed referrals.

“I kept going to the doctors and he just kept giving me painkillers...I think my GP let me down a bit... having to fight with him to get referrals... That was probably the hardest bit.” (Study 28).²⁶

Rare & Unprepared: Shock, Fear, and Uncertainty

Receiving a sarcoma diagnosis was often abrupt and devastating, intensified by limited prognostic clarity and low public awareness.

“...I was just so surprised after everything being. . .” yes, yes everything looks good, everything looks good”. Then bang. . .” (Study 33).²⁷

Participants described struggling to process unexpected news and to communicate it to others who had never heard of sarcoma. These early experiences of uncertainty, shock, and limited understanding appeared to shape how participants entered treatment, often carrying forward a sense of vulnerability and loss of control.

“... it’s hard to understand myself, but it’s also hard to almost talk about it, because you’re not quite sure.” (Study 9).²⁸

Theme 2: Treatment as Threat

Building on the uncertainty and disruption described in diagnostic phase, treatment was widely described as invasive and overwhelming, both physically and emotionally. Three subthemes capture these experiences:

The Invasiveness of Multimodal Treatment

Participants across studies described chemotherapy, radiotherapy, and surgery as highly invasive experiences that reshaped their bodies and lives. Fatigue was the most frequently reported side effect, often described as debilitating.

"It wears me out. It wears me out." (Study 12).²⁹

Surgical procedures, often involving limb-sparing surgeries, extensive resections or at times amputations, were described as permanently life-altering. For many, the fear of potential limb loss or loss of function was particularly distressing.

"I think that just the fact that I couldn't be physically active...it would be the beginning of the end sort of thing ..." (Study 11).³⁰

The Burden of Recovery

Recovery from treatment, specifically surgery was described as arduous, prolonged and multifaceted process extending beyond physical healing.

"I went from being independent to being dependent... I had to have help getting into the shower and even dressing myself... I just felt like crying or screaming!" (Study 36).³¹

Persistent complications such as pain and slow wound healing prolonged recovery and challenged expectations of returning to normality:

"It was an enormous recovery physically; afterwards it took me I would say a good year to physically recover..." (Study 26).³²

Others experienced recovery as a challenging period, where anticipated relief often gave way to more uncertainty and the realisation that a return to 'normal' was no longer possible.

"The only thing worse than going through cancer treatment is after cancer treatment. . . that first month or two after treatment was like oh my gosh, you're relearning your whole life.... " (Study 27).³³

" 'Right, that's it, you're cured. Let's get back to normal now,' and I thought, 'No, I'm not cured.' " (Study 30).³⁴

For many, these recovery experiences marked not an end point, but a transition into longer-term bodily, functional, and psychosocial changes that shaped life beyond treatment.

Theme 3: No Longer the same – Altered Lives & The Loss of Self

Extending the disruption described in earlier themes, this theme, the most frequently referenced across studies, reflects the profound psychosocial transformation experienced by many individuals with sarcoma. Participants described feeling “no longer the same”, as sarcoma and its treatment disrupted their bodies, identities, and social roles. Four subthemes capture these experiences:

Living in a Changed Body – Shame & Visible Scars

Alterations to the body, such as deep surgical scars and amputations, were described as profoundly disruptive to body image and identity with many trying to conceal marks or avoid public spaces.

"... I don't wear shirts anymore with short sleeves...I guess I'm a little bit...embarrassed about it." (Study 24).³⁵

The Weight of Functional Loss – Disrupted Roles, Lost Independence, & Disability

Participants described the profound impact of functional loss on daily life, independence, and identity.

“For example, making dinner on crutches and trying to carry hot pans is absolutely hopeless” (Study 13).³⁶

Physical limitations disrupted participants’ roles as parents, partners, employees, and athletes with many now identifying as *“being disabled”*, unable to fulfil former roles or sustain the same relationships.

“I’m embarrassed because I could do this before... I feel a little less cool, less sporty and somewhat less of a man. [. . .]” (Study 13).³⁶

“My daughter has a disabled mother, and she is often sad when I cannot be with them.” (Study 14).³⁷

Social Disconnection – Isolation, Stigma, & Feeling like a Burden

Many participants described a deep sense of social disconnection, shaped by both perceived visible bodily changes and practical constraints of functional loss.

“Before I had cancer, I had a lot more friends. After I had to quit football, I lost contact with many...” (Study 14).³⁷

“No, people forget a little. Planning things that I cannot attend...they do not think that I am disabled and cannot manage what they do.” (Study 14).³⁷

Participants described being viewed through their impairments and struggling with other’s inability to grasp the lasting effects of sarcoma.

“It has taken me two years to admit it. . . I’m disabled. I’m disabled because of people staring at me...” (Study 27).³³

Many described how concerns about the emotional impact of sarcoma on loved ones contributed to feelings of guilt and distress, shaping how they experienced their relationships.

“They [family] start crying and ask why? Nobody knows why, so I felt guilty for hurting them [after sharing diagnosis]” (Study 37).³⁸

The Emotional Cost of Sarcoma: Fear of Recurrence & Distress

Participants described the enduring emotional weight of living with sarcoma, marked by persistent fear, anxiety, and sadness that extended well beyond treatment. Fear of recurrence was the most pervasive and enduring emotional impact across studies.

"Any lumps, bumps, that kind of thing, you start to think, "Oh no, what if that's another recurrence?" ... You know, every time you go for a scan, every time you go for a follow-up appointment..." (Study 30).³⁴

For many, this fear was compounded by the rarity of sarcoma, unpredictable course, and the absence of clear prognostic markers.

"With the breast cancer, I still had the false safety of well, it might go wrong, but it will take a while. I still have some time. And with this one...it really feels like a race against time..." (Study 37).³⁸

Alongside these fears and anxiety, many participants described profound sadness, and hopelessness in the aftermath of treatment.

"From the moment I had operated on my leg, I became a different person, and it affected me a lot ..., I feel sad, I am no longer the person, that I was..." (Study 1).³⁹

Theme 4: What Helped along the Way – Support & Strength in the Face of Sarcoma

Among the ongoing uncertainty, altered identity, social, emotional and functional disruption, participants also described a range of ways of coping, responding, and adapting over time.

Self-Management: Activity, Reframing & Acceptance

Participants described self-management strategies as vital to preserving a sense of normality. Exercise, diet, clothing choices, and planned daily activities were used to actively regain strength and normality.

"I want to be as normal as I can be. I'm wearing long trousers in the summertime to cover the scar [. . .] By doing this, I am first and foremost (participant's name) and not a former cancer patient." (Study 15).⁴⁰

Alongside these practical efforts, participants described consciously reframing their experiences as a form of meaning-making – finding acceptance, gratitude, changed perspectives, and in some cases faith, as sources of strength.

"...After having had cancer, I have become more positive.... What I went through, and the fact that I was as strong as I was, gave me more zest for life..." (Study 13).³⁶

Other participants described actively seeking information about sarcoma and its treatment as a way to prepare, regain a sense of control, and reduce uncertainty.

"I said how long have I got...I felt desperate to know...it was very hard to make any decisions or plans, unless you really know..." (Study 19).⁴¹

Choosing Not to Know: Preserving Hope through Selective Engagement

In contrast to those who sought detailed information to prepare and feel in control, other participants described deliberately limiting engagement with illness-related information or discussion as a way to preserve hope and prevent sarcoma from dominating daily life.

"... if someone asked me anything [reference to sarcoma], I would say immediately ... You can talk about whatever you want but not about that... Whoever it is. I don't like to talk..." (Study 1).³⁹

Relational & System-Level Support – Not Facing Sarcoma Alone

Participants emphasised the importance of both personal and professional support in coping with sarcoma and navigating its uncertainty.

"Family is a big deal too...I came down for radiation everyday five days a week and I had a different driver every day, which was remarkable." (Study 23).⁴²

Beyond family, support from peers with sarcoma was highly valued, providing a level of understanding not found in family or general cancer groups.

"When you go to general cancer groups, people have got so many different experiences, whereas we're all sarcoma. Yes, we've all got, maybe, different types of sarcoma... but it's still sarcoma...Nobody's heard about it before they have it and we've got that in common. I find that just hugely beneficial." (Study 30).³⁴

Supportive relationships with healthcare professions were also central in providing reassurance, information, and continuity of care. Adaptation was described not only as an individual process, but also as something shaped by support from others and by interactions with healthcare systems.

"It makes you feel like they're just as invested in your health and your recovery as you are. So, it makes you feel better...[when talking about rehabilitation]." (Study 8).⁴³

Theme 5: What do People with Sarcoma Need?

Participants also described unmet needs across the trajectory, highlighting how adaptation could be hindered when timely diagnosis, clear information, and specialist, individualised care were not available across treatment, rehabilitation, and survivorship.

Diagnostic Improvement

Participants highlighted the need for faster, more reliable diagnostic pathways and greater awareness of sarcoma among both the public and healthcare professionals.

“Everything could have gone faster if people had been more aware that this could be sarcoma” (Study 33).²⁷

“the poor sister of cancers [sarcoma], like Cinderella in the fairytale, being the little one who got nothing” (Study 3).⁴⁴

Specialist, Individualised & Integrated Sarcoma Care across Treatment, Rehabilitation, and Survivorship

Participants strongly emphasised the need for specialist, coordinated, and individualised care throughout the sarcoma trajectory. Having confidence in a knowledgeable and experienced team was described as central to feeling safe during treatment.

“I had every faith in [surgeon’s name], he’s a sarcoma specialist. So, I actually had, immediately, confidence in, you know, the team that were going to be looking after me.” (Study 30).³⁴

In contrast, those who received care in non-specialist settings described feeling abandoned and uncertain about who was responsible for their treatment and recovery.

“I had been back to [residential location], no CNS [clinical nurse specialist], no nothing. GP said she’d never met a sarcoma patient before. People didn’t know what it was, so I felt like an orphan really....” (Study 30).³⁴

“People don’t know about sarcoma. Hospitals don’t, wherever I go...it’s not common and no one knows about sarcoma.” (Study 8).⁴³

Clear, consistent, and tailored information across all stages was repeatedly identified as a key need, particularly post-treatment, when many participants felt ill-prepared for recovery and rehabilitation.

"But for me, ... we spoke quite regularly about the surgery, but not after... And if you know what the impact is afterwards, then I would have wanted to know more, like...My knee will be taken out, I will get a new knee and what will happen then?" (Study 10).⁴⁵

Equally important was access to specialist and individualised rehabilitation care.

"For me, if the [care in the] rehabilitation center is how I experienced it, it is better to go home. It did not have any added value. (...)" (Study 10).⁴⁵

*"...she [healthcare professional] compared my amputation to some nerve damage she had in her hand...it was clear to me that she hadn't dealt with a sarcoma patient." (Study 20).*⁴⁶

These accounts suggest that psychosocial adaptation in sarcoma was shaped not only by the disruptions individuals faced, but also by the extent to which care systems were able to respond to their ongoing informational, rehabilitative, and supportive needs.

2.4 Discussion

This systematic review synthesised qualitative evidence on the psychosocial impact of sarcoma in adults, drawing on 40 qualitative studies of predominantly high methodological quality. Across studies, consistent findings strengthen confidence in the generalisability of the core themes at a conceptual level. The themes identified show how sarcoma is experienced as a cumulative and ongoing psychosocial disruption. This disruption often began early with prolonged and fragmented

diagnostic pathways, intensified through invasive treatment and difficult recovery, and extended into long-term changes in identity, embodiment, functioning, and social life. At the same time, individuals described actively adapting through self-management, meaning-making, selective information engagement, and support from others. This synthesis highlights adaptation as a dynamic process unfolding alongside persistent disruption and unmet needs across the sarcoma trajectory^{47,48}.

Across the synthesis, psychosocial impact unfolded along a trajectory that often began ‘in the dark’ (Theme 1). Diagnostic pathways were prolonged and fragmented, involving misattributed symptoms and delayed referrals, generating uncertainty and mistrust consistent with findings across other rare cancers ⁴⁷. Diagnostic delay functioned both as a temporal challenge and as an early psychosocial rupture, shaping fear and complicating individuals’ efforts to make sense of sarcoma from the outset ²⁸. These early disruptions appeared to set the tone for subsequent experiences, shaping how participants encountered treatment and later made sense of ongoing psychosocial change.

Treatment was experienced not as a resolution but as an ongoing threat (Theme 2), with multimodal treatment described as invasive physically and emotionally. Surgery, chemotherapy, and radiotherapy resulted in permanent bodily change and reduced independence, with pain, fatigue, scarring, and limb loss becoming enduring reminders of survival at a significant personal cost ^{5,41}. Recovery was rarely linear and instead represented continued vulnerability rather than closure ⁴⁹. The findings further suggest that delayed or disrupted rehabilitation may hinder adaptation, particularly where oncological priorities conflict with functional restoration. These tensions may be especially salient in sarcoma given the diversity of treatment

pathways and the prolonged demands of multimodal care ⁵⁰. In this way, treatment and recovery did not mark a transition out of disruption, but often deepened it, extending uncertainty and vulnerability into life beyond active care.

Post-treatment life was marked by enduring physical, psychological, and social change with many describing a sense of being ‘no longer the same’ (Theme 3). A central tension in this synthesis was a paradox of visibility and invisibility: although sarcoma is rare and poorly understood, its consequences were often highly visible through scars, prostheses, mobility aids, and functional limitations. Body image issues were therefore pronounced, contributing to shame and diminished confidence ^{33,36}. Functional impairment further disrupted identity by threatening independence and valued roles, including parenting, relationships, social activities and careers ^{31,39}. Inability to engage in childcare, household tasks, work, or previously valued physical activities appeared to intensify loss and was consistent with patterns associated with poorer psychosocial adjustment and quality of life ^{8,51}.

These disruptions were further compounded by social isolation, stigma, and persistent emotional distress. Across studies, a profound sense of ‘social disconnection’ became evident with participants frequently withdrawing from social situations due to both physical limitations, and because they felt misunderstood or reduced to their impairment. Emotional distress, often described as an ‘emotional cost of sarcoma’, encompassed fear of recurrence (FoR), anxiety, and low mood with FoR emerging as particularly salient and intrusive, echoing wider evidence identifying it as a major concern for people living with sarcoma ⁵². This synthesis demonstrates how distress is sustained through the intersection of lasting physical change, social misrecognition and stigma, and the ongoing effort to manage how

sarcoma is seen by others. As such, adaptation appeared to involve ongoing efforts to manage not only functional and emotional consequences, but also the social meaning of living in a changed body. Comparative evidence suggests that these interlinked challenges particularly those related to rarity, disability, and visible bodily change following intensive treatment, may be especially salient in sarcoma ^{7,47}.

Despite these profound disruptions, individuals identified ‘what helped along the way’ (Theme 4). Adaptation emerged as a response to cumulative disruption and was described as a dynamic, non-linear process involving active self-management (e.g., physical activity, lifestyle adjustment) alongside cognitive strategies such as reframing, acceptance, and meaning making. These approaches appeared to support agency amid ongoing uncertainty, with distress and adaptation often co-existing. For some meaning-making involved recognising personal strength or changed priorities, aligning with broader evidence on post-traumatic growth (PTG) in cancer populations ^{53,54}.

While there is currently no PTG research in sarcoma, previous sarcoma reviews suggest that psychosocial wellbeing can co-exist with substantial functional disruption, supporting the view that positive change may occur alongside ongoing impairment rather than following its resolution ⁶. Adaptive variability was also reflected in patterns of information engagement, ranging from active information-seeking to deliberately ‘choosing not to know’, consistent with evidence that selective engagement can be adaptive when aligned with coping preferences ⁵⁵. Adaptation was further shaped by ‘relational and system-level support’. Family support, peer connection, and continuity with knowledgeable and compassionate healthcare professionals appeared to facilitate coping and meaning-making, while

difficulties navigating fragmented services often undermined these processes, consistent with prior sarcoma evidence ^{56,57}. These findings suggest that adaptation was not solely an individual process, but one shaped by relational and healthcare contexts across the illness trajectory. For adults with sarcoma, adaptation appeared to depend not only on personal coping preferences and resilience, but also on the availability of social support, continuity of care, and access to sarcoma-informed healthcare professionals.

Finally, participants consistently reported unmet needs across the sarcoma trajectory (Theme 5), particularly regarding timely diagnosis and access to specialist, integrated care that supports recovery, gaps repeatedly highlighted in previous reviews ^{6,12}. Early diagnostic experiences shaped subsequent care, with specialist sarcoma support fostering trust, while fragmented diagnostic experiences reinforced uncertainty and abandonment, consistent with evidence that diagnostic delays can carry enduring psychosocial consequences in sarcoma ⁵⁷. Many participants also felt ill-prepared for recovery, reporting limited information about functional consequences and poor access to sarcoma-informed rehabilitation. Rehabilitation in sarcoma is inherently complex and protracted, shaped by tumour heterogeneity, treatment type, and competing clinical priorities ⁵⁸. These findings highlight the importance of coordinated, sarcoma-centred care to support longer-term adaptation and quality of life. Moreover, these unmet needs help explain why adaptation was more difficult for some participants than others.

2.4.1 Clinical Implications

Findings from this synthesis indicate that adults with sarcoma may experience substantial psychosocial disruption linked to visible bodily change, reduced function, altered identity, and difficulty adjusting to life after treatment. If adaptation is understood as an ongoing process unfolding across the sarcoma trajectory, these findings highlight the need for assessment and support that extend beyond acute treatment and attend to emotional distress, functional, relational, and identity-related consequences. The findings also support the need for sarcoma-informed, individualised including early rehabilitation planning and prehabilitation where appropriate, to prepare individuals for anticipated functional change and reduce long-term burden ^{58,59}.

Across the reviewed studies, clear and ongoing communication with sarcoma-informed professionals was described as central to psychosocial wellbeing and adaptation, highlighting the importance of continuity and sensitivity across the care trajectory. However, given the rarity of sarcoma and the limited number of specialist centres, access to specialist care is often constrained. The findings therefore point to both the value of specialist input where available, and also to the importance of improving sarcoma awareness among GPs, primary care clinicians, and non-specialist teams to support earlier recognition, appropriate referral, and more informed care. The pervasive uncertainty described across diagnosis, treatment, and survivorship also suggests a need for psychosocial support that extends beyond acute treatment. Although sarcoma-specific intervention evidence remains limited, approaches that support meaning-making, acceptance, and psychological flexibility may be especially relevant for addressing uncertainty, identity disruption, emotional distress, and fear of recurrence within coordinated sarcoma care. In this regard,

emerging sarcoma-specific evidence ⁵² suggest that greater psychological flexibility is associated with lower fear of recurrence, highlighting its potential value as a therapeutic target in supporting adjustment and wellbeing.

2.4.2 *Strengths & Limitations*

A key strength of this review is that it synthesised a wide and contemporary body of qualitative research to provide a coherent account of adult psychosocial experiences across the sarcoma trajectory, with most included studies rated as high quality. Analytic depth was strengthened through reflexive team interpretation drawing on expertise in sarcoma care, psycho-oncology, and lived experience. The present synthesis also extends on prior syntheses findings ^{11,12} by focusing exclusively on adults, incorporating recently published studies, and conceptualising adaptation as an ongoing process across the illness trajectory. Rather than treating psychological, social, and functional impact as separate domains, this synthesis highlights how these experiences interact within a broader psychosocial adjustment process, with continuity of sarcoma-informed care and rehabilitation emerging as central to adaptation.

However, several limitations should be acknowledged. Many studies offered limited reflection on how researcher position and interaction may have shaped data generation and interpretation. In addition, most studies were conducted in Western countries and within specialist and centralised sarcoma services and predominantly reflected post-treatment experiences. As such, the findings may underrepresent experiences of individuals receiving care in non-specialist settings, during earlier diagnostic phases, or in palliative contexts. Additionally, the heterogeneity in sarcoma subtype, stage, and treatment pathways may obscure subgroup-specific

experiences. Age-related differences may also have been obscured. This synthesis specifically aimed to explore the psychosocial impact of sarcoma in adulthood and included studies with participants across a wide adult age range. However, adulthood is not a homogenous category, and experiences may differ across younger, middle-aged, and older adults. Older age may be particularly important to consider in relation to self-image, as bodily change, altered function, disability, amputation, or dependency may carry different meanings in later life. Finally, excluding GIST and Kaposi sarcoma narrows the generalisability of the findings to the sarcoma groups included in this synthesis, as psychosocial experiences in GIST and Kaposi sarcoma may differ due to their distinct clinical and treatment contexts.

