

Impact of Pathologist Involvement in Sarcoma and Rare Tumor Patient Support Groups on Facebook

A Survey of 542 Patients and Family Members

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• **Context.**—Patients with rare tumors have difficulty finding reliable information about their disease. Facebook patient support groups allow patients to educate one another.

Objective.—To investigate how these patients perceive the value of pathologists, both in Facebook groups and real-world patient care.

Design.—Survey links were posted in 12 Facebook patient groups: 6 with an active pathologist member (angiosarcoma, epithelioid hemangioendothelioma, epithelioid sarcoma, dermatofibrosarcoma protuberans [×2], and desmoid fibromatosis), and 6 without “active” pathologist involvement (aggressive angiomyxoma, chondrosarcoma, Ewing sarcoma, leiomyosarcoma, liposarcoma, and osteosarcoma).

Results.—A total of 542 people responded (403 were patients): 264 from groups with a pathologist, and 278 from groups without active pathologist involvement. Of groups with an active pathologist, respondents agreed the pathologist’s posts helped them better understand their disease

(107 of 119; 90%) and relieved some of their disease-related anxiety (92 of 119; 77%). And for these groups 98% (117 of 119) of respondents agreed that having a pathologist in their group was a good thing; 83% (192 of 232) wanted more pathologists involved. More respondents from groups with an active pathologist (219 of 236; 93%) than without one (215 of 252; 85%) agreed: “pathologists are an important part of the patient care team for patients with cancer and other rare tumors” ($P = .008$).

Conclusions.—This study is the first to evaluate the impact of pathologist interaction with Facebook patient support groups and to assess perceptions about the specialty of pathology from a large group of patients with rare tumors. Pathologist involvement in Facebook patient groups appears to positively influence patient perception of the importance of pathologists. We hope these data will encourage more pathologists to participate in Facebook patient support groups.

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Facebook (Menlo Park, California) is a social media platform that is not monomorphic; that is, its depth and breadth span beyond seemingly trivial human interests.¹ Facebook is the second most visited Web site, second only to Google (Mountain View, California). As of June 2017, Facebook has 2 billion monthly users.² Although it may seem that this platform’s users are consumed with videos of cats and political opinions, there are significant

communities of patients gathering and communicating with one another who are otherwise geographically separated. A patient from an angiosarcoma support group commented, “I went for more than 30 years without meeting another person [with angiosarcoma].”³ Thus, these groups are able to provide a sanctuary for the patient who otherwise would be forever isolated from any other person living with their particular disease.

As patients continue to seek information regarding their own health care via the Internet, the relationship between the patient and physician remains dynamic. Health care is becoming bidirectional, in that the patient is actively seeking information about his or her own condition to become a more active member of his or her own health care team.⁴ This bidirectional model contrasts with the dated, unidirectional way, in which the physician was the sole provider of medical knowledge and the patient a passive recipient. With this change in the physician-patient relationship comes a necessity for the physician to stay informed and be willing to adapt to the evolving health care system. Thus, it is vital for physicians to consider and include the Internet in their daily practice of medicine.

Lay patients have access to endless amounts of information, some of which is from reliable, vetted sources;

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however, other information may be confusing, misleading, or intentionally deceptive. It has always been the physician's role in health care to act as a reliable source of information for the patient and his or her caregivers. In this new age, with endless access to an abundance of information, the physician can become not only a patient educator, but also an information referee for the patient: determining information that is valid and applicable versus deceptive and factitious.

One way in which physicians can referee this stream of health care information is through social media. Social media is a fast, accessible, and interactive method to reach and communicate with people throughout the world. This is especially true for the interaction for patients with rare diseases. Patients congregate in support groups online to share experiences, provide support, and educate one another. Patient support groups on Facebook are an example of this type of community.

