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Clinical Research

Most Patients With Bone Sarcomas Seek Emotional Support and Information About Other Patients' Experiences: A Thematic Analysis

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Abstract

Background Online discussion forums allow individuals who otherwise may be strangers to create a community where they can seek and share information. Patients with bone sarcomas and their support networks use discussion forums dedicated to cancer support. There is a paucity of published reports regarding the care experience of patients with bone sarcomas because studies on online discussion groups have primarily focused on some of the more common cancers, including breast and prostate cancer. Understanding commonly discussed themes among patients with bone sarcomas would allow treating physicians to have a better understanding of patient concerns when providing patient education and counseling.

Question/purpose We performed this study to review posts from bone sarcoma internet discussion boards to establish common themes related to the care experience of patients with sarcomas.

Methods Online discussion forums were identified using the search term "sarcoma discussion forum." After identifying 12 websites, we excluded closed forum groups, websites with missing or invalid links to forums, and nonpublic forums, such as groups on Facebook. These websites include profiles and photos that are personal, and sufficient author anonymity could not be achieved for this study. Posts written between January 1, 2012, and May 1, 2022, posted on five discussion boards were reviewed and collected until we reached a point of data saturation in which we agreed that the collection of additional posts would not reveal new themes. Discussion threads were filtered to identify posts pertaining to the most common bone sarcomas: chondrosarcoma, Ewing sarcoma, and osteosarcoma. Grounded theory—the methodology of repeated analyses of qualitative data to identify recurring themes or concepts—was used to analyze posts. Caregiver posts were delineated from patient posts and categorized separately for subgroup analysis. Grounded theory, although a qualitative method, endeavors to integrate the strengths inherent in quantitative methods with qualitative approaches. Grounded theory categorizes words, language, and the meanings these imply and seeks to organize and reduce the data gathered into themes or essences, which, in turn, can be fed into descriptions, models, or theories. Our analysis used three reviews of text to assign and group codes based on repeating ideas or concepts. The first

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Ethical approval for this study was waived by the University of California Los Angeles's Human Subjects Research Review Board.
This study was performed at the University of California Los Angeles, Santa Monica, CA, USA.

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review (open coding) aims to assign codes based on the verbatim text included by the author to capture the specific thoughts and ideas of the post. The second review (axial coding) aims to consolidate the ideas of posts by applying broader concepts to each post. The third and final review (selective coding) aims to further consolidate the themes of each post by trying to embody the main message contained in a post. A total of 570 posts from 139 threads were collected and analyzed using grounded theory. Twenty-five axial codes and four selective codes were created. We defined data saturation by the absence of a new open code in the analysis of a block of 50 posts to ensure that signals of saturation were not accepted too early in the analysis.

Results The four selective codes included emotional aspects or connecting with others, information support: diagnosis, information support: treatment, and information support: recovery. Of these four codes, emotional aspects and connecting with others was the most prevalent theme (78% [445 of 570] of posts) followed by information support: treatment (49% [282 of 570] of posts). Information support: diagnosis and information support: recovery were each captured in 15% of posts.

Conclusion Analysis of posts reveals that the two most common themes involve seeking out emotional support and information about the experiences of others with various treatment modalities. Although most of the posts we assessed contained experiential information and emotional support rather than directed medical advice, future studies should assess the accuracy of information shared among online sarcoma forums.

Clinical Relevance Physicians caring for patients with sarcomas should not only address patient concerns related to medical care, but also provide emotional support directly and assist patients by providing resources to peer support outlets, including online discussion forums. Although we cannot ascertain the proportion of patients who use online sites given the anonymity of posts included, these findings suggest common experiential themes across patients with sarcomas outside their doctors' offices. It is important that providers be aware of reputable forums to provide as resources for their patients. The Musculoskeletal Tumor Society may further benefit from endorsing one or more of these forums and providing physician oversight to monitor misinformation.

Introduction

The internet is increasingly used to obtain health information, with recent studies showing that more than 70% of online users use the internet as a source of health-related information [4, 9, 22, 24]. Health information related to diagnoses and treatment options is readily available online, providing patients with resources that can aid in their decision-making. Discussion forums and online support groups additionally allow patients to seek and share information with others who are facing similar illnesses. Prior studies have analyzed the use of discussion boards in the setting of other illnesses or injuries, including brachial plexus injury and congenital upper extremity differences including congenital malformations such as radial longitudinal deficiency, ulnar dimelia, and polydactyly, among others [6, 17].

There is an increasing reliance on internet resources in the online community of patients with cancer [5, 14]. Studies examining the role that discussion forums play in the experience of patients with cancer have primarily focused on some of the more common cancers, including breast, prostate, and pediatric cancers [1, 2, 12, 20]. In contrast, the diagnosis of bone sarcoma is less common, and the experience of patients with bone cancer is less well understood. Annually, there are approximately 3900 people diagnosed with bone sarcomas; osteosarcoma, Ewing sarcoma, and chondrosarcoma are the three most common [3, 23].

