

Locating Patient Expertise in Everyday Life

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ABSTRACT

Coping with a new health issue often requires individuals to acquire knowledge and skills to manage personal health. Many patients turn to one another for experiential expertise outside the formal bounds of the health-care system. Internet-based social software can facilitate expertise sharing among patients, but provides only limited ways for users to locate sources of patient expertise. Although much prior research has investigated expertise location and systems to augment expertise sharing in workplace organizations, the transferability of this knowledge to other contexts, such as personal health, is unclear. Guided by expertise locating frameworks drawn from prior work, we conducted a field study to investigate expertise locating in the informal and everyday context of women diagnosed with breast cancer. Similarities between patients' expertise locating practices and practices of professionals in workplace organizations suggest similar support strategies could apply in both contexts. However, unlike professionals, unsolicited advice often triggered patients to locate expertise. They identified expertise through various forms of gatekeeping. The high-stakes nature of problems patients faced also led them to use triangulation strategies in anticipation of breakdowns in expertise location. Based on these key differences, we explored five design additions to social software that could support patients in their critical need to locate patient expertise.

Categories and Subject Descriptors

H.5.3 Group and Organization Interfaces: Computer-supported Cooperative Work; H.5.2 User Interfaces: User-centered design

General Terms

Design, Human Factors

Keywords

Expertise location, expertise sharing, patient expertise

1. INTRODUCTION

Martha was recently diagnosed with cancer. Her doctor says that her form of cancer is treatable and that many patients go on to live long and productive lives. Coming to grips with her initial shock, Martha decides she needs to understand more about her cancer,

her options, and strategies for managing day-to-day efforts associated with treatment and recovery. To whom should she turn for these different types of critical expertise?

Acquiring new knowledge and skills to manage personal health can empower individuals to cope with a new health issue, such as cancer. Certainly, formal sources of professional medical expertise, such as one's team of health-care providers, are one critical means for such empowerment. However, everyday information seeking from peers and the broader community is also an empowering force [25][26]. Friends, relatives, and other patients, can offer a wealth of practical tips and advice, as well as their own physical and emotional experience of managing similar health situations. In contrast to professional medical expertise obtained from formal sources associated with the health-care system, we refer to this experiential form of knowledge gained by coping with and managing illness as *patient expertise* [4].

Systems designed to meet patients' information needs (e.g., personal health records) often privilege the provision of professional medical expertise, such as health status or treatment options [17]. Outside the bounds of the health-care system, Internet-based social software (e.g., message boards, web forums, online communities, blogs, and wikis) provides a popular means for peers to share patient expertise about the practical, everyday management of treatment decisions, side effects, social relationships, and daily responsibilities [4]. Despite the growing health-related use of social software [2][9][27], little empirical work describes the ways that patients use these tools to locate patient expertise. Prior research describes how individuals find expertise in structured and process-driven contexts, such as the workplace within an organization [18], but it is unclear if the types of mechanisms at play in those settings also apply to less formal, everyday situations of managing personal health. Quite simply, an expertise locating system designed for use in organizations might be ineffective for patients in the personal health context of everyday life.

In this work, we enhance our understanding of the everyday expertise locating behaviors of patients. Our goal is to inform the design of social software to support patient expertise sharing. We address how patient expertise location in the context of personal health relates to organizational expertise location in the more structured and process-driven context of the workplace. We seek to understand whether differences in the personal health context nuance patient expertise location in unique ways.

We begin with an overview of prior research that uncovers gaps in our understanding about *how* individuals locate patient expertise. To fill those gaps, we describe the organizational expertise location framework we use to inform our investigation. We then

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describe the context and methodology of the field study we conducted to explore the everyday expertise locating behaviors of individuals during their treatment for breast cancer. After we describe mechanisms for locating patient expertise, we conclude with implications that our findings offer for the design of tools to augment and enhance patient expertise location.

2. RELATED WORK

Growth in health-related use of social software provides increasingly diverse ways to share patient expertise [2][9][27]. Although observations of online health communities highlight the prevalence of patient expertise exchanged [4][20], it can be difficult for users to gain awareness of the expertise available without multiple interactions that build relationships [16]. Many tools encourage users to broadcast questions to an entire community, assuming that someone with the appropriate expertise will notice and respond [33]. Alternatively, users might also locate expertise passively by maintaining a profile of their health experiences upon which other users can post comments to warn of potential problems [13]. Similar to prior research in non-health contexts that tells much about patterns of online interaction among users [11], observations of patients' use of social software have provided few clues about how users actually find other people with the expertise they need.

Ethnographically-inspired studies have investigated how people find expertise, but those are commonly conducted in formal organizational settings. Informed by a field study of expertise locating practices of software developers, McDonald and Ackerman [18] offer a framework that describes how people find, or 'locate', expertise within such organizational settings. They found that **expertise location** is comprised of complex, iterative, and sometimes interwoven behaviors to determine who has what expertise (i.e., **identification**), to narrow down a pool of candidate sources to approach for help (i.e., **selection**), and to repair breakdowns in identification or selection (i.e., **escalation**).