2.4.3 *Future Directions*

Future research should examine how psychosocial needs in sarcoma evolve over time through longitudinal qualitative designs, with particular attention to active treatment, palliative care, surveillance, and recurrence. Greater representation of older adults, ethnic minority groups, and those treated outside specialist centres is needed to address gaps in the evidence base and potential disparities in care. Future studies should also explore how age-related differences across adulthood may shape psychosocial impact, particularly in relation to self-image, bodily change, functional loss, and adaptation. Finally, research evaluating the implementation of sarcoma-specific rehabilitation and integrated psycho-oncology interventions would support translation into practice.

2.4.4 *Conclusion*

This review shows that sarcoma involves profound and enduring psychosocial disruption alongside ongoing efforts to adapt. The findings suggest that

adaptation is best understood as a dynamic process unfolding across diagnosis, treatment, recovery, and survivorship, rather than as a fixed endpoint. Experiences of uncertainty, embodied change, and identity disruption are shaped by relational and healthcare contexts, highlighting the need for coordinated, specialist care that supports meaning-making, rehabilitation, and longer-term psychosocial adaptation.

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Chapter 3: Empirical Study – Study 2

Psychosocial Impact of Sarcoma: Factors Influencing Distress & Wellbeing

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Abstract

Background: Sarcoma is a rare and heterogeneous cancer type characterised by complex diagnostic pathways, diverse treatments, and long-term physical consequences. Compared with more common malignancies, individuals with sarcoma experience heightened psychosocial distress and reduced psychosocial wellbeing, often driven by delayed diagnosis, uncertainty, social isolation, visible bodily change, and functional impairment. Psychosocial factors in sarcoma remain poorly understood. Given the increasing number of sarcoma survivors and the lifelong disability many individuals face, there is a need to identify factors influencing psychosocial distress and wellbeing to inform sarcoma care.

Methods: A cross-sectional survey was completed by 163 adults with sarcoma across disease stages. Measures assessed anxiety and depression, body image distress, self-compassion, perceived social support, and pain interference. Descriptive analyses, correlational analyses, and hierarchical multiple regression analyses were conducted to examine psychosocial predictors of anxiety and depression.

Results: Clinically significant distress was common, with approximately two-thirds of participants reporting elevated anxiety and nearly half reporting elevated depression. Psychosocial variables explained 32% of the variance in anxiety and 47.5% in depression, with demographic and treatment factors contributing minimal additional variance. Lower self-compassion and higher pain interference were the strongest predictors of both **anxiety and depression**. Body image distress independently predicted depression, while perceived social support was not a significant predictor of either depressive or anxiety symptoms.

Conclusions: Psychosocial distress is prevalent among adults with sarcoma and appears primarily driven by modifiable psychosocial factors. Findings highlight the importance of integrating psychosocial assessment and targeted interventions into sarcoma-specific models of care.

Key words: Sarcoma, Oncology, Risk Factors, Protective Factors, Psychosocial Distress

3.1 Background

Sarcoma is a rare and highly heterogeneous group of malignancies that poses distinctive clinical and psychosocial challenges. Sarcomas can arise in bone, cartilage, or soft-tissues and encompass over 70 distinct histological subtypes, resulting in marked variability in disease presentation, treatment pathways, and outcomes ¹. Because sarcoma accounts for approximately 1% of all adult cancers, its rarity contributes to diagnostic complexity, limited public and professional awareness, and fragmented care pathways ².

Beyond clinical complexity, sarcoma is associated with substantial psychosocial burden, with elevated levels of psychological distress across the cancer trajectory, including anxiety, depression, fear of recurrence, and reduced quality of life ^{3,4}. Individuals with sarcoma often experience enduring physical impairment, pain, fatigue and visible bodily changes, contributing to body-image issues, mobility limitations, and disruption to social functioning, relationships, and emotional wellbeing ^{3,5,6}. The rarity of sarcoma may further exacerbate these difficulties, contributing to uncertainty and isolation through limited access to tailored information and support ². While the psychosocial burden associated with sarcoma is increasingly recognised, empirical research examining factors associated with psychosocial distress and wellbeing remains relatively underdeveloped.

A systematic review by Franzoi et al.⁷ synthesised evidence on the psychosocial impact of sarcoma and identified high levels of anxiety and depression, social withdrawal, and helplessness. It highlighted substantial heterogeneity across the literature, with findings varying according to treatment type, disease phase, sarcoma subtype, age, gender, and tumour site. Variation in study methods and outcome measures further limited firm conclusions about how psychosocial

difficulties are experienced across sarcoma groups. Franzoi et al.⁷ therefore highlighted the need for further research examining how psychosocial impact differs across patients to better inform tailored psychosocial assessment and support in sarcoma care.

Additionally, qualitative research has begun to explore the lived experience of sarcoma. These studies consistently show that psychosocial challenges extend beyond anxiety and depression to include functional loss, altered body image, social disruption, stigma, and identity loss^{8,9}. Kosir et al.¹⁰ conceptualised psychosocial adaptation in sarcoma as a dynamic and interconnected process, with both protective factors (e.g., supportive relationships, adaptive coping) and risk factors (e.g., body image issues, pain, social withdrawal) that shaped their wellbeing.

Evidence from wider psycho-oncology literature suggests that psychosocial wellbeing is shaped by the interplay of physical and psychosocial factors, with symptom burden and pain being associated with higher distress, and social support acting as a protective factor against anxiety and depression¹¹. Other factors including body image concerns¹² and self-compassion¹³ have also emerged as potential risk and protective factors, respectively. Within sarcoma-specific literature, previous studies have shown that anxiety and depression may vary according to demographic and clinical factors such as disease phase, social support, coping processes, pain, and cancer-related shame^{4,14–16}. More recently, Robinson et al.¹⁷ examined factors associated with depressive symptoms in adults with sarcoma, identifying younger age, lower household income, lower emotional support, and reduced exercise as significant factors. These findings are particularly relevant in sarcoma, where illness experience may differ from that of more common malignancies because of rarity, prolonged treatment pathways, functional limitations,

and body-altering interventions such as amputation. However, research in sarcoma remains limited in its exploration of the broader psychosocial factors that may shape distress and wellbeing, in particular self-compassion and body-image distress.

The importance of examining the predictors of distress and wellbeing in sarcoma is reflected in current psycho-oncology guidelines and service frameworks. In Ireland, the Model of Care for Psycho-Oncology ¹⁸ emphasises the need for tailored, evidence-based psychosocial care, and a similar emphasis is evident internationally in the National Comprehensive Cancer Network 2025 in USA ¹⁹, and the Australian Cancer Plan 2023 ²⁰. Although psychosocial interventions such as cognitive behavioural, acceptance-based, mindfulness-based, compassion-focused, psychoeducational, and relaxation approaches have shown benefit in oncology more broadly, this evidence is drawn mainly from mixed cancer samples and more common cancers such as breast and colorectal cancer, rather than sarcoma-specific populations ^{21,22}. Accordingly, their effectiveness in sarcoma populations remains less clear. Sarcoma-focused literature continues to highlight a lack of targeted psychosocial care models for this group ^{1,7} indicating need for research and care approaches tailored to people with sarcoma. In the present study, the terms “psychosocial wellbeing” and “psychosocial distress” are used as umbrella terms to refer to emotional and social functioning following diagnosis, incorporating mood (anxiety and depression), pain interference, body-image, self-compassion and perceived social support ^{23,24}.

The present study aimed to examine psychosocial factors associated with psychological distress and wellbeing in adults diagnosed with sarcoma. Based on the literature to date, we hypothesized that:

1. Anxiety and depressive symptoms would be elevated compared with normative populations.
2. Self-compassion, body image distress, perceived social support, and pain interference would be associated with anxiety and depressive symptoms.
3. Anxiety and depressive symptoms would be predicted by self-compassion, body image distress, perceived social support, and pain interference, as well as by demographic and clinical characteristics.

3.2 Methods

3.2.1 Study Design

A cross-sectional survey design was used. Ethical approval was obtained from the Hospital Ethics Board and from the relevant University Ethics Board. Participation was voluntary and anonymous, and all participants provided informed consent before survey completion. This study was conducted and reported in accordance with the STROBE guidelines for cross-sectional studies ²⁵.

3.2.2 Participants and Recruitment

Participants were recruited using in-clinic and online methods. In-clinic recruitment took place at the nationally designated centre for sarcoma care in Ireland, through the weekly sarcoma clinic. Clinicians identified eligible patients during routine follow-up appointments. Online recruitment was facilitated through St. Vincent's Sarcoma Ireland Network (SSIN), Sarcoma Cancer Ireland (SCI), Sarcoma UK, and other sarcoma related social media and peer-support communities via Facebook, Reddit, and LinkedIn. Participants self-selected by accessing the Qualtrics survey link. Snowball sampling was also used.

Eligibility criteria included (1) a current or past diagnosis of sarcoma, (2) ≥ 18 years, and (3) sufficient English proficiency to complete the survey. To ensure a

clearly defined study population, Gastrointestinal Stromal Tumours (GIST) and Kaposi sarcoma were excluded due to their distinct treatment pathways and psychosocial challenges, including long-term targeted therapy in GIST ²⁶ and virus-related stigma and care pathways in Kaposi sarcoma ²⁷. Individuals with significant cognitive or communication impairment preventing survey completion were excluded. In clinic, this was determined by clinician judgement; online, eligibility depended on participants being able to complete the survey. PPI involvement included a sarcoma patient reviewing the survey before data collection to ensure clarity, accessibility, and acceptability.

3.2.3 Procedure

Patients approached in clinic received hard-copy study materials, provided written consent, and could complete the survey in hard-copy or online. The study was also advertised in the clinic waiting room using leaflets and a QR code linking to the online survey. Online participants viewed the same materials electronically, provided digital consent, and completed the survey via Qualtrics (see Supplementary Materials 1-3).

3.2.4 Measures

1.1.1.1 Demographic and Clinical Characteristics

Demographic characteristics included age, gender, education, ethnicity, employment status, and country of residence. Clinical characteristics included time since diagnosis, sarcoma type, sarcoma location, treatment status, and treatment type. Validated measures were used to reduce measurement bias.

1.1.1.1 Hospital Anxiety and Depression Scale (HADS)

HADS was used ²⁸ to assess anxiety and depressive symptoms, a scale commonly used in sarcoma research ¹⁴⁻¹⁶. It comprises two 7-item subscales scored

from 0 to 21, with higher scores indicating greater symptomatology. A clinical cut-off of ≥ 8 threshold was used to indicate elevated anxiety or depressive symptoms; scores of 0–7 were considered normal, 8–10 mild, 11–15 moderate, and 16–21 severe. Cronbach's alpha value was $\alpha = .84$ for depression and $\alpha = .86$ for anxiety.

1.1.1.1 *Patient-Reported Outcomes Measurement Pain Interference Short Form 6b (PROMIS-PI)*

PROMIS-PI scale assessed the degree to which pain interfered with engagement in social, cognitive, emotional, physical, and recreational activities over the past 7 days²⁹. Scores ranged from 0 to 4 with items being converted to T-scores (mean = 50, SD = 10), where higher scores indicate greater pain interference. Scores of ≤ 55 were considered within normal limits, 55–60 mild, 60–70 moderate, and > 70 severe. It has been validated for use with sarcoma³⁰. Cronbach's alpha value was $\alpha = .96$.

1.1.1.1 *Self-Compassion Scale Short Form (SCS-SF)*

The 12-item SCS-SF assessed self-compassion³¹, a measure widely used in oncology cohorts¹³. Items are rated on a 5-point scale, with higher mean scores indicating greater self-compassion. Scores were categorised as low (1.00–2.49), moderate (2.50–3.50), and high (3.51–5.00). The measure reflects six components of self-compassion: self-kindness, self-judgment, common humanity, isolation, mindfulness, and overidentification. These can also be considered in terms of compassionate self-responding (self-kindness, common humanity, mindfulness) and uncompassionate self-responding (self-judgment/self-criticism, isolation, overidentification), in line with growing evidence for a broader two-factor structure³². Cronbach's alpha value was $\alpha = .88$ for the total scale, $\alpha = .81$ for compassionate self-responding, and $\alpha = .84$ for uncompassionate self-responding.

1.1.1.1 *Body Image Scale (BIS)*

The 10-item BIS assessed body image distress³³. It has been used in sarcoma studies⁶. Participants rate their agreement with items on a four-point Likert scale (0= ‘not at all’ to 3= ‘very much’). Items are rated from 0 to 3, yielding total scores from 0 to 30, with higher scores indicating greater distress. A cut-off of ≥ 10 indicated clinically relevant body image concerns. Cronbach’s alpha was $\alpha = .93$.

1.1.1.1 *Multidimensional Scale of Perceived Social Support (MSPSS)*

The MSPSS is a 12-item measure of perceived support from family, friends, and a significant other³⁴. Items are rated on a 7-point scale, with higher scores indicating greater perceived social support. Mean scores of 1–2.9 indicate low support, 3–5 moderate support, and 5.1–7 high support. It has been widely used in oncology settings³⁵. Cronbach’s alpha was $\alpha = .94$.

3.2.5 *Analysis*

A priori power analysis indicated that, for a multiple regression model with four predictors, a minimum sample of 50 participants was required to detect an effect size of .30 with 80% power at $\alpha = .05$. All statistical analyses were conducted using IBM SPSS Statistics (Version 31.0). All tests were two-tailed with statistical significance set at $\alpha = .05$.

Missing data were handled using listwise deletion for multivariable analyses. Assumptions of normality, linearity, homoscedasticity, and multicollinearity were examined and met. Descriptive statistics summarised demographic, clinical, and psychosocial characteristics, and those scoring in the clinically elevated range were calculated using established cut-offs. Pearson correlations examined associations among psychosocial variables.

Pearson correlations examined associations between continuous variables (demographic, clinical characteristics and psychosocial variables), independent-samples t-tests were used for binary variables, and one-way ANOVAs for categorical variables with more than two groups. Variables significantly associated with anxiety and/or depression were retained as covariates. Two hierarchical multiple regression models were conducted to examine predictors of anxiety and depression. Covariates were entered in Block 1 and psychosocial variables (pain interference, body image distress, perceived social support, and self-compassion) in Block 2.

3.3 Results

A total of 164 individuals completed the survey. Missing data were minimal (<5% per variable).

3.3.1 Participant Characteristics

Sociodemographic and clinical characteristics are presented in Table 5. The sample was predominantly female and white, with participants residing primarily in Ireland, UK, and US. The majority were aged between 30–49 years or 50–64 years, had tertiary-level education, and were employed or retired. Most had soft-tissue sarcoma followed by bone sarcoma. Extremities (arms, legs) and trunk were the most common tumour sites. At the time of survey completion, some were undergoing treatment, some had completed treatment, and some reported no evidence of disease. The majority had received multimodal treatment.

Table 5*Socio-Demographic and Clinical Characteristics of the Sample (N = 164)*

Variable	Category	n (%) or M (SD)
Age (years)	—	48.91 (14.35), range 18–82
Gender identity	Male	34 (21)
	Female	128 (78)
	Non-binary/Third gender	1 (0.6)
	Prefer not to say	1 (0.6)
Education	NFQ ($\leq$ Level 5)	38 (23)
	NFQ (Level 6 and 7)	43 (26)
	NFQ ($\geq$ Level 8)	83 (51)
Employment status	Employed	81 (49)
	Unemployed	32 (20)
	Retired	33 (20)
	Illness-related absence	18 (11)
Ethnic background	White-Irish	65 (40)
	White-British	39 (24)
	White–Other	45 (28)
	Asian background	6 (4)
	Black background	1 (0.6)
	Other ethnic background	5 (3)
	Prefer not to say	2 (1)
Country of residence	Ireland	64 (39)
	United Kingdom	43 (26)
	United States	35 (21)
	Other countries	22 (13)
Sarcoma group	Soft tissue sarcoma (STS)	121 (74)
	Bone sarcoma (BS)	35 (21)
	Mixed STS & BS	2 (1)

Variable	Category	n (%) or M (SD)
Primary tumour location	Sarcoma NOS	6 (4)
	Extremities	81 (49)
	Trunk	56 (34)
	Pelvis	16 (10)
	Head & neck	5 (3)
	Other/multisite	6 (4)
Current treatment status	Currently undergoing treatment	46 (28)
	Completed treatment	45 (27)
	Not yet started	2 (1)
	Palliative care	12 (7)
	Watch and wait	16 (10)
	No evidence of disease	43 (26)
Time since diagnosis (years)	—	6.4, range 0.2–46.6
Treatment intensity	None	2 (1)
	Single treatment	52 (32)
	Multimodal treatment	110 (67)

Note. M = mean; SD = standard deviation, NFQ = National Framework of Qualifications

3.3.2 Descriptive Statistics and Clinical Thresholds

Descriptive statistics and clinical thresholds are presented in Table 6. Using established cut-offs (≥ 8), 66.5% of participants reported clinically significant anxiety symptoms and 46.3% clinically significant depressive symptoms. Moderate-to-severe anxiety symptoms were observed in 39% of participants, while 23% reported moderate-to-severe depressive symptoms. Body image distress was in the clinical range for 61.9% of participants. Self-compassion scores were distributed across low (26.3%), moderate (50.6%), and high (23.1%) categories. Perceived social support was generally high, with 70.6% reporting high support and 3.8% low support.

PROMIS Pain Interference T-scores were elevated relative to population norms ($M = 60.17$, $SD = 9.69$), with 54.8% reporting moderate-to-severe interference. In line with hypotheses, the sample means indicated high levels of anxiety and depressive symptoms, substantial body image distress, and high levels of pain interference, while perceived social support was generally high.

Table 6

Descriptive Statistics and Clinical Threshold Classifications for Psychosocial Measures

Measure	N	Range	M	SD	Category / threshold	n (%)
HADS–Anxiety	164	0–21	9.57	4.35	Normal (0–7)	55 (33.5)
					Borderline/Mild (8–10)	45 (27.4)
					Moderate (11–14)	42 (25.6)
					Severe (15–21)	22 (13.4)
					Above clinical cut-off (≥ 8)	109 (66.5)
HADS–Depression	164	0–21	7.24	4.29	Normal (0–7)	88 (53.7)
					Borderline/Mild (8–10)	38 (23.2)
					Moderate (11–14)	34 (20.7)
					Severe (15–21)	4 (2.4)
					Above clinical cut-off (≥ 8)	76 (46.3)
Body Image Scale (BIS)	160	0–30	14.49	8.75	Below clinical cut-off (< 10)	61 (38.1)
					Above clinical cut-off (≥ 10)	99 (61.9)
Self-Compassion Scale–SF	160	1–5	2.97	0.79	Low	42 (26.3)
					Moderate	81 (50.6)
					High	37 (23.1)
MSPSS (Total)	160	1–7	5.52	1.23	Low support	6 (3.8)

					Moderate support	41 (25.6)
					High support	113 (70.6)
PROMIS Pain Interference (T-score)	159	41–78 †	60.17	9.69		
					Within normal limits (≤ 55)	45 (28.3)
					Mild (55–60)	27 (17.0)
					Moderate (60–70)	64 (40.3)
					Severe (> 70)	23 (14.5)

Note. HADS = Hospital Anxiety and Depression Scale; BIS = Body Image Scale; SCS-SF = Self-Compassion Scale-Short Form; MSPSS = Multidimensional Scale of Perceived Social Support. Percentages reflect valid cases only. † PROMIS T-scores are standardised (M = 50, SD = 10).

3.3.3 Associations and Group Differences in Anxiety and Depression across Demographic and Clinical Variables

Correlation analyses showed that younger age was associated with higher anxiety, $r = -.29$, $p < .001$, but not depression, $r = -.13$, $p = .110$. Time since diagnosis and treatment amount/intensity were not significantly associated with either outcome (see Table 7).

