

Assessment of Familiarity With Work-up Guidelines for Bone and Soft Tissue Sarcoma Among Primary Care Practitioners in Minnesota

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Abstract

Objective: To assess familiarity with sarcoma guidelines among primary care practitioners (PCPs) in Minnesota.

Participants and Methods: Surveys were distributed at 2 educational conferences held in Minnesota on April 16-17, 2015, and October 24, 2015. The PCPs were asked a series of questions about their current practice, past experience with sarcoma, and familiarity with sarcoma guidelines. They were then given a series of case presentations and asked to indicate if they would pursue a sarcoma work-up given the information provided.

Results: The study group included 80 physicians and 32 nurse practitioners (NPs). Over their careers (median, 14 years), physicians reported seeing a mean of 2.2 cases of soft tissue sarcoma and 0.7 cases of bone sarcoma. The NPs reported seeing a mean of 0.7 and 0.2 cases, respectively, over their careers (median, 8 years). Both physicians and NPs reported low familiarity with sarcoma guidelines. When challenged with case presentations for which urgent referral to a sarcoma specialist is recommended, more than 50% of PCPs did not indicate that they would refer patients. The PCPs who had previous experience with soft tissue sarcoma and bone sarcoma estimated that only 17% and 23% of their patients, respectively, were diagnosed within 1 month of presentation. The most reported reason for a delayed diagnosis was the PCP advising the patient to “watch and wait.”

Conclusion: Minnesota PCPs have seen very few cases of sarcoma and report low familiarity with sarcoma guidelines. When challenged with case presentations, PCPs made decisions inconsistent with established guidelines. This study supports ongoing efforts to increase sarcoma awareness.

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Sarcoma represents a rare, heterogeneous group of tumors that can originate from soft tissue (~80%) or bone (~20%) and often involve the extremities.¹⁻³ Early diagnosis and subsequent multimodality treatment are critical to reduce morbidity and mortality from this aggressive disease.⁴ Despite well-defined referral guidelines, the diagnosis of sarcoma is often delayed.^{5,6} This delay is due to the rarity of the disease and inconspicuous presentation as well as other patient and practitioner factors.

Benign soft tissue masses are at least 100 times more common than malignant soft

tissue sarcomas (STSs).³ Therefore, determining which masses warrant further evaluation can be a challenge for clinicians. The most common presenting symptom for an STS is a gradually enlarging, painless mass, although some patients present with pain, paresthesia, or edema in the affected extremity. Current guidelines for STS from the United Kingdom recommend referring all patients with any of the following signs/symptoms: a soft tissue mass greater than 5 cm, a painful lump, a lump that is increasing in size, a lump of any size that is deep to the muscle fascia, or recurrence of a lump after

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previous excision.^{5,7} According to one study, the best predictor of malignancy is tumor depth, followed by size (>5 cm) and history of rapid growth.⁸ Magnetic resonance imaging is the imaging modality of choice for suspected lesions and should be obtained promptly.

Bone sarcoma is less common than STS. Osteosarcoma accounts for roughly half of all bone sarcomas. Most patients present with localized pain over several months' duration that may gradually increase in intensity or wax and wane over time.⁶ Bone pain at night must always be considered a red-flag symptom requiring further investigation. Physical examination may reveal a mass and/or swelling that is tender to palpation. According to the European Society for Medical Oncology, the presence of persistent nonmechanical pain in any bone lasting more than a few weeks warrants immediate investigation.⁹ It is recommended that patients be referred to a specialized treatment center before biopsy. Plain radiography (2 planes) is the first investigative step, followed by magnetic resonance imaging.

Previous studies have suggested that sarcoma diagnosis may be delayed due to assumptions of nonmalignancy by primary clinicians who are much more likely to encounter benign disease rather than sarcoma.¹⁰ The aim of this study was to gain a better understanding of this observation through administration of a survey to primary care practitioners (PCPs; physicians and nurse practitioners [NPs]) at 2 conferences in Minnesota. Information on practice characteristics, experience with sarcoma, familiarity with sarcoma guidelines, and perceived barriers to a timely diagnosis was obtained. The PCPs were then given a series of case presentations and asked if an urgent work-up was indicated. Finally, we asked participants whether they felt they had the resources to make a timely diagnosis and to indicate reasons why prior patients had a diagnosis that was delayed.

