Global and regional disparities in access to specialist sarcoma services

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Aims

Cancer care guidelines have been developed in many subspecialities, usually in advanced health systems. However, there are notable global disparities in healthcare access, which can impact sarcoma care. Unfortunately, there is a lack of global data on this subject. Our aim was to describe access to sarcoma care based on a comprehensive global survey among orthopaedic oncologists, and assess for global as well as regional differences.

Methods

A 25-question survey was emailed to the attendees of the 2024 Birmingham Orthopaedic Oncology Meeting and included questions about the respondents' training and practice, access to sarcoma centres, and specific items for sarcoma diagnosis and treatment. For data analysis and comparison, countries were grouped geographically and per the World Bank's income classification.

Results

A total of 192 specialists from 47 countries completed the survey (67%). Overall, 40% declared that most patients in their country were treated in a specialized sarcoma centre. Declared access to specific diagnostic technology ranged from 69% (translocation studies) to 86% (various immunohistochemistry). Only 31% stated having access to proton therapy and 82% to all possible reconstruction methods. Compromise of ideal surgical management because of prior treatments and financial constraints was declared to have happened regularly in 40% and 17% of practices, respectively. Regions with better-developed healthcare systems had improved access to all aspects surveyed. Similar results were observed when comparing high-income countries against low- to middle-income countries.

Conclusion

Our study highlights substantial global and regional disparities in access to sarcoma services, which could potentially impact clinical outcomes. Further studies are needed to clarify this reality.

Take home message

- This study highlights notable global disparities in access to specialized sarcoma care, emphasizing the need for improved resource allocation and treatment strategies.
- Less than 50% of orthopaedic oncology specialists who were surveyed reported that a specialized sarcoma centre was the primary treatment location for sarcoma patients in their region, with treatment delays and inadequate initial procedures being common challenges, particularly in low- and middle-income countries.
- Addressing these disparities through tailored healthcare policies, resource optimization, and global collaboration is essential to enhance sarcoma care and patient outcomes.

Introduction

Musculoskeletal tumours are a heterogeneous group of neoplasms, considered to be rare compared with other common conditions affecting this system. Their malignant variant, sarcomas, account for 1% of adult malignant tumours, but almost 15% of paediatric cancer.[1,2] Nonetheless, this statement does not fully capture the complexity of musculoskeletal oncology today.

Sarcomas are among the rare cancers that have the most challenging diagnostic process. There are over 70 subtypes of soft-tissue and bone sarcomas,[3] which may require a combination of treatment methods such as surgery, systemic therapy, and radiation therapy. However, this is contrasted by reports of increased diagnostic delay[4,5] and numerous medical visits before an effective diagnosis is reached.[6] This causes a greater proportion of patients to be referred to specialized sarcoma centres after prior inappropriate treatment and delays that can all significantly impact subsequent procedures and overall prognosis.[7,8]

Guidelines and best practices for cancer care, including sarcomas, have been developed under ideal conditions and in highly developed health systems.[9-11] However, there are significant global disparities in treatment, research, technology, and rehabilitation resources across different regions. These disparities can have an even more substantial impact on rare diseases such as sarcomas, where diagnosis is already a challenge.[12,13] Despite the right to health becoming legally binding in the International Covenant on Economic, Social and Cultural Rights (ICESR)[14] (1966), progress in sarcoma care remains challenging. Article 12 of the ICESR states:

- The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
  - (d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.

This effectively means that even if a state does not have sufficient resources to provide good healthcare, there needs to be movement in the direction of progressive realization. However, evidence of baseline figures for access to sarcoma care and any progress is lacking in the literature.

Therefore, the aim of this study is to describe access to sarcoma care based on a representative global survey among orthopaedic oncologists, capturing their perceptions of current local practices, along with specific challenges and limitations. We also analyzed disparities in the responses of surgeons from different geographical regions.

Methods

Three of the authors (EB, AP, LJ) of this study constructed a 25-question survey (Supplementary Table i) to address global disparities and potential challenges. The 2024 Birmingham Orthopaedic Oncology Meeting (BOOM) organizing committee revised and approved the final poll.