Physicians can become more involved in Facebook support groups to help mediate discussion and act as a reliable source of information. Facebook groups provide a powerful forum that allows enhanced ongoing communication between patients. Pathologists are being welcomed to Facebook support groups and find it enhances their experience in the health care profession.³ Often "behind the scenes" when it comes to direct patient care, pathologists are experts in certain disease processes and the pathophysiology behind diagnoses. With this, pathologists can provide tremendous benefit to patients seeking knowledge in these groups. One of the authors of the present study (J.M.G.) has been volunteering in a variety of Facebook patient support groups since 2014. This pathologist has been involved in various Facebook support groups by interacting with patients and their families, explaining what pathologists do and pathology terminology, helping them navigate the cancer care system, answering general questions, and providing reliable information to educate these patients about their disease.^{3,5-9} Anecdotally, the patients reported that they enjoy having this pathologist in their groups and find the pathologist's posts and comments helpful. In this study, we aimed to more formally assess patients' perceptions of pathologist involvement in their Facebook support groups. Specifically, we wanted to gauge the patient's opinion of having a pathologist involved in his or her support group. Additionally, we investigated the patient perception of the role of pathologists as a part of the patient care team. We hypothesized that this involvement would benefit patients and help patients understand the role and importance of the pathologist in their health care team, leading them to want more physicians to be involved in their groups in the future.

MATERIALS AND METHODS

Upon approval and exemption from the University of Arkansas for Medical Sciences (Little Rock) Institutional Review Board, we created a survey via the online survey service SurveyMonkey (San Mateo, California). In order to use the website's advanced analytic features, we paid \$75 for an upgraded subscription. Following the generation of the survey, the administrator of each Facebook support group was contacted to explain the survey and to gain permission to post the survey link in the group. After receiving approval, the survey was posted in each support group with a message explaining that participation in the survey is completely anonymous and voluntary. The survey was posted in each Facebook support group, and survey responses were collected

Table 1. Facebook Sarcoma and Rare Tumor Patient Support Groups Surveyed^a

Facebook Groups With Active Pathologist Involvement (No. of Respondents)	Facebook Groups With No/Minimal Pathologist Involvement (No. of Respondents)
Angiosarcoma (53)	Aggressive angiomyxoma (21)
Epithelioid hemangioendothelioma (32)	Chondrosarcoma (81)
Epithelioid sarcoma (18)	Ewing sarcoma (40)
Desmoid fibromatosis (60)	Leiomyosarcoma (84)
Dermatofibrosarcoma protuberans (88)	Liposarcoma (17)
Dermatofibrosarcoma protuberans 2 (13)	Osteosarcoma (35)

^a List of the 12 Facebook patient support groups surveyed. There were 6 groups that had a pathologist involved in their groups; 6 groups had no or minimal active pathologist involvement.

during a period of 3 weeks, after which the surveys were closed to new responses.

We surveyed 12 Facebook support groups, 6 of which had a pathologist involved (FBSGp) and 6 of which had no or minimal active pathologist involvement (FBSGx; Table 1). Pathologist involvement was defined as a pathologist joining the support group and actively engaging with its members. Examples of engagement include: answering questions regarding disease processes, providing reputable sources of information, giving emotional support when indicated, and commenting on posts in the group. Facebook support groups that had pathologist members who rarely or never posted or commented in the group were considered groups with no or minimal pathologist involvement (FBSGx). We created a survey that was tailored to the type of group in which it was posted: Facebook support groups with a pathologist involved versus those with no or minimal active pathologist involvement.

RESULTS

In the 3 weeks that these surveys were posted in the 12 Facebook support groups, we received 542 responses from patients and family members of patients who had sarcoma or rare soft tissue tumors (FBSGp: 264; FBSGx: 278). Of the 542 respondents, 74% (403 of 542) were actually patients themselves, and the remainder comprised parents or family members of patients (5 respondents did not indicate whether they were a patient, parent, or family member). Most respondents were female (85%; 459 of 542), and the peak age range was 45 to 54 years (170 of 542; 31%). The characteristics of the respondents are presented in Table 2.

The participants answered the question, "Who makes the final diagnosis of cancer?" (Figure 1). Approximately 70% of respondents from both groups recognized that pathologists made the final diagnosis of cancer (FBSGP: 70% [165 of 237]; FBSGx: 69% [175 of 252]). A subset of respondents thought that oncologists made the final diagnosis of cancer (FBSGp: 26% [62 of 237]; FBSGx: 28% [70 of 252]). We also found that only 80% (384 of 479) of all respondents thought that pathologists had doctoral degrees (Table 3).

