

The Development of an eHealth Tool Suite for Prostate Cancer Patients and Their Partners

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Prostate cancer is the most common cancer among men in the United States and the second leading cause of cancer deaths among white, African American, Native American, Alaskan Native, and Hispanic men. Those at highest risk are men aged 50 years or above; 65% of prostate cancer patients are older than 65. African Americans are 56% more likely to develop prostate cancer than are whites, and men with a first-degree relative with prostate cancer are twice as likely to be diagnosed as those without such a family history.^{1,2}

Helping newly diagnosed prostate cancer patients fill their needs for information, support, and decision making has been addressed directly by clinicians and a wide range of printed materials. But in recent years, Internet resources have been increasingly available and used as such materials can immediately disseminate, manage, and tailor health information to serve a global audience.³ Despite questions of universal access and a broadening digital divide for some audiences, health information is the seventh most popular use of the Internet.⁴ Given its flexibility and potential, the challenge for content developers is how to best leverage the Internet's capabilities.

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ABSTRACT

Background: eHealth resources for people facing health crises must balance the expert knowledge and perspective of developers and clinicians against the very different needs and perspectives of prospective users. This formative study explores the information and support needs of posttreatment prostate cancer patients and their partners as a way to improve an existing eHealth information and support system called CHES (Comprehensive Health Enhancement Support System).

Methods: Focus groups with patient survivors and their partners were used to identify information gaps and information-seeking milestones.

Results: Both patients and partners expressed a need for assistance in decision making, connecting with experienced patients, and making sexual adjustments. Female partners of patients are more active in searching for cancer information. All partners have information and support needs distinct from those of the patient.

Conclusions: Findings were used to develop a series of interactive tools and navigational features for the CHES prostate cancer computer-mediated system.

Interactivity, limitless ability to tailor content, broad audience demographics, low cost, and immediacy of information access suggest that the Internet has vast potential for many applications, especially health. The Web can disseminate health information in a personal and persuasive manner that has never before been available with such ease and economy. “eHealth” is a term used to describe both the practice of health care that is supported by electronic processes and communication and the body of health information available through electronic devices. Many expect the new world of electronic health systems to bring widespread improvement in health and prevention through mass consumer self-education.³ With greater access to medical records and information, growing numbers of individuals are becoming partners in their own health care. With this opportunity and responsibility, patients are realizing increased self-efficacy and lo-

cus of control—essential steps in improving an individual's health and perception of life quality.

As a young technology, however, eHealth lacks a historical track record and, consequently, provides practitioners relatively little evidence to show what works, what does not, and why. The literature suggests that, despite growth of access (especially via mobile devices), there are significant barriers to eHealth resources.⁵ Access to eHealth as an electronic health communication resource is problematic for 40% of the US adult population. There are also barriers created by deficits in eHealth literacy, specifically a deficit in any one or a combination of six literacy domains (reading, health, information, scientific, computer, and media).

Other research suggests additional barriers to effectively connecting the literate with eHealth resources, in particular individual differences such as gender,⁶ age,⁷ and cognitive preferences.⁸ There is much left to learn about how different audiences respond—or don't—to the Internet and how to extend tailoring beyond content to address the wide array of differences in individual patients. Critical questions remain: Are eHealth initiatives inherently biased in favor of certain demographic groups? Have we exhausted the tailoring potential of this intricately intimate mass medium? This study considered these questions as a way of understanding why the first Comprehensive Health Enhancement Support System (CHES) Prostate Cancer eHealth initiative did not receive the same level of use as did the CHES Breast Cancer eHealth initiative. Findings were used to guide redevelopment of a prostate cancer Web support and information system.

