Meeting Cancer Patient Needs: Designing a Patient Platform

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Abstract

Cancer patients have a variety of unmet informational and support needs. Yet to date, online cancer resources only address a small number of these needs. The goal of this project, *kanker.nl*, is to address the changing needs of Dutch cancer patients for both information and support. *Kanker.nl* is a novel collaboration between institutions that provide complementary patient services: a major cancer charity, patient organizations and comprehensive care centers. To design a platform that is both innovative and useful to patients, we conducted a series of design research studies with patients including focus groups, interviews and surveys. Results suggest a demand for this type of platform, openness towards sharing medical information anonymously, and the inherent complexity of information searches in this environment. Based on these findings, we present an interactive prototype and proof of concept.

Keywords

Health 2.0; online community; design research

ACM Classification Keywords

H5.m. [Information interfaces and presentation (e.g., HCI)]; H.5.2 [User Interfaces]; J.4 [Social and Behavioral Sciences]; L.6.1 [Virtual Community];

General Terms
Experimentation; Design Research

Introduction
There are over 2.2 million people living with cancer in the European Union. As people live longer, the lifetime cancer risk rises [1]. In cancer, cells begin to divide uncontrollably crowding out other health cells. Cancer is not a single disease but rather a group of over a 100 diseases with most of them named according to the organ or type of cell in which they originate [2]. Although different cancer types result in different outcomes, many of the same treatments are used across cancer types such that people with different types of cancer may have overlapping experiences.

People living with cancer have changing needs for information and support over time, yet the formal health care system generally fails to meet them. In this project, we explore how a health 2.0 patient platform can supplement formal care to address currently unmet needs. Research documents a variety of unmet needs for cancer patients including psychological support [3], managing practical problems related to daily living and providing information about genetics and the disease itself [4] with needs changing over the course of treatment [4].

Websites and patient-communities have been shown to address the concerns that researchers have identified as unmet needs for cancer patients. For example, in online discussions, patient communities provide a combination of medical information and support to one another [5]. Online forums appear to benefit the psychological and emotional state of users, helping people feel more in control of their condition,

empowered and able to participate in health care decisions [6, 7 & 8]. And, in online communities patients help one another cope with day-to-day management issues [9].

Although the needs of cancer patients are well studied and the opportunities suggested by online tools known, cancer platforms to date have not addressed the dynamic and diverse needs of patients. Current sites either provide medical information or peer discussion – not both. The goal of Kanker.nl is to create one unified web platform that harnesses both types of expertise, layering the expert perspective (often associated with web 1.0) and dynamic community (a web 2.0 methodology) together.

In this project, we propose and test the ideas of a unified patient platform. This program is a unique collaboration between patient organizations, a large cancer charity and institutions that collect outcome data on cancer patients, with each type of organization providing complementary expertise and resources to the project. The vision for the platform is based upon previous research findings, discussions with the parent organizations and insights developed within the core team. But, this vision is only a beginning. To achieve the project's goals, we have begun project development with design research starting with exploratory work in the area of needs and preferences and then moving on to participatory design sessions to test the core ideas of the platform. In this paper, we present the findings of this research as well as the resulting prototypes. We are currently conducting feasibility studies and began active development in January 2012.

Project Participants

The kanker.nl program is a collaboration between three Dutch entities: comprehensive care centers that run cancer registries, collect outcome data on cancer patients and optimizes cancer care (IKNL, or Dutch Comprehensive Care Center); the umbrella organization for 25 cancer patient organizations (NFK, Dutch Cancer Patient Federation); and the main cancer charity in the Netherlands that organizes campaigns, educates the general public, and funds research (KWF, or Dutch Cancer Society). This national collaboration is unique in that it brings together patients and professionals with complementary expertise and resources.

Through these partner organizations, we have access to both expert-generated information and knowledgeable patients interested in participating in peer-to-peer knowledge sharing. *Kanker.nl* will integrate these types of expertise together, layering patient knowledge and insight on top of the expert-generated clinical information. The result will be a platform for all cancer patients to tag and store articles, recommend information, discuss content in groups and receive tailored vetted information.

The goal for this phase of the project is to design a platform that is both innovative and meets the needs of users. In the development process, we are balancing the goals of building platform with particular characteristics and developing a user-centered design. We do this by designing the platform along with people directly affected by cancer in a process we are calling DWUNFU, "design with us not for us".

In interviews, focus groups and a survey, we asked potential users for feedback to help us in the design of the system. We covered the following types of functionality: 1) personal profile, privacy and sharing; 2) expert-generated information; 3) user-generated information and support; 4) matching and connecting with other members; 5) discussion groups and blogs.

Methods and Procedures

In the first stage of our design research, our goal was to better understand our potential users. We conducted semi-structured interviews of patients and ex-patients and covered topics related to the core site functionality. We also asked people about needs, Internet use, privacy concerns and how they describe their experience. We interviewed 12 people with different types of cancer (7 women) average age of 46. All of them had experience with the Internet, most with social media (75%).

To inform the design of particular functionality of the site, we then held a series of five focus groups – four with people diagnosed with cancer and one with immediate family members of cancer patients; a total of 26 people participated (5-8 per group, 14 women, mean age 49). In each focus group, we discussed ideas for the site and did short activities including creating a summary profile, ranking functionality of the site and designing a personal homepage. Each activity was run in two groups.