The next question prompted respondents to rate how much they agreed or disagreed with the statement that "Pathologists are an important part of the patient care team for patients with cancer and other rare tumors." Of the respondents from groups with a pathologist, 93% (219 of 236) agreed (or strongly agreed) with this statement, compared with 85% (215 of 252) of participants from the

	Respondents, No. (%)
Patient	403 of 542 (74)
Parent	87 of 542 (16)
Family member	47 of 542 (9)
Not indicated ^a	5 of 542 (1)
Age, y	
18–24	8 of 542 (1)
25–34	59 of 542 (11)
35–44	140 of 542 (26)
45–54	170 of 542 (31)
55–64	114 of 542 (21)
65+	47 of 542 (9)
Not indicated	4 of 542 (1)
Sex	
Female	459 of 542 (85)
Male	82 of 542 (15)
Not indicated	1 of 542 (0)

^a “Not indicated” means that respondents did not provide an answer for that survey question. Respondents younger than 18 years were not allowed to participate in the survey per Institutional Review Board protocol.

groups without a pathologist. The difference between these values was statistically significant (Student *t* test *P* = .008; Figure 2).

The following set of questions was asked to the groups that had a pathologist involved only, because it touches on how the respondents perceive the impact of the pathologist participating in their group. The groups with a pathologist involved were asked if they recalled interacting with the pathologist or reading posts from the pathologist (*n* = 237). Those who stated that they had interacted with the pathologist on their Facebook page (118 of 237; 50%) were prompted with a subset of questions that were not asked to those who denied interacting with the pathologist or did not recall. These responses are depicted in Figures 3 through 6.

	Overall, No. (%)
Associate’s	8 of 479 (2)
Bachelor’s	31 of 479 (6)
Master’s	56 of 479 (12)
Doctoral	384 of 479 (80)

Overall, most of these respondents felt the pathologist helped them understand their disease, understand the role of pathologists, and relieve their disease-related anxiety.

We then asked the groups that had no/minimal active pathologist involvement if they would like to have a pathologist involved in their Facebook support group in the future. Most respondents stated that they would like to have a pathologist in their group (193 of 251; 77%), with 20% (49 of 251) unsure, and only 4% (9 of 251) stating no (Figure 7).

Finally, all 12 groups were asked if they would like to have other doctors from different specialties involved in their Facebook support groups. Although most of the respondents were interested in having physicians from other specialties involved in their Facebook support group (319 of 483; 66%), there was a significant subset that stated they were unsure (138 of 483; 29%; Figure 8).

Those who acknowledged interest in having other physicians involved in their Facebook support group were prompted to suggest other specialties they would like to see participate. Among the many specialties suggested, the top 3 were oncology, surgery, and radiology. Other suggestions included internal medicine, pain management, holistic medicine, and psychiatry.

DISCUSSION

Our survey study uncovered the enthusiasm patients and their family members feel about having a pathologist at their fingertips through an accessible platform like Facebook.