The CHES computer-mediated information and support initiative was developed at the University of Wisconsin–Madison for patients with several high-profile diseases. The systems were tailored to specific patient and support audiences, based on extensive needs assessment with patients and families and with ongoing contributions from clinical specialists.^{9,10}

The system has been evaluated in several clinical trials with breast cancer patients^{11,12} and with human immunodeficiency virus HIV/AIDS patients.¹³ Both populations using the system in the studies showed health competence, emotional, and quality-of-life benefits compared with controls. The initial development of CHES for prostate cancer patients included a substantial needs-assessment study of both prostate cancer patients and their spouses. The results of which are detailed in a 2004 unpublished technical report entitled *Developing and evaluating a computer-based system of information and support for prostate cancer patients* written for the American Cancer Society by D.H. Gustafson, R.P. Hawkins, and E.W. Boberg.¹⁴ Both men and their partners rated how well each of more than 100 needs was being met and the relative importance of each need. Both patients and partners felt that care-delivery needs were most important, followed by information needs and then by support needs. However, care-delivery needs were also far more satisfied so that when weighted unmet needs scores were created (that is, when the degree to which a need was unmet was weighted by its importance), information needs clearly required the most

attention⁹ and were thus the focus for development of the CHES module for prostate cancer.

When CHES researchers first created a module to address prostate cancer, they incorporated the same basic structural system of information, tools, and communication that was used in the breast cancer and HIV/AIDS studies. The system's information component consisted of an online library describing treatment options; drug therapies; side effects; cancer and other family medical and financial support-service phone numbers; frequently asked questions; and breaking news on cancer. The tools component included psychosocial tools to help with making treatment decisions as well as managing stress and relationship issues related to the disease. A discussion board was incorporated as a forum to allow men to communicate with each other, share individual experiences, offer recommendations, and provide emotional support. A personal stories section made available actual patient accounts of their cancer experiences. Other interactive components included an action plan, calendar, medications log, health status record, and journal. Expert help in locating and interpreting information was available from a cancer information service specialist, who responded within 1 or 2 days. For immediate assistance, the National Cancer Institute Live Help link was included.

Unlike the breast cancer system, an early study of the CHES prostate cancer module showed limited use by patients and relatively weaker effects. This paper describes the formative research and development process employed to improve the original system. The development team sought to answer the following questions:

- Why was the early version of the system not more effective?
- What information and features are needed to create value for the patients?
- What is the most efficacious manner in which to deliver such information to prostate cancer patients?

A thorough review of the literature was conducted to identify existing peer-reviewed research related to the information and support needs, as well as information-seeking behaviors, of prostate cancer patients. In particular, the research and development team sought out research about the efficacy of eHealth in disseminating prostate cancer information and support. The literature provided substantive evidence detailing patient and spouse or partner needs related to communication competencies, sexual functioning, and managing intimate relationships, as well as issues related to patients' cognitive competence while they dealt with prostate cancer. Specifically, the literature directed the development team's attention to the following:

- How individual differences (sex, age, cognitive style, computer literacy) influence perceptions and use of computer-mediated systems and the resulting implications for Web design^{15–17}
- The role of partner involvement in decision making,¹⁸ reestablishing satisfactory sexual function,^{19–23} support, and recovery²³
- The prostate cancer patient's comparatively high level of stress and anxiety, especially as related to decision making

(as noted by W. Dale, unpublished University of Wisconsin–Madison grand rounds lecture, 2006)²⁴

- Complex issues related to posttreatment stress and anxiety due to changes in treatment effects (ie, sexual function, bladder and bowel control, and the resulting effects on self-image), as well as posttreatment expectations and intimate relationships^{19–21}
- Understanding the physical and cognitive needs of middle-aged and older men whose cognitive capacity may be not only diminished by age but also exacerbated by the stress and anxiety of coping with disease,^{24–27} as well as patients' perspectives of the disease trajectory and their corresponding need for support and information²⁸

METHODS

Evaluation of the Current CHES Module

Following a review of the literature, the development team identified major themes related to patient/partner information and support needs in an eHealth environment. Needs included the following:

- Comprehensive information about treatment alternatives
- A navigational system that was intuitive for patient use and appropriate for the range of age, education, computer literacy, and cognitive style
- Couples' support services related to sexual problems resulting from treatment
- Guidance in anticipating practical needs, taking proactive measures in managing the illness, and creating an environment of lowered decision-making ambiguity
- A simple, straight-to-the-point path to resources, including only essential content and avoiding information overload

Using these themes, the development team members evaluated the existing CHES prostate cancer Web site. The content on the existing site was considered to be generally appropriate and complete, with some updating needed to reflect changes in the field since the first CHES version was developed. Existing psychosocial tools addressing relationship and stress management were judged to be appropriate for both patients and their partners. The team identified the following gaps in information and support:

