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Abstract

The Personal Education Plan (PEPTalk) was a collaborative, multi-disciplinary research project (2005-2006) based at the University Health Network's Princess Margaret Hospital to design an information system to provide web-based health information resources to both patients and clinicians under a shared umbrella of patient education. This article provides an overview of the PEPTalk project methods and outcomes, and documents the contributions of librarians throughout the design and clinical implementation stages of the project. Librarians brought expertise about information seeking behaviours of both patients and clinicians to the project; liaised across institutional and professional boundaries; developed a classification system for online learning objects, and educated project team members about information and health literacies. The contributions of librarians on the PEPTalk project illustrate the need for boundary spanners, information brokers, knowledge translators, and change champions in the design and implementation of patient education delivery systems. There are new roles emerging at the intersections of clinical practice and health information provision. There is a need for the traditional skills and expertise of librarians and other information professionals in tailoring health information; yet the design and implementation of patient education systems also require the development of new knowledge and the application of advanced information literacy as it pertains to both clinicians and patients.

Keywords

Patient education, information professionals, tailored information, clinical practice, information system design

Introduction

While having access to clinically reliable health information is recognized as a key component in patient care, it is less well known that providing tailored information packages to patients with chronic illness contributes to improved health outcomes (Brug et al.; Campbell et al.; Skinner et al.). In this regard, new information systems are emerging to provide tailored, clinically reliable online resources to support patient education needs (Bental, Cawsey and Jones). While it is acknowledged that librarians are involved in the production and management of many such health information systems (Bella et al.), non-traditional roles are seldom considered. Here, we offer an alternative approach to understanding the role of information in patient care by examining the processes that are needed to support its effective delivery and use in clinical settings. We do so by highlighting the particular contributions of librarians in the design and implementation of the Personal Education Plan (PEPTalk) project.

The PEPTalk research project was funded by Inukshuk and Centennial College and based at the University Health Network's Princess Margaret Hospital in 2005-2006. The project team consisted of clinicians, physicians, educators, community partners and librarians, and aimed to achieve three outcomes: to develop tailored, culturally relevant educational resources for people with chronic illness; to design new clinical practices to support patient education delivery that centered on 'prescribing' tailored information to patients; and to create an extensible information system to store, share and maintain the Web-based resources. This article: 1) situates the PEPTalk project in the historical context of librarian roles in patient education, 2) describes the methods used by the PEPTalk project team, 3) outlines the project outputs, and 4) examines the particular contributions of librarians on the PEPTalk project as a means of highlighting potential roles for information professionals in patient education.

History of Librarian Roles in Patient Education

Broadly speaking, librarian roles in patient education or consumer health education are typically defined in relation to the proliferation of online health information. The *Pew Internet and American Life Project* reports that 80% of Internet users access online health information to learn about disease-specific conditions and other health-related topics (Fox), but patients rarely evaluate the quality of the information they find on the Internet in terms of its accuracy, relevance, bias or currency (Crespo). Furthermore, some clinicians fear that there is too much health information on the Internet to be of use (Al-Bahrani and Plusa) or that patients may encounter misinformation (Weiss and Moore). For example, Black and Penson found shortcomings in websites about prostate cancer with regard to currency, disclosure and attribution.

For many years, librarians have advocated for more clearly defined roles in patient education and for recognition from physicians and nurses of the skills and resources they offer (Harris). In 1996, the Medical Library Association and the Consumer and Patient Health Information Section (CAPHIS/MLA) issued a Policy Statement in an effort to clarify the role of librarians, in which patient education was defined as "a planned activity, initiated by a health professional whose aim is to impart knowledge, attitude and skills, with the specific goal of changing behaviour, increasing compliance with therapy and, thereby, improving health" (MLA). In the Policy Statement it was noted that roles for librarians in patient education reflect their training in collection management, knowledge and resource sharing, advocacy, access and dissemination of information, education and research (MLA). These roles depend in a significant way upon collaboration with other professionals (RUSA). Librarians recognize the importance of collaboration, which "must take place within the organization, within the institution, within the profession, across disciplinary and professional boundaries, and within the information industry" (Rice-Lively and Racine).

