The Journey Project: a case study in providing health information to mitigate health disparities

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THE JOURNEY PROJECT

Much has been written about the increasing disparities in health in the United States [1–4]. As these disparities seem to correlate to differences in socioeconomic status, ethnicity, gender, and age, they have emerged as an important social justice issue of our time. One means identified by many professions to mitigate health disparities is health information, including health literacy, the provision of which should lead to better health outcomes. Identified as a fundamental right, receiving understandable health information is emphasized by the Joint Commission [5].

In the health care provision arena, professions such as nursing, library science, and public health have also asserted that comprehensive information will promote better health outcomes [6, 7]. Better access to information related to negotiating the health care system has also been identified as an area of concern, as the system continues to grow in complexity. Unfortunately, most patients are not health literate and much of the health information regarding the health care system is provided in a complex manner they do not readily understand [5].

In an effort to respond to the multiple information needs of cancer patients, the Journey Project emerged as part of the Virginia Commonwealth University Libraries’ Social Work Information Specialist in Context Fellowship, was designed to merge social work and consumer health librarianship skills in order to improve the provision of health information to patients. A resource notebook was created encompassing the many dimensions of cancer health information. A social work informationist distributed the notebooks and provided individualized consultations with respect to patients’ health information needs. Areas of congruence as well as key differences between social work and consumer health librarianship emerged during the course of the project. Merging the two professions into the role of a social work informationist increased the ability to attend holistically to clients’ health information needs.

PROJECT DESIGN

Inspired by the National Cancer Institute’s Navigator Programs [9], the Journey Project was designed to provide SWI services to facilitate cancer patients’ ability to manage their health care as well as to assist them in understanding their conditions and diagnoses, their treatments, and the health care system from which they received services. The health care system in this case was a large, urban, teaching, and treatment center, the VCU Massey Cancer Center (MCC). This center is one of sixty-one National Cancer Institute–designated institutions [10] and has been an internationally recognized center of excellence since 1974. As one of the nation’s leading cancer centers, it serves patients who have a wide range of health literacy and information needs.

The Journey Project was designed in partnership with the MCC Linen-Powell Patient Resource Library director. Unfortunately, because of the volume of patients, the library’s staff and volunteers are unable to work with patients on a consistent, individualized basis in order to ensure that all understand the information they are given. The Journey Project focused on helping patients make sense of the vast quantities of information provided and offering a resource for dealing with difficult emotional health-related issues.

JOURNEY PROJECT NOTEBOOK

In the project planning process, it became apparent that simply organizing the information was a substantial barrier to managing the information. Responding to this need, a Journey Project notebook was created. Taking into consideration patients’ many care providers, the notebook incorporated sections thought to be meaningful to most patients.

Development of the notebook sections (Table 1) was based on information gathered from the many care providers throughout the VCU MCC and the greater VCU Health System and took approximately six months to complete. Interviews were conducted with oncology nurses, oncology psychologists, med-
ical social workers, and administrative members of the VCU Health System. Often figuring out the right person from whom to gather information was difficult. The VCU Health System includes approximately 200 specialty areas offering many of the most advanced state-of-the-art treatments and technologies [11]. Finding a way around the myriad centers, institutes, and levels of administration to understand how the system worked is daunting and time consuming. Reaching clarity in a complex system takes time and energy, two things that many cancer patients do not have.

PROJECT IMPLEMENTATION

After developing the notebook’s contents, a recruitment plan was created. An oncologist, known to be an advocate for well-informed patients, was approached to serve as an initial gatekeeper for physician implementation. With his consent, the SWI worked specifically with his patients. As the project began, there was a bit of concern that the SWI would be perceived as a barrier to the provision of health care. Just the opposite happened. More than once, the oncologist working with the Journey Project waited to see a patient because he knew that the SWI was still talking with the patient. Other oncologists requested SWI services during the six months of the project. Physicians requested both the provision of additional information specific to patients’ health concerns and some basic counseling when patients or family members were having a hard time coping with the situation they were experiencing. Over all, approximately 100 patients were approached as participants in the project. Because of resource limitations, only 20 patients were provided Journey Notebooks, although almost all of the patients received other additional print material. Counseling sessions, as differentiated from information provision sessions, were few because of time constraints. Approximately 10 patients requested additional time with the SWI.

