Thematic Analysis of Online Discussion Forums for Bone Sarcomas

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ABSTRACT

Background: Online discussion forums allow people from all over the world to come together and create a community where they can seek and share information. Patients with bone sarcomas and their support network utilize discussion forums dedicated to cancer support.

Questions/Purposes: The objective of this study was to review posts from bone sarcoma internet discussion boards to provide a thematic framework related to the sarcoma patient experience. Understanding commonly discussed themes amongst patients would allow treating physicians to have a better understanding of patient concerns when providing patient education and counseling.

Patients and Methods: Using Google and Bing search engines, online discussion forums were identified using the search term “sarcoma discussion forum.” Five discussion boards, including Cancer Research UK, Cancer Survivors Network, Macmillan Cancer Support, HealthBoards, and Inspire were reviewed. Posts written between January 1, 2012 and May 1, 2022 were collected. Posts from administrators or site moderators, duplicates, and those without substantive volume of text were excluded from final analysis. Discussion threads were filtered to identify posts pertaining to the most common bone sarcomas: chondrosarcoma, Ewing’s sarcoma, and osteosarcoma. Each post was reviewed 3 times through open coding, axial coding, and selective coding to establish common themes.

Results: A total of 634 posts from 139 threads were collected and analyzed from five discussion forums. Of these, 570 were included in the final analysis. Twenty-seven axial codes and four selective codes were created. The four selective codes included: (1) Emotional Aspects/Connecting with Others, (2) Information Support: Diagnosis, (3) Information Support: Treatment, and (4) Information Support: Recovery. Of these four codes, Emotional Aspects/Connecting with Others was the most prevalent theme (78% of posts) followed by Information Support: Treatment (49% of posts). Information Support: Diagnosis and Information Support: Recovery both were captured in 15% of posts. Posts pertaining to recovery from bone sarcomas centered primarily around fears of recurrence more so than the physical challenges and timeline associated with long-term recovery.

Conclusion: Patients with bone sarcomas and their family members frequently utilize online discussion forums to connect with others and gather information about the diagnostic process, varying treatment options, and challenges of recovery. 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. Our findings highlight that physicians caring for bone sarcoma patients should not only address patient concerns about treatment and recovery, but also emphasize the importance of providing emotional support as well as resources to find both professional support and informal support groups for patients and their family members. Future studies should aim to identify the most effective modalities of emotional support resources for this group of patients, which may include involvement of psychosocial oncology and other mental health care providers.