There is a paucity of published reports regarding the care experience of patients with bone sarcomas because studies on online discussion groups have primarily focused on some of the more common cancers. Understanding commonly discussed themes among patients and caregivers allows treating physicians to have a better understanding of patient concerns when providing patient education and counseling. Additionally, understanding these concerns allows for improvement in the patient experience, particularly in settings where patient navigators can be used.

The primary objective of this study was to review posts from bone sarcoma internet discussion boards to establish common themes related to the care experience of patients with sarcomas.

Materials and Methods

Using Google and Bing search engines, we identified online discussion groups using the search terms "sarcoma discussion forum," "sarcoma," "osteosarcoma," "Ewing sarcoma," and "chondrosarcoma." We did not use broader search terms such as "cancer" or "tumor," because we felt these words were too broad and would introduce too much variability in discussion, which may not pertain directly to patients with sarcomas, given the great variability in treatment and prognosis among cancer types. Although osteosarcoma, Ewing sarcoma, and chondrosarcoma have many differences, there are many unifying themes among them, including their typical locations, impact on musculoskeletal function, improvement in prognosis with negative-margin surgical resection, rarity, and their mesenchymal stem cell origin. These provided a cohesive

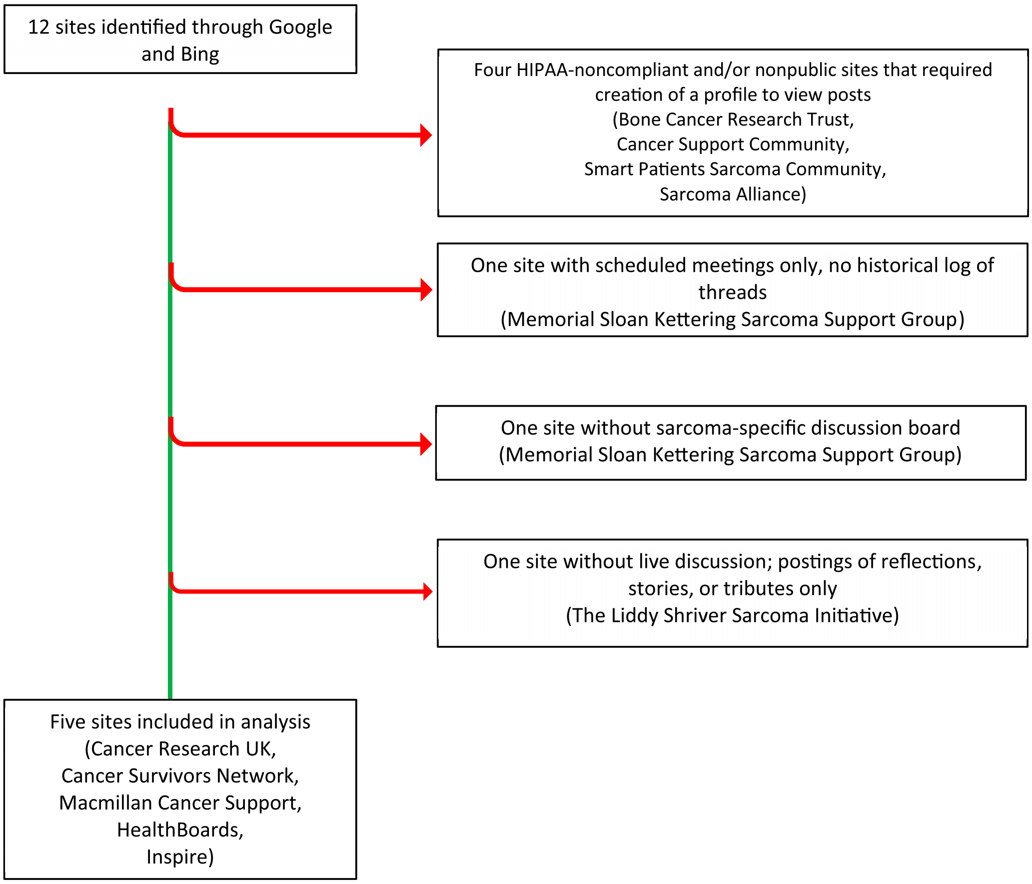

Fig. 1 This flowchart depicts inclusion and exclusion criteria for queried sites.

sample, which is necessary for grounded theory to make sense of the apparent disconnectedness of qualitative data.

