Designing Tailored Internet Support to Assist Cancer Patients in Illness Management

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Abstract
This paper describes the development and a preliminary usage analysis of a novel Internet-based support system that assists cancer patients in symptom monitoring and disease management. The system, called WebChoice, allows patients to monitor symptoms over time, and provides access to evidence-based self-management options tailored to their reported symptoms as well as a communication area where patients can ask questions to a clinical nurse specialist and exchange experiences with other cancer patients. A currently ongoing randomized clinical trial evaluates effects of WebChoice on patient outcomes. This paper describes essential features of WebChoice, steps we used to design it as user-friendly as possible; and preliminary findings on patients’ use.

Key words: Internet-support, cancer patients, symptom self-management, online communication.

Introduction
Cancer patients often experience multiple physical, functional, and psychosocial symptoms and problems during treatment and rehabilitation. Failure to detect and relieve these symptoms causes considerable distress, yet short hospital admissions allow little time for symptom management support. Moreover, side-effects of treatment are often worst after the patients are discharged to home. Therefore, patients could greatly benefit from Internet-based support that can extend traditional health services into their homes to help them manage their symptoms and problems independent of scheduled hospital or doctor appointments.

Empowering patients to take a more active role in their own health care and provide them with equal access to health services and information have been declared high priority health policy goals. Internet portals are important means to facilitate this, and the widespread use of the Internet offers unique opportunities to meet these goals. Internet portals allow patients to communicate with care providers between clinical encounters, monitor their symptoms and health problems from home, can provide information to help patients better understand and manage their illness and become more engaged in their care. A recent systematic review of 24 randomized clinical trials (RCTs) on the effects of interactive health communication applications (IHCA) from the Cochrane collaboration (2007), concluded that IHCA have a positive effect on knowledge, social support, and clinical outcomes; and that it is more likely than not that they also improve self-efficacy for people with chronic disease.

An increasing number of patients are using the Internet as supplement to traditional clinician information. However, the amount of information available on the Internet can be overwhelming and the quality of online information is often questionable. To be truly useful, Internet resources should be able to address patients’ individual symptoms, problems and health concerns that can change during different stages of their illness and rehabilitation. WebChoice builds on this knowledge. In this system, patient information is based on an individually tailored symptom assessment and adapts instantaneously to patients’ changing problems and needs, as described below.

The WebChoice Application
Patients can access WebChoice from their home computer with the Internet Explorer web browser. WebChoice has two modules: one for breast- and one for prostate cancer patients, that are presently tested in a RCT with patients from throughout Norway. WebChoice contains:

1. An Assessment Section tailored to the individual patient that allows patients to elicit and report their symptoms, health problems and priorities for care along physical, functional psychosocial and behavioral dimensions, including distress and priorities for care. Using branching logic, questions are personalized to previous responses. Superfluous questions are eliminated, which allows for an expansion in breadth and depth that helps patients find a closer match between the symptom descriptions and their actual illness experiences. Patients can use the Assessment in many useful ways: to monitor improvements/worsening of their condition, prepare a hospital/care provider consultation, or obtain tailored advice from the knowledge base described below. Satisfactory reliability and convergent and discriminant validity of the Assessment Section has been demonstrated in previous studies, and the instrument clearly distinguishes between type and stage of disease and treatment over time.

2. A Self-Management Intervention Section. Patients’ self-reported symptoms trigger the display of the appropriate subset of self-management activities to choose from. Each message contains an explanation of what the activity is, how to perform it, potential risks, side effects, contraindications, when to contact a physician, level of evidence, references to the source of information from
where the evidence was obtained, and links to other relevant, reliable Web sites that contain related information. This information can be printed out for further reading; or entered into an individualized Care Plan. The knowledge base that contains several hundred options for evidence-based self-management strategies presented in patient-friendly language and is regularly updated by the information specialist team at the Center for Shared Decision Making in Oslo.