- Incomplete treatment content, with a need to expand conventional treatment (eg, watchful waiting, surgery, and radiation) to include alternative or emerging treatment modalities, such as cryotherapy and proton therapy
- A need for more detail on conventional treatment
- A need to develop a navigational system aligned with male hypermedia preferences (ie, Web site information architecture that reflects linear, brief, logical, and practical presentation of information)
- A need to ensure more complete analysis of all factors that should be integrated into decision making and to stimulate more active participation by patients in decision making and disease management

- A need for information and interactive tools to help couples collaboratively address and resolve sexual problems resulting from cancer treatment

Focus Group Selection and Procedure

In order to gain a deeper understanding of the extent of and variation in the patient/partner experience, as well as to validate the existing literature, the development team conducted focus groups to explore survivors' and partners' disease narratives against the backdrop of an illness trajectory.

The goal of the focus groups was to collect full, rich descriptions of the needs of prostate cancer patients and their partners for information and other resources. We asked the patients and partners in these groups to describe resources that could have improved their cancer experiences. We also asked them about priorities and organizational options for CHES. Participants were recruited for 5 focus groups.

All patients recruited were survivors of 6 months or more beyond treatment, and 10 of them (white men aged 57–80 years) were recruited by the primary robotics surgeon at a midwestern research hospital; in addition, 4 partners of those 10 survivors agreed to participate. Due to the absence of minority participants at that hospital, minority survivors were recruited by the primary prostatectomy surgeon at a southern cancer center; 4 African American survivors (aged 50–65 years) as well as 2 partners of those 4 survivors agreed to participate. Additional information on the prostate cancer experience was provided via 6 in-depth interviews with patients (4) and partners (2) (these were former patients recruited by their surgeon who practiced at a midwestern research hospital).

Each focus group began with an explanation of the CHES Web site and a description of the prostate cancer illness process for which they were asked to give feedback. The trajectory used was based on research done by Gray et al,²⁹ who cited 5 concern domains of managing the impact of prostate cancer: (1) dealing with practicalities, (2) stopping illness from interfering with everyday life, (3) keeping relationships working, (4) managing feelings, and (5) making sense of it all. The CHES research team translated the original 5 domains to the following 7 practical, time-linked stages: (1) needing a biopsy, (2) dealing with a cancer diagnosis, (3) treatment decision making, (4) coping with treatment, (5) posttreatment coping, (6) coping if treatment did not work, and (7) returning to “normal.” Based on feedback from initial participants, the trajectory was revised to the following 6 stages: (1) coping: dealing with a diagnosis; (2) deciding: choosing a treatment; (3) preparing: getting ready for treatment; (4) recovering: healing and adapting; (5) adjusting: sex, side effects, and more; and (6) living: the new “normal.”

Semistructured interviews were used in the final 2 groups to prompt participants to narrate their prostate cancer experiences and to compare their experiences. These participants

also provided feedback on prototypes for a diagnostic algorithm to aid treatment decision making as well as an interactive symptom-tracking calendar. Participants were then invited to post their needs for information, tools, and support on a wall-size chart of the illness trajectory. Afterward, participants collectively considered all participant contributions and were asked the following questions:

- Is anything missing from the chart?
- Is there anything that needs to be moved or located in more than one place?

Data Analysis

Comments of all participants were combined for comparison to the illness trajectory. The research team discussed emerging themes. Coding was based on the initial trajectory and emerging themes. Transcripts were reviewed by 3 members of the research team and compared for agreement.

Emerging thematic clusters largely reinforced the conclusions from the literature review. Men showed more interest than did women in being able to access specific information directly. Women showed broader interest in all topics related to the cancer experience, with more focus on psychosocial issues.