Groups were identified directly from search engine results and found in the resulting support group pages. Internet sites were chosen if they contained posts written in 2016 or later and were related to sarcoma care. We excluded closed forum groups, sites that did not allow for contributors to maintain anonymity, and nonpublic sites. We initially identified 12 sites with online discussion boards through our search (Fig. 1). We excluded four of these sites because posts were not public and required the creation of profiles to view posts, which was identified as an exclusion criterion in our methodology. We excluded two because they did not provide a link to access online support groups and another because the links to support groups were invalid. We identified five online discussion boards: Cancer Research UK, Cancer Survivors Network, Macmillan Cancer Support, HealthBoards, and Inspire. Discussion threads on each of the five websites were filtered to identify posts related to the most common bone sarcomas: osteosarcoma, Ewing sarcoma, and chondrosarcoma.

We collected posts if they were written between January 1, 2012, and May 1, 2022. In discussion threads started before January 1, 2012, we collected and analyzed only posts authored after this date. Data collection included the title of the discussion thread, the date and time of the post, the contributor's username, and the precise text of the post. Posts collected included ones authored by patients themselves as well as caregivers and other family members to better understand the impact of the care experience of patients with sarcomas on patients and their family members. We excluded posts from the final analysis if they were authored by site administrators or moderators, duplicated across multiple discussion threads, or lacked a substantive volume of text to allow for analysis (such as, "Thank you for your reply, I am not so good in medical terms or in English as well. I will check both links that you sent me" or "Will do lovely:)").

Grounded theory, although a qualitative method, endeavors to integrate the strengths inherent in quantitative methods with qualitative approaches by categorizing words, language, and the meanings these imply and seeks to organize and reduce the data gathered into themes. This methodology involves the repeated analyses of qualitative data to identify recurring concepts, which are then coded and grouped into categories. These categories are then further integrated into a central idea or theme that allows researchers to better understand qualitative data pertaining to their research problem [23]. The theory uses three reviews of texts to assign codes based on repeating concepts.

Two investigators (AEP and AS) reviewed each post three times with open, axial, and selective coding to establish common themes. Our analysis used three reviews of text to assign and group codes based on repeating ideas or concepts. The first review (open coding) aims to assign codes based on the verbatim text included by the author to capture the specific thoughts and ideas of the post. The second review (axial coding) aims to consolidate the ideas of posts by applying broader concepts to each post. The third and final review (selective coding) aims to further consolidate the themes of each post by trying to embody the main message contained in a post. Both reviewers agreed on the final axial and selective codes created.

Each post could be assigned multiple axial and selective codes if there were multiple themes encompassed in a single post. Upon an evaluation of all posts that were collected, the final axial and selective codes appeared to capture the variety of themes contained in the posts, and we reached a point of data saturation [18]. Qualitative data, although initially appearing diverse and disconnected, form patterns and themes without the introduction of new ideas or concepts in repeated posts. For example, there were threads with 20 comments or more, and often the topic discussed would change as more authors posted replies. This resulted in various open, axial, and selective codes per thread. We believe that analyzing each post allowed us to capture the theme contained in each post, and this is consistent with the methodology used in other studies seeking to identify common ideas through thematic analysis [6, 7, 17].

In all, we collected and analyzed 634 posts specific to bone sarcomas from 139 discussions from five discussion forums. After we excluded posts from site administrators or moderators (35), duplicates (seven), and those without a substantive volume of text to allow for analysis (22), 570 posts were included in the final analysis. We could not determine the total number of individual contributors because one website, Macmillan Cancer Support, removed the unique username of contributors if they were former members; however, there were at least 282 individual contributors across the sites (Cancer Research UK: 92 contributors; Cancer Survivors Network: 95 contributors; Macmillan Cancer Support: at least 37 contributors; HealthBoards: nine contributors; Inspire: 49 contributors). Breakdown by contributor status showed that 52% (299) of posts were written by patients and 36% (204) were posts by

Table 1. Selective and axial codes

Selective	**Emotional aspects/connecting with others**
Axial	Emphasizing the importance of sharing with others
	Looking to hear from others in a similar situation
	Providing contact information to others for offline discussion
	Expressing gratitude for online community
	Supporting and encouraging others in their journey with cancer
	Psychological and emotional impact of cancer (depression, anxiety, impact on family members, etc.)
	Struggling to cope with loss (or upcoming loss) of a loved one
Selective	**Information support: diagnosis**
Axial	Imaging/biopsy
	Staging/surveillance
	Symptoms
	Timing
Selective	**Information support: treatment**
Axial	Seeking and sharing personal experiences with surgical treatment—side effects, recovery
	Seeking and sharing personal experiences with radiation therapy—side effects, recovery
	Seeking and sharing personal experiences with chemotherapy—side effects, recovery
	Seeking and sharing personal experiences with alternative treatments—side effects, recovery
	Sharing experiences and deciding whether to pursue amputation
	Seeking and sharing experiences with a prosthesis
	Sharing experiences and deciding whether to pursue limb salvage
	Seeking and sharing recommendations on physicians/institutions for treatment
	Discussing experimental treatment/trials
Selective	**Information support: recovery**
Axial	Timeline of recovery
	Finding new ways to accomplish activities of daily living and high-level activities
	Discussing experiences with physical therapy
	Discussing physical challenges (mobility, nerve pain, balance, etc.)
	Concerns about recurrence

friends, family members, and caregivers. The contributor status could not be determined for 12% (67) of posts.