The survey included closed and open-ended questions about the respondent's training and practice,[6] along with their impression regarding access to sarcoma centres locally, availability of specific items for diagnosis and treatment,[9] financial coverage,[2] local health systems (public and private),[3] and their patient's prior treatments or delays in management at the moment of definitive treatment in their centres (Supplementary Material).[3]

The form was sent via SurveyMonkey (USA) to attendees of the 2024 British Orthopaedic Oncology Management (BOOM) by email and shared via social media. The BOOM group consisted of specialists from over 150 oncology units in 47 countries and was endorsed by all major orthopaedic oncology organizations. Out of the 285 registered attendees, 192 completed the survey (67% response rate) between 1 December 2023 and 20 January 2024, with all participating nations represented (Supplementary Material). The survey did not require the completion of all questions before submission; however, missing data were found only in 6/192 (3%) of responses. All responses were anonymously collected.

Statistical analysis

For data analysis, countries were grouped geographically into seven regions: North America, Latin America, Europe, Asia, Australasia, the Middle East, and Africa. Furthermore, we conducted a comparison based on each country's gross domestic product (GDP) per capita, utilizing data from the year 2022 along with the World Bank's classification by income. We compared high-income economies with low- to middle-income economies, where the GDP per capita is either higher or lower than USD $13,845, respectively (Supplementary Material 2). Responses from physicians from high-income and low- to middle-income countries were compared using the paired *t*-test for continuous variables and the chi-squared test for categorical ones, after normality verification. A p-value < 0.05 was considered to be a statistically significant. Data were analyzed with SPSS v. 29 (IBM, USA).

Results

A total of 192 orthopaedic oncology specialists participated in the survey. The main regions represented were Europe (45%), followed by North America (17%), Latin America (15%), Asia (14%), Australasia (5%), the Middle East (4%), and Africa (2%). Almost all the participants (97%) were either locally trained, meaning that they underwent a period of surgical training within their own health system or country (n = 99, 52%), or had fellowship training in another country (n = 88, 45%), while only four participants reported being self-trained (2%). Most participants (n = 165, 86%) practised at least partially in their public health systems and treated both adult and paediatric patients (n = 159, 83%). Overall, 98% (n = 189) stated being members of one or more orthopaedic oncology societies, and half of them had a certified sarcoma training programme in their country (n = 95, 50%). Table I shows the characteristics of the participant's practice and region.

Health system and oncological coverage

In 70% (n = 131) of the respondents' practices, most patients (> 90% of patients covered) are covered by private or public insurance, whereas only in 18% of cases patients are mostly not covered (< 50% of patients covered by insurance). Similarly, most declared (90%) that the majority of their patients (> 50%) with tumorous conditions were treated in public hospitals. Nonetheless, out-of-pocket payment was necessary for oncological treatment and/or implants used

Table I. Participants' region and practice.

Region	Responses, n (%)
Africa	3 (2)
Asia	26 (14)
Australasia	9 (5)
Europe	85 (44)
Middle East	8 (4)
North America	32 (17)
Latin America	29 (15)
Training	
Locally trained	99 (52)
Fellowship training overseas	88 (45)
Self-trained	4 (2)
Practice	
Public system	84 (44)
Private system	27 (14)
Both	81 (42)

in 25% of their practices (n = 48), and most declared that conditions were not the same for public or private healthcare (68%, n = 128).

Access

Globally, 40% of respondents stated that most patients in their countries (referred to as > 90%) were treated in a specialized sarcoma centre, while 63% (n = 122) of them declared that patients have relatively 'easy' access to its referral unit. On specific imaging technology, 72% declared to have relatively wide access to advanced nuclear medicine studies, such as positron emission tomography (PET)-CT, while 86% and 69% did the same regarding access to a wide range of diagnostic immunohistochemistry and translocation studies, respectively (Table II).

