Partnering to Encourage Health Information Seeking by Patients in an Urban Clinic

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Abstract:

Health literacy and health information literacy have been identified as essential to achieving a healthy society and an informed and empowered citizenry.\textsuperscript{1,2,3} Librarians, particularly health sciences librarians, have long embraced health information literacy whole-heartedly,\textsuperscript{4} but health literacy has also been adopted as a concern of clinical medicine and public health. Librarians frequently contribute their services and expertise to meet the information needs of individual health professionals, patients and consumers, but their work on health literacy could benefit from greater exposure and recognition across the health care spectrum. One route to this recognition is through collaborative work and partnerships in which the value of health information literacy and health information seeking are more clearly articulated and, ideally, linked to improved health outcomes. This paper will report on work informed by the theoretical framework put forth by Don Nutbeam, a public health researcher who views health information seeking as a fundamental component in achieving health literacy and ultimately, improved health outcomes.\textsuperscript{5} In this pilot project, a multidisciplinary team that included librarians worked together to develop and test the feasibility of a mobile phone application aimed at increasing health information seeking by expectant mothers. It will also distinguish between “a partnership” and “a collaboration” and will suggest that effective work in health literacy may require roles for librarians that differ from those traditionally assumed in delivering health information services.

Keywords: Information literacy, health literacy, collaboration, partnership
Background and Setting

The setting for this study is a Federally Qualified Health Center located in a neighborhood of low income residents in the city of Philadelphia, Pennsylvania in the northeastern U.S. The Health Center employs a variety of health practitioners who offer an array of healthy living activities such as cooking and nutrition classes, dental care, physical fitness classes, and behavioral health counseling. Because the Center is owned and staffed by Drexel University, faculty and staff of varied backgrounds have worked with Center staff on many projects in the past but none has involved library and information services nor is there a protocol for assessing or improving health literacy. As information professionals and informatics educators and researchers, we were keenly aware of this gap and recognized it as an opportunity to understand the needs of the community more fully and potentially to address any gaps in care.

Given our prior interest and research on collaboration patterns of library and information science faculty, we were particularly desirous of learning how health sciences librarians could join and contribute to multidisciplinary teams engaged in health literacy activities. We therefore assembled a team consisting of a public health nurse, a health sciences librarian, and three informatics faculty members, two with library and information science backgrounds and one with a background in human factors.

Approach

As a first step, we conducted semi-structured interviews with patients awaiting care at the Center. Our purpose was to determine the degree to which these patients experienced the “digital divide.” Through this research, we learned that most patients were able to connect to the Internet, but they often did so using a cell phone rather than a computer and that they rarely sought health information on the Internet. We determined that our primary objective would be to develop and test a simple, replicable intervention that would promote successful and satisfying information seeking by patients by guiding them to key resources tailored to topics relevant to their education and information needs and experiences. In consultation with the Center’s Director, we targeted groups of expectant mothers who attend regular meetings that combine prenatal education and clinical care. This enabled us to design a program that would build upon their degree of cell phone “connectedness” as a way to demonstrate and encourage health information seeking.

The team reviewed the topics discussed in the prenatal classes and familiarized itself with the Center’s approach to prenatal care so that we could tailor messages to the most likely specific information needs. We then developed a library of text messages tailored to the topics in each of the class sessions and the health sciences librarians selected credible sources of Internet information, pinpointing the exact location of the pertinent information and converting it into a tiny url (shortened version of the full Internet address) and inserting the link into the text message. The librarian and the clinical coordinator reviewed the websites to ensure that they were written at an appropriate literacy level. Patients could click on the link to access the specific portion of the website and experience a successful Internet “search” for health information. In addition to messages tied to individual class sessions, additional ones relating to timely topics (staying hydrated in hot weather, eliminating alcoholic drinks at holiday time) plus a series of meditation and self-affirmation messages were created at the request of the Center staff. Examples of the messages are in Box 1.
We used an automated service to send the messages twice weekly. Once the Institutional Review Board (IRB) approval had been secured, patient enrollment began and continued for nine months (September 2010-June 2011). A total of 31 women (approximately three-quarters of those who were eligible) participated and completed the informed.

We assessed their patterns of health information seeking using a seven-item Likert-type questionnaire which presented a behavior with an example such as “I know that there are people who know a lot about a particular topic so I ask them rather than ask just anybody” and “I look for answers to my questions on the Internet. Responses ranged from “Never” to “Always.” An anonymous follow-up survey was sent to all participants at the conclusion of the project. Throughout the project, we met as an interdisciplinary team to discuss how it was progressing, whether any changes needed to be made and if so, how they might affect the outcomes. Such continuous communication is critical in maintaining the level of trust necessary in successful collaborations. We report details of this study in Green, 2012 and Dalrymple, 2013.