Similar types of collaborative practices have been observed in other organizational settings [8][28], as well as informal settings, such as peer-based 'How To' websites [30][31]. The expertise location framework offers a useful starting point for enhancing our understanding of patient expertise sharing in everyday life. Yet, it is unclear how an expertise location construct derived from formal, organization-based work plays out in the informal and everyday context of personal health. Unique behaviors for locating patient expertise could serve to elaborate the design space for expertise locating systems for informal settings in general as well as for patients. We draw on the prior work from organizational settings to shape our study of the expertise locating that takes place among breast cancer patients in the informal context of their everyday lives.

3. STUDY METHODS

We investigated patient expertise location in the informal context of breast cancer patients' everyday lives through a qualitative field study. We investigated behaviors used to locate patient expertise from informal sources, such as peers and the broader community, rather than medical expertise from their formal team of health-care providers. We attempted to reduce the potential burden on participants by selecting an approach similar to Paepcke [23], in which we conducted interviews and observations in each participant's home. This method allowed us to interact with multiple participants and observe them in their natural 'work' setting with the supportive artifacts they use (e.g., personal

information collections, calendars, email, web pages, online communities). The field study and data set were part of a larger study that investigated personal health information management practices.

3.1 Study Context

Marked by information-intensive *patient work* [32], the breast cancer experience offered a rich context to investigate patient expertise location in the informal context of everyday life. We model the breast cancer setting as an integrated support community that crosses both formal, the health-care system, and informal, peer and community-based, contexts. In this work, we focus on the informal, everyday context in which individuals seek patient expertise from their peers and the broader community.

Expertise location practices have largely been studied in formal contexts, such as the workplace in an organization [18]. Recently, expertise location has also been studied in informal contexts, such as Internet-based social software, such as How To websites [30][31]. We have drawn upon this related work to guide our study. However, it is an open question as to whether prior findings generalize to the personal health context of patient expertise sharing.

The breast cancer setting shares a number of similarities with workplace settings that serve as the context for much prior research on expertise location. Both are highly complex, social, and collaborative settings where expertise sharing facilitates work to reach common goals. Just as organizations structure work through specialized roles, patient work is often distributed among patients, their formal health-care team, and their informal support system of relatives and friends, who collaborate to manage the patient's health [32]. In addition to role specification, the expertise in both settings shows more or less topical specification. For example, a software engineer might have experience with operating systems or web development, just as a cancer survivor might have experience with chemotherapy or radiation therapy.

Yet, the structured and process-driven context of workplace organizations and the less formal, everyday context of breast cancer have important differences. The boundaries and roles of a patient's informal support community are less fixed and less clearly defined than those of the workplace. Incentive structures that can limit expertise sharing in work settings, such as competition and hierarchy [15] or trade secrets [23], appear greatly diminished in breast cancer. Instead, cancer survivors' desires to 'give back' reflect a highly altruistic spirit, similar to other informal contexts of expertise sharing [30][31]. Furthermore, the breast cancer experience is laden with emotional complexity not typical of workplace settings. These differences could influence patient expertise location and shape the design of supportive tools in unique ways.

3.2 Data Collection and Analysis

We collected data through semi-structured interviews spaced at roughly equal intervals over six weeks with each of 15 participants. We interviewed participants twice in their homes for 90 minutes and twice over the telephone for 30 minutes. We audio-recorded and transcribed interviews. During home interviews, we photographed the artifacts participants' used to manage their health. We observed their use of this information by accompanying each participant to a clinic appointment of their choosing. Two of the 15 participants became too busy with their cancer experience to complete the second home interview.

We created a case report for each participant by collecting excerpts from transcripts in which they discussed expertise seeking and use behaviors. We coded data from case reports using an initial coding scheme informed by prior expertise location research [18]. The categories of our coding scheme included expertise locating mechanisms for (1) identifying sources of expertise, (2) selecting which sources to approach, and (3) repairing breakdowns in expertise location. We expanded and elaborated the detail of our coding scheme to include codes for (4) expertise provision (5) value of expertise and (6) barriers to sharing. We present common themes associated with locating patient expertise that appeared across participants.

All participants were women who ranged in age from mid 30's to early 70's and were highly diverse in socioeconomic status, level of education, use of technology, and extent of their support networks. One participant identified herself as Hispanic, one as Native American, and the remaining participants identified themselves as Caucasian. Eleven participants were experiencing breast cancer for the first time and four were experiencing it for the second time. Participants received different treatments, some more than one type. Eleven participants were undergoing chemotherapy, 7 underwent surgery, 3 were undergoing radiation therapy, and 1 was undergoing hormone therapy.

4. EXPERTISE LOCATING BY PATIENTS

All participants sought expertise from informal sources, such as friends, family, researchers, health professionals who were not members of their health-care teams, as well as from other patients. Participants sought expertise to help them solve problems that were medical in nature, personal in nature, or a mix of the two (see Table 1). Many, but not all problems can be considered *high stakes* because of the critical implications of their solutions for the health of the participant. Participants did not always identify health professionals as sources of expertise for issues that were medical in nature. Nor did they always identify other patients as sources of expertise for more personal issues.