Sometimes known as "informationists" or "clinical knowledge workers", librarians are an integral part of the interaction between clinicians and patients by "retrieving, synthesizing and presenting medical information" (Davidoff and Florance 997). The clinical informationist identifies the information needs of all members of the healthcare team as well as patients and their families [Davidoff and Florance; Detlefsen; Guise et al.). Davidoff and Florance also suggest that librarians (or informationists) must play a role in improving the health information systems used to retrieve information, and focus on tailoring information to best suit when, how and what information will be most appropriate to both the healthcare professionals and the patient.

Kreuter et al. define tailoring as "any combination of information or change strategies intended to reach a specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment" (487). An important role for librarians in clinical settings is to support patient care by providing clinicians with information that is tailored to their needs through "quality-filtering" (Guise et al.).

There are also specific ways that librarians can support the tailoring of information for patient education. In a variety of contexts (e.g. academic or public library settings) librarians can conduct mediated searches of consumer health information using instruments designed to assess the accuracy of online health information, such as Health on the Net Foundation, DISCERN online, National Complimentary and Alternative Medicine (NCCAM), and Minervation's Evaluation Instrument for Health Care web sites (Keane). They also take on the equally important role of health literacy advocate, or health information evaluator (Crespo). According to the American Medical Association, functional health literacy is defined as, "the ability to understand basic health care communications, such as prescription instructions and insurance forms" (AMA) and as "the ability to read, understand, and act on health information" (Andrus

and Roth 283). Librarians support information tailoring through health literacy by providing patrons with easy-to-read or "plain language" health information.

Articles in the library and information science (LIS) literature on health information systems design usually describe librarian participation in terms of traditional skills such as providing access to information, collection development and or resource selection. In a recent systematic review of the literature on informationists, Rankin, Grefsheim and Canto identify roles for informationists in developing new technologies but define these roles somewhat narrowly, as "gathering meta-information about clinical questions" (195). Elsewhere, Klein-Fedyshin et al. report on a project, initiated by the Process Improvement Team of the University of Pittsburgh Medical Center, which involved a collaborative effort among health sciences librarians, nurses, rehabilitation therapists, and patient education staff. The article describes the outcome of the project's primary goal which was to increase patient participation in recovery following coronary artery bypass surgery by providing an educational video. The library's goal in the project was defined largely in terms of its traditional role to: "promote use of [library's] resources, promote recognition of their information expertise and collaborate in a valued institutional project" (Klein-Fedyshin et al. 441). In addition, Koonce et al. describe a collaborative initiative between the Eskind Biomedical Library and the Vanderbilt University Medical Centre that developed an online interactive portal, the Patient Informatics Consult Service (PICS), to improve patient and family access to health information and allow patients to schedule appointments, pay bills, and send confidential electronic messages. Librarian's roles in PICS involved the selection of patient education resources and their ongoing maintenance in terms of currency and appropriateness.

Overview of PEPTalk Project Methods

The PEPTalk project (2005-2006) was a close collaboration between the project team of researchers from the *University Health Network* (UHN), *Centennial College*, and the *Adaptive Technology Resource Centre* (ATRC), including educators, clinicians, librarians, information architects, web-designers and videographers. Other stakeholders in the project included clinical partners from the UHN and the University of Toronto in the areas of diabetes, breast cancer, head/neck cancer and family medicine. Community partners included: *St. Christopher House*, a social services agency in Toronto; and, *K-Net*, a community network comprised of 60 First Nations communities across Ontario and Quebec. The design of this interdisciplinary and inter-institutional project reflected an effort to further the goal of information sharing where clinicians of all types and from a variety of organizations worked together to share patient education information and resources.

The project team used participatory design research methods, including participant observation, interviews, workshops and focus groups, to iteratively obtain input from clinical and community partners at every stage. Partner consultations consisted of workshops and focus groups for all project stakeholders on such topics as: roles and responsibilities; achieving buy-in from all stakeholders; validating results from the

inventory of educational resources contributed by each partner; and conducting needs assessment for all clinical sites.

