

Catalyzing Social Support for Breast Cancer Patients

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ABSTRACT

Social support is a critical, yet underutilized resource when undergoing cancer care. Underutilization occurs in two conditions: (a) when patients fail to seek out information, material assistance, and emotional support from family and friends or (b) when family and friends fail to meet the individualized needs and preferences of patients. Social networks are most effective when kept up to date on the patient's status, yet updating everyone takes effort that patients cannot always put in. To improve this situation, we describe the results of our participatory design activities with breast cancer patients. During this process, we uncovered the information a social network needs to stay informed as well as a host of barriers to social support that technology could help break down. Our resulting prototype, built using Facebook Connect, includes explicit features to reduce these barriers and thus, promote the healthy outcomes associated with strong social support.

Author Keywords

Health Consumers, Social Network, Participatory Design

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. J.3 [Life and Medical Sciences]: Health.

General Terms

Design

UNDER-UTILIZATION OF SOCIAL SUPPORT

Social support is a critical ingredient to physical and mental health when facing cancer care [13,18]. However, social support does not magically appear, and people are reluctant to ask for help—even when they need it. Ironically, social networks are often ready and willing to provide help. Psychological research shows that people significantly underestimate the willingness of others to help [8]. Central to these underestimations is that people place a high weight on the burden of the request on potential helpers [7,8,15]. However, these weightings often occur without explicit information from the social network. Thus, we are faced with a situation where patients need help and have a social

network that wants to help, but useful helping is not occurring to the extent that it could.

RELATED WORK

Social networks must be aware of a cancer patient's situation in order to offer help appropriately. The importance of this network was highlighted by a study of prostate cancer patients. These researchers advocate creating communication technology that does not simply view the clinic to patient relationship, but puts the patient at the center and acknowledges that the clinic is one of many channels of communication, along with friends and family [24]. Technology to support the widespread dissemination of health information within a social network has not been studied in research communities, but has arisen through grassroots effort in the form of a few websites. CarePages [3], theStatus [23], and CaringBridge [4] provide places for patients to both inform their social networks, by posting messages or other content, and receive messages of support from these networks. These tools help keep the social network informed, but are not designed to catalyze or manage helping activities. Instead, these tools function mostly like a blog, which both allows patients the freedom to post in whatever format they choose, but also might overwhelm a patient who is uncertain about what to post. The privacy features on these sites either give permission to see everything or nothing; they do not have any granular privacy controls. Beyond these existing ways for a patient to update their social network, a website called LotsaHelpingHands does provide ways for patients to ask for help from their friends and family [17]. A coordinator can work on behalf of the patient to create the helping community; coordinators can request help that members of the community can see and sign-up for. We applaud and support these existing grassroots websites that support sharing health information within a social network and requesting help for a patient. These efforts did not emerge based on research or on business efforts, rather these services are all provided free to patients.

Although the research community has not delved deeply into the role technology should play in the social support of cancer patients, new research is emerging on the many needs technology can fulfill. Hayes et al. studied the experience of being a cancer patient and identified ways that pervasive technology could help in this increasingly chronic care setting [11]. Related to our research, Hayes et al. identify the potential impact flexible mobile capture

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Figure 1. a) Group 1 discussing design ideas b) Group 2 creating paper prototypes c) Participant sharing her design journal

could have on a cancer patient's ability to update their social network with text, audio, or pictures. Taking another broad look at the activities and needs of cancer patients, Pratt et al. describe the need for technology to support breast cancer patient's Personal Health Information Management needs [21]. Patients collect many kinds of health related information and use this information to play an active role in their cancer treatment.

In a related vein of work, the strong push for Personal Health Records (PHRs) will also impact, and could nicely complement, the technology we propose developing. In the United States a massive push is underway to develop and deploy Electronic Medical Records (EMRs) in doctor's offices and hospitals. Accompanying this is the opportunity for patients to have these electronic records available to them as well. The idea behind a PHR is that a patient should be able to electronically pull copies of their medical records from every provider they visit to create a complete medical record [14]. Although PHRs have been widely envisioned to support a single user, two newer PHRs include features that enable users to share their medical records. Microsoft's HealthVault has sophisticated privacy features that allow users to decide who has read or write access for every part of their record [12] and Google Health allows users to share read access on their entire record [9].

Research into the ways existing social software could impact patients is also revealing promising new directions. Self-help bulletin boards for breast cancer patients have been shown to decrease depression and promote growth and psychosocial wellbeing [16]. Discussion boards and forums are used by breast cancer patients to exchange information and share their experiences. Research has shown that these exchanges go beyond emotional support and also include informational and instrumental support from patients who develop expertise as they go through treatment [5]. Finally, other researchers are working within the cancer community to use the power of social networking and tagging of information to find new ways to connect patients with needed community resources [25].

There is a diverse landscape of emerging technologies for health consumers, yet researchers are just beginning to examine how health consumers can best be supported. Our

motivation for conducting this research is to first, understand more about what sharing and collaborating patients want to do with their social networks and then second, how technology should support these needs. One option for this research would have been to start by studying an existing system, but we wanted to know more about what the underlying needs of breast cancer patients are as well as how they would design for themselves without constraints. The findings from this research both motivate the need for the existing systems, and describe how this technology could evolve to better support breast cancer patients and their social networks.