Table 1. Examples of problems for which expertise was sought

Medical	Personal
Reading and understanding a pathology report	Deciding to work or go on disability during treatment
Deciding between single & double mastectomy	Finding a yoga class for cancer patients
Understanding the process & implications of genetic testing	Discovering self-care remedies, such as goji tea

4.1 Initiating the Identification Process

We identified two conditions that trigger expertise identification. First, participants described several cases in which they, like professionals in organizations, clearly recognized their own need for expertise, which motivated an active and explicit search to identify suitable sources who could offer the requisite expertise. However, just as prevalent were cases in which participants located expertise as a result of *unsolicited offers* of advice from others. In these cases, it was after such encounters that participants assessed whether they recognized their own need and actively initiated expertise location. Before describing the mechanisms participants used to identify expertise, we describe how participants understood and reacted to their initiation of expertise location that resulted from unsolicited offers.

Ten participants discussed multiple examples of being the target of unsolicited offers from friends, family, and even strangers. In just over half of the cases, participants found unsolicited offers helpful, particularly when those offers were proactive, took account of their personal situation and preferences, or provided pointers to supportive background information. Some participants took specific measures to signal their openness to unsolicited offers from others. For example, one participant received unsolicited offers through comments left on the blog she maintains about her health situation:

I let people come to me ... I've gotten all these comments, not because I'm commenting on people - I comment back but I don't really go out and pursue it. (P13)

Other unsolicited offers were less helpful, often because of a poor fit with participants' specific health situation and preferences or a lack of supportive background information.

She brought over this little goody bag of just stuff that she said was helpful for her when she was going through breast cancer...But interestingly some of the stuff she had in there was not anything that would be at all helpful for me. (P4)

Everybody thinks that they got the best care, or that they have the best surgery or they had the best reconstruction, but that's more of an affirmation to make them feel like that they can go on. (P1)

I run into one woman that I don't even know that overheard a private conversation and she got all oh! I'm a two time survivor! And for the next like hour that was all I got from her, and it was horrible. It's like - you know? Go away. Don't want or need that. So like I said, if there's somebody that can't be positive, then I can't have them around. (P15)

Although the participant in the first quote appreciated the "goody bag", she recognized that the implicit advice it carried did not meet her preferences for self-care. As reflected by the second and third quotes, some participants reacted negatively to unsolicited offers perceived to meet the source's needs rather than their own needs.

Unsolicited offers are similar to 'gift queries' [14], in which someone seeks information in anticipation of another person's needs. Abrahamson et al. [1] associate altruism and helping behaviors with a similar pattern of unprompted consumer health information seeking by lay information mediators. The diagnosis of cancer could 'mark' a patient, signaling their need for similar forms of social support from their support community and beyond. Patients, like the participant who blogged about her experience, might also encourage social support by making themselves 'open' to receive it. Similar strategies are observed in online helping communities for health [13] and crafts [31].

4.2 Identifying Expertise

Participants described four general mechanisms that helped them come to know about potential sources of expertise. These expertise identification techniques include: past experience with personal networks, gatekeeping, localization of expertise through grouping, and artifacts. Because some identification behaviors have been described in prior research, we focus on unpacking new expertise identification behaviors that emerged, including use of multiple gatekeeping strategies, reliance on grouping mechanisms, and minimal use of artifacts.

4.2.1 Past experience with their personal networks

Participants drew upon their everyday knowledge about the skills and backgrounds of their family and friends to guide their identification of sources. This identification aid aligns closely with ‘everyday experience’ reported in prior work [18]. Our participants drew upon their everyday experience across multiple contexts (i.e., family, work, community, health). Participants who experienced a recurrence drew upon relationships developed during their prior cancer experience. Newly diagnosed participants discovered expertise available within their personal network through word of mouth:

I was also really surprised when I started talking to people how - they said oh yeah, my mother had breast cancer 15 years ago, or oh yeah, my sister has had it. It's amazing how many people either had it or knew someone who had it. Like my next door neighbor, I didn't even realize, she had breast cancer 12 years ago, I didn't know. (P4)

Use of personal networks was the most common identification aid described by participants, particularly by those participants with rich personal networks. Participants valued trusted relationships of long-time friends. However, some participants noted worry that their information requests could burden family or friends who were dealing with their own serious personal issues:

I haven't talked to her for a while because this [her granddaughter's surgery] was a big ordeal and everything. (P14)

4.2.2 Use of gatekeepers

Participants relied on key individuals in their personal networks who played three variations of the gatekeeping role to assist with expertise identification: *conduits*, *contact brokers*, and *champions*. Eleven participants discussed their use of two or more of these variations. The variations we found are specializations of a general notion of gatekeeping as a result of how each spans the border between one or more organizations or communities.

Briefly, prior work notes how gatekeeping roles could specialize in different work contexts [18]. For example, the conduit function of ‘technological gatekeepers’ [3] funnels information resources into organizations from external sources. Others highlight the referral function offered by ‘contact brokers’ [23] and ‘information concierges’ [18], who connect colleagues with others. Playing a central organizational role, the ‘information mediator’ [6] leveraged their breadth of knowledge and trouble shooting skills to filter, synthesize, and translate information for colleagues in a customer support organization. Abrahamson et al. [1] identify similar ‘go-to’ sources as ‘lay information mediators’ in the consumer health context. Similar to our findings, variations of gatekeeping, rather than a uniform gatekeeping role, have emerged in studies of other contexts [21].

