Building a Portal to Health Resources for Cancer Survivors

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Problem Statement

Cancer patients and their relatives access the WWW health resources when they covertly question the diagnosis and treatment, often with a positive impact on health outcomes. Thus, "cancer survivors" (post treatment) may continue to use the WWW as an information source. Little research exists related to the information needs of cancer survivors, their caregivers and how these needs can be met.

Background

➡ In 2020, #cancer survivors will increase to 18 million, dramatically increasing provider demand.
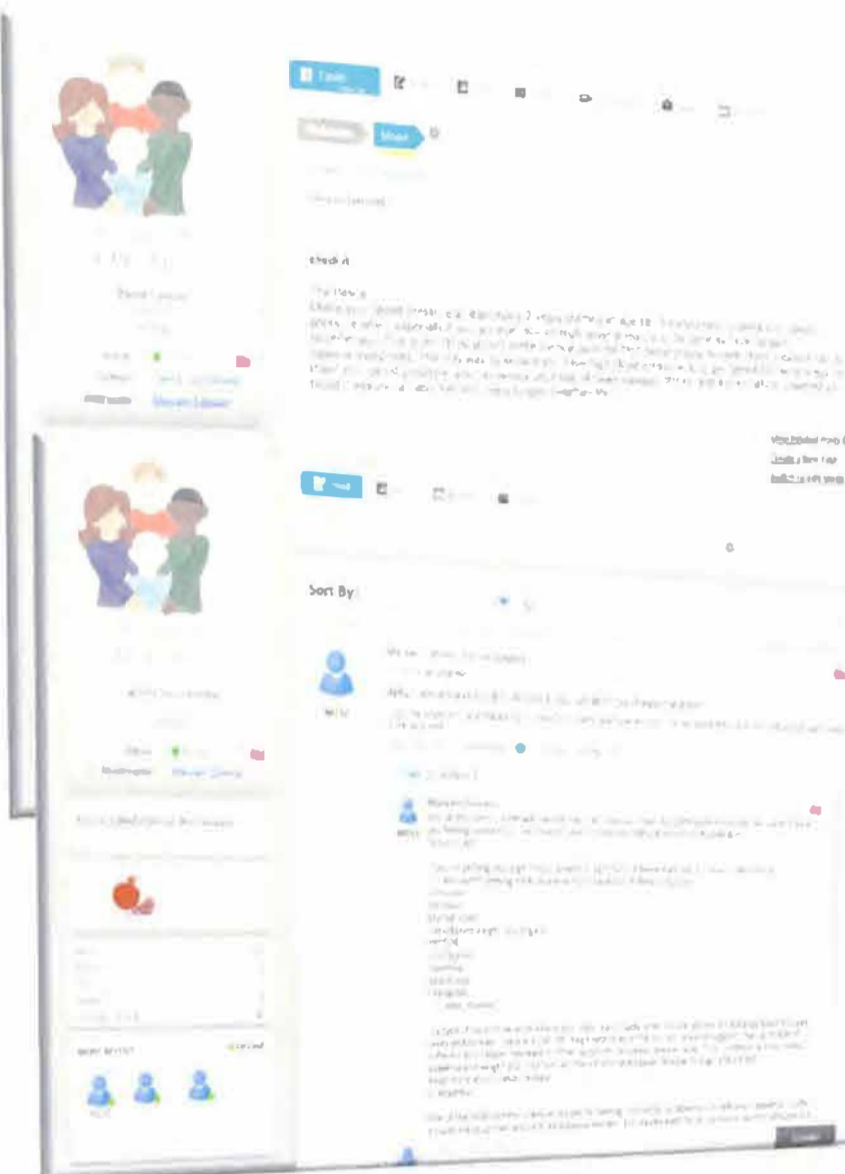➡ Survivors will access WWW health resources.
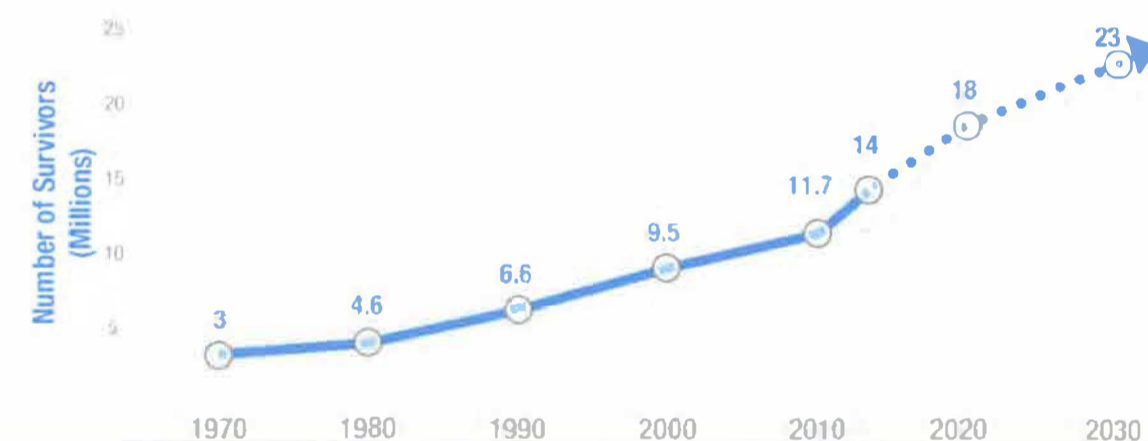
➡ Two engagement frameworks were developed to provide theoretical and empirical aspects for patient participation in health: The Patient Behavior (Patient perspective) framework and Patient Engagement (Clinician perspective) framework.

