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Library Outreach to Support Groups: A Case Study

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Abstract

Information sharing is a key component of patient and caregiver support groups. Hospital libraries that provide consumer health and patient information services can increase their visibility among support groups through presentations, facilitator training, brochures and other media. This case study details a project at a regional medical center in Virginia to provide outreach to groups that met regularly at the hospital or nearby facilities. Initial evaluation suggests that group members who attended librarian presentations are likely to use the health sciences library and MedlinePlus in the future.

Keywords

Outreach; support groups; self-help groups; consumer health groups

INTRODUCTION

Health-related support groups, either professionally led or as part of a self-help organization, are a popular way for patients and caregivers to share personal experiences, to gain education on their conditions or diseases, and to connect with existing support systems. In an excellent two-part series on the history, theory and organization of cancer support groups, Fobair traced the earliest hospital-based support and education patient groups to “tuberculosis classes” at Massachusetts General Hospital in 1905 (1). Since then, groups have formed around nearly every chronic and acute condition, disease or surgery for the mutual benefit of group members.

One main benefit for participants of support groups is information sharing, both from other group members and from professionals, either as facilitators or as invited speakers. Information shared at such meetings can vary widely from existing services, to employment issues, to new treatments (2). Hospital librarians, especially those who provide services to patients and the public, are in an excellent position to reach out to such information-seeking consumer groups.

In a study published in *The Journal of Hospital Librarianship*, Anderson and Olmstadt discussed a library outreach project to hospital support groups. Their project focused on training groups how to find existing reliable health information on the Internet. They found that such presentations increased the visibility of the library and that participants felt that such presentations increased their knowledge of how to find quality information on the Internet (3).

SETTING

Inova Fairfax Hospital is an 833-bed regional medical center in Northern Virginia. The Health Sciences Library serves students, residents, medical staff, nurses, and hospital staff. It is also open to patients, their families and the public. Services to consumers include a patient education reference service by professional librarians, public access computers and a Consumer Health Resource Center of approximately 3000 volumes. Anyone may check out books from the Consumer Health Resource Center and use the professional collection and electronic resources at the library.

In 2008–2009, the Health Sciences Library hosted a 2nd Year National Library of Medicine Associate Fellow. Among the projects selected for the Fellow included expanding outreach to patient support groups which either met at the hospital or which were led by health system staff.

METHODS

With the library director, the librarian developed a list of services that would be offered to support group facilitators. Services offered included:

- handouts on library resources for condition/disease or MedlinePlus;
- presentations on topics such as library services;
- finding quality health information online, and communicating with clinicians;
- a librarian-staffed table outside of meetings;
- individualized reference services for group members and facilitators; and tours of the library.

When thinking about possible services, the decision was made to be as flexible as possible, as the librarian was unsure of what formats or kinds of presentations would be most helpful.

The librarian was unable to find a comprehensive list of support groups that met at the hospital; therefore, a list was developed by searching the Inova Health System web site, searching the Internet for “Inova Fairfax” and “support group,” and monitoring the *Washington Post* Fairfax Health Calendar, which is published weekly online and in print. The librarian identified thirty five support groups that met at the hospital or in nearby health system locations. Most were facilitated by health system staff, others were associated with self-help organizations, and a small number had unapparent sponsorship.

Over the course of several weeks in the fall of 2008, the librarian contacted the facilitators as identified by the listings on the Internet or in the Health Calendar. The librarian emailed those facilitators for whom an email address was supplied and called others. The librarian was unable to contact all groups. Some facilitators did not return calls, some groups were not currently active, and a couple of identified contact people were no longer active in the group.

Once contact was made, the librarian proceeded to offer options for services, facilitators made choices, and group-specific interventions were provided. Limited evaluation was conducted of presentations to support group members.

PRESENTATIONS

As of June 2009, the librarian had given six presentations to support groups—Crohn’s and Colitis; Traumatic Brain Injury; Spinal Cord Injury; Pulmonary Hypertension; Ostomy; and

Breast Cancer. Approximately ninety patients and caregivers have attended the presentations. Groups ranged in size from seven to twenty. Presentations were held during regular group meetings, and, depending on the amount of group questions and comments, were approximately twenty minutes.