Conduits: Participants identified expertise through gatekeepers who functioned as *conduits* by carrying information resources between participants and sources outside their support community. Serving a conduit function resembles aspects of the technological gatekeeper [3]. In some cases, gatekeepers funneled in information to the participant and at other times the gatekeeper acted as a point of contact to pass messages between the participant and an external source. Ten participants discussed their use of conduit forms of gatekeeping. In several examples, these gatekeepers channeled stories about the experiences of friends who were breast cancer survivors or informal recommendations

from health professionals. Other examples demonstrate how gatekeepers relayed messages between participants and external sources. For example, the sister of one participant served this conduit function:

I talk to other people to find out what questions they would ask. My sister asked a nurse practitioner if she knew what she would ask related to -I can't remember if it was the genetic testing or if it was -oh, it was about what does it mean that this tumor is disappearing and so this woman had some questions related to that that I wouldn't have thought of asking. (P11)

Contact Brokers: Gatekeepers also served the function of introducing participants to sources of expertise outside their support community, resembling the referral function of ‘contact brokers’ [23] and ‘expertise concierges’ [18]. Nine participants discussed gatekeepers who introduced them to sources they did not yet know (i.e., a friend of a friend). These gatekeepers were often networked with other specialists through tenure in a particular social context, such as a long-time church member who knew several fellow members who were breast cancer survivors:

At church, my aunt introduced me to a lot of people, this person's had breast cancer and this person's had breast cancer. And then so I mean I would have never known and so that's been kind of interesting to find - I go to a small church and the amount of people - I belong to a Bible study and there's 22 of us, there's 11 women and 11 men, and out of the 11 women five of us have had breast cancer. (P2)

Champions: Participants also identified expertise through gatekeepers who were distinguished *champions*, resembling ‘information mediators’ [1][6]. Champions were themselves key sources of expertise who bridged knowledge across domains and helped participants fill in gaps and synthesize information they obtained. Like information mediators, champions leveraged a breadth of knowledge that often crossed multiple domains (e.g., a breast cancer survivor and a registered nurse). The champion was commonly a close family member or friend, much like lay information mediators [1]. Eight participants discussed repeated interactions, covering multiple problems, with champions, whom they referred to as “a godsend”, “my sponsor for confirmation”, “my guiding post”, or “my source to go to”. For example, one participant described how the expertise of her champion, who was a coworker, a breast cancer survivor, a registered nurse, and worked in medical research, spanned many boundaries:

I talked with a woman that I work with who is a research coordinator and who had breast cancer, I asked her to review the consent form and then I kind of talked to her about it. ... I was able to get that study protocol from the coordinator. And she was able to send that to me so I'm able to review the protocol... just really knowledgeable. She's a nurse, she's an RN, she's very knowledgeable about BC, she's very knowledgeable about research and she is just someone I trust because I've worked with her so long. (P13)

The common characteristics of gatekeepers are just as critical in the personal health context as they are in an organizational context. Two participants described their use of community gatekeeping programs, such as the American Cancer Society, to obtain referrals to connect with local support services or other cancer survivors. Sometimes these attempts to facilitate expertise identification are not effective. For example, one participant used a local patient mentor program, but the matched mentor seemed to lack resources the participant needed:

I went to the Cancer Center and they have this thing where they try and hook you up with somebody...I got a phone call from a lady. Well ... she's 72 now, and wonderful, wonderful lady. ... but the unfortunate thing was this lady had just been re-diagnosed again with breast cancer so just starting chemotherapy. So she kind of was in the beginning of - not in a place where she would really be able to be as much support as I would want, because she has her own things to deal with. (P3)

4.2.3 Localization of Expertise through Grouping

Participants described both physical and virtual mechanisms that brought together sources of expertise in a single location. These mechanisms create groups of individuals who deal with similar situations and who share similar interests or contexts. These groups are key sources for expertise.

Localizing expertise was often, but not always, the reason for creating the group. For example, an explicit goal of many face-to-face or internet-based cancer support groups is to facilitate the exchange of information and support among cancer patients. Other mechanisms localized expertise by happenstance, such as clinic spaces, where patients sharing the same health-care providers or treatments come into regular contact. In addition to support groups and clinics, participants described a wide range of other locations that group individuals with cancer-related expertise, including cancer retreats, cancer-related social networking web sites, community-based cancer resource centers, special interest groups, lectures, classes, fundraisers, and parties.

Participants used localization of groups as a technique for coming in contact with a wide range of individuals likely to have the desired expertise. Both face-to-face and online cancer support tools were seen as key potential locales that often provided valuable exchanges:

That [support] group probably was the most powerful group of people and women that made, helped me make my [surgery] decision to where I came to in the end, truly. (P3)

I think we all share ... and so I'm starting to go through Taxol so those that have gone through it, you know, can give me advice on what I'm looking towards and the new lady that's there [at the support group], she's going to glean information from the rest of us in starting her treatments and everything. (P2)

It [comments on my blog by other patients] kind of helped me sort through logically why I wanted - why I was interested in the [clinical trial] study itself. So I was able to kind of check it out in my mind ... (P13)

Prior research describes the value of analogous localization mechanisms, such as intranets, team meetings, brown bag lunches and company picnics that foster interaction among professionals [6][23]. Community-based groupings (e.g., clinics, special interest groups) share characteristics with 'information grounds' [12] that serve as locations for information-rich exchanges. Face-to-face cancer support groups share similarities with the workplace 'war stories' among photocopy technicians [22], while online cancer support communities share similarities with newsgroups, bulletin boards, and other forms of online help communities [30][31].