On treatment resources, only 59/192 (31%) stated having access to proton therapy and 157/192 (82%) to all possible reconstruction methods, including allograft and endoprosthetic reconstructions. A specialized bone bank was accessible to 165/192 (86%) of our respondents, and 118/192 (62%) had access to high-quality locally manufactured prostheses.

Prior treatments and delays in management

Most respondents felt that ideal surgical treatment was not usually compromised because of prior inappropriate management 115/192 (60%); however, this happened constantly for 77/192 (40%) of them . Similarly, treatment was delayed at least regularly because of financial constraints in 17% of practices, while in only 76/174 (43%) and 78/122 (64%) of respondents, patients could start their treatments for an osteosarcoma in less than two weeks in the public and private health systems, respectively (Table III).

Disparities among regions

Disparities among regions were high for most of the items interrogated. Among health systems, respondents from Europe and Australasia had a more preponderant impression of 'easy' access to a sarcoma service (85% and 78% of responses, respectively), followed by North America (50%), Asia (50%), the Middle East (43%), Africa (33%), and Latin America (31%). Similarly, insurance coverage in > 50% of patients was more frequent for respondents from North America (100%), Europe (89%), Australasia (89%), and the Middle East (86%), while it was less common in Latin America (71%), Asia (56%), and Africa (0%).

Regarding access to specialized treatment, 63%, 54%, 33%, and 33% of respondents from Australasia, Europe, North America, and Asia, respectively, declared that sarcoma patients were treated mostly in sarcoma centres (> 90%). On the contrary, this happened only in 14%, 14%, and 0% of responses from the Middle East, Latin America, and Africa, respectively. Important differences were observed in the perceived access to all diagnostic and therapeutic resources investigated within regions (Table II).

Compromise of adequate treatment because of prior inappropriate procedures happened at least regularly in more than half of the survey responses from Africa (100%), the Middle East (75%), Asia (62%), and Latin America (52%). Moreover, it was less frequent in responses from North America (28%), Europe (30%), and Australasia (33%). Correspondingly, delays in treatment for financial reasons were declared to happen at least regularly in 59%, 34%, and 33% of Latin American, Asian, and African responses, respectively, while it was less frequent in other countries (Table III).

Disparities within regions

Most regions presented some disparities among answers from different countries. In Asia, all respondents from Japan, Korea, China, and Singapore reported easy access to a sarcoma centre, whereas the opposite was observed by respondents from Pakistan, Indonesia, the Philippines, and India. Similarly, at least regular delays in treatment for financial reasons were expressed by all respondents from Indonesia, Pakistan, and the Philippines, compared with none from Japan, China, or Thailand. Even more, significant contrast between answers on reconstruction alternatives were observed in Asia, Latin America, the Middle East, and Europe (Ukraine compared with most others). Table IV illustrates the most significant differences within regions.

Access according to income

Respondents from high-income countries declared easy access to a sarcoma centre, and more than 90% of patients were treated in a specialized hospital in 74% and 49%, respectively, compared with 11% and 8% in those from low-to-middle-income economies ($p < 0.001$). Moreover, all diagnostic and most therapeutic resources investigated showed significantly better access for the respondents from high-income countries compared with low-to-middle-income economies (Table V).

Similarly, delays for financial reasons happened regularly in 11% of responses from high-income countries, compared with 56% of those from low-to-middle-income ones ($p < 0.001$). Finally, 76% of respondents from low-to-middle-income countries reported at least regular compromise of

Table II. Access to specialized diagnostic and therapeutic resources.