In order to contextualize our qualitative findings within a large population, we conducted a survey with 534 respondents (304 men, mean age 61).

Results

In the sections below, we present results by theme.

Medical information

Consistent with previous research, our survey found that being closer to diagnosis, older and male are all associated with increased information needs [e.g. 10]. Focus groups and interviews were consistent with survey findings; participants discussed searching for information particularly around the time of diagnosis. In design sessions, older men asked for information-oriented site functionality more than women and women tended to be interested in both information and making connections through the site. We expect that different types of users will access different functionality of the site.

People in interviews and focus groups express frustration in finding the information that they want amongst information online. People found existing Dutch language sources fragmented and difficult to navigate. One expert patient describes how he addresses this problem by regularly recommending helpful articles to other patients. This behavior of vetting and recommending information will be integrated into the site design.

Experiential information

Participants expressed interest in reading and sharing experiences, particularly with those who have the same tumor type. Most participants want a combination of medical and experiential information. The proportions vary by person. Juxtaposing the expert and user-generated content in a clear way will be a central design challenge for the site.

Seeking and Avoiding Information

Focus group participants and interviewees expressed conflicted feelings about information seeking. Although people want to know about their conditions and the experiences of others, they also want to protect themselves from negative information. Many people had come across information online that upset them. In some cases, individuals stopped seeking information altogether for fear of coming across disturbing content. Focus group participants talked about the importance of timing; participants want to choose when and if they see certain types of information or read negative stories. In most affected families, relatives were more open to reading information even when the person diagnosed was not. Although more research is needed to understand the complexity of information seeking and avoidance, it was clear that information, particularly negative information, should not be presented by default to users. Participants want control such that they can decide what to read and when.

Tailored information

Partially because of the sheer amount of information online, participants were interested in the idea of personally tailored information. Unfortunately, it was not clear for patients exactly how to tailor the information. Previous research suggests possibilities but findings on information avoidance suggest that users should have the ultimate control of what information they see. We will test different strategies in A/B testing.

Support and Online Discussion

Interviewees and focus group participants, even computer savvy individuals, had mixed feelings about health forums. They found that forum users were

unkind to each other. As a result, they stressed the need for moderation of discussions. Participants also requested ways to search through discussions.

Profile, Privacy and Matching
We conducted design sessions in which participants wrote out the qualities they would most likely to want in a profile. In subsequent work, we asked focus group participants and survey respondents about privacy and sharing data.

When designing a profile for the site, participants want to know medical information, including tumor type, role on the site (patient, family member, researcher), treatment phase (including treatment status, treatment history and diagnosis date), and not personal or lifestyle oriented information. Participants also wanted to know where other members received treatment to compare experiences.

Similarly, when participants, reported on privacy in the survey, they were more willing to share medical information (e.g. tumor type, diagnosis date, etc.) than information about their lives (e.g. work experience, number of children, etc.). In addition, respondents want to share experience, but they want to do so anonymously; participants do not want their medical history linked to their last name or specific location, particularly among younger people reentering the work force.

Matching and connecting
Kanker.nl will match members with one another. Our results here indicate that being younger, female and active online is associated with more interest in matching. People who use social media were more

interested in also connecting on *kanker.nl*. But connecting on this site is not social, participants preferred the term "connection" over "friend". The appeal of matching and connecting on the site was to combat feeling alone; the site could show there are others in a similar situation.

Survey respondents want to be matched according to medical and demographic information, with tumor type being the most important feature, along with phase of treatment and time since diagnosis. Other lifestyle-oriented information – living institution and family situation – was important, although less so.

The results of the findings have been integrated into a prototype that would be the focus of the poster (Figure 1 below).
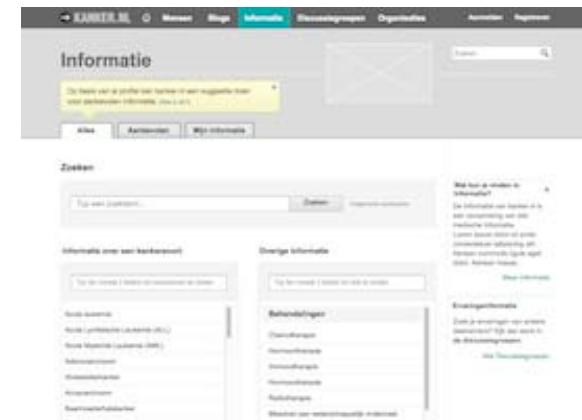
Figure 1. Prototype screenshot of the site's information section. Users will have immediate access to their choice of information: all available information, tailored information, or articles they have bookmarked themselves.

Conclusions

Kanker.nl will be a patient platform that delivers tailored medical information and hosts peer-to-peer discussion for all types of cancer patients and their families. In doing so, the site will allow for matching patients, recommendation of relevant information, cross-tumor discussions and crowd sourcing around medical information. In order to design a platform with the best chance of being useful to people in different situations and different stages in treatment, we have conducted a set of studies using converging methods. The research suggests the need for such a platform, a desire to share medical information and insight and interest in accessing the experience of others. The research also highlighted challenges in design including providing the right amount and type of information and giving control to patient members. We will continue to address and refine our design by developing and testing prototypes and early product iterations.

Acknowledgements

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