Prior work describes potential barriers, such as social loafing, to group participation in social matching systems [29]. However, the localizations described by our participants suggest an absence of motivational barriers in the personal health context. Instead,

patients reflect an altruistic nature of self-help groups because they are often eager to share their knowledge with other patients [24].

Despite the advantage of grouping mechanisms to bring together people with similar diagnoses, localized groups did not always guarantee effective identification of expertise. Geography, time, and treatment side effects were all barriers participants associated with expertise identification through support groups. A common complaint was the need to travel long distances to support groups while suffering treatment side effects. Others noted limited time to share expertise at support groups:

We were only there [at the support group] for about an hour, so - and when there's nine people sharing, you only have a small amount of time. (P3)

I haven't been very active online because being on the computer made me kind of nauseated, you know? And so I haven't really kept up with - I haven't really been detailed with my cyber friends if we can call them, about what's been going on. (P13)

The second quote highlights the common challenge of identifying expertise in the face of treatment side effects that can also limit participation in virtual support groups. Another participant noted the challenge of finding expertise given the unstructured nature of tools like blogs:

Blogs give you lots of problems, people with serious problems, but they rarely give you people who solved it. (P7)

Although the infusion room or the waiting room provides opportunities for localized grouping, these clinic spaces can also be problematic because their primary function is for cancer care, rather than patient expertise sharing. For example, one participant indicated the suboptimal setting of the clinic for dialogue and sustained connection with another cancer patient:

I had wanted to ask this one gal that I had run into in the chemotherapy room ... she had been given a premedication that was making her really drowsy. So she was having a hard time talking, she was really sleepy...I just didn't have enough information to find out what exactly she meant by her chemo not working. (P4)

4.2.4 Identification of Expertise through Artifacts

In work settings, historical artifacts can significantly assist the identification of expertise [18]. However, only a few of our participants described substantial use of artifacts for this purpose. Handouts from clinics and cancer resource centers that contained lists of local cancer support groups were one of the most common artifacts used by participants to identify expertise. One participant used ratings on amazon.com to determine which breast cancer books would be most helpful. Participants who were experiencing breast cancer recurrence described retrieving information from their own archive of personal health information related to their prior treatment experience. For example, one participant maintained an archive of personal calendars dating back several years, which she used to look up contact information.

Participants' lack of artifact use is surprising in contrast to the prevalence of this identification aid in prior expertise locating studies. However, organizations serve as a formal infrastructure wherein artifact sharing and reuse within organizational boundaries can be encouraged. In contrast, most patients lack an

integrative infrastructure that crosses the multiple contexts in which they identify expertise.

4.3 Selecting Expertise

Once participants identified candidate sources of expertise, they relied on key criteria to determine which source(s) to approach for help. Similar to prior work on expertise location in organizational settings, our participants used criteria, such as performance characteristics [18] and social ties [28], to judge the suitability of potential sources for meeting their needs. The most common selection criteria described by participants included source knowledge, sharing a cancer bond, strength of relationship, similarity of interests, lifestyles and preferences, source accessibility and response expectation, and source transparency. Some criteria appear unique to the personal health context, such as the importance of the cancer bond and transparency. Although some selection criteria (e.g., strong social tie) were common across a number of problems for which participants sought expertise, other criteria (e.g., specialized knowledge) were tightly coupled to the specific type of problem.

4.3.1 Source Knowledge

Participants frequently described selecting sources based on the specialized knowledge they offered. Those areas of knowledge were offered by sources ranging from health professionals, lawyers, caregivers, beauticians, breast cancer foundation workers, artists, researchers, to cancer survivors. Source knowledge, as a selection criterion, is similar to competence and performance-related criteria used by professionals to locate expertise in organizations [18].

The area of knowledge suggests the role played by the source (e.g., health professional, informal caregiver, patient, and survivor) in relation to cancer. Several participants repeatedly selected a particular source with specialized knowledge in multiple domains, thus filling multiple roles (e.g., had specialized knowledge from being both a cancer survivor and a cancer researcher). *Champions* commonly met this criterion.

Some sources, particularly gatekeepers with professional health-care ties, could facilitate the provision of insider knowledge that participants could not directly access on their own, such as drug package inserts, clinical trial protocol documentation, or contact information for health-care providers who were also cancer survivors. One participant obtained recommendations for breast specialists by targeting her selection of sources to those working in health-related fields:

The kinds of people that I contacted were people who were in health-care related fields. So they had reason to know who, you know, but if you're a doctor who would you want your wife to see? Right, so you have reason to know about that individual surgical skill. (P1)

4.3.2 Shared Cancer Bond

The second most frequent selection criteria described by participants was the special relationship they have with others who share a cancer diagnosis, as one participant told us:

We share a bond... it's a sisterhood and that's exactly what it is. (P2)

Two participants even maintained lists of contact information for breast cancer survivors they had become acquainted with for sustained contact. Participants associated the cancer bond with sources who offered insights, comfort, and understanding that

family members or friends who had not experienced a cancer diagnosis could not:

I can talk to my friend and I can talk to my family about what's going on with me, but they don't really understand what that means. They understand that you don't feel well, and they're empathetic and they're sympathetic to that, but there's still a bit of a barrier, a bit of a wall because they don't know what I'm going through. They don't know if I'm stressed out. They don't understand what if I get stressed out because I can't do something that should be so simple, I can't make a decision about something (laughs) or whatever. To them, they're like just do it. Whereas with someone who's going through the same thing that I am, you're kind of going yeah, I couldn't do that either today. And sometimes you just can't. (P13)