The project team used a content delivery platform called The Inclusive Learning Exchange (TILE)[1] developed by ATRC to implement the PEPTalk Information Prescription Process. The system needed to enable doctors, nurses, pharmacists, clinical educators, case workers, etc. to set up patient profiles to 'prescribe' personalized patient education plans; it also needed to facilitate patient access to resources prescribed to them. Furthermore, although the TILE system, as the container or delivery vehicle for the information, was designed as a set structure that could not change from clinic to clinic and implementation, a standards-based approach to information was designed to ensure flexibility, thus enabling any information to be slotted into the information prescription interface. That is, by building a way for information to be classified in the system, any information prescription could be written for any chronic disease case or issue, using the PEPTalk platform.

Project Outputs

One of the primary goals of the PEPTalk project was to develop tailored, culturally relevant educational resources for people with chronic illness with the belief that better health outcomes would result. Project evaluation activities included usability testing, interviews and surveys with patients (N=8), and usability testing with clinicians [N=8]. These results are reported elsewhere (Atack, Luke and Chien). PEPTalk[2] is currently undergoing further testing and development as part of the Social Sciences and Research Council of Canada (SSHRC)-funded project Advanced Patient Education for Cancer Survivors (APECS) (2007-2011), which examines the use of online health information resources among women with breast cancer and measures their impact on patient self-management abilities and health professional care processes[3].

A second output of the PEPTalk project was an extensible model for patient education delivery that incorporates:
1. A database of tailored culturally relevant educational resources for people with chronic illness;
2. New clinical practices that account for online information seeking behaviours including awareness of information literacy and health literacy issues as they pertain to patient education;
3. An information system to:
   a. store, share and maintain clinically reliable Web-based resources;
   b. enable clinicians to set-up patient accounts and prescribe appropriate educational resources;

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[1] (http://www.barrierfree.ca/tile).

[2] www.peptalk.ca

[3] In addition to PEPTalk, the APECS study interventions included two other Princess Margaret Hospital initiatives: www.caringvoices.ca, a social networking site designed to support breast cancer survivors at every stage of their journey, and the Survivorship Transition Employment Project (STEP), an online course for survivors of breast cancer contemplating their return to the workplace.

c. enable patients to set-up their own accounts to access prescribed resources and browse for other resources.

In the remainder of this article, we examine the processes that are needed to support the design and implementation of PEPTalk by highlighting the particular contributions of librarians to the project.

Librarian Roles in the PEPTalk Project

Librarians were involved in most aspects of the PEPTalk project. Some roles were more traditional, including literature searches, evaluating information resources, and organizing and assigning metadata to resources. Other librarian roles included the iterative design of the PEPTalk process, especially with regard to educating both clinicians and patients about information and health literacies.

First, librarians conducted literature reviews and developed annotated bibliographies on key aspects of patient education from the Health Sciences, Medicine, Medical Informatics, Nursing, Library and Information Science, and Communication literature. This helped the project team to understand the information needs and behaviours of two distinct user groups: patients and clinicians. Further research was undertaken throughout the project as the need arose, on such topics as: understanding the relationship between information and communication technologies (ICT) and health outcomes to guide the process of designing new information practices and systems; and the production of multimedia learning objects (e.g. how to produce an educational video).

Secondly, librarians liaised with clinical and community partners to identify and evaluate information resources for the online repository, they provided in-depth reference research and selected electronic resources to provide information in the areas of breast cancer, head/neck cancer and diabetes. In particular, librarians provided support to clinicians in understanding how to tailor information resources by, for example, breaking larger manuals into topic specific components relevant to chronic illnesses. In addition, librarians evaluated clinical content and health resources submitted by clinicians and health care professionals for cultural relevancy, literacy levels and content specificity.

Thirdly, librarians organized the information resources in the database by developing a framework that included three broad categories: Understanding Disease, Health Promotion and Managing Health; and several topics including: symptoms, diagnosis, monitoring, therapies, self-care, lifestyle changes with chronic illness, nutrition, exercise, community support, coping, and general works. These categories and topics were validated and assessed by clinicians based on their clinical experience. In the next phase librarians evaluated classification systems and metadata suitable for both patients and clinicians to further describe each of the resources. Metadata would describe the resources according to type (e.g. text, graphics, or video) and would further support the search and prescription functions of the PEPTalk system. The Planetree classification system (Cosgrove) was chosen because it uses patient-friendly or plain

language to classify the search and reference terms; whereas, for example, MeSH (Medical Subject Headings) uses medical terminology, such as, "neoplasm" instead of "cancer". In addition to keywords, other categories of metadata included: title, language, description of the resource, lifecycle of the resource (i.e. who created and validated it, name of the affiliated organization), and copyright information. Once the information resources were converted from Word to HTML documents, the librarians assigned metadata and they were uploaded into the repository.