3. An Information Section where patients can access reliable Internet resources, such as information about specific tests, treatments and potential side-effects, suggestions for a healthy life style, information about patients’ rights or support groups, and more. All information in the Self-management and Information sections complies with the HON Code of Conduct (http://www.hon.ch/HONcode/Conduct.html) for medical and health Web sites that promote the highest principles for privacy, security, credibility, and reliability of information on Internet health sites.

4. A Communication Section where cancer patients can share their experiences with other patients and obtain professional support. It includes: (a) an unrestricted support Forum for group discussion, allowing users to post messages anonymously, and; (b) a Question and Answer area where patients in private can ask questions to a clinical nurse specialist (CNS) in cancer care. The CNS enters the communication area daily, and also participates in Forum discussion when appropriate.

5. In addition patients have access to a Diary where they can keep personal notes.

While components 3-5 can also be found in other Internet support systems, what makes WebChoice’s distinct from and unique compared to other systems are its two main components: (1) the tailored Assessment Section linked to (2) the Self-Management Intervention Section that allows patients to choose those evidence-based self-management options tailored to their identified symptoms and problems that are most appropriate and manageable to them.

All pages in WebChoice are based on language independent templates that are expanded at run time by separating the content from the system into separate files. The system is generic; content adjustments, e.g. to fit it to patients with different diagnoses, can be dynamically performed without making any changes to the system.

Strong security measures are implemented to protect patients’ submitted information. Norway has one of the strictest policies for processing of personal data in the world. WebChoice was one of the first Internet solutions that were allowed to give patients online access to own health information. Unfortunately, this required a very comprehensive security package that until quite recently was only available for patients using Internet Explorer on a Windows PC. However, this restriction is changing and will allow us to make WebChoice available through other browsers.

Patients are authenticated using a smart card based public key (PKI) solution. All administration is done remotely through a separate interface. The connection between the secured server and the patient is encrypted using SSL technology to protect against unauthorized access. Other procedural and technical protections are implemented, such as storing data behind an Internet firewall, robust data integrity and auditing controls, and training of staff authorized to access patient data. All procedures comply with the Norwegian Personal Data Act (equivalent of HIPAA).

Developing WebChoice as a User-friendly Application

When designing Internet support for seriously or chronically ill patients such as WebChoice, it is crucial to provide content that patients perceive useful and easy to understand, and that the interface is user friendly. To assist us in this task, we conducted a series of focus groups with end-users, expert reviews and iterative usability tests.

Focus Groups. Focus groups were conducted early in the design process. Participants were recruited from the Norwegian Cancer Society’s breast and prostate cancer interest groups. Using a semi-structured interview guide, participants were asked about their information needs during different stages of their illness from diagnosis through treatment and rehabilitation; perceived information gaps and barriers to obtaining adequate information; patients’ choice of resources when looking for information and support; desired level of detail and comprehensiveness; communication needs with health professionals and other patients; perceived barriers to and benefits of using the Internet to find support for managing their illness; and feedback on proposed WebChoice components. The focus groups provided important feedback that resulted in adjustments and added functionality of WebChoice, such as more differentiated reports. Based on patients’ requests, WebChoice now contains three types of reports: a trend report that visualizes distress of patients’ reported symptoms over time that patients can self-select for display; an assessment summary that ranks patients’ reported symptoms by their priority for care to aid communication with health care providers and keep a focus on those symptoms that are most important for the patient; and an individualized self-care plan that summarizes those self-management activities patients have selected to alleviate their individual symptoms. In addition, the Diary function was added, as well as more detailed information patients requested about social benefits one may be entitled to.

Expert Reviews. Two usability specialists were asked to perform an expert review on WebChoice. This involves an evaluation of a website in terms of its consistency with established usability principles, known as heuristics. An expert review usually entails a structured walkthrough of typical tasks; analysis of interface architecture; critique of detailed design issues, including page layout, controls, color, wording; and a prioritized list of selected and specific recommendations for design changes. Expert
reviews are particularly valuable at an early design stage. Many usability problems can be identified and fixed before the system is tested with real users.