As each patient was seen, the project’s goals of providing information and support were briefly explained, and the patient was asked if additional information would be beneficial. If the patient was interested in hearing more about the project or in talking with the SWI about other matters, the SWI met with the patient until the oncologist was available. As the SWI engaged each patient, she assessed the patient’s emotional comfort with her current situation, engaging patients and family members in conversation about their feelings, their concerns, and their fears. Often some of the expressed feelings would be mitigated by providing additional information or simply through the SWI’s support and understanding. Over time, the SWI prepared a canvas bag filled with the most common additional information sources that patients requested (Table 2).

PROJECT FINDINGS

At the beginning of the project, many patients seemed happy to have someone to speak with as they waited for the oncologist but seldom requested information. As the project continued, the SWI began to understand that sometimes it was not that patients did not want information, it was that they did not know what questions to ask. As the SWI engaged the patients in conversation, she began to insert questions into the conversation to assess the patients’ level of understanding. Often it was only after the SWI mentioned a topic that patients realized that they had unanswered questions. Commonly, patients had not thought to ask questions such as how long a particular test was expected to take, why a particular test was being administered, or even what could be expected on their next visit.

| Table 1 |
| Journey Project notebook |
| --- |
| | Section name | Information included |
| Your Cancer Care Team | Contact information for team members and description of each team member’s role |
| Appointments | Calendar and list format for tracking appointments, appointment note pages with space for appointment questions and physician answers |
| Treatment | Treatment scheduling pages, treatment reaction and symptoms pages, pain management pages |
| Labs | Common blood tests received, including information on how to interpret results; charts for tracking lab tests |
| Medication | Charts for prescription information, including dosage and necessary notes or reminders; pharmacy page for contact information |
| Financial Section | Space for recording dates of service, including provider and reason for appointment; amount paid re: copay and/or deductible |

| Table 2 |
| Commonly provided information |
| --- |
| Virginia Commonwealth University (VCU) Medical Center Patient Guide |
| Deciphering Medspeak brochures from the Medical Library Association* |
| MedlinePlus bookmarks from the National Network of Libraries of Medicine† |
| Commonly provided information Rx tool kit [Internet]. The Network; 2008 | cited 8 May 2008. |<http://www.nlm.nih.gov/hip/infoRx/interior.html>- |
| Booklets from the National Cancer Institute such as: |
| † Virginia Commonwealth University. Community outreach information network [Internet]. The University; 2008 | cited 8 May 2008. |<http://www.library.vcu.edu/coin/>- |

* Medical Library Association. Deciphering medspeak [Internet]. The Association; 2008 [cited 8 May 2008]. <http://www.nlm.nih.gov/resources/medspeak/>- |
† National Network of Libraries of Medicine. Health sciences libraries information Rx tool kit [Internet]. The Network; 2008 [cited 8 May 2008]. <http://www.nlm.nih.gov/hip/infoRx/interior.html>- |
Another realization was that many patients were not comfortable requesting additional information, especially from someone they did not know. For many patients, requesting information was only done after a professional relationship had been established and they had spoken with the SWI on more than one visit. Two possible explanations for the discomfort have emerged. The first is that patients might not be comfortable disclosing their lack of knowledge and asking for help. A second possible explanation is that issues of trust and diversity, part of navigating any professional relationship, needed to be resolved before the SWI’s services were considered valuable.

Although the project was explicitly designed to provide information to patients, often it was not the patients who needed or wanted additional information, but family members or caregivers. Cognizant of confidentiality issues, the SWI never discussed patients’ conditions with family members without the patients’ consent and presence. Sometimes, though, the requested information was not for or about the patient. The SWI was often asked to help family members and other caregivers get health information for their own health needs.

Additional print information, other than that often carried by the SWI, was requested by about half of the patients seen. While most of the information requested was available through the VCU Resource Library, in a few instances the SWI had to search for the information requested, especially if it was not cancer related, as happened with a few patients.