Fourthly, librarians' knowledge of information seeking needs and behaviours, and information and health literacy informed the tandem development of the "PEPTalk Process" and a continuing education course to support clinician learning about the value of tailored information. In getting feedback from clinicians on the development of the "PEPTalk Information Prescription Process" (see Figure 1), librarians ensured that clinicians considered both their own information needs and behaviours, and those of their patients. In the spirit of iterative participatory design techniques, clinicians were asked for their reactions to paper-based mock-ups and to reflect on the way they currently delivered patient education: Did they anticipate any barriers to using the system in clinical or community settings (i.e. in patient education centres or patient's homes)? Did they have suggestions about how to make PEPTalk easier to use? What changes in their behaviours would need to take place to support this new form of patient education delivery? For example, clinicians were asked to consider an aspect of the PEPTalk Information Prescription Process, which borrows to some degree from the traditional 'reference interview', where the clinician assesses the information needs of the patient and their readiness to learn during the consultation.
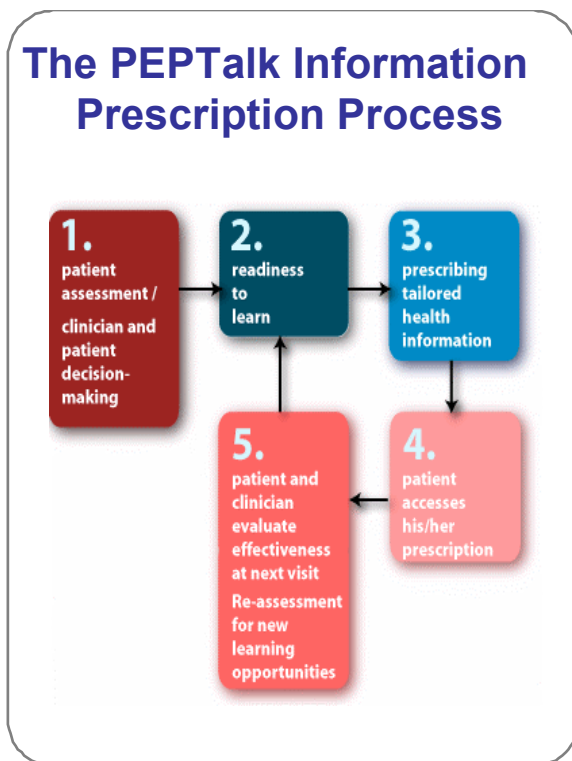

Figure 1. The PEPTalk Information Prescription Process

At the same time, the project team also created an online continuing education course for clinicians. The course teaches clinicians to use PEPTalk, about the principles of tailoring information, and how to practically incorporate the new information delivery practices into their day-to-day workflow. The five modules include: [1] Tailored patient education; [2] Understanding the process; [3] How to use the PEPTalk system; [4] Introduction to finding and evaluating Internet resources; and [5] patient-clinician communication.

Librarians also took on other project-related tasks that included assisting with the ethics submission, designing research posters and handouts, creating and delivering presentations, providing input on design research instruments (i.e. surveys, interview guide), and conducting usability testing.

Discussion

In addition to the project outputs outlined in the previous section, an aim of the PEPTalk project was to increase information sharing across institutional and professional boundaries. In the early stages of the project, the principle investigators identified the need to create information structures that would be easily transferable across clinics. It was in this context that particular roles for information professionals on the project became apparent.

Upon reflection, one principal investigator observed that in putting together the research team he did not consciously set out to hire librarians; rather his interest was in hiring people who were well trained in aspects of information management, information science, design, and methodologies associated with the collection, taxonomy, and use of information. In some respects the hiring of librarians was opportunistic given the primary investigator's association with the Faculty of Information (FI) at the University of Toronto and history working as a researcher on FI projects. The content development phase of the project had a very short timeline (one year) but the project was in essence a straightforward content development exercise that needed to move very rapidly. The engineering aspects of the PEPTalk interface development were also a key consideration, and so having members with expertise in aspects of usability and information behaviour was very important.