The librarian began every discussion with an introduction to the library, including location and hours. The librarian handed out and explained the library's services to patients and families. Presentations included a "show and tell" of a selection of relevant materials from the Consumer Health Resource Center. Materials included not only books dealing specifically with the disease or condition of the members but also general wellness and caregiver titles. The librarian introduced MedlinePlus and talked briefly about the challenges of finding reliable health information on the Internet. After an initial description of the library and its services, discussions were driven by group questions and comments.

Originally, the librarian anticipated giving presentations that included PowerPoint slides and demonstrations of MedlinePlus and other online resources. On the advice of a social worker who facilitates the Traumatic Brain Injury and Spinal Cord Injury groups, presentations were instead more informal and conversational. This allowed for more back and forth discussion among the librarian, facilitators and group members. In the case of group members in the Traumatic Brain Injury and Spinal Cord Injury groups, this two-way information sharing was typical of their interactions with other professionals, as detailed in an article about the programs: "Many of these professionals found themselves learning as much about trauma from the group members as the group members learned from them. The format developed was to have members introduce themselves and describe their experiences as they related to the professional's line of work...In this way, the experience of mutual aid, a vital ingredient of the group process, was extended to include the medical professionals in the hospital"(4).

Early on in the project, the librarian realized the importance of being flexible when working with support groups, particularly with regards to scheduling, a finding also noted by Anderson and Olmstadt. Patient support groups meet at times convenient to group members. Groups typically meet on nights or weekends. The librarian only met with one group during regular business hours. Flexibility was also required in terms of information provided, depending on group interest, level of knowledge, or experience with Internet resources. Often this required quick thinking and taking cues from the group during the presentation. This flexibility in one case made it easier for one facilitator to suggest an impromptu visit to the library during one meeting.

Fairly early into the first presentation, the librarian began to think of group members as "super consumers." Typically, health information is described as either professional/scholarly or patient/consumer. Many group members that the librarian met have been in the position of learning as much as possible about their own condition and then educating others, including family members, employers, even their own health care providers. This is perhaps typical of many other people with chronic illness (5). Questions were often very detailed and specific. One group was curious as to when their medications would become available generically. Dietary supplements were mentioned, as well. Very few were interested in basic patient education materials. Many were much more interested in how they could get access to professional resources, as opposed to the consumer materials. In a sense, the group members were the content experts in the conversations, and the librarian was the means of facilitating the access to materials and, at times, the educator on distinguishing trustworthy information of the Internet from the bad. In the case of one group whose members were particularly interested in research, the librarian talked about how to read a

research paper to ascertain its relevance and validity. Group members were always encouraged to consult their healthcare providers about information they find.

Because patient support group members are used to being the experts of their own conditions, they often gave recommendations to the librarian about resources. The librarian has been given copies of specific articles that were particularly helpful to group members, directed to recent reports, and even sent two humorous patient-story books for the Consumer Health Resource Center.

PROFESSIONAL INSERVICES

The librarian was invited by facilitators of Inova-led patient support groups to present to staff, as opposed to the groups themselves. While the librarian would not be meeting with patients directly, these presentations were opportunities to remind health system staff about the services that are offered to them, as well as to their patients and clients. A number of these departments/divisions are not located at the hospital, so staff may not have had regular reminders of what the library could do for them.

The librarian met with the staff of *Inova Life with Cancer*, which offers a full calendar of educational, information and support programs every month. The librarian and a colleague presented during a regular staff meeting about services to staff, group facilitators and patients/clients. The librarian also presented to the Inova Juniper program, the largest provider of HIV/AIDS services in Northern Virginia. Both of these programs were off-site. These sessions presented a two-fold opportunity: to inform these staff members of information resources available to their patients as well as to direct them to the library for their own professional needs.

The librarian was also invited to be a “brown bag” speaker to Radiation Oncology staff, and has been invited to upcoming meetings of inpatient and outpatient diabetes staff.