The two specialists used the 10 usability principles for user interface design defined by Nielsens’s as framework to evaluate WebChoicee. They came up with 35 recommendations for improvement that were subsequently implemented to improve WebChoice’s interface.

Usability Testing. When an early version of WebChoice was ready, we started repeated usability evaluations with a small sample of intended end users. This is an iterative process that involves testing the system and then using the test results to change it to better meet users’ needs. Test participants were recruited from the Norwegian Cancer society’s interest groups. We made sure that testers represented varied end-user characteristics such as age, level of education and previous computer experience. Sessions were videotaped. We used Morae™ software for automatic recording and analysis of all events on the screen, such as when the user clicked a link, pressed a key, opened a dialog box, or viewed specific text. The usability tests identified several weaknesses in the design, and resulted in interface adjustments to allow more flexibility to patients, e.g. the ability to search for individual symptoms and a better overview to find detailed information. Our attention to user-friendliness seems to have paid off; after WebChoice has been implemented, very few patients’ phone calls to the technical support line are related to usability problems with the interface.

Patients’ Use of WebChoice: Preliminary Results

The WebChoice application is currently being tested with 320 breast and prostate cancer patients from throughout Norway who so far are recruited into RCT and are followed with five repeated measures over one year. In this paper we report patterns of use of WebChoice for patients in the experimental group during the first eight study months. Patients are recruited to the study through adverts in News papers, on the Norwegian Cancer Society’s website and its membership magazine, as well as through information pamphlets mailed to patients from the Norwegian National Cancer Registry. The study is approved by the IRB. Inclusion criteria are: (i) undergoing treatment for breast- or prostate cancer; (ii) above 18 years of age; (iii) able to speak and understand Norwegian, and: (iv) Internet access at home.

An activity log provides details of all server traffic for each user. Two summary reports are generated from these activity log data to provide statistics of use patterns: (1) a Usage Report providing information about system activity within a certain period of time, such as the number of users who logged on the to system, how many visits different sections of the system attracted, the total duration spent in these system sections, how many messages were submitted to the Forums; (2) a User Report providing information about each patient’s use of the system, such as the number of visits to each of the sections, visit durations, the number of assessments made as well as the number of messages, posts and diary notes written.

While the study is still ongoing and final reports must await further investigations, interesting usage patterns have started to emerge from these summary reports and preliminary content analyses of patient’s messages in the communication area.

Our preliminary usage analysis contains data from 43 women and 31 men undergoing treatment for breast- or prostate cancer who logged on to the system at least once between March-October 2006 (constituting 71% of study participants in the experimental group with access to WebChoice). The mean age for breast cancer patients with access to WebChoice is 50 years (SD=7.6) and for the prostate cancer patients 67 years (SD = 7.7).

Measuring usage patterns of internet-based information and support services can be a complex process. In our usage analysis of WebChoice, use is measured by “visits” to different sections of the system and the “duration” of these visits. A “visit” indicates simply that a user has entered this particular section and does not correspond to the user’s actions in this section. In other words, even if a user views several web pages or makes several web server requests within, say, the Information section, this is still only counted as one “visit” to the that section.

Intensity of use is indicated by the time spent in a section of the system during a visit, i.e. “duration”. Gustafson et al note that “this measure is complicated because we do not know whether a person is using the site for those minutes or eating lunch” (p.1461). If you simply count duration as the time spent from entering a section until leaving this section you run into the related problem that some users do not log out of the system after visiting a section. We have attempted to minimize these problems by using a “maximum duration” rule when generating statistics for the Reports from the activity log: If a user when visiting a section has not made a web server request in the last 20 minutes the visit is “aborted” in the Report and ten minutes are added to the duration for this visit since the last web server request. This is because most usage consists of reading information – an activity which cannot be logged.