For some problems, such as dealing with common cancer treatment side effects, the specific type of cancer a potential source had been diagnosed with did not play a significant role in selection. For example, advice for dealing with hair loss was just as useful coming from a source with ovarian cancer as a source with breast cancer. For other problems, such as treatment decisions, sharing not only a similar diagnosis but close alignment of treatments or experience of side effects played a vital role in selection. Sources with recently completed treatment were also selected because they were thought to provide timely and accurately recalled advice. For example, one participant told us about valuable advice she obtained by selecting a friend who had already completed treatments she was considering:

I talked with - it was a new friend I've made ... she's had two breast cancer diagnoses and the first time was a lumpectomy and the second time was a mastectomy. And so my friend put us in touch with each other and she was a really great resource and she's very free with her information and very willing to share, she's great. So I was able to ask her really direct questions as far as the surgery itself and her recovery and I asked her were there any hints or tips or anything that might help me with recovery or make things a little easier. And she had some good ideas for that. (P8)

Participants highlighted barriers to expertise sharing that stem from variability among the diagnoses, treatments, and side effects experienced by patients. Thus, close similarity of health situations, perhaps like departmental similarity of professional workers who tend to keep selection 'local' [18], was a particularly important selection criterion associated with the cancer bond. One participant expressed frustration at failing to locate other patients who were also dealing with a rare side effect:

Well, no one has been in my situation. That's the problem. (P7)

4.3.3 Strong Social Tie

The next most frequently discussed selection criterion was the strong social tie of a long-standing or close friendship. Sources who were close friends provided familiarity, trust, likability, and dependability that made it easy for participants to seek expertise. Participant 'P2' described the "*camaraderie*" that developed as she connected with and incorporated breast cancer survivors into her personal network. Many participants described the importance of trust and honesty in sources of expertise and commonly associated those characteristics with long-standing relationships:

So when they said you'll also need to meet with a radiation oncologist, I said what in the world's going on, and so forth. And I did a little reading and it said yes, sometimes radiation is required, but I called [radiation oncologist] who's a close friend, we ski together every year, and said this is what's happening, they want me -and she said, yeah, I think they're right. So you know, she's not any better than - in fact she's retired so she's not as up to date as the people I will have here, but somehow because she's a friend there's a certain amount of trust there. And I do trust my doctors, but when you have friends that are specialists in certain areas. (P7)

The importance of social tie strength as a selection criterion could stem from the highly emotional experience and intimate topic of health situations, such as breast cancer. Abrahamson et al. [1] also note the importance of close social ties with lay information mediators. The *champions*, relied on by so many participants, might have been particularly instrumental because they provided a breadth of source knowledge as well as likability through the strong social tie they shared with participants. Social relationships also play an important role in expertise selection among professionals in organizational settings that are not necessarily as emotionally charged [28].

4.3.4 Similar Interests, Lifestyles, and Preferences

Participants also described selection criteria related to shared interests (e.g., art), interaction preferences (e.g., email), health preferences (e.g., naturopathic medicine), lifestyle factors (e.g., profession), similar world views, values, and demographics (e.g., age and education). The importance of similar indicators about the social circumstance in which expertise is shared is highlighted in prior work [29]. Our youngest participant, for example, told us how she selected both books written by cancer survivors and online health communities that were “geared towards young people with cancer” (P13). In many instances, participants found expertise sharing easier when sources were familiar with their interests, lifestyle, or preferences. For example, one participant described the importance of the world view she shared with her friend, who was a breast cancer survivor, for sharing expertise:

Having cancer affects your life in terms of meaning and that kind of stuff and so [my friend] and I have talked a little about that. Like I said though, I don't know that's something that people necessarily think about, or if they do it doesn't seem like something that they - I don't know - maybe can articulate very well? But I think one of the things that kind of, a connection that I have with [my friend] is just that I think we are both sort of that way and so we both kind of talk about that kind of thing in general, not necessarily just in terms of cancer ... I think we know enough about each other to know that those kind of things are things that we both are concerned about and that would be something that we could talk about with each other because we both have similar concerns like that. (P4)

4.3.5 Source Accessibility and Response Expectation

Accessibility of the source and the expectation that they would get a response were also key selection criteria. Participants often selected the most accessible sources, such as those with whom they interact with frequently (e.g., coworkers), who were easy to meet (e.g., lives nearby), or had fewer commitments than other sources (e.g., a single and retired friend). For example, one participant maintained a list of accessible sources in her files:

There's a file with basically notes about various...people who are good, [who I] might want to contact, people who had mastectomies who are willing to talk to me or people who've had breast cancer who are willing to talk to me. (P11)

Another participant told us about her plans to meet with other breast cancer patients who live nearby:

There are a couple of people who I've talked to [through my breast cancer blog] who I would like to try and meet. We've kind of talked that idea around about meeting and kind of sharing our common experiences. (P13)

Participants also selected sources likely to respond to their requests. For example, participant ‘P1’ selected sources for whom she had done favors for in the past with the expectation of a reciprocal response: “So I was calling in chips all over the place.” In addition to offering a trusted relationship, friends may be more likely to respond to requests for help than others. For example, one participant told us how she could depend upon a response from a good friend:

I know I can reach my friend. You know, my doctor, I'm leaving a message with you know, at least one intermediary. And they're very good about passing the messages on and all that, but it's just - you know, I know I can talk directly to my friend. If I leave a message somewhere she'll call me back. (P11)

Participants also selected sources who were proactive in their prior support efforts. Just as the employees accounted for the ‘load on the source’ using call lists and word-of-mouth [18], our participants also took into account the workload on candidates. For example, participants told us that they chose not to select sources consumed with personal issues:

So her sister just passed away like a week ago from breast cancer and I just ran into her a few days ago...So I told her a little bit, I didn't want to freak her out because she's already got enough on her plate. (P15)

4.3.6 Source Transparency

Sources who offered honest, straightforward, and traceable advice were commonly selected by participants. Participants described transparent sources as being “no nonsense” (P7) and “upfront and very free with her information” (P8). This was particularly true of sources who were breast cancer survivors. For example, one participant valued sources who were open to “show and tell” their surgeries and offered honest explanations:

I just think it's beneficial to have more people explain it in real terms, not so they want to make it look good in a pamphlet so it reads nicely and all that kind of stuff. Doesn't have to read nicely all the time, because reality is it's not all nicely. It's what it is. (P3)

In addition to the trustworthiness participants associated with honest and open sources, a few participants highlighted the value added by sources who provided them with pointers to supporting reference information (e.g., a research article or book). When sources could not provide this reference information, participants experienced a barrier. They felt uneasy about utilizing the advice until they could “check it out” (P4) with other sources, such as the internet or one of their health-care providers.

Although research in organizations has not necessarily highlighted the importance of honesty or reference information as selection

criteria, these issues share similarities with ‘performance criteria’, such as suitability of explanations [18]. The need for accountability in an organization could result in a lack of need for the same level of explicit transparency, yet equivocation certainly needs to be managed in many different social settings.

4.4 Anticipating Breakdowns in Expertise Locating

In the discussion above we highlighted a range of techniques for expertise identification and selection. However, the patient expertise location behaviors we uncovered also reveal a number of barriers participants faced, such as the challenge of locating sources who share not only the same diagnosis, but similar treatments, side effects, and stage of care. Similarly, gatekeepers who lack specific details about the participant’s situation often resulted in dead-ends that initiated a new search for expertise.

A cancer diagnosis generates ‘high stakes’ problems; problems for which an error in judgment has dire consequences. As a result, we saw something distinct from the repair mechanisms previously observed during identification or selection (i.e., ‘escalation’ [18]). Instead of waiting for a failure in expertise identification or expertise selection, participants engaged in two distinct forms of *triangulation* in the anticipation of potential breakdowns. Participants relied, in parallel, on strategic and separate applications of identification and selection to garner expertise covering a topic area.

First, participants polled multiple sources, by requesting the same information from each, to see if they were getting the same answer. However, triangulation was not an undifferentiated broadcast request:

[I sent] out emails to people I thought would be knowledgeable to say ‘who’s the best in town on these issues’? And what I was doing was almost like a triangulation or whatever you’d call it, to see what names came up again and again and again. And to see what the patterns were. And so a number of key patterns emerged in terms of who folks thought were the best medical specialists for breast cancer in the area. (P1)

Of course he thought I should go on a fast (laughs)... he just offered this piece of advice, which is interesting. I find that lots of people have all kinds of advice that they just kind of give spontaneously...I haven’t seen anything documented...And so normally I think I would have heard something about fasting if it was supposedly - I mean there’s some pretty alternative things out there, which I’ve actually heard of from different sources, I mean they sort of corroborate, collaborate or whatever. Which actually makes me think well, maybe there’s something to this and I’ve not heard anything about fasting, I mean even in the alternative press, I haven’t even run across it and I even looked for it on the Internet. (P4)

In the first quote the participant sought health professionals in her personal network to determine their collective judgment about the most qualified breast surgeon in the area. While in the second, the participant worked to “corroborate” the unsolicited offer she received with additional sources.

Second, triangulation occurred when participants gained insights into a problem by collecting viewpoints from specific, yet varied perspectives. For example, one participant, who was deciding among different treatment options, attempted to approach breast

cancer survivors who had both undergone and decided against each option she was considering:

[I] tried to, you know, ask as many questions to as many people that I meet that have, you know, had mastectomies or had radiation, trying to get opinions ... I spoke with women in the support group and there’s been a few of them that had mastectomies, not had reconstruction. There’s only one woman in there that’s had a mastectomy that also had to have radiation and is now having reconstruction. (P3)

Another participant integrated the different bits and pieces of advice she collected from several different sources:

... but meditation, it took me a while to be convinced that that would be helpful to me ... I heard research on it that indicated there was something to this, I think I went to the library and I just checked out some CD’s and stuff by meditation teachers and after listening to or reading quite a bit, I finally - it was interesting to me because what I found out worked for me wasn’t something that I could necessarily go to any one meditation teacher and have them say this is how it works and if you keep at it, this is how it can work for you. It was more me listening to a lot of different stuff and sort of picking out what ultimately worked for me. (P4)