Furthermore, the principal investigator affirms that the librarians on the project contributed expertise in knowledge management and information science, from the collection, tagging, indexing and end-user evaluation aspects to providing input on usability and systems design for the clinical interface. While the use of learning object repositories is not necessarily new, the skills associated with their design and use, particularly in clinical settings, are not well established or documented in the literature. Thus the ability of the research team to move quickly, adapt thinking, make trade-offs in design, and provide key expertise in information use was very important.

In the LIS literature, librarians have a long history of linking information sources and information users (Khurshid; Rice-Lively and Racine). New approaches to intermediary

roles are developing, causing librarians to re-define or strategically re-position their skills (Marfleet and Kelly; Corcoran; Fichter; Sturges; Huwe). For example, librarians mediate between online information sources and users by developing tools such as Web-based portals to organize and coherently present selected information sources and provide guidance to information users. In addition, Crespo notes that, librarians "… help users to develop a critical approach to assessing the information resources… so readily available" (361).

In the context of patient education or consumer health information provision, "librarians most closely operate as what Latour (2005) describes as 'intermediaries' [in that] they 'transport meaning' without 'transformation'"(qtd. in Bella et al. 34). This means that librarians' provision of health information is not intended to have a therapeutic effect, which is in contrast to the patients' experience in receiving health information from doctors, nurses, social workers or dieticians. However, Haythornthwaite (1996) observes that, " [w]hile the librarian is traditionally viewed as the intermediary between the patron and the information source, the possibility exists to expand that role to include manipulation of network structures to facilitate the flow of information" (331). Potentially, information professionals can increase their understanding of how information networks evolve by participating in the design and implementation of information systems that deliver patient education, which may facilitate information delivery and use.

Following this idea, we note in particular that the contributions of librarians on the PEPTalk project highlight the need for 'information surrogates', to borrow Macintosh-Murray's terminology, in the design and implementation of patient education delivery systems. In a study on the effect of 'medical errors' on organizational learning, Macintosh-Murray examines the flow of information in clinical settings and concludes that; "a surrogate in an information-related role may intervene successfully with staff and engage in preventive maintenance and repair of routines" (iii). She identifies a range of professions, the Professional Practice Leader/Educator (PPL), the pharmacist, and the unit manager, as being potential 'surrogates' through their work as: 1) boundary spanners, 2) information brokers, 3) knowledge translators, and 4) change champions. Macintosh-Murray suggests that librarians may also be suitable in these roles.

First, as boundary spanners, librarians functioned to bridge interdisciplinary gaps between professionals and institutions -- liaising with clinicians to gather, evaluate, select and validate resources suitable for a database of information that can be tailored to meet individual information needs of patients. Second, librarians were information brokers in that they identified and strived to meet the information needs of the research team at various stages of the project. Third, while knowledge translation formally implies the application of evidence to the development of policy and standards, in the context of practical application of standards, librarians applied library and information science (LIS) principles to the organization and classification of online learning objects, ensuring they were tagged for efficient search-ability and use by clinicians and patients alike. Finally, the role of change champion in this context suggests that librarians actively educated clinicians about information and health literacy, and the principles of tailoring information

as they relate to patient and clinician information design and use. In this sense, librarians on PEPTalk played a key role in rendering tacit knowledge about patient education explicit.

Conclusion

Healthcare is an activity dominated by information, and patients need timely access to relevant information. Effective delivery of patient education can aid clinicians in implementing effective chronic disease management strategies. In this context, boundary spanners, information brokers, knowledge translators, and change champions are needed. These new roles are emerging at the intersections of clinical practice and health information provision.

Tailoring health information builds on LIS training and expertise yet also requires the development of new knowledge and practices that include the application of advanced information literacy skills as they pertain to both clinicians and patients. We have seen in the PEPTalk project that there are ways to fashion these roles vis-à-vis librarians' traditional knowledge domains and their application to the health information context by participating in the development of patient education delivery systems and their implementation in clinical settings.

Acknowledgements

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