Patients and family members are overwhelmed by the diagnosis of cancer and often do not know where to look for answers, information on the treatment options, or community resources for support during the cancer journey. A unique relationship was forged with a patient and health education librarian at the Mayo Clinic in Arizona and an American Cancer Society navigator, which encouraged collaboration to better meet the informational and supportive healthcare needs of patients. This article addresses the background of the project, the steps taken to establish the relationship, space allocation, and need for confidentiality. The innovations produced by this partnership also are discussed, including development of cancer pathfinders and cancer communication blogs for patients, as well as comarketing of services.

The Mayo Clinic in Scottsdale, AZ, is a multispecialty healthcare practice focused on the provision of high-quality and cost-effective care that reflects the organizational value: the needs of the patients come first. In 2002, the National Cancer Institute recognized the Mayo Clinic’s contribution to clinical care, education, and research on cancer-related issues by extending its Comprehensive Cancer Center designation in Rochester, MN, to include sites in Florida and Arizona (Mayo Clinic Comprehensive Cancer Center, 2011). The cancer center’s focus is on understanding the molecular basis of cancer and working to find innovative measures to predict, prevent, diagnose, and treat cancer. In addition, the philosophy of the program includes finding the most effective resources to assist patients and family members through their journey with cancer. More than 16,000 patients with cancer are treated at Mayo Clinic facilities each year, making it one of the largest and most geographically diverse cancer centers in the United States (Mayo Clinic Comprehensive Cancer Center, 2011).

The concept of providing guides to assist patients and family members through their cancer journey evolved through the leadership of Harold P. Freeman (Harold P. Freeman Patient Navigation Institute, 2011), a surgical oncologist at Harlem Hospital. After realizing that many patients encountered significant barriers to care because of a lack of understanding of available services, insurance issues, and confusion about tests and treatments for cancer, Freeman wanted to develop a patient navigator, a volunteer who would help patients and family members navigate their journey through cancer detection, treatment, and follow-up. “I compare it to providing a lifeboat. Navigators know where the rocks are and can guide [patients and family members] safely to shore,” Freeman said (American Cancer Society [ACS], 2009).

In 1990, the first program launched at Harlem Hospital showed remarkable increases in five-year survival rates and earlier diagnosis of cancers (ACS, 2009). The program was the basis on which the Patient Navigator and Chronic Disease Act of 2005 was signed into law. The law amended the Public Health Service Act to authorize a demonstration grant program to provide patient navigator services to reduce barriers, to improve healthcare outcomes, and for other purposes. Since that time, patient navigators through the ACS have reached out across the country and often are embedded in healthcare organizations such as Mayo Clinic. The ACS navigator program uses trained staff to work for the benefit of patients with cancer and their families to navigate through their illness and survival. ACS nav-
gators in Arizona are embedded in hospitals where they have offices and provide services on a continuum of care including support and survivorship groups, prosthetics and wigs, transportation and housing accommodations, and the provision of printed resources supplied by the ACS.

Many studies have been conducted to determine how patients behave when seeking health information during prolonged illness. Anker, Reinhart, and Feely (2011) noted that many tools are available for those seeking health information and encouraged future research on the social and relational functions of information seeking. In addition, they have recommended that healthcare practitioners discuss health information-seeking options with their patients. According to Zanchetta and Moura (2006, p. 803), “patients are the experts of their experience,” so health information must be as complete as possible for patients to make informed clinical-care decisions.

Methods

In 2003, a planning group made up of Mayo Clinic staff was formed at the Mayo Clinic practice in Arizona to work on a joint venture to establish and provide a patient quality-of-life provider model that would include a designated cancer resource area for patients and family members. A site visit initially was made to the Mayo Clinic in Rochester, MN, which previously implemented this model. The director of medical libraries visited colleagues, including ACS navigators as well as the ACS director of client services in the Phoenix metropolitan area, to discuss models currently in place and opportunities that collaboration would provide. Initial discussions centered on the pre-employment educational and experiential specifications of the navigator, as well as ongoing education and professional development opportunities, orientation to the Mayo Clinic culture, and whether the position would be funded or volunteer. ACS agreed to solicit funding for a paid position. For initial education and orientation, ACS provided specific information on communication techniques, emphasizing that the navigator was a link to health information and not a health advisor. Because a navigator position already existed at the Maricopa Medical Center in the Phoenix area, many of the logistics of training had already been implemented. In contrast to the program established at other hospitals, which involved the navigator interviewing patients in their rooms, the navigator position at the Mayo Clinic was developed for walk-in, nonscheduled appointments in conjunction with patients’ chemotherapy class or visits to the patient library. Strategically placing the ACS navigator in the Patient and Health Education Library allowed collaborative opportunities between the RN educator who taught the chemotherapy class and the medical librarian who managed the library resources. In addition, placing the navigator in a location that encouraged patients to use all the resources available provided more opportunities to interact with patients and family members regardless of where they were in the cancer journey.

In establishing an area for the patient navigator, a confidential office was required, as well as chairs for patients and family members, bookcases to hold ACS books and brochures, and space for prosthetic supplies and wigs. In addition, information about the navigator services, including a trifold brochure, presentations at work units, articles in the in-house electronic newsletter, and appropriate signage, was prepared and circulated to all employees in the organization. Consideration also was given to whether the position should be part-time, but the planning team quickly determined that the position needed to be full-time to accommodate the needs of patients and their family members. The education criteria for the navigator included an undergraduate degree in psychology, social work, or health care. ACS conducted the initial interviews for the position and then the top candidate was sent to meet the team at Mayo Clinic and to ask any questions regarding the position and its responsibilities. Although the navigator works in the physical environment of Mayo Clinic, the navigator is compensated and benefited by ACS. Also considered by the planning group was whether the navigator would have access to patients’ medical records; in the end, access was not provided because the ACS navigator keeps a documented record of encounters in an ACS database. The navigator has a distinct name tag that includes both the ACS affiliation and that of Mayo Clinic. In addition, if needed, volunteers trained by the Mayo Clinic are available to assist the navigator. Health Information Portability and Accountability Act concerns were addressed, and the navigator signed a document both at ACS and Mayo Clinic to ensure patient confidentiality and privacy in discussions.