Triangulation requires identifying and selecting a set of sources with specific characteristics. This process was easier for participants who had rich personal networks offering a range of characteristics, expertise, and perspectives. Without access to such a network, locating a set of candidate sources required significant effort. In addition, when unsolicited offers were perceived as potentially fruitful, it could spawn additional, and unexpected, work to corroborate through triangulation. When unanticipated, this process can be particularly taxing for patients who have little energy for tasks other than keeping up with daily life in the midst of treatment. Extending our prior quote, after failing to corroborate advice on fasting with alternative sources, participant ‘P4’ shared regrets associated with this effort:

I tried to be really tactful, I said I’m not saying I don’t think this was a bad thing, I think it was a good thing for you, because you felt you like you needed to do it and you did it, I think that’s great. But I don’t think it’s the right thing for me. I should have just kept my mouth shut and said okay, thank you, like I do with most unhelpful advice! (P4)

5. DISCUSSION

By demonstrating how analytical constructs drawn from expertise location in organizational settings play out in the personal health context, our field study provides significant insight into systematic, everyday expertise location behaviors used by individuals facing high stakes situations. We discovered new expertise identification techniques, expertise selection techniques, and anticipatory breakdown recovery techniques not identified in prior work. These include (1) the initiation of identification through unsolicited offers, (2) the identification of expertise through use of multiple variations of gatekeeping, numerous grouping mechanisms, and minimal use of historical artifacts, (3) the vital role that specificity of health-related experiences and source transparency plays in selection, and (4) the use of triangulation to mitigate potential breakdowns.

This range of new behaviors extends prior empirical descriptions of expertise location in organizational contexts and initiates a bridge between our understanding of expertise locating in formal

organizations [18] and in the informal context of everyday life [30][31]. For example, our findings suggest an interesting parallel to the evolution in theories of information behavior [34]. Just as information behavior reflects both active forms of information seeking and passive forms of information encountering [10], expertise location could also reflect a similar distinction between the initiation of identification through both solicited and unsolicited advice. Whereas positive implications are commonly associated with information encountering [10], our findings suggest that expertise location through unsolicited advice can also carry negative associations. In addition, patients' use of triangulation suggests an important distinction between expertise location in organizations and in illness - patients simply cannot afford to fail their one shot to solve a high stakes problem. Rather than risk failure, patients garner expertise from many sources to build sound and personalized solutions *a priori*.

Although we observed many expertise location behaviors similar to those in organizations, the unique behaviors of patients suggest that the personal health context calls for specific design features. We offer the following suggestions for developing and enhancing software for patient expertise locating. In particular, we focus on internet-based social software systems that host patient forums and other patient interaction mechanisms with the goal of facilitating patient-to-patient information sharing.

First, the diverse selection criteria used by patients suggests the need for tools that provide users with fine granularity in specifying the expertise they seek, such as query filters [19], contextual background about candidate sources [7], or visual presentation of results to compare source characteristics [5]. Existing social software often limits patient search facilities to diagnosis and demographics. These systems could be enhanced with searchable profiles that incorporate treatments, side effects, lifestyle information, strength of social tie, and role, as well as type and level of health-related knowledge. Some of this information could be directly imported from a personal health record, such as Google Health (www.google.com/health).

Second, patients also need ways to manage unsolicited offers. For example, some participants made themselves 'open' to advice by sharing information about their situation with others. Similar phenomena are observed in other informal contexts [31]. This strategy can save the user time required to search for expertise, but can lead to undesired advice. Features that allow users to mark their profiles as 'open' for particular advice could help them leverage this low-cost strategy. Social networking tools, such as Facebook (www.facebook.com) offer similar features to mark one's profile as 'looking for' friendship, dating, networking, etc.

Third, the range of gatekeeping mechanisms used by participants to identify expertise suggests the value of supporting both the identification and recognition of suitable gatekeepers. Users could volunteer to serve in one of many gatekeeping roles or could be elected to a particular gatekeeping role based on their prior interaction history and social connections in the community.

Fourth, although social software encourages the broadcast and exchange of a significant amount of useful content, tools could be enhanced to capture and organize those artifacts in problem-based collections for community reuse. For example, users could collaborate to revise, extend, or annotate evolving collections of artifacts specialized to support common problems (e.g., surgery checklist, questions to ask your oncologist). The trail of users who

have 'touched' those artifacts could be referenced to obtain additional information to facilitate artifacts reuse.

Fifth, triangulation strategies suggest the need for patients to not only issue information requests to multiple sources, but to do so in parallel. Features, such as problem-specific workspaces could assist users in collecting and synthesizing multiple streams of advice related to a particular problem. Dedicated workspaces could provide methods for summarizing patterns of advice (e.g., poll counts), as well as hooks to the advice received and related background material for further context.

6. CONCLUSION

Our investigation of expertise location in the personal health context demonstrates how individuals find patient expertise during the breast cancer experience. Although these behaviors overlap with some behaviors observed in organizations, locating expertise in the personal health context required new strategies and behaviors. Unique issues associated with patients' behaviors do much to enhance our understanding of the complexity and collaborative nature of patients' information work. We extend prior expertise location research by providing insights that help to bridge our understanding of expertise location across formal and informal contexts. Patient-centered functionality that supports diverse selection criteria, the management of unsolicited offers, identification of gatekeepers, artifact sharing and reuse, and triangulation can greatly enhance the design space of internet-based social software to facilitate patient expertise sharing and meet critical needs of patients.

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