Access to:	Africa	Asia	Australasia	Europe	Middle East	North America	Latin America	All
Sarcoma centre (> 90% patients)	0	8 (33)	5 (63)	44 (54)	1 (14)	10 (37)	4 (14)	72 (40)
Nuclear medicine (PET-CT)	0	16 (62)	8 (89)	76 (90)	7 (88)	19 (59)	12 (43)	138 (72)
Immunohistochemistry	3 (100)	21 (81)	9 (100)	77 (92)	7 (88)	28 (88)	19 (68)	164 (86)
Translocation studies	2 (67)	11 (44)	4 (44)	65 (78)	3 (38)	20 (63)	7 (25)	112 (60)
Proton therapy	0	6 (23)	0	50 (60)	0	2 (6)	1 (4)	59 (31)
All reconstructions	2 (67)	15 (58)	8 (89)	79 (93)	5 (63)	31 (97)	17 (61)	157 (82)
Bone bank	2 (67)	19 (73)	9 (100)	80 (94)	2 (25)	32 (100)	21 (75)	165 (86)
Local endoprosthetics	3 (100)	12 (46)	4 (44)	59 (69)	4 (50)	24 (77)	12 (43)	118 (62)

PET, positron emission tomography.

Table III. Prior treatments and delays in management. Values are presented as n (%).

Variable	Africa	Asia	Australasia	Europe	Middle East	North America	Latin America	All
Compromise of adequate treatment								
Not often	0	39 (10)	67 (6)	71 (60)	25 (2)	72 (23)	48 (14)	60 (115)
Regularly	67 (2)	39 (10)	33 (3)	25 (21)	38 (3)	25 (8)	28 (8)	29 (55)
Very often	33 (1)	19 (5)	0	5 (4)	38 (3)	3 (1)	21 (6)	10 (20)
Always	0	4 (1)	0	0	0	0	3 (1)	1 (2)
Delay for financial reasons								
Never	0	23 (6)	33 (3)	52 (44)	25 (2)	9 (3)	7 (2)	31 (60)
Not often	67 (2)	42 (11)	56 (5)	47 (40)	63 (5)	81 (26)	35 (10)	52 (99)
Regularly	33 (1)	15 (4)	11 (1)	1 (1)	0	6 (2)	35 (10)	10 (19)
Very often	0	19 (5)	0	0	13 (1)	3 (1)	24 (7)	7 (14)
Time to treat osteosarcoma								
Private system								
< 2 wks	67 (2)	77 (17)	86 (6)	46 (18)	83 (5)	82 (14)	57 (16)	64 (78)
2 to 4 wks	33 (1)	14 (3)	14 (1)	41 (16)	0	17 (3)	29 (8)	26 (32)
4 to 12 wks	0	9 (2)	0	10 (4)	17 (1)	0	14 (4)	9 (11)
> 12 wks	0	0	0	3 (1)	0	0	0	1 (1)
Public system								
< 2 wks	0	36 (9)	78 (7)	56 (45)	13 (1)	56 (13)	4 (1)	43 (76)
2 to 4 wks	0	28 (7)	22 (2)	33 (27)	38 (3)	44 (10)	46 (12)	35 (61)
4 to 12 wks	2 (100)	36 (9)	0	9 (7)	50 (4)	0	23 (6)	16 (28)
> 12 wks	0	0	0	3(2)	0	0	27 (7)	5 (9)

adequate treatment because of prior inappropriate procedures, whereas this happened in only 30% of those from high-income countries ($p < 0.001$).

Discussion

The Universal Declaration of Human Rights was established in 1948, which marked the beginning of modern human rights. The approach to health as a human right has been incorporated into many legal instruments since then to provide freedom and rights to the population, and ensure quality and accountable access to health services. Despite significant efforts and tremendous progress on various fronts, there are still dramatic disparities observed worldwide in the access to well-established measures to treat less frequent diseases such as sarcomas.[15]

Cancer outcomes depend on various factors; however, early detection and effective treatment are the mainstays of improved outcomes. The European Cancer Organization has defined the essential requirements for providing quality cancer care for soft-tissue and bone sarcomas. The document highlights that specialized sarcoma centres are essential for delivering high-quality care.[16] These centres should have

Table IV. Countries where there is a significant contrast in answers.