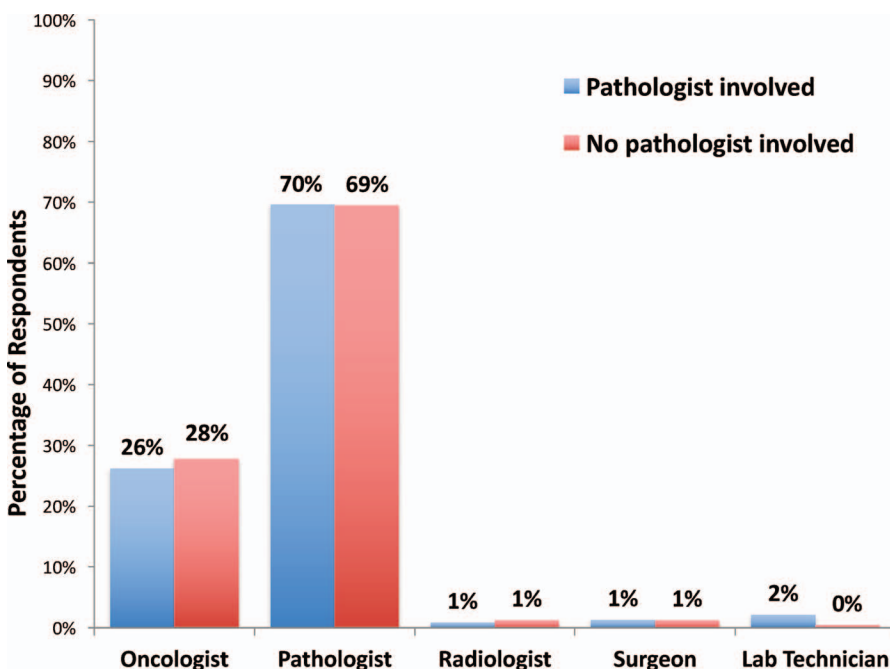
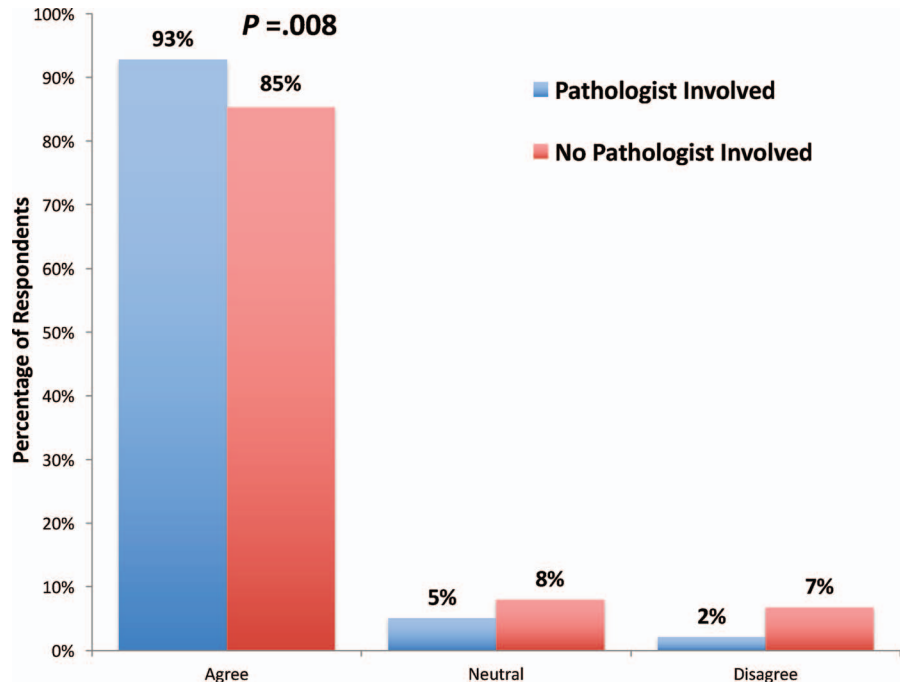


Figure 1. “Who makes the final diagnosis of cancer?” Groups with a pathologist involved (blue) responded: oncologist, 26% (62 of 237); pathologist, 70% (165 of 237); radiologist, 1% (2 of 237); surgeon, 1% (3 of 237); and lab technician, 2% (5 of 237). Groups without active pathologist involvement (red) responded: oncologist, 28% (70 of 252); pathologist, 69% (175 of 252); radiologist, 1% (3 of 252); surgeon, 1% (3 of 252); and lab technician, 0% (1 of 252).

Figure 2. Responses to the statement “Pathologists are an important part of the patient care team for patients with cancer and other rare tumors.” More respondents from groups with a pathologist (219 of 236; 93%) than without active pathologist involvement (215 of 252; 85%) agreed with this statement ($P = .008$). A minority were neutral, 5% (12 of 236) and 8% (20 of 252), respectively, or disagreed, 2% (5 of 236) and 7% (17 of 252), respectively.



With the power of social media, we obtained 542 responses in only 3 weeks, with an expenditure of \$75. Of these 542 total respondents, 403 were actual sarcoma and rare tumor patients themselves. With traditional methods, studies of this sample size can take an enormous amount of time, effort, and money to compile responses. Here, through the Facebook platform, we were able to reach an abundance of patients with rare diseases and gain significant results with a minimal investment of time and money.