PARTICIPATORY DESIGN METHODOLOGY

We used Participatory Design (PD) to create technology that would increase utilization of social support for breast cancer patients. PD is a methodology for designing collaboratively with users and is based on the principle that both system builders and users have valuable skills and knowledge to contribute to the design process [10]. Working with participants on the design of a new system serves two primary purposes. First, the systems we design with participants better reflect users' needs and values. Second, the design process helps us learn more about the people we are designing technology to support.

For these reasons, we are committed to including breast cancer patients and survivors in the design process. However, we have struggled to find a balance between involving participants in the design process and not overly burdening them. Instead of asking participants to work with us for many months throughout the design process, we have asked for a shorter commitment from a larger number of participants. This approach is consistent with other PD efforts in the health domain [1], and it allows people to participate who would not have been able to commit to longer-term involvement.

During this research, we created and collaborated with two design groups of breast cancer patients, survivors and close friends. Each group met three times for two-hours each time, with one week between meetings; the two groups were separated by 2 months. To compensate for this shortened engagement with participants, we have been careful to leave channels of communication open with past

Design Group 1	
Meeting 1	<ul style="list-style-type: none"> • Discuss topic of sharing health information • List ‘types of health information’ you might share • List ‘people to share with’ (became ‘people who help’) • Individual design work: <i>What to show on a secure webpage for friends and family?</i> • Share designs with group and discuss ideas
Meeting 2	<ul style="list-style-type: none"> • Discussion sharing scenarios and concerns: <i>Accuracy, personal relevance, and improvements</i> • List ways others can be involved • Prototype and discuss mock-up of meeting-one design
Meeting 3	<ul style="list-style-type: none"> • Review & iterate on mock-up of meeting-2 design • Discuss permissions and sharing through examples
Design Group 2	
Meeting 1	<ul style="list-style-type: none"> • Present idea for helping system • Discuss asking for and offering help: <i>Discuss how this could be done through a website</i> • Add to Group 1 list of ways to help • Review & Critique asking for help webpage prototype
Meeting 2	<ul style="list-style-type: none"> • Re-design process for requesting help and review other designs prototyped at home between sessions • List descriptors about healthy helping community • Discuss and prototype status indicator idea
Meeting 3	<ul style="list-style-type: none"> • Deep discussion of barriers to asking for & receiving help • Specify functionality for proxy and coordinator roles • Prototype homepage: calendar & people-centric interfaces

Figure 2. Meeting agenda of activities for two design groups

participants, including sending out a newsletter and soliciting feedback as our work develops.

We recruited participants through flyers, emails, and online postings and compensated participants \$110 for attending all three meetings. The meetings were videotaped and we photographed and kept copies of artifacts generated during the sessions.

We roughly followed a future workshop flow with each group. Future workshops involve describing and critiquing the current way of doing things, envisioning how the system could work better, and finally designing a new system [10]. During the envisioning and designing activities, participants used paper prototyping to describe their design ideas individually between sessions and as a group (see Figure 1a&b). One successful approach to brainstorming was collaborative list-making (e.g. list of people who help, list of ways to help, list of health information to share). To facilitate different styles of

interaction, we provided opportunities for both group collaboration and individual work time. Between sessions, the research team mocked up the group’s ideas and implemented some of the designs as a Facebook Connect web application. We shared these prototypes with the group to further iterate on the ideas. We also asked participants to do about an hour of homework between sessions and gave them a design notebook where they were encouraged to record ideas to discuss at the beginning of the next meeting (see a participant’s notebook in Figure 1c).

Design Group 1: Sharing and Collaboration

The first design group included two members of our research group and four external participants. The external participants included one woman currently being treated for breast cancer and three female breast cancer survivors. Participants’ ages ranged from 58 to 77, and all four were regular computer users. The women in this group had been, or were being, treated for stage 1 or 2 breast cancer. Three participants were college graduates and the other was a high school graduate.

We intended to have the first design group focus on the topic of sharing and collaboration between breast cancer patients and their social networks. The group worked on designing a secure webpage where a cancer patient could post content for their social network. Although existing technology offers similar functionality [3,4,23], the group was not familiar with this technology and started with a blank slate. We chose not to begin by introducing them to the existing technology because we did not want to influence participants’ priorities or constrain their ideas. As the group progressed, the priorities of the participants led to a much greater emphasis on how social networks can help breast cancer patients, rather than the planned sharing and collaborating focus. Figure 2 describes the activities we did with the design groups during each of their three meetings.

Design Group 2: Helping

The second design group included two members of our research group and five external participants. The participants included four female breast cancer survivors, and one woman who was close friends with a breast cancer patient. They were between 47 and 57 years old and used computers regularly. Four participants were single, and three had obtained college degrees. All four of the survivors had been treated for stage 2 or 3 breast cancer.

