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Research Article

Exploring the Role That a Helpline Could Play for People Diagnosed With Sarcoma and Their Carers

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Background: Sarcoma represents a group of cancers that carry a disproportionate impact on the well-being of people who are diagnosed and carers. Unlike more common cancers, limited tumour-specific support exists for people with sarcoma and carers. The aim of this study was to explore the potential role a telephone helpline could play in supporting people diagnosed with sarcoma and carers.
Methods: This study utilised an exploratory qualitative approach with a social constructionist framework. Semistructured interviews were conducted with people diagnosed with sarcoma, carers, bereaved carers and health professionals. Reflexive thematic analysis was conducted to determine themes.
Results: 43 semistructured interviews were conducted with people with sarcoma ($n = 12$), carers ($n = 11$), bereaved carers ($n = 4$) and health professionals ($n = 16$). Five themes were identified: 'the current system is not meeting needs,' 'holistic support,' 'a source of credible information,' 'the helpline operator' and 'centralised support for my sarcoma.'
Conclusion: Significant unmet needs continue to exist for people diagnosed with sarcoma and carers. A community support helpline was conceptualised as a helpful and effective tool for meeting the medical, psychosocial and information needs of all people impacted by sarcoma.

1. Introduction

Sarcomas are rare primary bone and soft tissue tumours that can occur in children, adolescents and young adults (AYA), and adults [1]. Globally, 96,201 cases of soft tissue and extraosseous sarcomas (bone sarcomas) were diagnosed in 2021 [2]. In Australia, approximately 2460 new cases of soft tissue sarcoma were diagnosed in 2022 [1], and 270 people were diagnosed with bone cancer in 2024 [3]. Five-year relative survival for both soft tissue and bone sarcoma is approximately 65%–71% in Australia [1, 4].

People diagnosed with sarcoma may receive surgery, chemotherapy and/or radiotherapy depending on their tumour type and location and prognosis [5]. Diagnosis and treatment can have a long-term effect on people with sarcoma. For example, surgical removal of bone or muscle can leave individuals with varying degrees of impaired function and mobility post-treatment [6]. Treatment can lead to structural impairments as well as activity and participation restrictions, pain and fatigue and may affect a person's quality of life [7]. Most individuals require rehabilitation following treatment, which necessitates coordination and

support [6] and ongoing management in the healthcare system [8].

In addition to physical and functional side effects of sarcoma and treatment, at least 20% of people experience anxiety, depression and psychological distress at diagnosis, during treatment and post-treatment [9, 10]. Distress following treatment has been correlated with poor physical functioning, social functioning, body image, quality of life, pain, financial difficulties, shame and stigma [7, 10].

Recent studies have highlighted the unmet needs of people diagnosed with sarcoma. Keegan et al. [8] identified AYA populations have information needs relating to treatment and fear of cancer recurrence as well as needing support for pain management, physical/occupational therapy, mental health and financial advice. A population study in the Netherlands ($n = 1099$) demonstrated the prevalence of unmet needs among people diagnosed with sarcoma with more than 30% reporting they received insufficient medical and nonmedical guidance [11]. Weaver et al. [12] highlighted people diagnosed with sarcoma ($n = 22$) experienced unmet needs relating to daily living, financial support, information and connection to community. Furthermore, carers of people with sarcoma ($n = 33$) reported unmet needs around support with medical aspects of caregiving, support for self, needing information about the person with sarcoma (in relation to their diagnosis, treatment and recovery), and financial support [13]. Both people with sarcoma and carers highlighted the need for more information about the disease and how to navigate the health system and how support could not always be accessed when required from the clinical team [12, 13]. Support interventions are needed to help people adjust to a sarcoma diagnosis and improve their quality of life [14]. Potential solutions include connecting individuals with health professionals who have sarcoma knowledge and sarcoma support groups for relevant and tailored support [12].

Given sarcoma is a rare cancer and specialised treatment is often centralised in metropolitan centres, many individuals need to travel for treatment [15]. In the UK, a telephone helpline demonstrated high satisfaction amongst people with sarcoma ($n = 108$), with 80% of individuals wanting a continuation of the telephone helpline due to the support provided and benefits of reduced travel time and costs [15]. In Australia, individuals currently do not have access to sarcoma-specific helplines. Access to telephone support has the potential to address unmet needs for people diagnosed with sarcoma and their families in a cost-effective format [16, 17].