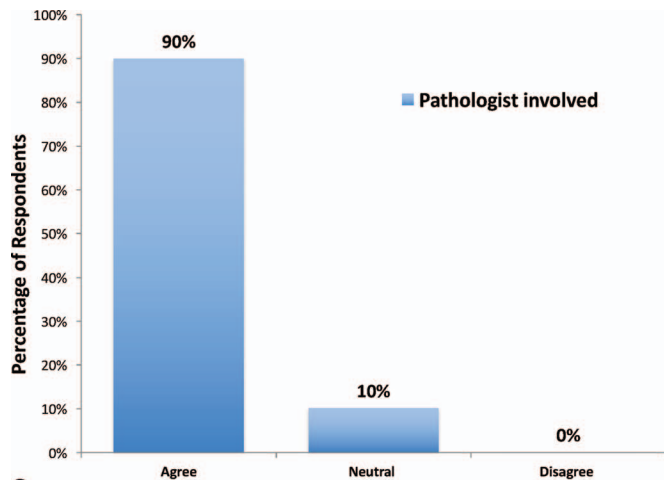
We found that pathologist involvement in these Facebook patient support groups improved the patient’s understanding and perception of the important role that pathologists play in patient care. There was a statistically significant increase in the percentage of patients who thought pathologists were an important part of the patient care team in the groups that had a pathologist involved versus groups that did not have a pathologist involved. We believe these data support the idea that pathologists interacting directly with patients via social media is not only welcomed by patients, but may also help counteract the widespread misunderstandings regarding the specialty of pathology.

Most of the respondents to this survey found it useful to have a pathologist involved in their Facebook support group. A total of 98% (117 of 119) of patients in the groups with a pathologist involved agreed that it was a good thing to have the pathologist participate in their online support group, and 83% (192 of 232) of respondents from these groups wanted more pathologists involved in their group. Of groups with no or minimal active pathologist involvement, 77% (193 of 251) of respondents wanted to have a pathologist involved in their group. It is reasonable to conclude that there is a demand for pathologists to engage in support groups such as these. The pathologist’s role as tumor expert and patient advocate, and his or her ability to be easily accessible are the main benefits that this interaction can provide to these patients. A limitation for this study is that all groups surveyed were those involving patients with rare neoplasms; perceptions and opinions toward pathologist involvement could be different in groups

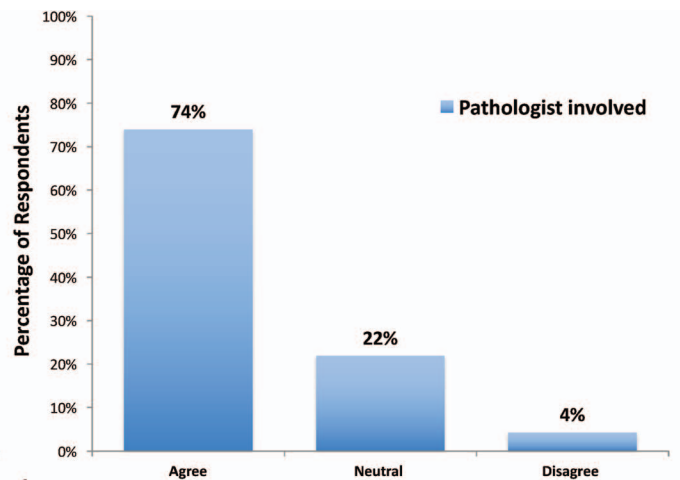
of more common cancers or noncancerous diseases. Further study of pathologist involvement in different types of patient support groups would be needed to evaluate this.

Previous studies have revealed that miscommunication between the patient and his or her physician and health care team can have a variety of negative emotional effects on cancer patients.¹⁰ Although pathologists volunteering in cancer patient support groups on Facebook are not part of the patient’s treatment team and do not have an official patient-physician relationship, we hypothesized that the interactions between patient and pathologist in these groups would lead to patients having an improved understanding of their own disease. Our survey found that most patients felt that having a pathologist involved in their Facebook support groups helped them better understand their disease (107 of 119; 90%). We believe that patients who are more savvy about their disease will have the potential to be more empowered and to have more effective conversations with their physicians and other health care team members.