Independent-samples t -tests and one-way ANOVAs showed significant group differences in anxiety by education level, $F(2, 161) = 6.97$, $p = .001$, with participants in the NFQ Level 6 and 7 group reporting lower anxiety than those in the NFQ Level ≤ 5 and NFQ Level ≥ 8 . Depression did not differ significantly by education level, $F(2, 161) = 1.72$, $p = .18$. There were also significant group differences by employment status for anxiety, $F(3, 160) = 2.95$, $p < .05$, and depression, $F(3, 160) = 3.50$, $p < .05$. Employed participants reported higher anxiety than retired participants, while post-hoc comparisons did not identify significant pairwise differences for depression. Primary tumour location differed significantly

for depression, $F(5, 158) = 2.34, p < .05$, but not anxiety, $F(5, 158) = 1.52, p = .188$. Participants in the ‘Other’ tumour location group reported higher depression scores than those with tumours in the extremities, trunk, or pelvis. No significant group differences in anxiety or depression were found for gender, ethnicity, country of residence, sarcoma subtype, and treatment intensity ($p > .05$; see Supplementary Table 1a and Table 1b).

Based on these analyses, age, education, and employment status were retained as covariates in the anxiety model. Employment status and tumour location were retained in the depression model, and age was also included on the basis of prior literature.

Table 7

Bivariate correlations of study variables.

Variable	1	2	3	4	5	6	7	8
1. Age	—							
2. Time since diagnosis	.09	—						
3. Treatment	−.18*	.25**	—					
4. HADS–Anxiety	−.29**	−.10	.06	—				
5. HADS–Depression	−.13	−.02	−.01	.57**	—			
6. Body Image (BIS)	−.28**	.22**	.18*	.35**	.45**	—		
7. Self-Compassion	.23**	.00	−.00	−.59**	−.56**	−.44**	—	
8. Pain Interference	.00	−.01	.03	.26**	.46**	.30**	−.17*	—
9. Social Support (MSPSS)	−.03	−.15	−.07	.00	−.12	−.18*	.20*	−.05

Note. Values represent Pearson correlations (two-tailed).

N ranges from 155 to 164 due to missing data across measures. * $p < .05$. ** $p < .01$.

3.3.4 *Associations Between Psychosocial Variables & Distress*

Correlations among psychosocial variables are presented in Table 3. Higher anxiety symptoms were associated with lower self-compassion, greater pain interference, and greater body image distress. Higher depressive symptoms were associated with lower self-compassion, greater pain interference, and greater body image distress. Perceived social support was not significantly associated with anxiety symptoms or depressive symptoms.

Greater body image distress was also associated with lower self-compassion, greater pain interference, and lower perceived social support. Higher self-compassion was associated with higher perceived social support, and lower pain interference.

3.3.5 *Predictors of Anxiety and Depression*

Hierarchical multiple regression analyses were conducted to examine predictors of anxiety and depression. Results are presented in Tables 8 and 9.

1.1.1.1 *Anxiety*

For anxiety, Block 1 covariates (age, education, employment status) accounted for 10% of the variance, $F(3,151) = 5.47, p < .001$. Addition of psychosocial variables (pain interference, body image distress, perceived social support, and self-compassion) in Block 2 significantly improved model fit, explaining an additional 33% of the variance in anxiety ($R^2 \text{ change} = .33, p < .001$). The final model was significant, $F(7,147) = 16.00, p < .001$, accounting for 43% of the variance ($\text{Adjusted } R^2 = .41$). Anxiety symptoms were independently predicted by lower self-compassion ($\beta = -.53, p < .001$), greater pain interference ($\beta = .18, p$

$< .05$), and younger age ($\beta = -.16, p < .05$), whereas body image distress and perceived social support were not significant.

Table 8

Hierarchical Multiple Regression Predicting Anxiety (HADS-A)

Predictor	B	SE B	β	p
Age	-0.05	0.02	-.16	$< .05^*$
Education	0.72	0.34	.14	.06
Employment	0.00	0.28	.00	.99
Body Image Distress (BIS)	0.02	0.04	.04	.59
Self-Compassion	-2.93	0.39	-.53	$< .001^{**}$
Social Support (MSPSS)	0.41	0.23	.12	.08
Pain Interference	0.08	0.03	.18	$< .05^*$

Model Summary

Model	R	R ²	Adjusted R ²	F	p
Block 1 (Age, Education, Employment)	.31	.10	.08	5.47	.001**
Block 2 (Full Model)	.66	.43	.41	16.00	$< .001^{**}$

R² change (Block 2) = .33, $p < .001$

Note. N = 155. Dependent variable = HADS Anxiety total score. * $p < .05$. ** $p < .01$.

1.1.1.1 Depression

For depression, Block 1 covariates (age, employment status, tumour location) accounted for 4% of the variance and did not significantly predict depression symptoms, $F(3,151) = 2.11, p = .10$. Addition of psychosocial variables in Block 2 significantly improved the model fit, explaining an additional 45% of variance (R^2 change = .45, $p < .001$). The final model was significant, $F(7,147) = 19.78, p <$

.001, accounting for 49% of the variance in depression (*Adjusted R*² = .46).

Depressive symptoms were independently predicted by higher pain interference ($\beta = .35, p < .001$), lower self-compassion ($\beta = -.44, p < .001$), and greater body image distress ($\beta = .16, p < .05$), whereas perceived social support was not significant.

Table 9

Hierarchical Multiple Regression Predicting Depression (HADS-D)

Predictor	B	SE B	β	p
Age	-0.01	0.02	-.02	.77
Employment status	0.38	0.26	.09	.15
Tumour Location	0.23	0.22	.06	.31
Body Image Distress (BIS)	0.08	0.04	.16	< .05*
Self-Compassion	-2.37	0.37	-.44	< .001**
Social Support (MSPSS)	0.08	0.22	.02	.70
Pain Interference	0.16	0.03	.35	< .001**

Model Summary

Model	R	R ²	Adjusted R ²	F	p
Block 1 (Age, Employment, Tumour Location)	.20	.04	.02	2.11	.10
Block 2 (Full Model)	.70	.49	.46	19.78	< .001**

R² change (Block 2) = .45, p < .001

Note. N = 155. Dependent variable = HADS Depression total score. * p < .05. ** p < .01.

3.3.6 Exploratory Analyses of Self-Compassion Subscales

Given that total self-compassion emerged as the strongest independent predictor of anxiety and depression, exploratory analyses examined associations between SCS-SF subscales and anxiety and depression (see Supplementary Table 2).

The *uncompassionate self-responding* components showed the strongest associations with distress. Higher *over-identification* was associated with higher anxiety symptoms ($r = .62, p < .001$) and higher depression symptoms ($r = .52, p < .001$). Higher *isolation* and higher *self-judgment* were also moderately associated with higher anxiety and depression symptoms. In contrast, the *compassionate self-responding* components showed that higher *self-kindness* and higher *mindfulness* were associated with lower anxiety and lower depression symptoms.

3.4 Discussion

To our knowledge, this is the first study to examine psychosocial factors associated with psychosocial distress and wellbeing in adults with sarcoma. The findings highlight a substantial burden of distress, with high levels of anxiety and depressive symptoms, body image distress and pain interference, reflecting the broader psychosocial and physical impact of sarcoma and its treatment. Psychosocial factors explained substantial variance in distress beyond demographic and clinical characteristics, with lower self-compassion and greater pain interference predicting both anxiety and depressive symptoms, and body image distress additionally predicting depressive symptoms. Overall, the findings suggest that potentially modifiable psychosocial factors may play an important role in shaping distress and adjustment among individuals with sarcoma.

The present study found high levels of distress, with 66% scoring in the clinical range for anxiety symptoms and 46% for depressive symptoms. These figures included both mild and moderate-severe symptom levels; 27% and 39% for anxiety symptoms and 23% and 23% for depressive symptoms, respectively. This is consistent with evidence that distress in sarcoma is common, though estimates vary. Franzoi et al.⁷ reported wide prevalence ranges for anxiety (21%–100%) and depression (6.6%–88%) across sarcoma cohorts, reflecting heterogeneity in samples, measures, and timing of assessment. When compared with sarcoma studies using the HADS, the moderate-to-severe rates (≥ 11) in the present study still appear relatively high. For example, Paredes et al.¹⁴ used a cut-off of 11 and above on HADS and reported anxiety rates of 21% to 29% and depression rates of 6% to 19%, while Paredes et al.¹⁵, using the same cut-off of 11, found that 25% of patients remained in the clinical range for anxiety and 11% for depression over time. In the current study, distress also appeared higher than pooled estimates across broader oncology populations, where³⁶, drawing on studies that used both the HADS and PHQ measures, reported pooled prevalence estimates of approximately 30% for anxiety and 33% for depression across cancer populations. This suggests that adults with sarcoma may experience high levels of psychological morbidity, especially anxiety, relative to broader oncology populations, although methodological differences across studies should be considered.

Several factors may help explain why distress levels were relatively high in the present study. First, Franzoi et al.⁷ highlighted that psychosocial outcomes in sarcoma may vary according to demographic and clinical factors. In the present study, however, anxiety and depression did not differ significantly by most clinical characteristics examined, including sarcoma subtype, tumour location, treatment

status, and treatment intensity or treatment type, suggesting that distress was evident across the cohort rather than in particular clinical subgroups. Younger age was the main exception, as it was associated with higher anxiety, which is broadly consistent with previous sarcoma and oncology literature ^{7,15,37}, although Robinson et al.¹⁷ found younger age to be associated with depressive symptoms in sarcoma. Younger age may therefore indicate a broader vulnerability to the developmental, occupational, relational, and future-oriented disruptions imposed by sarcoma. Finally, direct comparison across sarcoma studies is limited by heterogeneity in both the measures used to assess distress and the disease stages at which patients were assessed. For example, ³⁷ used the DASS-21 in sarcoma survivors whereas ³⁸ used the PHQ-9 and GAD-7 in mixed phases: such differences in screening tools, scoring frameworks, and time of assessment make direct comparison with the present findings difficult.

Body image distress and pain interference were also highly prevalent in this study. Body image distress was reported by 62% of participants, higher than the approximate 40% reported by Wei et al.⁶ in young adult long-term sarcoma survivors using the same measure and cut-off, and higher than rates reported in broader oncology studies using the BIS in patients treated for head and neck cancer and breast cancer ^{39,40}. This may partly reflect the mixed treatment phases represented in the current sample, where treatment-related bodily changes may have been relatively recent for some participants. Body image distress remains underexplored in sarcoma, but the elevated levels observed here are consistent with the significant impact that sarcoma treatment can have on appearance, functioning, and adjustment to bodily change ^{7,37}. Pain interference was also elevated in this study, with over half of participants reporting moderate-to-severe levels. Persistent pain is commonly

reported in sarcoma and broader oncology populations and is associated with reduced quality of life and psychological distress^{36,37}.

Psychosocial factors accounted for substantial variance in distress, beyond demographic and clinical covariates. Lower self-compassion and greater pain interference were associated with higher anxiety, while greater pain interference, lower self-compassion, and higher body image distress were associated with higher depressive symptoms. These findings suggest that distress in sarcoma is shaped not only by demographic or disease-related factors, but also by potentially modifiable psychological and functional processes. Prior sarcoma research likewise indicated that psychological processes matter, with greater denial and less humour associated with higher anxiety and depression¹⁵. For depression in particular, the present findings suggest that it may be more closely linked to the combined impact of pain-related disruption, negative self-evaluation, and body-related concerns. The association between pain interference and depressive symptoms is also consistent with evidence linking pain-related functional impairment to poorer psychological wellbeing in sarcoma and wider oncology populations^{4,11,36}. This was one of the most important findings of the study, suggesting that psychosocial factors were highly relevant to distress in this cohort.

Self-compassion emerged as the strongest predictor of both anxiety and depression, consistent with wider psycho-oncology research linking greater self-compassion to better adjustment¹³. In the present study, anxiety and depressive symptoms were most strongly associated with *uncompassionate self-responding*, particularly over-identification and isolation, while *compassionate self-responding* showed protective associations. This pattern is consistent with evidence that mixed

cancer patients (including breast, lung, and colorectal cancer) with ‘high self-compassion’ report lower anxiety and depressive symptoms, while those with ‘high self-coldness’ report greater psychological distress ⁴¹. To our knowledge, this is the first study to examine self-compassion and its subcomponents in relation to distress in sarcoma, suggesting that self-relational processes may play an important role in psychological adjustment in this population and may have implications for intervention development.

Pain interference emerged as an important predictor of both anxiety and depressive symptoms in the present study, while body image distress independently predicted depressive symptoms. Importantly, pain interference here referred not simply to pain severity, but to the extent to which pain disrupted day-to-day functioning. This suggests that pain-related disruption to everyday life may be closely linked to psychological wellbeing in sarcoma. The association between pain interference and depressive symptoms is consistent with evidence linking pain-related functional impairment to poorer psychological wellbeing in sarcoma and oncology populations ^{4,17,36}. Body image distress, in turn, appeared particularly relevant to depressive symptoms, which is in keeping with evidence that body image issues are associated with depressive symptoms and psychological distress in cancer populations ⁴². As previously mentioned, body image distress remains relatively underexplored in sarcoma, and to our knowledge, this is the first study to show that body image distress independently predicted depressive symptoms in adults with sarcoma.

Correlational analyses further showed that greater pain interference was associated with higher body image distress, consistent with evidence that pain and

functional limitations contribute to poorer psychosocial adjustment in sarcoma ⁷. In contrast, higher self-compassion was associated with lower body image distress, aligning with psycho-oncology research indicating that self-compassion is associated with more adaptive adjustment and lower distress following cancer ⁴³. Body image distress was also associated with higher uncompassionate self-responding, and lower mindfulness with greater pain interference, suggesting that pain-related disruption, body-related concerns, and negative self-evaluation may be interconnected. Although self-compassion has not, to date, been examined in relation to body image distress in sarcoma, the present findings suggest that self-compassion may represent a clinically relevant psychological process linked to how individuals adjust to treatment-related bodily change.

Finally, in the present study, perceived social support was not independently associated with anxiety or depressive symptoms, despite extensive evidence supporting its protective role in cancer populations ⁴⁴. This is partly consistent with previous sarcoma research by ¹⁶ who found associations between social support and depression, but not anxiety. In the present sample, perceived support was high overall, with limited variability, which may have reduced the likelihood of detecting associations with distress. Small significant associations were nevertheless observed, such that higher perceived social support was associated with higher self-compassion and lower body image distress, suggesting that support may be more closely related to broader psychological adjustment than to distress symptoms directly in this cohort. It is also possible that the recruitment of many participants through sarcoma support networks or online communities contributed to the high levels of perceived support reported. This is important because high perceived support in the present sample did not appear to buffer against anxiety or depression in the way often

observed in broader oncology literature. At the same time, general measures of perceived social support may not fully capture the disease-specific unmet needs, uncertainty, or illness-related isolation experienced by people with rare cancers ². This interpretation is also consistent with the finding that higher isolation, as measured by the self-compassion scale (SCS-SF), was associated with greater anxiety and depressive symptoms in the present study. As such, it may be that social connectedness in sarcoma may be more complex than can be captured by a broad measure of perceived support alone.

3.4.1 Clinical Implications

These findings highlight the central role of self-compassion, pain-related disruption, and body image concerns in psychosocial distress and wellbeing in sarcoma, with important implications for psychosocial care. Distress in sarcoma appears to be shaped by a combination of risk factors, including pain-related disruption, body image concerns, and younger age, alongside protective factors such as self-compassion. Routine screening for these risk factors may support earlier identification of individuals who may benefit from psychosocial support ¹¹. A stepped-care approach may be particularly appropriate. Individuals with mild distress may benefit from psychoeducation, community supports, peer support, and low-intensity psychological interventions, whereas those with more persistent or moderate-to-severe distress may require referral to specialist psycho-oncology or mental health services, fitting with the Psycho-oncology Model of Care and Stepped Care Model ¹⁸.

The findings also suggest implications for intervention development across the treatment trajectory. Self-compassion may represent a particularly relevant

intervention target in sarcoma. Compassion-focused and mindfulness-based interventions have shown benefit across mixed cancer populations and may offer a promising approach in sarcoma ¹³. This may be especially important for younger adults, who reported higher levels of anxiety and may be more vulnerable to the psychological impact of diagnosis, treatment, and uncertainty about the future. Given the increasing emphasis on prehabilitation in oncology ⁴⁵, interventions that support more adaptive responses to illness-related challenges before or around the start of treatment may help buffer against later distress, particularly where patients are anticipating surgery, bodily change, pain, or functional disruption.

Pain interference and body image distress also emerged as clinically important, suggesting that multidisciplinary approaches that address both may be particularly valuable in sarcoma care. This may include pain management and rehabilitation to address functional impact, and psychological support for body image concerns and coping with disruption to everyday life ⁴⁶.

3.4.2 Limitations & Future Research

Several limitations should be considered. First, the cross-sectional design precludes conclusions about causality or directionality. Second, the sample was largely self-selected and recruited through sarcoma support networks and online platforms, which may limit generalisability and may also have contributed to the high levels of perceived social support observed. Individuals who were more socially connected, more motivated to participate in psychosocial research, or better able to complete the survey may therefore have been overrepresented, while those who were more clinically unwell may have been underrepresented. Some demographic and clinical data, including disease-related information, were patient-reported rather than

confirmed through healthcare records, which is less optimal and may have introduced some inaccuracy. Additionally, the exclusion of GIST and Kaposi sarcoma means that the findings may not be generalisable to these sarcoma subtypes, which have distinct treatment pathways and psychosocial considerations. Finally, the cohort was predominantly female, highly educated, and largely from White and Western backgrounds, and may not fully represent more socio-demographically diverse sarcoma populations. This is important because psychosocial distress and access to support may differ across cultural, socioeconomic, and other demographic groups.

Future research would benefit from longitudinal designs and more diverse sarcoma populations. Greater consistency in how distress is measured and reported in sarcoma research is also needed, whether through a sarcoma-specific distress measure or more standardised reporting of thresholds and interpretations, to support clearer comparison across studies.

3.4.3 Conclusion

This novel and important study demonstrates a substantial burden of psychosocial distress among adults with sarcoma and identifies self-compassion, pain interference, and body image distress as key risk and protective factors to psychosocial distress and wellbeing. These findings highlight the importance of addressing both physical symptom burden and psychological adjustment processes in sarcoma care. Interventions targeting self-compassion, pain-related functioning, and body image adjustment may be particularly relevant for improving psychological wellbeing in this population.

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Chapter 4: Integrative Discussion

4.1 Introduction

This chapter provides an integrated discussion of the major research project as a whole. Through a biopsychosocial lens (Engel, 1980; Lehman et al., 2017), sarcoma was understood not only as a rare and heterogeneous cancer, but as a condition whose impact is shaped by the interactions between disease and treatment, uncertainty, altered functioning, relationships, identity, and wider care contexts.

This chapter begins with an overview of the major research project and a summary of the key findings. It then brings the findings from both studies together in an integrated synthesis and considers their relevance in relation to current sarcoma literature, psycho-oncology, and clinical psychology. The chapter then discusses the theoretical implications of the findings, their implications for sarcoma care and clinical psychology practice, methodological strengths and limitations, reflexivity and positionality, future directions, and overall conclusion.

4.2 Overview of the Research Project and Summary of Key Findings

4.2.1 Overall Project Aims

This major research project examined the psychosocial impact of sarcoma in adults, with particular attention to distress, wellbeing, and adaptation. Previous literature had established that psychosocial burden in sarcoma is substantial and had begun to clarify some of the challenges faced by people with sarcoma, but the evidence base remained limited in important respects. Existing research was stronger in demonstrating burden than in explaining how adults live with sarcoma and adapt to its consequences, and which psychosocial factors influence distress and wellbeing (Almeida et al., 2021; Franzoi et al., 2023; McDonough et al., 2019; Meek &

Baliousis, 2025; Sebio et al., 2025; Storey et al., 2019; Q. Wang et al., 2025). More specifically, there was a need for an adult-focused synthesis of qualitative research that could integrate psychosocial impact and adaptation more clearly, and for more focused empirical evidence on psychosocial factors associated with distress and wellbeing in adults with sarcoma, particularly in relation to underexplored variables such as self-compassion and body image distress.

