

ISSUES IN CANCER SURVIVORSHIP

Social media and survivorship: Building a cancer support network for the 21st Century

Bette Weinstein Kaplan



Surviving any type of cancer is challenging enough; finding other people who are also going through the struggle—while respecting their privacy—can add to the difficulty. Patients need information and support in order to make important decisions about their treatment. The most effective therapy is a dialogue between patients and caregivers, which is not often easy when patients travel a great distance for specialty treatment and then leave the area to return home and recuperate.

A MODERN SOLUTION

Herbert Wolfsen, MD, his research assistant, Christianne Wolfsen, and their colleagues at the Mayo Clinic in Jacksonville, Florida, found a modern-day solution. The researchers had been using various communication methods to maintain contact with their patients with esophageal cancer (EC) for a number of years. They established a network of patients using phone, e-mail, and fax. However, the researchers found that patients were still seeking answers from third-party media and a number of Internet resources to supplement the information the staff provided. In addition, patients did not want to be constrained to a particular geographical area or time of day in which to make a phone call when they had a question; when patients had a question, they did not want

to wait for an answer. This was an ideal situation for using social media, and in 2008, the Mayo Clinic team formed an online chat group on Facebook.

Wolfsen presented the group's idea at the 2011 Annual Scientific Meeting of the American College of Gastroenterology (ACG) in Washington, DC.¹ He told ACG, "Our goal was to establish a Facebook group to assist patients and families as they anticipate and cope with surgical and postoperative

The Facebook chat group can answer questions physicians cannot answer.

challenges." The researchers tested the concept with a group of 65 patients, 53 men and ranging in age from 53 to 87 years who lived in the United States and Mexico. All the patients had received a diagnosis and treatment for Barrett high-grade dysplasia and EC. Forty patients had undergone esophagectomy via surgery or radiofrequency ablation.

YOUTUBE AND MORE

The GI patient group uses their online community to share information about advanced endoscopic imaging

and mucosal resection, preparing for surgery, and evaluating the differences between traditional surgery and minimally invasive esophagectomy. A majority of the discussions and supportive conversations concerned strategies for coping with life after surgery with patients discussing such issues as diet and nutrition and problems with swallowing and regurgitation.

Surgical esophagectomy can be difficult, often leading to numerous digestive, nutritional, and lifestyle concerns for patients and their caregivers. Postoperative sequelae comprise problems with swallowing, reflux, nausea, fatigue, sweating, and diarrhea after eating, as well as chronic severe cough and aspiration. An important component of the Facebook conversations is the advice and support shared among patients, their families, and their caregivers during recovery.

Wolfsen emphasized in his presentation to the ACG conference that the Facebook group provides more than support. "Our patients and their families are focused and devoted to educating others about their experience with the diagnosis and treatment of this cancer." As the Facebook project evolved, the staff extended invitations to patients with newly diagnosed Barrett high-grade dysplasia or esophageal cancer who were contemplating their treatment options. The opportunity to

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learn from other patients who had gone through the experience is invaluable.

The group's Facebook page is private and is accessible by Mayo Clinic invitation only. Physicians do not offer medical advice to the group, but are in touch with their patients individually.

ANSWERS ONLY A PATIENT CAN GIVE

The Mayo group concluded that what they were doing was invaluable to survivors of EC, and it has become a popular forum where patients help and support each other and their families. Interestingly, the Facebook chat group could answer questions many physicians could not answer. Wolfsen noted, "Physicians can talk about the technical aspects of esophageal cancer and its treatment, but we don't really know what it means to have issues with breathing, eating, sleeping, and just trying to live a normal life after cancer treatment because we haven't had this experience."

STAFF ALSO BENEFITS

The Facebook group is helpful for the staff as well; it helps them to better understand their patients' concerns and struggles. "Many of the techniques, methods, medications, and lifestyle changes our patients develop to cope are not in the textbooks—they are word of

mouth," Wolfsen explained. "Nothing works the same for each person, and every patient's experience is valuable."

The staff now disseminates new medical information by posting messages, links to YouTube videos, announcements, group meeting schedules, and information on treatment options for new patients. They plan to create podcasts of the EC survivors' meetings and will also host online events to encourage interaction with other cancer survivors.

A SURVIVOR'S NEWSLETTER

"Esophageal cancer is one of the scariest, loneliest diseases that we have," says EC survivor Mary Duggar; however, she is doing what she can to change that characterization. Duggar launched Esophageal Cancer Support Group, an e-mail newsletter that she sends to EC patients. Duggar worked as an advocate for survivor support issues while serving on the Board of Directors for the

Esophageal Cancer Awareness Association (ECAA). In addition, she recently started Esophageal Cancer Support Inc for patients and survivors nationwide.

Duggar knows firsthand how invaluable information from a survivor is for persons coping with a diagnosis of esophageal cancer. This committed EC survivor often hears from patients who tell her that she is their only source of information or that they live alone and do not go out much, so she is their only outside contact. n

Bette Weinstein Kaplan is a medical writer based in Tenafly, New Jersey.

REFERENCE

1. Wolfsen C, Burling MC, Tomczyk P, Wolfsen H. Social Media for Survivors of Esophageal Cancer. Paper presented at: 2011 Annual Scientific Meeting of the American College of Gastroenterology; October 28-November 2, 2011; Washington, DC.

Patient support newsletter

Patients who wish to receive the Esophageal Cancer Support Group newsletter are invited to write to Mary Duggar at mhpduddar@gmail.com. Mary is always willing to help, whether she is sharing her coping strategies or lending support via a phone call or e-mail conversation.



Let us answer your questions!

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Please include your full name and degrees, name of institution or practice, and city and state with your question.