BROCHURES

In some cases, group facilitators were interested in making their group members aware of library services, but the librarian was unable to meet with the groups. In two cases, these were caregiver groups that were made up of family members of patients currently in the hospital. For the adult caregiver group, the librarian was asked to create a brochure of library services for caregivers that could be either handed out in biweekly support group meetings or given to individual caregivers, regardless of whether or not they attended the meetings (Appendix A). The librarian also was invited to meet with parents of hospitalized children, but on the particular evening scheduled, none of the parents were willing to leave their children's sides. The librarian spoke to the staff facilitators of the meetings and left brochures that could be given to parents. The librarian has been invited to a future meeting of the entire Child Life staff to share resources for parents and staff.

In other cases, such as a regular transplant group, groups have fairly set educational program schedules and were unable to accommodate another speaker. In those cases, the librarian sent library and MedlinePlus brochures to interested facilitators.

OTHER SERVICES

In addition to being the featured speaker at a regular group meeting, the librarian was also invited by the Ostomy Support Group of Northern Virginia to participate in their annual products and services fair and to write a short article in their bimonthly newsletter. At the fair, held in a hospital conference room, the librarian exhibited books from the Consumer

Resource Center, presented a looping slide show on a digital picture frame and handed out library and MedlinePlus brochures. Over the course of two hours, the librarian spoke to all thirty participants individually, answering questions and hearing personal stories. For the newsletter article, the librarian focused on library services and offered some advice on judging the reliability of health web sites (Appendix B).

EVALUATION

In an attempt to assess the impact of presentations to patient support groups, a couple of months after meeting, the librarian asked facilitators of three groups to send group members a short evaluation.

Evaluation questions:

1. Since the library presentation, have you used MedlinePlus? (yes or no)
2. Since the library presentation, have you visited, called or emailed the Inova Fairfax Hospital Health Sciences Library? (yes or no)
3. Since the library presentation, are you more confident in your ability to find health information? (yes or no)
4. If you have a health information need in the future, how likely are you to use MedlinePlus? (very likely, likely, uncertain, unlikely)
5. If you have a health information need in the future, how likely are you to use the Inova Fairfax Hospital Health Sciences Library? (very likely, likely, uncertain, unlikely)
6. Please share any comments/suggestions about the library presentation. (open ended)

Responses were collected on SurveyMonkey. Few responses were collected by this method. Of the twenty-eight group members who attended the three presentations, only five completed the online evaluation. Two (40%) respondents had visited MedlinePlus since the library presentation, and two had visited the health sciences library. Five (100%) felt more confident in their ability to find health information. Four (80%) were very likely or likely to use MedlinePlus in the future and one was uncertain. Five (100%) were likely to use the health sciences library in the future. Four provided comments, all positive.

Given the low response of evaluations sent via email weeks after the group presentations, evaluations were given to a later group immediately after the presentation.

1. If you have a health information need in the future, how likely are you to use MedlinePlus? (very likely, likely, uncertain, unlikely)
2. If you have a health information need in the future, how likely are you to use the Inova Fairfax Hospital Health Sciences Library? (very likely, likely, uncertain, unlikely)
3. Please share any comments/suggestions about the library presentation. (open ended)

Of twenty respondents, nineteen (95%) stated that they were very likely or likely to use MedlinePlus in the future, with thirteen (65%) responding "very likely." One (5%) was uncertain. None responded "unlikely." Seven respondents (35%) were very likely to use the health sciences library in the future and seven (35%) were likely to use the library. Six (30%) were uncertain. Again, no one responded "unlikely." Several participants provided comments, all positive.

Sample comments from both evaluations included: “I wish I had heard it years ago”; “[The librarian] did a wonderful job of making information & technology accessible...” and “very informative.”