There is a need to improve the overall support available to people with sarcoma and carers throughout Australia. The aim of this study was to explore the potential role a helpline could play in supporting people diagnosed with sarcoma and carers.

2. Methods

2.1. Study Design. This study utilised an exploratory qualitative research approach, rooted in a social constructionist framework [18]. This framework aims to derive meaning from participants' accounts of their social interactions and experiences [18]. The researchers focused on understanding the meanings constructed by participants, seeking insights into the unmet needs of individuals with sarcoma and carers, and how this might be addressed using a helpline. Ethics approval was gained from Curtin University (HRE2021-0683).

2.2. Participants. Participants were recruited via social media (Facebook, X and LinkedIn) and through Sock it to Sarcoma! and the Cooper Rice-Brading Foundation. Eligibility criteria for people diagnosed with sarcoma included being over 16 at the time of the interview, being diagnosed or treated for sarcoma within the last 10 years, and living in Australia. Carers and bereaved carers of people who were diagnosed and treated for sarcoma in Australia were also invited to participate.

Health professionals were recruited through personal contacts and snowballing techniques. Health professionals were eligible if they had previously been involved in treating or supporting people with sarcoma.

2.3. Data Collection. All participants received an information sheet and provided consent. Semistructured interviews were conducted face-to-face, via telephone or via Microsoft Teams. An interview guide and prompts, which underwent prior review by consumers, were used to elicit examples. Interviews with people diagnosed with sarcoma and carers focused on: required support; current and previous unmet needs; their perspectives on the potential role, how it should work in practice and the qualifications and experience of suitable providers; and when and why they might access this service. Interviews with health professionals sought their perceived benefits of a sarcoma-specific helpline. Interviews were conducted with participants in each group until information power was achieved [19].

2.4. Data Analysis. Interviews were transcribed verbatim and analysed using reflexive thematic analysis. Braun and Clarke's [20] six phases for thematic analysis were used to derive themes. These steps include familiarising with the data, generating initial codes, searching for themes, reviewing, defining and naming themes, and producing the final manuscript.

2.5. Quality and Rigour. Several methods of quality and rigour including credibility, dependability and transferability were engaged [21]. Data coding was completed by two researchers (GH and CF) to identify meanings and verify themes. An audit trail of all study steps and decisions was kept. Researchers adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [22] to enhance the transparency of reporting of results.

3. Results

Interviews were conducted with 43 people including 12 people with sarcoma, 15 carers (4 bereaved), and 16 health

professionals. Demographics are presented in Table 1. Five themes were identified: 'the current system is not meeting needs,' 'holistic support,' 'a source of credible information,' 'the helpline operator' and 'centralised support for my sarcoma' (Figure 1). The theme 'holistic support' included three subthemes: 'psychosocial support,' 'connecting with services' and 'financial support.' The theme 'the helpline operator' included three subthemes: 'a nurse or psychologist,' 'sarcoma knowledge and experience' and 'information delivery.' Participant quotes are denoted with the following: P = person with sarcoma, C = caregiver, BC = bereaved carer and HP = health professional.

3.1. The Current System Is Not Meeting Needs. This theme outlines the failure of the healthcare system to meet the needs of individuals and carers. For example, participants highlighted negative experiences of the healthcare system, primarily due to health professionals' lack of sarcoma knowledge.

> *"...she 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." (P12)*

There was also a focus on treating physiological symptoms, while ignoring psychosocial issues faced by individuals:

> *"I think on a grand scale, I think once treatment is done, unless there's actual physical need for you to be hospitalised, then you're sent home." (HP3)*

> *"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." (P17)*

BC1 also mirrored similar concerns around the lack of support:

> *"I don't feel like I had a lot of support. We never really got any formal handout or any guidance as to who to contact? We wanted to know what support there was out there... That's the biggest thing, when you think of what now, the only person you could go to was the oncologist. What do we do? What are the options? There wasn't really anything online." (BC1)*

3.2. Holistic Support. This theme describes the holistic biopsychosocial and practical support needs of individuals and carers. People needed support from diagnosis, treatment through to recovery and palliative care and bereavement. A range of support needs were identified:

Table 1: Demographic characteristics.