We examined different use of the Forum, Messages, Diary, Assessment, Information and Intervention sections of WebChoice. Study participants with access to WebChoice visited sections of the system a total of 4,993 times during the eight-month period from March to October 2006 for a total duration of 489 hours and 26 minutes, averaging 5.88 minutes per visit. Table 1 provides an overview over use of the main WebChoice sections from March to October 2006 and for one representative week during this period.
of use 8. 50% of study participants with access to have a better overview over the users who logged on to representative week during this longer period when we therefore also looked at the system level use for a system; at the end of August 62 users had logged on. We during this eight-month period, with more users later in ongoing since March 2006, the number of users increased study participants (and hence (58% of women who logged on to WebChoice users) has been March and October 2006. Because the recruitment of study participants and hence WebChoice users) has been ongoing since March 2006, the number of users increased during this eight-month period, with more users later in the year. At the end of May 20 users had logged on to the system; at the end of August 62 users had logged on. We therefore also looked at the system level use for a representative week during this longer period when we have a better overview over the users who logged on to the system - what Brennan et al calls a “snapshot view” of use. 50% of study participants with access to WebChoice logged on to the system at least once during the week from 14th August to 21st August 2006 (16 out of 32 female users and 12 out of 24 male users).

Both breast cancer and prostate cancer patient users visited the Forum more often and spent more time in the Forum than any other section of WebChoice. These findings are congruent with usage reports of other computer-based systems, highlighting the popularity of the system’s communication areas.

### Online communication

Postings in the Forum section and messages in the “private” communication area to exchange messages with the CNS can provide important insights about patients’ communication online. While a few studies have analyzed online messages between patients and physicians, online patient-nurse communication and the potential for nurses to support patients via the Internet is as of yet largely unexplored. Furthermore, little is still known about gender differences in the use of online discussion groups. We therefore examined all forum postings from the 43 women and 31 men undergoing treatment for breast- or prostate cancer who logged on to WebChoice at least once during that period, resulting in a total of 355 postings and 174 e-mails to the nurse. Our preliminary content analyses (1) compared the content of patient-nurse messages to messages posted on the forum and (2) explored gender differences in messages submitted to Forum during March - October 2006.

<table>
<thead>
<tr>
<th>Mar-Oct06 (8 months)</th>
<th>14th to 21st Aug06 (1 week)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WebChoice Section</strong></td>
<td><strong>All users (n=74)</strong></td>
</tr>
<tr>
<td>Forum</td>
<td>2629 (7.84)</td>
</tr>
<tr>
<td>Messages</td>
<td>707 (4.48)</td>
</tr>
<tr>
<td>Assessment</td>
<td>626 (2.02)</td>
</tr>
<tr>
<td>Interventions</td>
<td>396 (4.01)</td>
</tr>
<tr>
<td>Information</td>
<td>357 (3.06)</td>
</tr>
<tr>
<td>Diary</td>
<td>278 (5.93)</td>
</tr>
</tbody>
</table>

74 users logged on to WebChoice at least once between March and October 2006. Because the recruitment of study participants (and hence WebChoice users) has been ongoing since March 2006, the number of users increased during this eight-month period, with more users later in the year. At the end of May 20 users had logged on to the system; at the end of August 62 users had logged on. We therefore also looked at the system level use for a representative week during this longer period when we have a better overview over the users who logged on to the system - what Brennan et al calls a “snapshot view” of use. 50% of study participants with access to WebChoice logged on to the system at least once during the week from 14th August to 21st August 2006 (16 out of 32 female users and 12 out of 24 male users).

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### Comparison between messages submitted to the nurse and the forum.

While the forum was the most visited section in WebChoice, more patients wrote at least one message in the patient-nurse communication area (n=45 or 61% of WebChoice users) compared to those submitting at least one posting to a forum (n=34 or 46% of users). This holds true for breast cancer patients as well as prostate cancer patients. 72% of female users sent at least one e-mail while 58% submitted at least one posting, and 45% of male users sent an e-mail to the nurse while 29% contributed to the forum. However, patients submitted on average more postings to the forum (mean=10.4, SD=10.5) compared to e-mails to the nurse (mean=3.9, SD=4.6).