Twenty-five axial codes and four selective codes were created through thematic analysis (Table 1). We defined data saturation by the absence of new open codes in the analysis of a block of 50 posts to ensure that signals of saturation were not accepted too early in the analysis.

Ethical Approval

University of California Los Angeles's Human Subjects' Research Review Board granted an exemption of this study from further review.

Results

The four selective codes included emotional aspects and connecting with others, information support: diagnosis, information support: treatment, and information support: recovery. Of these four codes, emotional aspects and connecting with others was the most prevalent theme (captured in 78% [445 of 570] of posts) followed by information support: treatment (captured in 49% [282 of 570] of posts) (Fig. 2). Information support: diagnosis and information support: recovery were each captured in 15% [84 of 570] of posts (Table 2).

Emotional Aspects of Connecting With Others

Our results highlight the importance of the websites in providing a forum for emotional support among patients with sarcomas. A breakdown of the axial code distribution reveals that most posts in the broader theme of connecting with others involved supporting others in their journey with cancer, discussing the psychologic and emotional impacts of cancer, and looking to hear from others experiencing similar situations (Table 1). The most frequently rated axial codes related to sharing encouragement and emotional support with others (Fig. 3A). Contributors not only offered encouragement to others, but also frequently shared resources they found helpful, including stories of other patients with the same type of bone sarcoma, online support groups, and mental health services. Posts focusing on the psychologic impact of a bone sarcoma diagnosis focused on caregivers and other family members, including siblings and cousins, in addition to the patients themselves. Contributors spoke of feelings of anger, fear, depression, anxiety, suicidal ideation, and fear of knowing that either they or a loved one would die. Some caregivers and other family members specifically sought out the advice and perspective of patients to better understand the patient experience so they could support their loved ones with bone sarcomas. Additionally, many contributors offered offline contact methods to communicate in a more private setting. Several posts emphasized the importance of forming a support network and not navigating the experience alone.

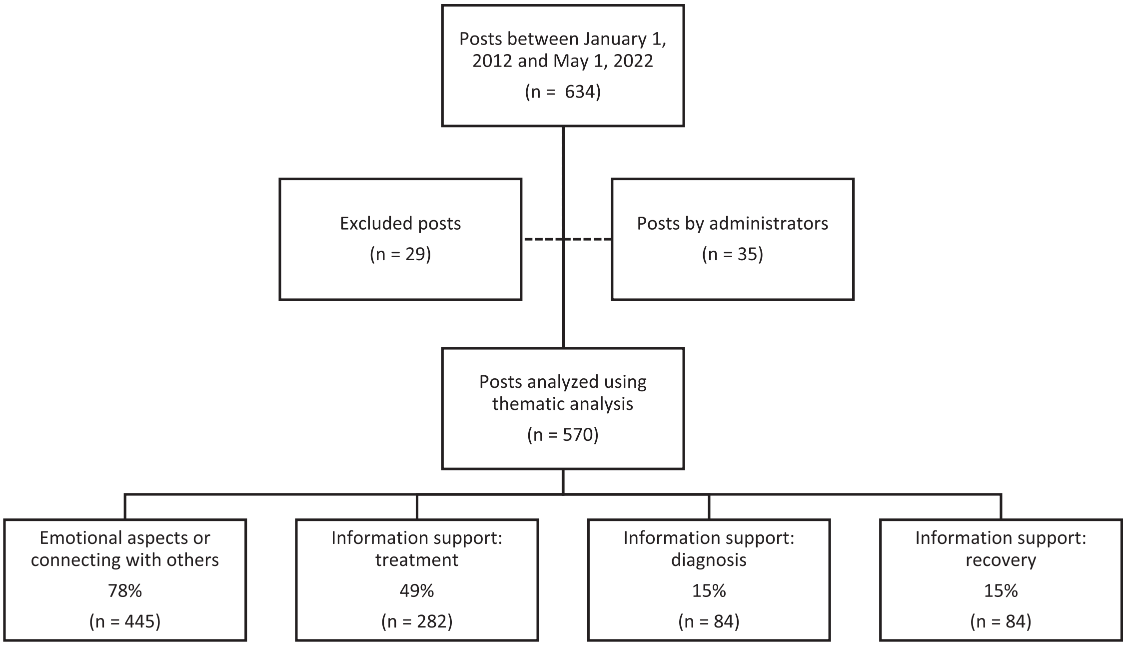

Fig. 2 This flowchart depicts the quantitative breakdown of selective codes.