People with sarcoma ($n = 12$)	
Age at interview (years)	
M (SD)	46.9 (12.3)
Min–max	21–61
	***N* (%)**
Age at diagnosis (years)	
Adolescent (10–19)	2 (17)
Adult (25–40)	1 (8)
Adult (41–60)	9 (75)
Sex	
Male	3 (25)
Female	9 (75)
State	
Western Australia	8 (67)
Victoria	2 (17)
Queensland	1 (8)
New South Wales	1 (8)
Location	
Metro	11 (92)
Rural	1 (8)
Sarcoma type	
Bone	4 (33)
Soft tissue	8 (67)
Carers ($n = 11$)	***N* (%)**
Age (*M*, SD)	53.5, 5.8
Min–max	43–59
Patient age at diagnosis (years)	
Adolescent (10–19)	10 (91)
Adult (41–60)	1 (9)
Sarcoma type	
Bone	7 (64)
Soft tissue	4 (36)
Carer sex	
Male	3 (28)
Female	8 (72)
State	
Western Australia	5 (45)
Victoria	3 (27)
Queensland	2 (18)
New South Wales	1 (9)
Carer role	
Parent	10 (91)
Spouse	1 (9)
Location	
Metro	11 (100)
Bereaved carers ($n = 4$)	***N* (%)**
Age (*M*, SD)	48.0, 17.7
Min.-max.	22–62
Patient age at diagnosis (years)	
Adolescent (10–19)	3 (75)
Young adult (20–25)	1 (25)
Sarcoma type	
Bone	4 (100)
Carer sex	
Female	4 (100)
State	
Victoria	3 (75)
Western Australia	1 (25)

Table 1: Continued.

Carer role	
Parent	3 (75)
Sibling	1 (25)
Location	
Metro	3 (75)
Rural	1 (25)
Health professionals ($n = 16$)	***N* (%)**
Sex	
Male	4 (25)
Female	12 (75)
State	
Western Australia	11 (68.8)
New South Wales	2 (12.5)
Australian Capital Territory	2 (12.5)
Queensland	1 (6.3)
Location	
Metro	16 (100)
Profession	
Nurse	8 (50%)
Oncologist	2 (12.5)
Physiotherapist	2 (12.5)
Surgeon	1 (6.3)
Counsellor	1 (6.3)
Exercise physiologist	1 (6.3)
Youth worker	1 (6.3)

"I would have liked a helpline that could direct me along the problem that I was having, whether it be physical, mental, or financial." (P1)

The most prevalent support needs identified were psychosocial support, connecting with services and financial support.

3.2.1. Psychosocial Support. Beyond a myriad of biological symptoms, a key experience by people with sarcoma was isolation, distress and overall poor mental health. Psychosocial support was identified as a key support need, with one carer stating:

"*Mental health in cancer patients is just as important because these are people that are facing either death or disfigurement because of their surgeries or a lifetime of expense for drugs and medications to keep themselves alive. The ramifications are huge. I think cancer patients and the connection of mental health is very much forgotten." (C3)*

Health professionals also recognised the need for psychosocial support:

"I think they feel a little isolated and often it's nice to have someone that has set-up rapport with these patients, that they can actually discuss some of the psychosocial aspects of their care as well." (HP2)

This feeling of isolation was additionally described by people with sarcoma:

"I feel sorry for anyone who started a journey just purely relying on the chemo programme and the surgical programme and your 20-minute appointment with a doctor to emotionally get you through the journey. I think you'd be a bit of a Trainwreck at the end of it if you were relying on those guys to make you feel good." (P1)

Carers were also left feeling like they were the only ones to provide emotional support, which left them feeling drained:

"The medical carers and the hospital staff did a great job of caring for my daughter, but it's the emotional needs of the individuals... my job was to be there... for her to debrief and just share her thoughts and her anguish... that plays on your mind—and just the exhaustion of dealing with that." (C7)