PARTICIPANTS AND METHODS

Study Cohort

The study was approved by the Mayo Clinic Institutional Review Board. The target group for this study was primary care physicians and NPs in Minnesota. Surveys were distributed at 2 conferences. The first conference

was the Minnesota Academy of Family Physicians "Spring Refresher" conference held April 16-17, 2015, in Minneapolis, Minnesota. The second conference was the annual Minnesota Nurse Practitioner Conference held on October 24, 2015, at the University of Minnesota in Minneapolis. A booth was set up at the 2 conferences, and PCPs in attendance were encouraged to fill out surveys as they passed by the booth. Physicians and NPs working in family medicine, internal medicine, and pediatrics were included. Specialists, resident physicians, registered nurses, and medical or nursing students were excluded. Participants were not incentivized to participate in the study.

Study Survey

The survey consisted of 3 sections: general questions, sarcoma familiarity questions, and delayed diagnosis questions. The sarcoma familiarity section included a series of case presentations, and participants were asked whether they would initiate a sarcoma work-up and/or refer each patient to a specialist.

General Questions. The survey contained general questions to determine how long the PCP had been in practice and how many patients were seen per day on average. Participants also indicated if they had attended postresidency conferences or training focused on sarcoma.

Sarcoma Familiarity Questions. The PCPs were asked to rate their familiarity with the guidelines for the work-up and diagnosis of STS and bone sarcoma from 1 to 10 (10 being highly familiar). They were also asked to rate their confidence using a similar scale from 1 to 10. Next, the participants were challenged with case presentations. They were given a list of clinical presentations and were asked to indicate whether the case warranted urgent work-up for sarcoma. The case presentations for STS and bone sarcoma are displayed in [Tables 1 and 2](#), respectively.

Delayed Diagnosis Questions. The PCPs who had previously evaluated one or more patients in whom sarcoma was ultimately diagnosed indicated the percentage of their

TABLE 1. Primary Care Practitioner Responses for Soft Tissue Sarcoma Case Presentations^a

Case presentation	Sarcoma work-up recommended by guidelines	Physicians pursuing work-up (n=67)	Nurse practitioners pursuing work-up (n=20)	Total cohort (N=87)
Nontender superficial mass measuring 2 cm	No	24 (36)	6 (30)	30 (35)
Nontender superficial mass measuring 5 cm	Yes	33 (49)	9 (45)	42 (48)
Nontender deep mass measuring 2 cm	Yes	27 (40)	11 (55)	38 (44)
Nontender deep mass measuring 5 cm	Yes	37 (55)	10 (50)	47 (54)
Painful mass measuring 2 cm	Yes	28 (42)	5 (25)	33 (38)
Painful mass measuring 5 cm	Yes	31 (46)	4 (20)	35 (40)
Nontender enlarging mass	Yes	49 (73)	13 (65)	62 (71)
Painful enlarging mass	Yes	42 (63)	8 (40)	50 (57)
Mass associated with constitutional symptoms	Yes	40 (59)	10 (50)	50 (57)

^aData are presented as No. (percentage) of participants.

patients who received the diagnosis within 1 month of presentation. One month from the time of initial medical evaluation to the time of diagnosis has been used previously as the cutoff for “physician delay” in diagnosis.⁴ The PCPs who had evaluated a patient whose diagnosis was ultimately delayed were asked to indicate the factors that contributed most to a delayed diagnosis.

RESULTS

Survey Participants

A total of 127 surveys were collected at the 2 conferences. The 15 surveys completed by medical and nursing students were excluded,

leaving 80 physician and 32 NP surveys included in the study. For physicians, the median number of years in practice was 14 years (interquartile range, 5-23 years) and the median number of patients seen per day was 18 (interquartile range, 13-20). For NPs, the median number of years in practice was 8 years (interquartile range, 3-15 years) and the median number of patients seen per day was 10 (interquartile range, 8-20). Not all surveys were filled out completely. Of the 112 surveys that were included, 87 participants filled out the STS case presentation questions and 93 participants filled out the bone sarcoma case presentation questions.