Patient behaviors	Patient: chronic disease self-management behaviors
Prepare Establish a relationship with a health care professional, requesting and managing appointment, and list of question and document. Seek and access the appropriate health care setting for professional attention, or unique need. **Interact** Manage medication, and insurance coverage Manage PHR Ask and learn about consequence of different option for treatments Evaluate screening / diagnostic tests and negotiate treatment plan with supervisor **Follow up** Involve more clinicians and collect more information, and share your PHR with them Follow up on referrals for treatment, diagnostic testing, and refilling medicine Follow up on referrals for treatment, diagnostic testing, and refilling medicine	**Prepare** Understand and evaluate patient's disease(s), the risks and benefits of treatment options Identify and secure services that support changing behavior **Act** Manage and monitor symptoms by following treatment plans/condition Know health targets

Patient behavior framework (patient perspective)

Functions	Functions' elements
Information, Way-Finding, and Analytics/Quality	Care comparison for providers, treatments, and medications
e-Tools	e-Visits as part of ongoing care
Interactive and integrated Forms: Online	Clinical trial records • Immunization (public health)
Patient-Specific Education	Care planning, Chronic care self-management, Reminders for daily care
Patient Access and Use	Publish/subscribe/set privacy/distribution for complete record.
Care Team-Generated Data	Shared care plans Team outcomes
Interoperable Records	Integrated with long-term post-acute care records
Collaborative Care	Chiropractic, Dentistry, Alternative medicine, Home
Community Support	Online community support forums and resources for all care team members,

Patient engagement framework (clinician perspective)

Objectives

➡ Discovering and analyzing regularities, patterns or trends from real time WWW searches for direct and non-direct health-related information performed by cancer patients, their contacts.
➡ Developing social connex to provide a collaborative environment for sharing experiences.
➡ Developing educational tools to provide patients with basic facts relevant to their health conditions.

Research Methodology

Conceptual framework of web based system.

This qualitative research is composed of three main phases:
➡ 1) developing an effective virtual environment (web-based system) for collaboration between patients and clinicians.
 ❑ pilot study: a course networking (CN) system will be used. The connex will provide collaborative environment for discussion.
 ❑ train patients by providing tips on how to get engaged.
➡ 2) patients monitored during web browsing.
 ❑ Technique of web usage mining to discover patterns and trends of the patients browsing behaviors.

➡ 3) open MRS, section PHR to help with patients to manage their health records.

OpenMRS

Results

It is anticipated that the project yields the following outcomes:
➡ *(1) create an effective technique to understand recovery information needs.*
➡ *(2) identify specific tasks in daily living that are leading to information seeking.*
➡ *(3) propose predictors on how information sources support recovery in real-time.*

The successful development and evaluation of this project will impact the design of patient-centered health care information systems

Conclusion

This project should have a significant impact on design of patient-centered health care information systems while enhancing consumers self confidence and motivation to engage in their health.

Further, it should help clinicians to understand values, and preferences of the health care consumers.

References

Cappiello, M., R. S. Cunningham, et al. (2007). "Breast cancer survivors information and support after treatment." Clinical Nursing Research 16(4): 278-293.

López-Gómez, M., C. Ortega, et al. (2012). "Internet use by cancer patients: should oncologists 'prescribe' accurate web sites in combination with chemotherapy? A survey in a Spanish cohort." Annals of oncology 23(6): 1579-1585.

Ruland, C. M., A. Jeneson, et al. (2007). Designing tailored Internet support to assist cancer patients in illness management. AMIA Annual Symposium Proceedings, American Medical Informatics Association.

Ziebland, S., A. Chapple, et al. (2004). "How the internet affects patients' experience of cancer: a qualitative study." BMJ 328(7439): 564.