Participants also highlighted the potential benefit from health professionals recognising the signs of distress, providing initial support and then referring as required:

"When it comes to the more extreme levels, which you hope they are trained to be able to recognise the signs of someone being in more distress and needing very specific help, then they have the pathway and the skills to be able to encourage that person to take the pathway that they're recommending." (BC7)

3.2.2. Connecting With Services. Participants viewed the helpline's role as spreading awareness of available services and facilitating access:

"I think letting people know what services are out there for them, there's somebody there to talk to who has either gone through it or had family members go through it and then talking it out with somebody who understands. Because it's not a well-known cancer and its quite difficult to treat and so it depends on where your sarcoma is as to what your outcome is going to be, that sort of info on a helpline will be beneficial." (P4)

"Connection would be good, because I should imagine the first person I speak to might be able to assess what it is that I'm looking for and connect me, with the social work type things specifically around sarcoma and also a peer support program." (C2)

3.2.3. Financial Support. Unmet support needs also extended to financial domains, which tended to fall outside standard healthcare. One health professional indicated that financial information is often not provided:

"I don't think it's discussed all that well. It's getting better, but I don't think we delve into their financial status much, I think it still is quite a barrier." (HP2)

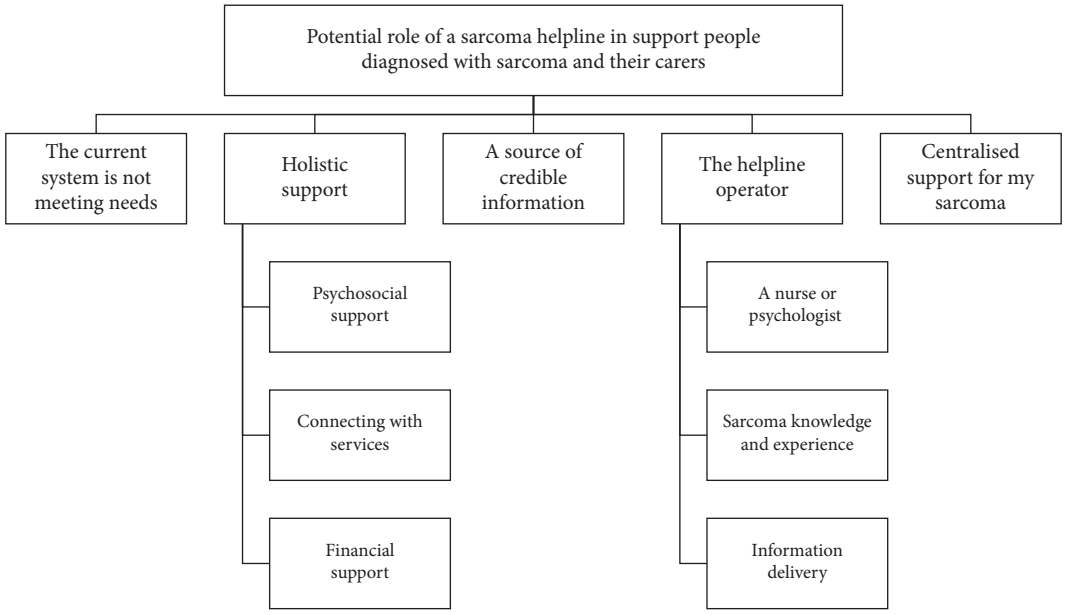

Figure 1: Themes and subthemes describing the potential role of a sarcoma helpline in supporting people diagnosed with sarcoma and their carers.

Similarly, individuals and carers indicated financial support is not part of usual hospital-based care:

"Yes, just zero support, financial support, at all. . . [we needed] just somebody to call when you've got questions and not necessarily just about treatment questions, but all of the other stuff that relates into it, like how do I get financial support, how do I talk to my employer if I need to take chunks of time off, what do I need to do, and can lead you to someone who can actually support you." (C5)

3.3. A Source of Credible Information. Credible information proved difficult for many participants to find. Most tried finding information by searching Google—which often caused anxiety given sarcoma's potentially poor prognosis.