Particular thematic clusters are summarized as follows:

Computer-Mediated Environments and eHealth Resources: Patient responses included the following:

- Patients and partners preferred a bulletin board discussion format compared with blog-format online discussions. However, most partners felt that their partners would not be inclined to use a discussion group for support. Most patients indicated that, if they did participate in a discussion group, their goal would most likely be information from an experienced patient rather than emotional or psychological support.
- Patients expressed a desire for a simple, straightforward path to immediately pertinent information.
- Patients and partners expressed varying levels of involvement and comfort with the Internet. Younger men and women indicated higher levels of ease and use.
- Most patients and partners believed that the Internet provides a viable resource but wanted to be assured of information credibility.
- About half the partners reported doing Internet research for general prostate cancer information.
- Most patients reported getting their information from friends who shared the experience (a particularly valued resource), health-care providers, and books.

Psychosocial Needs: Patient responses included the following:

- Most patients disclosed that they experienced anxiety related to waiting for things to “happen” at various times throughout the prostate cancer journey.
- Although the men did not indicate a need for help or support from a discussion group, many indicated that they relied on partners, family, and friends, especially those who had experienced cancer, for support.

- Most reported relying on friends, family, or acquaintances who had “been there” (ie, already had prostate cancer) for “expert” subjective information.
- A number of participants cited communication issues with partners and other close relationships that arose during the cancer experience.

Responses from partners included the following:

- Although several partners and patients indicated that the cancer experience had brought them closer, most partners expressed some degree of frustration about their partners’ not “sharing” information or feelings. Several women had been so affected by the situation that they felt isolated from the entire process.
- Many women felt a need for guidance in bridging the unique communication problems inherent in talking about the disease, including dealing with a range of patient responses such as denial, fear, anger, depression, pessimism, mood swings, and other emotional changes. Several women wished they had talked to a survivor’s wife before their own husband’s treatment.

Content Needs: Participants who had no family history of prostate cancer indicated a need to build base knowledge about prostate cancer and associated issues, such as survival rates, treatment options, side effects, doctor selection, and insurance coverage.

Many patients and partners felt uncertain about the decision-making time frame. Some reported not being fully apprised of the watchful-waiting option. Others indicated frustration at having to choose between ambiguous alternatives. Although some wanted specific and comprehensive guidance in how to approach making a decision, many relied on the recommendations of their physicians. Several younger men felt confident that their own Internet research had resulted in an appropriate treatment decision. A number of participants reported second-guessing their treatment decisions after recovery, when the full extent of side effects was apparent.

All participants expressed a need to have full information on how the cancer would impact quality of life. Most participants reported that posttreatment incontinence and sexual function problems played out as anticipated. One spouse felt that, as a couple, they had not done enough research on incontinence prior to treatment and were not properly prepared for all possible complications. Some reported fewer problems and quicker recovery from incontinence than expected, while others felt they had encountered more problems and experienced longer recovery than anticipated. Many patients indicated the need for practical tips on how to deal with life while incontinent.

No participants reported better-than-anticipated outcomes for sexual function. Most men communicated the importance of sexual function to their self-image and quality of life. In the one group of 4 African American participants, preserving sexual function was often the primary criterion for selecting a treatment.

Among older partners, there was a reluctance to discuss erectile dysfunction and associated feelings and concerns.

Although most partners indicated that sex was important in their relationships, all regarded patient survival to be their primary concern. Partners, in particular, wanted help with sexual problems: specifically, how to get the patient to talk about sexual concerns and alternatives and helping patients get beyond anger and depression.

Most participants reported some anxiety at all stages of the illness trajectory. Feedback indicated that the trajectory presented in the focus groups was accurate and complete. Many expressed frustration and fear about not knowing what questions to ask and reported ongoing anxiety over wondering when to take action and knowing what actions to take.

Applying Feedback to Web Site Redesign

As the development team considered the thematic clusters and the typical trajectory, discussions centered on how to fill information and support gaps and adapt the existing hypermedia environment to be more conducive to male cognitive preferences, stimulate more active patient participation, encourage patients' interaction with their partners, and attend to partner support and content deficits. Existing components of the CHES Web site, such as the information library, the stress and relationship sections, and most interactive tools, were evaluated as appropriate.