Continent	Country (mostly yes)	Country (mostly no)
Easy access to a sarcoma centre (mostly yes vs mostly no)		
Asia	China, Japan, Korea, Singapore	Hong Kong, Indonesia, Pakistan, Philippines, India
Europe	All except Poland, Estonia, Italy, Portugal, and Spain	Ukraine
Latin America	Uruguay	Brazil, Ecuador
Access to all reconstruction methods (mostly yes vs mostly no)		
Asia	China, Indonesia, Thailand	Hong Kong, Singapore, Korea, Pakistan, Philippines
Europe	All except Denmark and Estonia	Ukraine
Latin America	Colombia, Ecuador	Uruguay, Venezuela
Middle East	Israel, Jordan, Turkey	Egypt
Regular delay in treatment for financial reasons (mostly yes vs mostly no)		
Asia	Indonesia, Pakistan, Philippines	China, Japan, Thailand
North America	Mexico	Canada, USA

A significant contrast is defined as a situation where one country has more than 80% positive responses and the other has less than 20%.

Table V. Access to specialized diagnostic, therapeutic resources, and delays per income. Values are presented as n (%).

Variable	Low-to-middle-income countries	High-income countries	All	p-value*
Access to:				
Sarcoma centre (> 90% patients)	8 (3)	49 (69)	40 (72)	< 0.001
Nuclear medicine (PET-CT)	43 (18)	81 (120)	72 (138)	< 0.001
Immunohistochemistry	32 (76)	89 (132)	86 (164)	0.041
Translocation studies	33 (14)	67 (98)	60 (112)	< 0.001
Proton therapy	2 (1)	39 (58)	31 (59)	< 0.001
All reconstructions	71 (29)	85 (128)	82 (157)	0.039
Bone bank	76 (31)	89 (134)	86 (165)	0.037
Local endoprosthetics	54 (22)	64 (96)	62 (118)	0.208
Compromise of adequate treatment				
Not regularly	24 (10)	70 (100)	60 (115)	
At least regularly	76 (32)	30 (45)	40 (77)	< 0.001
Delay for financial reasons				
Not regularly	44 (18)	89 (81)	75 (99)	
At least regularly	56 (23)	11 (10)	25 (33)	< 0.001

*Chi-squared test.
PET, positron emission tomography.

a core, specialized, multidisciplinary team, and access to necessary resources and technology for delivering such care.

Our research findings shed light on the challenging situation of sarcoma care across the globe. Just under 50% of orthopaedic oncology specialists who were surveyed reported that a specialized sarcoma centre was the primary treatment location for sarcoma patients in their region. Moreover, the responding surgeons' impressions of accessibility of specific technology for diagnosis or treatment ranged widely, from only 31% of the surveyed specialists for proton therapy to 86% for a specialized bone bank. In addition, 40% of surgeons reported that they regularly encountered difficulties in providing ideal treatment as a result of a previous inappropriate procedure.

This statement is consistent with the high rate of unintentional resections reported in some series worldwide.[7]

Various factors determine health disparities. Our study highlights substantial regional differences in healthcare access within regions and across countries, which can have an impact on clinical outcomes. It is well documented that high-income regions tend to spend up to ten times more on cancer per capita as compared to low- to mid-income countries,[17] resulting in higher five-year survival rates for most cancers in richer countries than in low-to-middle-income countries.[18,19] This highlights the vital role that resources play in determining cancer outcomes. This is particularly noticeable when comparing five-year net survival rates for females with breast cancer between different countries. For example, the survival rate from 2010 to 2014 was over 85% in the USA or UK, but only 72% in Colombia and 68% in Thailand.[20]

There is a lack of global data on the care provided to sarcoma patients. However, our research at least indicates that surgeons from regions with well-established healthcare systems perceive that a better insurance coverage for sarcoma treatments is provided, resulting in lower out-of-pocket expenses for patients. Additionally, universal treatment of sarcoma patients at specific sarcoma centres is perceived to be lower in regions such as Asia, Latin America, Africa, and the Middle East. Moreover, if we only consider responses from physicians working in low- to middle-income countries, the perceived universal treatment of sarcoma patients in specialized centres is almost nonexistent (8%). Furthermore, the perception of delays in treatment is five times more frequent in respondents from these countries compared with high-income countries. Overall, substantial differences were observed for all items analyzed and compared within regions of lesser and more development, as well as when analyzed by income. Interestingly, the perceived availability of local endoprosthetic arthroplasties for financially constrained patients was found to be similar across participants from high-income and low-to-middle-income countries. While access to well-established commercial brands of prosthesis is typically linked to economic resources, it seems that more financially constrained healthcare systems have developed their own alternatives to address this issue locally.