4.2.2 *Summary of Study 1*

Study 1 synthesised qualitative evidence on adults' experiences of sarcoma and identified sarcoma as a cumulative psychosocial disruption. Across the included studies, diagnosis, treatment, recovery, and survivorship were associated with uncertainty, altered body image, functional loss, identity disruption, social disconnection, and ongoing adaptation. Rather than presenting adaptation as a fixed outcome, the synthesis showed it as an ongoing process shaped by coping, meaning-making, family and peer support, continuity of care, rehabilitation, and access to sarcoma-informed professionals. Its main contribution was to bring psychosocial impact and adaptation together within an adult-focused account of sarcoma experience.

4.2.3 *Summary of Study 2*

Study 2 examined various psychosocial factors that may influence anxiety and depressive symptoms in adults with sarcoma. The findings showed substantial distress within the sample and indicated that lower self-compassion and greater pain interference predicted both anxiety and depression, while body image distress additionally predicted depression. These findings suggest that distress in sarcoma is

shaped not only by demographic or illness-related factors, but also by potentially modifiable psychosocial processes relevant to assessment and intervention.

4.3 Integrated Synthesis of Findings Across Study 1 and Study 2

4.3.1 *Distress in Sarcoma: Substantial, Persistent, and Embedded in Lived Disruption*

A consistent finding across both studies was the prominence of psychosocial distress in adult sarcoma. Study 2 identified high levels of clinically significant anxiety (66.5%) and depressive symptoms (46.3%), particularly anxiety, within the sample. This is in keeping with previous sarcoma literature showing elevated anxiety, depression, and broader psychosocial difficulty, although estimates have varied across studies (Franzoi et al., 2023; McDonough et al., 2019; Storey et al., 2019). Study 1 adds important context to these findings by showing that psychosocial impact in sarcoma cannot be reduced to anxiety and depressive symptoms alone.

In Study 1, the emotional impact of sarcoma was embedded within the wider experience of diagnosis, treatment, recovery, and survivorship. Fear, sadness, uncertainty, hopelessness, frustration, and guilt were described as part of living through delayed diagnosis, invasive treatment, altered bodily functioning, disrupted relationships, and ongoing fear of recurrence. Emotional distress therefore appeared closely tied to the broader psychosocial realities of sarcoma, including its rarity, unpredictability, body-altering treatment, and the extent to which it disrupted everyday life.

The findings across both studies suggest that psychosocial distress in sarcoma is closely linked to lived disruption such as functional loss, reduced

independence, uncertainty about the future, disruption to valued roles and relationships, and altered bodies and self-experience. In some accounts, it was also compounded by fragmented or poorly coordinated care (Denissen et al., 2024; Fauske et al., 2025). This is consistent with biopsychosocial understandings of illness, in which distress is shaped through the interaction of biological, psychological, and social influences rather than by disease or treatment factors in isolation (Engel, 1980; Lehman et al., 2017). In sarcoma, these influences may appear particularly closely connected because the physical, relational, and existential consequences of cancer are often experienced together rather than separately.

These findings also suggest that psychosocial distress is not confined to diagnosis or treatment timepoints. In Study 1, emotional difficulties extended into recovery and survivorship, particularly where assumptions of recovery did not match the continued experiences of pain, uncertainty, disability, fear of recurrence, or altered identity. Study 2 supports this broader picture, as clinically significant anxiety and depressive symptoms were evident across the sample rather than appearing limited to one particular treatment group or phase of illness. Previous research has similarly shown that emotional difficulties in sarcoma may persist over time and may not improve in step with physical recovery (Day et al., 2022; Tang et al., 2015; Younger et al., 2020).

This is consistent with the wider psycho-oncology literature which shows that distress may persist beyond active treatment and into survivorship (Lai et al., 2012; Pitman et al., 2018; Wang et al., 2018; Wang & Feng, 2022). However, in sarcoma the end of active treatment may not mark the end of distress, for some individuals, it may be the point at which the longer-term implications of sarcoma

become more apparent. This longer-term distress may be shaped by ongoing surveillance, fear of recurrence or progression, and the longer-term consequences of rare, intensive, and body-altering treatment. This is also consistent with emerging sarcoma evidence showing that fear of recurrence may be particularly high in this cohort, with levels exceeding the overall mean reported across other cancer types including prostate, breast, and colorectal cancer (Petrella et al., 2023). The rarity of sarcoma may further intensify this experience through delayed diagnosis, limited professional familiarity, fragmented pathways of care, and reduced access to clear information and diagnosis-specific support, all of which have been shown to shape psychosocial outcomes in rare cancers and rare disorders such as CF (Low et al., 2024; Von Der Lippe et al., 2017). Psychosocial distress in sarcoma may therefore be understood as embedded in the broader clinical realities of sarcoma, where recurrence, progression, rehabilitation, and uncertainty, often remain especially salient across the illness trajectory.

4.3.2 Embodiment, Identity, and Disability-Related Change

Both studies highlighted the extent to which psychosocial experience in sarcoma is shaped by altered embodiment, pain, and function. In Study 1, participants described sarcoma through bodily change and limitation, including altered appearance, scarring, prostheses, pain, fatigue, restricted mobility, dependence, and reduced physical capacity. These were not described as physical consequences alone and appeared to be closely connected to changes in confidence, participation in everyday life, relationships, identity, and expectations for the future. Study 2 reflected a similar pattern, with greater pain interference predicting both anxiety and depressive symptoms, and greater body image distress predicting depressive symptoms. These findings are consistent with previous sarcoma research

linking distress with pain, poorer physical functioning, and body image concerns (Franzoi et al., 2023; Holzer et al., 2020; Tang et al., 2015; Wei et al., 2024), while also helping to clarify why these issues may be so psychologically significant in sarcoma.

Pain appeared particularly important in this respect. In Study 1, pain was described both as a symptom and as part of a broader experience of bodily limitation and changed normality. Participants linked pain to disrupted sleep, reduced activity, lower confidence, dependence on others, and difficulty maintaining ordinary routines and roles. Study 2 adds to this by showing that it was pain interference, that is, the extent to which pain disrupted daily life, which predicted both anxiety and depressive symptoms. This suggests that the psychosocial significance of pain in sarcoma may lie especially in the extent to which it disrupts mobility, independence, daily activity, and participation in valued roles. Similar patterns have been reported in other cancer populations. Teo et al., (2015), for example, found in women with upper-extremity lymphedema following breast cancer treatment that pain intensity predicted depressive symptoms and that body image dissatisfaction mediated the relationship between pain and depressive symptoms. Teo et al., (2018) also found in gynaecologic cancer that symptom burden was more strongly related to physical and functional wellbeing, whereas body image dissatisfaction was more closely related to emotional wellbeing. The present findings overlap with this wider literature, but also suggest a somewhat different pattern in sarcoma, where pain interference itself remained directly associated with anxiety and depressive symptoms. This may reflect the extent to which pain in sarcoma is often experienced alongside reduced mobility, altered bodily capacity, rehabilitation demands, and difficulty maintaining everyday roles and routines. In that context, pain may be especially significant not

only because it is distressing in itself, but because it can disrupt independence, participation, and the ability to live in familiar ways, which in turn may impact adaptation and adjustment.

A similar pattern was evident in relation to body image. In Study 1, body image concerns were closely linked with shame, concealment, visible difference, discomfort in social and public settings, reduced confidence, and altered identity. These concerns were not simply about appearance, but about living in a body that had changed in visible and functionally significant ways. Body image was often experienced through the combined effects of scarring, altered movement, reduced bodily capacity, and the need to manage how those changes were seen by others. Study 2 adds to this by showing that body image distress independently predicted depressive symptoms, suggesting that body image distress in sarcoma is closely tied not only to appearance, but also to altered function, social visibility, and the broader experience of bodily change. This interpretation is consistent with wider sarcoma literature showing poorer body image among patients with primary malignant bone tumours compared with healthy controls (Holzer et al., 2020), and with more recent evidence that body image dissatisfaction in adolescent and young adult sarcoma survivors is associated with depression (Wei et al., 2024). The present findings add to this literature by showing that, in an adult sarcoma sample, body image distress remained relevant even when considered alongside other psychosocial factors.

Identity disruption was closely tied to these experiences. In wider psycho-oncology, cancer has long been understood to affect identity, roles, relationships, and assumptions about the self, particularly where illness and treatment disrupt everyday functioning and require adjustments (Pearce et al., 2020; Tack et al., 2022). In

sarcoma, existing qualitative research has similarly pointed to altered identity, changed roles, and disruption to participation in everyday life (Meek & Baliousis, 2025; Wang et al., 2025). Study 1 built on this by showing more clearly that adults with sarcoma often described becoming different from who they had previously been, with this sense of being “no longer the same” encompassing bodily disruption, role disruption, relational disruption, and a broader loss or reshaping of identity. Considered alongside Study 2, which identified lower self-compassion, greater pain interference, and greater body image distress as key factors associated with anxiety and depressive symptoms these findings suggest that distress in sarcoma is shaped by both symptoms themselves and by their implications for self-evaluation, confidence, everyday functioning, and the experience of living in a changed body.

Role disruption appeared especially important in understanding this process. In Study 1, many participants described not simply feeling distressed, but feeling unable to live in the ways that had previously organised identity and self-worth. Work, parenting, physical activity, social life, intimacy, and everyday routines were all affected (Fauske et al., 2015; Taylor & Pooley, 2017). Participants also described dependence, mobility restriction, altered bodily capacity, and difficulty participating in ordinary activities in ways that suggest disability may be relevant to understanding the longer-term impact of sarcoma. The findings of Study 2, such as pain interference predicting both anxiety and depressive symptoms, while body image distress predicted depressive symptoms, suggest that psychosocial distress in sarcoma is shaped not only by illness and treatment, but by the longer-term consequences of reduced independence, visible difference, disrupted participation, and altered confidence in carrying out valued roles. In this way, the loss of familiar

roles and capacities may contribute to practical difficulty and also to a broader sense of becoming different from one's former self.

These findings are consistent with previous qualitative work in sarcoma describing altered identity, biographical disruption, and efforts to establish a new normal after treatment, particularly where survivors continue to live with bodily change, physical restriction, and uncertainty (Meek & Baliouis, 2025; Wang et al., 2025). It also echoes wider cancer literature suggesting that adjustment is often not a matter of returning to a pre-illness self, but of renegotiating identity in the context of changed bodily and social realities (Pearce et al., 2020; Tack et al., 2022). What may be especially pronounced in sarcoma is the extent to which visible bodily change, altered movement, functional restriction, and dependence can occur together. This can make adaptation to an altered sense of self especially difficult, as bodily change is lived not only through appearance, but through mobility, activity, social participation, and everyday functioning.

Overall, the findings suggest that the psychosocial impact of sarcoma is closely tied to how bodily change is lived in everyday life. Pain, body image, function, identity, and role participation were not separate domains of experience, but closely interrelated aspects of living with sarcoma. Psychosocial distress in this context appears shaped by the presence of symptoms or visible change and by their implications for independence, social participation, sense of self, and the loss or disruption of previously valued roles and capacities.

4.3.3 Uncertainty Across Diagnosis, Treatment, and Survivorship

Uncertainty appeared to be an important part of psychosocial experience across both studies. In Study 2, anxiety was particularly prominent, with a high proportion of participants reporting clinically significant anxiety symptoms. Anxiety in sarcoma also did not appear confined to one clear subtype or phase of illness. Younger age predicted anxiety symptoms, but most clinical variables were not strongly associated with anxiety, suggesting that anxiety may be relevant across the sarcoma trajectory rather than only during diagnosis or active treatment. This is broadly consistent with previous sarcoma literature suggesting that psychosocial distress is not limited to one point in the illness trajectory. Paredes et al., (2012b) found that a notable minority of patients continued to report anxiety or depression in the clinical range from diagnosis into treatment, while Tang et al., (2015) showed that distress remained evident from diagnosis to one year after surgery.

Study 1 helps to clarify what this anxiety may relate to. Participants described uncertainty from the beginning of the sarcoma pathway, through delayed referral, symptom ambiguity, dismissal, and difficulty making sense of a rare diagnosis. Uncertainty then continued through treatment, recovery, and survivorship in the form of fear of recurrence, concerns about bodily change and function, and difficulty knowing what to expect from the future. Viewed alongside these findings, the high levels of anxiety identified in Study 2 are likely to reflect more than general emotional distress. They suggest the strain of living with ambiguity, unpredictability, and limited control across multiple phases of illness.

This is especially relevant in sarcoma because uncertainty may be intensified by rarity. As discussed in Chapter 1, rare cancers may involve delayed diagnosis,

fragmented pathways, limited clinician familiarity, fewer disease-specific resources, and reduced opportunities for diagnosis-specific peer support (Dufresne & Olivier, 2025; Low et al., 2024; Von Der Lippe et al., 2017). This was evident in Study 1, where participants often described uncertainty not only as a consequence of disease unpredictability, but also as something reinforced by the wider experience of living with a rare cancer that others knew little about. Uncertainty in sarcoma therefore appears to be shaped both by the illness itself and by the context in which that illness is encountered.

One particularly important form of uncertainty concerns recurrence and the future. Previous sarcoma research has identified fear of recurrence as a prominent and enduring concern, and has linked it with poorer emotional functioning and lower psychological flexibility (Petrella et al., 2023; Younger et al., 2020). The present findings are consistent with this, but they also suggest that uncertainty in sarcoma extends beyond recurrence alone. In Study 1, uncertainty also concerned what the diagnosis meant, how treatment would affect the body, whether recovery would restore previous functioning, and whether life would feel stable or recognisable again. This broader view may help explain why anxiety was so marked in Study 2. It suggests that anxiety in sarcoma may be tied to both fear of disease progression and also to the longer-term unpredictability of living with bodily change, altered function, and an uncertain future.

These findings suggest that sarcoma, as a rare cancer, may be associated with high levels of uncertainty and anxiety across diagnosis, treatment, recovery, and survivorship, rather than only around diagnosis or recurrence concern alone. This ongoing uncertainty may contribute to sustained emotional strain and help explain

why psychosocial distress in sarcoma can remain clinically significant beyond active treatment, and why adaptation may continue to be difficult long after treatment has ended.

4.3.4 *Social Support, Connection & Being Understood*

Social support was important across both studies, but the findings pointed to different aspects of social experience. In Study 1, participants frequently described social disconnection, isolation, feeling like a burden, and frustration at not being understood by others. These experiences were often linked to rarity, visible bodily change, altered functioning, and the difficulty of explaining sarcoma to people who knew little about it. Participants also described the value of family support, supportive professionals, and, in particular, contact with others affected by sarcoma. In Study 2, participants reported high levels of perceived social support. However, it was not associated with anxiety or depressive symptoms. These findings suggest that the experience and role of social support in sarcoma may be more complex than is captured by broad measures of perceived support alone.

Existing literature likewise points to the importance of social support, although findings in sarcoma have been variable across some studies. In mixed cancer populations, social support is often associated with better psychological adjustment and lower distress (Lv et al., 2022; Mehnert et al., 2018). Sarcoma research has also suggested that perceived social support can be a determinant of wellbeing, although not consistently across psychological outcomes. For example, Paredes et al., (2012a) found associations between social support and depression and overall quality of life, but not consistently with anxiety. Research on rare cancers and rare illnesses such as cystic fibrosis has also shown that patients often

experience social isolation, limited understanding from others, and difficulty accessing diagnosis-specific sources of support (Heus et al., 2021; Low et al., 2024; Von Der Lippe et al., 2017). The present findings fit with this broader literature, but suggest that in sarcoma the issue may not be social support alone, but whether support feels sufficiently informed, practical, and understanding of the realities of living with a rare cancer.

This becomes clearer when the findings of the two studies are considered together. The measure used in Study 2 to assess perceived social support, the MSPSS, focused on perceived emotional and relational support from family, friends, and a significant other. It therefore captured whether participants felt supported by close others, but it did not assess practical support needs, sarcoma-specific support, or whether others understood the particular bodily, functional, and social consequences of sarcoma. Study 1 suggested that these aspects matter. Participants often described the importance not only of having people around them, but of receiving support that recognised the long-term and often invisible consequences of sarcoma, including altered functioning, reduced independence, fear of recurrence, and the difficulty of rebuilding everyday life. Support from others with sarcoma, or from professionals with specialist knowledge, was often valued because it reduced the burden of having to explain, justify, or translate one's experience (Wang et al., 2025). This suggests that future research may benefit from using broader or more sarcoma-sensitive measures for support, including support that captures practical needs, illness-specific understanding, and the extent to which support feels responsive to the distinctive bodily, functional, and relational consequences of sarcoma.

The findings from Study 2 also suggest that felt isolation may be more relevant to distress than general ratings of support alone. In the exploratory analyses, isolation, as a component of uncompassionate self-responding, showed strong associations with anxiety and depressive symptoms. This suggests that a person may report support being available while still feeling fundamentally alone, separate, or not fully understood in their illness experience. The qualitative findings support this distinction. Participants often described the difficulty of explaining sarcoma to others, the sense that people forgot or failed to grasp the longer-term consequences, and the experience of being seen primarily through impairment rather than recognised more fully as a person (Fauske et al., 2015; Martins et al., 2019, 2022). Emotional isolation and social misunderstanding may therefore persist even in the presence of supportive relationships.

The characteristics of the Study 2 sample are also relevant here. Participants reported high levels of perceived social support overall, and recruitment occurred largely through sarcoma support groups, online communities, and related networks. It is therefore possible that the sample included people who were already relatively connected to supportive others or peer communities, and may not fully reflect the experiences of adults with sarcoma who are more socially isolated or less engaged with support networks. This may explain why perceived social support did not emerge as a significant predictor of anxiety or depressive symptoms in this cohort.

These findings suggest that social connectedness in sarcoma cannot be understood solely in terms of whether support is available. What appears especially important is whether support is perceived as understanding, relevant, and responsive to the specific uncertainties, bodily changes, and functional disruptions associated

with sarcoma. This may help explain why sarcoma-specific peer support and knowledgeable professional support were experienced as especially meaningful in Study 1, and why some individuals may remain socially distressed even when they report support from others.

4.3.5 Adaptation as Ongoing, Non-linear, and Shaped by Context

How adults responded and adapted to sarcoma became an important issue across both studies. In Study 1, participants described the ongoing process of living with the emotional, social, relational, and functional consequences of sarcoma. In Study 2, lower self-compassion, greater pain interference, and greater body image distress were associated with poorer psychological outcomes. This indicates that adaptation in sarcoma is not a straightforward process of recovery over time. Rather, it appears to involve the ongoing effort to live with uncertainty, bodily change, altered roles, and continuing psychosocial strain, while drawing on different personal, relational, and practical resources to manage this.

Study 1 showed that adults adapted to sarcoma in different ways. Participants described self-management, practical adjustments, selective engagement with information, reframing, acceptance, and reliance on support from family, peers, and professionals. Adaptation was not described as a fixed outcome or a complete transition. It was often partial, effortful, and accompanied by fear, sadness, uncertainty, frustration, and disruption to everyday life. This suggests that adaptation in sarcoma is better understood as an ongoing response to disruption than as a final state of resolution. Similar ideas are reflected in broader psycho-oncology literature, where adaptation is understood as a dynamic process shaped by coping, meaning-

making, social connection, and context rather than by any single trait or strategy (Zhu et al., 2024).

Study 2 also helps to clarify how adaptation may be shaped in sarcoma, even though it did not examine adaptation directly. Lower self-compassion and greater pain interference predicted anxiety symptoms, while lower self-compassion, greater pain interference, and greater body image distress predicted depressive symptoms. These factors may also be understood as clinically important risk factors for more difficult adaptation, as they point to some of the psychological and embodied challenges that may make it harder to live with the longer-term consequences of sarcoma. Pain interference reflects the extent to which symptoms disrupt functioning, independence, and daily roles, while body image distress reflects difficulty living with visible and bodily change. Lower self-compassion may be especially important, as it may reflect greater difficulty responding to suffering, limitation, and perceived inadequacy with self-kindness rather than self-criticism, whereas higher self-compassion may represent a protective factor. This is also consistent with wider cancer literature linking self-compassion with lower distress and better psychological adjustment (Bitan et al., 2025; Krok et al., 2025). Earlier sarcoma studies have explored factors associated with emotional adjustment across phases of illness, including demographic, clinical, coping, and social variables (Eichler et al., 2023; Paredes et al., 2011, 2012a, 2012b; Robinson et al., 2025; Tang et al., 2015). However, to our knowledge, this is the first study in an adult sarcoma population to examine self-compassion and body image distress and identify them as clinically important factors. Considered alongside Study 1, these findings suggest that self-compassion, pain interference, and body image distress may be important in

understanding why adaptation appears more manageable for some adults with sarcoma than for others.