Orientation for the navigator was coordinated collaboratively through ACS with general orientation for all new staff members at the Mayo Clinic in Arizona. In addition, the navigator is welcome to attend any continuing education program at the Mayo Clinic, as well as cancer-specific groups outside of Mayo Clinic and ACS. Knowledge of cancer-related insurance issues also is required of the navigator to better assist patients regarding cancer-related issues; this is offered through ACS. Written competencies for the job description as well as age-specific competencies, the recommendation that all staff are understanding of and can use age-appropriate methods to communicate with patients across the life span, were included with the initial orientation and used for evaluation.

The role of the navigator was evaluated collaboratively by an on-site director, medical librarian, and the director of the local branch of ACS. The evaluation was prepared by ACS personnel with input on performance from Mayo Clinic staff members. ACS was responsible for the salary and benefits of the navigator, and Mayo Clinic provided space, equipment (i.e., a computer,
Implications for Practice

- Forming collaborative and cooperative relationships between resources can help patients to better understand their diagnosis and treatment options as well as the supportive care measures that can best relieve stress during this difficult journey.
- Encourage cancer caregivers to be aware of the wide variety of resources for patients with cancer and their information needs, and work collaboratively to meet those needs.
- Information resources should be broadened to meet the unique needs of each patient and family member whenever they need assistance.

Printer, phone, fax machine, and photocopier), office furniture, supplies, and printing of promotional materials, as well as funding for an on-site visit with navigators at the Mayo Clinic in Rochester.

The ACS navigator has primary responsibilities including assisting patients and family members with accommodations while patients undergo treatment, finding appropriate support groups by cancer type, and organizing and conducting programs such as Look Good, Feel Better, which focuses on personal care measures including hair care and makeup suggestions specific to patients with cancer and offers tips and suggestions for maintaining positive self-image. In addition, the ACS navigator is responsible for fitting wigs and prostheses. The ACS navigator markets those services to both ambulatory and hospital settings through posters, business cards, and presentations at departmental meetings to heighten awareness of the services available to patients with cancer.

Navigator and Medical Librarian Collaboration

Because the ACS navigator is located in an office in the consumer health library, the medical librarian and the ACS navigator have worked collaboratively with each other to provide needed services in a timely manner. The navigator keeps the librarian apprised of current and newly published booklets and information from ACS, and together they review the library’s collections to ensure that the appropriate books are available for patients to reference during their care. In addition, the librarian and navigator work in cooperation to highlight cancer awareness by updating the patient library displays on a monthly basis, focusing on national observances, such as prostate and breast cancer awareness. Using visual models, posters, and books, the displays offer information to patients on specific cancers, which naturally draw them into the environment of the library for additional information and assistance. Because the ACS navigator visits patients in clinical areas, the librarian is always available to share information on how to contact the navigator and also serves as a resource on cancer information. Having a navigator in the Mayo Clinic’s library improves that individual’s understanding of the site, thereby increasing opportunities to market ACS services in the organization. Working collaboratively, the navigator and librarian add their expertise of assisting patients with their specific needs, regardless of where patients are in their cancer journey. The medical librarian has an extensive collection of cancer-related medical textbooks, consumer health books, and books on various types of cancer, treatment options, coping with changes in body image, palliative care, and grief. In addition, the librarian is a member and contributor to the Mayo Clinic Comprehensive Cancer Education Network and provides quarterly book reviews of cancer-related books to a newsletter generated for patients. Cancer chemotherapy education classes also are held in the library’s classroom. The consumer health library averages 1,500–2,000 unique visits per month and the ACS navigator benefits from the traffic through the library in promotion of the cancer navigator services, averaging 200–250 interactions with patients per month.

Working with the ACS navigator, the medical librarian developed, and continues to update, a cancer pathfinder available for patients’ use in the library’s computer kiosks. The pathfinder offers links to relevant and reliable Web sites for patients with cancer. In addition, Care Pages® links are included so that patients and family members who use the library can blog about current updates surrounding their care, share good wishes, and keep in touch with friends and family (www.carepages.com/mayoclinic).

Another project was undertaken by the Patients and Health Education Library staff to implement the use of handheld audio devices from Playaway®, mp3 players preloaded with meditations and music that allows the patients to listen to selections while waiting for appointments or procedures to minimize stress and anxiety. The devices were recommended by the ACS navigator and the medical librarian to patients and family members who were encountering longer wait times during their diagnosis or treatment. Patient feedback was extremely positive and plans are underway to download patient education content as well as Mayo Clinic history vignettes. In addition, other portable devices are being reviewed to enhance the information available to help patients and family members better understand their diagnosis and treatment plans, ask questions, and, ultimately, have better outcomes.

Conclusion

Working collaboratively in a collegial relationship and placing the needs of the patient first enhanced the quality of information and resources that the patients and their families receive at the Mayo Clinic. That partnership has helped to improve patient information and communication among caregivers. Available resources are continually evaluated, and the cancer center conducts a patient-satisfaction survey addressing their concerns pre- and post-treatment. Plans are currently underway to build additional resources, such as tablets for patient use, and to continue planning collaborative efforts for the patients and family members.

References


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