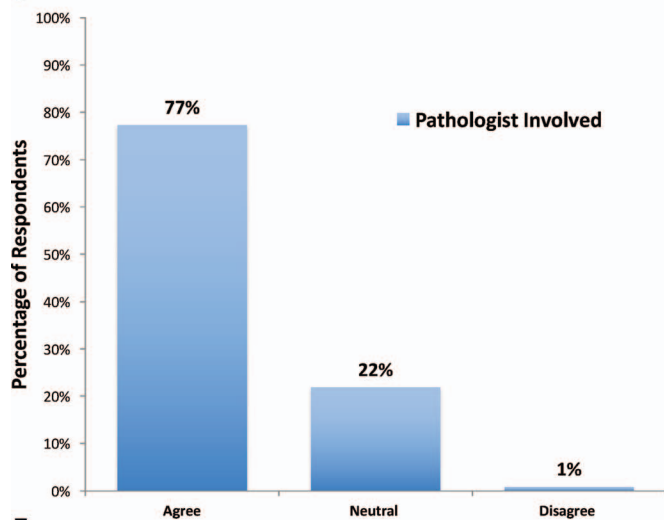
Most patients felt that the pathologist’s comments in their Facebook support group relieved anxiety that they had regarding their disease (92 of 119; 77%). We believe that “relief of anxiety” qualifies as an act of healing.⁹ Pathologists may not treat patients, but they have the potential to help heal patients and family members by the simple act of being involved in their patient support groups on Facebook. In fact, a member from the angiosarcoma group commented that they “have benefitted tremendously from [the pathologist’s] thoughtful comments and feedback” and that they “hope that more pathologists will join . . .” The fact that 27% (132 of 489) of respondents in our survey believed that oncologists (not pathologists) were the doctors who made the final diagnosis of cancer indicates that there is still much work to be done regarding educating patients about the roles pathologists play in patient care. We propose that Facebook patient support groups be free and easily accessible environments in which pathologists can interact with patients and educate them in this regard.



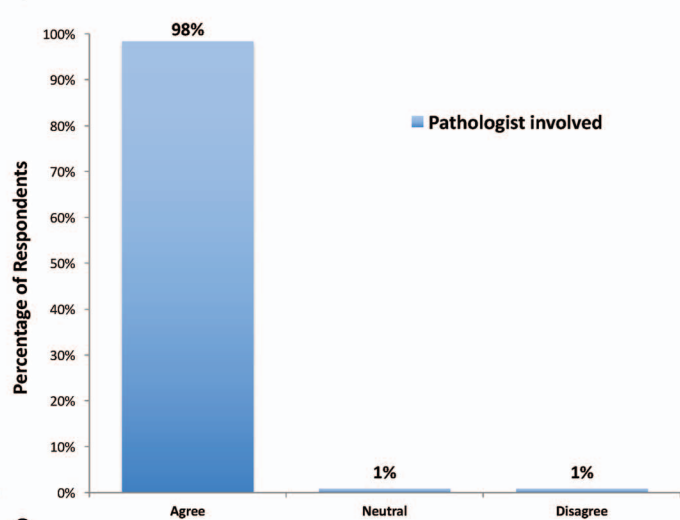
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Figure 3. Percent of responses from the groups with pathologist involvement to the statement “The pathologist’s posts helped me understand my disease.” A total of 90% (107 of 119) of respondents agreed with this statement, 10% (12 of 119) of respondents were neutral, and no respondents disagreed.

Figure 4. Percent of responses from the groups with pathologist involvement to the statement “The pathologist’s posts helped me better understand the role of pathologists in patient care.” A total of 74% (88 of 119) of respondents agreed with this statement, 22% (26 of 119) of respondents were neutral, and 4% (5 of 119) of respondents disagreed.