"I was crying because I'd been looking at Doctor Google and the survival rates for this were 35 percent and I thought wow, I didn't even make it to 50 years of age and I'm going to die." (P6)

"I knew that that would be just scary and I told [name] and the whole family right from the beginning we're not going trawling on the web and be scared, we're going to listen to our doctors and be guided by them." (C2)

Conversely, acquiring accurate information about sarcoma gave people certainty, hope and empowerment.

"That sort of information is good because then you understand now why they want to cut it down further, why they want to amputate a bit lower. But if they hadn't explained that and if we hadn't kept asking the question, you're kind of flying half blind and trying to make a decision with information that's lacking." (C4)

Participants identified that a helpline would assist them find credible information.

"What are the treatment plans? What is the prognosis? If you just have somebody on a helpline to discuss that with, it might have been a lot better." (C7)

Provision of credible information was also a focus for health professionals. HP13 noted that while information is provided, people may want it at different times or presented another way:

"What we've come to realize, I think because there was never a dedicated service, is that we need to have information like this in whatever form families want to receive it. I think people want to make sure they've understood, they've got all the information they need. . .- People also need to be confident that the information they're getting is accurate and credible." (HP13)

3.4. The Helpline Operator. Who delivers the information was viewed by some participants as almost as important as the information itself. Three subthemes emerged: a nurse or psychologist, sarcoma knowledge and experience and information delivery.

3.4.1. A Nurse or Psychologist. The need for emotional support was a main consideration in relation to people's views about the qualifications and experience of the helpline operator. One carer mentioned: *"A nurse, a psychologist would be fabulous."* (C4). Participants tended to identify psychologists/counsellors for provision of emotional support:

"They would probably need to be a professional counsellor because the sensitivity of the people that they're going to be dealing with, the mental sensitivity." (P5)

In contrast, nurses were seen to have knowledge of the continuum of care and were viewed as an intermediary between the healthcare system and individuals:

"A go-to person, like a nurse, for example if you get referred to the WA State Sarcoma Service, you get referred to some of the nurses there and that's quite important for follow-up and things like that." (P3)

". . .but then being able to refer—I mean you could look at it like a nursing model and so that's the nurse, can do some of that sort of symptoms stuff but maybe not. And then an ability to refer or knowing a network of these are the people that they can go to for your rehab needs or your whatever else you need." (HP4)

3.4.2. Sarcoma Knowledge and Experience. For all groups, *knowledge* of sarcoma-specific information is pivotal:

". . .my thought is that you would probably need some kind of counselling background with specialised understanding of sarcoma. . ." (HP4)

"Look, definitely knowledge of sarcoma." (P6)

"They need to have a really good clinical knowledge of sarcoma." (C4)

However, one health professional suggested that support needs across cancers are similar, therefore, sarcoma knowledge and experience is not necessary; *". . .whatever cancer, it's usually the same things that you need to consider." (HP1).*

Another participant suggested talking with a sarcoma survivor would be useful:

"If they were talking with somebody that has already been through it, they would feel comforted by the fact this person knows how I'm feeling, what I'm going through." (P5)

3.4.3. Information Delivery. Participants also highlighted the importance of *how* the telephone support person interacts with callers and provides support:

". . .you've got your clinical team there to give you all the hard facts; they're the ones who are doing the diagnosis, treatment and they're the ones either giving you good news or bad news. And so you need. . .somebody out there who can listen, talk and knows what you're going through." (P4)

"You need that warm, friendly voice down the end of a phone and being supportive. It's one thing to know the information, but it also needs to be delivered in a very kind and compassionate way." (C4)

3.5. Centralised Support for My Sarcoma. People with sarcoma and carers highlighted a need to have access to information when required. For many, their journey consisted of short, infrequent exposure to health professionals who had the answers they needed, which did not always align with when the myriad of diverse questions arose. Individuals and carers were left to try and answer questions themselves.