TABLE 2. Primary Care Practitioner Responses for Bone Sarcoma Case Presentations^a

Case presentation	Sarcoma work-up recommended by guidelines	Physicians pursuing work-up (n=69)	Nurse practitioners pursuing work-up (n=24)	Total cohort (N=93)
Localized bone pain lasting 1 wk	No	12 (17)	1 (4)	13 (14)
Localized bone pain lasting 4 wk	Yes	48 (69)	15 (63)	63 (68)
Localized bone pain increasing in intensity	Yes	51 (73)	16 (67)	67 (72)
Diffuse (more than 1 bone) pain lasting 1 wk	No	7 (10)	4 (17)	11 (12)
Diffuse (more than 1 bone) pain lasting 4 wk	No	34 (49)	14 (58)	48 (52)
Bone pain accompanied by tissue swelling	Yes	47 (67)	10 (42)	57 (62)
Bone pain with a palpable mass	Yes	47 (67)	15 (63)	62 (67)
Bone pain at night	Yes	36 (51)	8 (33)	44 (47)

^aData are presented as No. (percentage) of participants.

Familiarity With Sarcoma

Both physicians and NPs reported low familiarity with sarcoma guidelines and low confidence in management. Among physicians, the median rating (on a scale of 1-10) for familiarity with sarcoma guidelines was 3 (interquartile range, 2-5) and the median rating (on a scale of 1-10) for confidence was 3 (interquartile range, 3-5). For NPs, the median rating for familiarity with sarcoma guidelines was 1 (interquartile range, 1-2) and the median rating for confidence was 1 (interquartile range, 1-2). Eight of 79 physicians (10%) and 1 of 30 NPs (3%) reported attending a sarcoma conference since graduation from their respective training programs.

The mean number of patients that physicians had evaluated who ultimately received a diagnosis of STS or bone sarcoma was 2.2 and 0.7, respectively. The mean number of patients that NPs had evaluated who ultimately received a diagnosis of STS or bone sarcoma was 0.7 and 0.2, respectively. 24 of 74 physicians (32%) and 19 of 29 NPs (66%) had never seen a case of STS. 42 of 72 physicians (58%) and 26 of 28 NPs (93%) had never seen a case of bone sarcoma. [Figures 1 and 2](#) illustrate the PCPs' experience with sarcoma.

STS Case Presentations

Of the 112 survey participants, 87 completed the STS case presentation questions. When challenged with potential STS cases, both physicians and NPs were most concerned with a nontender enlarging mass—62 participants (71%) indicated that this presentation would warrant prompt referral. Participants were least concerned about a nontender superficial mass measuring 2 cm, with 30 (35%) indicating a need for urgent referral. The percentage of physicians and NPs who would pursue an STS work-up given various presentations is shown in [Table 1](#).

Bone Sarcoma Case Presentations

Of the 112 survey participants, 93 completed the bone sarcoma case presentation questions. When challenged with potential bone sarcoma cases, PCPs were most concerned with localized bone pain increasing in intensity (67 [72%] pursuing work-up), localized bone pain lasting 4 weeks (63 [68%]), and bone

pain with a palpable mass (62 [67%]). The PCPs were less concerned about diffuse bone pain lasting 1 week (11 [12%]) and localized bone pain lasting 1 week (13 [14%]). The percentage of PCPs who would pursue a bone sarcoma work-up given various presentations is shown in [Table 2](#).

Subset Analysis

On a subset analysis of both STS and bone sarcoma, there were no major differences in clinical decision making with regard to PCP type (physicians vs NPs), years of clinical experience, number of sarcoma cases diagnosed, confidence, or familiarity with guidelines.

Delayed Diagnosis Questions

The PCPs having prior experience with STS estimated that 17% of their patients were diagnosed within 1 month of presentation. Those having prior experience with bone sarcoma estimated that 23% of their patients were diagnosed within 1 month of presentation. The most common reasons for delayed diagnosis in both diseases were that the patient was initially advised to “watch and wait,” followed by a delay in the referral process due to specialist availability, insurance coverage issues, and patient factors such as missed appointments. Other factors contributing to delayed diagnosis were delays in imaging, misinterpretation of imaging, and time constraints placed on PCPs. Forty-one of 78 (53%) PCPs felt they had optimal time and resources to make a prompt diagnosis. Some PCPs indicated limitations on spending for imaging, particularly for uninsured or underinsured patients. Many indicated that their patients presented to medical attention very late.

