

MyHealthPortal: Using an Electronic Portal to Empower Patients with Breast Cancer

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Organization:	Fox Chase Cancer Center
Mechanism:	PAR: HS09-087: Mentored Research Scientist Research Career Development Award (K01)
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Summary: Patient use of online electronic medical records has the potential to improve health outcomes. Educational materials that are made available within a patient-accessible electronic medical record (PAMR) will not only help patients understand their clinical data, but will also support them through use of integrated behavioral and health communication strategies in a comprehensive format that contributes to optimum care. Breast cancer, the most common cancer and the second-leading cause of cancer deaths among women, accounts for 29 percent of all new cancer diagnoses in the United States. A diagnosis of breast cancer often evokes fear and distress. Studies show that breast cancer patients report that their providers often fail to understand their psychosocial and communication needs in addition to their need for information and skills to manage their illness and deal with the major life changes and potential emotional problems that usually accompany it. To bridge the divide between patients and the health care system, one objective of this research is to integrate personal information from an electronic medical record with educational and support content about breast cancer treatment decisionmaking and care management into the MyHealthPortal patient portal. A second project objective of this Mentored Research Scientist Research Career Development Award is to enhance the principal investigator's career development through education and training activities.

Using an iterative developmental process, this work will be accomplished through four phases of the research plan to ensure a user-centered design, and the acceptance of the portal among both the targeted audience and health care providers. Phase 1 includes survey research to assess existing institutional portal users' satisfaction with the current portal and to identify features in need of improvement. Phase 2 consists of a qualitative study to identify breast cancer patients' information needs and preference for a PAMR-integrated portal. Phase 3 includes a qualitative study to explore breast cancer clinicians' attitudes and expectations regarding the implementation of a patient portal that integrates shared medical records and e-communication capability that will impact doctor-patient relationship. Phase 4 includes both cognitive user and usability testing for system refinement to maximize MyHealthPortal's usefulness and patient satisfaction. Once fully developed, the study will evaluate the feasibility of the portal system in a pilot randomized controlled trial study with 120 breast cancer patients to examine the impact of the MyHealthPortal system on patient outcomes including: cancer-related distress, information competence, coping self-efficacy, physical quality of life, and doctor-patient communication. Intervention participants' satisfaction with and usage of the MyHealthPortal system will also be evaluated.

The findings of this research and the developmental process that it will employ will be applicable to

the breast cancer population, but could also serve as a model for PAMR-integrated system development and implementation among other cancer populations. The research will also provide preliminary data to support a R01 proposal that will examine the efficacy and cost-effectiveness of the MyHealthPortal system in a larger study.

Dr. Wen identified a mentorship team suited to provide expertise in major areas of relevance to the research activities. Enrollment in three core courses will advance the investigator's career and research goals. Dr. Wen will attend a series of seminars and workshops as well as present and attend at annual meetings and conferences across a variety of research topics directly related to the training needs identified by the mentorship team.

Specific Aims:

- Develop a patient-centered Web-based portal (MyHealthPortal) for breast cancer patients undergoing treatment in a Comprehensive Cancer Center. **(Ongoing)**
- Conduct a pilot randomized controlled trial study to assess the feasibility and potential impact of the MyHealthPortal system with early-stage breast cancer patients. **(Ongoing)**

2011 Activities: The project began in August 2011 and focused primarily on project start-up activities including the preparation of materials for institutional review board approval. Recruitment of study subjects was initiated and Dr. Wen began the subject interview process. Completed interviews were transcribed and reviewed. The medical component of the portal was finished and additional content is in progress.

Preliminary Impact and Findings: This project has no findings to date.

Target Population: Cancer: Breast Cancer, Women*

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions and the electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use

** This target population is one of AHRQ's priority populations.*