### Gender differences in postings submitted to Forum.

More women submitted at least one posting in a Forum (58% of women who logged on to WebChoice between March – October 2006) compared to the number of men who submitted at least one posting (29% of men). Female users also posted on average more messages in the Forum (mean=11.52, SD=11.82) compared to e-mails to the nurse (mean=7.4, SD=5.00), totaling 289 postings from breast cancer patients and 66 postings from prostate cancer patients in the eighth-month period examined here. These postings were coded according to response categories in Klemm et al’s coding scheme. Table 3 below shows the number and percent of postings in each category. Because postings could contain more than one response category, the sum of categories is greater than the number of postings.

### Table 3: Response categories by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Personal experiences</th>
<th>Information giving</th>
<th>Information seeking</th>
<th>Support</th>
<th>Thanks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (n=31)</td>
<td>66 postings</td>
<td>19 (29%)</td>
<td>12 (18%)</td>
<td>14 (21%)</td>
<td></td>
</tr>
<tr>
<td>Female (n=43)</td>
<td>289 postings</td>
<td>53 (18%)</td>
<td>64 (22%)</td>
<td>49 (17%)</td>
<td>16 (6%)</td>
</tr>
</tbody>
</table>

Personal experiences, such as telling about their illness and treatment history, was the most frequently used message type for both men and women, which is consistent with findings reported by Klemm et al. Contrary to Klemm et al’s study, however, women in our study were more information giving (e.g. sharing personal knowledge with others) than men, while men were more information seeking (e.g. asking others about their experiences). Both gender groups were equally supportive of each other, but men were more often thankful in their responses than women. It is of course possible that these differences relate not only to gender but also to diagnosis and age. Considering that breast cancer treatment is more standardized than treatment for prostate cancer, the finding that men were more information seeking and less information giving than women might be related to the diagnosis as well as potential gender differences in communication style.
Discussion

WebChoice applies several, innovative mechanisms to strengthen patients' knowledge and illness management skills, and to provide them with individually tailored, just-in-time information and peer and professional support from their homes at the point and time of need. Preliminary results suggest that WebChoice successfully meets the needs of cancer patients with high levels of usability and use, regardless of age or previous computer experience.

Active WebChoice use by 71% of the participants in our study is consistent with other studies as are the findings about the popularity of WebChoice's communication functions. Our study reveals interesting gender differences in number and types of messages submitted by breast cancer compared to prostate cancer patients that have not been much explored earlier. However, as diagnosis, treatment and average age differ between these two groups, more research on online communication among patients with less gender specific diagnoses is needed to explore this further. Another important issue to address in future research is the extent to which topics patients bring up for discussion vary across culture.

The fact that more patients submit messages via e-mail to the nurse as compared to the Forum, and that the nature of these messages in different communication areas differ, provides new insights into online nurse-patient communication and the role nurses can play to support patients over the Internet. WebChoice allows nurses to reach patients not previously reached by traditional health services. Most of the questions patients asked did not require a physician to answer, but could appropriately be addressed by the CNS. Since unanswered questions and concerns often are an important reason for scheduling a doctor’s appointment, this suggests that nurse-provided communication and advice through the Internet may have a potential to reduce unnecessary office visits as well as needless suffering and worry. Future research should address these effects. As cost concerns and shortages of health professionals continue to rise, online peer- and professional support provided by nurses could prove a viable health care supplement that can improve delivery of high quality patient care in the future.

The use patterns identified in this study provide important information for further improvements and are useful indicators of which features of the WebChoice system patients perceive as particularly useful. We have received feedback from several users that different features of the system are useful at different stages of the disease. For example, newly diagnosed patients are frequent users of the information component, while recidivist or patients with long illness experiences are particularly active in the communication forum. This is awaiting further analysis.

While any firm conclusions must await study completion, preliminary results are promising that WebChoice can make significant contributions to improve symptom self-management, symptom distress and quality of life, and emotional well-being of cancer patients. In addition, this study provides unique insights into cancer patients' information and communication needs that are important for the design of effective support interventions.

References