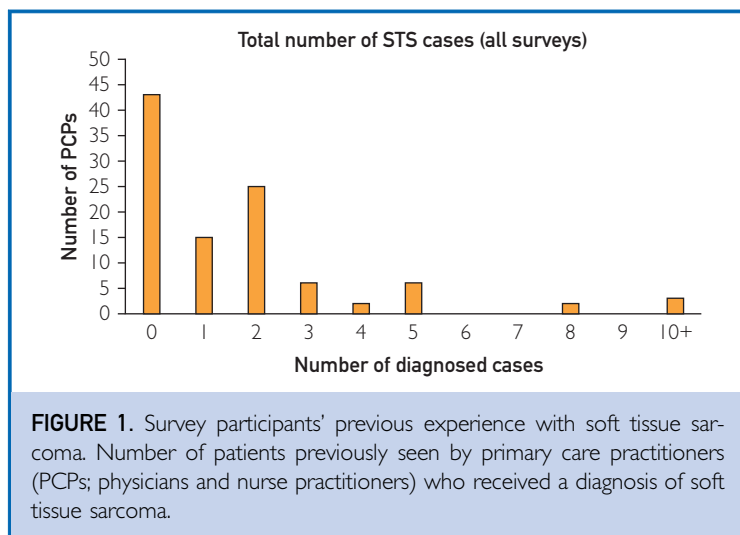
DISCUSSION

Sarcoma is a rare but potentially fatal malignancy with a diagnosis that is often delayed due to a combination of patient and health care professional factors. The current study utilized a survey to identify PCP familiarity with sarcoma guidelines and to assess clinical decision making through case presentations. Both physicians and NPs reported limited prior experience with sarcoma, low confidence in their ability to diagnosis the disease, and low familiarity with sarcoma guidelines.

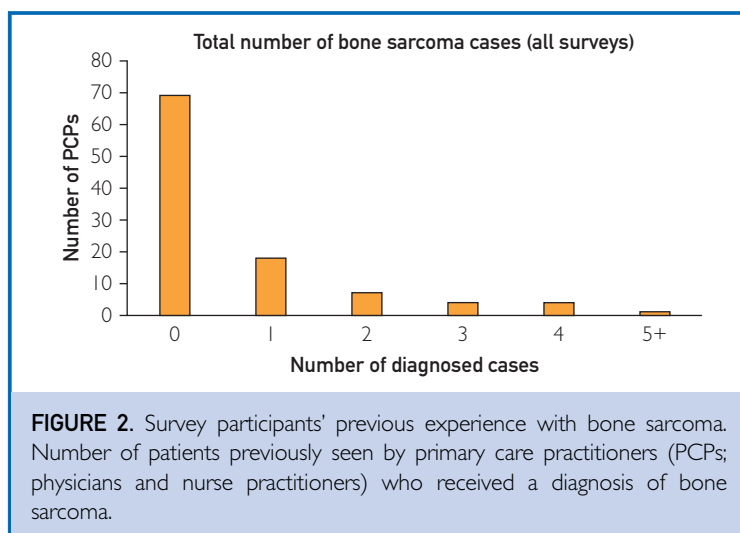
When PCPs were challenged with case presentations, clinical decision making was largely inconsistent with established guidelines (Tables 1 and 2).

Of the following cases that *should have* prompted an STS work-up, the percentage of physicians (n=67) and NPs (n=20) acting in accordance with guidelines was low: nontender superficial mass measuring 5 cm (49% [n=33] and 45% [n=9]), nontender deep mass measuring 2 cm (40% [n=27] and 55% [n=11]), nontender deep mass measuring 5 cm (55% [n=37] and 50% [n=10]), painful mass measuring 2 cm (42% [n=28] and 25% [n=5]), painful mass measuring 5 cm (46% [n=31] and 20% [n=4]), nontender enlarging mass (73% [n=49] and 65% [n=13]), and painful enlarging mass (63% [n=42] and 40% [n=8]). Of particular concern is that only half of physicians and NPs indicated they would pursue a sarcoma work-up for a mass, superficial or deep, measuring 5 cm because larger lesions are more destructive and more likely to metastasize.³ Of the following cases that *should have* prompted a bone sarcoma work-up, the percentage of physicians (n=69) and NPs (n=24) acting in accordance with guidelines was also low: localized bone pain lasting 4 weeks (69% [n=48] and 63% [n=15]), localized bone pain increasing in intensity (73% [n=51] and 67% [n=16]), bone pain accompanied by tissue swelling (67% [n=47] and 42% [n=10]), bone pain with a palpable mass (67% [n=47] and 63% [n=15]), and bone pain at night (51% [n=36] and 33% [n=8]).