Table 2. Representative quotations for selective codes

Selective	**Emotional aspects/connecting with others**
	"I am feeling very lost and alone. It is so hard having to juggle everything. It would be so nice to chat to others whose children have cancer, too."
	"I'm not sure what I can advise as to how cope psychologically. I think it's different for the person having the treatment than the family around. I coped better during treatment when all my family struggled and now I'm not coping mentally at all. [...] I felt that society wanted me to be brave and positive and the more people told me how brave and strong I was, the more pressure I felt to hide how I really felt. [...] I have made a support network to help me through. Don't try to do it alone, it's too difficult. Just talk!"
	"I wanted to find out from you how your son's surgery went and how he is doing. If you wouldn't mind, I would love to get in contact with you. I would really appreciate if we can exchange email and talk."
	"I just want to try and understand what my son is feeling and anything I can do to make him more comfortable."
	"In all honesty I will die from chondrosarcoma but I don't know how or when and for me right now I'd rather just die. I think on suicide quite a bit, especially at night. I just want to get it all over, and I know it's awful but I want my family to be able to move on and have me as a memory and not a burden. I'm not going to get better and I'd rather just be at peace, I'm scared of a long drawn out death and just want to go. But my condition doesn't lend itself to that. There's so little info out there for me I just don't know where to turn or what to do."
Selective	**Information support: diagnosis**
	"I have recently learnt that I have a secondary tumor that has returned again in my left shoulder, which is currently less than 1 cm. Are secondary chondrosarcomas more aggressive? I am very tired all of the time and I have a constant ache."
	"[...] got a pain in his leg at the end of June dismissed it as a strained muscle and steadily the pain has got worse leading to a diagnosis of a hip fracture. From this, he had a CT scan which showed secondary cancer on his lungs (this was 4 weeks ago) until now they were not sure what the primary was—until today."
Selective	**Information support: treatment**
	"She is going to have knee salvage procedure in 10 weeks. We are so worried about her. I am wondering if there are any different metal protheses to use and how is her life is going to be. Are you aware of any new development in this regard."
	"[...] I've gone through 4 treatments so far and I think another 2 before limb salvage surgery. Surgery is gonna consist of partial replacement of right humerus bone and removal of some soft tissue around bone that has been infected. Just wondering if anyone out there that had this type of surgery would be willing to share some info with me."
	"I was also not happy to do chemotherapy but felt like there was no other option as the recurrence rate without it is very high. I did the MAP protocol. [...] For me the main side effect was mouth sores and general tiredness."
	"[...] has recently been diagnosed with a chondrosarcoma in his sacrum. [...] He was booked in for surgery next week to remove the tumor but because it has grown up alongside important nerves in his spine, the consultant is now recommending looking into proton beam therapy first (as they can't remove the tumor in one piece, without leaving him with severe bladder, bowel, etc., problems and loss of mobility). I guess I am on here to ask if anyone knows much about this treatment or has even travelled abroad to receive it?"
	"I will be getting casted for my prosthesis and wanted to ask for anyone's personal experiences with getting used to their prosthesis and getting back to their old selves."
Selective	**Information support: recovery**
	"I would appreciate sharing about treatment options and life after treatment, how fast one can walk again."
	"I would absolutely not recommend amputation! I have regained great range of motion and live a very full and normal life. Having said that, I cannot jog, run, ski or do any high-impact sport but I believe that is a tradeoff I am happy to make for keeping my leg. [...] I am so grateful for the surgeon that saved my leg and gave me back my life."
	"Long-term effects are a chronic foot drop and muscle atrophy of lower left limb. Have been able to do most sports and remain active."

Table 2. continued

Selective	**Emotional aspects/connecting with others**
	"Personally, I've found the aftermath of treatment as stressful and traumatic as the time she was in hospital. The fear that the cancer might return is the worst, it's like a sword hanging over you."
	"I'm coming up to my 3 monthly xrays, 9 months after my osteosarcoma was removed. I've been ok leading up to previous scans but I'm not coping well with it this time. I'm struggling to sleep, it's affecting my ability to work or just function. I'm terrified of what they might show up."
	"I hit the gym to get fit a year ago and soon realised the implant was wearing out! I had surgery [...] I'm back getting fit, cycling and at the gym. I've started doing a little bit of jogging on it, and I wondered how other people are getting on with their implants and activities? I'm so determined to run a 5 km but I just don't know if this is ever going to happen."
	"Limb salvage is not an easy road. It is not something that when the chemo stops and the hair grows back your life resumes as normal. Limb salvage is a lifelong maintenance process. Technology is sooo much better now than it used to be but still it requires "tune ups". I often wonder what life would be like if I would have chosen the amputation route [...] then I see my own two feet and am thankful I have tried so hard to save it!! However tired, worn out and scarred this limb of mine is, it tells a story. My story."