The second design group was assembled to iterate on design ideas generated by the first group and iterated on by our research team. The group focused primarily on creating a system to support social networks helping patients during breast cancer treatment. The activities we did during each of the three meetings are listed in Figure 2. Design Group 2 began with a more narrow view of the problem we wanted to tackle, and we used artifacts and lists from Group 1 to confirm and add to our findings about the problem. We showed them our initial idea of an online system where patients can request help and members of their social

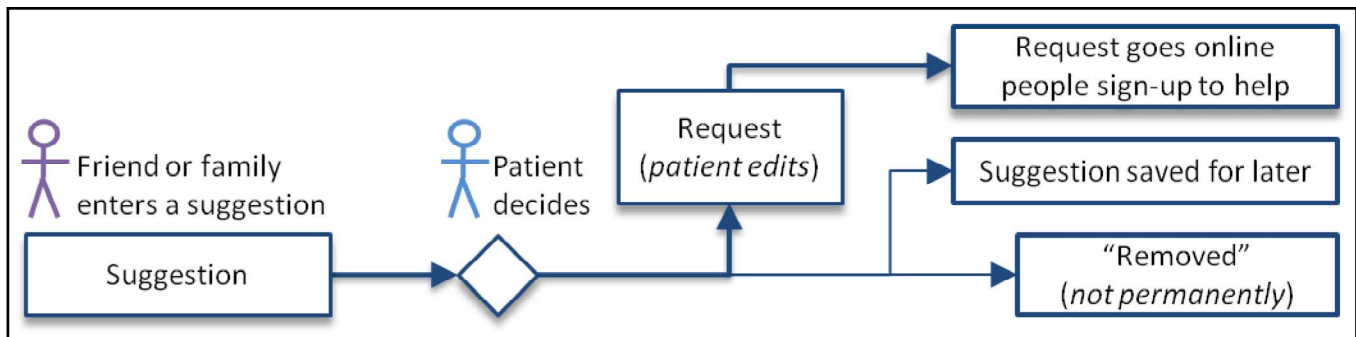


Figure 3. System for soliciting help from a social network. The process can begin with a suggestion from someone else or be initiated by a patient asking for help.

networks can sign up to help. Our high-level model of requesting and offering help is shown in Figure 3.

We described the system we envisioned in terms of Sally, a fictitious breast cancer patient who was recently diagnosed and will need help after her upcoming surgery. Sally creates a profile in the system and sends her friends and family a link to the system, where she will grant them permission to see her content. Sally's surgeon advised her that she would have limited mobility in her right arm for a few weeks after surgery, so Sally enters a help request online asking for someone to vacuum her house once a week for a few weeks. Her friend, Marsha, signs up to do the first week. After considering Sally's surgery, Marsha suggests that Sally might also want to ask for help walking her dog. Having already talked to her husband about being the dog-walker for a few weeks, Sally declines Marsha's suggestion.

RESULTS FROM PARTICIPATORY DESIGN

The participatory design sessions yielded two types of results. First, we gained a better understanding of how sharing, collaboration, and helping within social networks presently works, what difficulties are inherent in current practice, and how the situation could be improved. Second, we designed technology to overcome the current difficulties and enable the participants' visions of how social networks could both be kept up to date and provide useful help to a patient. We begin by describing what we learned about sharing, collaboration, and helping between breast cancer patients and their social networks. We follow this with the designs the two groups created to improve the way breast cancer patients collaborate with their social networks.

Who Helps

During the first meeting with Design Group 1, we created a list of everyone with whom a cancer patient might share health information. Driven by participants' responses, this activity quickly changed into creating a list of everyone who does helpful or supportive things for a cancer patient. During this design activity, they also began listing things people can do to help a cancer patient. Figure 4 shows a picture of the list of people created during the first meeting. The group listed family, friends, professional connections, other patients and survivors, oncology professionals, and

many other examples of people who might receive information related to their cancer. Design Group 2 had a similarly broad view of the people who might be involved in helping or receiving cancer-related information. Each individual shared different amounts and types of information with different people and anticipated the need to continue this pattern with the technology they designed.

The Value of an Informed Social Network

Given the opportunity, a social network can do many things to help a breast cancer patient. A large list of specific ideas, generated by both groups, is available in Figure 6. The benefit of a helpful social network is difficult to overstate. Members of the design group recognized that during their cancer treatment there were things they were incapable of doing for themselves. At doctor's appointments, *"I brought my friends because they brought along their pad and pencil and they actually asked questions while I sat there looking at the doctor. All I could think about was, 'oh my god, this is what I have.' I mean, I was thinking about totally opposite things, you know, 'What am I going to do? How*

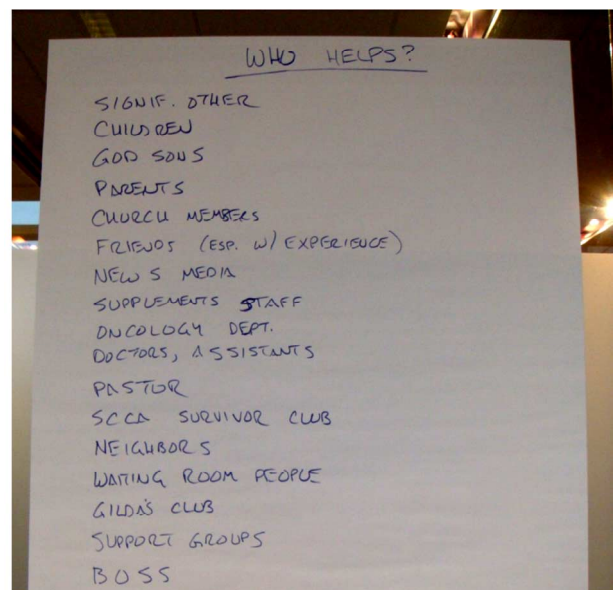


Figure 4. Design group 1's list of people who help and people who might receive cancer-related information