"You don't want to disrupt the professor, one of the top orthopaedic surgeons, to say I'm not feeling that great, what can I do?, when your GP doesn't really understand sarcoma, do you go to a GP? You've got to book into your GP, you can't get into your GP, you've got a two week wait for them. Is there anyone that can help?" (P1)

This was further highlighted when participants discussed times when they did have support. One carer reported that another mother who had experience caring for a child with sarcoma, offered and provided 24/7 support:

"They were our go-to. We didn't see them all the time, but she was always available on the end of the phone if I needed her. It's that peer-to-peer support that was so vital for me." (C1)

Many participants outlined they needed support around diagnosis as they were in shock, experiencing feelings of uncertainty and anxiety, and had many questions:

"Diagnosis is a really surreal time and I think it takes time to really process exactly what you're feeling. I think if I was able to call someone on that very first weekend,. . .that may have helped, because [Child] was diagnosed on the Friday and we didn't get to [city] for the biopsy till the Tuesday, so there were a few days there it was just—it was letting family know; it was pretty much a definite diagnosis. . . due to the scan and things. Maybe that call for initial conversation around diagnosis. My sister said to me don't Google, whatever you do." (C6)

Some participants thought the helpline should be available outside business hours:

"24/7. Because people can reach crisis point and have thoughts going through their head about lots of things at any time of the day; there's no rhyme or reason when people think and feel what they do." (C3)

While 24/7 access was preferred, the feasibility and practical limitations were questioned:

"9 to 5, I think would work. I suppose that makes that little bit easier maybe for this to be set up because obviously then you're not having to pay people extra money to work from 6 until 1 o'clock in the morning." (P5)

"I think that will be a challenge. And also hours they're available. Sometimes when you're busy during the day, everything's okay, but when it gets to night-time…" (P1)

4. Discussion

Given the effectiveness of telephone helplines in addressing unmet needs in cancer [23] and sarcoma in the UK [24], the current study aimed to understand the role a community telephone helpline in Australia could play in supporting individuals diagnosed with sarcoma and carers. Overall, participants viewed a sarcoma helpline as a potential solution to support people with sarcoma and carers. While this study focused on perspectives of people in Western Australia, we found that people in other Australian states had similar views.

Participants outlined that outside hospital admission or outpatient treatment, contact with health professionals with sarcoma knowledge is rare. A helpline service was conceptualised as a supplementary service, filling gaps left by infrequent contact with knowledgeable health professionals and challenges associated with establishing good communication between individuals, carers and health professionals. This is particularly important given the extended course of sarcoma treatment. Time from diagnosis to remission varies greatly (estimates vary from 9 to 120 weeks for bone sarcoma and 4–614 weeks for soft tissue sarcoma) [25]. Treatment, for example, intermittent chemotherapy, is often characterised by long breaks between cycles [26]. These long gaps between contact with treating teams leave people with sarcoma with significant questions and no way of accessing credible support. A helpline may alleviate unmet needs and potentially reduce poorer health outcomes for people with sarcoma by providing access to information and support [24]. Previous research has demonstrated that people with rare diseases (including rare malignancies) and carers do access rare disease helplines to gain information on their disease, find a specialised centre/expert and for social care [27].

Participants in this study universally outlined the need for the sarcoma support helpline to not only provide support for physiological challenges, but also provide holistic support across psychosocial, emotional and financial domains. Babac et al. [28] similarly highlighted the need for rare disease helplines to provide medical and psychosocial support, guidance in reducing information chaos and accessing appropriate referrals. Previous research has identified the value of holistic and compassionate care in bolstering health information provision [29, 30]. Medical consultations which include communication skills of openness, positivity and empathy improve engagement, user-perceived effectiveness, and trust [29–31]. However, despite the pervasiveness of helplines, there is a paucity of research on the best practices of helpline operators.

A unique challenge for people with rare and less common cancers is the lack of credible, online information [32]. While this was reported by many participants, this experience is not unique to our cohort. The UK National Sarcoma Survey (2016) [33] identified that 45% of people with sarcoma felt they were not given enough information at diagnosis. Our Australian research identified that individuals do not have access to adequate information regarding treatment and side effects, prognosis and recovery, and psychological and financial services [12, 14]. A sarcoma-specific helpline could address the information needs by providing information tailored to the individuals' needs and diagnosis.