Information Support: Diagnosis

In addition to describing the emotional impact of learning of a cancer diagnosis, contributors described their paths to diagnosis, highlighting signs and symptoms leading to diagnosis (Fig. 3B). Most posts under this theme focused on the diagnostic process for a patient with metastasis or recurrence. Additionally, there was discussion of the various imaging modalities and biopsies involved in the process. Although not the majority, there were several contributors who began discussion threads asking to hear about the experiences of others with a confirmed diagnosis to compare symptoms before seeking out medical services to alert their physician of their concerns.

Information Support: Treatment

Contributors frequently sought and shared information about various treatment modalities, including surgical and nonsurgical options. Surgical treatment options generally involved amputation and limb salvage, and several contributors sought out the experiences of patients with prosthetics to help decide between treatment options. Generally, patients who opted for limb salvage expressed gratitude for being able to keep their limb despite the number of procedures or surgical complications endured throughout the process. Contributors often expressed fear of losing a limb, with some adamantly against treatment plans that would result in limb loss. Nonsurgical treatment options discussed included chemotherapy, radiation, alternative therapies (such as diet changes or vitamins), and experimental treatments or trials. Discussion of alternative therapies and experimental treatments or trials was minimal, with only 2% of posts referring to these treatment methods. A breakdown of the axial code distribution revealed that most posts in the broader theme of treatment involved seeking and sharing experiences with surgical treatment, chemotherapy, and deciding whether to pursue limb salvage (Fig. 3C). Finally, some contributors sought recommendations on physicians and institutions for treatment.

Information Support: Recovery

Discussions of recovery from bone sarcomas centered around fears of recurrence, more so than the physical challenges and timeline associated with long-term recovery (Fig. 3D). Contributors discussed the long-term side effects of treatments, including nerve damage and limited use of the limb in the setting of limb salvage. They also discussed the challenges associated with attempting to return to activity levels before diagnosis. Some posts highlighted the long-term effects of having a prosthetic limb, including subsequent surgeries. Some contributors expressed confidence in their decision-making based on their recovery, whereas others questioned whether the alternative surgical plan would have been the easier route. Of the 17 posts that specifically discussed recovery from limb salvage, three contributors questioned whether having an amputation would have been better in terms of the recovery itself or overall functionality. Three other contributors were confident in their decision to choose limb salvage and expressed the importance of keeping their limb even if it was not fully functional. One contributor reflected that decisiveness in choosing amputation has allowed him to live a long, productive, and fulfilled life.

Discussion

The increasing reliance on internet resources in patients with cancer provides patients with a forum where they can