**Health Literacy and Health Information Seeking**

Our understanding of health literacy has been influenced by the work of Don Nutbeam, a researcher who views health literacy as a public health issue. In Nutbeam’s view, actively seeking health information is a component of health literacy that transcends the understanding of words and the ability to follow directions. His three levels of health literacy range from fundamental literacy (understanding words and their meanings) to personal advocacy; the second level is health information seeking. In this framework, health literacy is a form of empowerment and personal advocacy that goes beyond the typical health literacy assessments. Our findings indicated that most women who took a health literacy test passed it, but that they had room to develop health information seeking habits and skills. That is, on the health literacy assessment tool we used (Newest Vital Sign), the typical score was 5 or 6 which “almost always indicates adequate health literacy” yet on our assessment of health information seeking, the mean score was 25 of 35 points. While there may be many explanations for this disparity, it suggests that health literacy is a complex phenomenon that manifests in multiple ways, some of which may have much in common with health information seeking. By working with a Health Center whose mission and values embody education and empowerment, we demonstrated the feasibility of introducing an enhanced text messaging system that acted as a convenient “on-ramp” to successful health information seeking on the Internet. Although in this small sample we were to unable to determine definitively the effect of this intervention on health literacy, we added another dimension to our understanding of health information seeking patterns in this population. This would not have been possible without the support of the Center’s Director and the participation and insights of the public health nurse.

**Collaboration or Partnership?**

Our theme today is “partnering to improve health outcomes” and so it is appropriate to pause for a moment to address the “partnering” aspect of this project. We may ask whether this project is a partnership or a collaboration, and what is the difference between them? Simply put, a partnership refers to “what something is” and a collaboration describes “something that...
is done. Partnerships imply an equal commitment accompanied by shared risks and benefits and focused on a specific problem or outcome. They may be political, charitable, or ideological agreements in which power is shared; sometimes the focus is sufficiently strong that the boundaries between professional groups fade and blur in deference to the overwhelming importance of the goal. Collaborations share many of the characteristics of a partnership but the participants contribute their expertise only to the degree it is needed to solve the problem without an expectation of reciprocation. Collaborations are therefore thought to be more project focused and possibly of less duration; when the goal or project is completed, the collaboration may cease.

In this project, a diverse group of professionals came together to promote health information seeking, an important aspect of health literacy. The team members possessed knowledge of public health nursing and health promotion, information system design, health seeking and use, and health information resources. The librarians contributed to the project by selecting and verifying appropriate information on the Internet to include in the text messaging system. The Center staff, particularly the public health nurse, coordinated the clinical aspects of the project, assisted in recruiting participants and advised the team about the target population and the needs of the Center. As individuals, members benefited from having a shared institutional environment; as a project team, they benefited from the long-standing and trusted relationship that was established between the Center and its patients over many years. The importance of this trust is difficult to overstate.

Although this was primarily a feasibility study, it offers several insights and advances our understanding of collaborations and partnerships in which libraries are involved. Given Carnwell and Carson’s definitions, this work was a collaboration rather than a partnership. In order to progress to a partnership, it is likely that the Center, the Library and the University would need to agree to establish a priority focus on improving health literacy. Our experience suggests that in the U.S., at least, funded health literacy efforts are dominated by clinical health professionals and public health practitioners while information professionals focus almost entirely on health information literacy. To engage more fully in health literacy, librarians may well have to forge alliances in which they are fully equal partners in a shared vision of health literacy that includes health information literacy, similar to that advanced by Nutbeam. In so doing, they may need to move beyond the boundaries of their professional practice, steps that may present challenges. In the project reported here, the clinical staff advocated strongly for the preservation of the “sacred space” of the group clinical care which prevented the other team members from experiencing the impact of the information seeking program on group dynamics. In addition, the IRB’s prohibition on direct contact with patients limited opportunities for soliciting patient participation in the design and conduct of the project. In the future, previous participants in the program could be involved as an advisory board. Such a move might bring the team closer to a true partnership than a time-limited collaboration; on the other hand, the varied underlying motivations of the team members are likely to differ and present additional challenges.

Summary
The project presented here was a collaboration that brought together a small group of professionals to accomplish a goal, but their differing backgrounds, professional cultures, and motivations for participation often required negotiation and adjustments. While we established the feasibility of an enhanced text messaging system, we acknowledge that projects conducted in clinical settings present challenges while also providing valuable insights into methods to promote health literacy. The project achieved its objectives of
establishing system feasibility, but additional work must be undertaken in order to progress
the path of establishing a relationship between health information seeking and improved
health outcomes as Nutbeam has suggested. Health sciences librarians who desire either to
advance this work will do well to collaborate on a short-term projects or enter into longer-
term partnerships that will increase the likelihood of success. Experiences such as the one
reported here can contribute to the creation of new models for library partnerships to improve
health literacy.

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