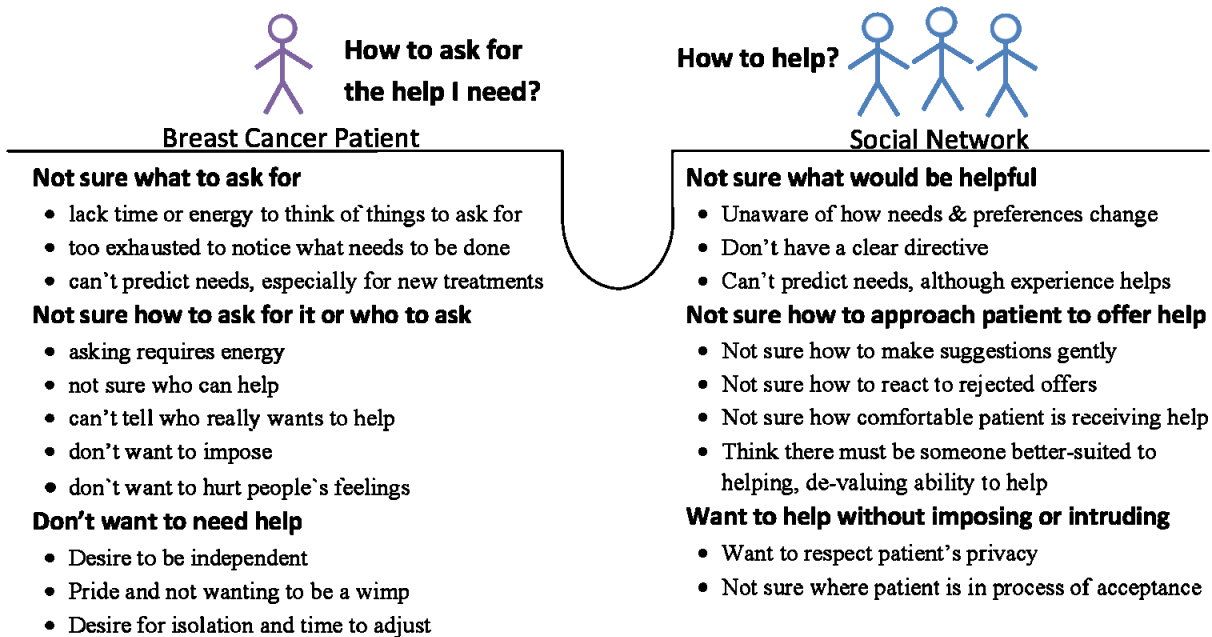


Figure 5. Barriers that Inhibit Social Support

am I going to work?' I mean just things, while they're sitting there writing the information, like this could take 4-6 weeks, you know, just information! And that was really helpful." Another participant got help with things she wasn't physically able to do, like visiting the library, "My Mom would get books for me, because I would go on the Internet and check out what I wanted and she would go pick them up for me." The strong link between information and ability to help was consistent throughout both design groups. Specifically, there were four types of information social networks used: (1) health information, (2) status information, (3) knowledge about the person, and (4) information about living through cancer.

Health Information

Participants in both design groups recognized that keeping friends and family up to date about their health status served to foster active helping networks. In the first design group, one of the participants drew a storyboard about her diagnosis process to describe to the group where technology could have helped. When she explained her storyboard to the group she described the picture after she got home from the doctor, "This is me telling my friends and my relatives and asking them to help look for information. Because, like I said, I didn't have a computer for years. Asking them to go on the Internet, any kinds of books, or anyone they know who might have the same thing, because there are different kinds of cancer, and basically looking for that. And to tell them I'm scared. Could you please keep by me? I'm scared." Telling her social network about her diagnosis went hand in hand with asking them for help finding information and asking them for emotional support.

Status Information

Participants in both groups described, with appreciation, supporters who would proactively seek information about

how they were doing even when they weren't forthcoming, "Even better than a phone call is to just go see them, because then you can see what they need." A patient might not tell their social network what they need, "If they're embarrassed or something and they don't want you to know..." Others agreed that just checking in on the phone could be insufficient, "Because they could be telling you over the phone you know, 'I'm fine. I'm eating. I'm healthy. I'm clean.' And then you go over and it's like, 'Oh my God!'... 'cus they don't want you to know or worry." We caution, however, that there is a fine line between assertive and helpful social networks and being overly pushy. The timing and the way helping was approached seemed to make a great deal of difference in how help was received.

Knowledge about the Person

Knowing someone well makes it easier to predict what that person would want and need and how to approach them about helping. The nuances of tailoring support to the person and the situation are difficult; participants reported that people who knew them better often did a better job. While the groups were able to come up with lots of ideas for ways cancer patients could be helped, they also said that "it's so individual" and can also depend on the timing and the person's emotional state. Another issue was not just what people needed, but also "what people will accept."

There were also more straightforward ways of using knowledge about a person to help them. A participant from the first group explained, "I think it's important for people to know, you know, well I like gardening. And I still like to garden, even though I can't get out and do gardening. So maybe somebody could come over and do some weeding for me or whatever." Another participant declared "I love movies!" and thought it would have been nice for people to bring her movies because she loves them so much.

Information about Living through Cancer

Knowledge about the cancer experience helped members of the social network know what to do. People who have been through cancer themselves or have had someone close to them go through treatment were a good resource because, “*At least they’ll know a little bit more about what to do, what you should do.*” In contrast, people who were out of touch with the realities of cancer treatment, “*just don’t know or realize how hard it can be with this sickness and going through it.*” Several participants described how they had used their knowledge to help other cancer patients.

Having an informed social network is a requirement of receiving good help. Sometimes social networks even have to take it upon themselves to actively investigate a patient’s situation and find ways to help. Social networks that know a patient well and have some understanding of the cancer experience were most helpful, but anyone with a desire to help and to listen to what is needed and what is unwelcome can provide invaluable service to a cancer patient.