It is important to note that disparities in healthcare access are not only observed between regions but also within them. For instance, in Asia there is a significant contrast in the responses for access to specialized sarcoma services between specialists from high-income countries as per GDP per capita, such as Japan, Singapore, and Hong Kong, and all others within the region. A similar situation is observed with the only respondent from Ukraine, which sheds light on the dissimilar situation that this country represents compared to the rest of Europe. In Latin America, a relevant contrast is observed when asking about delays for financial reasons, probably related to the presence of a universally public compared with private insurance in a developing country.

The challenge of addressing global and regional disparities in access to specialized sarcoma care is a complex one. Since health access is closely interlinked with economic development and regional progress, general solutions that do not take this vital limitation into account may not have the desired impact. Developing a tailored approach that takes into consideration regional limitations, and establishing frameworks and detailed stepping stones, could be a good starting point. However, achieving success may require analyzing individual data in large series with global participation, along with the widespread use of registries in populated regions such as Asia and Latin America.

Our study has some limitations that should be acknowledged. First, it is a survey that included only participants of the 2024 BOOM meeting, which was an international academic meeting held in the UK. Thus, our survey may not be representative on a global scale, and there may be a selection bias towards more academic or engaged members of the oncology community. However, participants from all continents and a large number of countries with active members of all major orthopaedic oncology societies were represented. Second, since our study format was a survey of treating physicians and not a detailed analysis of individual patient data, our results may be affected by recall bias and may not accurately represent the reality of individual and regional practice, especially in geographical areas with a small number of participants, such as Africa. Thus, it is important to clearly state that the results of this survey represent the responses and, consequently, the impressions of well-engaged orthopaedic oncologists worldwide. While this may be a representative sample of specialists, the methodology of our study might limit our ability to accurately reflect the true reality of certain scenarios. Finally, differences in practices are more complex than just regional or economic. Therefore, our analysis based on these aspects may oversimplify the multivariable causes that affect health access and development in certain areas such as sarcoma treatment.

Meetings such as the 2024 BOOM meeting are a platform for global experts from regions with diverse healthcare needs and access to treatment facilities to highlight the disparities in healthcare. The insights of this survey on the access to sarcoma services on a global scale can help health organizations in formulating national policies and resource-stratified guidelines to optimize healthcare access in lesser-developed health systems. It also serves as a base for enhancing further collaborative initiatives in the complex and infrequent field of musculoskeletal sarcomas, ultimately improving the quality of care for these pathologies.

Supplementary material

The survey BOOM consensus meeting participants, the survey itself, and a table showing the number of participants from each country, organized by region.

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E. Botello is a board member of ISOLS and SLATME. L. Jeys reports royalties or licenses and support for attending meetings and/or travel from Implantcast, payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from Zimmer Biomet, Implantcast, and Stryker, all of which are unrelated to this study. L. Jeys also holds leadership or fiduciary roles in EMSOS and ISOLS. M. Laitinen reports support for attending meetings and/or travel from Tree-Step, unrelated to this study. A. Puri is on the editorial board of *The Bone & Joint Journal*, *Bone & Joint Open*, *Bone & Joint 360*, the Sarcoma International Advisory Board, and APMSTS. T. Zamora is a member of the SICOT Tumors subspecialty committee.

Data sharing

The data that support the findings for this study are available to other researchers from the corresponding author upon reasonable request.

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Ethical review statement

Ethical approval was not required for this study, as it did not involve human participants, identifiable patient data, or animal subjects.

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