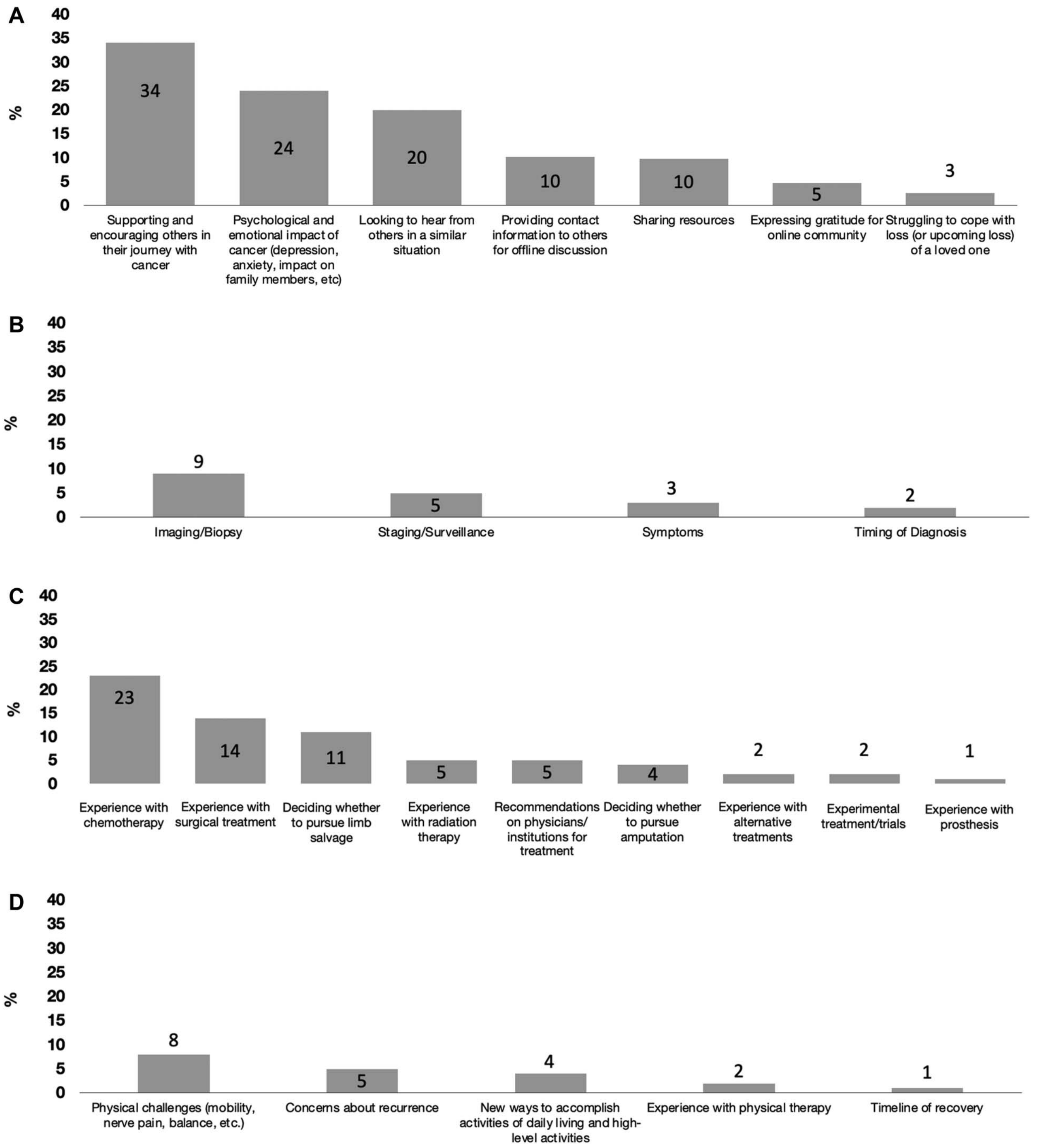

Fig. 3 These graphs represent (**A**) the axial code distribution for selective code "emotional aspects or connecting with others," (**B**) axial code distribution for selective code "information support: diagnosis," (**C**) axial code distribution for selective code "information support: treatment," and (**D**) axial code distribution for selective code "information support: recovery."

seek and share information related to their diagnoses. Discussion boards present unique communities in which these patients and families can connect to people with similar challenges and remove the barriers of geography in establishing this connectedness. These forums also provide a deidentified environment in which patients may ask questions they may be embarrassed to ask of a healthcare provider or family member. Compared with some of the more prevalent cancer diagnoses, there is a paucity of published reports regarding the care experience of patients with bone sarcomas. A bone sarcoma diagnosis is emotionally challenging and presents long-term life challenges to the patients and families receiving them.

Our investigation of discussion forum posts on five websites related to the three most common bone sarcoma diagnoses reveals that the two most common themes in this patient population involve seeking emotional support and information regarding the experiences of others with various treatment modalities. Contributors also used online forums to discuss diagnosis and short-term and long-term recovery.

Limitations

Our study excluded nonpublic forums, such as discussions posted on Facebook and similar forums. These social media outlets include profiles and photos that are personal, and sufficient anonymity for authors could not be achieved for this study. This characteristic also eliminates our ability to exclude multiple posts from the same contributors across multiple sites. Additionally, we could not assess differences in responses based on gender, age, or position in a family (bread winner or dependent). This would likely add substantial information to our understanding of the psychologic impact of sarcomas among various populations and is a rich avenue for future research. Neither could we discern the level of misinformation contained in posts, which would be an interesting and informative pathway for future study. We believe the public websites provided sufficient data to identify the key themes of issues affecting individuals and family members. Further, our methodology relies on the subjective analysis of posts by investigators, which can limit a complete understanding of the message trying to be conveyed by contributors. The use of grounded theory in qualitative research has been established as an acceptable means of data analysis [23], and all posts were independently reviewed and agreed on by two separate researchers. We endeavored to ensure completeness of defining data saturation by the absence of new open codes in the analysis of a block of 50 posts, although there is no set a priori sample size in qualitative research as there is in quantitative research. Saturated sets are full, rich, and complete. We feel that the four axial codes developed in our study reflect the experience of patients with sarcomas and, further, that the more specific open and selective codes prioritize information in each of those categories.

From our investigation, we could not determine how frequently posts influenced decision-making. This issue was particularly salient regarding the frequently encountered decision of whether to pursue limb salvage. Although we could not ascertain ultimate decision-making based on our methodology, this would be an interesting question for a prospective study. Additionally, we did not assess for misinformation contained in posts.

Online health forums are susceptible to misinformation [8, 10, 11]; however, most posts we assessed contained experiential information and emotional support, rather than directed medical advice. Future studies should assess the accuracy of information shared on online sarcoma forums. Finally, we performed a combined analysis of posts by patients and caregivers as opposed to separate analyses. This prevented us from fully elucidating the differences in experiences by the patient compared with that of a caregiver or another loved one. However, given the young average age of patients with bone sarcomas, we felt this methodology appropriately captures the patient and caregiver experience, because the caregiver is often the main advocate for the patient in this setting. Ideally, we would have analyzed this separately for pediatric and adult populations, but we were limited by the identifying information available through these forums. Future studies should aim to conduct separate analyses for pediatric and adult populations and should consider the use of video-based platforms such as Youtube and TikTok, because these are popular social media outlets for adolescents.