Barriers that Inhibit Social Support

Design Group 1 began to touch on some of the difficulties they experienced receiving the support they wanted. Then, we talked extensively with Design Group 2 about the barriers standing between patient needs and social networks’ abilities to provide for those needs. Participants characterized the problem as a gap between the patient—who would benefit from help—and members of their social network who want to provide help. To probe further, we facilitated a 45-minute discussion during which the group generated lists of barriers that foster this gap from the perspectives of both the patient and their social network. We summarize these results in Figure 5.

Participants identified four strategies to ameliorate these barriers in an online system. First, participants recommended explicit representations of help requests. Making help requests explicit could help the social network overcome the barrier of not knowing what would be helpful or whether help is wanted.

Second, participants recommended visual overviews of their social network and helping activity. These overviews would help people within the social network’s existing helping activity and identify additional opportunities to provide help. This strategy makes explicit what is—and what is not—occurring, and could alleviate the problem where family and friends think that someone else probably knows the patient better or is better-positioned to help. An additional goal of this strategy is to encourage a sense of community and activism in support of the patient.

Third, in response to suggestions that the system provide a way for social networks to suggest help, participants recommended features to say ‘no thank you’ to help they do not want. This feature also supports the social network’s desire to tailor their help to the patient’s individual preferences because they can be assured that patients had the opportunity to say ‘no’. Polite template messages for

saying ‘thank you for thinking of me, but no thank you’ will make it easier for patients to say no, but will not entirely alleviate the social difficulties of rejecting unwanted help.

Fourth, participants recommended features to assess the willingness of specific individuals in their social network to help. Breast cancer patients did not want to ask for help from people who did not want to give it or who would have to overextend themselves to provide help. Having a system where members of the social network can identify themselves as someone who wants to help could enable patients to overcome the barrier of feeling unsure about whether someone really wants to help. Another aspect of the system that addresses the difficulty of asking for help is that the patient is asking a whole community of friends and family instead of a specific person who might feel obligated to help if asked individually.

Designs to Create an Informed Social Network

As we described previously, an informed social network needs health information, status information, knowledge about the patient, and an understanding of cancer. Ways to provide these types of information can be observed in the functionality participants designed.

Health Information to Share

Participants kept a wide variety of health information and were interested in the ability to share it online with select members of their social network. Information they envisioned supporting included: Appointment info & calendar, Question list, Contact information, Notes from clinic visit, Recording from clinic visit, Hand-outs & brochures, Medical records (e.g. blood work, pathology report, x-rays, etc.), Medication List & Prescriptions, Books, Journal or Diary, Photos, and Websites. The list they generated is consistent with the types of information other researchers have observed patients collecting [5].

Content would also be created specifically for the purpose of updating the social network. Participants wanted to post general background information about their diagnosis and treatment plan as well as add educational links where people could learn more if they were interested. Additionally, they envisioned blog functionality for posting updates and getting replies from friends and family.

Each participant in Group 1 wanted to share differently and envisioned having the ability to control how each object was shared. A participant said, “*There are certain people that need to see certain information and other than that, quite frankly, I don’t think it’s any of their business.*”

Caregiving Information

Participants also designed for times when people in their social network might need more specific health information in order to take care of them. To provide this kind support, a friend, family member, or neighbor would need to be informed about what is happening with the patient’s health in general, but would also need more specific information about medications and emergency contact information. A participant described how she dealt with this, “*When I was*

first diagnosed with breast cancer I made up a little half sheet of medical information and gave one to my mom, to my ex-husband, gave one to my best friend, and put one on the refrigerator, and one at work. It has who my important medical people were and my best friend's phone number. And on the back of it I had a list of all my medications. So they all got that and then I carried one in my purse." Following up, another participant said, *"You do get really sick during your treatment time and could have a friend visiting, and not have your husband or daughter or mother available,"* (who would know how to take care of you). Correlating the past solution to a future design, one woman said, *"I thought that was a good idea. What really struck me is that people need to know more about what you might have to have during this time and your doctor's name, and all that could be put on the Internet."* Close friends and family would have access to a lot of medical information, but a larger set of people would have access to this type of information in case they help take care of the patient.

Collaborative Question List

Question lists were of great interest to participants, who imagined having multiple types of question lists that other people could view and add to. For example, other people might add questions for the doctor. The collaborative question list could also help outsourcing research tasks if the social network used that information to seek information for the patient. Having the functionality available would show a patient's network what you are thinking about and what you need answers to so they could act accordingly. Question lists represent yet another way to have dialogue with one's social network.

Status Indicator

The goal of the status indicator was to quickly record and post status information to help keep the social network up to date. These posts could also help people who are unfamiliar with cancer learn more about the patient experience and encourage them to tailor their behavior appropriately. Participants wanted the status indicator to be both flexible and provide for very fast interactions. They envisioned having a text box, check boxes with symptoms, emoticons, and slider bars to indicate things like energy level. Each user would be able to use the feature that expressed their status and that information would be logged over time and shared with the social network.

Maintaining Awareness of the Big Picture

The list of 'Things that are important to me' serves as a way for cancer patients to convey to their social network what they care about. We established that knowing more about a patient can empower a social network to act intelligently when proactively providing help. This list also served as a reminder to the patient and the social network that their life is about more than just cancer. For example, the participant who explained how much she liked to garden wanted to put that on her list in the hopes that it might prompt someone to come help her take care of her garden.