Based on focus group feedback, the interactive discussion group component of the system was reexamined. The design team considered a blog format versus a discussion group forum to facilitate new patient interaction with experienced patients; however, the discussion group forum was maintained, based on feedback indicating that the blog would be a confusing way to find information, particularly for older patients. Both patients and partners expressed the importance of being able to connect with those who share the cancer experience; patients also emphasized their need for anonymity while doing so. To provide identity-protected environments, separate discussion groups were created for both patients and supporting family and friends. In these separate groups, both patients and their support providers were able to receive reassurance from other patients, exchange personal expressions of support, and maintain ongoing interactions with other patients as needed or desired. And because the groups contained patients and partners from all points in the disease experience, this eHealth intervention was particularly well suited to meet the simultaneous needs for anonymously delivered peer expertise.

Four tools were created to address patient/partner needs within the design parameters established by the team: (1) Step-by-Step, (2) Interpreting Your Diagnosis, (3) Managing Sexual Problems, and (4) an interactive symptom-tracking calendar.

The existing prostate cancer Web site featured a library-style design, with a homepage that included a topics index, cancer tips, and current research news. This approach had been successful with female breast cancer patients, who tend to prefer broader searching behaviors; but it may not have offered enough structure for many men. The approach to information seeking may have contributed to cognitive over-

load or simply frustration over having to dig down into content to find specific information.

Both patients and partners described specific information needs at each stage of the illness trajectory, as well as anxiety caused by delays in getting information, sorting through ambiguous information, not knowing what questions they should be asking health-care providers, and a sense that they were missing important action steps.

RESULTS

Step-by-Step

Step-by-Step was conceived as an alternative way to navigate the Web site, providing direct access to practical guidance and focused information that is aligned with the patient's current place in the illness trajectory. Step-by-Step appears on the homepage both as an icon in the index and as a boxed list of six links across the top of the page. A click on either brings up a dialogue box featuring illness phases on 6 tabs. Clicking on any tab will reveal the individual step's Web page, featuring a brief description of the illness phase and each of the following resources:

What to Do and Consider: This disease-related activity checklist was designed to lower user anxiety and cognitive overload by providing a concise list of responsible actions appropriate at each step of the illness. The activity checklist addressed practical issues that the patient should consider or act upon. At step 1, for example, patients were asked to consider keeping a list of questions that come up, to consider whether they were adequately communicating with their partners, and to schedule follow-up screening exams. Managing their own involvement should help patients feel a greater sense of control and confidence. For those needing more depth, direct links to deeper information are included.

Questions to Ask Yourself: These are intended to help patients monitor their mental health and to identify signs indicating the need for professional assistance. These questions also help draw patients' attention to relational issues with their partners, encouraging communication and disclosure that are particularly appropriate to that step.

Questions to Ask Your Doctor: This is a focused list of questions for each step of the disease trajectory.

Checklists and Guides: These provide direct links to specific information that is related to the step's focus. Step 2 patients, for example, are provided with links to the Watchful Waiting Web page, to help them determine whether there is an urgency to decide on treatment, and to the Optimism Resource Guide.

Interpreting Your Diagnosis

Many survivors reported that they felt unqualified and insecure about making their own treatment decisions and, consequently, that they relied heavily on their medical providers to guide or make such decisions. The literature and a number of focus group participants indicated that abdicating treatment decision making could lead to posttreatment regret.^{30,31} To better equip themselves to question possible medical provider bias and to actively participate in treatment

choices, patients needed a better understanding of the subjective nature of diagnostic tests and the criteria used by doctors for test interpretation. Patients also needed a context in which to make sense of tests and guidance through decision-making milestones. A branching concept map was developed to walk patients through the decision-making process. The map was designed to help patients recognize and think through critical decision points leading to treatment. Patients were first asked to consider their biopsy results, then introduced to an explanation of diagnostic tests. From there, patients were provided with links to the Partin tables and nomograms to assess risk. The map suggests the appropriate point at which to seek a second opinion and ends with links to a treatment-comparison table that presents options along with their pros, cons, and side effects. The map also links to a decision-making tool that evaluates treatment alternatives in relation to quality-of-life preferences. In its entirety, the map empowers patients through a systematic method of informed decision making.

Managing Sexual Problems

The pervasiveness of sexual problems following most prostate cancer treatments suggested the need for customized resources to meet the unique needs of prostate cancer patients and their partners. The existing CHES prostate cancer Web site offered standard information about posttreatment sexual function but little to assist the patient and partner in adapting to sexual changes, managing the psychological and relationship problems resulting from such changes, and rebuilding intimate relationships.