The findings also indicate that adaptation in sarcoma is not shaped by personal factors alone. In Study 1, participants described how adaptation was supported or constrained by the wider context in which they were trying to live after sarcoma, including healthcare relationships, access to specialist and rehabilitative support, opportunities for sarcoma-specific peer connection, and the extent to which others understood the longer-term consequences of the disease. Considered alongside Study 2, this suggests that the factors associated with distress, such as pain interference, body image distress, and lower self-compassion, are unlikely to be managed in isolation from the social and clinical contexts in which people are living. Adaptation in sarcoma therefore appears to depend on both individual response and also on whether the wider context is sufficiently supportive, understanding, and responsive to ongoing need.

Importantly, adaptation did not emerge as the opposite of distress. In Study 1, participants often described coping, acceptance, reframing, or meaning-making alongside continuing fear, sadness, role loss, and uncertainty. Higher self-compassion was associated with lower anxiety and depressive symptoms, but high levels of distress were still evident in the sample overall. This suggests that wellbeing and distress are not best understood as mutually exclusive states in sarcoma. Instead, adaptation may involve differing degrees of distress and wellbeing existing alongside one another. This is consistent with wider cancer literature showing that positive and negative consequences of illness may coexist rather than replacing one another (Lai et al., 2012; Yao et al., 2023). In sarcoma, this may be

especially relevant because adaptation often involves living with lasting bodily and functional consequences rather than returning to a previous state.

Overall, the findings suggest that adaptation in sarcoma is best understood as an ongoing and uneven process rather than a completed state of recovery. It unfolds in the context of uncertainty, bodily change, functional disruption, altered roles, and changing support needs, and is shaped by both individual and contextual influences. Study 1 showed that adaptation involved practical, emotional, relational, and meaning-based responses to these disruptions, while Study 2 identified self-compassion, pain interference, and body image distress as clinically important factors that may help explain why adaptation is more difficult for some adults than for others. In this sense, adaptation in sarcoma involves more than recovery or the reduction of distress. It appears to involve finding ways of living within a changed life, while negotiating the coexistence of ongoing distress, adjustment, and attempts to move forward.

4.4 Theoretical Implications

4.4.1 Conceptualising Distress in Sarcoma Beyond Symptoms

An important theoretical implication concerns how distress in sarcoma is understood. In broader psycho-oncology literature, distress is often conceptualised through emotional symptom constructs such as anxiety and depression, sometimes alongside broader patient-reported outcomes such as quality of life or psychosocial functioning (Ghiglieri et al., 2023; Grassi et al., 2023; Mehnert et al., 2018).

Sarcoma literature has followed a similar pattern, most often examining outcomes such as quality of life, distress, anxiety and depression, unmet needs, and coping, while also highlighting marked heterogeneity in methods and measures (Franzoi et

al., 2023; McDonough et al., 2019; Storey et al., 2019). Although this work has established that psychosocial burden in sarcoma is substantial, it has offered less clarity about how distress is organised within everyday experience and why it may take the forms that it does.

The present findings suggest that distress in sarcoma cannot be fully understood in terms of anxiety or depressive symptoms alone, or through poorer scores on broad psychosocial or quality of life measures alone. Across the two studies, distress appeared closely bound up with altered embodiment, pain-related disruption, body image distress, uncertainty, disrupted roles, social disconnection, and changes in self-experience. Study 1 showed that emotional distress emerged within prolonged diagnostic uncertainty, invasive treatment, altered bodily function, social misunderstanding, and continuing fear of recurrence. Study 2 showed that distress was associated not only with anxiety and depressive symptoms themselves, but with pain interference, body image distress, and lower self-compassion. Together, these findings suggest that distress in sarcoma is embedded in lived disruption. It arises not in isolation from illness experience, but through the interaction of bodily, psychological, relational, and contextual factors. In this respect, the findings support a biopsychosocial understanding of distress, but also develop it more specifically in relation to sarcoma by showing how rarity, visible bodily change, functional limitation, and uncertainty may become central to how distress is experienced and maintained (Engel, 1980; Lehman et al., 2017).

This also has implications for how psychosocial burden in sarcoma is theorised more broadly. Previous reviews have suggested that sarcoma has a distinctive psychosocial profile, but have often been limited by broad outcome

frameworks and inconsistent measurement (Franzoi et al., 2023; McDonough et al., 2019; Storey et al., 2019). The current findings suggest that distress in sarcoma may be better understood as a response to cumulative psychosocial disruption across diagnosis, treatment, recovery, and survivorship, rather than as a limited emotional outcome. This is closer to how psychosocial functioning has been conceptualised in some mixed-cancer literature, where emotional wellbeing is understood alongside self-mastery, social functioning, role participation, and the capacity to maintain continuity in daily life (Ghiglieri et al., 2023). However, the present findings suggest that in sarcoma this disruption may be particularly shaped by rarity, body-altering treatment, pain-related interference, and threats to independence and identity. Theoretical models of distress in sarcoma therefore may need to account not only for symptom severity, but for the lived meanings of bodily change, uncertainty, disability, altered social experiences, and the effort required to adapt to a changed life.

4.4.2 Embodiment, Identity, and Disability-Related Change

A second theoretical implication concerns how embodiment and identity are understood in sarcoma. In broader cancer literature, changes in self-concept and identity have been linked to altered body image, functioning, and social participation (Pearce et al., 2020; Wang & Feng, 2022). The present findings suggest that, in sarcoma, these processes may need to be understood in more explicitly biopsychosocial and disability-informed terms. Study 1 showed that adults often experienced sarcoma through bodily change and limitation, including pain, scarring, altered movement, dependence, and reduced physical capacity, and that these experiences were closely tied to confidence, role participation, and a sense of becoming different from one's former self. Study 2 supported this pattern by

showing that pain interference predicted anxiety and depressive symptoms, while body image distress predicted depressive symptoms. In sarcoma, bodily change therefore appears both as a physical consequence of treatment and as something that can reshape the sense of self and everyday life.

This is theoretically important because it suggests that psychosocial functioning in sarcoma may not be adequately captured by models that treat physical function, body image, identity, and emotional distress as separate domains. Instead, the findings support a biopsychosocial account in which bodily change, psychological meaning, and social participation are closely intertwined (Engel, 1980; Lehman et al., 2017). Rare illness and rare cancer literature points in a similar direction, showing that psychosocial outcomes are shaped by several factors including disease factors and also by uncertainty, limited knowledge, treatment demands, and wider social context (Horick et al., 2017; Low et al., 2024; Von Der Lippe et al., 2017). Sarcoma may make this especially visible because aggressive treatment, difficult rehabilitation, and altered function can affect both what the body looks like and what it can do.

A disability-informed perspective is also useful here, particularly for sarcoma. Study 1 suggested that for some participants the psychosocial impact of sarcoma was shaped not only by cancer itself, but by reduced independence, altered mobility, dependence on others, and difficulty maintaining valued roles. Magasi et al., (2022), in survivors of breast cancer, head and neck cancer, and sarcoma, similarly showed that some long-term cancer effects are better understood through their impact on activity, participation, and disability identity rather than impairment alone. This also aligns with amputation literature showing that adjustment may

involve adapting to disability-related change, including role constraints, reduced autonomy, altered everyday functioning, and changes in self-representation and identity (Hutchison et al., 2024; Roşca et al., 2021). The theoretical implication, therefore, is that psychosocial functioning in sarcoma may be better understood through the interaction of altered embodiment, functional loss, disability-related change, and the social meanings attached to these experiences.

4.4.3 Adaptation as a dynamic process: self-relational and contextual perspectives

A third theoretical implication concerns how adaptation is understood in sarcoma. In psycho-oncology, adjustment has increasingly been conceptualised as an ongoing process shaped by coping, meaning-making, and social context, rather than as a simple return to previous functioning (Zhu et al., 2024). The present findings support that view and suggest that it may be especially relevant in sarcoma. Adaptation did not appear as a completed transition or a state free from distress, but as an uneven process of living with continuing uncertainty, bodily change, and disruption to everyday life.

A more specific theoretical contribution concerns the role of self-relational processes. Study 2 identified lower self-compassion as a clinically important factor associated with both anxiety and depressive symptoms. This suggests that psychosocial adjustment in sarcoma may depend partly on how individuals relate to themselves when faced with pain, bodily change, limitation, and uncertainty. In other words, the emotional consequences of sarcoma may be shaped by both external disruption and also by whether suffering is met with self-criticism and isolation or with greater self-compassion. Research in mixed cancer populations has similarly linked greater self-compassion with lower distress and better psychological

adjustment (Bitan et al., 2025; Krok et al., 2025). In this respect, the present findings extend that line of work into sarcoma and suggest that self-compassion may be relevant as both as a protective factor for distress and as part of how adaptation is managed over time.

The findings also suggest that adaptation in sarcoma cannot be understood solely as an individual psychological task. Study 1 showed that adaptation was supported or constrained by the wider context, including healthcare relationships, rehabilitation, sarcoma-specific peer support, and the extent to which others understood the ongoing consequences of the disease. This indicates that adaptation in sarcoma is shaped not only by personal coping, but by the interaction between self-relational processes, embodied change, and the wider social and clinical environment in which people are trying to rebuild life after sarcoma.

4.5 Clinical Implications

4.5.1 Implications for Assessment

These findings suggest that psychosocial assessment in sarcoma should extend beyond general distress screening alone. In psycho-oncology, routine distress screening remains an important component of care, but the Irish Psycho-oncology Model of Care and the UK Psychosocial Care Pathway also highlight the need for broader assessment of psychosocial need across the cancer pathway. In Ireland, this includes recognition of psychosocial distress as part of the cancer experience and timely access to appropriate psychosocial support. UK personalised cancer care guidance similarly emphasises holistic needs assessment and care planning. The National Comprehensive Cancer Network (NCCN) Distress Management guidance

likewise recommends routine distress screening followed by more detailed assessment of the concerns contributing to that distress.

Applied to sarcoma, these findings suggest that assessment may need to include exploration of both anxiety and depressive symptoms, and also pain interference, body image distress, uncertainty and fear of recurrence, functional change, role disruption, social disconnection, and the person's experience of living in a changed body. The current findings indicate that psychosocial distress in sarcoma is often closely tied to altered embodiment, disrupted daily activity, visible difference, dependence, uncertainty, and changed relationships. Assessment may therefore be most informative when it explores not only whether distress is present, but also what it relates to, how it is affecting daily life, and which factors may be increasing risk or supporting adjustment. This is consistent with earlier sarcoma research suggesting that sarcoma experiences are shaped by interacting risk and protective factors rather than by illness variables alone (Kosir et al., 2020; Paredes et al., 2012a, 2012b; Tang et al., 2015).

These findings also suggest that psychosocial assessment in sarcoma may need to be repeated across the illness trajectory rather than concentrated at diagnosis or during treatment alone. Psychosocial difficulties appeared relevant not only during active treatment, but also in recovery, rehabilitation, surveillance, and attempts to resume work, parenting, relationships, and other valued roles. A sarcoma-informed psychosocial assessment may therefore benefit from being sensitive to age, illness phase, current function, rehabilitation needs, practical pressures, and the extent to which available support is informed and responsive to sarcoma-specific difficulties. In practice, this may mean combining brief screening

with more individualised clinical assessment where indicated, so that difficulties such as pain-related disruption, shame about visible difference, uncertainty, or reduced self-compassion are less likely to be overlooked.

4.5.2 Implications for Psychological Formulation

These findings support the value of individualised psychological formulation in sarcoma. In psycho-oncology, distress screening is important, but symptom scores alone cannot explain why one person develops persistent psychosocial difficulties while another with a similar diagnosis or treatment history adjusts differently (Grassi et al., 2023). Kosir et al., (2020) made a similar point in relation to young people with sarcoma, arguing for a dynamic understanding of adaptation based on interacting risk and protective factors rather than a one-size-fits-all model. The present findings support that position in adults with sarcoma and suggest that formulation offers a useful way of integrating bodily, psychological, relational, and contextual influences into a coherent account of distress and adaptation.

A formulation approach is especially relevant because the current findings suggest that psychosocial distress in sarcoma is shaped by interacting risk and protective factors rather than by diagnosis or treatment variables alone. Lower self-compassion, greater pain interference, and greater body image distress emerged as clinically important risk factors associated with anxiety and depressive symptoms, with younger age also relevant to anxiety. Higher self-compassion may, in turn, be understood as a protective factor. Study 1 gives important context to these findings by showing how such factors are lived in everyday life: pain was linked with disrupted sleep, reduced activity, and lower confidence; body image concerns with shame, concealment, and visible difference; and distress more broadly with

uncertainty, disrupted roles, and social misunderstanding. Formulation in sarcoma therefore needs to account both for symptoms and for how distress is organised through altered embodiment, functional loss, uncertainty, identity disruption, and social context.

These findings can be applied across different clinical models. A cognitive-behavioural formulation may help map how pain interference, fear of recurrence, altered body image, and uncertainty contribute to threat appraisals, avoidance, withdrawal, and low mood. A compassion-focused formulation may be especially relevant where shame, self-criticism, or isolation are prominent, given the importance of self-compassion in Study 2 and the themes of guilt, visible difference, and altered identity in Study 1. Acceptance-based formulations may also be useful where the central difficulty concerns living with ongoing uncertainty, bodily change, and limits on mobility and functioning. Across models, the key implication is that formulation in sarcoma should remain person-specific, biopsychosocial, and attentive to both risk and protective factors.

4.5.3 Implications for Intervention

Building on the formulation implications outlines above, these findings also suggest a need for psychosocial interventions in sarcoma that are both evidence-based and more clearly tailored to sarcoma-specific difficulties. Although psycho-oncology has an established evidence base for interventions such as cognitive behavioural therapy (CBT), Acceptance and Commitment Therapy (ACT), and compassion-focused therapy (CFT) in cancer more broadly, sarcoma-specific psychosocial intervention research remains very limited (Hwang et al., 2023; Semenenko et al., 2023). The sarcoma literature has repeatedly identified unmet

psychosocial, informational, and survivorship needs, indicating that more tailored support is required for this population (Fauske et al., 2025; Franzoi et al., 2023).

The present findings indicate that intervention targets in sarcoma may need to extend beyond emotional distress alone to include uncertainty, pain-related disruption, body image distress, altered functioning, fear of recurrence, shame, and disruption to roles and identity as important aspects of psychosocial difficulty. Lower self-compassion, greater pain interference, and greater body image distress were also associated with poorer psychological outcomes, suggesting that these may be clinically meaningful targets for intervention. This points towards approaches that address not only anxiety and depressive symptoms, but also the experience of living with a changed body, reduced function, and ongoing uncertainty after sarcoma. CBT, ACT, and CFT may therefore provide useful starting points where distress is maintained by threat appraisals, avoidance, uncertainty, body-image issues, shame, self-criticism, altered self-experience, or adjustment difficulties (Fan et al., 2023; Fawson et al., 2024; Paslaru et al., 2025).

Existing psycho-oncology approaches offer useful starting points, but they may require adaptation to address the combination of rarity, uncertainty, pain-related disruption, body image distress, functional loss, altered identity, and rehabilitation or survivorship needs associated with sarcoma. The wider service-level implications of this are considered in the following section.

4.5.4 Implications for service development and multidisciplinary care

These findings suggest that psychosocial care in sarcoma may be most effective when it is embedded within wider sarcoma care rather than delivered separately from rehabilitation and survivorship support. Study 1 showed that

psychosocial adaptation was shaped not only by the individual, but also by the systems in which care was received. Participants valued specialist, coordinated, and individualised sarcoma care, and described feeling safer when professionals were knowledgeable, continuity was present, communication was clear, and rehabilitation or survivorship needs were recognised. By contrast, non-specialist care, fragmented pathways, poor communication, and inadequate rehabilitation often intensified uncertainty and feelings of abandonment. This is consistent with wider rare cancer literature, which has highlighted the psychosocial importance of care coordination, information, and access to expertise (Horick et al., 2017; Low et al., 2024; von der Lippe et al., 2017).

A clear implication is the need for service models that support timely, ongoing, and appropriately matched psychosocial care across the sarcoma pathway. A stepped-care approach may be particularly useful, in line with psycho-oncology models of care, with psychoeducation, peer and community support, and lower-intensity psychological input available for those with milder difficulties, and referral to specialist psycho-oncology or mental health services for those with more persistent or moderate-to-severe distress. The findings also suggest that this support may need to extend beyond acute treatment, given the continuing uncertainty, fear of recurrence, altered function, and adjustment difficulties described across treatment, recovery, rehabilitation, and survivorship. Because access to specialist sarcoma services is limited by the rarity of the disease and the small number of specialist centres, these findings also point to the importance of improving sarcoma awareness among GPs, primary care clinicians, and non-specialist teams to support earlier recognition, appropriate referral, and more informed care.

The findings further suggest that psychosocial care in sarcoma is unlikely to be most effective if delivered in isolation from rehabilitation and wider multidisciplinary input. Rehabilitation appeared psychologically important, not only practically important, because pain, altered function, body image, and identity were closely linked. Recent rehabilitation guidance for primary bone and soft tissue tumours similarly emphasises holistic needs assessment, patient-centred care, effective communication, access to specialist allied health professionals, and rehabilitation from diagnosis into long-term survivorship and, where needed, end-of-life care (McCarthy et al., 2024). The clinical implications therefore extend beyond one-to-one therapy. They include MDT-level and pathway-level developments such as psychologically informed communication, better integration of psychological and rehabilitation care, more coordinated transitions through survivorship, and sarcoma-informed pathways that recognise the distinctive combination of rarity, uncertainty, pain-related disruption, body image distress, functional loss, and altered identity associated with sarcoma.

4.6 Reflexivity and Positionality

As a researcher, reflexivity and positionality are crucial, particularly when conducting and interpreting qualitative research, because as researchers we are not separate from the research process and may shape it through our assumptions, experiences, values, and personal views (Dodgson, 2019). Reflexivity became increasingly important across this major research project because my relationship to the topic changed in an unexpected and deeply personal way. Midway through the project, my grandfather developed a lump in his leg and was investigated for suspected sarcoma, but was initially misdiagnosed with a haematoma. After several months of repeated biopsies, uncertainty, fear, and confusion, he was diagnosed with

stage IV soft tissue sarcoma, specifically leiomyosarcoma. Within two weeks of receiving the diagnosis, he was moved into palliative care, and less than two months later he died. This meant that, while conducting doctoral research on sarcoma, I was also encountering sarcoma within my own family. The topic therefore shifted from being one of academic and clinical interest to one that had become personally significant.

This experience brought my personal and professional worlds into much closer contact. As a trainee clinical psychologist undertaking doctoral research on sarcoma, I was in the unusual position of already knowing a great deal about the condition at the point when someone close to me was being diagnosed with it. I expected that knowledge to be helpful. In practice, it did not create a sense of mastery or preparedness. I knew the seriousness of sarcoma, its diagnostic difficulties, and its potential for rapid progression, yet I was unable to change what was happening. My position in relation to the research therefore shifted over time, as I tried to understand what it meant to continue researching sarcoma while also grieving my grandfather.

My lived experience of sarcoma influenced how I engaged with the data and how I interpreted certain findings. It heightened my sensitivity to several themes in the thesis, particularly diagnostic uncertainty, healthcare trust, rapid functional decline, dependence, family distress, mortality, and the unevenness of adaptation across the sarcoma pathway. Before this experience, I understood these issues largely through the literature and participant accounts. During and after my grandfather's illness, they became much more personal and relatable. I found myself reading the data with greater sensitivity to the strain of "knowing but not knowing,"

the frustration and anger associated with delayed clarity, and the shock of witnessing profound bodily and functional change over a short period of time. The qualitative material on disruption, disability, palliative transition, and the difficulty of adaptation therefore carried a different weight for me than it had earlier in the project.