Figure 5. Percent of responses from the groups with pathologist involvement to the statement “The pathologist on the Facebook support group helped relieve some of my disease-related anxiety.” A total of 77% (92 of 119) of respondents agreed with this statement, 22% (26 of 119) of respondents were neutral, and 1% (1 of 119) of respondents disagreed.

Figure 6. Percent of responses from the groups with pathologist involvement to the statement “Overall, having a pathologist involved in this group is a good thing.” A total of 98% (117 of 119) of respondents agreed with this statement, 1% (1 of 119) of respondents were neutral, and 1% (1 of 119) of respondents disagreed.

Being involved in these patient support groups can change the way pathologists and other physicians view a patient’s disease, as well as change the way patients perceive pathology as a whole.⁹ As the preferred method of information exchange and education changes from nightly news and newspapers to online resources like social media, medicine must adapt in order to best educate the patient.¹¹ In turn, this will strengthen the partnership between physician and patient. Through this study, we aimed to assess patient perception of pathologist involvement in their Facebook support groups. We were able to confirm our hypothesis that this involvement would benefit the patient and help the patient understand the importance of the pathologist in his or her health care team, and that

these patients would want more physicians involved in their groups in the future. With rare disease groups such as the ones surveyed, access to a pathologist who is an expert in that particular disease is undoubtedly beneficial to these patient populations.

A further potential benefit of Facebook patient support groups, particularly for rare diseases, is the potential for more effective patient recruitment for research. Our simple survey study clearly demonstrates the vast reach that Facebook affords to investigators, allowing many patients to be enrolled very quickly and at low cost. The potential extends beyond mere online survey studies and can have significant positive impact on recruiting patients for more traditional research studies as well. Corrie Painter, PhD, a

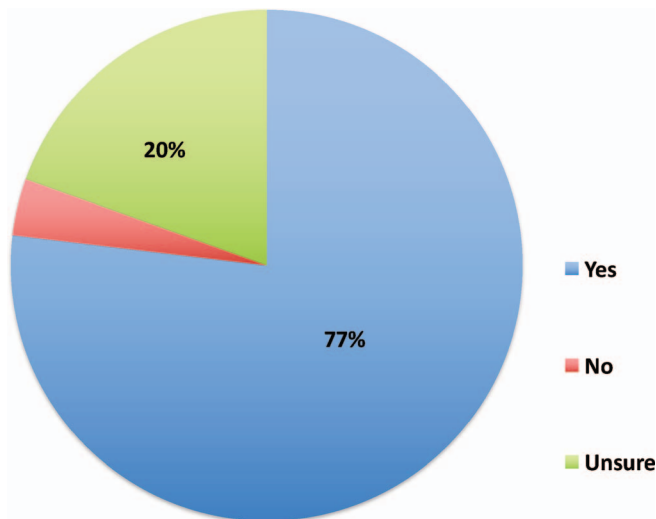


Figure 7. Percent of respondents from the groups without active pathologist involvement when asked, “Do you want a pathologist involved in your Facebook support group?” A total of 77% (193 of 251) said yes, 20% (49 of 251) were unsure, and 4% (9 of 251) said no.