A sexual support module was developed to address the following needs:

- Removal of patient-imposed barriers to sexual change
 - Creation of the relationship resources necessary to support successful changes in intimacy, particularly methods for improving communication, enhancing other aspects of intimacy, and involving partners in decision making related to sexual function
 - Development of attitudes conducive to making successful sexual changes
 - Guidance to patients and partners in exploring alternative treatments for erectile dysfunction and appropriate sexual aids
- In answer to these needs, the team developed a suite of tools for managing sexual problems that focused on promoting communication and interaction related to expectations, priorities, and strategies to improve sexual relations.

Section 1: Roadblocks: This section addressed patient attitudes that may interfere with realistic expectations of and conscientious work toward rebuilding a new sex life. A 7-question interactive survey identified thoughts that may slow the adaptation process. Patients were asked to reframe their stereotypes of satisfying sex and encouraged to seek help when unable to make progress on their own.

Section 2: Your Partner: This section focused patients on the need to include intimate partners in the healing and rebuilding process. Patients were provided with guidance in

building compassion and understanding for their partners and for experimenting with new forms of intimacy.

Section 3: Priorities: This section was designed to help facilitate communication between partners through a 6-item interactive survey that asked them to individually identify the aspects of sex that were most important to them. Responses from both partners were gathered. A comparison report was generated to initiate discussion leading to better understanding of couples' individual perspectives and differences that need to be resolved in moving forward.

Section 4: Treatment: This section offered a comprehensive table of treatment alternatives and sexual aids. The table provides information on how treatments and devices work and which patients have the best results, as well as side effects, pros, and cons. In many cases, links were provided to photographs and/or diagrams showing what devices look like and how they operate.

Section 5: Optimism Guide: The last section of the tool was based on Martin Seligman's work in learned optimism³² and was created to give patients a simple 5-step tool to help break negative-thinking cycles that are common not only in the long recovery of sexual function but also throughout the cancer-coping process. This cognitive-restructuring exercise engages the patient in identifying negative thoughts, assessing their impact and validity, correcting false perceptions, and recognizing the benefits of removing unproductive thinking habits.

Interactive Symptom-Tracking Calendar

Many patients neglect to give providers complete information about symptoms because of assumptions made about recovery. The interactive symptoms calendar was created to encourage more active attention to and reporting of posttreatment symptoms and aimed at the early detection of recovery problems as well as improved patient recovery time and treatment satisfaction through active participation in the recovery process. The team created 2- to 3-question surveys assessing the common posttreatment symptoms: pain, urinary and fecal incontinence, and sexual function. Patients accessed the surveys by clicking on the symptom-tracking icon featured on the interactive calendar. The CHES module tracked patient entries. With a click, patients could view their symptom history for pain, bladder, fecal, and sexual function symptoms. Results could be called up by specific time periods and printed for reporting at medical appointments. In addition to improving patient reporting and involvement, the calendar was designed to lower anxiety by providing visual evidence of patient improvement over what often seems like an endless journey back to "normal."

Initial anecdotal feedback from focus group participants indicates a positive response to the new tools and structural changes to the Web site.

LIMITATIONS

Limitations of this research included the lack of participation by growing population segments, especially Hispanic and Asian patients. Future research should include a broader pop-

ulation and consider studying by whom, how, and when specific patient tools are used in comparison to more traditional resources.

CONCLUSIONS

Men dealing with prostate cancer have health information-seeking needs that are influenced by individual differences and abnormal levels of stress caused by the cancer diagnosis. These patients often avoid in-depth disease and treatment research, leaving it to their partners, even though research suggests that a patient's active involvement in addressing cancer issues results in better clinical outcomes and levels of patient satisfaction. Based on the literature and this focus group research, the CHES project team created 4 tools to improve an existing prostate cancer information and support system for a new clinical trial. Initial anecdotal feedback from system users indicated favorable response and good us-

age. Results of a forthcoming clinical trial should provide additional information on whether these design elements made a significant contribution to patient usage, self-efficacy, and/or improved quality of life.

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