This personal proximity also made me more aware of what can remain under-recognised in research language. Experiences that may appear relatively contained in academic writing, such as diagnostic delay, functional decline, or need for support, may in lived reality involve fear, helplessness, panic, grief, and profound disorientation for both patients and families. At the same time, this increased sensitivity created risks. There were points, particularly during the qualitative synthesis, when I became concerned about over-identifying with certain themes or giving greater emphasis to issues that felt especially close to my own experience. Reading and re-reading participant quotations about uncertainty, bodily change, disability, fear, and palliative transitions sometimes felt especially challenging. At times I needed to slow down, step back from the material, and return to the data later in order to consider whether my reading was being shaped more by grief than by the accounts themselves. I tried to distinguish between being sensitised to the data and being pulled too strongly by my own experience by repeatedly returning to the dataset, checking interpretations against the breadth of included studies, and remaining attentive to themes that did not map so closely onto my personal experience.

Supervision was essential in helping me manage this. Ongoing discussions with my research supervisors provided space to reflect on how my lived experience

might be shaping interpretation, emotional responses, and analytic emphasis. These conversations helped me remain aware of the risk of foregrounding some issues, particularly uncertainty, disability, palliative transition, and mistrust in care, more strongly than others. Input from my field supervisor, with specialist experience in cancer and sarcoma care, was also important in helping me contextualise both my personal responses and the wider clinical and systemic issues raised in the thesis. Returning to the data, revisiting interpretations, and writing reflexively were all part of staying grounded in the material rather than relying too heavily on what felt personally familiar or emotionally compelling. In this sense, reflexivity was not separate from rigour in this thesis; it was one of the ways rigour was maintained.

My lived experience also increased my awareness of the importance of context and representation in sarcoma research. My grandfather was treated in a rural area of Romania, within a healthcare system under considerable financial and structural pressure. This drew my attention more sharply to how sarcoma experiences are shaped not only by disease and treatment, but also by access to specialist care, rehabilitation, follow-up, palliative support, and broader healthcare resources. It also made me more aware of the limits of a predominantly White, female, Western sample in Study 2, even though I had deliberately explored demographic variables such as country of residence and ethnicity. This reinforced for me that psychosocial research in sarcoma must attend more carefully to those whose experiences are represented and those who may still remain less visible within the evidence base.

Overall, my lived experience of sarcoma influenced how I understood, interpreted, and carried this research. It made me more attuned to the experiences

described by adults living with sarcoma and their families, while also requiring greater caution around assumption, emphasis, and interpretation. The aim was not to remove personal experience from the research, but to recognise how it was shaping my perspective and to work as carefully and transparently as possible with the position I now occupied in relation to the topic.

4.7 Methodological Reflections, Strengths, and Limitations

This major research project has several methodological strengths. A central strength lies in the overall design, which combined a qualitative meta-synthesis with a quantitative survey study and, in doing so, allowed psychosocial impact in adult sarcoma to be examined through both lived experience and specific psychosocial factors associated with distress and wellbeing. This gave the project both breadth and depth. A further strength was the quality and relevance of the evidence brought together. The qualitative synthesis drew on a substantial and contemporary body of research, with most included studies rated as high quality, and provided a clearer adult-focused account of psychosocial impact and adaptation than had previously been available. The quantitative study also strengthened the project by examining psychosocial variables that have received little research attention in adult sarcoma, particularly self-compassion and body image distress, alongside pain interference and perceived social support. A further strength is that interpretation across the project was informed within the research team by specialist clinical expertise in sarcoma care and reflexive engagement with lived experience, which helped support a more clinically grounded and contextually sensitive reading of the findings.

There are, however, important limitations across the project as a whole. The project brings together two different forms of evidence, each with its own limits. The

qualitative synthesis could only reflect what has been examined in the available literature, while the survey study was limited by the features of a self-selected cross-sectional sample. As a result, the project offers a strong account of psychosocial impact and associated factors, but it cannot establish causality and is unlikely to capture the full range of experiences across all adults with sarcoma. In addition, the quantitative study did not include a comparison group, which limits the extent to which the findings can distinguish what may be more specific to sarcoma from patterns that may also be seen in other cancer or non-cancer populations.

Representation is also an important issue. Across both studies, Western settings, specialist services, and relatively engaged participants were more visible than non-specialist settings, earlier diagnostic phases, recurrence or palliative care, and those who may be more socially isolated or less able to participate in research. The survey sample was also predominantly female, highly educated, White, and recruited largely through support networks and online platforms.

A further limitation concerns heterogeneity. Sarcoma includes multiple tumour subtypes, treatment pathways, anatomical sites, and stages of disease, all of which may shape psychosocial experience differently. Although this project was designed to identify patterns across adult sarcoma, some subgroup-specific differences may have been obscured and may limit generalisability as a result. In both studies, GIST and Kaposi sarcoma were excluded to preserve conceptual coherence, given their distinct treatment pathways and psychosocial challenges, including long-term targeted therapy in GIST (Yang et al., 2019) and virus-related stigma and care pathways in Kaposi sarcoma (Collier et al., 2024). The findings are therefore most applicable to adults with bone sarcoma and soft tissue sarcoma subtypes. In Study 2, some clinical and demographic information was self-reported

rather than confirmed through medical records, which may also have introduced some inaccuracy.

Despite these limitations, the convergence across the two studies strengthens confidence in several key conclusions, particularly the importance of uncertainty, altered embodiment, pain-related disruption, body image distress, and the ongoing nature of psychosocial adaptation in sarcoma. Overall, this major research project provides a clearer adult-focused account of psychosocial impact in sarcoma while also identifying specific psychosocial factors associated with distress that may be clinically important. It also highlights what is still needed in the field, including more longitudinal research, more socio-demographically diverse samples, greater attention to underrepresented stages of the sarcoma pathway, and more consistent assessment of psychosocial outcomes in adult sarcoma along with more psychosocial intervention studies.

4.8 Methodological Implications and Future Directions

The findings of this major research project highlight several methodological priorities for future sarcoma psychosocial research. One is the need for greater conceptual and measurement precision. Existing sarcoma literature has been useful in showing that psychosocial burden is substantial, but it has often relied on broad quality-of-life or general psychosocial measures that do not always capture what may be most salient in sarcoma, such as rarity-related uncertainty, visible difference, altered function, rehabilitation burden, and more specific forms of social misunderstanding or isolation. This was also evident in the present project, where the qualitative findings suggested that the social experience of sarcoma involved more than the availability of general support, while the survey findings indicated that

broader perceived social support did not account for variation in distress in the sample. Future research would therefore benefit from either adapting existing measures or developing more sarcoma-sensitive assessment approaches.

A second priority is the need for more longitudinal and explanatory research. The present findings suggest that psychosocial difficulties in sarcoma develop across diagnosis, treatment, rehabilitation, and survivorship, and that adaptation cannot be understood well at a single time point. Earlier sarcoma studies have provided some indication that distress changes across phases of illness, but sustained longitudinal research remains limited. Future studies should therefore examine how uncertainty, pain interference, body image distress, self-compassion, social disconnection, and fear of recurrence develop over time, and how these are related to later psychosocial outcomes.

A third priority concerns representativeness. Several recent studies have examined barriers to recruiting underrepresented groups to clinical research, including cancer patients such as breast cancer, and have identified recurring challenges around language, trust, study burden, transport, cost, work and caregiving demands, and lack of culturally responsive recruitment processes (Heffernan et al., 2023; Vindrola-Padros et al., 2025). These issues are especially relevant to sarcoma research, where recruitment is often difficult because sarcoma is rare, care is concentrated within specialist centres, and many studies depend on support organisations, online communities, or specialist services to reach participants. These approaches are understandable and often necessary, but they can also produce samples that underrepresent people treated outside specialist centres, those with fewer resources, those who are less connected to support networks, and those from

minoritised ethnic or linguistic backgrounds. Vindrola-Padros et al., (2025), for example, found lower research participation across all ethnic minority groups in their hospital sample and highlighted the importance of translated materials, interpreters, family involvement in decision-making, and greater ethnic diversity within research teams. Heffernan et al., (2023) similarly reported that recruitment was improved by translated study documents, participant incentives, and reducing the number of in-person visits. These issues matter in sarcoma because healthcare systems, access to specialist care, and available resources are not experienced equally, and psychosocial experience is likely to vary accordingly. This is also consistent with wider cancer literature suggesting that ethnic minority patients experience poorer psychological outcomes and quality of life (Luckett et al., 2011).

Future sarcoma research therefore needs to place greater emphasis on inclusion at the level of study design and recruitment strategy. This includes broader recruitment beyond specialist centres and support groups where possible, attention to healthcare-system differences and local resource constraints, inclusion of participants from more diverse ethnic, socioeconomic, and geographical backgrounds, and better representation of those in recurrence, metastatic, and palliative phases. It also includes reducing practical barriers to participation by considering travel, time, cost, language, and accessibility from the outset. Fisher-Hoch et al., (2023) argue that successful recruitment of underrepresented groups depends on understanding community context, reducing participant burden, using culturally and linguistically appropriate communication, and involving trusted staff who are familiar to the communities being recruited. If future sarcoma studies continue to recruit mainly through specialist, English-speaking, and relatively

engaged populations, the evidence base will remain narrow and may not reflect the experiences of those whose access to care and support is more limited.

Finally, the field now needs more intervention and implementation research. Building on the factors identified in this project, the next step is to examine how they can be targeted in acceptable, feasible, and effective ways within sarcoma services. This includes intervention development, but also service-level research on how communication, care coordination, rehabilitation access, and transitions across the care pathway affect psychosocial outcomes.

4.9 Conclusion

This major research project examined the psychosocial impact of sarcoma in adults through two linked studies. Study 1 showed that sarcoma is experienced as cumulative psychosocial disruption, often beginning in diagnostic uncertainty and extending through treatment, recovery, and survivorship into altered embodiment, identity, function, and social life. Study 2 showed that adults with sarcoma report a substantial burden of anxiety and depressive symptoms, and that lower self-compassion, greater pain interference, and greater body image distress are especially relevant to psychosocial outcome.

A central contribution of this major research project is that it provides a more integrated account of distress and wellbeing in sarcoma than has generally been available in the literature to date. The findings suggest that psychosocial functioning in sarcoma cannot be understood adequately through generic distress models alone. Distress appears closely tied to bodily change, pain-related disruption, uncertainty, altered self-experience, social disconnection, and the quality of support and care available. Adaptation, in turn, is not a simple endpoint or the absence of difficulty. It

is better understood as a dynamic process of living with change, negotiating identity, managing uncertainty, and trying to establish meaning and participation under altered conditions.

This research project also has clear implications for clinical psychology and sarcoma care. It supports broader psychosocial assessment, individualised formulation, psychologically informed rehabilitation, and service models that recognise psychosocial need across the illness trajectory rather than only during acute treatment. It highlights the potential importance of self-compassion, body image distress, pain interference, and fear of recurrence as clinically relevant areas for assessment and intervention. It also suggests that specialist, coordinated, and sarcoma-informed care is itself psychosocially important.

More broadly, this major research project contributes to psycho-oncology and clinical psychology by showing that psychosocial distress in a rare and body-altering cancer cannot be understood separately from the body, from relationships, or from systems of care. In sarcoma, psychosocial burden is lived through all of these at once. Any adequate understanding of distress and adaptation in this population therefore needs to remain contextual, embodied, relational, and attentive to the realities of living with and beyond rare cancer.

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Appendix: Summary of Psycho-Oncology Journal Author Requirements

A permanent archived copy of the Psycho-Oncology author guidelines, corresponding to the April 2026 version:

<https://onlinelibrary.wiley.com/page/journal/10991611/homepage/forauthors.html>

Note. This table extracts the journal requirements most relevant to the two studies planned for submission to Psycho-Oncology.

Requirement	Chapter 2 manuscript	Chapter 3 manuscript
Intended manuscript	Study 1: Qualitative systematic review on the psychosocial impact of sarcoma	Study 2: Cross-sectional empirical study on factors influencing distress and wellbeing in sarcoma
Journal category	Review	Original Paper
Word limit	5,000 words maximum	4,000 words maximum
Maximum tables/figures	6 figures and/or tables	5 figures and/or tables
Maximum references	60 references	40 references
Abstract	Structured abstract, maximum 250 words	Structured abstract, maximum 250 words
Abstract format	Background; Aims; Methods; Results; Conclusions	Background; Aims; Methods; Results; Conclusions
Required main headings	Abstract; Background; Methods; Results; Discussion; Implications (clinical and research); Limitations; Conclusion	Abstract; Background; Methods; Results; Discussion; Implications (clinical and research); Limitations; Conclusion
Reporting guideline	PRISMA for systematic/scoping reviews; systematic reviews must be pre-registered with PROSPERO	STROBE for observational research/cross-sectional studies; STROBE checklist to be uploaded with submission
Specific content requirements	Key elements of a rigorous review should be evident, including explicit research question, rationale for type of review, search strategy, and inclusion criteria	Clinical implications should be made explicit
Word count exclusions	Title page, abstract, keywords, tables, figures, legends, references, acknowledgements, funding source information, data availability statement, and supplemental appendices are excluded from the word count	Title page, abstract, keywords, tables, figures, legends, references, acknowledgements, funding source information, data availability statement, and supplemental appendices are excluded from the word count
References currency	80% of references should be from the last 5 years, except seminal/classic papers	80% of references should be from the last 5 years, except seminal/classic papers
Author contributions	CRedit author contributions required immediately after the conclusion and before the reference list	CRedit author contributions required immediately after the conclusion and before the reference list

Keywords	Up to 10 keywords, listed alphabetically; journal advises inclusion of 'cancer' and 'oncology' for indexing	Up to 10 keywords, listed alphabetically; journal advises inclusion of 'cancer' and 'oncology' for indexing
Main text formatting and core manuscript requirements	Word or .rtf submission in English; title should be short and informative without abbreviations; manuscript must include acknowledgements, conflict of interest statement, abstract, keywords, main text, references, and ethical statement where relevant	Word or .rtf submission in English; title should be short and informative without abbreviations; manuscript must include acknowledgements, conflict of interest statement, abstract, keywords, main text, references, and ethical statement
Tables	Tables should be self-contained, complement rather than duplicate the text, be supplied as editable files rather than images, and include concise but comprehensive legends and footnotes understandable without the main text; abbreviations must be defined in footnotes	Tables should be self-contained, complement rather than duplicate the text, be supplied as editable files rather than images, and include concise but comprehensive legends and footnotes understandable without the main text; abbreviations must be defined in footnotes
Table footnote/statistical notation	Footnote symbols should be used in this order: †, ‡, §, ¶; *, **, *** should be reserved for P-values; statistical measures such as SD or SEM should be identified in headings	Footnote symbols should be used in this order: †, ‡, §, ¶; *, **, *** should be reserved for P-values; statistical measures such as SD or SEM should be identified in headings
Figures and legends	Figure legends should be concise but comprehensive and understandable without reference to the text; define symbols, abbreviations, and units of measurement	Figure legends should be concise but comprehensive and understandable without reference to the text; define symbols, abbreviations, and units of measurement
References style	References numbered consecutively in order of appearance; in-text citations as superscript numbers; Vancouver style content expected	References numbered consecutively in order of appearance; in-text citations as superscript numbers; Vancouver style content expected
Appendices / supporting information	Appendices published after references; for submission they should be separate files and referred to in the text; supporting information may be hosted online	Appendices published after references; for submission they should be separate files and referred to in the text; supporting information may be hosted online
Ethics / approvals	Not usually applicable unless review methods required ethics-related statements, but journal ethical and conflict of interest requirements still apply	Ethics statement and committee approval details, including approval number where applicable, must be included in the manuscript; written informed consent should be noted where relevant
Data availability / data sharing	Data availability statement required on acceptance; if data are shared, include repository and persistent identifier; if not shared, provide appropriate statement	Data availability statement required on acceptance; if data are shared, include repository and persistent identifier; if not shared, provide appropriate statement

Appendices – Chapter 2

Appendix A: PROSPERO Registration

17/04/2026, 13:54

PROSPERO


PROSPERO

International prospective register of systematic reviews

Psychosocial Impact of Sarcoma: A Systematic Review of Qualitative Studies

Rahela Beghean, Fiadhanit O'Keeffe, Fionnuala Larkin, Louise O'Driscoll

To enable PROSPERO to focus on COVID-19 submissions, this registration record has undergone basic automated checks for eligibility and is published exactly as submitted. PROSPERO has never provided peer review, and usual checking by the PROSPERO team does not endorse content. Therefore, automatically published records should be treated as any other PROSPERO registration. Further detail is provided [here](#).

Citation 1 change

Rahela Beghean, Fiadhanit O'Keeffe, Fionnuala Larkin, Louise O'Driscoll. Psychosocial Impact of Sarcoma: A Systematic Review of Qualitative Studies. PROSPERO 2024 CRD42024571502. Available from <https://www.crd.york.ac.uk/PROSPERO/view/CRD42024571502>.

REVIEW TITLE AND BASIC DETAILS

Review title

Psychosocial Impact of Sarcoma: A Systematic Review of Qualitative Studies

Original language title

Not applicable

Review objectives

What is the 'psychosocial impact' (emotional distress, social isolation, body image issues, changes in relationships) of sarcoma on individuals?

- What psychosocial factors influence the experience of Sarcoma?
- What are the psychosocial needs (managing depression, anxiety, fear, disability, pain, finance, service accessibility) of individuals with Sarcoma?

CHIP Tool

Context: Sarcoma (Individuals with sarcoma across various settings, e.g., hospitals, clinics, community, and homes, throughout their diagnosis, treatment, and survivorship journey).

How: Qualitative Research (This study will use qualitative methods to explore the psychosocial impact of sarcoma. Through interviews, focus groups, and thematic analysis, it will gather in-depth insights into the lived experiences of sarcoma patients).