Designs for Catalyzing Helping Activity

The first group generated a long list of things other people could do to help, but did not have time to delve into the details of how requesting help and receiving help could be facilitated by technology. After the first group, we generated more ideas for the structure of a helping system. Group 2 began with that starting point and designed ways to request and offer help, view all these help requests and offers, and utilize proxy and coordinator roles to ease the burden on over-taxed patients.

Requesting and Offering Help

Participants emphasized the importance of designs to facilitate requesting or offering help. They cited challenges patients face in knowing what to ask for because they have difficulty predicting their needs over time, have low energy levels, and are coping with side effects. Participants expressed concern about the wearing effects of treatment on their energy and personal standards. As patients became progressively more exhausted, they cared less and less about keeping up with regular tasks like bills and housekeeping. One participant remarked: *"I was so fatigued I didn't see the dust bunnies, I didn't care about [doing household chores]"* The social network also typically lacked experience with the cancer experience and required information to determine how to help. Ironically, when patients' needs were greatest, they struggled to reach out for help: *"I just was too tired to even be able...to be able to formulate a way to ask for help...even the thought of having to go through all the reasons that I needed help and what I needed done."*

To address these problems, participants recommended design features to prime patients—and their social networks—with ideas on what help to solicit or offer. Using an initial list of useful help from design Group 1, Group 2 participants added new items to make a more comprehensive list. The list participants generated (see Figure 6) reflects both kinds of help they received and kinds of help they would have liked to receive.

Participants' insights into a breast cancer patient's state-of-mind when approaching the system directly influenced the interface for requesting help. Initially, we had suggested to participants that the interface could offer a few help suggestions and also provide a blank form users could fill out to ask for any type of help. The problem with the blank form was that exhausted, overwhelmed, or inexperienced patients might not know what their social network would be willing to do. The new interface design will reduce the cognitive load on the patient soliciting help by including a long list of kinds of help that others have found useful, much like Figure 6. Next to each item on the list is a 'Yes' and a 'No' button. Clicking 'Yes' next to an item makes it expand so the patient can fill in more detailed instructions and information and say when they would like the help. A user will always be able to go back and change what they want and will also have the option to ask for help that is not on our list by filling out a blank form with a title,

<u>Medical-Related Tasks</u>	<u>Everyday Chores</u>	<u>Managing/Coordinating Tasks</u>
Come to appointment Provide transportation Assist with drains/self care Provide list of questions Describe non-obvious things to know Research options to consider Gather / collect information Put me in touch with person or organization Put others in touch with me Help interpret medical documents Ensure I'm comfortable after surgery	Run Errands Do Laundry Clean areas of house Change linens Arrange/provide Meals Arrange 3rd party meal service Arrange 3rd party cleaning service Stock shelves with groceries Do yard work/gardening Going to bank Take me shopping Take care of garbage	Help me get organized Help me with bills Discern how to maximize benefits Manage communication with family/friends Coordinated needed help Organize schedule/calendar Arrange outings Make sure I get to appointments on time
<u>Other Ways to Help</u>		
Come over for a visit Bring flowers Send cards Provide play dates/activities for kids Share funny books & movies Offer babysitting Transportation for kids	Share humor strategies Hold fundraiser Help sort out work issues Come exercise with me Go for a walk Check in with me about exercising Come watch movies with me	Do dog walking & pet care Spiritual care visits if desired Bring over reading material Visit to play games/cards Go to library to get books Take me to library/bookstore

Figure 6. Help that would be useful to breast cancer patients

description, and time(s). A similar interface supports the social network by suggesting ways they could help.

Viewing Help Requests and Offers

As a group, we made paper prototypes of the interfaces for seeing all the help a patient has asked for, what people have signed up for, and what help will be needed soon. We generated three main visualizations for seeing help requests (see Figure 7). Participants felt it was very important to integrate pictures of members of their network into all these visualizations. In the example of the calendar, a participant explained that with the picture, “I can start thinking about that person, that they’re coming.”

Calendar

A weekly calendar view could be used to visualize all the upcoming scheduled help events. Members of the social network could use the calendar to see upcoming requests that are unfulfilled and to sign-up for those slots. The calendar could also display other relevant events, such as upcoming treatments or appointments, so the social network is aware of the patient's schedule and can volunteer or suggest appropriate help. This view also helps patients see upcoming help embedded with the other items on their calendar.

Pieces of a Whole

A personalized shape, such as a wreath, cross, or heart, is shown divided into small sections. Each section represents a help event –someone doing something helpful. When members of the social network sign-up to help, that piece becomes theirs. They can have a copy of the pieces they have signed up for (electronically) and can see how their contribution fits into a bigger effort. The patient also sees a visual representation of his or her helping community.

People

A visualization of everyone who has helped or signed up to help can be explored to see what help each person has signed up for or completed. This view allows the social network to see the extent of the patient’s social network, and it provides another way for patients to see everyone who is part of their helping network.