DISCUSSION

The project was focused on promoting library services among consumer groups that meet regularly at the hospital. Based on preliminary evaluation, this seems to have been successful. The project also allowed librarians to experiment with the kinds of services and formats that might be useful in reaching out to such groups. Flexibility seems to be key to the success of working with such groups. Additional, more formal research would need to be conducted to more formally assess the effectiveness of each type of intervention or whether such outreach truly increases the use of library services by support group members or affiliated staff.

Outreach to internal support group facilitators has led to unexpected collaborations for the library and librarian. The facilitator of the caregiver support group invited the librarian to attend weekly multidisciplinary geriatrics consult rounds, a new role for the librarian. When contacted by the librarian regarding patient support groups, education staff at the Inova Juniper Program asked the librarian to collaborate with them on improving the organization of their own HIV resource center. Staff members that had attended professional inservices have routinely contacted the library for reference and other support.

Another possible benefit of the library’s outreach to support groups was additional, free publicity. At least one group included the upcoming library presentation in its listing in the *Washington Post* Fairfax Health Calendar. Presumably, those that scan the health calendar are interested in some aspect of health and, though there is no way to document an effect, perhaps others in the community would be encouraged to visit the library once becoming aware of its existence. Groups also publicized the library presentation on their own websites and in newsletters.

This project has expanded the visibility of the Health Sciences Library among patient support groups and staff. Additional research is required to assess the impact of such outreach on library use or health outcomes. However this case study, and the work by Anderson and Olmstadt, suggest that patient support groups represent an area of potential growth in consumer health outreach.

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Appendix A

Adult Caregiver brochure (front and back)

Adult Caregiver brochure (inside pages)

Appendix B

Pouch article

Used with permission of the Ostomy Support Group of Northern Virginia

The Pouch

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June/July 2009

Need Health Information? Ask a Librarian!

By Kate Flewelling, MLIS— 6/2009

Finding health information that is trustworthy and accurate can be a challenge. The Inova Fairfax Hospital Health Sciences Library provides access to health care information for professionals and the public. Professional librarians can help you find health information for you and your family. Services include:

Librarians: Experts at finding health information and teaching others how to find it.

Lending Library: Consumer Health Resource Center section with books, pamphlets and videos that can be checked out. Books are available on a wide variety of topics and conditions including: nutrition, exercise, colorectal cancer, inflammatory bowel disease, and caregiver support.

Professional collection: Professional books and journals are available for in-library use.

Computer workstations: Public access computers include access to health-related databases and the Internet.

Photocopy Service: Self-service copy machines are available. Photocopies are 20 cents per page.

Professional research services available (call for pricing)

The library is located in Inova Fairfax Hospital on the first floor of the atrium (top of the escalator). The public is encouraged to visit from 5:00--8:00 PM on Monday through Friday or 9:00 AM – 5:00 PM on Saturday.

Looking for information on the Internet?

Many people use the Internet to look for health information. While there are many excellent resources online, it is important to be savvy when deciding what web sites to trust. Websites containing misleading or even dangerous information can look very professional. Always remember: Anyone can put up a website. Would you trust health advice from just anyone?

Some signs of a reliable health web site:

- Web address: ends in .gov, .edu, or .org
- Sponsor is a trusted authority on the topic
- Purpose of the web site is stated and clear
- Authors and editorial board are identified and qualified
- Content is reviewed regularly and the date of last update is included
- Privacy policy is easy to locate

Some warning signs:

- The site is promoting one viewpoint, treatment or drug over all others
- Any of the signs of a reliable site are missing
- Information sounds too good to be true
- Site is full of grammatikal errors and spelling mistakes
- The only available contact information is for Webmaster

Good place to start: MedlinePlus.gov

MedlinePlus, a service of the National Institutes of Health, contains over 750 health topics, tutorials, surgery videos, a medical encyclopedia and other health information resources. It contains links to trustworthy information throughout the web, including the latest news, overviews of health issues, research, statistics, organizations, clinical trials, and much more.

Questions? Contact **the Inova Fairfax Hospital Health Sciences Library**
 3300 Gallows Road, Falls Church, VA 22042
 (703) 776-3357
 Fairfax.Library@inova.org
www.inova.org/healthlibrary