Issues of Interest: The psychosocial impact of sarcoma on individuals (The study will focus on key psychosocial issues such as emotional distress, social isolation, body image issues, and

Appendix B: PRISMA 2020 Checklist

***Note: Page numbers correspond to pages in manuscript submitted to journal of Psycho-Oncology**

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 2
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 4-5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary Material 2
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 6-8
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pages 6-8
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pages 7-8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Not applicable
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Pages 6-8
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pages 6-8
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pages 6-8
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pages 6-8
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Not applicable

Section and Topic	Item #	Checklist item	Location where item is reported
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Pages 8-9
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Not applicable
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Not applicable
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 9
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Not applicable
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Not applicable
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Pages 10-17
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Not applicable
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Not applicable
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 3
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 18-21
	23b	Discuss any limitations of the evidence included in the review.	Page 23
	23c	Discuss any limitations of the review processes used.	Page 23
	23d	Discuss implications of the results for practice, policy, and future research.	Page 22
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5-6
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5-6
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not applicable
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 2
Competing interests	26	Declare any competing interests of review authors.	Page 2
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Pages 7-8 Table 4

Appendix C: Supplementary Material 1 (ENTREQ Checklist)

Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ Checklist (Tong, *et al.*, 2012)

Item No.	Guide and Description	Report Location
1. Aim	State the research question the synthesis addresses	Background
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	Methods (Data synthesis)
3. Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved)	Databases, search strategy and process - <i>CHIP</i>
4. Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	Literature search - <i>Inclusion and exclusion criteria</i>
5. Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources	Databases & search strategy and process – <i>Electronic searches & searching reference lists</i>
6. Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)	S1 Figure – <i>CHIP search strategy</i>
7. Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	Study selection – <i>Fig 1 PRISMA flow diagram</i>
8. Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions)	Table 1 - <i>Characteristics of included studies</i>
9. Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development)	Fig 1 – PRISMA flow diagram
10. Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g.	Study quality assessment

	assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings)	<i>-methods & results</i>
11. Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting)	Methods, Study quality assessment – <i>Table 2 - CASP</i>
12. Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required	Study quality assessment – <i>methods</i>
13. Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale	Study quality assessment – <i>S3 File. NICE</i>
14. Data extraction	Indicate which sections of the primary studies were analyzed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software)	Methods – <i>data extraction of relevant qualitative data</i>
15. Software	State the computer software used, if any	Nvivo v15
16. Number of reviewers	Identify who was involved in coding and analysis	Data synthesis
17. Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	Data synthesis
18. Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)	Results mapped to Study Frequency table 3 and <i>Theme Summary</i> table 4
19. Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive	Inductive process - <i>Theme Summary</i> Table 4
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation	Results - <i>Quotations and all sources given – Table 4</i>
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)	Discussion

Appendix D: Supplementary Material 2 (Search Strategy)

CHIP

Context	Sarcoma individuals at hospitals, outpatient clinics, communities, their homes
How	Qualitative methods
Issues	Psychosocial impact of sarcoma on the individuals with sarcoma Psychosocial factors influencing the experience Psychosocial needs of individuals with sarcoma
Population	Individuals with Sarcoma

Concept 1: Sarcoma

Concept 2: Psychosocial impact

CINAHL

Search 1: relevant subject headings for concept 1	(MH "Sarcoma") OR (MH "Soft Tissue Neoplasms") OR (MH "Bone Neoplasms+") OR (MH "Neoplasms, Connective and Soft Tissue+")
Search 2: keywords for concept 1	Sarcoma OR "Bone cancer" OR "Bone neoplasm*" OR "Bone tumor*" OR "Bone sarcoma" OR "Soft tissue cancer" OR "Soft tissue neoplasm*" OR "Soft tissue tumor*" OR "soft tissue sarcoma" OR "perivascular epithelioid cell tumor*" OR "PEComa" OR "GIST" OR "solitary fibrous tumour" OR "SFT" OR "Vascular Sarcomas" OR "Malignant peripheral nerve sheath tumours" OR "soft tissue tumor*"
Search 3: Combine search 1 and 2 with OR	
Search 4: relevant subject headings for concept 2	(MH "Support, Psychosocial+") OR (MH "Attitude+") OR (MH "Behavior and Behavior Mechanisms+") OR (MH "Self Concept+") OR (MH "Body Image+") OR (MH "Stress, Psychological+") OR (MH "Behavioral Symptoms+") OR (MH "Fatigue+") OR (MH "Mental Health") OR (MH "Psychological Well-Being") OR (MH "Quality of Life+") OR (MH "Adaptation, Psychological+") OR (MH "Coping+") OR (MH "Defense Mechanisms+") OR (MH "Emotions+") OR (MH "Psychosocial Functioning") OR (MH "Psychology, Social+") OR (MH "Pain+") OR (MH "Survivorship")

Search 5: keywords for concept 2	psychosocial OR psycho-social OR "psychosocial factor\$" OR socio-emotional OR psychological-social OR "psychosocial issue*" OR "psychosocial impact*" OR "Psychosocial implication*" OR "Psychosocial harm*" OR "Psychosocial benefit*" OR Stress OR Anxiety OR Depression OR coping OR "emotional distress" OR resilience OR fatigue OR loneliness OR "sexual function" OR "social support" OR relationships OR "financial stress" OR "money concern" OR "money worry" OR "social isolation" OR "Return to work" OR "return to sport" OR "Self-esteem" OR "body image" OR "Social stigma" OR "emotional adjustment" OR "psychological well-being" OR "adaptive behavior\$" OR "patient* experience*" OR survivor*
Search 6: Combine search 4 and 5 with OR	
Search 7: Combine search 3 with search 6 with AND	
Limiters:	"interview*" or "focus group*" or "survey*" or "questionnaire*" or "observ*" or "discourse analysis" or "content analysis" or "interpretive phenomenological analysis" or "IPA" or "thematic analysis" or "narrative analysis" or "conversation analysis" or "grounded theory" or "qualitative analysis" or "qualitative" or "mixed method"

Medline

Search 1: relevant subject headings for concept 1	exp "Neoplasms, Connective and Soft Tissue"/ OR exp Sarcoma/ OR exp Bone Neoplasms/ OR exp Soft Tissue Neoplasms
Search 2: keywords for concept 1	Sarcoma.mp OR "Bone cancer".mp OR "Bone neoplasm*".mp OR "Bone tumor*".mp OR "Bone sarcoma".mp OR "Soft tissue cancer".mp OR "Soft tissue neoplasm*".mp OR "Soft tissue tumor*".mp OR "soft tissue sarcoma".mp OR "perivascular epithelioid cell tumor*".mp OR "PEComa".mp OR "GIST".mp OR "solitary fibrous tumour".mp OR "SFT".mp OR "Vascular Sarcomas".mp OR "Malignant peripheral nerve sheath tumours".mp OR "soft tissue tumor*".mp
Search 3: Combine search 1 and 2 with OR	
Search 4: relevant subject headings for concept 2	exp "Behavior and Behavior Mechanisms"/ OR exp Self Concept/ OR exp Stress, Psychological/ OR exp Behavioral Symptoms/ OR exp Fatigue/ OR exp Mental Health/ OR exp Adaptation, Psychological/ OR exp

	Defense Mechanisms/ OR exp Emotions/ OR exp Psychosocial Functioning/ OR exp Psychology, Social/ OR exp Pain/ OR Resilience, Psychological/ OR exp "Quality of Life"
Search 5: keywords for concept 2	psychosocial.mp OR psycho-social.mp OR "psychosocial factor\$.mp OR socio-emotional.mp OR "psychological-social".mp OR fatigue.mp OR "psychosocial issue*".mp OR "psychosocial impact*".mp OR "psychosocial implication*".mp OR "psychosocial harm*".mp OR "psychosocial benefit*".mp OR "Social Isolation".mp OR "Social Stigma".mp OR stress.mp OR anxiety.mp OR coping.mp OR "emotional distress".mp OR "sexual function".mp OR "social support".mp OR relationships.mp OR "money concern".mp OR "money worry".mp OR "financial stress".mp OR "return to work".mp OR "return to sport".mp OR loneliness.mp OR "Emotional Adjustment".mp OR "Body Image".mp OR Depression.mp OR "Mental Fatigue".mp OR "Psychological Well-Being".mp OR "Self-esteem".mp OR "adaptive behavior\$.mp OR "patient* experience*".mp OR survivor*.mp
Search 6: Combine search 4 and 5 with OR	
Search 7: Combine search 3 with search 6 with AND	
Limiters: Adults English language Humans	interview*.mp or "focus group*".mp or survey*.mp or questionnaire*.mp or observ*.mp or "discourse analysis".mp or "content analysis".mp or "interpretive phenomenological analysis".mp or IPA.mp or "thematic analysis".mp or "narrative analysis".mp or "conversation analysis".mp or "grounded theory".mp or "qualitative analysis".mp or qualitative.mp or "mixed method*".mp

Web of Science (no subject headings)

Search 1: keywords for concept 1	Sarcoma OR "Bone cancer" OR "Bone neoplasm*" OR "Bone tumor*" OR "Bone sarcoma" OR "Soft tissue cancer " OR "Soft tissue neoplasm*" OR "Soft tissue tumor*" OR
----------------------------------	--

	"soft tissue sarcoma" OR "perivascular epithelioid cell tumo*" OR "PEComa" OR "GIST" OR "solitary fibrous tumour" OR "SFT" OR "Vascular Sarcomas" OR "Malignant peripheral nerve sheath tumours" OR "soft tissue tumo*"
Search 2: keywords for concept 2	psychosocial OR psycho-social OR "psychosocial factor\$" OR socio-emotional OR psychological-social OR "psychosocial issue*" OR "psychosocial impact*" OR "Psychosocial implication*" OR "Psychosocial harm*" OR "Psychosocial benefit*" OR emotions OR Stress OR Anxiety OR Depression OR coping OR "emotional distress" OR "cognitive functioning" OR "psychological adaptation" OR "social adaptation" OR resilience OR adjustment OR fatigue OR loneliness OR "sexual function" OR "social support" OR relationships OR "financial stress" OR "money concern" OR "money worry" OR "social isolation" OR "Return to work" OR "return to sport" OR "Self-esteem" OR "Self-concept" OR "body image" OR "Social stigma" OR "emotional adjustment" OR "quality of life" OR "psychological well-being" OR "adaptive behavio\$" OR "patient* experience*" OR survivor*
Search 3: combine searches with AND	
Search 4: Add limiters with AND	"interview*" or "focus group*" or "survey*" or "questionnaire*" or "observ*" or "discourse analysis" or "content analysis" or "interpretive phenomenological analysis" or "IPA" or "thematic analysis" or "narrative analysis" or "conversation analysis" or "grounded theory" or "qualitative analysis" or "qualitative" or "mixed method*"

PsychINFO

Search 1: relevant subject headings for concept 1 No relevant subject headings for sarcoma	N/A
Search 2: keywords for concept 1	Sarcoma OR "Bone cancer" OR "Bone neoplasm*" OR "Bone tumo*" OR "Bone sarcoma" OR "Soft tissue cancer" OR "Soft tissue neoplasm*" OR "Soft tissue tumo*" OR "soft tissue sarcoma" OR "perivascular epithelioid cell tumo*" OR "PEComa" OR

	“GIST” OR “solitary fibrous tumour” OR “SFT” OR “Vascular Sarcomas” OR “Malignant peripheral nerve sheath tumours” OR “soft tissue tumo*”
Search 3: Combine search 1 and 2 with OR	
Search 4: relevant subject headings for concept 2	(((((DE "Psychosocial Factors" OR DE "Community Resources" OR DE "Protective Factors" OR DE "Psychosocial Outcomes" OR DE "Risk Factors" OR DE "Social Resources") OR (MM "Resilience (Psychological)")) OR (MM "Psychological Stress")) OR (MM "Anxiety")) OR (MM "Depression (Emotion)")) OR (DE "Coping Behavior" OR DE "Coping Style")) OR (MM "Adaptive Behavior")) OR (MM "Interpersonal Relationships")) OR (DE "Social Support" OR DE "Perceived Social Support")) OR (DE "Self-Concept" OR DE "Self-Compassion" OR DE "Self-Confidence" OR DE "Self-Esteem")) OR (DE "Quality of Life" OR DE "Health Related Quality of Life" OR DE "Quality of Work Life")) OR (DE "Body Image" OR DE "Body Dissatisfaction" OR DE "Body Esteem" OR DE "Body Image Disturbances"))
Search 5: keywords for concept 2	psychosocial OR psycho-social OR "psychosocial factor\$" OR socio-emotional OR "psychological-social" OR fatigue OR "psychosocial issue*" OR "psychosocial impact*" OR "psychosocial implication*" OR "psychosocial harm*" OR "psychosocial benefit*" OR "Social Isolation" OR "Social Stigma" OR stress OR anxiety OR "adaptive behavio\$" OR coping OR "emotional distress" OR "cognitive functioning" OR "psychological adaptation" OR "social adaptation" OR resilience OR adjustment OR "sexual function" OR "social support" OR relationships OR "money concern" OR "money worry" OR "financial stress" OR "return to work" OR "return to sport" OR Resilience, Psychological OR loneliness OR "Interpersonal Relations " OR Emotions OR "Emotional Adjustment" OR Pain OR "Self- Concept" OR "Body Image" OR Depression OR "Mental Fatigue" OR "Quality of Life" OR "Psychological Well-Being" OR "Self- esteem" OR "patient* experience*" OR survivor*

Search 6: Combine search 4 and 5 with OR	
Search 7: Combine search 3 with search 6 with AND	
Limiters:	"interview*" or "focus group*" or "survey*" or "questionnaire*" or "observ*" or "discourse analysis" or "content analysis" or "interpretive phenomenological analysis" or "IPA" or "thematic analysis" or "narrative analysis" or "conversation analysis" or "grounded theory" or "qualitative analysis" or "qualitative" or "mixed method*"

Appendix E: Supplementary Material 3 (Eligibility Criteria)

Inclusion Criteria

- Peer-reviewed empirical studies employing established qualitative methodologies (e.g., interviews, focus groups, qualitative analysis).
- Participants currently or previously diagnosed with sarcoma.
- All sarcoma subtypes and stages, with the exception of Gastrointestinal Stromal Tumours (GIST) and Kaposi's sarcoma.
- Mixed-methods studies, provided that qualitative data could be clearly extracted and analysed independently.
- Studies published in the English language.
- Participants aged 18 years or older at the time of study participation. Studies including participants under 18 years were eligible only where adult data were analysed and reported separately.
- Studies reporting empirical qualitative findings.
- Studies in which the psychosocial impact of sarcoma was not the primary focus were included where a distinct section, theme, or subtheme addressed psychosocial experiences; only relevant qualitative data were extracted.
- Studies exploring the perspectives of caregivers, family members, or healthcare professionals were included where these accounts explicitly described or illuminated the experiences of individuals living with sarcoma.
- Studies conducted in any geographical location.
- No restrictions were placed on year of publication.

Exclusion Criteria

- Quantitative studies without a qualitative component.
- Unpublished manuscripts, theses, conference abstracts, editorials, commentaries, or review articles.
- Studies including mixed diagnostic groups (e.g., multiple cancer types) where findings for participants with sarcoma could not be clearly distinguished.
- Studies including mixed respondent groups (e.g., patients and caregivers) where patient data could not be clearly separated.
- Studies focusing exclusively on caregiver, family member, or healthcare professional experiences without direct reference to patient experiences.
- Qualitative studies that did not include raw patient data, such as verbatim quotations.

Appendix F: Decision Tracking Sample

Decision Tracking for Study 1 (Qualitative Systematic Review)								
Study	Year	Title	Notes / Query	Label	Reviewer 1 Decision (RB)	Reviewer 2 Decision (ER)	Reviewer 3 Decision (FO'K/L'OD)	Action / Notes
Priyanto et al	2023	Physical Well-Being Needs of Bone Cancer Patients during Treatment in the Hospital: A Qualitative Study.	AGE: 4 participants under 18 - data cannot be separated for extraction. Should we revise eligibility criteria?	AYA?	Maybe	Exclude	Exclude	Action: to double check that data for 18+ participants cannot be extracted
Martins et al	2024	A Qualitative Study of the Factors Influencing Patients' Experience of Soft Tissue Sarcoma in the United Kingdom.	AGE: unclear if included under 18 - data cannot be separated for extraction. Needs another review	AYA?	Maybe	Maybe	Include	to include following aother review - participants >18
Weaver et al	2020a	The unmet needs of patients with sarcoma	AGE: The study did not provide details on the age of participants at the time of the study. They provided age at the time of diagnosis with the miniumum being 15yrs of age. However they did state that participants were eligible to participate in the study if they were over 16 years of age at the time of their interview. So it is unclear whether any of the participants were <18yrs of age at the time of the interview, but some could have been based on the	AYA?	Maybe	Exclude	Exclude	Exclude since its AYA
Weaver et al	2020b	The complexity of diagnosing sarcoma in a timely manner: perspectives of health professionals, patients, and carers in Australia.	AGE: This study have the same sarcoma participants as the previous study. Again, study did not provide details on the age of participants at the time of the study. Participants were eligible if they were over 16 years of age at the time of their interview. Provided ages at time of diagnosis with min being 15yrs. So it is unclear whether any of the participants were <18yrs of age at the time of the interview, but some could have been based on the eligibility	AYA?	Maybe	Exclude	Exclude	Exclude since its AYA
Pearce et al	2020	Renegotiation of identity in young adults with cancer: A longitudinal narrative study.	AGE: recruited participants between ages 16-30 but there is no way to tell if those included are <18. Also it's mixed cancers - with sarcoma participants data all combined and not separated to be able to extract. Should I contact author to get clarification on age....? but since the sarcoma data were not separated this study might be excluded anyways	AYA & Mixed Cancer	Maybe	Exclude	Exclude	Exclude since its AYA
Wang et al	2019	Assessment of patient experiences following total sacrectomy for primary malignant sacral tumors: A qualitative study.	AGE: included participants between ages 13-75 and data was not separated to be able to include 18+ only. Also it is mixed cancers and data not extractable for sarcoma. Same as above.	AYA & Mixed Cancer	Maybe	Exclude	Exclude	Exclude since its AYA

Appendix H: Sample of Audit Trail for Thematic Synthesis *Thomas & Harden, 2008)

Stage 1. Line-by-line coding	Stage 2. Descriptive themes	Stage 3. Analytical themes
SummaryReference STS (lower and upper extremity) surgery (n=28) - amputation (n=5), radiation (n=28), chemotherapy (n=10) (1) changes in mood, (2) worry, and (3) body image concern themes overlapped and were not mutually exclusive. Changes in mood ----- Experiencing Low Mood----- Low mood at the time of diagnosis was accompanied by fear and shock in participants. Additionally, majority of participants who reported during the phase of treatment and recovery, linked their low physical symptoms and physical limitations due to surgical procedures. One participant expressed how direct the impact of physical limitations had been. Participants emphasized that the psychological impact impacted their perceived QOL. One woman who reported experiencing more difficulty controlling her emotions. Two participants reported experiencing distress before receiving their diagnosis having a particularly hard time. ----- Loss of control and independence --- In addition to the disruption of a normal routine during treatment, participants felt that their life was being scheduled for them by secretarial personnel, which contributed to the feeling of loss of independence. Invasive surgical procedures resulted in a lack of or reduced mobility (75%) participants and made them dependent on others in their daily endeavors. Participants reported having to adjust their routine activities and hobbies, which were physical in nature. Three participants and those who made a full recovery reported the time to be limited to the time in treatment and recovery from the treatment. Participants whose disease has returned, or those who experience complications reported ongoing struggles with loss of independence. Independence was reported to be burdensome and difficult to accept. CODE STRIPES • Shame • Shame • Shame • Fear & anxiety over functional loss • Fear & anxiety over functional loss • Impact on mood • Impact on mood • Impact on mood • Impact on mood • Disruption to life • Disruption to life • Mobility • Mobility • Mobility • Mobility • Living with limitations - Mobility, Identity & Loss of Independence • Living with limitations - Mobility, Identity & Loss of Independence • Living with limitations - Mobility, Identity & Loss of Independence • Living with limitations - Mobility, Identity & Loss of Independence	○ Adapting to a shorter life ○ Adjustment difficulty ○ Ambivalence ○ Challenges ○ Coping ○ Disruption to life ○ Experience of Diagnosis... ○ Experience of loneliness ○ Experience of Post-treatment... ○ Experience of Prognosis ○ Experience of Return... ○ Experience of Survivor... ○ Experience of Treatment ○ Experienced losses ○ Experiences with HCP ○ Facilitators to adjustment... ○ Factors influencing QoL ○ Feeling like a burden ○ High price to pay for care... ○ Impact on Mood ○ Impact on sports ○ Impact on work ○ Information-seeking behavior... ○ Lifestyle changes ○ Men vs Women ○ Not feeling understood ○ Not trusting sarcoma ○ Patient's Needs ○ Pervasive Uncertainty ○ Physical impact ○ Positive Impact ○ Social impact	✓ ○ In the Dark - Delays, Diagnosis... ○ Fragmented diagnosis... ○ Rare & Unprepared... ✓ ○ No Longer the Same - ... ○ Living in a Changed... ○ Social Disconnection... ○ The Emotional Cost... ○ The Weight of Function... ✓ ○ Treatment as Threat ○ The Burden of Recovery... ✓ ○ The Invasiveness of... ✓ ○ Chemotherapy &... ○ Changes in coordination... ○ Diarrhea ○ Fatigue ○ Impact on fertility... ○ Mood ○ Nausea ○ Sexual function ○ Shortness of breath... ○ Weakened immunity... ✓ ○ Surgery ○ Pain ○ Sleep ✓ ○ What do people with sarcoma... ○ Diagnostic improvement... ○ Specialist, Individual... ✓ ○ What Helped Along the way... ○ Choosing Not to Know... ○ Relational & System... ○ Self-Management - ...
- Initial inductive coding of extracted findings across the included studies. - Codes were grouped into descriptive themes representing recurring patterns across studies. - Analytical themes were then generated to provide a more interpretive account of the data.		