At least one contributor expressed suicidal ideation in a post. In response to this post, another contributor and a site administrator responded by offering emotional support as well as professional resources to reach out to. Although the topic of self-harm was not prevalent in the posts we analyzed, it may arise on forums, and online moderators and physicians should be aware of and prepared to respond to whether that response is online or in-person. Online response should include resources to the national suicide hotline and other readily accessible resources. Physicians should consider implementing screening tools along with using their relationships with patients to identify risk factors for self-harm and provide mental health resources.

Discussion of Key Findings

Online discussion forums serve as a valuable resource for patients and caregivers of those with bone sarcomas in creating an informal space in which they can offer each other emotional support and obtain information through the testimonies of others. Our investigation corroborates themes observed in other studies analyzing online posts, particularly that users were searching for emotional connections, discussing personal details of their condition and journey, and sharing information with others [2, 7, 8, 13, 15-17].

Recently, there has been a focus on the delivery of emotional support to patients with sarcomas. Prior research has demonstrated there is anxiety caused by a new diagnosis of sarcoma, with roughly 50% of patients feeling constant anxiety and 5% reporting suicidal ideation [21, 25]. Further, patients often feel isolated given the rarity of their diagnoses, which limits coping through connectedness with others [19]. Discussion boards offer a unique outlet for these patients to connect with peers who may be geographically separate. The emotional support offered through these forums most often comes directly from others facing similar situations, and the gratitude expressed in many posts for these online communities supports the positive role of discussion boards in this manner. We believe these discussion forums serve a distinct purpose separate from the care provided by healthcare professionals. This resource is readily accessible to patients or caregivers to find others who are experiencing similar challenges.

Our findings highlight unique aspects of care related to bone sarcoma, including a relatively longer and more complex pathway to diagnosis than other orthopaedic conditions, which requires nuanced decision-making during diagnosis, staging, and surveillance. These processes often result in anxiety for patients with sarcomas and their families, which is reflected in our findings. Compared with prior orthopaedic studies investigating rare conditions such as brachial plexus injury and congenital upper extremity deformities, those with sarcoma expressed more anxiety about the evaluation and surveillance processes [6, 17], reflecting the possible increased role of patient-facing materials that explain the utility of various imaging and biopsy studies in diagnosis and follow-up. Additionally, our analysis of treatment and recovery posts revealed that online discussion forums supplement education provided by physicians. That is, rather than seeking out the technical aspects of amputation or limb salvage, contributors were primarily interested in others' experiences with recovery from surgery, complications, and long-term results. The desire to share experiences was similarly identified in other orthopaedic reports studying online community postings [6, 17].

These findings suggest that patients may benefit from being actively guided to online forums, because patients and families can obtain important experiential information and support that may not be adequately communicated in a clinical visit. The notion that patients with aggressive neoplastic bone disease and their families are filled with anxiety, fear, concerns, a thirst for information, and the need for the support of others facing similar crises, and seek assistance from online groups or discussion forums, is an important reminder to the healthcare team. It is important that providers be aware of forums to provide as resources for their patients with similar experiences. The Musculoskeletal Tumor Society may benefit from endorsing one or more of these forums and providing physician oversight to monitor misinformation. Although our analysis of the forum content indicates unified themes for these patients, our study did not analyze the quality of the content across the five included forums and there were instances of misinformation from individual users across each of these sites. Although none of the included forums had explicit physician overnight, posts from moderators and administrators battled misinformation, and these sites could be used as a basis of potential forums to offer for physician engagement within these forums.

Conclusion

Our analysis of discussion forums reveals broader themes related to the experiences of patients with bone sarcomas. Physicians caring for patients with sarcomas should not only address patient concerns related to medical care but also provide emotional support directly and assist patients by providing resources to peer support outlets that may provide experiential information for patients and caregivers. Although sarcoma centers often have psychologists and social service resources, these forums are complementary to these resources because they provide patients and caregivers with an outlet to connect with their peers. Surgeons must realize that patients and their families sometimes desire advice from those outside the medical profession, and surgeons should be prepared to help families navigate appropriate resources about the diagnosis of sarcoma, including informing them of online communities. In addition, given the rarity of diagnosis and frequency of reporting of feelings of isolation, physicians may consider becoming involved in or establishing local programs that facilitate in-person interaction for these patients. More research—including elucidating the differences in experiences between patients and their caregivers, as well as differences between adolescents and adults—is needed to capture the emotional subtleties in this population to best support patients with sarcomas.

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