LESSONS LEARNED

Through the Journey Project, the SWI was able to experience how the two professions, social work and consumer health librarianship, interact with the health care system. Both the social work profession and the library profession value self-determination [12–14]. The ultimate goal of the health care industry, however, is not necessarily self-determination, but health as defined by the biomedical model [15]. Although in conversation, every health professional that the SWI spoke to about self-determination stated that each patient should be informed and empowered and make decisions with the health care provider, there were times that the SWI observed providers implicitly valuing compliance over empowerment. Some health care providers were overheard judging patients based on decisions about treatment. This judgment was seldom done in an explicit manner but was implied through the use of the labels “non-compliant” and “lazy” as well as through providers’ complaints that a patient not doing what was expected.

Three key differences between social workers and consumer health librarians emerged during the SWI’s experience. The first difference was seen in providing information to patients. While providing information is a common task for both professions, their goals are often dissimilar. For consumer health librarians, it is enough to provide the requested information. This is an insufficient end for social workers, who feel that engaging the patient, or client, in a conversation to assist in understanding the provided information is an important aspect of their role. The second difference concerns the two professions’ expectations of patient and physician roles. The resource library took a very firm stand on the information to be presented to the patients: that which had already been vetted by the physicians, because physicians knew what was best for the patient as well as what the patient needed to know. The SWI’s position was that the health information needs identified by the physician and patient might not be the only important dimensions in understanding the patient’s health and health care. From a social work position, health is often not simply defined from a biomedical model, but also takes into consideration the social, political, and natural environment in which each person lives [16].

The last difference between the professions is their conceptions of how to respond to the problem of health disparities. Although most consumer health librarians are aware of the differences in health outcomes for different groups of people, their professional focus is making health information more accessible. In providing services through the Journey Project, the SWI came to realize that, with respect to understanding the health care system, health disparities do not only result from what information the patients do or do not have. For at least one patient, it was not about the lack of information she had about her condition, it was about trusting the system. In one situation, services were offered to an African American woman in her late sixties. The patient responded that she was not interested in working with the SWI because she would only work with her physician. She went on to say that she was not going to be seen by any students or anyone other than her physician because she was aware of how the health care system had treated her community in the past. Bringing up the Tuskegee Experiment, this patient relayed that her personal experience with the health care system had led her to be very skeptical of anyone offering services other than her oncologist, who was an African American man [17]. This experience spurred the SWI to consider the alternative issues that might be part of an individual’s resistance to engaging the health care system.

CONCLUSION

The ability of the SWI to respond to both the information needs and the affective needs of patients and their caregivers was an essential part of the project. Although the two professions, social work and consumer health librarianship, have differences, providing both skill sets seemed to be valuable in helping patients navigate a complex health care information environment.

Consumer health librarian skills, gained by the SWI in the training phase of the fellowship, were instrumental in providing quality health information.
Although well versed in use of the Internet to find information, social workers are seldom trained to evaluate information found on the Internet, as information literacy is not stressed in social work curricula. Knowing how to find health information and especially how to evaluate its merit is a requirement for providing health information in an ethical manner.

The social work skills that the SWI brought to this project were equally important. Bound by professional ethics regarding what can be discussed with patients, consumer health librarians are not trained to engage with patients on an emotional or psycho-social level. For many of the patients with whom the SWI worked, the ability to engage authentically and empathically was as important to the patient as the health information provided. The SWI’s ability to sit with patients and caregivers who were experiencing difficult emotional and physical circumstances enhanced the trust and relationship between the patients and the SWI. This is a difficult and time-consuming process requiring social work training.

Because of the relevance of both skill sets in providing services to project patients, further exploration regarding how to integrate them is needed. Because of limited available resources, it may not be possible to support a hybrid position such as the SWI in most health care facilities. The results of this pilot project, though, provide evidence that both cancer patients and their caregivers need these integrated services. One possible solution is for consumer health librarians to work collaboratively with health social workers to develop programs such as the Journey Project that incorporate the provision of services that meet both the information needs and affective needs of patients.

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