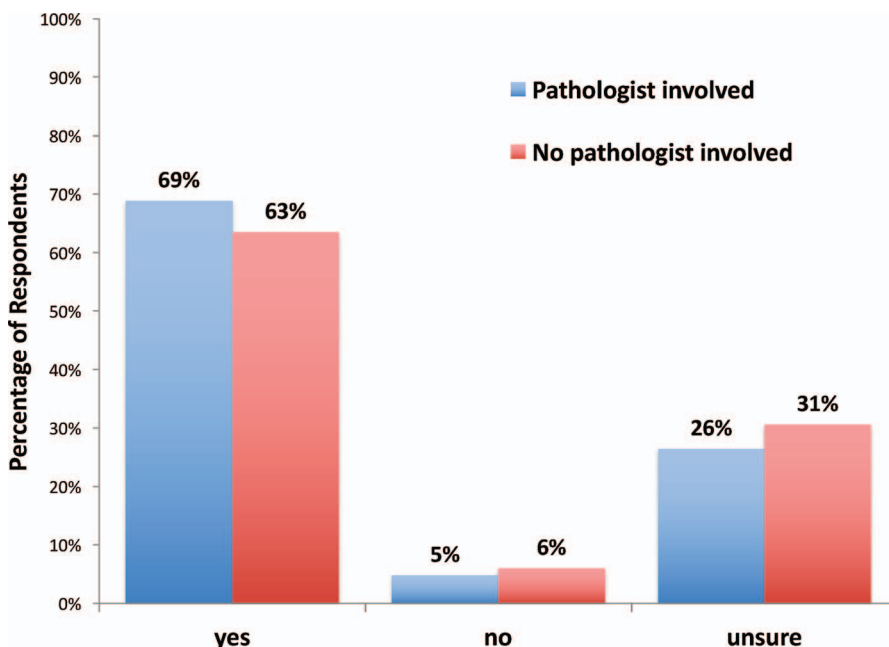
cancer researcher and angiosarcoma survivor, is the administrator of the angiosarcoma Facebook patient support group.¹² She and her team at the Broad Institute (of the Massachusetts Institute of Technology [MIT] and Harvard, both in Cambridge, Massachusetts) have organized several studies of cancer patients (including those with angiosarcoma, prostate cancer, and metastatic breast cancer) using Facebook patient support groups and other social media channels to recruit patients.^{13–16} Their currently ongoing study of angiosarcoma patients, which involves molecular testing via patient saliva samples, was able to recruit more than 200 participants in 10 weeks.^{17,18} David et al¹⁹ previously conducted a survey study of dermatofibrosarcoma protuberans (DFSP) patients via Facebook support groups. The study procured 218 respondents in just 3 weeks. Each respondent completed a survey of more than

100 detailed questions regarding the diagnostic delays, clinical and pathologic features, signs and symptoms, and emotional and social burden of having DFSP. Most importantly, 5 DFSP patients from the Facebook patient support groups became bona fide members of the research team, completing the Collaborative Institutional Training Initiative program (Miami, Florida) ethics training required by the Institutional Review Board. These patients were named on poster presentations of the data from this study and will be coauthors on the final peer-reviewed publications (currently in progress).¹⁹ The success of that DFSP survey study led to a more extensive prospective study (currently ongoing) in which patients will be recruited from the DFSP Facebook patient support groups, will be added to a DFSP patient registry, will have their pathology materials and records reviewed by the investigators, and will be followed up during a period of 15 years via direct contact between pathologist investigators and patient participants via Facebook messenger (as well as email, phone, and more traditional methods).^{3,5}

Facebook is not the only social media platform used by patients to interact with physicians. Oncologists, patients, and other interested parties often use Twitter (San Francisco, California) to share information relevant to cancer. A wide variety of cancer-focused “Twitter chats” exist, in which participants come together at a scheduled time and have a live conversation on Twitter about a particular cancer-related topic. A structured and organized list of cancer hashtags has also been created so that users can more easily find tweets about the specific type of cancer they are interested in.^{20,21} These are tracked by the health care hashtag tracking Web site Symplur.com (Upland, California), allowing users to see which types of cancer are being discussed most actively, who the key Twitter users discussing a given type of cancer are, and how many tweets and impressions are being generated during a given time period for each different type of cancer.

As clinical medicine becomes bidirectional, acting as an informational referee for patients in online support groups may become a norm for practicing physicians.⁴ With this,

Figure 8. “Would you like to see more medical doctors from other specialties involved in your support group?” Groups with a pathologist involved (blue) responded: yes, 69% (159 of 231); no, 5% (11 of 231); and unsure, 26% (61 of 231). Groups without active pathologist involvement (red) responded: yes, 63% (160 of 252); no, 6% (15 of 252); and unsure, 31% (77 of 252).



physicians can diminish the amount of misinformation patients face when searching their own condition on the Web. It is apparent that many patients are secure with having physicians engaging in their support groups, and so we urge readers to investigate this venture for themselves. Weigh the benefits and risks. Seek insight from those who have already traversed this new role for health care providers, and reach out to a group of patients that sparks your particular interest.²² If pathologists embrace this, it could very well change the future of the specialty, leading to a dramatic and positive shift in public perception of the role of pathologists in patient care.

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