Appendices – Chapter 3

Appendix I: STROBE Checklist

STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies

***Note: Page numbers correspond to pages in manuscript submitted to journal of Psycho-Oncology**

	Item No	Recommendation	Page(s) in manuscript
Title and abstract			
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Pages 4-6
Objectives	3	State specific objectives, including any prespecified hypotheses	Pages 6-7
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Pages 7-8
Participants	6 (a)	Give the eligibility criteria, and the sources and methods of selection of participants	Pages 7-8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Pages 8-9
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	
Bias	9	Describe any efforts to address potential sources of bias	See Pages 8-9
Study size	10	Explain how the study size was arrived at	See Page 10
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	See Page 10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	See Page 10
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	See page 11

		(b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	See Tables 2-5
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest	See Tables 1-2
Outcome data	15*	Report numbers of outcome events or summary measures	See Table 2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	See Table 4- 5
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	See Page 14 & See S2
Discussion			
Key results	18	Summarise key results with reference to study objectives	See Page 15-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	See Page 21-22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	See Page 15-19
Generalisability	21	Discuss the generalisability (external validity) of the study results	See Page 20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	N/A

Appendix J: Supplementary Table 1a*Associations of Categorical Demographic and Clinical Variables with Anxiety and Depression*

Variable	Test	Anxiety	Depression
Gender	Independent-samples t test	$t(160) = -0.79, p = .430, d = -0.15$	$t(160) = -0.21, p = .838, d = -0.04$
Education	One-way ANOVA	$F(2, 161) = 6.97, p = .001, \eta^2 = .080$	$F(2, 161) = 1.72, p = .182, \eta^2 = .021$
Employment status	One-way ANOVA	$F(3, 160) = 2.95, p = .035, \eta^2 = .052$	$F(3, 160) = 3.50, p = .017, \eta^2 = .062$
Sarcoma subtype	One-way ANOVA	$F(4, 159) = 1.32, p = .267, \eta^2 = .032$	$F(4, 159) = 2.25, p = .066, \eta^2 = .054$
Primary tumour location	One-way ANOVA	$F(5, 158) = 1.52, p = .188, \eta^2 = .046$	$F(5, 158) = 2.34, p = .044, \eta^2 = .069$
Treatment intensity	One-way ANOVA	$F(5, 158) = 0.58, p = .716, \eta^2 = .018$	$F(5, 158) = 1.66, p = .147, \eta^2 = .050$
Country of residence	One-way ANOVA	$F(15, 148) = 0.65, p = .833, \eta^2 = .061$	$F(15, 148) = 0.93, p = .537, \eta^2 = .086$
Ethnicity	One-way ANOVA	$F(9, 154) = 0.79, p = .623, \eta^2 = .044$	$F(9, 154) = 0.58, p = .808, \eta^2 = .033$

Note. Anxiety = HADS Anxiety total score; Depression = HADS Depression total score. Gender was analysed using independent-samples t tests. Education, employment status, sarcoma subtype, primary tumour location, treatment status, country of residence, and ethnicity were analysed using one-way analyses of variance (ANOVAs). Effect sizes are reported as Cohen's d for the t tests and eta squared (η^2) for the ANOVAs. Two-tailed tests are reported.

Appendix J: Supplementary Table 1b

Post-Hoc Comparisons for Significant Group Differences in Anxiety and Depression

Variable	Outcome	Comparison	Mean diff.	SE	95% CI	p
Education	HADS-A	NFQ Level $\leq$ 5 – NFQ Level 6 or 7	2.44	0.94	[0.23, 4.65]	.027
Education	HADS-A	NFQ Level $\geq$ 8 – NFQ Level 6 or 7	2.90	0.79	[1.03, 4.77]	< .001
Employment status	HADS-A	Employed – Retired	2.35	0.88	[0.05, 4.64]	.043
Primary tumour location	HADS-D	Other – Extremities	7.16	2.47	[0.03, 14.30]	.049
Primary tumour location	HADS-D	Other – Trunk	7.79	2.49	[0.60, 14.98]	.025
Primary tumour location	HADS-D	Other – Pelvis	8.60	2.65	[0.97, 16.24]	.017

Note. HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; Mean diff. = mean difference; CI = confidence interval. Post-hoc comparisons were conducted using Tukey's HSD; only statistically significant pairwise comparisons are shown.

Appendix K: Supplementary Table 2

Pearson Correlations Between Self-Compassion Subscales and Key Study Variables

Variable	1	2	3	4	5	6
1. Self-Judgement	—					
2. Isolation	.52**	—				
3. Over-Identification	.59**	.59**	—			
4. Self-Kindness	-.50**	-.41**	-.51**	—		
5. Common Humanity	-.49**	-.35**	-.50**	.63**	—	
6. Mindfulness	-.43**	-.33**	-.56**	.51**	.57**	—
7. Anxiety (HADS-A)	.43**	.45**	.62**	-.41**	-.32**	-.44**
8. Depression (HADS-D)	.34**	.50**	.52**	-.47**	-.34**	-.41**
9. Body Image Distress (BIS)	.35**	.38**	.37**	-.36**	-.33**	-.25**
10. Social Support (MSPSS)	-.21**	-.23**	-.12	.13	.16	.07
11. Pain Interference	.04	.13	.15	-.14	-.13	-.18*
12. Age	-.20*	-.17*	-.29**	.13	.14	.13

Note. Values represent Pearson correlations (two-tailed).

N ranges from 155 to 164 due to missing data. * $p < .05$. ** $p < .01$.

Appendix L: Study 2 Poster Invitation



PSYCHOSOCIAL WELLBEING AND DISTRESS IN SARCOMA

Do you, or someone you know, have a current or past diagnosis of Sarcoma?

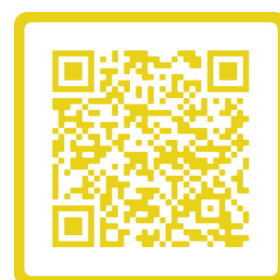
We are conducting a research study to **understand the psychosocial impact of sarcoma** on the individual.

- **Purpose:** Our study seeks to understand and explore the unique psychosocial challenges faced by individuals living with sarcoma, a rare type of cancer affecting bones, cartilage, and soft tissues and identify factors that affect their well-being and distress.
- **Why it Matters?** Your participation will contribute to a deeper understanding of the challenges faced by individuals with sarcoma and inform targeted interventions to enhance support services.
- **Who Can Participate?**
 - Individuals who have or have had a diagnosis of Sarcoma
 - 18 years of age or older
 - Able to understand and respond in English

Scan the QR code to see more

OR use the following URL:

https://ucc.qualtrics.com/jfe/form/SV_bHt1IQ6r9YyyCqO



SCAN ME

Study conducted in collaboration with St. Vincent's University Hospital and St. Vincent's Sarcoma Ireland Network.

This research has obtained ethical approval from the University College Cork Clinical Psychology Research Ethics Committee (CPREC) and has been approved by St. Vincent's University Hospital Ethics Committee

Appendix M: Supplementary Material 1 (Participant Information & Consent Form)



PARTICIPANT INFORMATION AND CONSENT FORM

STUDY TITLE: Psychosocial Wellbeing and Distress in Sarcoma

NAME OF PRINCIPAL INVESTIGATOR: Dr. Louise O'Driscoll, Principal Specialist Psychologist in Psycho-oncology

You are being invited to participate in a research study. Thank you for taking time to read this.

WHAT IS THE PURPOSE OF THIS STUDY?

The aim of the study is to gain a deeper understanding of the psychosocial impact of sarcoma. Sarcoma can pose unique challenges to individuals and their families, affecting various aspects of their lives. This study seeks to explore the emotional, social, and psychological experiences of individuals diagnosed with sarcoma, with a focus on exploring and identifying factors that may influence psychosocial wellbeing and distress.

WHY HAVE I BEEN CHOSEN?

You have been chosen to participate in this study because you have been diagnosed with sarcoma or have a history of sarcoma diagnosis. Your first-hand experience and perspectives are crucial for gaining a comprehensive understanding of the psychosocial aspects of sarcoma and identifying factors that influence wellbeing and distress in individuals with sarcoma.

WHAT WILL HAPPEN IF I VOLUNTEER?

Participation in this study is completely voluntary. There is no obligation to participate, you can withdraw from the study at any stage up to the point of data submission. Deciding not to participate in this study will not affect your future treatment in any way. If you agree to participate, you will be asked to complete a survey comprising questions about various aspects of your life, including your experiences with sarcoma, emotional wellbeing, pain, body image, social support, and coping strategies. The survey is expected to take approximately 20-30 minutes to complete.

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

While there are no direct benefits to you from participating in this study, your participation will contribute to advancing knowledge in the field of sarcoma research. The findings may lead to the development of improved support services and interventions tailored to the needs of individuals with sarcoma, ultimately enhancing the quality of care and support provided.

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

We do not anticipate any negative outcomes from participating in this research, however, participation may involve emotional discomfort or distress due to the nature of the questions asked about your experiences with sarcoma, including aspects of diagnosis, management of sarcoma, and the impact of sarcoma on your life, which may evoke difficult emotions or memories. If you feel that participating in this study could possibly cause you distress, do not participate. If you choose to participate and experience distress at any point, please contact your GP or hospital for referral to psychology services. You can also contact the Irish Cancer Society Support Line and speak to a nurse on 1800 200 700.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?

If you decide not to participate in this study your treatment will not be affected in any way.

CONFIDENTIALITY

Your privacy and confidentiality are of utmost importance. All information collected during the study is anonymised at source. This means that your name, address or date of birth will not be collected during this survey. As such, once your survey response is collected, we will not be able to identify who the responses refer to.

WHAT WILL HAPPEN TO THE INFORMATION I GIVE?

The anonymized data will be securely stored on the University College Cork One Drive system. On completion the data will be stored for a minimum of 10 years.

WHAT WILL HAPPEN TO THE RESULTS?

The information you provide will contribute to a report as part of a Major Research Project and will be submitted to UCC as part of the Doctor in Clinical Psychology course requirements. The results may contribute to research publications and/or conference presentations and may also be used in future research studies/projects.

COMPENSATION

No, we are not paying patients to take part in the study.

LIABILITY

Your doctors are adequately insured by virtue of their participation in the Clinical Indemnity Scheme.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

This research project is being conducted by the School of Applied Psychology in University College Cork (UCC), St. Vincent's Sarcoma Ireland Network (SSIN) and St. Vincent University Hospital (SVUH). The research team consists of Rahela Beghean, Lead Investigator and Trainee Clinical Psychologist with UCC and HSE, Dr. Fiadhnaith O'Keeffe, Senior Lecturer in UCC and Academic Supervisor, Dr. Fionnuala Larkin, Senior Lecturer in UCC and Co-Academic Supervisor, Dr. Louise O'Driscoll, Principal Specialist Psychologist in Psycho-oncology in St. Vincent University Hospital (SVUH) and Field Supervisor, Hazel Murray, Advance Nurse Practitioner for Sarcoma in SVUH, Aine Sheridan, Clinical Nurse Specialist in Sarcoma, and Dr. Mark Doherty, Consultant Medical Oncologist in SVUH. This study is not receiving any external funding.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

The St. Vincent's Healthcare Group, Ethics and Medical Research Committee and the University College Cork Clinical Psychology Research Ethics Committee (CPREC) have reviewed and approved this study.

CONTACT DETAILS

If you have any queries about this research, you can contact the Trainee Clinical Psychologist, Rahela Beghean, by email on rahelabeghean@umail.ucc.ie.

RESEARCH PARTICIPANT'S RIGHTS

If you have any questions about your rights as a research participant, then you may contact the Hospital's Quality & Patient Safety Department 01 2214013. Please note that agreeing to participate in a research program with St. Vincent's University Hospital, you acknowledge that you have read, understood and agree to this Participant Information and Consent Form.

HOW IS MY DATA SECURED

- St. Vincent's University Hospital operates and uses appropriate technical and physical security measures to protect your data.
- We will not collect any identifiable information such as name, date of birth, or address. As such, the data that we will be collecting, will be fully anonymized.

STORAGE OF DATA

- We will keep your data for a minimum of 10 years, as per UCC's policy. This may mean that some information is held for longer than other information.

YOUR RIGHTS

- We will not collect any identifiable information such as name, date of birth, or address. The data that we will be collecting, will be fully anonymized. You have the right to withdraw from the study at any stage up to the point of data submission. At this point your data will be combined with that of other participants and can no longer be retracted.

CHANGES TO THIS INFORMATION

- We may decide to make changes to this Participant Information and Consent Form. If a change is made, we will notify you in person of such changes. An updated Participant Information and Consent Form will be provided to you in advance of any change actually taking effect.

CONTACT US

- For further information or if you have any questions or queries about this Participant Information and Consent Form, please contact:

By letter:	Doctor of Clinical Psychology, School of Applied Psychology, University College Cork, Co. Cork
By email:	rahelabeghean@umail.ucc.ie
By telephone:	087-439-8047

CONSENT FORM**PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX**

- I have read and understood the Participant Information and Consent Form
YES ☐ NO ☐
- I understand that my participation is voluntary
YES ☐ NO ☐
- I have had the opportunity to ask questions and discuss the study
YES ☐ NO ☐
- I have received satisfactory answers to all my questions YES ☐ NO ☐
- I have received enough information about this study YES ☐ NO ☐
- I understand that I am free to withdraw from the study at any time (up to the point of data submission) without giving a reason and without this affecting my future medical care.
YES ☐ NO ☐
- I am aware of the potential risks, benefits and alternatives of this research study.
YES ☐ NO ☐
- I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.
YES ☐ NO ☐
- I understand that any secondary or incidental findings/results uncovered during the study, which are not directly related to the primary research objectives, will be handled with care and consideration. These findings will be managed according to established protocols, with appropriate action taken if they are deemed to have significant clinical implications, ensuring my wellbeing and privacy.

YES ☐ NO ☐

- I understand that my data will be stored for 10 years and the information I provide will contribute to a written thesis, may contribute to research publications and/or conference presentations and may also be used in future research studies/projects

YES ☐ NO ☐

- I am 18 years or older

YES ☐ NO ☐

- I am an individual having been diagnosed with Sarcoma

YES ☐ NO ☐

- I can read and write.

YES ☐ NO ☐

- I can provide informed consent

YES ☐ NO ☐

- I give informed consent to have my anonymised data processed as part of this research study.

YES ☐ NO ☐

STORAGE & FUTURE USE OF INFORMATION:

- I give permission for material/data to be stored for possible future research related to the current study without further consent being required but only if the research is approved by a Research Ethics Committee.

YES ☐ NO ☐

FOR STAFF/INVESTIGATOR ONLY

Patient/Outpatient gave explicit consent for their data to be processed as part of this research study.

YES ☐ NO ☐

Investigator's Signature: _____

Date: _____

Investigator's Name (block capitals): _____

Appendix N: Supplementary Material 2 (Questionnaire & Measures)

The following are a list of demographic questions

1. Gender:

- ☐ Female
- ☐ Male
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ Other (please specify)

2. Please state your age in the box below:

3. Education: Please specify education level

- ☐ No formal education/ training
- ☐ Primary education NFQ Levels 1 or 2
- ☐ Lower Secondary NFQ Level 3- Junior/Inter/Group Certificate
- ☐ Upper Secondary. NFQ Levels 4 or 5- Leaving Certificate
- ☐ Technical or Vocational NFQ Levels 4 or 5
- ☐ Advanced Certificate/ Completed Apprenticeship NFQ Level 6
- ☐ Higher Certificate NFQ Level 6
- ☐ Ordinary Bachelor Degree or National Diploma NFQ Level 7
- ☐ Honours Bachelor Degree/ Professional qualification or both NFQ Level 8
- ☐ Postgraduate Diploma or Master's Degree NFQ Level 9
- ☐ Doctorate (PhD) or higher NFQ Level 10
- ☐ Prefer not to say
- ☐ Other (please specify)

4. Ethnicity:

- ☐ White-Irish
- ☐ White-Irish Traveller
- ☐ Roma
- ☐ White-British
- ☐ White-Eastern European
- ☐ Any other white background
- ☐ Black or Black Irish African
- ☐ Black/Black Irish Caribbean
- ☐ Any other Black background
- ☐ Asian/Asian Irish Chinese
- ☐ Asian/Asian Irish Indian/Pakistani/Bangladeshi
- ☐ Any other Asian background
- ☐ Arabic

- ☐ Mixed ethnic background, write in the description
- ☐ Any other ethnic group, write in the description
- ☐ Prefer not to say
- ☐ Other (please specify)

5. Employment Status:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed looking for work
- ☐ Unemployed not looking for work
- ☐ Retired
- ☐ Student
- ☐ Other (please specify):

6. Country of Residence/Location:

- ☐ Ireland
- ☐ UK
- ☐ Other (please specify)

The following are a list of clinical information questions.

7. Date of Sarcoma Diagnosis: ____/____/____ (MM/YYYY)

8. Type of Sarcoma (e.g., liposarcoma, synovial sarcoma, osteosarcoma, chondrosarcoma etc.):

9. Location of primary Sarcoma:

- ☐ Extremities (arms and legs)
- ☐ Trunk (chest, abdomen)
- ☐ Head and neck
- ☐ Other (please specify):

10. Current Treatment Status:

- ☐ Currently undergoing treatment
- ☐ Completed treatment
- ☐ Not yet started treatment
- ☐ Palliative care
- ☐ Pending/"Watch and Wait"
- ☐ No evidence of disease (NED)
- ☐ Other (please specify)

11. Types of Treatment Received (check all that apply):

- ☐ Surgery
- ☐ Chemotherapy
- ☐ Radiation therapy

- ☐ Targeted therapy
☐ Immunotherapy
☐ Other (please specify)

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
 Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite Often
3		Hardly at all	3		Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____
 0-7 = Normal

Self-Compassion Scale Short Form (SCS-SF)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. Indicate how often you behave in the stated manner, using the following scale:

Almost never					Almost always
1	2	3	4	5	

1. When I fail at something important to me I become consumed by feelings of inadequacy.
2. I try to be understanding and patient towards those aspects of my personality I don't like.
3. When something painful happens I try to take a balanced view of the situation.
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.
5. I try to see my failings as part of the human condition.
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.
7. When something upsets me I try to keep my emotions in balance.
8. When I fail at something that's important to me, I tend to feel alone in my failure
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared
by most people.
11. I'm disapproving and judgmental about my own flaws and inadequacies.
12. I'm intolerant and impatient towards those aspects of my personality I don't like.

BODY IMAGE SCALE

In this questionnaire you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

Name: _____

Date: _____

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?				
Have you felt <u>less</u> physically attractive as a result of your disease or treatment?				
Have you been <u>dissatisfied</u> with your appearance when dressed?				
Have you been feeling <u>less</u> feminine/masculine as a result of your disease or treatment?				
Did you find it difficult to look at yourself naked?				
Have you been feeling less sexually attractive as a result of your disease or treatment?				
Did you avoid people because of the way you felt about your appearance?				
Have you been feeling the treatment has left your body less whole?				
Have you felt <u>dissatisfied</u> with your body?				
Have you been <u>dissatisfied</u> with the appearance of your scar?				
	Not Applicable			

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

Pain Interference – Short Form 6b**Please respond to each item by marking one box per row.****In the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
PAININ3	How much did pain interfere with your enjoyment of life?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAININ8	How much did pain interfere with your ability to concentrate?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAININ9	How much did pain interfere with your day to day activities?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAININ10	How much did pain interfere with your enjoyment of recreational activities?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAININ14	How much did pain interfere with doing your tasks away from home (e.g., getting groceries, running errands)?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

In the past 7 days...

		Never	Rarely	Sometimes	Often	Always
PAININ26	How often did pain keep you from socializing with others?.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Appendix O: Supplementary Material 3 (Debriefing Form)

PARTICIPANT DEBRIEFING FORM

Thank you for taking the time to participate in this research project.

Information on a number of self-referral and support services is available below. Referral to community mental health and primary care psychology services is available via your GP.

If you feel the need for additional support, the following options are available:

- If you are interested in receiving support from the Psycho-oncology team at SVUH, please discuss this with your consultant or medical team, who can refer you to the service. The Psycho-oncology team provides specialized psychological support to help manage the emotional and psychological challenges that can arise from dealing with sarcoma.
- If you or someone close to you have serious concerns about your mental health, or if you feel you need urgent support, please contact your GP or attend your local A&E for immediate assistance.
- For further support, you can also contact the Irish Cancer Society Support Line at 1800 200 700, where you can speak to a nurse about your concerns.

If you know of any other individuals with Sarcoma who may be eligible and interested in completing this survey you can forward this link to them [LINK TO SURVEY STARTING WITH INFORMATION FORM.](#)