The majority of carers and bereaved carers in this study were parents of AYA patients, which reflects sarcoma incidence in these populations [1]. Parents reported they did not trust currently available online information and would like the option to access a helpline to receive sarcoma-specific information and support and to talk to someone who understood their experience. A recent scoping review found that people caring for AYAs with cancer may have needs and experience burden in the following areas: physical, psychological, social, financial and additional roles associated with caring [34]. In a qualitative exploration of parents' experiences of caring for a child with cancer, Davies et al. [35] outlined the advice parents provided for other parents which included asking for help and services to enable them to care for their child, themselves and their families.

Given the psychosocial stressors placed on all people impacted by sarcoma, the helpline operator was conceptualised as someone who provides empathy, understanding and fosters a feeling of 'being heard'. A key finding was that participants desired a nurse or psychologist helpline operator, as they have knowledge and experience. There is also the potential that the title of 'nurse' or 'psychologist' may improve the credibility of the helpline [36] and increase referrals, given the potential harm from misinformation and stated low quality of existing information. Other studies have also highlighted that people with cancer prefer the helpline operators to have an appropriate professional background and skills [27, 37]. Participants may also prefer to talk to people with lived experience of cancer [37].

Participants outlined a need for extended helpline operating hours given the unpredictable nature in which questions can arise following a sarcoma diagnosis. Other studies have similarly discussed operating hours required for helplines [28, 38]. However, the practical and financial feasibility was consistently questioned. A similar service such as the Sarcoma UK Support Line, which caters for a much larger population, has 10a.m.–3p.m. operating hours. In addition, individuals can use text messaging and email to interact with the service [33]. Call back systems and follow-up calls may also assist individuals if they call outside of operating hours [28]. Such approaches could be usefully replicated if a helpline service were set up in Australia.

4.1. Limitations. This study focused on recruiting people with sarcoma, carers, bereaved carers and health professionals who were involved in caring for people with sarcoma in Australia. Many of the participants were recruited via the community organisation Sock it to Sarcoma! and may be more likely to use a helpline. This sample is therefore not representative of all people diagnosed with sarcoma and their carers. The majority of carers in this study were parents of AYAs. Further research is required to explore whether other carers may also benefit from additional support provided through a helpline. Demographic factors including ethnicity and language have been strong predictors of telephone helpline use [39]. We did not have many participants from culturally and linguistically diverse backgrounds who may have different or more extensive support needs. Previous studies have highlighted the need to have culturally and linguistically diverse staff available to support people from different backgrounds [37]. Exploration of Indigenous Australian people's needs for culturally appropriate support may provide insight into reducing health disparities.

4.2. Future Research. Prior to implementing a sarcoma helpline, guidelines are needed to support the helpline operator. Further research is required to determine training needs for helpline operators and facilitate access to information and referral pathways. Once established, the helpline will also need to be evaluated. Outcomes that might be assessed once the helpline is established include decision-making, satisfaction with the service, anxiety, distress and unmet needs, confidence in asking questions; and communication with healthcare providers. While participants indicated the need for telephone support, they also wanted improved quality and availability of information. Our team is currently co-developing online information to better address the needs of people with sarcoma and carers.

The cost and sustainability of the helpline service also need to be considered. A range of different funding sources may be required to support sustainability of the service. Considerations should include what supports people are seeking, the average duration of calls and the availability of medical information [27]. Quality assurance and monitoring of the helpline service will also be required. Development of the helpline and considerations of costs may be informed by findings from McCaffrey et al. [40], who are currently exploring the economic and social return on investment for cancer helpline information and support services in Australia.

5. Conclusion

This study demonstrates that people with sarcoma and carers require additional support. We explored the role a helpline could play in addressing unmet needs of people with sarcoma and carers. Following diagnosis, people experience loneliness and disconnection and require information and holistic support. This support and information cannot always be accessed through the health system, particularly given the challenges associated with establishing communication between health professionals, individuals and carers. Individuals have a need for ongoing support from diagnosis through treatment and survivorship or when palliative care is required if the disease progresses. Participants felt that implementation of a helpline would assist in addressing their unmet needs and facilitate referral for additional support when required. Further research is required to establish and evaluate a sarcoma helpline service in Western Australia that supports people locally and interstate. The costs and sustainability of establishing a helpline service also need to be considered.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Conflicts of Interest

The authors declare no conflicts of interest.

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