Our survey results are consistent with observations in actual clinical settings. A prior retrospective study of patients with sarcoma found that 74% and 88% of STS and bone sarcoma cases, respectively, presented to medical attention with at least one guideline feature to prompt urgent referral, but only 43% and 54%, respectively, were referred to secondary care for investigation for STS and bone sarcoma.¹¹ Another study found that the main reason for patient delay in STS presentation is lack of pain from an enlarging mass.¹² In the current study, the presence of pain did not seem to substantially alter clinical decision making. Even in the setting of a painful mass, less than 50% of survey participants elected to pursue a sarcoma work-up.



Responses to case presentations did not vary substantially with regard to PCP type (physician vs NP), years of clinical experience, prior experience with patients with sarcoma, confidence, or self-identified familiarity with guidelines. It is discouraging that PCPs who had prior experience with sarcoma and those who self-identified as having high familiarity with sarcoma guidelines did not differ from those who had less experience and familiarity in their decision making. It is also discouraging that those reporting postgraduate participation in sarcoma conferences or lectures also did not differ in clinical decision making. Only 8 participants reported ongoing



sarcoma education, which limits any conclusion that can be drawn regarding its effectiveness. Additionally, the low number of physicians and NPs included in the study limit the ability to detect a difference between these 2 groups.

Limitations of the current study include recall bias, incomplete surveys, misinterpretation of questions, and generalizability of results. One possible contributor to a low percentage of PCPs indicating a sarcoma work-up may have been incorrectly assuming that only one patient presentation could be selected despite clearly worded instructions. In this scenario, the participant may have selected the presentation that was *most* concerning for sarcoma instead of *all* scenarios that should prompt a work-up. There is also concern for selection bias based on who took the effort to fill out the questionnaire, and as such, our study group may be enriched for physicians and NPs who are more interested in continuing medical education. Despite these limitations, we believe this study provides insight into how PCPs approach the work-up of soft tissue lumps and bone pain.

Future directions may include performing a larger study at a national level and further determining the role of education in improving clinical decision making. Although prior attendance at a sarcoma conference after training did not appear to improve decision making in this study, there may be more effective methods to improve awareness and education. For example, a course dedicated to sarcoma work-up guidelines with a follow-up assessment in 1 month, 6 months, and 12 months may improve retention of knowledge via spaced repetition.¹³ A future prospective study in a more controlled clinical environment such as Kaiser Permanente or another regional health care system could allow for standardized teaching of PCPs. Within such a system, decision making could be evaluated before and after teaching, which would provide useful information on the effectiveness of education. Further education of physicians and NPs at national meetings and continuous feedback from the specialty center and physician back to the PCP regarding a patient's diagnosis and outcome would be valuable.

Finally, clinician knowledge is only one of many factors that contribute to a delayed diagnosis in sarcoma. In the free response section of the survey, PCPs listed the following factors as contributing to delayed diagnosis: patient delays in presentation, clinical time constraints, insurance restrictions, delays in obtaining imaging, and misinterpretation of imaging. Thus, increasing public awareness of sarcoma, improving clinical workflow, and addressing barriers to prompt referral and diagnosis are imperative.

CONCLUSION

Primary care practitioners in Minnesota evaluate very few cases of sarcoma and report low familiarity with sarcoma guidelines. When challenged with case presentations, PCPs made decisions inconsistent with established guidelines. The PCPs identified several factors contributing to delayed diagnosis in their patients. Continued efforts to increase sarcoma awareness are imperative.

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Abbreviations and Acronyms: NP = nurse practitioner; PCP = primary care practitioner; STS = soft tissue sarcoma

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