Supporting Proxy and Coordinator Roles

Motivated by vivid memories of the exhaustion they experienced during cancer treatment, Design Group 2 participants recommended designs to support two new roles that people in their social network could fill. The first of these is a “proxy,” which patients described as someone they trust to interact with their social network on their behalf. Proxy responsibilities include (a) setting up the help

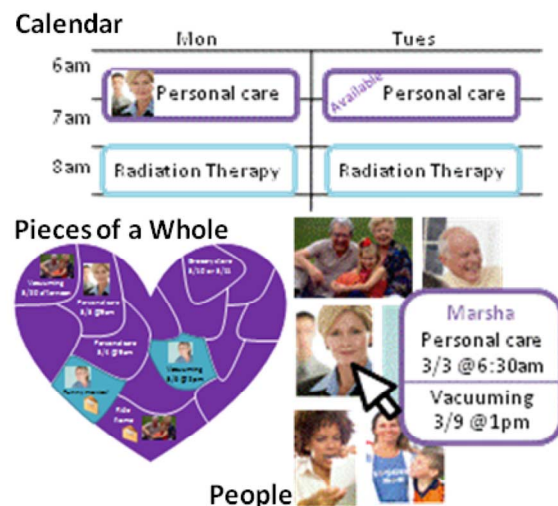


Figure 7. Three interfaces for viewing help requests

system to “start the ball rolling,” (b) inviting people into the patient's helping network, and (c) deflecting unwanted offers (i.e., participants felt a ‘no thanks’ coming from the proxy was gentler than a rejection from the patient). Besides being too tired and overwhelmed to have time to set up a profile and invite people, they also expressed reluctance to ask people to be part of their helping network. One participant explained, “I don’t want to bother anybody.” Participants specified that a proxy would have permission to do everything a patient can do –ask for help, edit requests for help, accept offers of help, field questions, and triage incoming messages of support. In sum, a proxy acts on the patients’ behalf with full access to system features. However, concern was voiced over tiring out the proxy, with one participant noting “I think they would get burned out real fast if they were doing everything.”

In addition to the proxy, participants also envisioned a new “coordinator” role. A coordinator is someone who manages one piece of the social support puzzle. Functionally, coordinators have a more limited scope of access within the system than proxies. For example, a coordinator could arrange rides or manage meals for the patient. The meals coordinator would have permission to edit the help request, answer questions about meals, and would be the contact point for people who sign-up to provide meals.

Returning to our fictitious patient Sally, her husband Jim could be a proxy who gets the system set up with Sally’s information and sends a link out inviting friends and family to become part of the helping network. Sally’s friend, Martha, could just sign-up to vacuum the house once – or she might ask to become a coordinator for all the housekeeping tasks. As coordinator, she could answer questions about what is needed, where the cleaning supplies are kept, and add new time slots if more help is needed.

IMPLEMENTATION

We implemented the designs on the Facebook Connect platform. Social Networking Software, such as Facebook, has emerged as a way to promote awareness among peer groups [2] and professionals at work [22]. We see great potential for utilizing this existing infrastructure and user base for promote awareness about the health status and needs of friends and family. Related work shows the potential impact that sharing calendar information within a family [20] or with family and co-workers [19] could have for promoting awareness of status and activities.

Using Facebook allows us access to an embedded messaging system, social networking functionality, and privacy controls. It also provides ways, such as posting messages to a user’s newsfeed or sending emails, for pushing information to the social network. Our implementation leverages several open-source technologies. It is written in Ruby on Rails and utilizes PostgreSQL for the database backend. The Rails Facebooker plugin permits our application seamless integration with Facebook’s social networking features using Facebook's "Connect" APIs.

We have implemented many of the design ideas generated by the groups. Six meetings with participants allowed us to develop reasonable initial designs, and our research team has continued to refine and iterate on those designs. The participatory design methodology provided us with the opportunity to ask participants questions and understand their reasoning behind their designs, recommendations, and decisions and we have used that understanding to make design decisions in their absence that we believe are consistent with their thinking.

The main page of the website (see Figure 8) is designed to provide an overview of all upcoming helping activities. The homepage includes a weekly calendar that shows a small picture of everyone who has signed up for a helping event, just as the Design Group 2 prototyped. There is also a daily, weekly, and monthly calendar view that can be navigated to in the left menu and that also contain picture previews of helpers associated with events.

Design Group 2 participants wanted to make asking for help easier for overwhelmed new patients. Figure 9 shows the page where new help requests can either be created from scratch or where patients can be prompted with ideas. Clicking ‘Show ideas for’ expands the categories and patients can select pre-filled in types of help.

We have iterated further on the ‘pieces of a whole’ idea and created a ‘Helping Quilt.’ Every time someone signs up and does something to help, a quilt piece with their picture on it is added to the patient’s quilt (see Figure 10). Hovering over a quilt piece provides more detail about what helpful thing that person did. This design fulfills the group’s desire to see everything the network is doing to help and can also serve as a way of acknowledging a helper’s contribution.

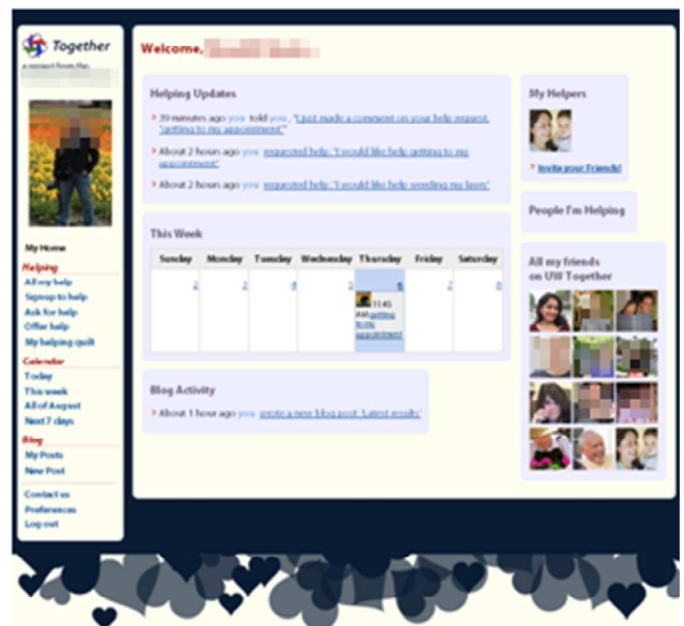


Figure 8. Homepage

Figure 9. Requesting Help

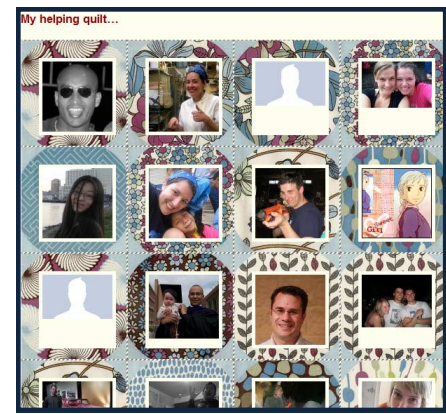


Figure 6. Quilt

CONCLUSION

Social support is an important, yet underutilized, resource for patients undergoing cancer care. Working alongside breast cancer patients in a participatory design process, we identified ways technology can catalyze such social support. Specifically, technology must facilitate keeping the social network informed, making help requests explicit, prompting users with help ideas, and allowing proxy and coordinator roles. We have also taken the first step in applying these findings by implementing a web-based system for cancer patients and their social networks built on the Facebook Connect platform. We believe utilizing the altruism of social networks will provide breast cancer patients with the support they need, freeing them to focus their attentions on treatment and recovery.

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REFERENCES

- Ballegaard, S.A., Hansen T.R. & Kyng, M. Healthcare in Everyday Life – Designing Healthcare Services for Daily Life. In *Proc of CHI'08* (2008).
- boyd, d. *Taken Out of Context: American Teen Sociality in Networked Publics*. [PhD Dissertation] Univ. of California-Berkeley, School of Information.
- CarePages. <http://www.carepages.com>
- CaringBridge. <http://www.caringbridge.org>
- Civan, A. & Pratt, W. Threading Together Patient Expertise. In *Proc of AMIA* (2007).
- Civan, A., Skeels, M.M., Stolyar, A. & Pratt, W. Personal Health Information Management: Consumers' Perspectives. In *Proc of AMIA* (2006).
- Depaulo, B.M., & Fisher, J.D. The costs of asking for help. *Basic and Appl Soc Psych*, 1, 1 (1980).
- Flynn, F.J., & Lake, V.K.B. If you need help, just ask: Underestimating compliance with direct requests for help. *J Pers Soc Psychol*, 95, 1 (2008).
- GoogleHealth. <http://www.google.com/health>
- Greenbaum J, Kyng M, editors. *Design at work: Cooperative design of computer systems*. Lawrence Erlbaum Associates, Hillsdale (NJ), 1991.
- Hayes, G.R., Abowd, G.D., Davis, J.S., Blount, M.L., Ebling, M., & Mynatt, E.D. Opportunities for Pervasive Computing in Chronic Cancer Care. In *Proc of Pervasive* (2008).
- HealthVault. <http://www.healthvault.com>
- Hewitt, M., Herdman, R., & Holland, J. (eds.) Meeting psychological needs of women with breast cancer. National Cancer Policy Board. National Academies Press, Washington DC, 2004.
- HIMSS Board of Directors. *HIMSS Personal Health Records Definition and Position Statement*. Information Management and Systems Society (HIMSS), 2007.
- Lee, F. When the going gets tough, do the tough ask for help? Help seeking and power motivations in Organizations. *Organ Behav Hum Decis Process*, 72, 3 (1997).
- Lieberman, M.A. & Goldstein, B.A. Self-help On-line: An Outcome Evaluation of Breast Cancer Bulletin Boards. *J Health Psych*, 10, 6 (2005).
- LotsaHelpingHands <http://lotsahelpinghands.com>
- Manne, S. Coping and social support. In: Weiner, I.B. (ed.) *Handbook of psychology*. John Wiley & Sons, Hoboken, 2003.
- Patil, S. & Lai, J. Who gets to know what when: configuring privacy permissions in an awareness application. In *Proc of CHI'05* (2005).
- Plaisant, C., Clamage, A., Hutchinson, H.B., Bederson, B.B. & Druin, A. Shared family calendars: Promoting symmetry and accessibility. *ACM Transactions on Computer-Human Interaction (TOCHI)* 13, 3 (2006).
- Pratt, W., Unruh, K., Civan, A., & Skeels, M.M. Personal Health Information Management. *Communications of the ACM*, 49, 1 (2006).
- Skeels, M.M., & Grudin, J. When Social Networks Cross Boundaries: A Case Study of Workplace Use of Facebook and LinkedIn. In *Proc of Group '09* (2009).
- theStatus. <http://www.thestatus.com>
- Weiss, J.B. & Lorenzi, N.M. Online Communication and Support for Cancer Patients: A Relationship-Centric Design Framework. In *Proc of AMIA* (2005).
- Weiss, J.B. & Lorenzi N.M. Synthesizing Community Wisdom. In *Proc of AMIA* (2008).